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A Winter's Tale: A Pastoral and Theological Exploration of the Responses of Families and Their Carers to Pre-natal, Peri-natal and Neo-natal Deaths

by

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The candidate confirms that the work submitted is his own and that appropriate credit has been given where reference has been made to the work of others

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In Memoriam

E.G.Pye D.Pod.M., M.Ch.S., S.R.Ch., M.R.S.H.
(1928-1999)

Abstract

The thesis explores, from a theological and pastoral perspective, the responses of individuals, families and their carers to the deaths of children in the pre-natal, peri-natal and neo-natal period. Setting the changes in both the theory and practice of bereavement care in their historical context, the thesis critically examines a diverse range of international bereavement literature, bringing them into dialogue with each other and offering informed reflection from both a theoretical/academic and multidisciplinary practice perspective which is of relevance to both clinical and non-clinical practitioners. Challenging the predominance of the medical model, the thesis argues that the needs of the bereaved are best met by a dialogical, holistic, person-centred, multi-disciplinary approach, which engages both virtues (particularly characterised by the notion of agape) and skills in reflective practice. Critical questions of identity, relationality and care are addressed not merely as theoretical constructs, but as part and parcel of human experience The first chapter outlines the major themes in the development of bereavement studies from Freud onwards, showing how early-life deaths only became the focus of serious attention relatively late in the twentieth century, and arguing that such early-life deaths are both 'like' and 'un-like' other forms of bereavement. The three following chapters look at miscarriage (and related issues), stillbirth, and neo-natal deaths respectively. Each chapter raises issues which are specific to these particular forms of bereavement and others which re-surface as common themes, extending the scope of the thesis from the effects of such deaths on the individual, to their effects on the family matrix and on caregivers. There is separate discussion of the effects of early-life bereavement on siblings. Finally, through a discussion of ritual and through the collation and analysis of a broad range of liturgical material, including rites concerning both the beginning and end of life, the critical relationship between liturgy and pastoral care is established as a key theme of the thesis.

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'Experience without theory is blind. Theory without experience is folly.'

(Immanuel Kant, *Critique of Pure Reason,* A.51.)

The twentieth century was undeniably a time of remarkable progress. This has been particularly apparant in the field of medicine, and not least in obstetrics and neo-natology. Over the course of the century, infant mortality, once (like maternal mortality) a common fact of life, was reduced to <1%. It remains a fact, nonetheless, that some babies still die in the period before, or shortly after, birth and, whilst the death of a baby is a subject no-one really wants to talk about, miscarriage, stillbirth and neo-natal deaths affect tens of thousands of families annually in the United Kingdom alone.

Changes in attitudes to such deaths have come slowly, for old taboos die hard and the agenda of medicine and its allied disciplines has been focussed on life rather than death.[1] Even in the developing field of bereavement care, it took nearly three-quarters of a century to establish that bereavement in the pre- and perinatal period leads to grief, and still longer to realise that this grief is so specific that a simple, uncritical application of general bereavement theory is not only inadequate but may, in some cases, actually damage the bereaved.

While there is still some way to go, since the 1970s a gradual change has been taking place. The confidence of the bereaved in articulating their feelings and emotions (not simply about death but about the care which they received), and a parallel rise in professional interest in the subject, has led to an opening up of a dialogue between the bereaved and their carers and between different professional disciplines which has been long overdue. A number of centres have played an outstanding role in these developments, two of which I have been privileged to work in or to spend time with - Bristol and Brisbane. Both centres have made contributions in the field of pre- and peri- natal care that have been unparalleled.

This thesis, born in the context of change, reflects on changing practice in the field of bereavement at the beginning of life. It is, however, neither a simple historical

account nor simply another practice handbook (although one hopes that it will make its own contribution to both historical understanding and to good practice). It brings together for the first time a diverse range of international material from a broad spectrum of disciplines. In so doing, and in offering critical and informed reflection from both a theoretical/academic and from a context-specific, multidisciplinary, practice perspective, it allows us to explore the underpinning values/experiences which have shaped current practice in the field and to identify what constitutes 'good' practice in an 'ecology of treatment' that is necessarily dialogical.[2]

There is a great need for this pluriform approach, especially in a field which is still rapidly changing. Technological and medical advancements have, too often, forced pastoral practice and theological and ethical reflection onto the 'back foot' making them reactive rather than proactive. The rise to an almost unchallenged predominance of the medical model in determining and shaping the basic understanding of the issues addressed by pastoral practice during the last century, is one in which pastoral practitioners have colluded and for which they must carry some burden of guilt.

This work, then, aims to be reflective rather than reactive, to look forward as well as back, to engage virtues and not just skills, and to argue that reflective practitioners, rather than just skilled technicians, are necessary to meet the needs of the bereaved; needs which have for too long been marginalised, especially where death comes so early in life. Such deaths raise questions which admit of no easy answers - When does life begin? What are persons and when do they begin (or stop...) mattering morally? Is human identity primarily a biological or relational construct?

If care of the bereaved is to be appropriate, these are questions which need to be addressed, and to be addressed not merely as theoretical constructs, but as part and parcel of human experience. Hence, the paradigm of care which is used here is one which is both interdisciplinary and dialogical. Whilst it does not reject the predominant medical model, it argues that it is limited. The approach of this work, therefore, is essentially holistic and person-centred, rather than atomistic and problem/task-centred.

The first chapter provides the necessary context of what is to follow, outlining the major themes in the development of bereavement studies from Freud onwards and showing how early-life deaths only became the focus of serious attention and study relatively late in the twentieth century. A major theme of the thesis is established, namely that, while there are important lessons to be learned from the study of adult deaths, death in early life raises particular issues which simply cannot be addressed adequately by a simple, uncritical application of general bereavement theory. These are deaths which are both 'like' and 'un-like' any other.

The three following chapters look at miscarriage (including sections on the termination of pregnancy, death in multiple pregnancies and ectopic pregnancy), stillbirth and neo-natal deaths respectively. Each chapter raises issues which are both specific to that particular form of loss and others which, while raised in more detail elsewhere, re-surface as common themes. Thus, in the chapter on miscarriage, issues of personal and relational identity are raised; in the chapter on stillbirth, the discussion is extended to consider the impact of such early-life deaths on the family matrix; in the chapter on neo-natal deaths, issues of care in the high-tech. environment are explored both from the perspective of families and extending it to that of their carers.

The bereavement experiences of siblings are explored in a separate chapter, not least because the bereavement needs of children is a field that has received particularly scant attention in professional literature. This chapter outlines a theory of developing death-awareness that presses beyond the conventional, influential models of child-development to include notions of spiritual development and the experience of the child within the family matrix as essential elements in bereavement care.

In each case, literature from a number of different disciplines is brought together and subjected to critical pastoral and theological scrutiny and analysis to provide a new perspective on both the development of, and current issues in, practice in each of these areas. Doing this helps both medical and pastoral practitioners to identify models of good practice, and, indeed, their opposite. This is done by way of the cumulative evidence, and also by examining some of the underlying assumptions,

particularly from a theological and pastoral standpoint, which have led to bereavement care developing in the ways in which it has. Thus, pointers to, and models of, future developments in the care of the bereaved are provided.

Finally, through a discussion of the place of ritual and the collation and analysis of liturgical material from an extensive range of sources, the critical relationship of liturgy to pastoral care is brought under scrutiny. A number of contemporary liturgies representing both the official rites of the Church and more recent moves towards the development of more context-specific and individual-centred liturgies are examined in detail. Detailed dialogue with, and analysis of, these rites lays bare many of the underlying themes of identity and care that are the theme of this thesis and offers positive suggestions for developing good practice to both liturgists and pastoral practitioners.

From these context-specific explorations, taken as a whole, a much more robust and theologically informed understanding and application of bereavement theory and practice is developed, which has important implications for both practitioners and for the bereaved. Underpinning all this is the belief, spelt out in this thesis, that bereavement is as much a social experience as a matter of individual psychology and is therefore best explored in a relational context. Whilst the individual has been the predominant focus of much of the writing on bereavement and grief in the twentieth century, which has itself been overly dependant on the predominant medical model, a broadening of perspective to include the insights of theological investigation, not least in theological anthropology, pastoral practice and liturgy, has much to teach us and offers much to enrich our understanding of a common human experience.

In summary, this thesis:

- *brings together, for the first time, relevant material from a wide range of disciplines and sources*

- *subjects the material, and the practice to which it gives rise, to critical analysis*
- *makes a cumulative case for a relationally-orientated way of understanding bereavement experience and related pastoral practice*
- *develops a rigorous theological and pastoral perspective on bereavement care after early-life deaths*
- *describes the ensuing application of a holistic, multidisciplinary approach in a concrete practice context*
- *establishes an economy of care, applicable to both medical and pastoral practitioners, that is reflective, holistic, person-centred and dialogical.*

NOTES:

1 In such a context, death is invariably seen as a 'negative patient outcome'.

2 D. Aldridge, *Spirituality, Healing and Medicine* (London: Jessica Kingsley, 2000), p.11.

Chapter 1. Setting the Scene

"Thou know'st 'tis common; all that live must die,
Passing through nature to eternity..."

(Hamlet, I, ii, 72)

Introduction

Hamlet's mother is, of course, right. All living things, by their very nature, are subject to decay and will, in the course of time, die. But it would appear that acknowledging the brute fact of our physical temporality and coming to terms with the reality of death can often be two very different things.

Death is a brutally familiar sight today through the media coverage of war, accident and disaster, with its graphic and pervasive visual images. Yet, these are second-hand encounters and so, for many people, their impact may become indistinguishable from fictional ones.[1] For most people, 'real' death is something that remains, for the most part, remote and impersonal, no longer part and parcel of everyday family life in a way in which it was a hundred, or even fifty, years ago. Improvements in health care, changes in the social environment and developments in medical technology over the course of the twentieth century have impacted upon, and drastically changed, the western world's encounter with death.[2] The rate of infant mortality has fallen dramatically to one-tenth of what it was at the end of the Victorian era, once-fatal diseases have now been eradicated and the human life-span, if not always life-quality, has been extended.[3] As a consequence, many people today will reach middle-age without ever having actually physically been in the presence of death or ever having seen the body of a dead person. The sick and the dying are removed from the home to the hospital or hospice, the bodies of those who do die at home are removed to the mortuary or the Chapel of Rest and so 'possession' quickly passes from the hands of the family or relatives into the hands of the professionals where death is sanitised and 'disposal' is all too often reduced to little more than a bureaucratic procedure.[4] In her classic book, *The Anatomy of Bereavement,*[5] Beverley Raphael notes how,

> the dying are isolated behind screens, cut off from the living, who are protected from them by clinical systems. The dead are mysteriously whisked away to the mortuary, ice cold, clinical and impersonal. Most medical institutions provide little opportunity or even a place where the bereaved can be with the dead person in privacy and closeness for last farewells.[6]

In recent years, things have slowly begun to improve. Yet, in distancing ourselves from the experience of death, we have become a 'death-denying', or at least a 'death-avoiding', society. If, over recent years, the door has been prised opened, death is still, it would seem, very much in the closet. Elizabeth Kübler-Ross says of this way of dealing with (or perhaps more correctly, failing to deal with) death, 'We hide it behind the sterile walls of the hospital and the cosmetic mask of the funeral home. But death is inevitable and we must face the question of how to deal with it...'[7] Robert Marrone sums it up well.

> Taken together, industrialisation, high-tech medicine, longevity, mobility and the portrayal of death in our language and the media have created and reinforced a predominant European-American attitude based on distancing ourselves from death and dying.[8]

Thus, whilst there has been a relatively recent emergence of a professional interest in death and its documentation in the twentieth century, death experienced at a personal level has arguably become the last great taboo of the twentieth century.[9] Death is seldom seen as *eu thanatos*, 'kindly death', but rather as the unwelcome interloper in our lives, an enemy to be defeated or a prison to be escaped, something to be avoided, something even obscene.[10] Western, post-enlightenment, technological society in which we have developed an increasing ability to manipulate or control our environment has encouraged us to see death in terms of failure and therefore as something to be hidden away and not to be talked about.[11] The physical, psychological, emotional and social reality of death is suppressed, and the bereaved are often stigmatised by their very association with it. As Vigen Guroian says, 'Death violates both the dead and the living.'[12] As a consequence, the bereaved become isolated within their communities or families and at times they may even be shunned by

those to whom they have looked in the expectation of family or social support.[13] Indeed, it has been suggested that it is contemporary society's failure to deal with its fear of death and dying that leads to so many bereaved people today needing professional counselling and/or psychiatric intervention.[14] Furthermore, Parkes has argued that, 'along with a decline in our ability to face death comes a decline in trust in the rituals that accompany and follow death.'[15]

The result of all this is all too often an unhealthy society in which there is a high degree of frustration, anger and unresolved guilt, both in coming to terms with our own mortality and in our dealings with those who have been bereaved. So complete is the denial process which surrounds contemporary death and dying that most of the ritual actions, both private and public, that denoted the presence of mourning and, by recognising it, enabled it to take place, have largely been abandoned in Western society.[16] Furthermore, we now make our personal and institutional language party to reinforcing our death-denying attitudes in order to protect ourselves from acknowledging the reality of death or from having to communicate about it with each other, with the dying, or with their families. We do not say, therefore, that someone has died, but that they have 'passed on' or 'passed over', that they have 'gone' or 'are asleep' (and what psychological havoc may we wreak, not least with children, by identifying, as did the Victorian poets and hymn-writers, sleep with death and the bed with the grave!). Similarly, today, doctors' patients do not 'die', rather they 'lose' them. Implicit in this language of 'losing' is the inference that that which was 'lost' might somehow be 'found' again. Physical death, however, is not like that, it does not admit to reversibility, the dead do not yet return to life, however much we might desire them to.[17] Or, again, such people do not die, rather we have 'failed to save them...' as though death, so often thus objectivised, was an enemy, invading the human body, something, or someone, to be fought off in an iatrogenic struggle in which health, life and good, battle for mastery against sickness, death and evil.[18] As C.S. Lewis, reflecting on the death of his wife, asks, 'She died, she is dead. Is the word so difficult to learn?'[19]

The re-emergence of the hospice, and the new development of hospices for children, even the very young, in the twentieth century, with its emphasis on palliation, care rather than cure, serves to underline for us the extent to which hospitals have become institutions fundamentally committed to physical cure at the expense of terminal care.[20] In such a context, despite a growing awareness of, and emphasis upon, good practice in this area,[21] death is often regarded with the embarrassment of failure and the dying and bereaved treated with discomfiture and even, at times, with hostility.[22]

Death in contemporary society is not primarily regarded as the natural consequence of our mortality, but as a denial of medical and professional skill. By their dying, patients may be perceived as somehow expressing to those who care for them, their impotence or failure in the presence of death. Similarly, relatives may often reinforce such feelings if their grief is expressed as anger towards medical and nursing staff.[23] The fact is, that death constantly reminds us of our human vulnerability in spite of all our technology. This sense of vulnerability is particularly heightened when death comes early in life, even before birth has occurred

It is important, therefore, that those responsible for caring for the bereaved resist the temptation to collude with the social, cultural and professional impetus that has led people to avoid recognising the true reality of what has happened. Such avoidance causes severe difficulties for the bereaved in making a healthy transition in their grieving after the death of a relative. The situation is exacerbated when the language of death is avoided because of uncertainty as to whether there was a life there in the first place which may now legitimately be mourned.

One thing at least is certain, to be of help to the bereaved one has at least to work through, if not ultimately to work out, one's own attitudes to death and dying as well as towards the bereaved who may well, by their very presence, become 'a symbol of what every human fears and what we each know, at least academically, that we must someday face.'[24] One must recognise also that death is not simply a biological

phenomenon. Death is also something that is personal, social and spiritual. Beverley Raphael expresses it thus,

> The death of a loved one means not only the loss, but also the nearness of personal death, the threat to self. One is close to death and may be touched or contaminated by it. All the personal and internalised meanings of death will be evoked by the death of a loved one. All the personal vulnerabilities associated with death will be aroused by its closeness to the self.[25]

As C. S. Lewis, reflecting on the death of his wife, wrote, 'It is hard to have patience with people who say, 'There is no death' or 'Death doesn't matter'. There is death. And whatever is, matters.'[26]

The reality for many people today is that the experience of death often happens without the cultural and social support necessary for healthy grieving. Grief-work cuts across the death-avoidance culture. Ros Weston and her colleagues have recently reminded us, therefore, that we need to develop *both* long-term preventative strategies which develop a culture of caring *and* short-term interventions which support and help those who through misfortune and tragedy find their own resources depleted.[27] In order to do this, however, we need to set such strategies in context, however briefly, since as Field *et.al.* remind us, 'the ways in which a society deals with death reveal a great deal about that society, especially about the ways in which individuals are valued.'[28] In the following section, therefore, I shall contextualise the cultural shifts which have taken place in regard to grieving over the past century by outlining some of the most influential literature in this field, with particular reference to the late-emerging literature on death in early life. In doing so, I shall also contextualise both current assumptions and practice in the care of the bereaved and set the scene for my own recommendations with regard to pre- and peri-natal deaths.

An historical overview of grief literature in the twentieth century

Freud and his successors (1900 - 1960s)

Despite the influential work of Sigmund Freud in the early years of the twentieth century on the place and importance of mourning, there was little sustained or systematic work in the next fifty years.[29] Among the few notable exceptions to this was the landmark article in 1944 by the American psychiatrist Ernst Lindemann.[30] This article provides us with the first systematic study of acute grief and of the implications of the death of relatives on survivors, for whom life, though significantly affected, continues. Despite its limitations, Lindemann's article is still one of the most often quoted articles in the field of bereavement studies.[31] Lindemann looked primarily at the psychological and somatic symptomology of acute grief and, although it is implicit in Freud, his article is the first place where we find explicit use of the now familiar term, 'grief work'. Lindemann's observation that the symptomology of grief is somatic as well as psychological is important. It underscores the reality that we experience grief *in our bodies* and not just in our minds. Human grieving is therefore always embodied, affecting us as *whole* persons.

The period from Freud to Lindemann encompassed two world wars with their horrifically high death tolls, and yet there was a marked absence of professional interest in death and bereavement at this time. The inherited social taboos surrounding death and grieving, coupled with the particular psychological approaches predominant in the early to mid-years of the twentieth century, may well have served to discourage professional interest in the exploration and examination of emotions such as grief, often described in terms of 'drive' variables, which were not then of scientific interest.[32]

Although Freud in fact wrote comparatively little about grief, his work was to prove influential in the development of twentieth century psychodynamic theories of grieving. Freud observed that mourning is a period of time during which the reality of

the death is progressively tested and the loss verified, and suggested that its function is primarily to cushion the impact of loss. In this way, the survivor is enabled to detach from the deceased as the libido is gradually withdrawn: 'Mourning has quite a precise psychical task to perform... its function is to detach the survivors' hopes and memories from the dead.'[33] Although such a process may be painful it is self-limiting, something through which the grieving person can progress and from which he/she can eventually spontaneously emerge.[34] Thus, a grieving response which lasted one to two years and then spontaneously ended, should be considered 'normal', whereas grieving which lasted for a longer, indefinite, period was to be categorised as 'pathological'. By the very act of thus distinguishing between 'normal' and 'pathological' grief, however, Freud established a normalizing psychology of grief which dominated bereavement research of the 1950s and 1960s and, in some areas, continues to shape it. Freud's lasting contribution was, however, to establish that although those who grieve may 'mimic' some of the observable signs of psychiatric disorder (deep dejection, loss of interest in the outside world, inhibited or altered states of activity, the deluded expectation of punishment, or the representation of the death *as* punishment), grief was, in fact, a perfectly 'normal' reaction to the loss of a loved person and that it fulfilled a therapeutic and restorative function.[35]

The theme of grief as 'illness' was, nevertheless, one which was to persist, for example, in the work of George Engel. He argued that the death of a loved person is a psychologically traumatic event with an observable pathology, directly parallel to physical injury. Grief is to be regarded as the disruption of personal well-being or health.[36] Just as the body requires a period of recovery after the infliction of physical trauma, Engel argued that a similar period of recovery is needed before the grieving person may be restored to a state of equilibrium or homeostasis.

Engel's contribution was thus to demonstrate parallels between the *process* of healing and the *process* of mourning that are implicit in Freud. Just as the process of healing can take either a healthy or a pathological course so, it was argued, grief or

mourning can be similarly 'healthy' or 'pathological'.[37] With the proper management, both would be completed over a period of time.

In his study of grief in adult life, Colin Murray Parkes similarly points out that, whilst grief is a normal response to a stress or stressor, the illness model may still be applied to grief with some validity.[38] Fundamentally for Parkes, however, grief is a 'consequence' of human relationships - where bonds are formed, the loosing of those bonds precipitates an emotional and somatic reaction. It is, in effect, Parkes would say, the price we pay for the capacity to love.

Arguments about what constitutes 'pathological' or 'abnormal' grief were to be developed during the years which followed by a number of writers, also predominantly in the psychoanalytic tradition, who built on the ground-breaking work of Freud.[39] These included Helen Deutsch and Melanie Klein, both of whom were to become influential figures in their field and were to make significant contributions to understanding the psychological process of grief. Klein, in fact, paid less attention than Freud to the 'yearning' of bereavement, laying greater stress instead on the significance of 'guilt' and its affects. For both of them, however, grief - as well as being 'normal' - could be 'delayed' or 'absent', 'acute' or 'chronic'. Despite a continuing measure of confusion about when grief or grieving actually is 'pathological', the characteristics which mark such variants are widely documented in the literature on bereavement and bereavement counselling.[40]

In an article published in 1937, Helen Deutsch argued that grief which was 'buried' and therefore unexpressed would eventually surface in the form of disorders with a psychiatric pathology.[41] Similarly, Melanie Klein argued in 1940 that, in the process of mourning, the grieving person experiences a modified form of (particularly manic) depression, which is progressively overcome as the mourning progresses.[42]

Deutsch had argued that the emotional manifestations of a woman whose baby died in the pre- or peri-natal period were not the manifestations of true grieving but the response to the 'non-fulfilment of a wish fantasy'.[43] Klein, however, argued that there was no difference between grief over the loss of an infant and that over a

significant and loved adult such as a spouse.[44] The view espoused by Deutsch, however, was to influence the approach of professionals dealing with women whose babies had died in the pre- or perinatal period up until the 1970s.

At a time, then, when understanding about grieving and its effects on individuals and their relationships was increasing, a significant group - women whose babies died - were being excluded and their needs neglected. Klein's belief that women *did* 'grieve' for their dead babies appears to have been neglected both in the literature on bereavement and in clinical practice, until it re-surfaced in 1970 in an article by an Australian obstetrician, P.F.H. Giles.[45]

In a follow-up study of 40 women whose babies had died in the perinatal period, Giles also observed that these women displayed emotional and physical reactions similar to those which could be seen after the death of a known and loved adult. He showed that the psychological manifestations of grief in newly-bereaved mothers reflected those which were noted and described in the writings of workers like Parkes,[46] who contributed significantly to the development of the 'process' theory of grieving. In such 'process' theories, a discernible pattern of grieving could be observed. This included phases of initial shock, emptiness, numbness, sadness, anger, guilt and blaming, restlessness (searching for the dead person), bargaining, and depression before the eventual resolution of grief. While process theory offers a useful and significant 'model' for grieving, the temptation to regard it as offering a 'blueprint' has often led to a too rigid sequential application. This fails to recognise both the 'ebb and flow', or 'episodic', manifestation of emotions, or that in different individuals various 'stages' of grief may either be predominant or absent. Indeed, the grieving person may revisit or return to a particular stage or stages several times in the course of their grieving. Another danger of process theory is that, as the application of a medical/psychiatric model of grieving, it can often allow little room for dialogue with the bereaved themselves and, instead of being descriptive of a course of grieving, can become prescriptive or normative.[47]

The somatic symptomology of grieving that accompanies the psychological manifestations of grief had first been systematically described by Lindemann in 1944.[48] His description of 'normal' but acute grief again rests heavily on the normalising psychology of Freud. Among both the psychological and the somatic manifestations of grieving, five key characteristics emerged: somatic distress (including sighing, shortness of breath or feelings of choking, exhaustion, disruptions in the processes of both sleep and digestion[49]), pre-occupation with thoughts about the deceased, guilt, anger, and the disruption or alteration of hitherto normal patterns of behaviour.

Significantly, Lindemann argued that the duration of normal grieving was dependent upon the outcome of the 'grief work', the purpose of which he described, in terms resonant of Freud, as being to allow the grieving person to 'detach' from the deceased by realising (i.e. accepting as real) the fact of the death and so opening the way to the forming of new bonds or relationships. Nonetheless, Lindemann also noted how the grieving process could be delayed or distorted in ways which led not only, as Freud had suggested, to clinical psychiatric disorders, but to the symptoms of physical disease or disorder such as asthma or ulcerative colitis. Indeed, it was noted how, in some cases, the bereaved would appear to acquire symptoms similar to those of the last illness of the deceased.

Lindemann also perceived that grieving has social as well as personal implications. He noted how those who were grieving would frequently become distanced from those around them and how their relationships with family or friends altered as former patterns of social interaction were relinquished or lost. Nonetheless, he also believed that the proper (i.e., psychiatric) management of grief could prevent prolonged or serious damage to the grieving person, and he acknowledged that, despite what he regarded as the limitations of their approach, 'religious agencies' have led the field in dealing with the bereaved.

> They have provided comfort by giving the backing of dogma to the patient's wish for continued interaction with the deceased, have

> developed rituals which maintain the patient's interaction with others, and have counteracted the morbid guilt feelings of the patient by Divine Grace and by promising an opportunity for 'making up' to the deceased at the time of a later re-union.[50]

Probably the greatest flaw in Lindemann's paper, however, was his belief that 'normal grief' could be resolved with the help of a psychiatrist in 4 - 6 weeks.[51] This view was later re-inforced by Caplan in his work on bereavement and 'crisis theory'.[52] Although Caplan was later to revise his opinions, this belief in the short-term nature of 'normal' grieving was to influence practice in the management of the bereaved for some thirty years.

Changing awareness (1960s - 1980s)

Caplan's views, like those of John Bowlby,[53] were also to influence the writings of the British psychiatrist, Colin Murray Parkes whose seminal work on bereaved adults is still one of the most respected books in its field and whose influence is recognised by Bowlby in the Preface to the third volume of *Attachment and Loss*.[54]

Although Parkes had first described grief in terms of stress,[55] he later came to regard grief and mourning, as Freud had done; i.e., as manifesting the normal period of transition following a major life-crisis. His principal contribution to the debate, however, was his clear and systematic description of the 'stages' of grief including 'alarm',[56] the 'numbness' that so characterises initial or early shock, 'searching' (in which he explores the episodic nature of grief with its acute, returning 'pangs'),[57] 'mitigation' (often expressed as the feeling that the dead person is still somehow 'present' - a form of denial of the death), anger, and guilt.[58]

Parkes' work was influential in identifying and describing both the characteristics of grief and the psychological and psychiatric risk factors related to the outcome of grieving. He made extensive acknowledgement of the debt it owed to the work of John Bowlby, whose wide-ranging three-volume work on attachment and loss

has been a major contributor to contemporary understandings of grief and mourning.

Bowlby's study was a conscious departure from 'the classical theories advanced by Freud'.[59] Bowlby's work was principally concerned with the exploration of affectional bonds or 'attachments', which he regarded as a basic form of behaviour stemming from a primitive biological defence mechanism.[60] The third volume of his work is concerned with loss, sadness and depression and explores the themes of grief and mourning. Bowlby was concerned to show how young children, separated from their mothers or other primary care-givers, went through three distinct stages or phases: 'protest', in which the child frantically searched for the 'lost' figure and protested at her departure; 'despair', when the lost figure failed to return, a stage characterised by the child lapsing into apathy and withdrawal and being in a state of abject misery; and 'detachment', as the child withdrew from the lost care-giver and began to seek new relationships.[61] The greater the attachment, Bowlby argued, the more intense the loss reactions will be. His work recognises the variability of individual personalities and begins with the recognition that, 'Loss of a loved person is one of the most intensely painful experiences any human being can suffer... to the bereaved nothing but the return of the lost person can bring true comfort'.[62]

In contrast to Lindemann and Caplan, Bowlby laid emphasis on the long duration of grief and on the difficulties which can ensue in the process of recovering from its effects. The belief that childhood loss was profoundly influential in the development of personality was of fundamental importance in Bowlby's work.[63] Grief was essentially about the breaking of affectional bonds or 'attachments' which had been established during a person's life. In this, the quality of the particular relationship is an important factor. Ambivalence over the quality of the relationship clearly affects both the course and the outcome of grieving.[64]

In 1970, two years prior to the publication of his own book on the subject, Parkes also wrote the preface to the first English edition of Elizabeth Kübler-Ross' *On Death and Dying*. This widely read and influential book firmly established the place and predominance of the process model of grieving in the theory and practice of work

with the bereaved. Kübler-Ross describes the various phases through which the dying patient passes on the journey from denial to acceptance, an anticipatory process which she argues is similar to that of actual bereavement.[65] Kübler-Ross points out how patients' first responses to the knowledge of their fatal condition are frequently those of shock, numbness, disbelief and a denial which often recurs throughout the grieving process. The patient may already at this early stage feel isolated and alone. This stage is followed, when the denial can no longer be wholly maintained, by one of anger, rage and resentment, sometimes with a specific target, at other times with random, or less clearly defined, targets. The third stage is that of 'bargaining', trying to postpone the inevitability of death, by establishing an 'agreement' with God (or fate) or by the setting of 'markers' (such as, for example, an anniversary or the wedding of a child, one last extension after which nothing further will be asked). This stage is frequently followed by one of depression when the inevitability of death is realised and the patient begins to grieve, not so much for past losses but for the loss of the future. Finally, with good management,[66] the patient is enabled to move towards acceptance. All these stages will be described in greater detail later in the examination of how families may respond to the death of a child.

Children featured little in the literature on bereavement until Simon Yudkin's article, 'Children and Death' appeared in the *Lancet* in 1967.[67] Yudkin was primarily concerned to show how children respond to death rather than to describe how others respond to the death of a child. Nonetheless, this article marked a breakthrough in the English literature on death and bereavement.[68] The first significant book on children and death did not, however, appear until the early 1980s.[69] Since that time, a number of books have been written on bereavement practice with children, including S.C. Smith and M. Pennels' excellent practice handbook[70] and Oliver Leaman's *Death and Loss: Compassionate Approaches in the Classroom.*[71] Most of these books, however, work within a Piagetian schema of the child's cognitive development and few consider the spiritual or religious development of the child in terms of death education or bereavement work. Exceptions to this are Robert Coles, *The Spiritual Life of*

Children[72] and Barbara Kimes Myers, *Young Children and Spirituality.*[73] From an English perspective, John Bradford's, *Caring for the Whole Child* is a valuable resource, although it does not address issues of death *per se*.[74]

Consideration of the impact of the death of a child in the pre-natal or peri-natal stage finds its first real expression, then, in P.F.H. Giles' 1970 article, 'Reactions of Women to Peri-natal Death.'[75] This compared the physical and emotional reactions of women whose babies had died, to the reactions of those who were grieving after the death of a loved adult. Whilst such early-life deaths occurred as frequently as 1:30 deliveries, he noted how the subject had hitherto largely been ignored in both the obstetric literature and in medical teaching. Giles pointed out that whilst, in the aftermath of the death, doctors treated women's physical symptoms through the prescription of sedatives, in about half the cases they avoided talking about, or allowing the woman to talk about, the death and its effects on them.[76]

From 1970 onwards a change in attitude can slowly be seen to occur. Giles' theme was picked up during the 1970s in the writing of significant workers like Kennell and Klaus,[77] and Page and Lewis,[78] and in the 1980s by Nichol,[79] Tudehope[80] and Raphael[81] in Australia, and Bourne and Lewis[82] in the United Kingdom, among an increasing number of professionals writing in the field,[83] whose work will be discussed in later chapters.

A further sea change (1980's - 2000)

During the 1980s and into the 1990s a further sea-change began, if somewhat belatedly, to take place. Writing about grief and bereavement became increasingly acceptable, both as a subject of serious scientific research and of popular interest and books on the subject proliferated.[84] Whilst much 'lay' writing on bereavement and grief is largely (and often usefully) anecdotal or autobiographical, focussing on the individual's 'survival' of bereavement and loss, professional writing has increasingly focused on issues of professional practice. Alongside the many 'broad-spectrum' books

on bereavement and bereavement counselling,[85] there have been an increasing number of books by both professional and lay writers during this period which deal specifically with the long-neglected and marginalised study of the death of a child or baby. These include, among the books by 'professionals', those by Elizabeth Kübler-Ross,[86] S. Borg and J. Lasker,[87] and Harriet Sarnoff-Schiff.[88] More recently, in a now proliferating market for books on death and loss, are works by Celia Hindmarch,[89] Rosemary Mander,[90] and Stewart and Dent.[91] This last book has an American counterpart in the work of Deborah Davis[92] and an Australian counterpart in the work of Judith and Michael Murray.[93] All of these, of which there are many other examples, are excellent books which, whether ostensibly written for professionals or parents, are essentially concerned with informing clinical practice.[94]

More recently still, the Freudian norm, that the role of 'grief work' is the breaking or relinquishing of emotional bonds with the deceased, has been challenged. Dennis Klass has argued that grief work is about accommodating the deceased into one's life in a new way,[95] Stroebe and Schut have proposed their dual-process model of grief, providing a novel, integrated theory of grieving,[96] while John Archer offers an excellent summary of grief theory from the perspective of evolutionary biology, providing a construct of *why* we grieve as we do, rather than *how* we grieve.[97] Such a psychological view of grief provides valuable links with the anthropological studies of earlier researchers like Van Gennep and those of more recent writers like Robert Cecil and Jennifer Hockey.[98]

Nonetheless, few, if any, of these books, go so far as to examine the beliefs which undergird and determine practice (though some touch, albeit briefly, on 'religious' aspects of death[99]). Just as there is a need to re-examine and re-evaluate existing descriptive and therapeutic models of bereavement and to develop new ones in the light of developing practice, so it is important to examine and evaluate the underlying principles which determine practice, as the practice itself evolves. Only by so doing will we adequately understand those underlying presuppositions and predispositions which, though present, have thus far attracted neither the attention nor

the critical examination which they deserve. This is essential if practice is to be properly understood, evaluated and progressed. As Shuchter and Zisook so aptly note,

> It should not be surprising that persons living through what is likely to be the most profoundly disruptive experience in their life are subject to dramatic changes in the ways in which they perceive themselves and the world around them... Frequently, there is a parallel evolution of belief systems reflecting changes in perceptions of how the world works.[100]

This view is echoed by Simon Rubin in his work on child deaths, who writes,

> The devaluation of the self that is now without the beloved child evokes the need to process and reorganize the self in relation to the deceased child, the self and the general world.[101]

A wider perspective - conceptualising death

In thanatological literature, recognition of the effect of the death of a baby, before birth or within the early years of life has been late to emerge. If the taboos of contemporary Western Society led to a failure to explore, at least until more recently, the effects of bereavement in general, those taboos surrounding the death of children have proved still harder and more difficult to break through. As Nancy Kohner and Alix Henley say,

> The significance of a baby's death has not been recognised in the past and bereaved parents have often struggled alone with a grief which others have neither understood nor acknowledged.[102]

Why this should be so is closely bound up with the wider struggle to determine the meaning, or meanings, of death, grief and loss for the individual and for the community or society. Beverley Raphael writes,

> Death has many meanings: the grim reaper; a sleep from which the sleeper does not awake; catastrophe and destruction; non-being; transition to another life; the end; the loss of loved ones; the death of self. It is the inevitable part of human experience. The knowledge of its inevitability is incorporated into the psychological structure of each person and it is accommodated in many different ways.[103]

Death, then, though universal, is conceptualised in many different ways and each individual death may admit to a wide range of different meanings within or between individuals, communities and societies, meanings which even within a single individual will almost certainly change with the passage of time and in the flux of circumstance. Grief, then, includes the search for meaning and thus involves spirituality.[104]

Though there are several components of bereavement that are common to the majority of cultures - crying or weeping (especially among women), anger or aggression (especially among men) and fear of dead bodies and/or ghosts/spirits, for example, the interpretation of the meaning of death and the way in which such meaning is translated into custom or ritual action is extraordinarily complex.[105]

It is important to set the search for meaning not only in its cultural but also its wider historical context. Philippe Ariès provides an invaluable critical summary of changing historical perspectives over the last five hundred years in this process of contextualisation.[106]

In *Limits to Medicine*, in a section that owes much to the work of Philippe Ariès, Ivan Illich explores the idea of 'natural death' as a key theme in any overview of the historical perspective of the search for meaning in death. He argues that the image of a 'natural death' as one which 'comes under medical care and finds us in good health and old age' is a recent concept.[107] He explores its development over the past five hundred years from the fifteenth century 'dance of the dead' to death under intensive hospital care. In line with the thesis of his book, that health has been, and is being, steadily 'expropriated' by the medical profession, he argues that in each stage of its development the concept of 'natural death' has become increasingly medicalised,[108] shaped by the institutional routines of medical practice and defined by its guardians and gate-keepers, the medical practitioner or doctor: 'the history of natural death is the history of the medicalisation of the struggle against death.'[109] In this schema, death moves from being a communal occasion for celebrating the renewal of life into a more personal, reflective experience in human self-consciousness in which the individual's

'dance' with death (often depicted with an hourglass) throughout the course of life, becomes an important motif.[110] Nonetheless, there still remained the shared norms that defined how people should die, as indeed, though less predominantly at this stage, how the bereaved should mourn.

As the meaning of death changed through time, so did the role of the medical practitioner and of the priest in their relation to the dying person. It was not originally the role of the doctor, certainly before the sixteenth century, to resist death but to help the dying person meet death and greet it consciously.

After this time, however, the aim of medicine became not simply to assist healing but to prolong life. Death was no longer the irresistible reaper but merely the effect of disease upon human organs. Death, no longer 'natural', could be resisted and the 'fight' against death had begun.[111] Disease could be classified and controlled, as the sick person, increasingly the 'patient', submitted ever more readily to the doctor's skill and judgement. With the rise of the hospital in the nineteenth century, the sick person is increasingly removed from family and community and his future handed over to public officials. In such circumstances, the 'patient' increasingly becomes the 'case' under the collective clinical gaze of the professional whose status is now increasingly defined by his peers and not the sick person.

It has been suggested by the sociologist Tony Walter[112] that this three hundred year process of the medicalisation of health and life, disease and death, in which death is progressively rationalised, reaches its apotheosis in Elizabeth Kübler-Ross' classification of the five psychological stages of dying.[113] Although 'spirituality' is deeply enshrined in the modern hospice philosophy, Walter, nonetheless, regards this 'modern' approach as exemplifying the way in which the twentieth century ideal of the dying trajectory is concerned more with emotional satisfaction rather than spirituality, with the doctor, or counsellor, replacing the priest at the bedside of the dying.[114] Jennifer Hockey argues rather that the openness of the hospice approach can be directly traced to its origins in the Christian tradition of hospitality or unconditional love.[115]

The concept of the 'good' death may well be one which provides the key to understanding the particular problems raised by the death of children by helping to explore just why it is that the death of a child, of whatever age or gestation, is so universally regarded as being a 'bad' thing in ways in which the death of an adult may not.

Under a regime of medicalised death, the 'good' death would primarily be that experienced at the end of a long life, free from pain and under the control of the professional. Mary Bradbury distinguishes between what she sees as contrasting representations of what constitutes 'good' death - the traditional sacred 'good' death, the medicalised 'good' death and the 'natural' 'good' death.[116] Nonetheless, she recognises that the dominance of medical culture means that few deaths today happen without any medical intervention and so medicalisation may 'leak' into the other models. This may confuse the bereaved over what a 'good' death actually is and create a dissonance between the understanding of the bereaved and those who act as the social arbiters of death, doctors and bereavement 'professionals', including representatives of the Church.[117]

If, then, the predominant definition is one in which a 'good' death is equated both with a measure of control and with death having been put off until life-aims have been fulfilled, then little could be considered further from the ideal than the death of a child, especially when the time of birth and the time of death occur in close proximity. Little wonder, then, that grieving such deaths should be associated with particular complexity and trauma.

It is my contention that, if the experience of the death of children in the pre- and peri-natal period is to be recovered from the definition of 'bad' death, we will have to enter into a more open and sensitive dialogue in which parents, doctors, nurses, chaplains and other 'death specialists' become fully attentive to each other. Previously rigid boundaries will then take on a more fluid quality, and the philosophical, ethical, theological and pastoral presuppositions of both past and present will be made subject to both critical evaluation and the voice of personal experience.

Some implications for grieving after pre-natal, peri-natal and neo-natal deaths

It may appear in this thesis that in answering the question, *'Why should we want to consider the question of pre- and peri-natal deaths at all?'* I want to 'have my cake and eat it.' Why should this be so?

On the one hand, I will argue against a view, once common and still lingering, that bereavement through the death of a child is not like other bereavements. Such a view, as we have seen, is most frequently promulgated by those in the psychoanalytic tradition. Crudely put, the suggestion is that the younger the child, the less like other bereavements it becomes, so that with infant deaths, and to an even greater extent with pre- and peri-natal deaths, the resemblance to grieving is barely there at all. We will see how this view, that the less time a child is with the parents the less significant is the nature of the loss, is one which predominated, even among the professionals, well into the 1970s. Whilst it is clear that there is no simple longtitudinal curve against which to measure either the intensity or duration of grieving, it is now widely recognised that the death of a child at any age has profound consequences in terms of grieving. Furthermore, the death of a child in babyhood or infancy raises particular issues which make it both like and yet unlike any other death. The 'un-naturalness' of the death of a child lies, I will argue, not in the age of the child, but in his or her unique place in the family matrix and because, by pre-deceasing parents, death has come 'out of season', challenging the 'natural' order of life. Nonetheless, old attitudes die hard and there are still those to whom things like, *'You'll soon get over it. It wasn't as if you had him/her long...'* or, *'What you never had you never miss...'* or, *'It's a good job he wasn't older, you would have missed him all the more...'* are said.

On the other hand, I will argue against those who recognise the place and importance of grieving the death of a child or baby (including prenatal deaths) but who see no difference between that and loss through death of adult friends or relatives. By taking general bereavement theories to be universally applicable, they argue that we

can readily distinguish between those griefs which are 'normal' and those which are 'pathological' and so, with appropriate intervention, help those who are grieving towards the eventual resolution of their loss - and that, after all, it might be argued, is the primary goal of any and all bereavement intervention.

I will argue, however, that the uncritical application of general bereavement theory has led to the mis-classification of some griefs after early losses through death; that what, in terms of the pattern, course and duration of grief after infant death, might be considered as falling within the parameters of 'normal' grieving has been too readily classified as 'pathological' because the criteria used are those more readily applied to the deaths of adults and inappropriate intervention has then been applied. This, I contend, can ultimately be as damaging as failing to recognise such griefs as griefs at all.

Consequently, I will argue that while grief after pre- and peri-natal loss is, in one sense, 'just like' grief after any other loss through death; in another sense, it is 'not like' those other griefs at all, and so needs the kind of particular consideration which takes account of the peculiarities and idiosyncrasies of such losses.

While, then, this may sound awfully like wanting to 'have one's cake and eat it', I will show how an examination of bereavement theory and its application, especially in the pre-natal, peri-natal and infant period, reveals a chronological pattern that demonstrates how closely connected these two views are. Prior to the 1970s, little or no recognition was given at all to those who were grieving after the loss of a baby or infant. Between 1970 and the mid 1980s, when the focus was predominantly on symptomology and pathology, recognition was increasingly given to the grief of mothers, and only slowly to that of fathers and other family members, but their grief was treated just like any other grief by the indiscriminate application of general bereavement theory. Over the last decade, the recognition of the peculiar and particular nature of grieving after the death of a baby or infant and a recognition of the variety of responses such an event elicits, has led to a re-appraisal of approach. This

progression will be apparent in the particular way in which I present the emerging literature in the field.

Furthermore, recent interest in holism in both pastoral and medico-nursing literature and practice has meant that 'spirituality' (often very loosely, and often inaccurately, described) has once again begun to emerge as an important component of whole-person care of the dying and the bereaved.[118] I shall argue that it is important that practice is informed by rigorous theological critique if this is to be effective, and if death and dying, grief and grieving are to be released from captivity to a too narrow, exclusively 'medical', model,

In the increasingly technological world of modern medicine, and especially in that of obstetrics and neo-natology, I shall argue, then, for the place of theological virtues and of theological reflection in what is, and must always remain, a deeply human situation. Only thus will care be both humane and person (rather than problem) centred. The language of human personhood and of what that means in terms of both experience, cognition and beliefs, and the structure of personal and inter-personal relationships, will, therefore, provide a recurrent theme in this work.

Such considerations are therefore of academic importance and, as such, should be subject to academic rigour, but they are also about how we deal sensitively and compassionately with those who are among the most vulnerable of our neighbours - those who are bereaved through the death of their baby. It is my contention that such people will be best served neither by theorising nor by uncritical practice alone, but rather by a 'both...and...' approach that reflects upon, learns from, and advances the research and experience of the last thirty years in particular and applies what has been, and continues to be, learned in ways which are both professional and humane.

NOTES:

1 I shall not attempt here to assess the impact of 'fictional' death in films etc., other than to say that I believe that a high exposure to it can distort our ability to distinguish between 'fictional' and 'real' death and may thus lead to a diminishing of our

ability to recognise and accept the reality of death as something that is universal, final and irreversible.

2 See P. Ariès, *Western Attitudes Towards Death* (Baltimore: Johns Hopkins University Press, 1974). This excellent book examines changing attitudes towards death in Western culture. Ariès argues that in contemporary culture death is 'furtively pushed out of the world of familiar things.' (p. 105). See also, I. Illich, *Limits to Medicine* (Harmondsworth: Penguin Books, 1977), who argues that 'natural' death has been replaced by 'medicalised' death, death controlled by professionals. Illich argues that the doctor has replaced the priest as the person most likely to be present at the point of death and to define its 'meaning'. Tony Walter says, 'Patients are not obliged to see the chaplain in the way they are obliged to see doctors and nurses: from the patient's point of view, the chaplain is an optional extra.' (T. Walter, 'Secularization,' in C.M. Parkes, P. Laungani and B. Young eds., *Death and Bereavement Across Cultures* (London: Routledge, 1997), p.177.).

3 Despite the advances which have led to a fall in infant mortality of <1% in the Western world by the beginning of the twenty-first century, it should be remembered that, of the estimated 1 million pregnancies that begin every day over half will end in miscarriage or stillbirth, between 15-20% are aborted, and of those children born live, some 10% will die in their first year of life. A. Oakley, A. McPherson and H. Roberts, *Miscarriage* (Harmondsworth: Penguin, 1990), p.5. As Martin Heidegger so wryly observes, 'As soon as man comes to life, he is at once old enough to die.' (*Being and Time* (London: SCM, 1962), p.289).

4 Ivan Illich speaks in this regard of 'disabling professions'. This 'medicalisation' of life and death has removed birth from the home to the hospital. Alice Lovell has argued that this has 'drawn women both as providers and users of care into a relationship with medicine characterised by male dominance and female subjugation.' As a result, the impact of miscarriage (and other perinatal deaths) has been devalued, 'put at the bottom of the bereavement heap.' ('Death at the Beginning of life,' in D. Field, J. Hockey and N. Small, eds. *Death, Gender and Ethnicity* (London: Routledge, 1997), p.31.).

5 B. Raphael, *The Anatomy of Bereavement* (London: Routledge, 1984), p.37.

6 Ibid., p.37. Although attitudes have begun to change and a growing sensitivity is being shown to the needs of the bereaved, there is a marked lack of consistency of care and the attitudes noted by Raphael are still far from uncommon.

7 *Death, the Final Stage of Growth* (Englewood Cliffs, NY: Prentice Hall, 1975). As Jennifer Hockey says, '...our conception of 'death' and its relationship to 'life', are not only expressed in, but also generated through, the culturally specific forms or institutions through which we manage death.' (*Experiences of Death: An Anthropological Account* (Edinburgh: Edinburgh University Press, 1990), p. 8.).

8 *Death, Mourning and Caring* (Pacific Grove CA: Brooks/Cole Publishing Company, 1997), p.16.

9 Hans Küng questions whether, with the scale of modern exposure to death, we can, in fact, speak of death as taboo, particularly through media reporting and film. (*Eternal Life* (London: SCM, 1984), p.159), a view more recently reinforced from a sociological perspective by Tony Walter (*The Revival of Death* (London: Routledge, 1994)). See also, P.A. Mellor, ' Death in High Modernity: The Contemporary Presence

and Absence of Death,' in D. Clark ed. *The Sociology of Death: Theory, Culture, Practice* (Oxford: Blackwell, 1993), pp.11-29, who argues that death is not 'forbidden' but 'hidden' and therefore 'sequestrated from public life.' (p. 11).

10 See for example, G. Gorer, *Death, Grief and Mourning in Contemporary Britain* (London: Cresset Press, 1965). 'Mourning is treated as if it were a weakness, a self-indulgence, a reprehensible bad habit instead of a psychological necessity... the majority of British people today are without adequate guidance as to how to treat death and bereavement and without social help in living through and coming to terms with the grief and mourning which are the inevitable responses in human beings to the death of someone they have loved.' (p.110).

11 There may be some significant differences here, especially concerning anger, between urban and rural communities, with rural communities regarding death as part of a 'natural' cycle; whereas urban communities operate with a predominant model of death as dysfunction. See J. H. Pye, 'A Life after Death: Some Notes for the Professional Worker', 1985.Unpublished lecture.

12 *Life's Living toward Dying* (Grand Rapids: Eerdmans, 1996), p. 27. Paul Ballard describes this 'modern' approach to death as 'what happens to marginalised people on the margins of society.' (*Facing Death: An Interdisciplinary Approach* (Cardiff: University of Wales Press, 1996), p. 10.).

13 The role of personal and social support in the outcome of mourning is well documented. See for example, S.K. Stylianos and M. Vachon, 'The Role of Social Support in Bereavement,' in M.S. Stroebe, W. Stroebe and R.O. Hansson, eds. *Handbook of Bereavement: Theory, Research and Intervention* (Cambridge: Cambridge University Press, 1993), pp.397-410.

14 F. Dominica, 'Reflections on Death in Childhood,' *British Medical* Journal, *294* (1987), 108-110. Catherine Sanders estimates that a third of all major bereavements 'result in problems where professional help may be required.' ('Risk Factors in Bereavement Outcome,' in Stroebe, Stroebe and Hansson, *Handbook of Bereavement*, p.255). The death of a child is particularly associated with psychiatric morbidity. The research of L. Edelstein in the mid-1980s suggested, however, that relatively few bereaved people sought professional help from sources other than GPs or clergy. (*Maternal Bereavement* (New York: Praeger, 1984)). The growth of professional bereavement support agencies, especially after pre- and perinatal deaths has been relatively late to emerge.

15 C. M. Parkes, 'Introduction,' in *Death and Bereavement Across Cultures*, p. 4. Durkheim describes this de-regulation of grief as *anomie* - not personal freedom but a sense of being at a loss. The issues of ritual and death are explored in detail in the chapter on the pastoral nature of liturgy.

16 The wearing of black or the drawing of curtains in the home of the deceased, for example, were clear social markers that the bereaved were engaged in a publicly recognised and sanctioned state - i.e. mourning. Victorian 'codes' of mourning rooted the mourning process in a social context, providing a framework to facilitate the passage through grief. For a good description of this transition see D. Clark, 'Death in Staithes,' in D. Dickenson and M. Jones eds. *Death, Dying and Bereavement*, (London: Sage Publications, 1993), pp.4-10.

17 One woman, whose husband had died six months previously, came to a course which I was running in 1995 on Loss and Grief. When I spoke about the three-fold nature of death as being something that is inevitable, final, and irreversible, she left the room. Talking with her later, she confided that this was the first time she had been made to face up to the fact that her husband was not just 'dead' but 'dead *and not coming back....*'.

18 On this theme see for example, Illich, *Limits to Medicine,* Chapter 5, 'Death against Death,' pp. 179-215.

19 *A Grief Observed* (London: Faber, 1966), p.16.

20 See Illich, *Limits to Medicine* and M. Foucault, *Birth of the Clinic* (New York: Pantheon, 1973). The issue of the value of neo-natal hospices was suggested to me as an area of research by the late Prof. David Baum in 1987.

21 It is not always easy to define what constitutes 'good' practice, as practice, by its nature, evolves. What may at one stage be regarded as good practice may be superseded as knowledge and experience lead to new insights. The fundamental question of what, in fact, shapes good practice and what, therefore, might allow a qualitatively definable standard of practice to be developed and implemented will, in part, be the subject of this work.

22 In, *Passing On* (Englewood Cliffs NJ: Prentice Hall, 1976), David Sudnow argues that because of this shift in the nature of hospitals, doctors and nursing staff (and, one might interpolate, even Chaplains!) may, albeit unconsciously, demonstrate a sense of discomfiture, guilt and even anger in their behaviour and attitudes when people who have been entrusted to their care die in the face of all their efforts.

23 It is not uncommon, in the early stages of grief for those surrounding the deceased and in whose care he or she has been, to become the objects of blame by grieving relatives as they seek to give meaning or reason for the death of the loved person. Such blaming (which will be explored in greater detail later) may have many targets, the self ('I should have seen it...'), the hospital or medical staff ('You should have done more...'), the Chaplain or other clergy - as those who stand proxy for God ('God took my husband/wife/child...') or even the dead person ('How could he/she leave me like this...').

24 Kübler-Ross, *Death, the Final Stage of Growth* p.26.

25 Raphael, *The Anatomy of Bereavement,* p.23.

26 Lewis, *A Grief Observed,* p.16. Lewis' description of his grief is combined with theological reflection, especially on the nature of God, suffering and the centrality of love.

27 R. Weston, T. Martin and Y. Anderson, *Loss and Bereavement: Managing Change* (Oxford: Blackwell, 1998), p. xi.

28 D. Field, J. Hockey and N. Small, 'Making Sense of Difference: Death, Gender and Ethnicity in modern Britain,' in *Death, Gender and Ethnicity,* p.1.

29 'Mourning and Melancholia,' *Complete Psychological Works of Sigmund Freud* (Standard Edition), ed. J. Strachey, vol. XIV, (London: Hogarth Press, 1917).

30 'The Symptomology and Management of Acute Grief,' *American Journal of Psychiatry, 101* (1944), 141-148.

31 Lindemann's study lacks any control group and is without any indication of the number or frequency of his subject interviews.

32 See J.R. Averill,'The Functions of Grief', in C.E. Izard ed. *Emotions and Personality and Psychopathology* (New York: Plenum Press, 1979), pp.339-367.

33 'Totem and Taboo,' *Complete Psychological Works of Sigmund Freud* (Standard Edition, vol. XIII), p.65.

34 By contrast, the development of bereavement work within healthcare structures which are predominantly orientated towards 'healing' or 'curing', has tended to treat bereavement as a medical condition. Grief has thus been pathologised.

35 In 'Totem and Taboo', however, Freud explored the notion that the bereaved may be tormented by the belief that they may have somehow contributed to or caused the death. (*Complete Psychological Works*, vol. XIII, pp.18-74).

36 'Is Grief a Disease? A Challenge for Medical Research,' *Psychosomatic Medicine, 23* (1961), 18-22.

37 Engel would measure pathological mourning in terms of the degree of functional impairment present in the grieving person. Debate still continues about when grief should, in fact, be considered pathological.

38 *Bereavement: Studies of Grief in Adult Life* (Harmondsworth: Pelican Books, 1975). Parkes identified several stages or 'phases' in the grief process - numbness, yearning and protest, and disorganisation. Later, he was to add a fourth phase - re-organisation. By contrast, Taylor *et.al.* argue that, '(b)ereavement is not an illness that can be cured. It is a situational adjustment to a loss that may take a lifetime of work.' J. Taylor, J. DeFrain and L. Ernst, 'Sudden Infant Death Syndrome,' in T. Rando ed. *Parental Loss of a Child* (Illinios: Research Press Company, 1986), p.174. Like Parkes, then, they regard bereavement as, fundamentally, a 'stressor', while, like Worden, they see its aftermath as 'work' orientated.

39 These arguments continue. It is interesting to note, however, that pathological grief finds no place in standard diagnostic manuals (e.g. DSM III/IV-R). It does not therefore seem to be regarded as an identifiable or measurable clinical entity. This may suggest that the concept is, at least in part, dependant upon cultural norms.

40 Alongside Freud, *Mourning and Melancholia*, see also K. Abraham, *Selected Papers on Psychoanalysis* (London: Hogarth, 1927).

41 'Absence of Grief,' *The Psychoanalytic Quarterly, 6* (1937), 12-22.

42 'Mourning and its Relation to Manic Depressive States,' *International Journal of Psychoanalysis, 21* (1940), 125-153.

43 *The Psychology of Women: A Psychoanalytic Interpretation*, vol.2, (Grune & Stratton: New York, 1944), p.263.

44 'Mourning and its relation to Manic Depressive States,' 125-153.

45 'Reactions of Women to Peri-natal Death,' *Australia and New Zealand Journal of Obstetrics and Gynaecology, 10* (1970), 207-10.

46 *Bereavement.*

47 Furthermore, medical models of grieving, as fundamentally atomistic, characteristically focus on particular aspects of grief (symptomology or pathology) and

therefore often fail to see the bigger picture and to recognise that when we grieve we do so as 'whole' persons. Terry Martin and Ros Weston offer a timely caveat:

> In understanding any phenomenon or experience in life, models and theories can play an important part. There is a danger in detaching and distancing ourselves from the immediacy and primacy of experience in abstractions and generalisations. Nevertheless, without some way of organising experience, we will learn little from it and face new experiences without resources to guide and inform our response. The importance of models and theories of grief is not to interpret events in a rigid and inflexible way, but to provide generalisable clues and patterns to the unfolding of what would otherwise be a bewildering variety of human experience.

Loss and Bereavement: Managing Change (Oxford: Blackwell, 1998), p. 9.

48 'The Symptomology and Management of Acute Grief,' 141-148.

49 This somatic symptomology is well described by C. S. Lewis, *A Grief Observed*, p.7.

50 'The Symptomology and Management of Acute Grief,' p.147.

51 Ibid., p.144.

52 G. Caplan, *Principles of Preventive Psychiatry* (New York: Basic Books, 1964). Crisis theory describes the state of helplessness into which the individual is thrown by a 'crisis' event. This occurs when former coping strategies fail and the individual turns increasingly to others for help. Crisis theory has provided a useful model in the understanding of bereavement, not only by underscoring the importance of social support in resolving grief, but in alerting people to the increased susceptibility to conscious or unconscious manipulation in the bereaved by those, professional or lay, by whom such support is provided. The Preface to this book was written by John Bowlby.

53 *Attachment and Loss*, 3 vols. (Harmondsworth: Penguin Books, 1991. First published, 1980).

54 *Bereavement.*. In the foreword to this study of adult grief, focussed mainly on the study of widows, John Bowlby makes the following observation:

> Considering the attention given to the subject by Freud half a century ago and the classical work of Lindemann in the early forties, it is remarkable that psychiatrists have been so long in recognising bereavement as a major hazard to mental health. Not until this past decade has any sustained research been mounted, and hitherto few books on grief by psychiatrists have been published.

See also, Bowlby, *Attachment and Loss* vol.3, p.3.

55 E.g., *Bereavement*, pp.46f; 'Bereavement and Mental Illness', *British Journal of Medical Psychology 38* (1965), pp.1-26.

56 Here, Parkes discusses the theories of 'fight and flight' with especial reference to Caplan's 'crisis theory' See Caplan, *Principles of Preventive Psychiatry*.

57 Parkes relates this to the stages described by Bowlby as the stages of 'yearning' and 'searching'. Bowlby, *Attachment and Loss* vol.3, p.85f. in which Bowlby identifies as the four phases of mourning (1) numbing (2) yearning and searching (3)

disorganisation and despair (4) reorganisation. Parkes refers to the second stage as 'yearning and protest' (op.cit.p.57.).

58 This section begins, again, with reference to Bowlby's, *Attachment and Loss* vol.3: 'To Bowlby anger is a normal component of grief...' (*Bereavement*, p.100.).

59 Bowlby, *Attachment and Loss* vol.3, p.1.

60 Attachment behaviour is, 'any form of behaviour that results in a person attaining or retaining proximity to some other differentiated and preferred individual.' *Attachment and Loss* vol.3, p.39. Such affectional bonds occur initially between infant and parent (or care-giver) and later between adult and adult. Views about the child's ability to differentiate between persons, to hold an idea of a particular person when that person is absent (person permanence/object constancy) were to play an important role in the debate over whether, or at what stage in their development, children can be said to 'grieve'. This debate continues and will be discussed separately later on.

61 Ibid., pp.15f.

62 Ibid., p.7.

63 This work was to be further developed in their explorations of grief in children by workers such as S. Anthony, *The Discovery of Death in Childhood and After* (Harmondsworth: Penguin, 1981) and I. Orbach and A. Glaubman, 'The Concept of Death and Suicidal Behaviour in Young Children,' *Journal of the American Academy of Child Psychiatry, 18*, 4 (1979), 668-678). One of the most significant articles on this theme, to be developed later, was that by M. Nagy, 'The Child's Theories Concerning Death,' *Journal of Genetic Psychology, 73* (1948), pp.3-27.).

64 This is very much in line with Freud's psychodynamic ideas about the place of ambivalence in *Mourning and Melancholia*.

65 It is important to note that these stages are not clear-cut and that process theory provides a model rather than a blueprint for the grieving experience. Those who grieve may fluctuate between stages over the course of grieving, demonstrating the 'episodic' nature of grief which may be experienced as 'waves' of emotion or distress (as Lindemann), ebbing and flowing like the tide.

66 This does not imply anything that is 'done for' the patient but the creation of an environment in which the impending death, because it is not being denied, verbally or non-verbally, by others, can be accepted by the dying patient as a reality. L. Pincus, *Death in the Family* (New York: Random House, 1974), provides a number of useful clinical descriptions from the context of systems theory which show how important the interaction between individuals in such a context actually is.

67 *Lancet,1* (1967), 37-41.

68 Two important articles, one by A.C. Cain, I. Fast and M.E. Erickson, 'Children's Disturbed Reactions to the Death of a Sibling', and the other by A.C. Cain, and I. Fast, 'Fear of Death in Bereaved Children and Adults', though not cited by Simon Yudkin in his article in *Lancet* had appeared in the United States in the *American Journal of Orthopsychiatry, 34* (1964), 741-52 and 278-79 three years earlier.

69 S. Anthony, *The Discovery of Death in Childhood and After* (Harmondsworth: Penguin Books, 1981).

70 *Interventions with Bereaved Children* (London: Jessica Kingsley, 1995).

71 London: Cassell, 1995.

72 London: Harper Collins, 1992.

73 London: Routledge, 1997.

74 *Caring for the Whole Child: A Holistic Approach to Spirituality* (London: The Children's Society, 1995).

75 P.F.H. Giles, 'Reactions of Women to Perinatal Death,' *Australia and New Zealand Journal of Obstetrics and Gynaecology, 170,* 10 (1970), 207-10.

76 For a broader family response see, for example, R.R. Vollman, A. Ganzert, L. Richer, and W.V. Williams 'The Reactions of Family Systems to Sudden and Unexpected Death,' *Omega, 2* (1971), 101-6.

77 J.H. Kennell, H. Slyter and M.K. Klaus, 'The Mourning Response of Parents to the Death of a Newborn Infant,' *New England Journal of Medicine, 238* (1970), 344-49.

78 E. Lewis and A. Page, 'Failure to Mourn a Stillbirth: An Overlooked Catastrophe,' *British Journal of Medical Psychology, 51* (1978), 237-41. See also E. Lewis, 'Mourning by the Family after a Stillbirth or Neonatal Death,' *Archives of Disability in Childhood 54* (1979), 303-306, and E. Lewis, 'The Management of Stillbirth: Coping with Unreality,' *Lancet, 2* b (1976), 619-20.

79 M.T. Nicol, J.R. Tomkins, N.A. Campbell, and J.S. Syme, 'Maternal Grieving Responses after Perinatal Death,' *Medical Journal of Australia, 144* (1986).

80 D.I. Tudehope, J. Iredell, R. Rodgers, and A. Gunn, 'Neonatal Deaths; Grieving Families,' *Medical Journal of Australia, 144* (1986), 290-291.

81 B. Raphael, 'Grieving Over the Loss of a Baby,' *Medical Journal of Australia 144* (1986), 281-2.

82 S. Bourne and E. Lewis, 'Pregnancy after Stillbirth or Neonatal Death,' *Lancet, 2* (1984), 31-33.

83 Among the most important 'early' books of the 1970s and 1980s are Pincus, *Death in the Family*, and L.G. Peppers and R.J. Knapp, *Motherhood and Mourning* (New York: Praeger, 1980).

84 Raphael, *The Anatomy of Bereavement*, provides a comprehensive and systematic overview of the development of theories of bereavement and grief management as well as being an excellent practice handbook.

85 Among the most respected 'broad-spectrum' book is William Worden's *Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner* (London: Routledge, 1991). Worden's work summarises and synthesizes much of the work done on bereavement and postulates an essentially task based theory of grieving. He regards the tasks of grieving as four-fold: 1. To accept the reality of the loss, 2. To work through to the pain of grief, 3. To adjust to an environment in which the deceased is missing, and 4. To emotionally relocate the deceased and move on with life. When Worden had first proposed his 4-task theory in 1983, he had defined the fourth task as, 'withdrawing emotional energy from the deceased **and investing it in another relationship**' (my stress). By 1991, Worden had revised this to say, 'to find an appropriate place for the deceased in their emotional lives'. Also of note is Susan Lendrum and Gabrielle Syme's, *Gift of Tears: A Practical Approach to Loss and*

Bereavement Counselling (London: Routledge, 1992). Using a blend of counselling practice and theory Lendrum and Symes provide both a theoretical framework for work with the bereaved with useful exercises and summaries. The work of Lendrum and Syme has recently come under criticism for its subjective emphasis on talking about feelings to the neglect of talking about the person who has died. Writers in the field of bereavement such as Walter argue that the deceased has an important place in the bereaved's on-going biographies and therefore there is as much a need to talk about the person who has died as about the emotions or feelings which the death of that person has precipitated. See, for example, Walter, T. 'A New Model of Grief: Bereavement and Biography,' *Mortality, 1*, 1 (1996), 7-25. A more specialised approach is developed by Alida Gersie in *Storymaking in Bereavement: Dragons Fight in the Meadow* (London: Jessica Kingsley Publishers, 1991). In this imaginative and creative book Alida Gersie reflects on the processes of grief through the use of myth and story and offers the reader a number of models in which metaphor and allusion can be used in processing the grief experience.

86 *On Children and Death* (London: Macmillan, 1983).

87 *When Pregnancy Fails: Coping with Miscarriage, Stillbirth and Infant Death* (London: Routledge and Kegan Paul, 1982).

88 *The Bereaved Parent* (London: Souvenir Press 1979).

89 *On the Death of a Child* (Oxford: Radcliffe Medical Press, 1993).

90 *Loss and Bereavement in Childbearing* (Oxford: Blackwell Scientific Publications, 1994).

91 *At a Loss: Bereavement Care When a Baby Dies* (London: Bailliere Tindall, 1994).

92 *Empty Cradle, Broken Heart: Surviving the Death of Your Baby* (Colorado: Fulcrum Publishing, 1991).

93 *When the Dream is Shattered* (Adelaide: Lutheran Publishing House, 1988).

94 Among other resources available for 'professionals' are videos such as the one produced by FSID or Jenni Thomas' video, 'On the Death of a Baby' produced by Oxfordshire Health Authority. For a review of this material see Review Article by J.H. Pye in *Audiovisual Librarian, 20*, 2 (1994), 154-155.

95 *Continuing Bonds: New Understandings of Grief* (Philadelphia: Taylor and Francis, 1996). This view is also tentatively put forward by Thomas Attig in *How We Grieve: Relearning the World* (Oxford: Oxford University Press, 1996), Ch.6. Attig's primary contribution, however, is to suggest that grieving, far from being passive, involves people constantly in active choice, in a process which he describes as 'relearning', whether in the Freudian sense of learning how to live in a world from which the deceased is now absent or, in Klass' terms, learning to live in new ways with our memories of the deceased. Similarly, Tony Walter has argued that, 'the purpose of grief is not to move on without those who have died, but to find a secure place for them.' ('A New Model of Grief'). I also find this view in the work of Therese Rando, who describes grieving as a process of 'accommodation' (a Piagetian term), integrating loss into the rest of life since 'a truly final closure cannot be obtained and is not even desirable.' ('Grieving and Mourning: Accommodating to Loss,' in H.Wass and R.A. Niemeyer eds. *Dying: Facing the Facts* (Washington DC: Taylor and Francis, 1995), p.221). Issues of 'closure' (when grief ends) have been a significant issue in modernist

theories of grief, which have focussed predominantly on 'getting over' grief, 'getting on' with life, and 'leaving the past behind'. The strength of 'new' theories of grief is that they offer a range of cultural and multi-disciplinary perspectives. In this sense, they may be described as 'post-modern' theories.

96 M. Stroebe and H. Schut, 'The Dual Process Model of Coping with Loss'. Originally presented as a paper at the *International Working Group on Death, Dying and Bereavement,* St. Catherine's College, Oxford, June 26-29, 1995.

97 *The Nature of Grief: The Evolution and Psychology of Reactions to Loss* (London: Routledge, 1999).

98 A. van Gennep, *The Rites of Passage* (Chicago: University of Chicago Press, 1960), R. Cecil, ed. *The Anthropology of Pregnancy Loss* (Washington DC: Berg, 1996), J. Hockey, *Experience of Death: An Anthropological Account* (Edinburgh: Edinburgh University Press, 1990).

99 This mostly takes the form of discussing the funeral and its importance in the psychological process of relinquishing the dead but largely ignores both the spiritual significance and theological implications of the death for the bereaved.

100 S.R. Schuchter and S. Zisook, 'The course of normal grief,' in Stroebe, Stroebe and Hansson, ed. *Handbook of Bereavement,* pp. 42-43.

101 S.S. Rubin, 'The Death of a Child is Forever: The Life Course Impact of Child Loss,' in Stroebe, Stroebe and Hansson ed. *Handbook of Bereavement,* p.289. Rubin argues strongly for a multidimensional approach to such bereavements.

102 *When a Baby Dies: The Experience of Late Miscarriage, Stillbirth and Neonatal Death* (London: Harper Collins,1991), p. 9.

103 Raphael, *The Anatomy of Bereavement,* p.19.

104 Death poses not only the question, 'What does *this* death mean?' but precipitates wider existential and theological questions like, 'Why do human beings exist?' and 'What is the meaning of life and to what end (or towards whom) is it directed?' The experience of death and bereavement can often lead to a 'cascade' of such questions which whilst they may lead, in some, to a profound existential anxiety, in others they may lead to a fundamental re-evaluation of life and a re-orientation of values, beliefs or actions.

105 See, P.C. Rosenblatt, D.A. Jackson and R.P. Walsh, *Grief and Mourning in Cross Cultural Perspective* (London: HRAF Press, 1976); Parkes, Laungani and Young, *Death and Bereavement Across Cultures.*

106 Ariès, *Western Attitudes Towards Death* and P. Ariès, *The Hour of Our Death* (London: Allen Lane, 1981).

107 Illich, *Limits to Medicine*. p.180.

108 On this theme see also Foucault, *The Birth of the Clinic*.

109 Illich, *Limits to Medicine*, p.181.

110 Ivan Illich argues that during the Middle Ages, in a transition from the dominance of cyclical time to that of liner time, death became the time when the linear time ends. He writes, 'The proliferation of clocks symbolises this change in consciousness. With the predominance of serial time, concern for its exact measurement, and the recognition of the simultaneity of events, a new framework for

the recognition of personal identity is manufactured. The identity of the person is sought in reference to a sequence of events rather than in the completeness of one's life span. Death ceases to be the end of a whole and becomes an interruption in the sequence.' (Illich, *Limits to Medicine*, p.187).

111 S. Pattison *Alive and Kicking: Towards a Practical Theology of Illness and Healing* (London: SCM, 1989), Ch.2 provides an excellent summary of the medical model.

112 In *The Revival of Death*, Walter argues that modern death has been de-socialised, de-culturalised and de-ritualised.

113 Kübler-Ross, *On Death and Dying*.

114 Walter, *The Revival of Death*, pp.57f.

115 J. Hockey, *Experience of Death: An Anthropological Account* (Edinburgh: Edinburgh University Press, 1990). The concept of *agape* is one which will be of great importance in this thesis.

116 'Contemporary Representations of 'Good' and 'Bad' Death,' in Dickenson and Johnson eds. *Death, Dying and Bereavement*, pp. 68-71.

117 John Archer has argued that, in recent years, the study of grief has been 'hijacked by psychiatry,' *The Nature of Grief*, p.2.

118 This involves a psychosocial as well as a biomedical model of therapeutic engagement. Writing in the 1990s, Colin Murray Parkes has this to say:

> Psychosocial medicine has been around a long time, but it used to be called 'tender loving care'. It relied on the communication skills and life experiences of the caregivers and was none the worse for that.

C.M. Parkes, 'Bereavement as a PsychoSocial transition' in Stroebe, Stroebe and Hansson, ed. *Handbook of Bereavement*, p.99. I shall argue in this thesis that the Christian concept of *agape* - unconditional love, provides a fuller and better model since its focus is not on the skills or experiences of the caregiver alone, but on the dying or bereaved person as valued 'other' in a dynamic of mutual care and recognition. Too often, however, spirituality has been defined solely in terms of religious affiliation. It has been too often assumed, therefore, that the conditions of the Patients' Charter have been met simply by the provision of a hospital chapel and by assuring access for patients to appropriate religious functionaries. Spirituality, however, is much wider than this. While it is beyond the scope of this thesis to discuss fully the nature of spirituality, see my contributions to the MA in Independent Practice (Nursing), University of Leeds and the MA in Healthcare Chaplaincy, University of Leeds and 'What do We Mean by 'Spirituality' and 'Spiritual Care'?' in J. H. Pye, *Dementia: A Challenge to Care* (Brisbane: Blue Nursing Services, 1997), pp. 15-34.

Chapter 2. Miscarriage and Other First-trimester Losses

Hermione: Pray you, sit by us, and tell's a tale.

Mamillius: Merry or sad shall't be?

Hermione: As merry as you will.

Mamillius: A sad tale's best for winter. I have one.

(A Winter's Tale, II, i 21)

Introduction - What is miscarriage?

The dialogue between Hermione and Mamillius in Shakespeare's, *A Winter's Tale* is a salutary reminder that not all stories have happy endings, even when the expectation that they will do so is as high as is generally the case with a planned or wanted pregnancy. Whilst most people would consider pregnancy to be a major positive life event, nonetheless, it is estimated that up to one fifth of all pregnancies ends in a miscarriage.[1]

Miscarriage, or spontaneous abortion, is defined under the 1992 Stillbirth Definition Act as any loss of pregnancy before the 24th. week of gestation. It is a much more common event than has often hitherto been acknowledged and it is estimated that, in the United Kingdom alone, miscarriage currently affects some 426,000 women and their families each year whereas there are some 640,000 live births.[2] Despite being so common, however, miscarriage and its impact has largely been overlooked in bereavement literature, to the extent that it has been poignantly described as a 'silent' problem and its effects as a 'hidden' grief.[3] Families who have experienced a miscarriage or miscarriages commonly describe the pain which they have felt when their emotional needs have gone unrecognised or have been blatantly ignored, not least by those to whom they have looked most directly for help or support. In an article describing its work, the Miscarriage Association begins, for example, by saying, 'A baby's death under any circumstances is extremely distressing, but a miscarriage is a taboo subject which no-one wants to talk about.'[4]

Jane Littlewood writes:

> Miscarriages and induced abortions may be difficult losses to cope with, because in most cases there is no body to mark the fact that a death has occurred. Furthermore, in social terms, these deaths tend to be treated as non-events - the deaths of non-persons. However, for the mother and to a greater or lesser extent, depending on his degree of involvement, the father, the unborn child may, indeed, have achieved the status of personhood.[5]

Families who experience a miscarriage are still some of the most marginalised among the bereaved, even among those whose bereavement occurs through the death of a child.[6] In part, this relates to difficulties in identifying when human 'being' begins, and begins to matter morally, and in establishing reliable criteria for defining the end and the beginning of life.[7] This, I will argue, is as much a theological question as it is a biological one.

To experience the death of a child is to experience that unseasonable death which signals, not only the physical death of an individuated human being, but also the violation of parental and familial hopes and expectations both for self and for an individuated other. Such feelings of 'loss' are often compounded in miscarriage where such individuation has not yet been unequivocably achieved. Hence, there may be confusion about whether a 'death' has occurred since it is far from clear whether any 'life' had yet begun which could in any sense now be described as having been extinguished.

Before discussing pastoral care after miscarriage, I will describe the phenomenon of miscarriage itself. It is important not to leave miscarriage hostage to medical definition alone, which might run the risk of making care overly problem-centred. Nonetheless, an understanding of the biological and physiological processes involved will clearly form an important part of any care which is both holistic and person-centred since to exclude the biological and physiological would be not only to fail to see the whole picture, but to display an equal arrogance of perspective. To view the woman who miscarries as a biopsychosocial unity, and above all as a person-in-

relation is, I would argue, essential to any care which is to be both person-centred and effective.

I will outline first, therefore, some of the known causes of miscarriage, and then go on to examine the effect of miscarriage on the psychological and emotional responses of women and their families. It will be my contention throughout that an understanding of the beliefs underlying the responses of professionals and others to miscarriage (such as that which concerns the perceived moral or relational status of the unborn human, irrespective of its biological development) is essential if care is to be both informed and effective. A theological and philosophical analysis and response, as much as a medical and social one, will therefore be a critical component of good practice whether in the hospital or in the community.

Physiological aspects of miscarriage

Miscarriages may be variously described according to type, gestational age, and previous obstetric history. Miscarriage may be 'threatened', 'complete' or 'partial', 'missed' or 'recurrent'. Whilst these events, and the experiences which cluster round them, may share much in common, there are also significant differences between them which call for differing emphases in their medical, social and pastoral management.

Spontaneous abortion

Put at its simplest, miscarriage is the premature delivery of an embryo or fetus showing no signs of life and before the gestational age of viability.[8] From a medical perspective, miscarriage may be construed as a 'natural' process and as a 'normal' variant in pregnancy, in that it is effectively a spontaneously initiated delivery and not primarily the product of either intervention or neglect.[9]

Pregnancy itself is a process which involves a complex interaction between the 'mother' and the developing pre-embryo, embryo or fetus.[10] In immunological terms, such a pre-embryo, embryo or fetus may be described as, in effect, a 'foreign' body

residing within the mother and dependent upon its host for its survival for most of the nine months of the human gestational period.[11] Where this symbiotic interaction breaks down, for whatever reason, a miscarriage or stillbirth may occur and the embryo or fetus is rejected or expelled.[12] To say on the basis of this, however, that a miscarriage is therefore simply 'nature's way' of rejecting an abnormal embryo or fetus is a clichèd over-simplification of the issues involved. It may sometimes, indeed, simply be untrue and such an 'explanation' may, for many women and their families, serve only to compound feelings of guilt or shame about the 'imperfect' being which they have created and feelings of failure about themselves.[13] In about 50% of miscarriages, nonetheless, there is some form of discernible genetic abnormality present in the embryo or fetus, especially in those miscarriages which occur between the 7th-14th weeks, the period in which the majority of miscarriages happen. The majority of such genetic 'errors', which occur during the division of cells (meiosis), are believed to occur purely by chance and are, at least in a genetic sense, simply 'bad luck'. The chances that a similar genetic 'accident' will recur in a subsequent pregnancy or pregnancies are only slightly increased after a first miscarriage with a gradual increase in incidence after any subsequent miscarriage or miscarriages.[14] In other cases (e.g., those involving balanced translocations[15]), the genetic inheritance of the parents may be involved and post-mortem examination of embryonic or fetal cells may reveal a genetic abnormality that may indeed prove to be recurrent. In such cases, a miscarriage may represent the loss not only of a particular pregnancy but also of the possibility of other, future pregnancies as well. Then, there is frequently a complex interaction of griefs which needs to be faced - for the current pregnancy and for the child or children which it represented, for fertility, for trust or belief in one's body,[16] and even in one's own future survival through one's progeny.

Sometimes infection, either in the mother or the fetus, may cause the miscarriage,[17] as may physical trauma either to mother or developing embryo or fetus; the effects of certain toxins, or abnormalities in the anatomy or physiology of the mother herself. The latter may include the imperfect development of the uterus or

vagina or an incompetent cervix.[18] There may also be other forms of immunological rejection which cause a miscarriage to occur, such as those involving an incompatibility between maternal and fetal bloods.[19]

Threatened miscarriage

In the case of a threatened miscarriage, one of the first characteristic signs that all is not well with the pregnancy is often the onset of bleeding.[20] Although the pre-embryo, embryo or fetus may still be alive at this stage, there may well now already be a raised level of anxiety as the putative mother, perhaps for the first time, contemplates what 'losing' the pregnancy might mean. Some women who have gone on subsequently to experience a spontaneous abortion describe, as one of the 'warning' signs of their impending miscarriage, that they did not 'feel' pregnant any longer. Such descriptions, while they may sometimes clearly refer to physical symptomology, are, however, often non-specific in character.[21] They are, nonetheless, significant since, in some cases, grieving may now begin. Appropriate pastoral care is as important at this time as medical care. The onset of grief before a death has actually occurred was first systematically described by Erich Lindemann in 1944.[22] 'Anticipatory' grieving, as he termed it, may include some or all of the physical, psychological and emotional sequelae of grieving.[23]

If the threatened miscarriage does not then occur, how the grieving process, already having begun, is reversed or halted is a vexed question. In some cases, the putative mother has already now begun to 'relinquish' the pregnancy. To learn that it is still intact may be problematic for her. She may, in fact, no longer trust her body and may thus progressively distance herself from the pregnancy, for fear that it will not now come to term, despite the fact that it is, for the moment, continuing. The maternal-infant bonding which begins before the birth may thus be interrupted or compromised.[24] For others, the 'scare' of a threatened miscarriage will simply give way to relief that the pregnancy is continuing and, whilst there may still be some

anxiety about a recurrence of symptoms, there seems to be little adverse effect on the developing relationship between the mother and the fetus and, for some, the bond may indeed be strengthened in the explicit realisation of what a loss the miscarriage would be.

If the threatened miscarriage does occur, the appearance of what is passed from the uterus depends on how far the pregnancy is advanced.[25]

Such miscarriages may be either complete or partial. A complete miscarriage is more common up to the eighth week of pregnancy; a partial miscarriage is more likely to occur after the eighth week of the pregnancy when the placenta has had time to become more firmly attached to the wall of the uterus. In such cases, when embryonic, fetal or placental material has been retained in the uterus, an evacuation of retained products of conception (ERPC) or a dilatation and curettage (D&C) will generally need to be performed after the miscarriage has taken place.[26] Many women who miscarry can feel violated by this procedure, even if they recognise that there are sound medical reasons for performing the ERPC/D&C, especially as it is carried out so soon after the miscarriage itself, and therefore at a time when the woman is feeling particularly physically and emotionally vulnerable. The ERPC/D&C is perceived to be primarily a gynaecological, rather than an obstetric procedure. This, for many women, increases their sense of being 'failed' mothers, and so contributes to the loss of identity, lowering of self-esteem or self-worth and even of the anger that is so common in the aftermath of early pregnancy loss. Furthermore, where a ERPC/D&C has been performed, post-operatively the woman will still almost certainly be sent to a gynaecological rather than an obstetric ward, often with little or no consultation or choice in the matter.[27] The rationale for this is often expressed by healthcare professionals in terms of 'saving' women from the distress of being with other women who are still pregnant or who have just had healthy babies. In reality it serves, for some women, to increase their sense of isolation and the feeling that they are somehow now only 'failed' mothers who are, at all costs, to be kept away from those

who are, by their capacity to produce healthy children, not a 'problem' either to their families or to the healthcare system.[28]

Missed abortion

With a so-called missed abortion, the embryo or fetus dies *in utero* but instead of being passed out of the uterus through the vagina, the entire embryo or fetus is retained in the womb.[29] Although some women may again be aware that something is 'wrong' with the pregnancy or have a vague or unspecified sense of disquiet, the first real indication that the developing embryo/fetus has died *in utero* often comes as a result of routine ante-natal screening such as the ultra-sound scan. Before 14 weeks gestation, the dead embryo may be removed by dilatation and evacuation (D&E), after 14 weeks, by induced delivery.

Pre-natal diagnosis and testing

The development of ultrasound scanning (USS), and especially the introduction of modern high-resolution scans, has had a profound effect on the management both of pregnancy and of miscarriage.[30] Seeing either the screen-image or, when it is available, a hard copy of the scan is something that may help to 'fix' the image of the developing 'baby' in the putative parents' minds. Especially for the father, it may be a landmark event in acknowledging or 'owning' the pregnancy as 'real'. If a pregnancy then 'fails' and miscarriage occurs, either the memory of the visual image projected by the 'scan', or their possession of a 'hard copy' of the image, may be the only tangible evidence parents have in the days, months and years to come that this particular 'baby' ever actually existed. The photo or recalled image may thus not only be treasured as a rare and valued memento (with, for example, the hospital appointment card), but it may also be of real significance and help later on in 'testing' the reality of their experience and as a focus for grief when, as is often the case, it may all seem to them like 'just a bad dream'.[31]

Termination of pregnancy

It is now increasingly possible to detect a wider range of abnormalities in the developing embryo or fetus and at a much earlier gestation than was possible hitherto.[32] In cases where ante-natal screening or testing (such as the Leeds or triple test) indicates developmental abnormalities, the question of the future of the pregnancy and its possible termination will now almost certainly arise. Some fetal abnormalities (such as anencephaly) are incompatible with life. Others positively indicate syndromes, but without any certainty as to the nature or severity of any associated defects. Yet other abnormalities are fully compatible with life even though they carry subsequent physical or mental impairment which may range from the insignificant to severe. Any decision to terminate the pregnancy for reasons of fetal abnormality will, therefore, need to be made on what are other than medical grounds alone. Such decisions are inevitably emotionally demanding and may, themselves, precipitate some, or all, of the sequelae associated with grieving. As Brien and Fairbairn remind us,

> It is now generally agreed that having a termination for foetal abnormality evokes the same feelings as any perinatal death with the added load that this death was of course chosen... In truth there are two deaths that are grieved; the first the death of hope for the perfect baby that occurred when the results were given, and later the actual death of the abnormal baby.[33]

Further, such deaths have been described as entailing a 'double taboo' - 'First people think something is wrong with you because your baby was defective. Then they look down on you for having an abortion.'[34] For many women, there may well be an emotionally uncomfortable ambivalence as both guilt and relief exist side by side. Research has indicated that women who are frequent church attenders experience these emotions - especially guilt - more than those who are infrequent or non-attenders. While the latter are less likely to have adequate social support, the former are more likely to be subject to disapproval even when the termination is for a fetal abnormality.[35]

If, for cultural, religious or personal reasons, termination of the pregnancy is not an option, the issue of routine testing for conditions such as Down's Syndrome becomes a questionable practice. There is often an underlying assumption on the part of many healthcare professionals that, if tests reveal the existence of fetal abnormalities, therapeutic abortion will be the norm. Even when unspoken, this assumption may put many women and their partners under pressure to make decisions which they may not wish, or not be ready, to make.

> A majority (of clinicians) would agree that the aim is to help mothers avoid the birth of severely handicapped children. Others would see the aim in a wider perspective, namely to reduce the burden of handicap in the community. And clearly some would see prenatal diagnosis as giving parents control over the quality of life and sex of their children... Clinicians currently have a role in drawing the line between what is regarded as acceptable practice and what is unacceptable, and their major partners in making such decisions must be the mothers and fathers of handicapped children, for they have the necessary experience to give informed advice to the rest of society.[36]

This ambiguity may well increase the stress placed on vulnerable families at a time when they are looking to professionals for guidance and advice in an alien and bewildering situation. The influence of professionals, both clinical and non-clinical, in such situations is likely to be profound and it is important that decision-making is not influenced by one particular way of seeing the issue (the medical model) alone, but that a whole range of factors, (medical, social, psychological, emotional and spiritual) are taken into account, and are enabled to be articulated, in the decision-making process. It is essential, then, that appropriate counselling should be given *before* pre-natal testing and not simply after, when problems have already been discovered, as is so often the case.[37] It is clear that there is a diversity of opinion both between doctors and between doctors and their patients about the purpose of prenatal testing and diagnosis.

Deciding to terminate a wanted pregnancy, rather than giving birth to a disabled child, is often both particularly distressing and extremely painful for the

putative parents. Adequate time needs to be allowed for information to be absorbed and an informed decision taken after the initial shock of the diagnosis.[38] Whilst things have slowly begun to improve, too often in the past putative parents have been pressed to make a decision for termination of the pregnancy too quickly, or have been left isolated with too little support in the decision-making process. The resultant guilt, not least for the perceived complicity in ending the pregnancy, has proved to be a burden which weighs heavily for many years to come.[39] In terms of psychological and emotional impact, the feelings which follow the termination of a wanted pregnancy may be very similar, though often with different emphases, to those experienced after a miscarriage. These feelings and emotions will be described in the following section. After a termination, however, issues of guilt and of perceived complicity in the 'death' of the unborn 'baby', often present after a miscarriage, are likely to be particularly prominent, traumatic and long-term.[40] Women in this situation may feel that, because they have 'chosen' termination for fetal abnormality, they do not deserve sympathy or understanding.[41] Consequently, they may avoid talking about their feelings with others for fear of being judged.[42] This feeling may well be reinforced by societal taboos that often consider 'abortions' as a homogeneous group.

In many NHS hospitals, women who opt for a termination of pregnancy, like those who suffer an intrauterine death, are often located in gynaecological rather than obstetric wards and may therefore come to perceive themselves (as noted above) as 'failed' mothers, or even 'failed' women. Sensitive, non-judgemental, pastoral care, including appropriate ritual care, is therefore paramount in such circumstances in affirming both the woman and her unborn child. As the Methodist Report, *Status of the Unborn Human*, reminds us, '...pastoral care is not less a part of our duty to the vulnerable than is our concern for the unborn, and it must not be overlooked or undervalued.'[43]

Psychological and emotional aspects of miscarriage

Sameness and uniqueness in bereavement experiences

In the medical context, the terms 'miscarriage' and 'spontaneous abortion', are 'value neutral', denoting the 'natural' ending of a pregnancy (i.e. without deliberate human agency or intervention) before the 24th. week of gestation. Notwithstanding their medical meaning, they may, nonetheless, have psychological or emotional overtones for parents and families which are difficult to manage. Among these, blaming, guilt, anger and profound disappointment may be predominant. 'Mis-carrying' may suggest 'carrying' that has been done 'badly' or 'wrongly' and the term 'abortion', because of its common usage, even when it is prefixed by the word 'spontaneous', may nonetheless carry overtones of a wilful act or complicity in the ending of a pregnancy. It is important to recognise that for all those involved, the psychological and emotional responses to a miscarriage will be as wide-ranging as those experienced in other types of bereavement. Despite a commonality in human experience, the significance of the loss which is incurred through a miscarriage will vary from person to person and from circumstance to circumstance and a measure of ambivalence about what has happened and about its significance (i.e. how that event is to be interpreted) is likely. Even where the objective, physical circumstances of the loss may be similar, the responses to that loss may differ widely, from relief that the pregnancy has ended (though frequently accompanied by some measure of guilt or lowering of self-esteem), especially in cases where the pregnancy was unplanned or unwanted,[44] to those in which the full range of grieving sequelae, physical, psychological and emotional, are manifested, particularly in the case of a wanted or planned pregnancy. Good ritual care, as an expression of pastoral care, is therefore an essential part of the care of such families.

Who, or what, is lost?

The perception of 'who' or 'what' has been 'lost' when a pregnancy ends in an early spontaneous abortion may be similarly varied, expressions of which may range from, 'I was never really pregnant...' through to, 'my baby has died...' Behind these expressions lie different experiences (or *post facto* rationalisations) of the reality of a distinct reality or human identity. The importance of questions of identity in the management of miscarriage is one which, though often ignored or underestimated, is of extreme importance and it will be discussed later in this chapter.[45]

Although it is generally accepted that the level of maternal-infant bonding increases the longer a pregnancy progresses,[46] perceptions of the status of what has been 'lost' through the miscarriage are determined by a broader complex of factors, of which this is one, and by their interaction. Hence, there is no direct correlation between intensity and duration of grief and gestational age.[47] Miscarriages are grieved for by some with a similar range of intensity and duration as are stillbirths, neo-natal deaths, death of an older child, or a loved adult.[48] What determines whether and how a miscarriage is grieved is clearly not simply the objective biological existence or development of a pre-embryo, embryo or fetus, but its subjective meaning.

It is still commonly assumed, nonetheless, that families in which there has been a miscarriage will have substantially less to grieve for than those whose babies have been stillborn or who die *post-partum*. Those who experience miscarriage may be led to suppress their grieving if they encounter this assumption. Such an assumption fails to recognise the reality of their particular 'loss' and thus implies that their grief is inappropriate and any overt show of emotion associated with it will often be met with disapproval or sanction. Such a view among professionals is well represented by Bourne and Lewis, who in the 1970s and 1980s did so much to raise the profile of the management of stillbirths.

> There is a well meant current tendency to emphasise that grief is unrelated to the duration of a failed pregnancy, but this is not quite

> true. Equating early miscarriage with late stillbirth may aggravate bewilderment and promote difficulties with mourning.[49]

They argue that, while 'parents of stillborn infants (uncommon, 1:100 births) should be encouraged to salvage everything they can from the experience and possibly to use spiritual solace if that helps them,' by contrast, 'people should not be pushed into magnifying miscarriage (common, 1:3-4 pregnancies) into a tragedy.'[50] Far from helping those who have miscarried,

> the overzealous may interfere with the healthy resilience that enables most people to get over an early miscarriage without becoming psychiatrically disturbed.[51]

The assumption that miscarriage is something to 'get over' demonstrates just how deeply entrenched, even among those working in the field of pre-natal death, are dismissive attitudes to miscarriage. Although Bourne and Lewis are undoubtedly right to caution against turning every miscarriage into a catastrophe, they are doing no more here than to remind us that subjective interpretation as well as objective 'fact' are determinants in the course and outcome in every incidence of grief and mourning. It is clear that for many people where the loss of a pregnancy represents the loss of child, this is something that they will never, in fact, 'get over', at all. Frances Dominica knows too well the effect that encountering such assumptions can have on those who are grieving:

> I believe that the pain of bereavement is greatly intensified when society expects you to get over it quickly and you are left feeling stranded because you are a long way from complete recovery.[52]

Indeed, she sees that the process of grieving, 'is never complete; parents will never 'get over' the death of their child...'.[53] In fact, the recognition of the adverse and inhibitive effect of denying the bereaved the opportunity to grieve openly was something that had been noted as early as the late 1960s although, as so often has proved to be the case, the lessons learned from studies of adult:adult grieving were only slowly applied

to the experience of adult:child grieving and seldom, if at all, to adult:unborn child grieving.[54]

Life in a 'dark land'

As with all bereavements, then, miscarriage may have potentially devastating psychological, emotional and spiritual effects for those concerned, especially if the need to grieve is not legitimated. The 1970 study by Giles of parents bereaved in the peri-natal period, for example, found that whilst doctors were prepared to treat physical symptoms in about half the cases they avoided any talk about the death of the baby.[55] There is no reason to think that these findings would not equally apply to much earlier miscarriages. On the contrary, given the fact that until recent years miscarriage has been excluded from so much of the bereavement literature that dealt with pre- or peri-natal deaths, it could be expected that doctors and other healthcare professionals would be even less likely to enter into such discussions with women who had experienced a miscarriage.

In the management of miscarriage, therefore, great care needs to be taken that those involved with families in which a miscarriage has occurred are as clear as possible about what the miscarriage means, or might mean, to the putative parents.[56] This requires openness and attentive, non-judgemental listening to what is being said, or left un-said, but also consistent use of terminology consonant with the putative parents' perceptions of who or what has been miscarried.[57] If, for example, a phrase like, 'your baby' or even 'he' or 'she' is introduced by the professional where it is not used by the parents, a value-judgement has then already been made which may not only be inappropriate (since it compromises the autonomy of the putative parents to define appropriate meaning or meanings for what has happened for themselves), but which may be unhelpful in that it may so easily lead to confusion, distress and guilt for those who may be led, against their instincts, to feel that other, competing meanings may carry a greater validity than their own. 'If they say it was a baby then perhaps it

really was one after all.....' would be one way in which this might be expressed. Careless talk may not only cost lives, it may, in such cases, define them![58]

Conversely, 'parents' who are equally clearly grieving the death of their 'baby' may be distressed to hear their 'child' somewhat insensitively described, however accurately in purely medical terms, simply as 'the products of conception'; by the use of the term 'embryo' or 'fetus'; or even as an 'it'.[59] This may be seen as minimizing or even denying the validity and reality of their loss. The use of such technical terminology, however medically accurate, may therefore itself have the direct effect of inhibiting the ability of the family to grieve in ways which are appropriate for them since any open display of emotion may be perceived as being discouraged or disapproved of as a particular meaning is, albeit inadvertently, imposed. Whilst this situation may have a deleterious effect on grieving, an even more acute variant may be one in which there is confusion or disagreement either between the partners themselves or within the family unit as to the significance of the event, what it might mean and thus how it ought to be related to. In such cases, those most intimately involved may need to be helped, first and foremost, to see that there may, in fact, be no one, single meaning for the event which excludes the possibility of other, different meanings or interpretations or which, of itself, invalidates them.

Thus it is clear that the appropriateness or otherwise of grief after a miscarriage does not relate simply to objective or objectifying questions or statements, such as biological status or gestational age, but to subjective variables: the meaning that this entity and its miscarriage has, and the language used to describe both the event and its significance. Meaning may not be something already established and fixed but something sought. What is sought is a point of reference in the disorganisation of grief or in the strangeness of a situation which has not previously been encountered:

> The really unexpected happens so seldom that few of us know how to deal with it. We all move, for most of the time, in a small circle of known possibilities. Outside this circle lies chaos, a dark land without guide-lines.[60]

For the parents whose baby has died, at whatever stage, the 'dark land' has been entered, a place of shattered dreams and of often unimaginable anguish, in which a sense of loneliness and isolation are often the only apparent companions. Thus, what is 'normal' in such situations is, like the grieving itself, unique to each individual. It is comprised, as we have seen, not only of the objective 'facts' of the event, but also of subjective interpretations which overlay those facts with meaning. Such meaning will be defined by the complex interaction of many factors, including personal psychology, emotional needs, social relationships, education, upbringing, religion and culture - all of which may be significant factors in the emotional, psychological or pastoral management of the miscarriage and its aftermath.

The personal uniqueness of grieving, therefore, needs to be both recognised and allowed, at least as long as, and insofar as, its expression does not constitute a significant threat to the well-being either of those concerned or of others. Whilst the grief itself may be legitimated, therefore, some of the forms in which it is given expression may not always be permissible in particular contexts.[61]

Those who care for such families and their emotional needs should, then, be person-centred rather than task-centred in their approach and will need to remember that their language and actions in such situations will seldom, if ever, be, or be construed to be, value-free. The myth that medicine is a value-free enterprise is a dangerous fallacy that needs to be dispelled if we are to be realistic about its aims and practice.[62] Ultimately, therefore, such language as is used ought to be open and dialogical, and to reflect the truth of the experiences, beliefs and values of those most closely involved in the situation rather than simply those current in society, the institution or, indeed, of the individual practitioner as has hitherto so often been the case.

Expectations and responses

As miscarriage is an event so intimately linked with a woman's body and its functioning, it is also commonly an experience in which self-perception[63] is altered, and self-esteem lowered. At the same time, there may be a heightened state of perceived guilt or sense of complicity in the event. This lowering of self-esteem is often expressed in the language of 'failure' - failure to bring a child to birth, being a failure to one's husband, partner or family or to a society in which the birth of a fit and healthy child is so manifestly deemed to be the norm, despite, as we have seen, the high incidence of miscarriage.

For many women, the initial, and frequently acute, emotion after a miscarriage, is therefore one of shock at the sudden 'loss' of a wanted pregnancy. In common with other examples of sudden or traumatic losses through death, this sense of shock may be accompanied by an initial period of denial or disbelief. Denial may be a way of trying to mitigate the trauma of an event whose reality may simply, at this stage, be something that is too great or too awful to countenance. 'I can't believe what is happening....' or 'It isn't true...' are responses that are frequently encountered by those dealing with the bereaved in the early stages of their loss. Whilst such denial may recur at intervals throughout the grieving process, it is often at its most acute in the early hours or days after the 'loss' has occurred. Even in the face of the physical evidence of a miscarriage, then, there may still be an unwillingness to accept that a pregnancy has spontaneously ended, and with it, the hopes, dreams or aspirations for self and others with which that pregnancy was endowed. In the early disorganisation which follows the news of the miscarriage, the putative parents may thus appear 'remote' or 'distant' from the event. For some, there may be little initial overt evidence of 'grief' or grieving, but rather a pervading dream-like sense of unreality. The need for sensitive support at this stage is great. Whilst an apparent lack of emotion may be seen as 'taking it well...' this may, in fact, be far from the case. The state of 'being pregnant' or

of being a 'parent' has suddenly given way to not being pregnant and, perhaps, to no longer being a parent and this takes both time and effort (grief work) to assimilate.[64]

Shock and numbness eventually begin to give way to a tentative intellectual acceptance of the reality of the miscarriage. Because of the physical intimacy of the event, the first question asked by women who have miscarried is often, 'What did I do, or fail to do, that caused this to happen?'.[65] It is here that simple, clear, factual information is often at its most important in mitigating any displaced feelings of guilt or blame and in restoring a sense of control.[66] All evidence suggests that what women who have miscarried require most in the immediate post-miscarriage period are (1) an acknowledgment of their loss and (2) clear information about what has happened, expressed in non-technical terminology, made available at the time of the event.[67]

Many women who miscarry report not only being shocked and frightened by the event itself but also by their powerlessness to control what is happening in or to their own bodies.[68] For some women, the experience of miscarriage may be, in physical if not in emotional terms, a relatively painless experience. For other women, however, there may be some accompanying physical pain which may be both frightening and acute, if relatively short-lived in comparison with the emotional pain which may follow the event.[69] Not only may the physical experience of miscarriage as a form of premature labour be painful in itself, but a woman may often be afraid of what she will see passing out of her body and of what the miscarriage may mean (both in terms of the current 'loss' and of her own ability of cope either in the present or the future). She may question, for example, whether this miscarriage will compromise her ability to bear other children. What may thus be being grieved for may simultaneously be of both present and future, of what is now unrealised and what may yet be unrealisable, of both self and other.

This is why, although it is still comparatively rare in the U.K. in the case of an early spontaneous abortion (though not in recent years with later losses in pregnancy), women are now increasingly encouraged to see the evacuated pregnancy, even though in the early stages of pregnancy there may be very little to see.[70] Dr. Alice Rothchild,

an obstetrician working in the United States where this practice of encouraging women to 'see' even very early pregnancy losses is much more well-established, says of this,

> I think that it is important for the mother to see what comes out. To see that this is what came out of you, and this is it, and it's ended. In fact, mothers who give birth to congenitally malformed babies do better if they see the baby. They don't focus on what was abnormal, but what was normal. They see that it had ten fingers and ten toes and they feel reassured. In that sense I think that it is good to save the products of what comes out and say, 'Look, see, this is what came out of you, and it has ended'. When you can't see what is going on, it is much harder to accept it.[71]

Experience teaches us that, in the vast majority of cases, the fantasy is more traumatic, and therefore more inhibitive of the resolution of grieving, than reality. Most people, after all, have little idea nowadays of what a dead body, still less a dead fetus, actually looks like.

It must always be remembered that the wishes of the parents should be paramount and need to be respected. They should neither be forced to see, nor be prevented from seeing, what has been 'delivered', nor should they be expected either to make an informed decision, or to follow through that decision, unsupported. Nonetheless, most women who choose to see the aborted pregnancy tend to cope better with their grief than those who do not. The sensitivity with which this often painful process is handled thus has a clear effect on psychological and emotional outcomes.

Whatever the physical trauma, then, the emotional and existential impact of miscarriage can be acute. In a short time everything has now changed for the putative parents as 'being pregnant' gives way once again to 'not being pregnant'. The level of consequent pain and distress which this causes can often be confusing to family or friends especially if, as in the early stages of pregnancy, there has been as yet little or no discernible change in the woman's outward physical appearance, or if few people had yet been told of the pregnancy.[72] It is hard for others to appreciate what such a

'loss' might mean for the putative parents. This is often a source of frustration and anger for parents. Although research has shown that community support is of great importance to 'recovery' after miscarriage, such support is often lacking except perhaps from those who have undergone a similar experience.[73] Family and friends may, consciously or unconsciously, collude in a conspiracy of silence, creating an atmosphere of denial that anything - pregnancy or miscarriage - has happened, and that life is continuing as normal. It may not, therefore, simply be a case of 'least said, soonest mended', or even a failure to know what to say, that leads to the pretence that all is as it was before; rather an unspoken belief that, life having not 'really' begun, there can be no death to mourn. For many people who have suffered a miscarriage this wall of silence may be all but impenetrable.

If the anger that is so often a part of the disorganising effects of grieving is now directed inwards, it may present itself as part of the guilt or self-hatred which is so often a key component of the depression which may follow the trauma of miscarriage.[74] If, on the other hand, the anger is directed outward and projected onto others, it may manifest itself as blaming for 'crimes' that are real or imagined. It is far from uncommon for partner's behaviour to be blamed for the miscarriage. When this happens, couples may need to be helped to see that the actual focus of their anger is the situation itself, and not themselves or another person. Although the experience of a shared loss may bond some families more closely together, a relationship already under stress may deteriorate further.[75] Anger in bereavement may either have this kind of specific focus (irrespective of whether that focus is justified or not!) or it may be quite non-specific, a 'grape-shot' kind of anger, hitting anyone and anything which comes within range. Other foci of anger or 'blaming', therefore, may be doctors, nursing staff, chaplains, nature, fate, or God.[76]

To dismiss any of the emotions following a miscarriage is to deny the putative parent or parents the opportunity they may need to grieve in a way appropriate to them and which represents the intensity of their investment in the pregnancy which has

now ended. Nonetheless, the view that the grief is self-referencing was commonly held until recent decades and still, in many cases, stubbornly persists:

> For a woman the psychological bereavement is tied to her own physical state. It means death as part of herself and not a separate person which means that despite the absence of tangible loss the experience of miscarriage may be profound.[77]

Whilst 'loss of self' may indeed be profound, and certainly needs to be recognised, disallowing any objective (non-psychological) referent for the unborn human imposes a physiologically restrictive view of what constitutes a distinct human being. Whilst not physiologically independent, an unborn child, at whatever gestational age, is relationally 'distinct', in which case grief following miscarriage is not only for a psychological loss but for a distinct, and differentiated, 'life' that is still both 'known and unknown'.[78]

As I have already suggested, however, the putative parents, particularly in the early stages of grieving, may be confused and ambiguous about the status which the unborn child has for them. It is essential, therefore, that practitioners have an adequately expansive understanding of the way in which human 'identity' or 'personhood' may be constituted for putative parents. Only then can their work validate and engage the experience of those who have been, or perceive themselves to have been, bereaved.

It is my contention, then, that any definition of 'personhood' or of personal identity which is to prove itself adequate to the task will have to offer a more than simply biological account of what it means to be a distinct human being. I argue, therefore, for the validity and importance of a relational account of identity that does justice to the operational beliefs of a significant number of bereaved putative parents.[79]

In Western Society, where peri-natal mortality has fallen to less than 1%, expectation that pregnancy will lead to a healthy baby at the end of nine months is now the norm. Nowadays, when many 'parents' are encouraged not only to take

responsibility for, but to play a greater part in 'planning' the progress of their pregnancy, through the formulation of birth plans etc., the sense of 'planning for a good outcome', and therefore of control, is heightened still further. Unfortunately, as a consequence, the more pregnancy management is 'owned' by the parents, the more intense the sense of perceived guilt may be when things go wrong.[80] As an experienced social worker, working in a large maternity hospital said,

> Maternity is meant to be a 'problem free' area. Having a baby isn't associated with problems because people have a higher expectation as to what the outcome should be... Having a baby is about society more than it is about medicine, therefore a higher level of criticism may be levelled when things go wrong.[81]

This belief is echoed by S. Borg and J. Lasker:

> Because of the advances in modern technology and the continuing fall in infant death rate, most couples begin their efforts to conceive with great confidence that they will have a favourable outcome. They feel that they are largely in control of their future, although they may have some fears during pregnancy, they expect to be among the large majority who give birth to healthy children. they are shocked when it turns out otherwise and frightened to discover that they have no control over what happens.[82]

When, therefore, a pregnancy miscarries, the accompanying level of initial shock and disbelief may be particularly acute since putative parents may not have considered this as a possibility.[83] Even in cases where there is a known or suspected problem with a pregnancy and risk information is given, parents may still simply be unable to take in what is being said and as a result they may similarly feel 'distanced' from what is going on. This sensation is often described as the situation being 'like a dream....' or as though 'it were happening to someone else, not me....' The putative parents may simply not be able to understand what is being said to them, which is why the terms used (although the perceived purpose of using periphrases for 'died' or 'dead' like, 'not being able to find the baby's heartbeat', is to 'soften the blow'[84]) need to be both clear and unequivocal.

Once again, confusion about the identity of who or what constituted the pregnancy may compound the problem. To have 'died' or to 'be dead' implies, after all, that one was, however fleetingly, 'alive'. But what precisely does that term mean when applied to an early fetus, even when that 'fetus' is also clearly 'my/our baby'? When death closely follows, or comes at the time of, birth there may be confusion about what this life 'meant'. How much more is this true when death comes before birth and even, in a sense, before there was a discernibly distinct human 'body' which could be said to 'die'. The earlier the miscarriage, the greater the confusion, especially where 'identity' is seen primarily as a biological, physical or locational construct. This will be addressed in more detail later in this chapter.

Variations on a theme

A number of other issues need at least brief mention at this point. One concerns the intrauterine death of a twin; another, the relation of miscarriage to new reproductive technologies (and especially the issues of selective feticide); and finally, ectopic pregnancy.

Multiple pregnancies

The discovery that a pregnancy is of twins may come as much as a shock as a surprise to some parents. Nonetheless, it is often regarded as being a 'special' pregnancy. Throughout both history and mythology and across many cultures, twins have been regarded as having an often 'magical' significance. For many parents, 'expecting twins' is often a source of great pride. Yet, the intrauterine hazards of any multiple pregnancy are great. In at least 50% of all pregnancies involving twins one fetus will not survive. Whilst this may happen at any stage, the majority of such losses occur in the first trimester.[85] Whilst there is some debate about when and whether the early discovery of twins should be made known to the mother (to avoid disappointment if one twin spontaneously aborts) it is now generally felt that the

parents should be told straightaway. This view is borne out by the wishes of most parents to know as soon as possible about twinning or other multiple gestations whatever the outcome may later prove to be. It is becoming increasingly clear that both the parents and, later, the surviving twin need to be offered appropriate support in resolving their 'loss' after the intrauterine death of a twin since, especially in the early stages of loss, grieving may be displaced or 'buried' so that 'bad memories get lost rather than relinquished.'[86]

In the case of a singleton intrauterine death in a multiple pregnancy, the fact that the mother may feel ambivalence about carrying a 'dead' and a 'live' twin simultaneously is often particularly problematic in terms of grieving the non-surviving twin. Although some women express the wish to 'hold onto their baby' as long as possible, many also feel that they are 'a walking coffin', before the 'dead' embryo or fetus is evacuated. Here, in terms of the pregnancy, it is not so much a case of 'to be or not to be' but of 'to be *and* not to be' simultaneously. Such a situation may seriously complicate grieving. Suffice to say here that enjoying the anticipation of one baby, whilst at the same time grieving the 'death' of another, living with both pregnancy and pregnancy-loss simultaneously, is a complicated task. Its psychological and emotional effects may be far-reaching. For many, the surviving twin will always be a reminder of the twin who did not survive.[87]

In cases where one embryo/fetus is found to be abnormal, couples may elect to have a selective feticide, usually by means of a lethal injection. Here the problems of carrying a dead and a live infant simultaneously is compounded by the guilt which frequently accompanies choice, even where the aim is to enhance the chances of survival of the co-twin. One study found that all mothers who had a second semester selective feticide on the grounds of fetal abnormality experienced grief over their dead baby. Many also felt that this grief had not been appreciated either by their families or carers and that the dead fetus had been 'ignored or forgotten'.[88]

Assisted reproduction

When a miscarriage follows the use of reproductive technologies, the effects of grief may be acute. Much assisted-reproduction technology is both physically and emotionally demanding and there may often be a repeating cycle of raised expectations and dashed hopes as a wanted pregnancy fails to occur or ends in a miscarriage again and again.[89] The tenacity with which some hold to the hope of pregnancy and parenthood, however, should not be underestimated and cannot be ignored. Where miscarriage portends infertility, this can have a devastating effect on some women and their families since it can precipitate grieving, not simply for what has been (the particular miscarriage) but for what might never be. Thus, what is grieved for is not only a pregnancy that has failed or a child who has died but for the child or children who will never be and, with them, the hopes and aspirations for self and others.[90]

Though infertility may not strictly be described as the 'death' of a child, it may represent the 'death of the hope of a child' and with it, in some sense, also the 'death' of a part of oneself and its consequences may therefore, for some, be as profound as if an actual death of an actual person had taken place and the ensuing grief as much in need of recognition as any other.[91] As Rachel says to Jacob, 'Give me children or I will die...'[92] Once again, we can see that issues which are primarily medically referenced may also have an existential or theological dimension to them and care needs, therefore, to be person-centred rather than problem-centred.

The technique known as 'fetal reduction' is usually discussed in relation to its ethical issues. Its implications for grief also, however, deserve attention. Fetal reduction entails the implantation into the uterus of multiple fertilised eggs instead of the more normal two or three which have been cultured *in vitro*. The embryos are allowed to develop in the uterus and then the number is later reduced, as in selective feticide, usually by lethal injection. In this case, however, the aborted fetuses are neither abnormal nor defective, simply surplus to requirement. The knowledge that one or more fetuses have been 'killed', albeit to improve the chances of development

and survival of another fetus may be traumatic to some putative mothers; to others it may simply be unacceptable since this would be to regard the life/death of some fetuses as means to an end, rather than seeing them as ends in themselves (i.e. as *already* beings-in-relationship).[93]

Ectopic pregnancies

About 0.5-1% of all pregnancies are ectopic i.e., where nidation occurs outside the uterus and the fertilised egg implants itself elsewhere, usually in the wall of the fallopian tubes, where it may begin to establish a placenta and to grow.[94] Although many such tubal pregnancies spontaneously abort at an early stage, some continue to develop and may come to threaten the life of the putative mother, especially if the developing pregnancy causes the fallopian tube to rupture and haemorrhage.[95] Discovering that a planned or wanted pregnancy is ectopic moves parents from initial joy and expectation quickly to anxiety of loss and anticipation of the necessity of surgery.[96] As ectopic pregnancies are potentially life threatening, initial post-operative feelings are principally ones of relief, followed only later by a sense of loss.[97] Such feelings of loss may be heightened if the fallopian tube is also lost with the termination of the pregnancy. Here again, a complex of griefs, for the loss of the current pregnancy, for other or all possible future pregnancies, for fertility, for loss of self and one's own future, as outlined above, may need to be faced as well. The emotional difficulties may be further heightened if, as in the case of a ERPC/D&C, the woman is treated simply as a surgical patient and not, where it is appropriate, as a mother or potential mother, and now as a bereaved mother.

Pastoral and theological aspects of miscarriage

Registration and disposal

As a non-viable fetus (<24 weeks) has no legal status, registration of neither 'birth' nor 'death' is required. When miscarriages take place in hospital the conceptus, embryo or fetus is the property of the hospital.[98] Until recently, it was still predominantly the case that such 'products of conception' were simply disposed of in the hospital incinerator or by contract, with other human 'waste' material. For parents who have undergone the trauma of a miscarriage, termination or ectopic pregnancy then to be told that their 'child' has simply been incinerated without any form of recognition or ritual may add both to the trauma of grief and to the burden of their guilt.[99] Since, in the immediacy of grief, many women wish to distance themselves from the emotional trauma of the miscarriage as quickly as possible, curiosity about what 'happened' to the aborted or terminated conceptus may only come several weeks or months after the event when reality is being tested. Parents may then return to the hospital to see staff and to ask questions which remain unanswered in their minds. This is especially true if such parents were not given the opportunity to see the products of the miscarried or terminated pregnancy or if, at the time, they did not wish to do so. For this reason, most hospitals now routinely photograph all but the earliest miscarriages and place a copy of the photograph in the mother's medical file for future reference and use. Many hospitals now also offer such families a form of certificate or a certificate of blessing which, although it has no legal status, at least recognises, and in a sense validates, the reality of that which has now been miscarried or terminated.

The lack of legal requirement to register a miscarried baby or to provide a 'funeral' or other service means that many parents also lack the opportunity for appropriate ritual for disposal or for naming the 'child' who has died. The potency of naming in establishing identity or affirming the reality of the pregnancy and of the 'child' it represented, ought not to be underestimated. Families may, therefore, need to

be given both the opportunity to talk through the significance of the name and of the appropriateness of the process of naming. It may, for example, be felt that a planned name, especially if it has particular family connotations, for example, should be 'reserved' or 'kept' for a future, surviving child even though some parents may wish to name an early miscarriage. Nonetheless, the family may also feel some guilt at 'denying' such a planned name to a baby who has died and see it as a further step in denying his/her reality or worth.[100]

Although some parents ask for the miscarried embryo or fetus so that they can make their own provision for its 'disposal' themselves, few in fact do so. Where parents do opt to make their own arrangements for the disposal, or where the miscarriage happens at home there are, nonetheless, serious issues which need to be considered and about which counselling or advice needs to be given. Many funeral directors are now becoming increasingly sensitive to the issues which surround miscarriage, though much insensitivity still persists. When a miscarriage happens at home, the parents may be even less aware of the options available to them than if they are in hospital. They may feel unhappy simply flushing the miscarried pregnancy down the toilet and into the sewage system or putting the aborted embryo out with the household waste. Some may opt to bury what physical remains there may be in their garden.[101] Whilst this may be helpful to some people at the time, there are a number of issues here which they may need to have spelt out to them. Firstly, any remains need to be buried deeply enough in order not to be disturbed by animals or, inadvertently, by other humans. Secondly, consideration will have to be given to the future. How will such families respond if, at some future time, they wish to sell or leave their home or need to move away from the area? Will psychological 'closure' have been sufficient to allow them to relinquish the physical site? In some circumstances, families have subsequently felt unable to let others occupy the garden where their 'baby' is buried, feel unable to talk about it, or cannot come to terms with the fact the garden may no longer be theirs to visit.

Where the miscarriage or termination happens in the hospital, this will not be an issue for them and the pain of not knowing where the 'baby' went can be sensitively managed. At Bristol Maternity Hospital,[102] the Chaplains negotiated with a local crematorium in the mid 1980s to accept miscarried embryos and fetuses on the condition that parental consent was obtained, the non-viable embryo was certificated by the attending doctor, and that each embryo was individually casketed and named (the surname alone would suffice as in, 'baby Jones'). The Chaplains would then arrange a monthly or quarterly visit to the crematorium, taking the accumulated remains from the hospital with them and conduct a short non-denominational service at the Crematorium. Whilst this system caused some initial anxiety for a few crematoria staff who did not see the need to treat miscarried pregnancies in this way, the system proved effective in reassuring parents that their 'children' had been 'disposed of' with an appropriate sense of dignity and respect.[103] Where parents have reservations about, or objections to, cremation, a burial can be similarly arranged. The size and physical nature of an embryo or early fetus, where the skeleton is largely unformed and the 'bones' have not yet calcified, means that there are no ashes remaining after cremation. This is difficult for some parents, who may need to have something more tangible to hold onto. With burial, which is usually in common but consecrated ground (not to be confused with a common or 'mass' grave!) there is at least a physical 'place' to visit in the future which may help to keep the memory of the miscarried 'baby' alive.[104] It provides a place to go and sit or somewhere to take flowers on anniversaries or simply a place for some people to 'be'. Even in the case of those with little or no acknowledged 'religious' belief, the need for some sort of ritual words or actions, particularly in respect of rites of passage, nonetheless apparently remains very strong. All those whose 'babies' died pre-24 weeks gestation at Bristol Maternity Hospital were given a booklet setting out simply the options which were available to them and were given the option of knowing when and where the 'funeral' would be taking place, whether or not they chose to attend. Even among parents who did not wish to either attend or even to know the time, place or date of the funeral,

there was, in general, a sense that 'something' was being 'done' and that whatever was being done, was being done 'properly'. This practice is now more widely adopted across the country.[105]

Notwithstanding the question of disposal, then, issues of ritual or significant rites of passage remain. Ideally, these serve to recognise and affirm the reality and significance of the 'baby' who has died, helping to facilitate 'closure', thus enabling the parents to integrate the baby who has died, to re-invest in their lives and to pick up the threads of daily life once again. In addition, the names of miscarried babies can be entered into a Book of Remembrance. Such books are usually kept in the hospital Chapel or other appropriate place and a copy of the entry may be given to the parents. Entries might consist simply of a name and a date or of a piece of prose or poetry, often written by the parents themselves. The similarity between such entries and those used by their Victorian forebears are, at times, quite remarkable. Such written memorials are a powerful reminder of the reality of the child or children who have been miscarried and provide, in the absence of a grave, a physical locus to which the bereaved may return either to test the reality of their experience or to remember at significant times, such as anniversaries or the prospective 'birth'-day of the miscarried baby. It is becoming increasingly recognised that it is often the provision of something tangible, such a Book of Remembrance (often provided by groups such as the Miscarriage Association or the Stillbirth and Neo-Natal Death Society), that is helping to change attitudes among healthcare professionals to those whose pregnancies miscarry or end at other times before or shortly after birth.

Some parents may opt to devise their own ways of marking the 'life' of the 'baby'. Often the focus is primarily on act, symbol or gesture rather than words, although poems, either written by themselves or others, are frequently used.[106] Candles, flowers, articles of clothing or toys which had been bought for the awaited baby will often find their place in such memorial acts, as may the copy of the scan or a photograph in the case of a discernible embryo or early fetus. Such memorials are often, by nature, intensely private affairs. Few, as we have noted, may yet have known

of the pregnancy which has now ended and even among those who did know about it, there may have been little understanding of the intensity of loss that was felt when the miscarriage occurred. Local clergy, or the hospital Chaplain, may nonetheless be asked to 'say a few prayers...' or 'give a blessing...', thus making the 'service' one which is 'real' or official.[107] Because the grief of parents whose children are miscarried has only been recognised in recent years, and because of the largely unresolved confusion about the 'status' of that which was miscarried, official liturgies or orders of service for those miscarried have been late to appear.

Autonomy and control

As noted above, the experience of miscarriage can raise issues concerning control, especially in the case of a wanted and planned pregnancy. The sense of 'loss of control' - not only over what is happening, or has happened, but even over one's body - after miscarriage, can be profound. Sensitive listening on the part of caregivers in what may, for some, be frightening circumstances, can do much to mitigate unnecessary suffering and may itself be a way of empowering those who feel powerless and even marginalised because of what has happened to them. To ask, 'What would you like...' affirms those whose greatest need is often to regain some sense of control in their lives. Even though what they would most like (i.e. a pregnancy which carries to term a live and healthy infant), they cannot have, it is important that those whose self-image and self-confidence may be badly damaged by the experience of miscarriage be allowed to regain some measure of control, both over their lives and their situation. Good pastoral care, therefore, lies in the enabling of free and open dialogue. In this way, the powerless become part of our 'moral landscape'.[108]

Agape

Such transfer of power is part of the unconditionality of love which Christian theology describes as agape - an unconditional love of neighbour which both creates and sustains community, since love is about the quality of relationship between persons. Indeed, it may be argued that it is precisely love-in-relationship which allows persons to be recognised as such and even, in a sense, which 'calls' them into being. For Christians, the equality of relationships in the Trinity becomes the pattern for the assertion of the fundamental equality of persons in human relationship.[109] Agape, therefore, provides a theological framework of care. As such, it includes a number of distinct, though inter-related, principles. Firstly, agape, provides a robust ethical underpinning of care, based on a holistic understanding of persons as simultaneously distinct and relational. Secondly, therefore, agape allows for a relationship of care which does not subvert or subsume either self or other. Thus, agape can be described not only in terms of the nature of the relationship, but also, thirdly, as a way of knowing which commits the carer to work positively for the other's good.[110] Simone Weil says, 'The capacity to give one's attention to a sufferer is a rare and difficult thing... Warmth of heart, impulsiveness, pity are not enough.' She then refers to the legend of the Grail, where the wounded king who is its guardian is asked, *'What are you going through?'* Weil says, 'The love of our neighbour in all its fulness simply means being able to say to him: 'What are you going through?'[111] Such care is, by nature, covenental rather than merely contractual in character.[112]

Identity

The second, and closely related, issue concerns questions of identity and how that is to be decided. Clinicians may be tempted to resolve the question by reference to a physiological definition, as I have already indicated. Yet, this may be quite different from the way in which parents are deciding the matter in their active relationship to their 'child'. Hence, pastoral care must engage with the way in which parents develop

their relationship to the miscarried 'child' and that requires the establishment of an open and attentive relationship with them, since the significant question of identity cannot be decided outside the relationships in which that identity is constituted. This construction of identity can happen at a very early stage. A fantasy or projected-identity may be constructed early in the pregnancy in order to visualise what is, as yet, invisible at least to the naked eye.[113] This projected identity may often 'out-pace' biological identity so that what, in purely physiological terms, may yet be barely more than a pre-embryonic cluster of cells, may already be attributed with all the qualities of human personhood. With no memories at this stage to look back on in order to 'reference' what this 'life' might mean, what Dennis Klass calls 'an empty historical track,'[114] a fantasy is projected which will only be counter-balanced or displaced as the pregnancy progresses and the 'fantasy' child is gradually replaced with the 'real' baby.[115] It may even be that after birth itself, the fantasy or 'inner baby' has to be relinquished in order for acceptance of, and bonding with, the actual and now 'outer baby' to take place.[116]

Unlike a stillbirth or neo-natal death, after a miscarriage there is no 'outside' baby, dead or alive, to replace the 'inside' one. What is mourned is often a fantasy or projection, as well as a child, potential or actual, according to the particular beliefs held about when 'life' begins, what it constitutes, or what its physical end might be perceived to mean, or to lead to. Whilst in practice such fantasies are essentially of an 'ideal' child who may do no wrong and of whom expectations because they can never be tested in reality may be wholly unrealistic, they should not simply be discounted since they may constitute the only known 'reality' which the parent(s) have to hold onto. What is being grieved for in such cases is, then, not a past grounded in experience (as with most other bereavements through death) but rather a future with all its un-realised, and now un-realisable, hopes, dreams and aspirations for self and other. Since identity is a relational as well as biological construct, the question of 'identity' which is involved here is not simply one which refers to the pre-embryo,

embryo or fetus but something which also shapes and changes the identity of the parent or parents. This is the other side of a relational construction of identity.[117]

Larry Kent Graham argues that 'the ministry of care requires a theory of personhood if it is to effectively increase the welfare of individuals and their communities.'[118] David Cook, has maintained, nonetheless, that 'few people except... those who are involved with pregnancy, seem to give much thought to the status of the fetus.'[119] This, however, is a question that lies at the heart of many of the most controversial issues of modern society, including abortion, embryo experimentation and the growing field of reproductive technologies and it is a question which is critical to the central thesis of this chapter.

In their book, *Ethics in Obstetrics and Gynaecology* McCullough and Chervenak write:

> All accounts about whether or not the fetus possesses independent moral status commit a common error: they seek to find or reject some time, prior to or at delivery, during which the fetus possesses some intrinsic characteristic that in turn generates independent moral status. This matter is endlessly disputed because it is endlessly disputable.[120]

Persons and potential persons

Within the broad spectrum of responses to the experience of a miscarriage, then, we find that there are those for whom the denial that a pre-embryo, embryo or fetus constitutes a 'person' or 'potential person' (and is therefore 'someone' to be grieved for) is their primary way of protecting themselves emotionally from the impact or potential impact of the loss of their pregnancy. This will often be expressed in such telling phrases as, 'You couldn't call it a real person after all....' or 'It wasn't really developed enough to be a baby'.[121] For such people, the medical term commonly applied to the spontaneously aborted pre-embryo, embryo or fetus, 'products of conception', may indeed of itself be a useful way of describing or naming what has been 'lost' or expelled. To a lesser extent, the terms 'pre-embryo', 'embryo' or 'fetus'

themselves may perhaps perform a similar linguistic or cognitive function. Such terms, including the impersonal pronoun, 'it', may thus be being employed not simply because the gender of the pre-embryo, embryo or fetus is ambiguous or unknown at this stage but precisely because they are terms which have a 'distancing' effect - after all, it is less easy to become emotionally attached to an 'embryo' than to a 'baby', or to an 'it' than to a 'he' or a 'she'.[122] We need also to recognise, however, that these linguistic 'markers' may, of themselves, be comforting constructions which serve to enable an absence of grief as much as they may be rationalisations for its absence or expressions of ambiguity or confusion. Thus, to use either the designation 'embryo' or 'baby' is to perform a particular speech-act which of itself establishes a certain kind of relationship with that which has been miscarried, whether or not that designation necessarily 'fits' the biological definition at any given time.[123] Thus, what are, objectively, barely more than clusters of undifferentiated cells may still, for some, be 'my baby', whilst a well formed and discernible early fetus may, for others, be regarded simply as 'the products of conception', an 'it', rather than a 'he' or 'she'.

This is something that has, however, largely been disregarded in the contemporary literature on the management of miscarriage where it is often recommended, or even assumed, that terms like 'products of conception' are always to be avoided with those who have miscarried. To do so, however, is itself to make an assumption about the way in which the putative parent or parents are relating to the 'embryo'/'baby'. Such disregard may be based on a number of premises, such as the assumption that all miscarriages are of planned or wanted pregnancies. To adopt this line not only gives a particular status to the pre-embryo, embryo or fetus but also assumes a meaning for the event which may not be that which is given to it by all those who miscarry. It is therefore an unhelpful and an inappropriate generalisation which risks imposing meaning on an event for which there may be other meanings, some of them indeed competing meanings, each with its own particular claims.[124] Indeed, such competing meanings may be experienced by the same person. Relief and guilt may co-exist, each with its own qualifying element, for example. Relief, for whatever

reason, may carry the qualifier that it wasn't 'really' a baby, whilst guilt may carry the qualifier that it was, nonetheless, a 'human life' after all.

Conversely, personhood may be attributed by some to the pre-embryo, embryo or fetus from the moment of conception. This will posit a radically different meaning or set of meanings on miscarriage. Even the earliest spontaneous abortion may be seen as the 'loss' of a 'baby' and may be accompanied, therefore, by part or all of the whole range of sequelae of grieving which may be present after other significant losses through death. Friedman and Gradstein note how a mental image of the child being carried is formed early in pregnancy. This is why those whose pregnancies miscarry can grieve for what others may regard as only undifferentiated tissue.[125] As Stewart and Dent remind us, 'We need to remember that grief reflects what the pregnancy, fetus or baby represented to the woman and her family.'[126]

The issue of human identity is, therefore, one which is both complex and controversial. Dominique Folsheid has noted the paradoxical nature of talking about a Christian perspective on the status of the human embryo. While she argues that it is something that cannot be established solely on the basis of Christian belief and practice, since neither scripture nor tradition offer an unambiguous account of the theological and moral status of the unborn human,[127] she recognises that not to offer such a perspective leaves the field open to a monopolisation by medical and scientific perspectives.[128] The question remains, however, whether scientific and medical discourse can itself legitimately say anything about human identity, though it undoubtedly has a great deal to say about biological development which is necessary to the wider debate. Both the Warnock Report and the Polkinghorne Report are examples of how this may be so.[129]

Although for Warnock the emergence of the 'primitive streak' as a point of biological development at 14 days forms a moral watershed, the report remains unclear about the *degree* of protection which embryos should consequently be offered in law. The pre-embryo and embryo, therefore, though biologically unambiguously human,

appear to admit to a wide-ranging ambiguity where 'person status' is involved. Warnock concludes, therefore, that scientific analysis alone cannot definitively determine either the meaning of, or the boundaries of, personhood, although its evidence can clearly contribute to the establishment of legal definitions and parameters.

The Polkinghorne Report, which built on the earlier work of both Warnock and of Sir John Peel's committee,[130] places great emphasis on potentiality - the potential of the pre-embryo and embryo to develop into a fully formed human being.[131] This, it characterises in terms of 'respect'.[132] Polkinghorne, nonetheless, stops short of allowing person status to the unborn human, describing the fetus as having a status 'broadly comparable to a living person.'[133] Thus, Polkinghorne, like Warnock, fails to answer the fundamental question of what sort of entity the human embryo *is*. Naomi Glichrist argues, therefore, that the status of the human embryo/fetus, like the status of all other human beings, is essentially an *ethical* consideration.[134]

It may ultimately be as impossible to resolve the contradictions involved here as it is to say definitively when exactly human life begins or when that life becomes personal with all the consequent rights that might be deemed to belong to persons but not to non-persons or pre-persons, not least the 'right to life' itself, whatever that may be taken to mean.[135] Perhaps, at best, then, we can only conclude, as Warnock does, that, whilst any human material must be regarded as being of 'value', the beginning of human personhood cannot be pinpointed as a biological, or even developmental, fact but is ultimately a moral decision and that '(s)cientific observation and philosophical and theological reflection can illuminate the question but they cannot answer it.'[136]

Conclusion

What is needed, above all, is sensitivity and respect for those who suffer the trauma of early-life death, even, perhaps, before others recognise that there was ever a

life to 'die'. Despite the advances in understanding over recent years, there remains, nonetheless, a long way to go. In 1989 the novelist Susan Hill, who herself experienced a miscarriage, wrote in her book, *Family*,

> 'Oh pooh, miscarriages,' an acquaintance said to me recently, 'miscarriages are nothing - everybody's had a miscarriage.' And yes, so they have... Nevertheless, I take issue with that woman's dismissive attitude, for the misery and grief one suffers at a miscarriage and the depression afterwards are out of all proportion to the seriousness of the event and bear no relation to it. Nearly everyone I have ever talked to about it and who has suffered one says the same.[137]

It is hard to believe, given how little things have changed, that it is now well over a decade ago since an editorial in the *Lancet* contained these timely words:

> It is now time to take stock and listen to the silent grief of the mother who does not dare to rock the boat by a seemingly silly request that society should view the pre-viable fetus as her own special baby.[138]

NOTES:

1 This includes *known* miscarriages and an estimation of the number where early spontaneous abortions occur before the putative mother knows she is pregnant. A. Oakley, A. McPherson and A. Roberts, *Miscarriage* (Harmondsworth: Penguin Books, 1990. Because of this variation, statistics for miscarriage vary greatly.

2 Ibid. There is indication that the numbers of miscarriages are, in fact, increasing due, in part, to the rising proportion of older mothers in our society. I. Kohn and P. Moffit, *Pregnancy Loss: A Silent Sorrow* (Headway, London: Hodder and Stoughton, 1994), p.56.

3 'The Hidden Grief' is the title of the Miscarriage Association's leaflet on coping with a miscarriage, based on extracts from Christine Moulder, *Miscarriage: Womens' Experiences and Needs* (London: Pandora, 1990). Moulder argues that insensitive or neglectful treatment after miscarriage serves only to make a bad situation worse. The Miscarriage Association was founded in Bristol in the early 1980s with a national committee being established in 1990. Similarly the Compassionate Friends was a Bristol-based group which went on to have national, and international, importance.

4 *The Miscarriage Association*, photocopied sheet, undated.

5 J. Littlewood, *Aspects of Grief: Bereavement in Adult Life* (London: Routledge, 1992), p.123. Oliver O'Donovan says,

> Plainly our attitudes to the unborn child develop as the child itself develops. We are not deeply involved by the loss of a baby in its earliest stages by spontaneous abortion. We do not, as a rule, accord these products of the womb those signs of recognition with which we note human birth and death: we do not baptise, we do not bury, we do not weep.

O. O'Donovan, *The Christian and the Unborn Child* (Bramcote: Grove Books, 1973), p.6. Since this was written, things have moved on. We *do* now bury, for example. It is, however his last statement that is most problematical since, for many whose pregnancies miscarry, it simply is not true. Weep they do, and the reason *why* they weep is that they recognise in that which is miscarried, a 'person' - their 'baby' - who is grieved for as an existent other. While, however, the personhood of even the early fetus may be recognised, it cannot be said to be recognised generally.

6 H. Pizer and C. O'Brien Palinski, *Coping with a Miscarriage* (London: Jill Norman Ltd.,1980), p.1.

7 The beginning of life debate has been critical in the issues surrounding 'abortion', especially non-therapeutic abortions, and, more recently, the status of so-called 'spare' embryos and their use in experimentation. The end of life debate has largely focussed on definitions of 'brain death', the treatment or non-treatment of patients in persistent vegetative state (PVS) and issues surrounding organ donation. Two issues which are germane to this particular work are the use in transplantation of the organs of anencephalic infants who are brought to term and who, while they will never have any conscious 'life' are, nonetheless, clearly not biologically 'dead', and the use of human pituitary from aborted fetuses in the treatment of Parkinson's disease. The decision by HFEA in August 2000 to allowed limited experimentation on embryos created as a result of stem cell technology has added another dimension to this debate. An excellent discussion of the contemporary issues of definition of life and death, albeit from a strongly utilitarian perspective, can be found in P. Singer, *Rethinking Life and Death* (Oxford: Oxford University Press, 1995). It is important to remember that prior to the birth of Louise Brown, the first 'test tube' baby, in1978, very little was known about human intrauterine life especially in its early stages.

8 The issue of viability is a complex one. The 1992 Stillbirth Definition Act reduced the age of viability from 28 weeks to 24 weeks. In practice, there are many practitioners who would now consider 22 weeks to be the current lower limit of viability. As medical technology develops, especially in the management of the premature newborn, the age of viability will continue to decrease.

9 Certain behavioural factors may increase a predisposition to miscarriage, such as heavy smoking or the misuse of drugs. Where these are predisposing factors there may be either an increased sense of guilt related to a perceived complicity in the death or an inability to link cause and effect where the putative mother cannot or will not acknowledge that her own physical well-being has a direct bearing on the healthy development of the embryo or fetus which she is carrying. Education rather than judgement may thus be the critical factor in the management both of the current miscarriage and of any subsequent pregnancy.

10 The term 'pre-embryo' is generally used to refer to the entity brought about by the fusion of sperm and ova in the first fourteen days after fertilization when the cells which will give rise to the embryo, placenta and membranes remain as yet

undifferentiated. The term 'embryo' refers to the same entity between fourteen days and eight weeks and the term 'fetus' is used after eight weeks but before birth.

11 This is often in stark contrast to the perception of most women who regard the embryo or fetus growing inside them as 'part of' themselves. This status of 'part of' yet 'different from' the self has been a major component in many of the ethical issues concerning the status of the unborn human, especially during this century.

12 Pizer and Palinski, *Coping with a Miscarriage*, p. 74-5.

13 It is not uncommon for this to be offered in the first instance as consolation for the loss. 'It's just nature's way...' or 'It was never meant to be....' is an over-simplistic response to an often traumatic event which may suggest to the family that their 'grief' will be seen, in such circumstances, as an inappropriate response to what some would term, either because of its frequency or because or its early occurrence in gestation, as being a 'normal' variant of pregnancy. Similarly, to say, 'You can always have another one...' is a cruel, though often kindly meant, comment since it both circumvents the impact of the current loss and denies the uniqueness of each pregnancy and the individual value that the putative parents may place on it. Guilt is often a major component of the emotional sequelae of pregnancy loss, not least because of the uniqueness of both the physical and emotional bond between parent and child. Responsibility is often assumed for the 'death' of the baby, therefore, which is, more often than not, misplaced. An examination of guilt in bereaved parents can be found in M.S. Miles and A.S. Demi, 'Towards a Theory of Bereavement Guilt: Sources of Guilt in Bereaved Parents,' *Omega, 14*, 4, (1984), 299-314. See also, A.S. Demi and M.S. Miles, 'Bereavement Guilt; A Conceptual Model with Applications,' in I.B. Corless, B.B. Germino and M. Pitman, eds. *Death, Dying and Bereavement: Theoretical Perspectives and Other Ways of Knowing* (London and Boston: Jones and Bartlett, 1994), pp.171-188.

14 Oakley et.al. (1990), p.146

15 Translocation is the term used to describe the re-arrangement of genetic information between chromosomes. When such translocations occur and are transmitted to the developing embryo they are significant factors in the production of many congenital abnormalities such as Down's Syndrome.

16 Many women speak of their bodies after miscarriage in the language of betrayal, as if their bodies represented something distinct or separate from themselves. Bodies, therefore, are spoken of as 'betraying', 'letting down' or even 'cheating' individuals whose shock may be to do as much with the loss of their own body image when faced, perhaps for the first time, with its fallibility, as with the loss of the pregnancy and the baby which it represented.

17 Rubella (commonly known as 'German Measles'), herpes simplex and cytomegalovirus are all known to be capable of damaging a developing fetus and hence are considered to be possible agents in causing miscarriage.

18 The diagnosis of a malformed uterus is usually made by a test known as a hysterosalpingogram (HSG). The technical term, incompetent cervix, for the inability of the cervix or neck of the uterus to bear the strain of the combined weight of the fetus and the amniotic fluids and so to rupture (usually during the second trimester of the pregnancy) may also be a source of guilty feelings in the mother who has miscarried. 'Incompetence' can, to the lay person, have pejorative overtones not

implied when the term is used as a medical *terminus technicus*. An incompetent cervix is not usually, however, the cause of an early spontaneous abortion but may more usually lead to a loss of pregnancy in the late-second or third trimester. The chances of loss of pregnancy through an incompetent cervix can now be greatly reduced by medical and/or surgical intervention.

19 These may include inappropriate levels of the hormones progesterone (associated with corpus luteum insufficiency), oestrogen and human chorionic gonadotrophin (HCG). Although an incompatibility between Rhesus negative and Rhesus positive bloods has been suggested as a possible cause of miscarriage this is often a problem more evident in the third trimeter and for the newborn infant. Diabetes may also be a cause of pregnancy loss.

20 It has been shown that approximately 50% of women who bleed during pregnancy will go on to miscarry. H. Pizer and C. Palinski, *Coping with a Miscarriage* (London: Jill Norman, 1981), p. 23.

21 Some of the first trimester symptoms of pregnancy, such as morning sickness or fatigue for example, may suddenly disappear where they had been present hitherto. In other cases, feelings of 'not being pregnant any longer' seem to be intuitive rather than being based on any absence of symptoms. See E. Standish, 'Loss of a Baby,' *Lancet, 1* (1982), 611-12.

22 'The Symptomology and Management of Acute Grief,' *American Journal of Psychiatry, 101* (1944), 141-148.

23 A good example of such anticipatory grieving in the biblical narrative occurs in 2 Samuel 12: 15-23 where David adopts a posture not only of penitence but of mourning for his son by the wife of Uriah the Hittite. The child has been struck down with a fatal illness. When the boy eventually dies after seven days, David has already in effect completed his mourning and now resumes normal life. The story ends with the acknowledgement of the temporal finality of death but hints at the possibility of future, post-mortem, reconciliation (vs.23). Judith and Michael Murray have suggested that anticipatory grief follows the same trajectory as 'normal', post-mortem grieving. They suggest that the 'stage' of grieving which is described by Parkes *et.al.* as 'bargaining' may be manifested at this stage, in an often unspoken way, by a strong tendency to compliance with whatever is suggested by medical personnel. J. Murray and M. Murray, *When the Dream is Shattered* (Adelaide: Lutheran Publishing House, 1988), p. 43.

24 J. Lumley, 'The Image of the Fetus in the First Trimester', *Birth and the Family Journal, 7* (1980), 5-12 shows that almost two-thirds of mothers viewed the fetus as a distinct person by the end of the first trimester. See also J.T. Grace, 'Development of Maternal-Fetal Attachment During Pregnancy,' *Nursing Research 38*, 4 (1989), 228-32. See also M.H. Klaus and J.H. Kennell, *Maternal-Infant Bonding* (St. Louis: Mosby, 1976). The experience of previous miscarriages or other early life losses may also inhibit the bonding process. It was a long-held assumption that mothers did not 'bond' with their babies until after birth and this undoubtedly contributed to the cultural belief that mothers (and certainly fathers!) did not grieve for babies who died in the prenatal period since significant attachment to the baby was not considered to have occurred. On the grief of fathers see next chapter. Little has been written about the impact of miscarriage on men. Although research has generally concluded that in all prenatal deaths the impact of loss is less in men than in their

partners, it is, nonetheless, true to say that differing expectations may mean that this order may well, in some families, and under some circumstances be reversed. Puddifoot and Johnson have noted how for many men 'the scan represents an opportunity for them to move from the periphery of the pregnancy' and that, after a miscarriage, this has a discernible effect on levels of grieving although men are still by and large expected to adopt the 'strong' or 'helping' role. J.E. Puddifoot and M.P. Johnson, 'The Legitimacy of Grieving: The Partner's Experience at Miscarriage,' *Social Science in Medicine, 45,* 6 (1997), pp. 837-845.

25 One woman who miscarried at home recovered a small but clearly discernible embryo from the toilet. She and her partner kept the embryo on a clean handkerchief and called their local G.P. The G.P. confirmed the miscarriage and, although he looked at the embryo, he did not remove it but rather left it with the couple. Because this was an early miscarriage (<24 weeks), it would have been quite in order for the couple simply to flush the embryo down the toilet or to put it in the dustbin. Because, however, they perceived the embryo both as being a part of themselves and as a significant, though undefined, other, they wished to show more 'respect'. If the miscarriage had taken place in hospital the embryo or fetus would have been the property of the hospital and would have been 'disposed of', usually in the hospital incinerator (although, even here, the putative parents can request that they be given the remains, however un-formed to dispose of themselves). In many cases, hospitals are now making provisions, usually through their chaplains, for the separate, respectful disposal of all aborted embryos and fetuses no matter how early in gestation this may occur.

26 This is an invasive procedure in which the neck of the uterus is dilated to allow the 'scraping' of its lining with a looped or spoon-shaped instrument (curette).

27 D. Davis, *Empty Cradle, Broken Heart: Surviving the Death of Your Baby* (Golden, Colorado: Fulcrum Publishing, 1991), p.27.

28 These feelings are not universal and so consultation is necessary. Whilst many women find it extremely painful to be around other mothers and their babies at this time, some may take comfort in not being 'separated' as it affirms their identity as mothers. One woman who specifically requested to go onto a post-natal rather than a gynaecology ward after her miscarriage said, 'I have to get used to the fact that there is a world full of babies out there and I may as well start now.'. The lack of genuine dialogue or communication that takes place in such decision making is a sad indictment of the hospital as a 'community of care' and an example of the kind of medical paternalism which is, albeit slowly, now being increasingly challenged. Despite much that is said about patient autonomy, circumstances such as these clearly demonstrate how little, in fact, this can mean in practice. The hospital is, in such cases, acting as a 'closed community' in which what is in the patient's best interest is often decided without reference to the patient herself. This remains equally as true today, even when the term 'patient' has given way to the term 'consumer'. Consumer 'rights' are still little in evidence in most hospitals! There is a clear distinction here between two fundamental approaches to patient (or consumer...) care. Whilst in the United States the governing principle is, 'What does (or would...) the patient want?', in the United Kingdom the governing question is, 'What is in the patient's best interest?'. It is clear that the latter is much more open to medical paternalism than the former and displays a marked contrast in philosophies which underlie doctor-patient relationships.

29 In terms of the psychological and emotional responses to early pregnancy loss, miscarriage where the embryo/fetus is expelled and intrauterine death where it is partially or wholly retained, may usefully be grouped together. The term missed abortion is also used to describe the situation where, although fertilization has occurred, the embryonic component of the conceptus does not form and so the embryonic sac contains no embryo. Due to the production of hormones in the trophoblast, however, the patient experiences all the symptoms of pregnancy. Where a cancerous growth known as a hydatiform (or vesicular) mole occurs due to the proliferation of the epithalium (outer layer of cells) of the chorion (the more external of the two fetal membranes) there is similarly no embryo, post-fertilization, but rather a cellular mass which forms a placental tumour which must be removed. Nonetheless, here too, because the hydatiform mole produces high levels of the pregnancy hormone HCG, the symptoms of pregnancy persist.

30 The ultrasound scan is routinely used in obstetrics both for the purpose of accurately assessing the gestational stage of the pregnancy and for the detection of anatomical abnormalities in the fetus. Where a routine scan is made it is usually done between the sixteenth and eighteenth week of the pregnancy, although in some hospitals it may be done much earlier, especially if terminations are routinely offered in cases of fetal abnormality. A second scan is made at around thirty-two to thirty-four weeks, primarily in order to monitor the growth rate and the position of the developing fetus prior to birth.

31 There is still considerable disagreement as to how the routine ultrasound scan should be regarded. Whilst some practitioners regard it as a purely medical procedure others regard it as being more of a 'social' event.

32 Many women are shocked when the ultrasound scan reveals conditions such as major heart defects in the developing fetus. There is a common perception that the role of the scan is simply to confirm that all is well rather than to reveal things that may be 'wrong' with the developing fetus.

33 J. Brien and I Fairbairn, *Pregnancy and Abortion Counselling* (London: Routledge, 1996), p. 134. There is no reason why parents should not see their baby after termination just as after any other pre- or perinatal death. One exception might be where the termination has been carried out by suction.

34 Father, cited in Kohn and Moffit, *Pregnancy Loss*, p. 106.

35 N.E. Adler, 'Emotional Responses of Women Following Therapeutic Abortion,' *American Journal of Orthopsychiatry*, *45*, 3 (1975), 446-454. Ironically, it would seem that women who continue with a pregnancy after testing has revealed abnormality in the fetus and who go on to give birth to a live but disabled child may also find social support lacking since they could have opted to have the pregnancy terminated but did not do so.

36 M.A and M.E. Ferguson-Smith, 'Relationships between Patient, Clinician and Scientist in Prenatal Diagnosis,' in G.R. Dunstan and E.A. Shinebourne eds. *Doctors' Decisions: Ethical Conflicts in Medical Practice* (Oxford: Oxford University Press, 1989), p. 29.

37 Brien and Fairbairn argue that counselling should be offered to all those who have to make a decision about a pregnancy. (*Pregnancy and Abortion Counselling*, p.

52). Such counselling should be appropriate, with clear referral aims and should ideally form part of the remit of the multidisciplinary team.

38 S.H. Elder and K.M. Laurence's work indicated that four-fifths of women who had had a TFA suffered acute grief reactions at the time of loss and that one quarter had unresolved grief reactions six months later. ('The Impact of Supportive Intervention After Second Trimester TFAs,' *Prenatal Diagnosis, 11* (1991), 47-54). The termination of a pregnancy which, while it will result in disability, is not *ipso facto* incompatible with life, may exacerbate guilt in the grieving process.

39 It may be very difficult for a woman who has just been given news that may be emotionally devastating, that her unborn child has died *in utero* or is significantly damaged for example, both to assimilate this information and at the same time to communicate it to her partner. Whilst it is clear that this information needs to be communicated within the context of the relationship, this may not always be served by the direct intervention of a third party. To do or say something for another person, whilst it may be construed as 'helping' them, may not in fact be to act in their best interests and may, indeed, serve rather to meet the needs of the helper more than the needs of those who are perceived as being helped. What is often much more appropriate in such circumstances is the adoption of a middle-way between the abandonment which may leave a distressed woman alone in a room until her partner arrives then imposes upon her the full responsibility for sharing difficult or complex information unaided or unsupported, and an over-protective presence which excludes her from the information sharing and communication process. More appropriate is the sensitive supportive presence of someone who can help those most intimately involved in this event both to speak and to be heard, to act and to be responded to. This requires the developed skills of 'active' listening, the ability to respond appropriately to the needs of others as well as the ability to balance proximity and distance in the flux of communication between others which respects their presence as others who are both distinct and autonomous. This balance in the dynamic of relationship is well expressed in A. McFadyen, *The Call to Personhood: A Christian Theory of the Individual in Social Relationships* (Cambridge: Cambridge University Press, 1990). He writes,

> Being for another must never become an overbearing form of presence in which the other may only live at second hand. Sorting out someone's problems for him or her, doing everything on his or her behalf, is not always enabling because it can remove the person from any possibilities of subjective engagement. What is enabling is the presence of one with another in tackling difficulties together. this may mean doing things on the other's behalf, but only in the presence of the other and with continual reference to the demands of his or her autonomy both now and in the future. (p.174).

Only when this happens, he argues, is personal autonomy respected and protected and the other allowed to remain 'ethically transcendent' and thus the 'organisation centre' of her/his life.

40 G. C. Forrest, 'When a Baby Dies,' in J.D. Baum, F. Dominica, R. N. Woodward, eds. *Listen My Child Has a Lot of Living to Do* (Oxford: Oxford University Press, 1990), p.110.

41 This can be particularly acute when there is disagreement over the termination with partners (who have limited rights in law), other family members, or

cultural/religious representatives. In extreme cases, this may even lead to denial that the pregnancy has ended or to the irretrievable breakdown of relationships. The organisation ARC (Antenatal Results and Choices), formerly known as SATFA (Support after Termination for Abnormality) offers support for families who have aborted wanted pregnancies on the grounds of fetal abnormality. Although re-named Antenatal Results and Choices, it is significant that their handbook for parents who have had an abnormality diagnosed in their unborn baby is wholly orientated towards termination. It offers no guidance for parents who may wish to continue with the pregnancy.

42 The decision to terminate a pregnancy may be made as much out of love for the unborn child as from considerations about self. See V. Davies, *Abortion and Afterward* (Bath: Ashgrove Press, 1991), p.60. Such feelings are similar to those felt by many mothers surrendering their babies for adoption. See, S. Roll, L. Millen and B. Backlund, 'Solomons's Mothers,' in T. Rando ed. *Parental Loss of a Child* (Illinois: Research Press, 1986), pp.257-68. The need to talk about the death of a loved other, of whatever age, is an important part of the grieving process. Talking helps to anchor the event in reality especially at a time when a predisposition to denial may be very strong.

43 Methodist Church, *Status of the Unborn Human* (London: Methodist Conference, 1990), p.29.

44 A woman who, for whatever reason, may have 'wished' that she was not pregnant may wonder, if she miscarries, whether she has 'made' it happen by wishing the pregnancy away. Such 'magical thinking' is common in the egocentric thinking of children and will be discussed further in the section on children and grief.

45 Worden argues that for the effective resolution of grief, '(f)ocus is essential... sadness must be accompanied by an awareness of what one has lost.' J.W. Worden, *Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner* (London: Routledge, 1991), p.47.

46 See J.H. Kennell and M.H. Klaus *Parent-Infant Bonding,* 2nd.edition (Mosby: St.Louis, 1982) and J. Lumley, 'The Image of the Fetus in the First Trimester,' *Birth and the Family Journal, 7* (1980), 5-12.

47 L.G. Peppers and R. Knapp, 'Maternal Reactions to Involuntary Fetal-Infant Death,' *Psychiatry, 43* (1980), 155-159.

48 The term 'loved adult' was one which became common in the writing about bereavement and death particularly from the 1960s onwards.

49 S. Bourne and E. Lewis, 'Perinatal Bereavement: A Milestone and Some New Dangers,' *British Medical Journal, 302* (1991), 1167-1168. Response to Editorial, 'When is a fetus a dead baby?', *Lancet, 337* (1991), 526.

50 Bourne and Lewis, 'Perinatal Bereavement,' 1168.

51 Ibid., 1167. This article represents, perhaps, no more than a natural 'balancing out' process. Having made the move from treating no miscarriage as emotionally significant to seeing every miscarriage as a 'disaster', potential or real, there is now a greater awareness of the wide range of meaning, and its subsequent emotion, which the experience of a miscarriage can carry. This Hegelian view is also held by David Tudehope of the Mater Hospital, Brisbane, who, like Bourne and Lewis, was a significant figure in changing opinion about the psychological and emotional

significance of pre-natal loss in the 1970s. Personal conversations with JHP, July-August 1997.

52 'Reflections on Death in Childhood,' *British Medical Journal, 294* (1987), 108-10.

53 Ibid., 109.

54 D.C Maddison and W.L. Walker 'Factors Affecting the Outcome of Conjugal Bereavement,' *British Journal of Psychiatry, 113* (1967), 1057-67.

55 P.F.H. Giles, 'Reactions of Women to Peri-Natal Death,' *Australia and New Zealand Journal of Obstetrics and Gynaecology, 10* (1970), 207-210.

56 Any meaning or meanings which the pregnancy may have had may, of course, change. This will almost certainly happen over the longer term but even in the early stages of the bereavement meanings may change or oscillate. The need for carers to listen attentively to what is being said at any time will thus be of critical importance.

57 Tony Walter says that 'telling the dead person's story tells the storymaker who the deceased was, and by extension who the storymaker is.' *On Bereavement: The Culture of Grief* (Buckingham: Open University Press, 1999), p. 71.

58 It is important to note that such language is not substantive (i.e., it is not a statement about biological development) but is performative (i.e., it says something about relational identity, the recognising or calling-into-being of the biological entity as 'other'). The use of the personal pronoun is particularly problematic with an early spontaneous abortion. It is often impossible to tell the gender of an early fetus simply by observation and even at a later stage the sex of the fetus may be ambiguous. This, however, will almost certainly be determined where there is a post-mortem examination of the embryo or fetus. A too casual use of 'he' or 'she' in talking to the parents may later be contradicted by autopsy results. The consequent confusion and/or anger may be profound. Parents may deny the results of the post-mortem on the grounds that a mistake must have been made, 'because our baby was a little girl...' or may accuse the hospital of negligence. These linguistic problems may cause real difficulty for staff especially where a 'baby' is being mourned and staff wish to avoid the impersonal pronoun, 'it' but do not yet have the evidence on which to use the more personal, 'he' or 'she'. The repetitive use of 'baby' or 'your baby' may be linguistically clumsy but may have less detrimental effects than a careless use of terminology that has to be 'un-learned'. The parents who have already begun to grieve the loss of a 'girl' may have to begin the grieving process all over again if the 'girl' turns out to be a 'boy'. This is far from being an academic issue and has had profound consequences in terms of grieving.

59 After miscarriage, one woman was presented by a small but clearly discernible embryo, lying in a kidney dish, by a junior doctor who asked her what she wanted 'done' with 'it'. Such attitudes may, however, extend beyond a simple lack of sensitivity into a coping mechanism (distancing) on the part of caregivers, often erroneously described as 'professionalism'. Thomas Attig has rightly argued that 'the tendency to fight feelings of tenderness and compassion with toughness often inhibits those of us who are in the thrall of atomistic thinking from offering help.' T. Attig, *How We Grieve: Relearning the World* (Oxford: Oxford University Press, 1996), p. 160. Roland Riem has described such 'defence' as 'a barrier to truth' R. Riem, *Stronger than Death: A Study of Love for the Dying* (London: DLT, 1993), p.43.

60 N. Bawden, *George Beneath a Paper Moon* (London: George Allen and Unwin, 1974). This novel is unusual in that it deals with pregnancy and pregnancy loss from a predominantly male perspective

61 An example of inappropriate action as a grief response would be of a person who expressed their powerlessness, grief and anger through physical violence directed towards equipment, staff, others or self. The appropriateness of such behaviour, though not the feelings which underlie it or the grief itself, would always need to be challenged and, where necessary, constrained. Similarly, whilst thoughts about suicide are not uncommon among the newly bereaved and represent the longing to be re-united with the person who has died, actual suicide attempts, whilst relatively rare, are not unknown especially where self-esteem is low and there may be a high degree of guilt. Whilst it often disregarded altogether, it is my contention that the (often acute) depression which may follow a miscarriage ought to be regarded and managed as a form of post-natal depression, itself a condition which has only recently received the serious attention which the condition warrants.

62 See I. Illich, *Limits to Medicine, Medical Nemesis: The Expropriation of Health* (Harmondsworth: Penguin, 1990) and F. Tassano, *The Power of Life or Death: A Critique of Medical Tyranny* (London: Duckworth & Co., 1995).

63 Self-perception refers here not only to the perception of one's own body - and many women are profoundly challenged by their powerlessness to control their bodies at the time of a miscarriage, but also of one's social identity - as 'mother', 'wife' or 'partner'.

64 One of the great confusions for many people whose children die is the question whether they are still 'parents'. Whilst this is more common in the case of a 'known' baby or child, the 'knowledge' of even an early pregnancy can precipitate such confusion in some individuals or couples. Even when those most closely involved with the miscarriage are clearly regarding themselves as 'bereaved parents', they may fail to find this status endorsed by others, either in the hospital or in the wider community - 'there wasn't a baby before, there isn't a baby now, what has changed', is a commonly perceived attitude. If there are other children in the family or who are born later, the question, 'How many children do you have?' can itself cause many problems for some. To count only those who are alive seems a betrayal of the child or children who never came to birth, to include them may prompt the question of where they are. Thus a parent with two 'living' children may say, 'three but one of them died...' although others, acutely aware that this may cause discomfort or embarrassment may simply say, 'Two...' but nonetheless struggle with the guilt of a perceived betrayal.

65 I shall concentrate primarily on the loss of a 'wanted' pregnancy. Ambivalence about being pregnant or indeed not wanting to be pregnant will in most cases provoke different responses in the woman and those who surround her. Nonetheless, even when the miscarriage is a cause of relief, it may well be accompanied by some measure of guilt that not wishing to be pregnant had somehow caused the embryo or fetus to 'die'.

66 Particularly in the early stages of grieving, the putative parents will 'search' for a meaning or reason for the death. Taking a headache tablet, running for a bus, having an argument or simply being a 'bad' person may all cited as 'reasons' why the pregnancy did not continue. The belief that the miscarriage was in some sense a 'punishment' inflicted by God or fate for some wrongdoing, real or imagined (often

unspecified, though not infrequently prior abortions), is not uncommon and will need to be both taken seriously and carefully addressed. The pseudo-theological suggestion that it was not just 'nature' but rather a result of divine or super-natural intervention, that it was God who 'took' the unborn child (even where the 'pay-off' is being an 'angel' as in 'God wanted him/her for a little angel...'), whilst not uncommon among those who are both struggling themselves to give meaning to the event or who wish to attribute meaning to it for others, suggests a God who is both capricious and arbitrary and who 'takes' children. This is far from a Christian understanding of the God who as the source of all being is described as the 'giver of life'. Nevertheless, such phrases as 'God wanted him/her for an angel....' or 'Jesus picks all the best flowers...', like 'it's a punishment because I was a bad person...', though based on a flawed theology ought not simply to be dismissed as being without any content as they may, in fact, represent the struggle to locate a particular, and often difficult, event within a wider framework on which one can reasonably rely. The sudden transition from 'being' to 'non-being' in others is one which is also threatening to the self. Part of the 'problem' of the death of children is that in the general 'order' of things parents do not expect their children to die before they do. Where 'death' happens before birth, the 'natural' order of being born, growing up, growing old and dying, is profoundly challenged. Such questions as 'Why did my baby die?' may therefore be as much philosophical, theological and existential questions as they are medical ones and careful listening is required to hear precisely what is being asked at such times.

67 Simply to acknowledge that a change of status - 'pregnant' to 'not pregnant' - has taken place and to accept that, within the broad spectrum of responses, the effects of this may be profound and to be able to say, where appropriate, 'It wasn't your fault...' or 'it wasn't anything which you did which caused the miscarriage to occur...' may help both to dispel common myths about the causes of miscarriage and to mitigate these initial feelings of perceived failure, fault or blame. This should not, however, be construed as a simple formula which obviates the need, first and foremost, to listen and to enter into an open and constructive dialogue.

68 This sense of 'powerlessness' or 'lack of control' may be a feature, not just of pregnancy-loss but of pregnancy itself.

69 C. Moulder, *Miscarriage: Womens' Experience and Needs* (London: Pandora Press, 1990), p.101.

70 This procedure is still less recognised than in the case of a late miscarriage or stillbirth, or in the case of a neo-natal death where there is a 'body' to be seen. In the next chapter we shall deal specifically with the issues surrounding the management of stillbirths.

71 Cited in Pizer and Palinski, *Coping with Miscarriage,* p.27.

72 Many families, in fact, wait until a pregnancy has become 'established' before telling others, whether friends or family. Where miscarriage occurs, either silence may be maintained or there is the double shock of the disclosure both of the pregnancy and of the fact that it has ended prematurely.

73 Here, I think that Worden is unduly optimistic. Whilst he recognises that miscarriage involves the loss of a person and that it is therefore important the grief work is done, he writes, 'Parents who have experienced miscarriages generally receive considerable support from family and friends.' (Worden, *Grief Counselling and Grief Therapy,* p.103.). Where there is support, it often comes primarily from other women

who have themselves experienced miscarriage. Bowlby identifies lack of social support as a pre-disposing factor in poor bereavement outcomes. J. Bowlby, *Attachment and Loss, vol. 3* (Harmondsworth: Penguin, 1981), p. 148. Such support is not only emotional and/or practical but may include ritual support. See chapter on liturgy and pastoral care.

74 This is seldom seen as a form of 'post-natal' depression although this is precisely what is being experienced.

75 Here the systemic approach of family therapy offers a good model for working with those who have experienced a miscarriage. See for example L. Von Bertalanffy, *General Systems Theory* (Harmondsworth: Penguin, 1968); D.A. Anderson, *New Approaches to Family Pastoral Care* (Fortress Press, 1980) and M. Bowen, *Family Therapy in Clinical Practice* (New York: Jason Aaronson Press, 1978). A good overview of some of the various approaches to family therapy can be found in S. Walrond-Skinner, *Family Matters* (London: SPCK, 1988), chaps, 2,5-9.

76 If people are feeling angry with God for 'letting them down' or 'causing' the death of their child, they will often project that anger onto the Chaplain as a much more tangible focus. Whilst people's understanding of the nature of God, like their understanding of themselves, may frequently be changed by a life-event such as the death of a child, this is not necessarily a negative experience and can be developmental of faith. For an example see M. Young and L. Cullen, *A Good Death: Conversations with East Londoners* (London: Routledge, 1996), p. 31. The interpretation of the death of a child as 'spiritual crisis,' which may have positive as well as negative resolution is one which will be explored in detail later.

77 A. Stewart and A. Dent, *At A Loss: Bereavement Care When a Baby Dies* (London: Bailliere Tindall, 1994), p.16. See also, H. Deutsch, *The Psychology of Women: A Psychoanalytic Interpretation* vol.2 (New York: Grune & Stratton, 1944), p.263.

78 This sense of 'both... and...' is well demonstrated in the poem by Nancy Leon at the beginning of Irving Leon's, *When a Baby Dies: Psychotherapy for Pregnancy and Newborn Loss* (New Haven: Yale University Press, 1990).

I lost you
when you'd just begun,
before the July river,
before the first light of day.
And with you
I took
one step closer
to death. (Quoted in part)

79 Alastair Campbell and his colleagues have argued that,

> neurological and behavioural factors alone are not sufficient to tell us how we should act towards foetuses and infants... since they fail to take account of the commitments that are so essential to life together in the human community.

A. Campbell, M. Charlesworth, G. Gillett and G. Jones, *Medical Ethics* (Oxford: Oxford University Press, 1997), p.84.

80 Those who, in other areas of their lives, exercise a greater measure of control in decision-making or action, tend to adapt to pregnancy loss less quickly than those

who are more used to regarding their lives as more determined by external agencies or factors.

81 Conversation with Gillian Gill, Social Worker at St. Michael's Hospital, Bristol, March, 1991.

82 *When Pregnancy Fails: Coping with Miscarriage, Stillbirth and Infant Death.* (London: Routledge and Kegan Paul, 1982), p.17.

83 My conversations with women who had experienced a first pregnancy miscarriage revealed that, although they had known about literature on miscarriage, this was a subject that they had not seen as relevant to them at the time. In the light of their experience, many women felt that some reference to miscarriage ought to have been part of ante-natal preparation; whereas, if it had been mentioned at all in ante-natal classes, the subject had been quickly passed over. In the *Report of the RCOG Working Party on the Management of Perinatal Deaths* (RCOG, 1985), the RCOG concludes that,

> Little or no reference to obstetric disasters is made in many of the booklets published to help women prepare for childbirth. The current emphasis on health and normality in pregnancy helps to reduce the awareness of miscarriage, stillbirth and neo-natal death... (8.1).

Where there is some knowledge of the risks of miscarriage these, nonetheless, appear to be largely displaced: 'Couples tend to be aware of the risk of miscarriage although their reaction afterwards indicates that it may have been a risk they thought of for others but not for themselves.' (8.2).

84 It is important to note, however, that a declaration of death may only be made by a doctor. This is why others, such as midwives or ultrasonographers, may in practice have little option other than to use such periphrases before death is confirmed.

85 E.M. Bryan, 'The Intrauterine Hazards of Twins,' *Archives of Disease in Childhood, 61* (1986), 1044-1045; E. Lewis and E. M. Bryan, 'Management of Perinatal Loss of a Twin,' *British Medical Journal, 297* (1988), 1321-23. I am grateful to Dr. Bryan for her conversation with me about the issues concerning the death of a twin and for her invitation to address and talk with the members of the Twins and Multiple Birth Association (TAMBA) group at the Queen Mary and Hammersmith Hospital in the late 1980s.

86 E. Lewis and E.M. Bryan, 'Management of Perinatal Loss of a Twin,' *British Medical Journal, 297* (1988), 1321.

87 One mother, frustrated by a crying child who was the lone twin survivor of an intrauterine death, was horrified to hear herself say to the child, 'You always were a wicked child, you even killed your brother before he was born.' She had thus verbalised some of the complicated feelings which she had suppressed for a long time and was subsequently to seek help in resolving them. Lone twins are not only a constant reminder of their non-surviving siblings, they frequently have (or feel that they have...) to achieve for both, rather than simply for themselves. This can be very difficult, especially if the non-surviving twin is idealised. After all, a child who does not physically exist can do no wrong. This may lead the surviving twin to have ambivalent feelings about their non-surviving sibling to whom all sorts of fantasy successes or endowments may be attributed.

88 E. Bryan, 'The Response of Mothers to Selective Feticide,' *Ethical Problems in Reproductive Medicine, 1* (1989), 28-30. See also E. Bryan, 'Infertility Treatment - Some Ethical Dilemmas,' *Holistic Medicine, 5* (1990), 167-169.

89 The success of reproductive technologies in securing pregnancy and the subsequent birth of a child is currently in the order of 20%. This may be interpreted either as only a 1:5 chance of conceiving/bearing a child or as comparable with the current success rate of natural fertilisation.

90 When the problem of infertility is present in only one partner, that person often carries an extra dimension of guilt in their grieving.

91 Irving Leon has argued that, in fact, 'grieving infertility may be more chronic and less readily resolved than mourning perinatal loss.' Leon, *When a Baby Dies,* p. 67.

92 Genesis 30:1.

93 Here, once again, grief may be closely related to choice. In fetal reduction, to chose *for* one is to choose *against* another and, in some cases, the grounds for choice may be purely arbitrary. Unlike other counties in which six or more embryos may be implanted, in the United Kingdom the maximum number of embryos the HFEA permits to be transferred in any one cycle is limited to three.

94 This happens in about 95% of ectopic pregnancies although nidation can happen, for example, in the wall of the abdomen or in the ovary.

95 Ectopic pregnancies account for about 12% of maternal deaths.

96 Advances in microsurgery and laser surgery have helped to reduce the incidence of infertility after ectopic pregnancy although 40% of women will fail to conceive after an ectopic pregnancy and 15% will have another ectopic pregnancy. Recent research with the drug, methotrexate (most commonly used in the treatment of cancer), to dissolve the embryo may offer an alternative to surgery although its use, at this stage, is extremely limited, especially in the UK.

97 June Kuczynski argues that men are likely to have the same emotional reactions to ectopic pregnancies as their partners. 'Support for the Woman with an Ectopic Pregnancy,' *Journal of Obstetrics, Gynaecology and Neonatal Nursing*, July/Aug. (1986), 306-310. See also C. J. Creech, 'Ectopic Pregnancy,' *Journal of the American Academy of Nurse Practitioners ,5*, 6 (1993), 249-257.

98 The Bristol Inquiry, chaired by Prof. Ian Kennedy, and the subsequent disclosure of the retention of baby's organs at Alder Hey Hospital on Merseyside has publicly highlighted practice which has been both longstanding and widespread. After *any* death in hospital, the body remains the property of the health authority or Trust and *not* of the relatives. The interim Report of the Bristol Inquiry in May 2000 and the subsequent Redfern Inquiry, recommended that forthwith consent should always be sought before the removal of any organs.

99 Even if the abortus is not regarded as being a 'baby' or 'child' there is often a concern that it should be 'disposed of' with some measure of respect (as proposed in the Polkinghorne Report). Those who stop short of regarding the abortus as a human 'life' or 'person' may nonetheless regard it as 'more' than, or qualitatively different to, other human 'material' such as a finger or appendix. (Nonetheless, it should be noted that there may also be profound 'grief' which follows the loss of a limb or organ. This

may be both for the 'missing' organ itself, for the former lifestyle or activities which it made possible or for activities which because of the 'loss' will not now be possible at some future time). In the case of the late abortus who 'survives', as is occasionally the case, there is the paradox of the neonatologist struggling to preserve a life which his gynaecological colleagues have actively sought to terminate.

100 The question of appropriate rituals for naming a baby who has died before, or at the time of birth will be dealt with in a subsequent chapter.

101 This would not be a legal option after the age of viability.

102 Now re-named St. Michael's Hospital.

103 For this to happen it is also necessary for doctors to complete a certificate of disposal and for parents to give their consent in order for the 'remains' to be accepted by the cremating authority.

104 Even though in the early 1990s Kohn and Moffitt were at least partially correct in their view that '(s)tandard religious customs and ceremonies are often not available to bereaved parents following pregnancy loss and newborn death,' they are simply wrong in their contention that hospital-arranged funerals are 'usually in a grave with other babies.' Kohn and Moffit, *Pregnancy Loss*, pp.146 and 159.

105 According to C. Jackman, H. McGee and M. Turner, 'Maternal Views on the Management of Fetal Remains Following Early Miscarriage,' *Irish Journal of Psychological Medicine, 10*, 2 (1993), 93-94, most women still did not see their miscarried fetus (85%) or know what burial arrangements had been made for the fetus (93%). See also C. Jackman, H. McGee and M. Turner, 'The Experience and Psychological Impact of Early Miscarriage,' *Irish Journal of Psychology, 12* (1991), 108-120 and D. Morris, 'Disposal Arrangements for Second Trimester Fetuses,' *British Journal of Obstetrics and Gynaecology, 95* (1988), 545-546. This article outlines the need for information on parental and staff reactions to hospital policies.

106 An often used piece is taken from Kalil Gibran, *The Prophet* (London: William Heinemann Limited, 1926), pp.20-23. This passage speaks of children as 'the sons and daughters of Life's longing for itself...' It is a powerful and evocative piece for many bereaved parents who struggle to find words and meaning which can express or help interpret their sorrow. Interestingly the focus of this piece is on the relational distinctiveness of children from their parents who may love them but not possess them.

107 Parents who are faced with a miscarriage may lack the knowledge or experience to know what they might ask for in such situations although they may know instinctively what they want. A sensitive and open approach can help them to express what they want to articulate in any 'service' that might follow.

108 G. Outka, *Agape: An Ethical Analysis* (New Haven: Yale University Press, 1972), p.13. The phrase 'moral landscape' is first found in the writings of Austin Farrer, 'An Examination of Theological Belief,' in B. Mitchell ed. *Faith and Logic* (London: George Allen & Unwin, 1958), p.16. Outka argues that traditionally agape 'has been thought to involve a rectifying bias towards the disadvantaged, handicapped and defenceless.' (p.91). It is thus about the bestowal of worth.

109 For a development of this argument, see Chapter 4. On social relationship and systems theory, see Chapter 3. Writing from a feminist perspective, Noddings argues for the primacy of a relational ethic over individualist ethics. She argues that such a relational ethic is founded upon shared human experience (particularly of pain and

suffering) and arises out of a commitment to others in caring and being cared for. N. Noddings, *Women and Evil* (Berkeley: University of California Press, 1989). It is important to recognise that to talk of the Trinity in this context is not just to use trinitarian language as a 'model' but to talk of a divine way of being which suffuses the whole of creation. It is, therefore, descriptive of how things really are. This point is clearly made by Alistair McFadyen, 'The Trinity and Human Individuality: The Conditions for Relevance,' *Theology, 95,* 763 (1992), 10-19. See also A. McFadyen, *The Call to Personhood: A Christian Theory of the Individual in Social Relationships* (Cambridge: Cambridge University Press, 1990). McFadyen argues that persons have to be understood in social terms and that this sociality is comprised of both horizontal (human:human) and vertical (human:divine) components, so that, ultimately, 'being a person means existing in relation' (*The Call to Personhood.* p.23). For McFadyen such 'existing in relation' is primarily dialogical and therefore it is difficult to relate his arguments to the personhood of the conceptus, embryo or fetus (although he does address the issue of maternal-fetal relationships on p.47). Nonetheless, he is chiefly concerned 'to describe individual identity in terms of response' (pp.30, 43) and to this extent the personhood of the unborn human is called into being as his/her presence is assimilated into the network of social relationships of which he/she is, and will be, a part. Even where the personhood of the unborn human is not recognised (or is undemonstrable) by other persons it can be argued that personhood is nonetheless bestowed by the calling into being of the conceptus by God. This is a view of personhood espoused by Kevin Kelly and Oliver O'Donovan. See also M.A. Farley, 'Feminist Theology and Bioethics,' in A. Loades, ed. *Feminist Theology: A Reader.* (London: SPCK, 1990), pp.238-317 and McFadyen, *Call to Personhood*, p.89. McFadyen further contends that the 'self' must transcend experience, since 'there is always an 'I' beyond the 'I' of present experience.' (*The Call to Personhood*, p.100). This construction of the self is very similar to that set out by Ian Ramsey in, 'The Systematic Elusiveness of 'I',' *Philosophical Quarterly 5*, 20 (1955), 193-204

110 On agape as a way of knowing, see Alastair Campbell, *Moderated Love: A Theology of Pastoral Care* (London: SPCK, 1984).

111 S. Weil, *Waiting on God* (London: Routledge and Kegan Paul, 1951), p. 59.

112 William May regards covenental care as both gratuitous and as involving a 'growing edge' which allows for the building of relationships. See W. May, 'Care and Covenant or Philanthropy and Contract,' in S. Lammers and A. Verhay, (eds) *On Moral Medicine* (Grand Rapids: Eerdmans, 1987), pp. 83-87.

113 There is some suggestion that this projection and subsequent attachment to the fantasy baby which is projected may begin even before conception when, for example, a couple decide to 'try for' a baby. Such putative parents may 'imagine' what their relationship with a child may be and even begin to 'map out' or 'play out' scenarios in order to 'test' what this might mean.

114 D. Klass, *Parental Grief: Solace and Resolution* (New York: Springer, 1988), p.13. The power of memory is evoked by the Holocaust survivor Elie Wiesel, for whom memory is a recurrent theme of his work. He writes:

> What would a man be without his capacity to remember. Memory is a passion no less powerful or pervasive than love. What does it mean to remember? It means to live in more than one world, to prevent the past from fading and to call upon the future to illuminate it. It is to revive

> fragments of existence, to rescue lost things... to combat oblivion and to reject death.

All Rivers Run To The Sea (London: Harper Collins, 1996), p.150. Later, Wiesel asks the question so often asked by parents whose children die, 'Did a survivor have any right to be happy?' (p.161).

115 Miscarriage itself has been described as 'the passing of a dream.' See E. F. Lieter, 'Miscarriage,' in T. Rando ed. *Parental Loss of a Child* (Illinois: Research Press, 1986), p.123.

116 A.J. Solnit and M.H. Stark had first postulated in the early 1960s the idea that babies, after birth, might not always live up to their mother's expectation of them. 'Mourning and the Birth of a Defective Child,' *Psychoanalytical Study of the Child, 19* (1961), 523-37. This idea was picked up again later by Emmanuel Lewis in the 1970s.

117 Thomas Attig writes, 'Deaths of children make us doubt our identities as parents, intensify our feelings of purposelessness and guilt, and often lead us to a belief that there is no fairness in the order of things.' (*How We Grieve*, p.84). Thus, the question of identity, of self or other, raises questions that are as much existential and theological as they are biological. Spirituality, as about 'who one is', is therefore intimately related to identity and therefore spiritual care, just as much as medical care, is a key component of whole-person care, and all the more so because it is so fundamentally relational.

118 *Care of Persons, Care of Worlds: A Psychosystems Approach to Pastoral Care and Counselling* (Nashville: Abingdon Press, 1992), p.70.

119 *The Moral Maze: A Way of Exploring Christian Ethics* (London: SPCK, 1983), p.97. The same could not, perhaps, be said of Roman Catholic moral theology where moral status is attributed to the embryo/fetus from the moment of conception. See, J. Mahoney, 'Religion and Assisted Conception,' in D.R. Bromham, M.E. Dalton and J.R. Jackson, eds. *Philosophical Ethics in Reproductive Medicine* (Manchester: Manchester University Press, 1990), p.85.

120 L.B. McCullough and F.A. Cervenak, *Ethics in Obstetrics and Gynaecology* (Oxford: Oxford University Press, 1994), p.100. My point is that, even if it were possible, resolution of this matter wouldn't help us since it is not to be decided by any ontology or metaphysics of personhood but by attentiveness to the way in which we attribute identity *in practice*.

121 It is significant that such language is often qualified by a question which seeks confirmation that this view is valid or acceptable. Thus the form will often be, 'You couldn't call it a real person after all....could you?' or 'It wasn't really developed enough to be a baby....was it?'. These are important verbal signals as to the tentativeness with which such assertions may be made and they need to be recognised for what they are.

122 Although pre-natal screening may now establish the gender of a developing fetus relatively early in the pregnancy, the use of the impersonal pronoun, 'it' may be used, not because the gender remains unknown but precisely because 'it' is impersonal. As soon as gender-specific personal pronouns are used a more-than-verbal change has taken place. Martin Buber's description of the differences between 'I-it' and 'I-Thou' relationships have a particular significance in this context. See, M. Buber, *I and Thou* (Edinburgh: T & T Clark, 1937).

123 Truth, therefore, is not to be judged by looking for a simple correspondence between objective, physical 'facts' and these words - the words themselves as performative utterences *do* something, in this case, establishing a relational identity. On performative utterances, see J.L.Austin, *Philosophical Papers* (Oxford: Clarendon Press, 1961), p.220.

124 It is critically important that caregivers should not make assumptions about the relationship between mother and baby, either before or after death. The importance of listening to the narrative of loss, including the events which precede it, is a pre-requisite of genuinely attentive care.

125 R. Friedman and B.Gradstein, *Surviving Pregnancy Loss* (Boston: Little, Brown and Co., 1992), p.7. Thus, 'relational identity' here precedes 'biological identity'. The relation between relationality and biology will be explored in more depth later in this chapter.

126 A. Stewart and A. Dent, *At a Loss: Bereavement Care When a Baby Dies* (London: Bailliere Tindall, 1994), p.16.

127 The biblical accounts of early pre-birth life are, for the most part, metaphorical. They make no attempt to give a biological account of intrauterine life. Isaiah and Jeremiah are both known and, in some sense, called by God before they are born (Isaiah 49:1, Jer.1:5); the Psalmist tells how the unborn child is 'knit' together in the darkness of the womb, the human form 'woven' in secret by the mystery of the divine touch (Ps.139: 13-16). Preganancy loss is also used as an image of divine punishment of human futility (Hosea 9:14, 2 Esdras 8: 8, 14). The writings of the Church Fathers, building on biblical tradition, are similarly shaped by contemporary world views.

128 D. Folscheid, 'The Status of the Embryo from a Christian Perspective,' *Studies in Christian Ethics, 9,* 2 (1996), 16-21.

129 M. Warnock, *A Question of Life: The Warnock Report on Human Fertilisation and Embryology* (Oxford: Basil Blackwell, 1984); J. Polkinghorne, *Review of the Guidance on the Research Use of Fetuses and Fetal Material* (London: HMSO, 1989).

130 J. Peel, *The Use of Fetuses and Fetal Material for Research* (London: HMSO, 1972).

131 The argument of 'potential' vs. 'actual' persons is well-documented in the philosophical and theological literature. As I argue that, of itself, this argument does not help us in defining the person-status of the early embryo, I will not explore these arguments further. A good account of the arguments is given in B. Steinbock, *Life Before Birth: The Moral and Legal Signicicance of Embryos and Fetuses* (Oxford: Oxford University Press, 1992).

132 Polkinghorne extends the principle of 'respect' to the dead fetus, 'in a way analogous to the respect we afford to a human cadaver on the basis of its having been the body of a human person.' (Polkinghorne, *Review of Guidance on the Research Use of Fetuses and Fetal Material*, 2.4). Many of the issues raised here have recently re-surfaced in the Redfern Inquiry (2001) on Organ Retention.

133 Ibid., 3.1. Thus, unlike Peel, Polkinghorne sees the critical categories as 'alive' or 'dead', not 'viable' or 'pre-viable'. A similar position is taken by the Methodist Report, *Status of the Unborn Human* (London: Methodist Conference, 1990), p.26.

134 N. Gilchrist, 'The Status of the Fetus,' in D. Evans, ed. *Why Should We Care?* (London: Macmillan, 1990), pp.56-67.

135 This was, in fact, the conclusion drawn by the Commission on Human Fertilisation and Embryology chaired by Lady Warnock.

136 Report of the Committee of Inquiry into Human Fertilization and Embryology (London: HMSO, 1984), p.90.

137 S. Hill, *Family* (Harmondsworth: Penguin Books, 1989), p.111.

138 Editorial, *Lancet,* 10 Dec. (1988), 285.

Chapter 3. Stillbirth

Lear: Why should a dog, a horse, a rat have life
and thou no breath at all?
(King Lear, 5:3)

Introduction - What is stillbirth?

The anguished cry of the aged King Lear who, at the very moment of happy expectation that he will at last be re-united with his youngest daughter, Cordelia, finds her cruelly snatched from him by her sudden and un-timely death, echoes the protest of so many parents whose children are stillborn. Often in the space of a moment, the happy anticipation of birth is frustrated by the tragedy of untimely death. Like others suffering pre-natal or perinatal loss, such parents experience the violation of present and future hopes, both those which they held for themselves and those which they held for their child or children. In place of the joy and anticipation which they once felt, they are left instead with only the bitter agony of an empty despair. They have come so close, only to have that for which they have waited denied them. Little wonder, then, that stillbirth has the ability to evoke such intense emotions in those who experience it and to leave such a sense of sadness and frustration in those around them, family, friends or professionals, to whom they will have looked for their care and support especially during their pregnancy.

Stillbirth, also sometimes referred to as a late miscarriage, is legally defined as any death which occurs after the 24th week of gestation, up to and including the time of birth.[1] Where the developing fetus dies *in utero* during this period, this is generally described as a 'known' stillbirth and, whilst in many respects a distinct bereavement experience, the psychological and emotional characteristics of the responses to such intrauterine deaths nonetheless bear many similarities to their pre-24 week counterpart, the early spontaneous abortion or miscarriage. Where a baby dies during labour or birth, health care professionals describe these as *inter-partum*, unexpected or 'fresh' stillbirths. These, too, share some common characteristics with miscarriages and

later intrauterine deaths. Notwithstanding this, the grief response is often more akin to the experience of sudden and traumatic deaths in infancy or childhood, such as Sudden Infant Death Syndrome (SIDS) or accidental deaths. In both forms of stillbirth, a stillborn child is defined as,

> any child which has issued forth from its mother after the twenty-fourth week of pregnancy and which did not at any time after being completely expelled from its mother, breathe or show any other sign of life.[2]

The key difference between the intrauterine death of a known stillbirth and the unexpected stillbirth which happens during labour or birth is that, in the case of the former, women enter labour knowing, at least intellectually, that the baby which they are carrying is already dead. In the latter, women enter labour with a live baby who then dies. The unexpected nature of the latter may prove a complicating factor in the grief which follows:

> When death occurs with little or no warning, and especially if it occurs in the younger years, then an extra parameter is added. There has been no opportunity for anticipation, for preparation beforehand. The death brings an extra effect of shock over and above the normal... It is not surprising that sudden, unexpected and untimely deaths are associated with greater problems for the bereaved than are anticipated deaths... sudden deaths prove to be a risk factor for poor outcome following bereavement.[3]

Elsewhere, Raphael argues against the once commonly-held belief that women would rapidly 'get over' a stillbirth or neo-natal death because she had not 'known' the baby or known it for very long. 'Nothing, of course,' she says, 'could be further from the truth.'[4]

Whilst prenatal deaths after the first trimester are less common than early miscarriages, stillbirths nonetheless represent approximately 1:80 of all births in the Western world and stillbirth annually affects some 4,000 women and their families in the United Kingdom alone.[5] Although stillbirth is still a relatively common experience, it remains, nonetheless, a taboo subject. The social unease that is found in talking about it can so easily lead to the kind of damaging and stigmatising 'conspiracy of

silence' that surrounds other pre-natal and peri-natal deaths.[6] In the late 1960s, Bourne had described how stillbirth was often treated as a 'non-event' and he suggested that current practice regarded a stillborn as 'a person who did not exist, a non-person, often with no name... an empty tragedy and a painful emptiness...'[7] Others have noted how the prevailing attitude is that 'there is nothing for the world to remember, and so nothing to mourn.'[8] Thus, the baby is diminished as a real 'person', reduced to what Charles Lamb describes as 'a nameless piece of babyhood', and grief is not legitimated.[9] Riches and Dawson argue that,

> Modern child-centred and health-valuing societies, with advanced medical systems and high expectations of longevity, tend to have few discourses which account for parental bereavement.[10]

The immensity of this form of loss is well summed up by Friedman and Gradstein:

> The loss of a pregnancy is a life crisis that is largely ignored by modern society, the fetus is regarded as a non-person, and its loss as a non-event. Society denies the importance of what has happened and discourages the expression of grief by letting the woman know that she didn't really lose anything.[11]

Stillbirths have been movingly described as 'a tragic juxtaposition of life and death',[12] and the sad sight of a limp and un-moving newborn baby, stands in stark contrast to the hopes and expectations of both the putative parents and their carers. In stillbirth, what is delivered now has physical characteristics which mark it out as being clearly and recognisably a human baby in more than a simply genetic sense. This is so even in the case of those babies who have severe physical abnormalities or who are badly macerated. Thus stillbirth, by and large, lacks the ambivalence characteristic of earlier intrauterine deaths about whether what has been 'lost' with the ending of pregnancy can be described as being a baby or not. Most parents who have a stillborn baby describe their experience as having a baby who then died, even though, by definition, the baby had no 'life' independent of the womb. This understanding is reinforced by the fact that, unlike miscarriage, the parents of a stillborn child are required by law to

register the birth-death.[13] As noted in the previous chapter, attachment to the developing fetus does not follow a simple curve against gestational age. It is also true that the relationship of the parents to the pregnancy may fall at any point across a broad spectrum of acceptance (bonding). Nonetheless, it is also true that the longer a pregnancy continues, the more likely it is that the parents' 'image' of the as yet un-born child, and of themselves as that child's parents, will become increasingly fixed in the parents' minds. Hopes, expectations and aspirations, both for themselves and for their as yet un-born child, will grow accordingly, especially in the case of a planned or wanted pregnancy. When intrauterine fetal movement can be felt, this imaging of the baby is often intensified. The imaging of the baby increases after the later gestational scans. Now, the contours of the body reveal a being who has a distinct shape, sucks his or her thumb, reacts to light or to loud or sudden noises and moves his/her limbs. As such 'bonding' increases, the unborn baby makes the gradual transition from fantasy to reality in the parents' lives.[14] In medico-legal terms, as for the parents, this being is now increasingly seen as a 'person' in his/her own right.[15] As the time for the baby to be born draws nearer, there is generally a heightened sense of anticipation and expectation.

As with an early miscarriage, the late miscarriage or stillbirth thwarts these hopes and expectations and leaves those who have done the hoping with a sense of emptiness and loss and, particularly in the case of a stillbirth, with a void in their lives that is often as tragically real as it is metaphorical. The sense of frustration that all that has been invested in the pregnancy has now come to nothing may, for some, be overwhelming.[16] Gone is that being, known, yet somehow still to be known, who was the un-born 'child' and yet there is no compensation in having an 'outside' baby to replace the 'inside' one whose life, both real and in fantasy, has been lived with for the period of the pregnancy, however long or short that time has been.[17] Many women describe how their arms, quite literally, 'ache' to hold a baby and, though lactation may be suppressed by the use of drugs, the feeling of having full breasts, yet with no baby to feed, heightens the sense of pain and futility.[18]

In the same way as I discussed early miscarriages in the previous chapter, I shall begin by describing the physiological experience of stillbirth, outlining some of the known causes for such a loss of pregnancy. This is necessary because the variable physiological experience can be one strong determinant in patterning any subsequent bereavement. I shall then describe some of the psychological and emotional responses to stillbirth which are experienced by women, their families (or other social networks) and by the professionals who work with them. To do so, I will draw on a range of literature, professional and lay, to demonstrate changing attitudes in both theory and practice, and, perhaps more importantly still, to reveal deep-seated and often still unchallenged assumptions which themselves shape and determine attitudes to the unborn human and to the relational networks of which they are a part. Thus, the literature is not just reviewed but is offered in such a way as to reveal both its limitations and its possibilities for emerging good practice. Finally, I will explore some of the practical and pastoral issues surrounding a stillbirth. Particular reference will be made to the ethical and theological issues which form some of the determinants of good practice and which help us to understand some of the reasons why people, both professional and lay, respond in the complex ways in which they do when dealing with such, so-called, 'obstetric disasters'.

Physiological aspects of stillbirth

There are a number of contributory causes which may lead to the death of a baby in the second and third trimester of a pregnancy, though in almost 50% of late pregnancy losses, the precise cause of death may remain unknown.[19] In the majority of cases of later pre-natal deaths, pregnancy continues normally until fetal movement or heartbeat suddenly ceases or a spontaneous labour begins. As with an early miscarriage, there may be some degree of accompanying physical symptomology and there may be a general 'sense of unease' felt by the mother that, whilst undefined, nonetheless needs to be taken seriously.

Sometimes the cause of the stillbirth lies with the anatomy of either the developing fetus or the mother. Where the latter is the case, as, for example, with an incompetent cervix, these may increasingly be conducive to early medical or surgical intervention.[20] Toxaemia (pre-eclampsia or, where seizures occur, eclampsia) may also contribute to the death of a baby in later pregnancy, as may genetic anomalies in the developing fetus.[21]

Known stillbirth

Where a known stillbirth occurs, labour usually follows the intrauterine death spontaneously within a fortnight, otherwise labour may need to be induced in order to minimize risk to maternal health. Some women whose babies die during their pregnancy wish to hold onto the hope that all will, despite the evidence to the contrary, in the end turn out well and so put off having labour induced for as long as possible. Others, whilst accepting that the baby has died, also want, nonetheless, to 'hold onto' the baby for as long as they can and so they too resist relinquishing their pregnancy until the last possible moment. Thus it is important that the loss of control which may be experienced when the death is confirmed is not compounded by making parents feel 'rushed' into decisions or procedures which they may not yet be emotionally capable of owning. Callahan rightly says that, '(t)o have a choice is to have some control, even a choice to do nothing.'[22] Friedman and Gradstein note that, '(i)t is our experience that when women take control, their hospital stay tends to be a less painful one.'[23] For most women, however, continuing to carry a baby who is known to have died *in utero* is an emotionally traumatic experience. Most wish to have labour induced, to give birth, and so to bring the pregnancy to an end as quickly as possible after the death has been confirmed. The effects of this will be discussed later in this chapter.

Unexpected stillbirth

A number of stillbirths occur when the placenta pulls away from the wall of the uterus during labour (placental abruption). In such cases, stillbirth happens sunddenly and unexpectedly. Another cause of unexpected stillbirth is birth hypoxia, resulting from the interruption of the oxygen supply by, for example, the umbilical cord becoming kinked, constricted, prolapsing or becoming entangled around the baby's neck. Sadly, in a significant percentage of unexpected stillbirths, the baby simply dies for no apparant reason.

Psychological and emotional aspects of stillbirth

> To everything there is a season, and a time to every purpose under heaven. A time to be born and a time to die. These well known words from the bible affirm the expected order of life. Between birth and death there is a time to live... But when the time to be born is also the time to die, when the beginning of life is the same as its end, when the time to live never comes, then this order is violated. The cry of the longed-for baby becomes a sob of bereavement from the family; the anticipated baptism becomes a dreaded funeral. This is a stillbirth.[24]

Expectation and loss

The emotional and psychological sequelae of grieving after a stillbirth may have much in common with those attending other types of early death (the known stillbirth with earlier miscarriages; the un-expected stillbirth with later forms of sudden and traumatic death). The proximity of birth and death, however, lends stillbirth a uniqueness which makes it particularly difficult for many families to come to terms with. In their study of the development of bereavement counselling, J. Thearle and H. Gregory note how in stillbirth two life events, known to be among the most stressful, - giving birth and coping with death - are brought together in a single event.[25] The resultant emotional contortion is intensified with the unexpected stillbirth when birth calls for celebration and death for grief. This may indeed prove to be beyond the

immediate psychological and emotional capabilities of some people.[26] Of atypical bereavement reactions noted after pre- and peri-natal deaths, the most common are those which follow a stillbirth.[27] Furthermore, poor management of stillbirth exacerbates the trauma for parents and can add to the 'un-reality' of the event. There is, therefore, a discernible correlation between levels of satisfaction of care and grieving outcomes which ought not to be overlooked.[28]

Although very little may be taken in by the parents in the immediacy of their loss, they nonetheless always seem to remember in detail later how they were treated by healthcare professionals.[29] Where parents feel that care has been neglected or badly handled or that they, or their baby, have not been respected, another layer of distress is added to their grief.[30]

In known stillbirth, the interval between finding out that the baby has died *in utero* (possibly some time after the death) and giving birth may be particularly traumatic. The gestational age and size of the fetus will mean that, in the absence of pressing medical reasons, a normal vaginal delivery of the dead fetus will generally be preferred to medical or surgical intervention. Where the death is known before spontaneous labour begins, the interval between learning of the death and delivering the dead baby may allow the parents the space to begin the grieving process (anticipatory grieving).[31] Nonetheless, as noted above, some women are simply traumatised by feelings that they have become 'a walking coffin'.[32] Now, birth, once anticipated with a sense of eager expectation, is anticipated with anxiety if not horror. What will it be like to give birth to a dead baby rather than a live one? Will it be more or less painful? What will the baby look like? Will it be a monster? Will it still be born 'whole'? These are all questions which may be asked by parents before the onset of labour. So great is the desire for a live baby, so great the horror of a dead one, that some cling tenaciously to the hope that a mistake has been made.[33] This form of denial is a self-protecting mechanism, common in the early stages of many bereavements, especially when such bereavement is sudden and traumatic. The notion that there must have been a 'mistake' is a way of clinging to hope beyond hope. In the

case of stillbirth it marks the refusal to accept that one's worst fears about the pregnancy can, and have been, actualised.

Since stillbirth is an event which breaks the normal conceptual categories of birth, it is difficult to find or attribute meaning to what has happened. Often, the higher the emotional investment in the pregnancy has been, the harder it is to accept that there will be no baby, or at least not a live one, at the end of it (hence the wish of many mothers to give birth as soon as possible after the death has been confirmed). There can, however, also be a real tension between alternating feelings of disgust and loathing about carrying a dead 'thing' inside her body, and love for the child who is both 'other' and 'part of self' and who has been carried and nurtured throughout the pregnancy. Consequently, other mothers still want to 'hold onto' the pregnancy for as long as possible, either because of their forlorn hope that all may in the end turn out well, or because it is acutely difficult to relinquish either the baby or the hopes and expectations for a shared future which that baby represented. Linda Layne describes such feelings as arising from the 'ironies of circumstance':

> Such ironies hinge on the fact that things did not turn out as expected. The depth of irony corresponds to the extent of the gap between what one expects will happen and what actually happens.[34]

This corresponds both with the knowledge that there are generally high expectations of pregnancy and child-bearing in modern western societies, and my argument that the depth and intensity of grieving after pre- and perinatal loss is directly related to the physical, psychological and emotional investment that has been made in a particular pregnancy. Pregnancy loss thus represents both a loss of the physical pregnancy and also a loss of innocence. Neither life nor the world will ever be the same. The experience of pregnancy loss may precipitate a fundamental re-evaluation or re-orientation of values, experiences or beliefs.[35] Thus, the death of a baby may not precipitate just a physical or psychological crisis, but a spiritual one. Recognition of this is of critical importance in the delivery of holistic, person-centred care.[36]

Event or non-event?

Before the mid 1970s, it was uncommon for women to be encouraged, or even allowed, to see their stillborn children. It was then a commonly held belief that parents did not really begin to bond with, and therefore to love or care deeply for, their child until after birth. Not seeing the dead baby was therefore considered by most medical professionals to be in the parents' best interest either because seeing a dead child would be distressing in itself or because of the fear of establishing a pathological bond. It may also have been an unrecognised form of self-protection on the part of those who perceived role is to 'prevent' such things from happening.

> It is as though, by not speaking of it, the death may be reversible, untrue; and that the actual words somehow make it real, perhaps even make it happen.[37]

For many practitioners it was, however, simply regarded as irrelevant.[38]

For many years the emotional and social significance of such peri-natal losses was thus either overlooked or blatantly ignored. Stamford Bourne describes this deliberate rapid distancing of the dead baby from the mother as the 'rugby pass' management of stillbirth.[39] Bourne was the first to argue that when doctors (representing the wider community of caregivers) treated stillbirth as a 'non-event' this had a detrimental effect on the grieving of mothers whose babies were stillborn and exacerbated the process of denial.[40] In the 1970s, a number of articles gradually began to erode the traditional view that stillbirth was a 'non-event' and could therefore, to all intents and purposes, be ignored. J.R.Wolff, P.E. Nielson and P. Schiller looked, over a period of three years, at fifty women who had experienced a stillbirth. They concluded that all but two of the women in the sample study (who were already being treated for pre-existent psychiatric disorders) showed grief reactions typical of those bereaved by the death of a known and loved person.[41] When such grief remained unrecognised or unacknowledged, the literature begins to report pathological grief reactions necessitating, in some cases, psychiatric intervention in the longer term.[42] Emmanuel Lewis argued that stillbirths were best managed by making the most of

what was available and could be remembered. He was one of the early advocates of parents seeing and holding their stillborn baby, arguing that when parents do not see their dead baby they imagine him/her as being terribly deformed or ugly. Seeing their child is often, therefore, a relief for many, since reality is rarely as bad as the fantasy. He pointed also to the importance of ritual in the grief experience and especially to the importance of the funeral.[43] The first systematic attempt to draw up some sort of guidelines for the management of stillbirths did not, however, emerge until almost the end of the 1970s, when the National Stillbirth Study Group produced its report, *The Loss of Your Baby.*[44] This report set the scene for what was to become established good practice in the years which followed.

Gradually, throughout the 1980s and into the 1990s, parents whose babies were stillborn have been encouraged to both see and hold their babies, to name them and to hold some form of funeral or memorial service. For some parents, whose babies are born dead, seeing and holding their baby is as natural and immediate a progression from giving birth, as it is for those whose babies are born alive. For others, the bringing together of parent and child is a much more gradual process (and with fathers often a slower process than for many mothers). In some cases, this bringing together of parent(s) and child begins with an initial conversation about the baby, how he or she looks, including any abnormalities, colouration (after a known stillbirth badly-macerated babies can be a dark purple hue) and gender. The baby will have been measured, weighed and photographed by the midwifery staff in the stillbirth room, been given an identification bracelet and, since the mid to late 1980s, dressed or wrapped appropriately.[45] As a prior stage to seeing their baby parents might first want (or be encouraged) to see the polaroid photograph taken of the baby and have the opportunity to talk about any issues which they might have arising from this, particularly regarding the baby's appearance.[46] When the parents feel emotionally capable of being in the presence of the dead baby, the baby will be brought into the room by a member of the nursing or midwifery staff and either held or placed in a crib or Moses basket initially at some distance from the bed.[47] From this point parents are

gently encouraged to move towards seeing, and then holding, their baby. If a member of staff holds the baby first, rather than expecting the parents to pick up the baby directly from the basket or crib, this can sometimes mitigate fears that holding a dead baby might be difficult or traumatic. The un-spoken message is, 'It's OK to hold this baby'. The question, 'Would you like to hold your baby?' often elicits a range of responses many of which contain an element of 'testing': for example, 'What do other parents do?'.[48]

For many 'new' parents who might be unsure or tentative about holding a 'live' baby, the prospect of holding their dead baby may provoke considerable anxiety. Not wanting to do so might seem like 'not caring', whilst wanting to do so might, it is sometimes thought, be considered 'macabre'.[49] Parents' ability to relate to their dead child may fall at any stage across the spectrum. Some may feel confident enough to want to move to holding their baby straightaway. Others may take hours or even days to do so and may not, in the end, feel able to do so at all. Sometimes the fear is not of the dead child him/herself but of the pain of separation - 'get to know' him/her then having to 'let go'. Some parents thus believe that it will be easier for them to cope in the long term if they do not see the stillborn baby at all. The evidence, however, suggests that the contrary is the case and that parents who decide not to see their stillborn child face greater difficulties in resolving their grief and re-investing their energies in life after the stillbirth.

Work which I carried at Bristol Maternity Hospital in the 1980s suggested that parents who both saw and held their dead babies resolved their grieving more effectively and over a shorter period of time than parents who neither saw nor held their babies. Interestingly, parents who saw but did not hold their babies, in the long term fared worse than either of the other groups. The reasons for this are complex and included previous obstetric history, experience and predisposing underlying psychology. Whilst seeing and holding the baby tends to dispel some of the worst fantasies about what a dead baby might be 'like', many of those who saw but did not go on to hold their baby found that seeing their baby, whilst reinforcing the reality of

the event, also brought home its overwhelming tragedy. Their withdrawing, without holding the baby, was a form of psychological self-protection. Many of the parents who fell into this latter category did not then go on to name their baby or to mark his or her death by attending a funeral or other memorial service.[50]

It may often be helpful to enable parents to focus on some positive aspect of their child's appearance - a well-formed hand or foot, for example, rather than on any deformity or abnormality. In a study by Forrest, the parents of deformed babies, when interviewed 6-14 months after their bereavement, all focussed on their babies' normally formed parts and none had found the experience of seeing their deformed baby horrifying.[51] Parents also value having the privacy of time alone with their child when they can undress/dress, wash and hold the baby. Some parents may also wish to provide their own momentos, photographing the baby or taking a lock of hair, perhaps.[52] Many parents will also gain much comfort from talking to their dead child, and this may help them to ventilate some of their feelings of sadness. One mother, cradling her dead baby said, 'Oh baby, how could you die on me now when I've cared for you and loved you so much over these past few months.' It was important that she should be able to articulate her feelings of sadness and abandonment rather than internalising them. Malcolm's oft quoted advice to the grieving Macduff in *Macbeth* is still timely, 'Give sorrow words: the grief that does not speak, Whispers the o'er-fraught heart and bids it break.'[53]

Patience, sensitivity and understanding are essential qualities for caregivers in such situations and, as so often, the best practice is both dialogical and virtue-led. A non-judgemental approach which recognises and acknowledges the confusion and sadness of the bereaved and has patience with their frailties will, in the end, pay its own dividends. Although there are good grounds for encouraging the seeing and holding process, parents who do not, or cannot, do so should never be made to feel guilty about this and they will need to hear that not seeing or holding the dead baby does not make them a 'bad' parent. Though physical deterioration of the baby after death will be progressive, there is essentially no reason why parents should not be

afforded the opportunity to see or hold their baby at any time before the funeral and the needs of individuals or families should always to be set above the convenience of the institution.

The main purpose of seeing and holding is to help parents test the reality of the death, to confirm the reality of the baby who has died, to create positive memories, to accept the reality of the loss in order that they may begin to adjust to a life without the anticipated and expected baby and to say their 'goodbyes' (closure).[54] The intensity of grief may be compounded where there is no externally known 'life' to mourn (i.e., one which has existed outside the womb). The complexity of grieving after a stillbirth, especially where the body is not seen or held has been compared with the experience of those whose relatives are reported as 'missing presumed dead' in wartime or after a major disaster such as an air or sea crash.[55]

Pastoral and theological aspects of stillbirth

The opportunity to 'value' and to 'own' such pre-natal lives is an important precondition for healthy grieving. Too often, however, the time which parents had with their baby during the period of the pregnancy or, albeit briefly, after delivery is either ignored or discounted by those who find it hard to understand why such putative parents should feel the need to grieve at all. This in itself may become a factor which serves to inhibit some parents from either recognising or engaging with their grief. Though we must continue to respect parents' wishes or abilities where this is not the case, it is nonetheless now widely accepted by professionals that time spent with the baby, touching, looking and talking has a real therapeutic value. Touch, therefore, establishes connectedness at a more than physical, or even psychological, level. In the ways outlined above, it is both a sign of, and an expression of, the connectedness which is a being-in-relationship with another:

> What we may not touch we may later find difficult to understand... In touching, we experience the world and one another... I touch and am

> touched. This knowledge creates a new community of those who had no confirmation of their existence.[56]

Touching is therefore a sign of the self in relationship and a confirmation of the identity of both toucher and touched. Seeing and touching the stillborn baby has not only a physical and psychological but also a theological and spiritual dimension to it.

Parental involvement in planning the funeral, and in the funeral itself, also affirms the reality of what has happened and of the child who has died. It recognises the value placed by the parents and others on the intrauterine life of that child and helps to effect some measure of closure. The funerals of stillborn babies may be arranged either by the hospital or by the parents themselves. It is important that in either situation parents are enabled to participate fully in mourning rituals.[57] The involvement of the hospital Chaplain in any funeral after a pre- or perinatal death, as one who has seen the baby, may help to affirm the baby as a 'known' other and offer parents a sign of on-going support and commitment to them as persons and as parents.

When the reality of the death finally sinks in, as shock and its related denial abates, the enormity of the loss occasioned by the ending of the pregnancy can precipitate acute grieving. The physical and emotional aftermath of a stillbirth can make the parents feel as though they are spiralling out of control. The inability to affect the outcome of the pregnancy may lead parents to feel that they have no control over what happens to them and this early period of grief is often marked by an intense vulnerability. Suddenly, the whole world may seem unsafe and many feel as though they are teetering on the brink of madness. The urge to blame, as a way both of re-gaining control and of trying to discover a reason for such an apparently meaningless tragedy may, for some, be overwhelming. For others, the sense of futility that pregnancy could end this way precipitates a despair in which even blaming seems pointless or futile and the whole world seems to have lost its meaning. As one bereaved mother said,

> All the work to create this baby, summoning his soul from who knows where, all to end as ashes in a little box. I can't stand the endless goneness of him.[58]

In this context the sensitive Chaplain can have much to offer, since 'anxieties about death, about meaninglessness, and about guilt constitute spiritual as well as therapeutic problems.'[59] The sense of existential futility following stillbirth is well described in Ecclesiastes 6:4-5, 'Its coming is a futile thing, it departs into darkness and in darkness its name is hidden; it has never seen the sun or known anything...' It is important, however, that healthcare professionals should, in the multi-cultural context of the modern hospital, be acquainted with the diversity of beliefs and practices, especially in respect of prenatal deaths, that are evidenced and which will shape the responses to stillbirth.[60]

Physical as well as mental functioning may be impaired after a bereavement, and parents may sit listless and distant, apparently unaware of what is going on around them. At this stage, they may simply not hear or take in even the most simple information which may need to be repeated several times and should be, wherever possible, written down for them. Crying, sometimes uncontrollable, may come in waves (episodic grief) and the periods of listless inactivity may be punctuated by restless wanderings. Other somatic symptoms, common after all bereavements, may be evident.[61]

At this time, clear, simple explanations about what has happened and what will now happen are very important for parents whose reference points for functioning in the world may have been severely compromised. Most parents' first question is, 'Why did this happen?' This question may reflect not only a desire to know the physical cause of death but may reflect also the deeper question, 'Why my baby...?' and even 'Why should babies have to die at all?'. Such questions may therefore not only be 'medical', but profoundly existential and theological, and this needs to be recognised and addressed by caregivers.[62] A simple, non-judgemental acceptance of people as and where they are in their grief and a commitment to gentle companionship may help to mitigate difficult feelings that may be both unexpected and frightening at this time and may communicate a much needed sense of value to those who may feel without value and often guilty.[63] The sense of not being abandoned, especially by staff, is very

important to many families who, while appreciating the need to be quiet and at times on their own, need to feel that they have not been left alone, in the sense of having passed beyond our care when the pregnancy has ended and delivery achieved.[64] A gentle and supportive presence by hospital staff is almost universally appreciated by families who may be overwhelmed by their grief and pain and are beginning to face the prospect of facing life without the anticipated and often longed-for baby. The sense that one is being listened to without judgement is particularly affirmative as parents recall the circumstances of the stillbirth, often rehearsing the scene many times over, as they attempt to locate and incorporate the experience in their life 'map'.[65]

As we noted earlier, one of the most powerful ways of affirming the 'reality' and value of the child born dead, as for a live-born child, is the process of naming. Naming helps to anchor the child in the world of reality, helps to shape his or her identity and establishes his/her place in the family system. Since the reality and identity of the child is usually more 'fixed' in the case of a stillbirth than in the case of earlier intrauterine deaths, there is usually less ambivalence about giving the dead child a name that has perhaps been chosen many months before or has particular family connotations. After a stillbirth, most parents consider themselves to a have had a baby who subsequently died. Such naming may be done informally - the baby may simply be called from the outset by their chosen name (and this should be recognised and used by caregivers) or may be formalised through a ritual or symbolic act. Whilst the sacrament of baptism is not usually conferred on those who have already died, local naming rites, both secular and religious, have now been developed by many of those whose work brings them into contact with bereaved parents on a regular basis.[66]

It is important to distinguish, however, between namings as such, important as these are, and other acts of recognition and/or of blessing which may be formalised in ritual or liturgical form. Parents whose babies have been stillborn may ask hospital staff whether they can have their baby baptised, simply because they do not know of other options which may be available to them or because they are using 'baptism' as a 'catch-all' description for any rite conferred on children which contains the elements of

recognition, naming and/or blessing. Some parents may actually want no more than a prayer to be said with them that recognises their sadness in the face of the death of their baby. Such active recognition of the birth/death experience will often be asked for even by parents who would not describe themselves as 'religious', but for whom such experiences have been profoundly life-changing and life-challenging and which may therefore for some be experienced as, or described as, 'spiritual'. Others, for whom baptism as both a religious as well as a social rite, would have been an important element in welcoming, naming and affirming any child, may be profoundly disappointed that baptism is not now an option.[67] For such parents, it is important to recognise that other options are available. Bristol Maternity Hospital, for example, developed a 'Service of Baptismal Desire' which was used either on the occasion of miscarriage, stillbirth or subsequently.[68] These rites are described and addressed in a later chapter.

The effects of stillbirth on family and other relationships

> When a child dies, it is the parents - and, sometimes, especially the mother - who are the main focus of care, but it is tremendously important to include the wider family, and most particularly the sisters and brothers. The parents will need help individually and together - women and men tend to grieve somewhat differently from each other - the other children will need help, and often the grandparents, too.[69]

Friends and members of the wider family may also have awaited the birth of a baby with a sense of eager anticipation. Grandparents and siblings may face a particularly strong emotional response which needs both recognition and acceptance.[70] It needs to be remembered that grief is expressed not only individually but also collectively by the family system and/or other social network and that the impact of such grief may affect those with whom the bereaved come into contact in a wide variety of ways.

Much of the work that has been done on bereavement in the last century has been orientated towards the individual. Those who work with the bereaved, however,

can be all too painfully aware of how the experience of bereavement, especially where that bereavement is sudden or traumatic, can create a disequilibrium within a complex network of relationships.[71] This is sometimes known as the 'ripple effect' of grief. Any child, alive or dead, both alters the dynamic of pre-existing relationships and re-configures the family system. On death, disequilibrium moves outwards from the individual through their network of social relationships. This can be imaged as an epicentre of grief moving outwards from the parents individually to their dyad and/or the inner circle of the family (including siblings and grandparents), through other family members and friends, out into the wider circle of acquaintances and the community at large.

In general, the further from the epicentre of the event, the less people will be affected by the death. As we have noted, where death occurs in the pre- or peri-natal period, fewer people will have seen or 'known' the child who has died and it may be difficult for others to recognise or understand the grief of such parents. This may, in turn, lead parents to feel angry that their grief is not recognised or validated and that the reality of their child is not being affirmed. They may also feel guilty because their grief appears to be at variance with what is expected of them. Thus, the sense of disorganisation and isolation felt by the bereaved may be both acute and disabling and may lead to emotional withdrawal into a 'safe' inner world from which even those who are closest to them may feel (or may actually be) excluded.[72] As I have shown, it is a recurring wish among bereaved parents that others would recognise and accept their feelings and their grief in ways which neither invalidate that grief nor minimise their loss. As Marcus Andronicus says, 'To weep with them that weep doth ease some deal; But sorrow flouted at is double death.'[73]

There are few types of bereavement other than after the death of a child, where the grief may be so acute or the range of responses so varied, whether before or after birth.[74] Whilst the death of a child impacts on a number of different levels - the individual parent, the parental dyad, the family system and the wider community or

society,[75] nonetheless, it is now being recognised that this complexity of grieving has remained unacknowledged.

> The consequences transcend the loss of the infant and have a significant impact upon the parents, other siblings, extended family, and wider community. Morbidity is substantial. Perhaps as important, it is largely unrecognised.[76]

Grief and the parental dyad

Since the beginning of the 1980s, a number of researchers have highlighted differences in parental grieving following the death of a child. Gender, like age, ethnic origin and social class, forms part of our social identity. These elements cannot be ignored when we consider the nature and course of grieving. Some have suggested that fathers' grief (which will be addressed shortly) is less intense than that of mothers. Others have suggested that fathers, by employing a number of different mechanisms, resolve their grief more quickly than their partners leading to a dyadal disynchronicity in grieving. Still others have suggested that there are gender differences in the type of grief experienced by parents that go beyond intensity, duration or socialised coping mechanisms. The first, and most important, fact to recognise, however, is that fathers *do* grieve.[77] Parental differences in grieving may be accounted for by a number of factors, including differences in attachment to the child who has died, different (gendered) coping mechanisms, differences in the ability or willingness of men and women to display emotions or feelings, and differing social expectations.[78]

Where grieving varies in intensity, is disynchronous, or follows a different pattern in the parental dyad, this can have a deleterious, even disastrous, effect on some relationships, especially where assumptions are made that a partner's experience of grief conforms to one's own. Couples may experience a roller-coaster ride between intimacy and isolation that can be emotionally draining. It is therefore now widely accepted by professionals, though often too little understood by those who have been bereaved, that the differences in the way in which grief is experienced, expressed and

dealt with need to be understood and taken seriously if misunderstanding or a breakdown in relationship is to be mitigated or avoided.[79]

> What each couple brings to their experience of grief in terms of individual qualities, communication, and knowledge of one partner by the other, will affect their passage through their present difficulties.[80]

The difficulty is, that the death of a child affects both partners in the dyad at the same time. Emotionally and physically depleted, they may lack the capacity to support their partner adequately and feel that the support which they need is deficient or lacking. The capacity for resentment and blame runs high, and sensitive intervention may be necessary. The tragedy is that each parent may look to their partner as their primary source of support precisely at the time when, because of the shared nature of the death, that person may be least able to give it. Sarnoff Schiff quotes a father whose baby had died in words which reflect the feelings of many fathers in similar situations:

> I think to some degree it put a wall between us because she reacted very differently to the baby's death than I did. It's become an area that to some extent is off limits for us to talk about. She couldn't accept that I didn't act as upset as she was. And I felt so helpless. You go to bed at night and your wife is lying next to you crying and that can be very difficult. What can you say? It's not like you had a fight and can roll over and kiss and make up. Some nights I didn't even want to come home because I knew I'd find her crying. It was easier to try to avoid the subject. I think that it helped when we finally understood that it's OK to feel grief differently.[81]

In working with the bereaved it is important to regard the family as a whole and to ask the questions, 'Who are this family? Who do they consist of? What do they value, need, demand, and fear? What are their dreams, now and for the future?'[82] so that we can take the dynamics of the family and the effects of inter-personal relationships seriously. In so doing, 'our goals in offering support will have to be tailored to what is realistic in each family.'[83] Consequently, appropriate support will need to strike the balance between flexible intervention and respect for both the privacy and the autonomy of the family with its internal dynamics.

It has long been recognised that depression-like symptoms in the bereaved are one manifestation (among others) of the maternal grieving process.[84] If anxiety or depression alone is used as an indicator, women appear to be affected by the death of an infant to a much greater degree than men. If, however, other indicators, such as excessive alcohol use, are factored in, then the differences in responses between men and women are significantly reduced. Both are responding to grief in what have been considered to be gender specific modes.[85] There is some indication that anxiety and depression in both men and women are markedly reduced where the bereaved attend church regularly as compared with sporadic attendance or non-attendance at church.[86] Church attendance offers both a faith structure within which to interpret life/death experiences and a supportive community within which grief may be expressed. The importance of the community of faith in pastoral care is attested by a number of writers on pastoral practice.

After hospitalisation, the return home can itself raise painful issues for bereaved parents. The sense of futility may reach a peak when the parents return to their home without the expected child. Clothing and baby equipment may have been bought by this stage and a room decorated - all, it seems, for nothing. Especially when the baby who has died has not been seen by others, it may be difficult for others to recognise or accept the intensity of the parents' grief or to recognise the baby as a 'real' person. This may lead them to avoidance or insensitivity. Grieving is a lonely process and, as with miscarriage, where the need to talk and to grieve is not legitimated, the sense of isolation felt by parents may be heightened. Eve Herd comments on how this may also be the case after later deaths,

> Back home there are long and painful days for the grieving parents, where there is a yawning vacuum after all the comings and goings of doctors, social workers and others who supported them before the child's death. They need the opportunity to express their grief; to cry and to talk of their loss and their pain - as they must if their grieving process is to happen naturally and to bring ultimate peace and wholeness to the sufferers. Their need for a sympathetic listener is as great after the death as before; indeed their pain may well intensify in

> the second year after the death, and loneliness is often a great problem.[87]

It is desirable, therefore, that bereaved parents should, as far as possible, be prepared for what may be a difficult re-structuring of prior relationships on their return to the community. Good communication between hospital and community (including appropriate communication between hospital chaplains and their community based colleagues) is essential, then, in establishing a seamless continuity of care for the bereaved.

Grief and fathers

Increasing recognition has been given over recent decades to maternal grieving for a baby who dies in the prenatal or perinatal period and has attracted considerable research. Relatively little research, however, has yet been done into the grief of fathers and in the following section I address aspects of this. I shall argue for a recognition of both similarities and differences in the grieving of mothers and fathers, advocating a systems-based approach to grief work with families bereaved through the death of a child in the early stages of life. This emphasises the interplay between connection and boundary, the tension between stability and change, and the importance of communication, as offering a constructive way forward.[88]

As we have already seen, pregnancy and its loss may be imbued with many different meanings and the investment in a particular pregnancy and the experience and response to its loss will vary from person to person. Grief is only one of the variables. It is over-simplistic, therefore, to assume that in the pre-natal period attachment to the baby is always greater on the part of the mother (although the unique physical intimacy between the mother and the child growing inside her means that bonding generally occurs at an earlier stage in mothers). Nonetheless, the *meaning* of the death of the child and the way in which it is integrated into each parent's psychological, social and faith structures may be very different.[89] Where individual parents feel that their feelings are not recognised, or even shared, by their partners, the feelings of isolation

can become even more acute and the relationship may be compromised or damaged by the perceived lack of support or even of a shared bond with the child who has died. Whatever the pre-existing quality of relationship, the death of a baby, like a birth, will inevitably precipitate change. Already strong relationships may be strengthened by the experience of shared tragedy and a sense of value in the other reinforced; where there have been pre-existing stresses in the relationship or where the birth of the child was looked to as a way of cementing an already weak relationship, the effects of the death of the expected child may be catastrophic. This is why an understanding of the differences, as well as the similarities, between the grief of mothers and fathers is so important and why the neglected emotional and grieving needs of fathers now needs to be addressed.[90]

Every child has a specific meaning, or cluster of meanings, for his/her parents.[91] As the child is often seen as a projection of self, such meaning(s) naturally differ between parents. In addition, however, there will also be shared meanings of promises, dreams, needs, hopes and responsibilities which are thwarted by death, challenging both self and the parental relationship. With the death of a child, a multiplicity of losses both functional and ontological occur, not least because when a child dies part of the self, both literally and metaphorically, dies too. As Kliman notes,

> Parents who lose a child are multiply victimised. We are victimised by the realistic loss of the child we love, we are victimised by the loss of the dreams and hopes we had invested in that child, and we are victimised by the loss of our own self-esteem.[92]

If we take, as an example, the application of a 'stage' theory of grief, we can see how differences in intensity and chronicity in grieving may occasion misunderstanding or conflict in the family matrix. Differences in the depth or duration of the denial which is often the first concomitant of grief may lead to a false impression on the part of one partner that the other partner (usually the father) does not care, or at least is not affected in a way which is benchmarked by one's own grief. As this stage is often followed by anger or blaming, it is easy to see how anger or guilt is projected onto

those nearest to hand. Similarly, because research suggests that there is a tendency for women to be more open or overt about their feelings than men, the fact that the male partner does not as easily express his grief may be also be taken for not caring or, at least, not caring as much. This difference in particular is heightened by deeply ingrained societal expectations of male behaviour, that 'big boys don't cry' or that the man will remain 'strong' for the sake of his partner. Tension between feelings and expectations may well be one reason why visible, or expressed, anger is more evident in fathers than in mothers in the early stages of parental grief.[93] Although societal expectations of gendered roles are now changing, such expectations persist. Even in recent years, the prevailing view in the few academic papers which have considered the grief of fathers after perinatal loss is that,

> (a)s far as there is an expected role for male partners, it is one of 'support'... It is quite naturally presumed that the response of the male partner will be much less than that of the woman who is directly involved physically.[94]

This view is now gradually being challenged. A recent study of men whose partners had miscarried concluded that,

> the scores of men on measures of grief and stress in these circumstances were not dissimilar to those reported for female cohorts.[95]

Whilst little research has been done on the psychological and emotional responses of men to early life losses, what little research there is on paternal grief has consistently suggested that men form attachments to the developing child which the pregnancy represents much later than a woman in whose body the biological and physiological changes associated with pregnancy are taking place.[96] For some putative fathers, therefore, 'owning' the pregnancy as real or valid, and therefore constitutive of a child or potential child, may only occur when he 'sees' the developing pregnancy on an ultrasound scan or, more traditionally, when he can physically feel for himself the baby moving within the mother's womb.[97] Thus, it is argued, a man who has not yet 'owned' an early pregnancy as 'real' (or for whom it carries a different significance,

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meaning or set of meanings than it does to the putative mother) may indeed find it hard to understand the intensity of emotion which is being exhibited by his partner if death occurs. She, as we have seen, may equally consider his emotional 'distance' as simply being cold or uncaring about the death. Equally, however, it needs to be recognised that the putative father's investment in the pregnancy may be 'higher' or greater than the putative mother's (a fact that often goes unrecognised in the hospital setting where it is the mother alone who is the 'patient').[98]

Harriet Sarnoff Schiff, herself a bereaved parent, writes of the predominant twentieth century, western norm:

> The stoicism, the insistence in our culture that men suffer in silence when faced with disaster, although slowly changing, is very much evident in bereavement.[99]

The difficulty men report in discussing their feelings after pregnancy loss may be attributed, in some cases, to a fear of losing face in front of others (especially other men). Inhibition in focussing on their own feelings is heightened where men see their role as primarily to support the mother. This is despite the fact that a number of researchers have concluded that many women feel further distressed and isolated when their partners refuse, or are unable, to talk to them about what has happened.[100] Paradoxically, my own work has revealed that many men do, in fact, wish that their grief and loss would be validated by others, and a common complaint is that the first question after the death of a baby is almost always, 'How is your wife?' and only second, if at all, 'How are you?'

It is clear, therefore, that many men have feelings of sadness, guilt and even emptiness after a miscarriage or stillbirth. They may be sad that the pregnancy, with all its hope and promise of a child at the end of the nine months, has ended. They may feel guilty (or angry) because they are powerless to change the way things are, or to 'protect' their partner from physical or emotional pain or suffering, or because they feel (or are made to feel) that they are to blame either because of something they did or of something which they failed to do. They may feel empty because, although they

were not physically carrying, or were capable of carrying, the child, the death has nonetheless left a void in their lives.

For many putative fathers, however, concern about their partner's physical health and emotional well-being means that in the immediate aftermath of the death they, all too often, put their own grief 'on hold'.[101] Furthermore, because, in the hospital setting, it is the woman who is the primary focus of care, the putative father may be made to feel that he has no identity or role to play apart from a duty to remain 'strong' for the sake of his partner.[102] As a consequence, he will often be the one who is asked for permission to carry out the post-mortem and to sign the consent forms; he will often be the one who is left to tell others what has happened, to register the death or to make other necessary arrangements. All of these factors may conspire to send the message that any grief on his part will be seen as a 'weakness' that is inappropriate and his grief may therefore be disenfranchised. Many grieving fathers feel bewildered by the expectations placed upon them at this time and may feel an inability to cope that, too often, goes un-recognised. Such feelings may heighten a father's sense of isolation after the death of a child and present a profound challenge to caregivers.

Although significantly more inter-disciplinary attention is now being given in many hospitals to the emotional needs of fathers, the view that, because they have not 'known' the child in the same way as the mother, their grief will be significantly less, still, then, persists:

> While the prospective father may share his wife's desire for a child, the fact that the pregnancy is not part of his physical self makes the experience less immediate, and often less real, for him... As a consequence the father may feel little or no attachment to his future child until late in the pregnancy or even until the child is born. Consequently, when the pregnancy is lost in the early months, or even later as with a stillbirth, the father may not yet have formed an attachment to his child and so may not mourn its passing as intensely.[103]

This is a dangerous generalization based on the premise that attachment is necessarily to the biological identity of the 'baby' rooted in the physical relationship possible only

for the mother. Relational attachment, however, offers us a different model of attachment in which the focus is not solely on the identity of the 'baby' but on the identity of the parents as well, and the relational meaning which binds one to another. From this point of view, the effect of pre-natal deaths may well be, as we have seen, as profound for putative fathers as/than it is for putative mothers, or more profound since the significant factor is the strength of the relational bonds to the baby and the consequent re-defining of personal identity both as *father* and as the father *of this child*.

Research into the different grief responses of men and women, such as those exhibited by widows or widowers,[104] suggests that such differences are not simply a matter of degree, but that men and women may well grieve in different ways. It is clear that fathers adopt different coping mechanisms to mothers after the death of a child. This is, of course, due in part at least to the fact that different avenues are open to different individuals. It is well known that many fathers 'cope' by throwing themselves into work or other activity as soon as possible after the death. Work offers a distraction from difficult feelings and may create a physical distance between the man and the source of his pain, identified in the home or his partner. The work environment has also traditionally been one in which other men collude in avoiding talking about what has happened and so enable a form of emotional denial to persist. This may be one reason for the consensus amongst bereavement theorists that fathers grieve less intensely and with less duration for their dead children than mothers after pre-natal deaths. Furthermore, it is generally argued that women's grief responses tend to be primarily centred on feelings (and talking about those feelings), whilst men's tend to be centred upon activity (doing rather than talking). Thus, while issues of support remain, both mothers and fathers need to feel that their need to grieve in their own way is legitimated. They need to be able to cry, to ventilate their anger, their guilt, their sense of failure, and to be able discuss how they may be feeling, without fear of reproach, explicit or implicit. They need to be able to articulate their confusion with all its inherent inconsistencies, knowing that they will simply be listened to and their views

valued without judgement. This is something that, as we have seen, is particularly hard for fathers to do, especially in Western Society with its established tradition that men should be 'strong' and in which they are discouraged from any open show of emotion.[105]

The Dual Process Model

The Dual Process Model (DPM) offers a radically different way of understanding gendered variety in grieving.[106] This dynamic model portrays grief as an oscillation between two fundamental processes. The first, described as 'loss-orientated', focuses on the deceased and on the painful thoughts or feelings associated with the death/loss. Such a process centres around what has traditionally been described as 'grief work' and is predominantly emotional. The second focuses on continuing life and is essentially 'task-orientated' - engaging in work or acquiring new skills - and is therefore one which is predominantly practical. In order to engage with practicalities, it may be necessary to avoid thoughts and feelings to do with the death/loss; to focus on the deceased, it may be necessary to withdraw from the practical. As it is impossible to engage in both processes at the same time, the bereaved 'oscillate' between two modes of being. It is this oscillation, or movement between the two modes, which provides the energy to move through grief towards resolution, with loss-orientation predominating in the early stages of grief and task-orientation gradually coming to predominate in the later stages.

The DPM is formulated without specific reference to gender, and is mainly concerned with understanding the varied responses to grief experienced by individuals. Nonetheless, it can provide a helpful means of understanding (gender) variations in the context of the parental relationship. The cultural accretions to gender tend to encourage men and women to handle their grief differently. In terms of the DPM, therefore, whereas women inhabit a world that is predominantly loss-orientated, moving from time to time into task-orientation; men inhabit a world that is

predominantly task-orientated, moving from time to time from the distraction of work into loss-orientation.[107] The Dual Process Model, integrating as it does the emotional and the practical, discourages us from oversimplification and thinking of gender differences in static ways. It acknowledges both that women are not so immobilised by their grief that they are incapable of 'doing' things (which is why, so often, it is expected that practical decisions and arrangements will be made or undertaken by their partners!) and that men are not so absorbed by 'work' that they are rendered incapable of thinking about their loss and responding emotionally to it. Both may oscillate between loss and task-orientation.[108] While there is relative fixity in the orientation of the partners, the DPM suggests that we might see this as facilitating both processes within the relationship.

Thus, the Dual Process Model has the potential to offer an integrated account of grieving which recognises both sameness and difference in grief between men and women and which therefore acknowledges and enables different but complementary paths through shared experience. Such a model, furthermore, is compatible with both evolutionary/biological and socialisation accounts of gender differences in grieving. Indeed, it offers an account of grief that allows for both Klass' notion of 'continuing bonds' with the deceased, and engagement with ordinary life from which the deceased is absent, which is the goal of traditional post-Freudian 'grief work'.

It is important to note that most gender-orientated theories of grief fail to take adequate account of the contemporary realities of family life and social relationships. Many women simply do not have the 'luxury' of time to grieve without the practical constraints of family life and the economic or career necessities of work. Conversely, many men, though they may take refuge in other forms of activity, do not have the guarantee of full-time (or even part time) employment in ways which were once the case. Thus, such models fail adequately to respect equality of personal and social identity or to take account of those situations in which role-reversal may mean that the woman is an equal, or even the principal, economic provider as well as being the principal care-giver within the family matrix. Thus, for both men and women, the

complexities of simultaneously grieving and re-engaging with life may be a necessary, if unwelcome, reality. The Dual Process Model, however, provides a rare opportunity to provide a synthesis of views which can account for both perceivable gender differences and similarities in the grief experience and a way of understanding the consequences of a lack of integration in the relationship as each partner oscillates.

Thus, whilst gender differences in grieving need to be both recognised and acknowledged in ways in which they have not been hitherto, they should not be overplayed. The differences in the nature and/or content or parental grieving is something that may be influenced by factors which go beyond simple biological differences between men and women. Personal psychology, education, upbringing, religious beliefs and culture all shape the way in which we grieve and these need to be taken into account in dealing with the bereaved. A systems based, or family-centred, approach which takes into account the complexity of inter-personal dynamics as well as the individuality of each member of the 'system', often offers the most productive way forward both for individuals and their relationships. In this way, the needs, and identity, of individual family, or group, members in their grieving is interpreted as part of, though not subsumed by, their participation in a complex network of relationships. Such relationships and the boundaries between them form the context, and indeed allow for the contextualization, of care.

The final word in this section, however, must go to a father who, when I asked him what he would most like to say to others about how they responded after the death of his son, said simply, 'Fathers grieve too!' The Dual Process Model helps us acknowledge both that fathers grieve and that their predominant mode of grieving may have a function in relation to their partner's own predominant, yet also oscillating, mode of grieving.

Grief and grandparents

> There are few grandparents who would not rather give their own life than see their grandchild die, and their grieving and suffering are acute. They suffer the loss of their grandchild, they witness their bereaved son or daughter's grief, and they may endure 'survival guilts' themselves.[109]

Elliot eloquently speaks of grandparents in such circumstances as 'sharing the emptiness'.[110] Many putative grandparents are deeply supportive, both practically and emotionally, at times of crisis and loss. Nonetheless, grandparents may also have their own grieving to do. In those cases where either their emotions or their beliefs differ from their child's this may, intentionally or unintentionally, precipitate feelings of guilt or other difficult emotions in the putative parents which might not otherwise be recognised or felt and which will frequently be unhelpful or inappropriate. They may, for example, exhibit either acute helplessness or become domineering or obstructive. Two themes emerge here. Firstly, grandparents have their own grief responses in relation to the baby who has died, rooted in their own belief and value structures. Secondly, where these responses differ from those experienced by their child, this can lead to misunderstanding or conflict. Either way, grandparents often perceive themselves as excluded from the circle of true grief.

Once again, therefore, a non-judgemental recognition of interpersonal dynamics within the family system is an important component of care, both for the individual and for the wider family. It is not uncommon, for example, for grandparents to deny the reality of a 'baby' who has been miscarried or stillborn, especially where there are already other grandchildren in the family. This may be a particularly painful experience for the putative parents who, in the face of this, are struggling to validate their own grief for a 'child' who has 'died', albeit before birth. On the other hand, the death of a 'grandchild' may be of particular significance to grandparents who may be desperate for a 'stake' in the future through their children and grandchildren. Such grandparents may be subject to 'survivor guilt',[111] or may now face the painful recall

of unresolved former losses in their own lives.[112] If the death of the baby has a genetic cause, grandparents may also feel guilty about whether they were responsible for the 'bad' gene.

Grandparents may thus be struggling simultaneously in their own grief with the fear of a potential loss of 'future', with the pain of their own current 'lost identity' as grandparents, with the loss of the grandchild him/herself, and with their inability to protect their own children from the pain and anguish which they are experiencing.[113]

Particularly acute may be the recall by putative grandparents of their own pre-natal or perinatal losses which will, in all probability, have been treated very differently twenty or thirty years ago.[114] Indeed, for many, the experience of their own child's loss may precipitate, for the first time, an acknowledged grief for their own earlier and un-resolved loss. Thus, grandparental grief may be complicated by a degree of confusion or ambiguity about exactly who or what is being grieved for at this time. After such deaths, it is far from uncommon for the putative grandmother to come and to talk, not primarily about her daughter's present bereavement, but about her own former losses.[115] Whilst it is often difficult to deal with these issues adequately within the constraints of the hospital setting, they nonetheless pose a real challenge and opportunity for those who are working with such families in the community, such as general practitioners and local clergy. Such unresolved former losses may be the un-recognised causes of long-term depression or other psychiatric disorders which, once recognised and articulated, may then be addressed. Whilst some grandparents display more denial than their children, generally the more distant the relative the less reality is challenged. This has been described as 'concentric circles of disbelief'.[116] Some grandparents appear, therefore, more vulnerable to the death of the grandchild and display higher levels of anger or guilt. The effect of this is sometimes to add an emotional burden to the bereaved parents who may feel the need to offer emotional support to their own parents at a time when their own emotional resources may be depleted and this, in itself, may, for some families, be a source of conflict.

Grandparents, especially if they live some distance from their children, may withdraw their support, consciously or unconsciously as time goes by. As they see former routines being re-established, they may assume that the crisis is past. Their own, more extensive, life-experience, including other bereavements, may aid their 'recovery' from grief at a faster rate than of their less life-experienced children. Generationally, grandparents may have closer contact with faith-communities and to the support which these can offer, than their often more secularised children.[117] The sociologist, Tony Walter notes how 'generational conflict' is expressed in the Compassionate Friends leaflet, *To Bereaved Grandparents*. The leaflet suggests that 'people need to grieve in their own way, but then hints at the merits of the parents' expressive style over the grandparents' stoical style...'[118]

Grief and siblings

For siblings, too, even an early pregnancy may carry a deep, if at times unarticulated, significance and the child who has been told that they will soon have a 'brother' or 'sister' may feel disappointed, angry, let down, cheated or even relieved, when the promise cannot then be actualised.[119] Dependent on a complex number of factors (including age, emotional and spiritual maturity, cognitive skills and the quality of pre-existing relationships with the parents), children may react in many different ways to the news that a pregnancy has miscarried or a baby has been stillborn. These may range from a total disinterest to acute grief, and their reaction may colour not simply their own present and future relationships with their parents (and even with themselves), but may also be a determining factor in how parents themselves interpret the miscarriage or stillbirth. For children, as much as adults, the death may bring questions of their own identity sharply into focus. Even where very young children may be apparently 'unaffected' by pre-natal sibling death, they may nonetheless be deeply affected by the resulting family disequilibrium. The particular issues which surround the grief of children, which have been long neglected, are both complex and

far reaching in the context of the family system and of individual grief responses and merits separate attention. The particular aspects of grief in children and adolescents are therefore dealt with in detail in a separate chapter. Suffice to say here, that children are often the most marginalised members of the family matrix after a bereavement and the failure to recognise and address the grief of children - and it is only relatively recently that it has been acknowledged that children grieve at all - can have far-reaching and potentially devastating effects which may only come to light much later, even in adulthood.

Grief and the caregiver

> Healthcare providers are often at a loss to know how to deal with expressions of grief... The outright expression of grief frightens us... The expectation that we keep tight control over emotions and repress our grief takes its toll on many of us.[120]

The same capacity to influence or determine what a death may mean may equally be present in hospital staff. As midwives, doctors or chaplains are expected to have dealt with similar situations before, they may be looked to by the putative parents both to define and interpret what has happened and to indicate what would be appropriate, or 'good', behaviour. Not infrequently, parents ask, 'What do other people do when this happens?'. This kind of question is asked not only to give some point of reference to a bewildering event but also to sanction/guide the person's response to it.

The belief-systems of caregivers, whether individually held or assumed in professional practice, may conflict with those of parents. Where this is so, issues of autonomy (both on the part of the parents and their caregivers) are clearly involved. In such circumstances, views about, or interpretations of, the meaning of miscarriages or stillbirths, other than the purely factual, should only be offered by practitioners when they are specifically asked for, and in the context of an open dialogue that does not seek to impose a particular meaning or meanings, but rather helps to explore what meaning or meanings there might be.[121]

In order to respect the autonomy of parents, it should always be made clear that personal views or interpretations of meaning remain at the level of personal beliefs and/or values. While these may be normative among those who participate in the same belief-system (and will always need to be respected), they neither deny nor invalidate the beliefs of others. Thus, for example, what in terms of clinical discourse may be described as 'products of conception', may nonetheless, for the putative mother, be 'her baby'. This subjective element needs to be both recognised and affirmed if autonomy is to be respected, personhood affirmed, and if psychological, emotional and spiritual needs are to be adequately and appropriately addressed. Conversely, members of staff who are, for example, practising Roman Catholics or strong evangelicals and hold that 'life' begins at conception (and that from this moment onwards such a life has all the status and rights of an individuated human being, although it may not yet necessarily be described as a 'person') will need to respect the views of those who do not consider the ending of their pregnancy as necessarily the extinguishing of a human life and/or a (potential) person. This is very different from the 'human' encounters which may build relationships between individuals. It is not inappropriate for a carer to say, for example, 'I had a miscarriage/stillbirth too. People assumed that I would 'get over it' quickly but in fact it took me some time.....'.

Both the life-experiences and the beliefs and values of staff, particularly those to do with mortality, may profoundly affect their ability to deal sensitively with the miscarriage or stillbirth and may also affect the way in which the parents and the wider family subsequently respond to their loss.[122] Caregiver responses and the quality of their care may profoundly shape the responses of parents and thus influence the progress and outcome of their emotional adjustment.[123] In a context predominantly geared to bringing new life into the world, death may be a profoundly disturbing experience. Staff's unwillingness to talk about the death or their avoidance of bereaved parents may increase feelings of guilt. Kohn and Moffit have noted that, 'when hospital staff do not offer bereavement services, most parents do not ask for the care they need and do not receive it.' They conclude, therefore, that, '(i)t is the hospital's responsibility

to train staff in bereavement protocols so patients are provided with this important service.'[124] As Borg and Lasker comment about healthcare professionals,

> It is in their power, through their reactions and the quality of care they provide, to control the enormous difference between a tragedy that is bearable and one made worse by insensitivity, error, or inattention to need.[125]

Few issues in the healthcare environment provoke such levels of stress amongst staff as death and bereavement. In the current climate, in which the status of medicine has often been elevated beyond what it can reasonably be expected to deliver, death is, all too often, seen in terms of failure - 'Death is not construed as an inevitable biological denouement but as a medical failure.'[126] Nowhere is this more the case than in the maternity unit where the juxtaposition of life and death is so evident.

The role of the chaplain, working with and alongside staff, in such situations can be invaluable and so a staff-orientated role for Chaplains will therefore be an indispensable component of patient/person-centred care, but only if time is taken to build relationships of trust and understanding with other staff. Since the Chaplain addresses the situation from a broader perspective than simply a nursing or medical perspective, (s)he will have an important role to play in an integrated care strategy.[127] The Chaplain who 'floats' onto a unit only when a crisis has occurred will always remain an outsider. The good chaplain will be regarded as an integral part of the 'team' and will therefore be better able to address the care needs of both patients and staff. Such a theology of presence expresses the chaplain's ability to be 'with' others at the moments of crisis, frustration and pain and to have the capacity to bear these without denying their effect on the sufferer. This pain-sharing role is part of an agapeistic understanding of pastoral care, integral to the chaplain's role as companion or accompanist of others, and hinges on a covenental orientation towards the other.[128] These issues are further explored in the chapter on neo-natal deaths in the context of the intensive care environment.

With an unexpected stillbirth, the difficulties for care-givers in communicating the death of the baby to parents are particularly acute and may be compounded if the mother is exhausted by the delivery, sedated or even anaesthetised. For those who have the sad task of breaking such bad news, it frequently seems like a denial of their role as carers, and an admission they have somehow 'failed' in this role.[129] Fear of being 'blamed' for the death or experiencing an adverse emotional reaction may make some caregivers 'distance' themselves from the parents and they may therefore appear as 'cold' or 'un-caring'.[130]

It is important to remember that staff, too, however commonplace their encounter with death, may grieve the death of a baby. They, too, need time and space to articulate their emotions and feelings in a safe and supportive environment. A 'mask' of professionalism (all too often interpreted as not caring) may hide an inner turmoil that is hard to bear.[131] They, too, may need to engage in parting rituals, including attending the funeral, as they 'let go' of a child in whose care they have been intimately involved.[132]

The sensitive Chaplain will be aware of the pressures to conform to perceived norms of behaviour that may ultimately be unhelpful to both staff and those for whom they care at such times. To allow staff to ventilate their grief appropriately, and to encourage them to share their feelings of grief with the bereaved, is an important facilitating and bridging role for chaplains and other pastoral caregivers that is often overlooked. It is important that staff, both individually and as a group, should be enabled both to de-brief each particular death in an appropriate and supportive context and should have access to on-going support where they can articulate and explore issues that are of importance to those who are faced with death as part of their professional, as well as private,lives.[133]

Grief and the community

A similarly wide range of responses to miscarriage, stillbirth and neo-natal deaths may be found by the putative parents within the narrower circle of their family and friends and in their wider community. Those who have not known that the woman was pregnant or have seen little physical outward change in her appearance, or who have little emotional investment in the pregnancy, may find it hard to comprehend or validate the intensity of feeling which may be present for some parents. It may be a case of feeling that, 'what you never had you never miss...' and therefore believing that things remain unchanged or as they were before. It may also, however, be the case that, whilst they recognise difficult feelings and emotions, family and friends in the community simply do not know how to respond. It is important, therefore, for staff to talk to couples after a miscarriage or stillbirth about the kind of reactions they might expect to meet when they return home.

Bereavement is an isolating experience and the tendency to adopt avoiding responses to other's grief may be intensified after miscarriage or stillbirth because of the taboos surrounding early-life deaths. Many bereaved parents feel, not without justification, that they are excluded from many ordinary human relationships, perhaps because they represent, because of their circumstances, what every parent fears.[134] Whilst the fear of saying 'the wrong thing' may be great, many among the bereaved would agree with the sentiment that, 'there is only one thing worse than speaking ill of the dead and that is not speaking of the dead at all...'.[135] Those who return home after a miscarriage or stillbirth may, nonetheless, find that they are treated as if nothing at all had happened. In some cases, particularly with earlier losses, friends or family are genuinely ignorant that anything has, in fact, happened. They may not have known that there was a pregnancy, still less a miscarriage or stillbirth and they may thus find the mood or emotions of the putative parents confusing or disconcerting. If and when they are then told, they may be confused or embarrassed by their ignorance and may feel that they do not know what to say.[136] Others who have known about the pregnancy

and the subsequent loss may respond in a variety of ways. Some may, as with other forms of bereavement through death, ignore or avoid the bereaved; others may offer 'advice' that may be more (or less!) helpful or appropriate. This may range from cliches like, 'It's all for the best...' or 'It's just nature's way' to offers of practical help, especially in the early post-bereavement period and a willingness to listen while the bereaved rehearse, often many times over, their experience, without passing judgement or offering a reason or solution.

There is much to suggest that some of the most helpful comments are made by those who have themselves experienced an early life death, although there is, of course, always the danger that assumptions will be made about a similarity of experience and response. For some parents, self-help groups become an important source of social interaction. Here, in the company of other bereaved parents, the bereaved feel 'safe', knowing that they have permission to talk about their child without fear of others becoming bored or embarrassed by their need to rehearse the story of their own loss and the circumstances in which their child died.[137] For other parents, particularly those whose grief has a pathologising effect, referral to specialist counselling services may be appropriate.[138] Many hospitals now have dedicated bereavement officers. In some cases such bereavement workers will also have a staff-orientated role. It is important, however, to strike a balance between specialist skills and continuity of care in dealing with the bereaved and endeavouring to prevent the unnecessary pathologising of grief.

Conclusion

The proximity of birth and death makes stillbirth an especially difficult experience of pre- and perinatal death in which low self-esteem may be compounded by a heightened sense of futility. Grief after stillbirth may be acute, as much for the father, and for other family members, as for the mother, though this has often been unrecognised or disregarded. Attachment to a baby is not simply physical but

relational and stillbirth may, therefore, have a profound effect on a person's perception of their self-identity. Thus, both men and women ought to be treated with equal sensitivity and care after stillbirth. This will involve the recognition of gender differences, as well as similarities, in grieving, since grief is as much a social and cultural construct as it is an emotional and psychological one.

Those involved in the care of the bereaved family, and not just the putative parents, need to remember that the dynamics of each family are unique. As Tolstoy notes in Anna Karenina, 'all happy families resemble one another; each unhappy family is unhappy in its own way.'[139] There is, therefore, a great need to treat people as individuals, but not at the expense of ignoring or minimising the impact of the social systems of which they are a part, and the effect which these have upon the grief experience. As Frances Dominica says, 'Each member of the family... has a right and a need to grieve and to express that grief in his or her own way.'[140] Neil Small puts it more bluntly, 'Loss presents major challenges to us as human beings - rigid sex-role stereotyping only adds to the pressures and distress.'[141] Good care recognises the complexity of what it means to be both an individual and a person-in-relationship.

In the care of both the bereaved individual and of each bereaved family, the motto of the Office of Aboriginal and Torres Strait Islander Affairs offers a good model of care - *'Respect, Recognise, Reconcile'* !

Perhaps the last word in this chapter should go to one of the pioneers of recognising the impact of stillbirth on families. In 1979 Emmanuel Lewis wrote:

> In the far east there is a cactus with white fragrant flowers that blooms briefly only every few years. Each bud opens visibly in front of one's eyes within a few hours. A family may sit together and watch the birth and death of the flower, for it brings good luck. A far eastern couple buried their stillborn in a little grave with a small headstone inscribed with the name of this cactus given to their child. An act of creative, poetic self-healing.[142]

NOTES

1 Stillbirth Definition Act, 1992. This Act lowered the gestational age of viability from 28 weeks to 24 weeks. Further advances in medical technology, especially in the treatment and care of the premature newborn will inevitably lead to a further reduction in the period after which the baby can survive outside the womb and independent of the mother (viability). There is some argument that, already, viability should be set at 22 weeks rather than 24 weeks.

2 Stillbirth Definition Act.

3 B. Raphael, *The Anatomy of Bereavement: A Handbook for the Caring Professions* (London: Routledge, 1984), pp.28, 30.

4 B. Raphael, 'Grieving over the Loss of a Baby,' *Medical Journal of Australia, 144* (1986), 281.

5 OPCS, *Mortality Statistics: General Review of the Registrar General on Deaths in England and Wales* (London: HMSO, 1991). Whilst a direct comparison between stillbirth statistics before and after the Stillbirth Definition Act of 1992 which changed the legal definition of stillbirth by reducing the age of viability from 28 to 24 weeks gestation is not possible, it is true to say that the number of stillbirths has, in fact, remained relatively constant. See ONS, *Mortality Statistics, Childhood, Infant and Perinatal* (London: ONS, 1996).

6 E. Lewis and A. Page, 'Failure to Mourn a Stillbirth: An Overlooked Catastrophe,' *British Journal of Medical Psychology, 51* (1978), 237-241.

7 S. Bourne, 'The Psychological Effects of Stillbirth on Women and their Doctors,' *Journal of the Royal College of General Practitioners, 16* (1968), 103-112.

8 S. Borg and J. Lasker, *When Pregnancy Fails: Coping with Miscarriage, Stillbirth and Infant Death* (London: Routledge and Kegan Paul, 1982), p.xiii.

9 C. Lamb. 'On an Infant Dying as Soon as Born', cited in J. Archer, *The Nature of Grief: The Evolution and Psychology of Reactions to Loss* (London: Routledge, 1999) p.191.

10 G. Riches and P. Dawson, 'Shoring Up the Walls of Heartache,' in D. Field, J. Hockey and N. Small eds. *Death, Gender and Ethnicity* (London: Routledge, 1997), p.61.

11 R. Friedman and B. Gradstein, *Surviving Pregnancy Loss* (Boston: Little Brown and Co., 1992), p.10. It is interesting that whilst they title their chapter on miscarriage 'an unrecognised loss', they title their chapter on stillbirth as 'the death of a child'.

12 C. Hindmarch, *On the Death of a Child* (Oxford: Radcliffe Medical Press, 1993), p.14. Alice Lovell describes the experience of birth and death as being in 'temporal collision' and argues that in stillbirth both events were not simply conflated by healthcare professionals 'but were treated as if one cancelled out the other'. ('Death at the Beginning of Life,' in *Death, Gender and Ethnicity*, p.38.).

13 Whilst a birth certificate is not issued for a stillborn baby, a medical certificate of stillbirth is issued by the attending doctor which has to be taken to the Registrar of Births, Deaths and Marriages within 42 days of the stillbirth (21 days for Scotland). The Registrar will issue the parents with a certificate of disposal to allow the burial or

cremation of the stillborn child to take place but *not* a birth certificate. Sometimes staff feel that they need to 'protect' parents from the stress of making decisions or undertaking practical, but necessary, tasks like registration. Such benevolent paternalism is, however, by and large misguided. Disempowered parents need to regain a measure of control over what has happened, and is happening, to them and to engage with the reality of what may, at times, seem a very unreal situation.

14 Unlike the mother who has already experienced the physiological, hormonal and emotional changes of pregnancy, for many fathers feeling the baby kick or move within the mother's womb may be their first real and tangible evidence that 'their' baby 'exists'. It is, for many putative fathers, a 'significant' moment in the pregnancy and in their own self-understanding in relation to their, as yet un-born, child.

15 Whilst still legally a non-person in the sense that, for example, the un-born child has no legal right of inheritance; nonetheless, the developing fetus now attracts an increasing moral and legal status so that, for example, the pregnancy may not be terminated after 24 weeks unless 'termination is necessary to prevent grave permanent injury to the physical or mental health of the pregnant woman; or that the continuance of the pregnancy would involve risk to the life of the pregnant woman, greater than if the pregnancy were terminated; or that there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped.' (*Human Fertilization and Embryology Act 1990*, Chapter 37, para. 37 (1) b-d. Amendment of law relating to termination of pregnancy. 1967 c.87.).

16 This sense of futility can be found in Old Testament texts in which the imagery of pregnancy and childbirth is frequently used (e.g., 'We have been with child, we have been in labour, but have brought forth wind.' Isaiah 26:18) . See D. Wiseman, 'Medicine in the Old Testament World' in B. Palmer ed. *Medicine and the Bible* (Exeter: Paternoster Press,1986), p.35.

17 There is a sense in which the birth of a live, healthy baby is, of itself, a type of 'bereavement'. A particular kind of relationship, one that has been established and built upon over the none months of pregnancy, has to be relinquished in order that parents can bond with the 'outside' baby who may be both 'like' and 'unlike' the baby on whose life the putative parents have speculated while he/she was still in the womb. Although pre-natal scanning can now pre-empt delivery, the gender of the baby can itself be a source of great joy, or disappointment, to the parents. For those whose fantasies focussed on a child of a particular gender, boy or girl, to have to come to terms with a baby who is not the 'right' sex can be, for some, a difficult experience. I have known women who have talked, with tears in their eyes, about, 'letting their husband down...' because the baby was a girl and not a boy, or families in which there were already three male children, 'trying for another', desperately hoping that the subsequent pregnancy would at last produce a girl.

18 One woman, describing her feelings after the death of her husband, described to me how she felt, 'like a Henry Moore statue', with a 'hole' in her middle where her stomach should be. Such feelings of emptiness which are a common affect of the grief which follows the death of a known and loved person are all too real in the case of the death of a baby in the pre- or peri-natal period.

19 Post-mortem examination reveals that approximately 15-20% of all stillborn babies have some form of genetic or chromosomal abnormality.

20 The technical use of terms like 'incompetent' may, if used to address, or used in the hearing of, parents or families, be itself a source of guilt or blaming on the part of those who interpret such terms as describing a general 'lack of competence' in 'mothering' or sustaining the pregnancy. The tendency of 'medicalised' childbirth to reduce the mother to no more than a system of uterine care exacerbates the sense of failure and increases low self-esteem when pregnancy does not lead to the birth of a live and healthy child. Those who, like Sally Cline, have subjected the field of bereavement theory and practice to a feminist critique have argued that women-centred deaths (such as pre- and peri-natal deaths) have been particularly marginalised, or even discounted, by society at large and by a male dominated medical system in particular. See S. Cline, *Lifting the Taboo: Women, Death and Dying* (London: Little Brown and Company, 1995), pp.162-196.

21 G. Macpherson, ed., *Black's Medical Dictionary*, 37th edition (London: A & C Black,1992).

22 D. Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death* (New York: Simon & Schuster, 1993), p.18. Alice Lovell, however, notes that, 'bereaved parents, at a vulnerable time, are at the mercy of patchy services, dependent on individual professional styles. Genuine choices and control remain illusory.' ('Death at the Beginning of Life,' in *Death, Gender and Ethnicity*, p.42.).

23 Friedman and Gradstein, *Surviving Pregnancy Loss*, p.64. Taking control over 'processes' may thus help to mitigate the effects of the powerlessness many women feel about their own bodies after a stillbirth or other early life loss.

24 Borg and Lasker, *When Pregnancy Fails*, p.51.

25 'Evolution of Bereavement Counselling in Sudden Infant Death Syndrome, Neonatal Death and Stillbirth,' *Journal of Paediatric Child Health, 28* (1992), 204. Miriam Stoppard has written that, '(b)eing able to cope has become the modern equivalent of trial by fire.' M. Stoppard in H. Pizer and C. O'Brien Palinski, ed. *Coping With Miscarriage* (London: Jill Norman Ltd., 1980), p.ix. I dislike the use of the word 'coping' since its root meaning is 'to cover up'. Thus 'coping' after bereavement often means the masking of feelings (often because of societal pressures) rather than dealing with them.

26 Although it may appear strange to talk about 'celebrating' such births, it is true to say that many parents derive great joy and wonder, albeit mingled with deep sadness, from seeing and cradling their child. Such parents may says things like, 'Oh, he's so beautiful... my darling baby...'.

27 G.C. Forrest, 'When a Baby Dies,' in J.D. Baum, F. Dominica and R.N. Woodward eds. *Listen My Child has a Lot of Living to Do: Caring for Children with Life-threatening Conditions.* (Oxford: Oxford University Press, 1990), p.101.

28 N.L. Collins, C. Dunkel-Schetter, M. Lobel and S.M.C. Scrimshaw, 'Social Support in Pregnancy: Psychosocial Correlates of Birth Outcomes and Postpartum Depression,' *Journal of Personality and Social Psychology, 65*, 4 (1993), 1244.

29 J. Walker, 'Care in Bereavement,' *Paediatric Nursing*, (Oct. 1990), 17-18.

30 Showing respect means, above all, recognising the importance of the baby's death to the parents, not treating it as an insignificant or 'minor' event.

31 Whilst J. Jolly has argued that grieving only begins when birth separates mother and baby (*Missed Beginnings* (London: Austin Cornish, 1987), it is clear that anticipatory grieving in the case of a known stillbirth is both real and common.

32 For some parents, grieving may begin even before the death is confirmed at the point when the belief that all is well with the pregnancy is compromised or lost and investment in the pregnancy begins to be withdrawn.

33 They'd told me he was dead but I just didn't believe it. The midwife said that I could have strong pain relief during labour because nothing I did would hurt the baby. I didn't have any pain relief, I wanted it to hurt because I thought that if it hurt he would be all right when he was born. All I can remember thinking was please, please don't let him be dead.

Bereaved mother, cited in J. Littlewood, *Aspects of Grief: Bereavement in Adult Life* (London: Routledge, 1992), p.123.

34 L. Layne, 'Never Such Innocence Again: Irony, Nature and Technoscience in Narratives of Pregnancy Loss,' in R. Cecil, ed. *The Anthropology of Pregnancy Loss* (Oxford, Washington DC: Berg, 1996), p.131.

35 L.K.Graham regards the self as a 'synthesis of values'. which is created and sustained by the connections of self with the world the self inhabits, including birth experiences (events) and relationships. (*Care of Persons, Care of Worlds: A Psychosystems Approach to Pastoral Care and Counselling* (Nashville: Abingdon Press, 1992), p.84.).

36 L.M.Wright has noted how the religious and spiritual beliefs of a family have been among the most neglected areas of care. ('Spirituality and Suffering: The Soul of Clinical Work with Families,' *Journal of Family Nursing, 3*, 1 (1997), 3-14.).

37 Raphael, *The Anatomy of Bereavement*, p.34. Raphael also notes that '(w)here others collude to avoid the reality/finality of the loss, it may also be difficult for the bereaved to move to the stage of accepting that the loved one will never again return' (p.43.).

38 The work of J. Kennell and M. Klaus did much to break down these traditional views. They argued that the bonding process between mother (and to a lesser extent father) and baby was a process which began early in the pregnancy. (*Parent-Infant Bonding* 2nd.ed. (St. Louis: C.V.Mosby,1982)). See also J. Kennell, H. Slyter and M. Klaus, 'The Mourning Response of Parents to the Death of a Newborn Infant,' *New England Journal of Medicine, 283* (1970), 344-349.

39 'The Psychological Effects of Stillbirths on Women and Their Doctors,' 103-112. I find it very curious that there is no reference to Bourne at all in Beverley Raphael's, *The Anatomy of Bereavement*, a work of great breadth and magnitude, especially in this context; and, while Rosemary Mander uses the term 'rugger pass' (sic) on two occasions (pages 25 and 74) in, *Loss and Bereavement in Childbearing* (Oxford: Blackwell Scientific, 1994), on neither occasion does she attribute the phrase to Bourne.

40 The predominant belief in this period was influenced the work of Freudians like Helen Deutsch. See Chapter 1.

41 'The Emotional Reaction to a Stillbirth,' *American Journal of Obstetrics and Gynaecology, 108* (1970), 73-77.

42 See Lewis and Page, 'Failure to Mourn a Stillbirth: An Overlooked Catastrophe,' 237-41.

43 'The Management of Stillbirth: Coping with Unreality,' *Lancet,* (b) *2* (1976), 619-620. Clare Gittings has movingly contrasted the funerals of children in pre-industrial England, which were simplified adult rites, with the contemporary treatment afforded stillborn babies who were not regarded as persons and whose bodies were often abandoned by the side of roads. *Death, Burial and the Individual in Early Modern England* (London: Routledge, 1988), pp.60-85. The permitting of the burial of unbaptised infants in consecrated ground in the twentieth century (though exclusion continued in some places until relatively late) has mitigated the effects of this and gone some way to regarding stillborns as dead children despite many continued taboos.

44 London: HEC, 1978. The work produced by SANDS, *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals,* published in 1991, updates this work, taking into account research into pre- and perinatal deaths done over the intervening decade. These guidelines are now a well-established and well-respected practice resource for those caring for women, their partners and their families after a stillbirth or other loss either in pregnancy or in the early stages after birth.

45 Accounts by mothers who had seen their babies, naked and vulnerable, led gradually to a change of practice in many hospitals in this period. One mother told me how her first sight of her stillborn baby had been in the hospital mortuary with its tiny form dwarfed by the adult-size white porcelain 'slab' on which it had been laid. She described, with tears in her eyes, how she had gathered up some green paper towels and used them to cover the body. Such practices failed to afford due dignity to either the mother or her dead baby. Thus it has become accepted practice to wrap or swaddle the stillborn baby just as one would wrap or swaddle any live newborn. The judicious wrapping of the head can minimise the initial impact of major head abnormalities as, for example, with an anencephalic infant. Leaving a hand or foot free to be seen and handled in such circumstances also helps to shift the gaze from the face or head (the natural point of focus) to another part of the body. When this practice was first introduced, however, I noted an increasing number of parents who would return to the hospital at a later date and would be particularly anxious to confirm the baby's sex. It occurred to me that when their baby was presented to them swaddled, some parents did not like to undress the baby for fear of 'offending' staff who had 'taken the trouble' to dress the baby or of appearing 'ghoulish' (some parents also feared that the dead baby might 'fall apart' if undressed). Thus, though their baby had been described by staff as a 'little boy' or a 'little girl' they had not been able to validate this information for themselves. This was confirmed in many conversations with parents of stillborn babies. Later practice was therefore to present the dead baby wrapped but to actively encourage parents to undress, wash, and touch their baby if they wished to do so, and to allow them the privacy for this, and therefore to validate the gender of the baby for themselves. When this was done the number of parents returning with questions about the sex of their dead baby soon diminished. This is a good example of how 'good' practice is established progressively and underscores the importance of listening to parents' stories, both the bad and the good ones, in shaping present and future practice. I am indebted to those many parents over the years who, either individually

or in groups, have helped me to reflect on my own pastoral practice and, where appropriate, to change it by telling me their stories and allowing me to enter their lives. It is important to note, however, that reference to the gender of the baby should only be made where this is known unequivocally. In some later miscarriages the poor development of the external genitalia may make determining the gender of the stillborn baby difficult. If the stillborn baby is described as 'a little girl' but the subsequent post-mortem determines that the baby was, in fact male, parents may have difficulty in accepting this. Having begun to mourn a daughter they must now relinquish the girl who never was and begin to mourn the son whom they had not hitherto acknowledged. Thus a 'double grief' may be experienced. Some parents may question the competence of their carers if such a mistake is made or question whether the post-mortem report is indeed that of their child. Great care therefore needs to be taken and if the appropriateness of using a particular gender pronoun is in doubt, then 'your baby' is a useful term (explaining to the parents why this is being used) but never, as I have heard used on more than one occasion, the impersonal, 'it'.

46 Some parents may request that photographs should not be taken of their baby for personal or cultural reasons and, where this is the case, the wishes of the parents need to be respected. Handprinting and footprinting, which may provide an acceptable alternative, is now increasingly used and provides a highly personal, indeed unique, memento of the child. One of the chief fears of many bereaved people, however, is that they will forget what the dead loved person looked like. This is all the more true of those whose babies die since they have had so little time with the physical presence to establish visual memories.

47 As it has become increasingly recognised how traumatic stillbirth can be, most hospitals now have a delivery room set aside for them. A typical room would be furnished with an ordinary single, or sometimes double, bed rather than the usual adjustable chrome bed and furnishings would be altogether 'softer' than the more clinical atmosphere of many other rooms. (this raises the question why a similar de-medicalisation of the context of birth cannot be encouraged when there is no 'problem'. The more clinical atmosphere of many delivery rooms communicates the message that birth is a medical procedure subject to the control of professionals rather than a 'natural' process in which those who attend the birth are 'accompanists' for the mother or family). In the case of an unexpected stillbirth this is clearly not the case and during birth itself the mother may be quickly transferred from the delivery room to the operating theatre in an attempt to bring to birth a baby who becomes distressed during labour or who suddenly expires in the womb or the birth canal. Research by Rosemary Manders has suggested that some midwives feel that the presence of a cot in the room where a known stillbirth is happening is inappropriate. She says, 'Unlike other equipment which has multiple uses, the cot has only one use and that is for holding a baby.' (*Loss and Bereavement in Childbearing*, p.58). In my view, the cot is not only a useful 'staging post' in the bringing together of parents and child but an affirmation that a dead baby is still a baby and commands our respect and care and can help in the creation of positive memories.

48 This may be an attempt to establish 'normative' behaviour. For most parents the death of a baby will be something which lies outside their prior experience. There is no 'right' or 'wrong' way of acting in this respect.

49 One father was worried in case the baby 'came apart' when held. Whether the baby will be warm or cold, rigid or limp are all questions which are asked in such

situations. Perhaps the greatest fear is that the baby will look like a 'monster' although in almost every case the fantasy of what the baby will look like proves in the end to be more traumatic than the experience of seeing and holding the baby who has died. As Rosemary Dinnage rightly remarks, 'The vacated body... is always the focus of mixed feelings of fear and love...' R. Dinnage, *The Ruffian on the Stair: Reflections on Death* (Harmondsworth: Penguin, 1992), p. 6.

50 J.H. Pye, *A Winter's Tale*. (Unpublished sabbatical paper, 1984).

51 'When a baby dies,' 101-112.

52 Where procedures are 'invasive' - unlike photography or footprinting, cutting the hair may be regarded as 'mutilation' - I would invite parents to undertake this themselves, if they so wished. Such actions should never be undertaken without parental permission or against parental wishes. The development and use of unit protocols is to be recommended. It is important, however, that training is given in how to use such resources.

53 IV, iii, 209.

54 This does not necessarily mean relinquishing bonds but, rather, re-defining them.

55 E. Lewis, 'Mourning by the Family After a Stillbirth or Neonatal Death,' *Archives of Disease in Childhood, 54* (1979), 303-306. A good example of this connection was the grief reaction of an elderly woman whose first great-grandchild was stillborn. In conversation she recounted how this experience had re-awakened thoughts about her brother who had been killed in the Battle of the Somme during the First World War and whose body had never been recovered. Many women who never saw their own stillborn or miscarried babies and who therefore never had the opportunity to grieve their loss may have similar intense grief reactions when they experience the stillbirth or miscarriage of a grandchild.

56 E. Moltmann-Wendel, *I Am My Body: New Ways of Embodiment* (London: SCM, 1994), pp.62 and 65. Moltmann-Wendel rightly notes how physical healing can come through touch, a theme which she explores through the healing miracles of Jesus in the New Testament.

57 An article in the *Nursing Standard* exemplifies the dangers of low parental involvement in the planning of the funeral. The author writes, 'Amid the trauma, I had allowed the hospital to make all the arrangements. the result was a totally meaningless service and a deep sense of regret.' C. Jay, 'A Chance to Say Goodbye,' *Nursing Standard, 12, 2*, (Oct. 1997), 26. The role of ritual in pastoral care as helping the bereaved to confront the ambiguities of the human experience of birth and death is discussed in detail in a later chapter.

58 D.L. Davis, *Empty Cradle, Broken Heart* (Golden, Colorado: Fulcrum Publishing, 1991), p. 9. Another bereaved mother had to have the ashes of her stillborn baby before she could accept the reality and finality of her death; another, who had twins, one of whom died, kept the ashes of the dead twin at the hospital until the surviving twin was well enough to be discharged, so that both babies could go home together.

59 J. Foskett and M. Jacobs, 'Pastoral Counselling,' in S. Palmer, ed. *Handbook of Counselling*, (London: Routledge, 1997), p.319. Pastoral counselling is an expression of, though not co-terminous with, pastoral care. Pastoral counselling

involves the application of counselling skills in a pastoral context and relationship in which theological insight is blended with the insights of the psychological and social sciences. The role of professionals in defining situations should not be underestimated. Lovell has noted how, 'as well as turning to midwives, doctors, nurses and other healthcare professionals, bereaved mothers - even the irreligious - looked to religious professionals for help.' ('Death at the Beginning of Life,' in *Death, Gender and Ethnicity*, p.42-43.). See also, J.R. Bohannon, 'Religiosity Related to Grief Levels of Bereaved Fathers and Mothers,' *Omega, 23* (1991), 153-159.

60 Article 601 of the *Islam Acts*, for example, recommends against offering prayers for a child who is stillborn. Similarly, in Judaism, Shiva is not said for any child surviving less than 30 days, although 'personhood' begins with the taking of the first breath.

61 While the mother may, at this time, still be bedbound or may find excessive movement painful, the father may pace up and down, often with head bent and hands clasped or arms folded. Such 'wandering' is a common affect of grief. See Chapter 1.

62 Wolff, Nielson and Schiller in a study of 50 women who had been cared for by an interdisciplinary team after the death of a baby at, or shortly after, birth concluded that, whilst all wanted to be told the reason for the death by a doctor, those who saw a chaplain also found this helpful. ('The Emotional Reaction to a Stillbirth,' 73-79.).

63 The sense of being a 'failed' mother may be particularly strong in the woman whose baby has been stillborn. Such a 'failure' in motherhood may be expressed in terms of failing self, partner, the unborn baby, family or society. For those whose first baby is stillborn questions about their right to titles like 'mother' or 'father' may be called into question. If a woman is moved to a gynaecology or general ward rather than a post-natal ward or placed in a room on her own then such feelings of failure may be exacerbated. The intention behind such practice is good - to spare such mothers the sight and sound of other mothers with their babies. Many women, however, feel alienated or as if they are being 'punished' by staff for their failure to produce a live child. Discussion with the mother and/or her partner may help to resolve some of these issues of low self-esteem, characteristic of pregnancy loss, and may, again, affirm a sense of worth or value by allowing ,and indeed encouraging, the taking of control, once again of one's life in a supported and supportive way. On the ward environment see, P. Hughes, 'The Management of Bereaved Mothers: What is Best,' *Midwives Chronicle and Nursing Notes*, August (1987), 226-229.

64 Similarly, discharge should never be hurried. When it is, there has often been the feeling, however unfounded, that this has been because the mother has been an embarrassment to staff. It is a sad reality that, in some cases at least, this may well be so. On discharge, follow-up visits should be established and support offered in order that parents should not simply feel themselves abandoned or, worse, rejected by a system that is more geared to delivering live and healthy babies.

65 Thomas Attig argues that listening to the survivor's story is an important element in understanding the significance of each particular loss through death. T. Attig, *How We Grieve: Relearning the World* (Oxford: Oxford University Press, 1996), p. 7.

66 See chapter on the pastoral nature of liturgy.

67 Few parents would now believe that an un-baptised baby would be destined for hell although some, especially from traditional Roman Catholic backgrounds, may hold onto a vestigial belief that this may be so, despite the official teachings of the Catholic Church. Such anxieties need to be treated with great pastoral sensitivity and not to be merely dismissed as superstition. Making light of, or dismissing, such fears may have profound consequences for individuals or families both in the their grieving now and in 'locating' their dead child later. I have spoken to a number of parents who have been haunted over the years by the fear that their miscarried or stillborn children are still 'around', 'lost souls' unable to be 'at rest' or 'at peace'. In extreme cases this may lead to disturbance in parents which needs some form of psychiatric intervention as well as pastoral support.

68 Similar liturgies can be found in other hospitals and some are now included in commercially available anthologies. See, for example, H. Ward and J. Wild, *Human Rites: Worship Resources for an Age of Change* (London: Mowbray, 1995). See also Appendix B in I. Kohn and P. Moffit, *Pregnancy Loss: A Silent Sorrow* (Headway: Hodder & Stoughton, 1994).

69 J. Tallon, 'The Compassionate Friends: Mutual Support by Bereaved Parents,' in J.D. Baum, F. Dominica and R.N. Woodward, eds. *Listen My Child Has A Lot of Living to Do: Caring for Children with Life-Threatening Conditions.* (Oxford: Oxford University Press,1990), p.152.

70 The is still a tendency to regard the mother as the 'patient' and to marginalise others. The necessity of recognising the dynamics of grieving within the family system is therefore crucial.

71 In contrast to the Freudian emphasis on the internal or intrapsychic dimensions of grief, Lily Pincus, *Death and the Family* (London: Faber, 1976), focuses on the nature of past and present relationships in exploring the effects of bereavement. Her essentially relational approach has much to offer in the current context.

72 The absence or masking of outward symptomology in such cases may reinforce the belief in others that grief has been resolved.

73 Shakespeare. *Titus Andronicus*, Act 3, scene 1.

74 Awareness of this is now being addressed by training for nursing, midwifery and medical staff. In Leeds, I run regular training sessions for staff, organised and paid for by the NHS Trust. Such recognition by managers of the importance of on-going training and support for staff in this area is a crucial element of good healthcare practice.

75 T. Rando, *Parental Loss of a Child* (Illinois: Research Press, 1986), p.6. The grief of the lone parent, although (s)he, too, is part of a complex network of relationships raises particular issues not least in terms of loneliness, isolation and lack of intimate support. Where the dyad is socially complex, as with gay or lesbian couples, further complicating factors are introduced into the grieving process.

76 S. Knowles, 'A Passage Through Grief - The Western Australian Rural Pregnancy Loss Team,' *British Medical Journal, 309* (1994), 1705. Daniel Callahan reminds us that, '(j)ust as we are embodied individual selves, we are also social selves.' (*The Troubled Dream of Life*. p.15.). See also, D. Klass, *Parental Grief: Solace and Resolution* (New York: Springer, 1988).

77 D.G. Benfield, S.A. Leib and J.H. Vollman, 'Grief Responses of Parents to Neonatal Death and Parent Participation in Deciding Care,' *Pediatrics, 62* (1978), 171-177; Lady Limirick, 'Counselling Parents who have Lost an Infant,' *Journal of the Royal College of Physicians, 13,* 4 (1979), 242-245; G.C. Forrest, 'Mourning the Loss of a Newborn Baby,' *Bereavement Care, 2* (1983), 4-5; R.I. Clyman, C. Green, J. Rowe, C. Mikkelsen and L. Ataide, 'Issues Concerning Parents After the Death of their Newborn,' *Critical Care Medicine, 8* (1980), 215-218; A. Dyregrov and S.B. Matthiesen, 'Similarities and Differences in Mother's and Father's Grief Following the Death of an Infant,' *Scandinavian Journal of Psychology, 28* (1987),1-15; J.C. Vance, F.M. Boyle, J.M. Najman and M.J. Thearle, 'Gender Differences in Parental Psychological Distress Following Perinatal Death or Sudden Infant Death Syndrome,' *British Journal of Psychiatry, 167* (1995), 806-811; Raphael, *The Anatomy of Bereavement,* p.231. Coping mechanisms, however, vary from person to person and may be highly idiosyncratic. W.H. Schatz has noted 7 male roles which can negatively affect fathers in their grieving. These include: being strong, competing, being a protector, a provider, a problem-solver/fixer, in control, and self-sufficient. ('Grief of Fathers,' in T. Rando (ed.) *Parental Loss of a Child,* p. 295.).

78 A. Dyregrov, 'Parental Reactions to the Loss of an Infant Child: A Review,' *Scandinavian Journal of Psychology, 31* (1990), 266-80. As G. Riches and P. Dawson note, however, 'even those men and women who appeared to fit into typically gendered patterns of grieving included in their accounts exceptional behaviour and sentiments which did not fit neatly into these conventional distinctions.' ('Shoring Up the Walls of Heartache: Parental Responses to the Death of a Child,' in *Death, Gender and Ethnicity,* p. 53.). They offer the caution, furthermore, that,

> (g)iven that over the last twenty years or so changes have occurred in the role of women and in the involvement of fathers in parenting, gender distinctions may be less useful in explaining marital tension following a child's death, than the degree to which partners share a similar understanding of the meaning of the child's death. (p.53).

Just as I have shown that mothers' responses are related primarily to emotional rather than physical/bodily bonds, so I am arguing here that the absence of the latter for fathers (i.e., the unborn child isn't in *his* body) cannot tell us anything about the former.

79 The timing of restoration of sexual relations is often a 'flashpoint' of marital conflict. Men may see physical intimacy as a way of expressing love for their partners and of re-establishing bonds. For many women, however, an early attempt return to sexual 'normality' is seen as insensitive and may be both physically and emotionally painful. Sometimes one partner may precipitate the breakdown of the relationship either as a form of self-punishment ('it's what I deserve...') or as a self-fulling prophecy (he/she's bound to leave me after this...). Understanding both the nature of grief and the importance of communication is therefore critical for the survival of many relationships.

80 J. Murray and M. Murray, *When the Dream is Shattered* (Adelaide: Lutheran Publishing House, 1988), p.36.

81 *The Bereaved Parent,* p.72.

82 A.Trapp, 'Support for the Family,' in A. Goldman, ed. *Care of the Dying Child* (Oxford: Oxford University Press,1994), p.77.

83 Ibid., p.81.

84 See, for example, Raphael, *The Anatomy of Bereavement,* pp. 247, 276.

85 Vance, Boyle, Najman and Thearle, 'Gender Differences in Parental Psychological Distress,' 806-811.

86 M.J. Thearle, J.C. Vance and J.M. Najman, 'Church Attendance, Religious Affiliation and Parental Responses to Sudden Infant Death Syndrome, Neonatal Death and Stillbirth,' *Omega, 37* (1995), 51-58. Beverley Raphael also notes that, '(t)he role of faith in the bereavement process is very valuable... Strong religious belief may seem the only source of survival... In each case the meaning and value of religious faith must be individually considered.' (*The Anatomy of Bereavement*, p.53.).

87 'Helen House,' in Baum, Dominica and Woodward, ed. *Listen My Child has a Lot of Living to Do,* pp.53-4.

88 Systems theory, first formulated by Ludwig von Bertalannfy in the 1940s, regards the family as an interacting whole (acting both within itself and with its environment) and not just a collection of discrete individuals in proximity (although the individual is not subsumed by the group). Systems theory is particularly appropriate in this context because of its concern with the interconnectedness of persons and hence with the concept of relationality which forms a central plank of this thesis. Many bereaved parents talk about 'not seeming to be a family anymore...'. Christian theology extends systems theory beyond the consideration of social systems by considering the place of such systems with their patterns of interconnectedness as both representing God's purposes for human beings and reflecting the nature of the divine economy. It is, however, noticeable how much contemporary pastoral practice is fundamentally individualistic and therefore fails to recognise the importance of the patterns of relationship between self and other and self and world which form the context of informed, effective and theologically grounded care. The dependence of much bereavement theory on the influence of Freud and his successors has also meant that the self has too often been regarded as an entity in isolation.

89 Irving Leon notes that 'although the father-to-be is unable to experience pregnancy biologically, his psychological journey strikingly parallels that of his wife...' I. G. Leon, *When a Baby Dies: Psychotherapy for Pregnancy and Newborn Loss* (New Haven: Yale University Press, 1990), p.3. There is little reason, then, to think that the ending of the pregnancy should have a substantially different psychological or emotional impact.

90 C.M.Sanders estimates that the incidence of separation or divorce among bereaved parents rangers from 50-90% compared with couples who have not had a child who died. ('Risk Factors in Bereavement Outcome,' in M.S. Stroebe, W. Stroebe and R.O Hansson, eds. *Handbook of Bereavement: Theory, Research and Intervention* (Cambridge: Cambridge University Press, 1993), p.264.).

91 This is well attested in the psychological, and especially the psychotherapeutic, literature. See, for example, S.S. Rubin, 'The Death of a Child is Forever: The Life Course Impact of Child Loss,' in *Handbook of Bereavement*, pp.285-299. See also, Leon, *When a Baby Dies.*

92 A.S. Kliman, 'The Parents,' in N. Linzer, ed. *Understanding Bereavement and Grief* (New York: Yeshiva University Press, 1977), p.191.

93 Neil Thompson argues that negative views of men's grief responses, such as anger, serve to inhibit their grieving and he argues, therefore, for a more flexible response in bereavement practice. ('Masculinity and Loss,' in *Death, Gender and Ethnicity*, pp. 76-88.). It may well be that responses which are regarded as socially unacceptable, such as anger, may even lead to a withdrawal of support on the part of professionals. It is important, therefore, to be able to validate the *feelings*, without sanctioning or condoning unacceptable *behaviour* (e.g. threatening staff). Peppers and Knapp note several examples of violent behaviour after perinatal loss, such as that of a father who punched his fist through a hospital wall. (L.G. Peppers and J. Knapp, *Motherhood and Mourning* (New York: Praeger, 1980). This is borne out in my own experience.

94 J.E. Puddifoot and M.P. Johnson, 'The Legitimacy of Grieving: The Partner's Experience of Miscarriage,' *Social Science and Medicine, 45*, 6 (1997), 837.

95 Ibid., p.838. See also M.P. Johnson and J.E. Puddifoot, 'The Grief Response in the Partners of Females who Miscarry,' *British Journal of Medical Psychology, 69* (1996), 313-328.

96 J. Cornwell, E. Nurcombe and S.L. Stevens, 'Family Response to Loss of a Child by SIDS,' *Medical Journal of Australia, 28* (1977),1; D. Tudehope, D.I. Iredell, D. Rodgers and A. Gunn, 'Neo-natal Death: Grieving Families,' *Medical Journal of Australia, 144* (1986), 290-1; J. Page, A. Liebermann and C. Hughes, 'How Fathers Perceive Perinatal Death,' *American Journal of Child Nursing, 15* (5) (1990), 320-23. See especially, Dyregrov and Matthiensen, 'Similarities and Differences in Mothers' and Fathers' Grief Following the Death of an Infant,' 1-15, which indicates that many fathers show a considerable degree of grieving after prenatal death. They also distinguish paternal from maternal grieving due to different levels of bonding (attachment), differences in coping mechanisms, and social or cultural constraints.

97 The first discernible fetal movements were once regarded as the point at which life 'began'. This was the time of 'ensoulment', when the soul entered the body and the developing fetus took on a new and different moral status.

98 A man who has a high emotional or cultural investment in producing a 'son and heir', for example, may feel the impact of pregnancy loss in an emotionally more traumatic way than the putative mother who may, for a variety of reasons, have had doubts about wanting the pregnancy in the first place but had bowed to the pressure from partner, family or community to bear a child. In such circumstances the capacity for blaming on the one hand and guilt on the other may be enormous.

99 H. Sarnoff Schiff, *The Bereaved Parent* (London: Souvenir Press, 1977), p.60.

100 R. Cecil, 'I Wouldn't Have Minded a Wee One Running About: Miscarriage and the Family,' *Social Science and Medicine, 10* (1994), 1415-1422. This appeared to be the case irrespective of the socio-economic class of the respondents See also Puddifoot and Johnson, 'The Legitimacy of Grieving', 839.

101 Borg and Lasker, *When Pregnancy Fails,* suggest that while, after a miscarriage, women tend to focus on the loss of the baby, men tend to focus on their partners. This is, as we have seen, largely due to western cultural expectations which traditionally casts the male in the role of the 'strong' protector for whom any outward

expression of emotion is seen as 'weakness'. This may make it particularly hard for the putative father to adjust to the loss incurred.

102 Having a 'role to play' is a significant phrase. One of the original meanings of 'persona' was that of a 'mask' worn by actors and hence it came to mean a role in a performance or drama. The man who is made to feel that he has no role or 'part' to play in the unfolding drama that is affecting his own life and relationships may not only feel excluded but may feel that he is a non-person and that, therefore, his own feelings or emotions have no place or status.

103 Friedman and Gradstein, *Surviving Pregnancy Loss*, p.9. See also, D. Davies, *Empty Cradle: Broken Heart* (Colorado Fulcrum, 1991), p.114.

104 C.M.Parkes, *Bereavement: Studies of Grief in Adult Life* (Harmondsworth: Penguin, 1975); Littlewood, *Aspects of Grief*; Stroebe, Stroebe and Hansson, ed. *Handbook of Bereavement.*

105 T.A. Helmrath and E.M. Steinitz, 'Death of an Infant: Parental Grieving and the Failure of Social Support,' *Journal of Family Practice, 6* (1978), 785.

106 M.S. Stroebe and H.A.W. Schut, 'The Dual Process Model of Coping with Loss,' Paper presented at the *International Working Group on Death, Dying and Bereavement,* St. Catherine's College, Oxford, June 26-29, 1995. This model marks a departure from other bereavement models since it does not regard grief work as essential for the eventual resolution of grief.

107 See also H. Schut, M. Stroebe, J. van den Bout and J. de Keijser, 'Gender Differences in the Efficacy of Grief Counselling,' *British Journal of Clinical Psychology, 36* (1997), 63-72.

108 A failure to oscillate between loss and task (what Strobe and Schut call 'restoration') would therefore be a useful indication of pathological or unhealthy grieving which might require more specialist intervention to aid resolution.

109 J. Tallon, 'The Compassionate Friends: Mutual Support by Bereaved Parents,' in *Listen My Child Has A Lot of Living to Do,* p.152.

110 B.A. Elliott, 'Neonatal Deaths: Reflections for Parents,' *Paediatrics, 62,* 1 (1978), 101.

111 The term 'survivor guilt' refers principally to the feelings of depression or guilt which may be experienced by those who survive a traumatic event in which others have died. An initial period which may be characterised by a sense of euphoria at having survived, is often followed by feelings of deep depression often characterised by questions like, 'Why did I survive when others did not?' This phenomenon was first recorded at the end of the Second World War in Jewish survivors. Survivor guilt may well be related to the phenomenon now described as post traumatic stress disorder (PTSD).

112 See footnote 55. An 'evolutionary' explanation of such grief is spelt out in Archer, *The Nature of Grief,* pp.215-217.

113 The latter may be particularly acute in grandparents who live away from their children and thus feel particularly 'distanced' from what is going on.

114 Z. Smialek, 'Observations on Immediate Reactions of Families to SIDS,' *Paediatrics, 62,* 2 (1978),160-165.

115 Notwithstanding what has been said in the previous section, generationally, it is unusual for putative grandfathers to talk in this way.

116 B.F. Friedman, P. Chodoff, J.W. Mason and D.A. Hamburg, D.A. 'Behavioural Observations on Parents Anticipating the Death of a Child,' *Paediatrics, 32* (1963), 610-25.

117 The gap between the faith, and grief, experiences of parents and children may now well be closing.

118 T. Walter, *The Revival of Death* (London: Routledge, 1994), p. 61. There are few articles which directly address the psychological and emotional needs of grandparents. One of the few is, J. Poznett and M.A. Johnson,' The Forgotten Grievers: Grandparents' Reactions to the Death of Grandchildren,' *Death Studies, 15* (1991), 157-167. Specialist bereavement support groups (SANDS, ACT, FSID etc.) now offer more in this area.

119 One child of primary school age, for example, reacted with intense hostility to the news of his mother's late miscarriage. He responded to his mother be saying, 'I hate you! Everyone else in my class has a brother or sister and now you won't let me have one.' The issue at stake here for the child was both the objective issue of a brother or sister and the subjective issue of his consequent status as an 'older brother'. This clearly demonstrates how the issue of identity affects not only the embryo or fetus which is miscarried or stillborn but also those in the web of relationships which constitute the family unit. The concept of identity as shaped and given coherence in a 'web' of relationships is particularly strong in A. McFadyen, T*he Call to Personhood: A Christian Theory of the Individual in Social Relationships* (Cambridge: Cambridge University Press, 1990) and T. Attig, *How We Grieve: Relearning the World* (Oxford: Oxford University Press, 1996). Bereavement breaks, or disrupts, such webs and the ultimate task of grief work consists in the re-making or re-building of our social networks.

120 I.B. Seeland, 'The Hidden Side of Grief,' in V.R. Pine, O.S. Margolis and K. Doka, ed. *Unrecognised and Unsanctioned Grief* (Springfield, Il.: Thomas, 1990), pp. 53-54.

121 This does not imply value-neutrality on the part of caregivers but a willingness to engage in the face-to-face interaction of genuine dialogue which is the *sine qua non* of good pastoral care, which builds community through conversation.

122 David Stoter rightly notes that, '(a)s carers attempting to travel with a patient, client or relative, it is important to recognise our own vulnerability and limitations and to identify areas where we feel threatened...' D. Stoter, *Spiritual Aspects of Healthcare* (London: Mosby, 1995), p. 12.

123 It has been argued that the attitudes of professionals particularly towards early deaths may, often unintentionally, reinforce guilty feelings in bereaved parents. 'Medical' beliefs about the point at which life begins might foster a tendency not to recognise (or to deny) that miscarriage or stillbirth constitutes human death and grief. Where the reality of death and/or grief is realised, staff may wish to avoid it for all the normal human reasons one finds death and the bereaved being avoided in the wider community. See, A. Lovell, 'Death at the Beginning of Life,' in *Death, Gender and Ethnicity*, p. 29-51.

124 Kohn and Moffit, *Pregnancy Loss*, p.124. Research I conducted in the late 1980s suggested that the existence of bereavement protocols was extremely patchy and that, where these did exist, few hospitals provided adequate training in their use.

125 *When Pregnancy Fails*, p.124.

126 Callahan, *The Troubled Dream of Life*, p.64. Later he says, 'The purpose of medicine is not to relieve all the problems of human mortality... medicine's role must be limited to what it can do.' (p.101).

127 This is not to suggest that midwives or doctors do not see the wider picture but simply that their role is often both more focused and more constrained by the demands of time. This is why a team-based approach is so critical in delivering appropriate person-centred care.

128 Gene Outka describes such agapeistic love as, 'a quality of relation between persons...' *Agape: An Ethical Analysis* (New Haven: Yale University Press, 1972), p.36; See, K. Barth, *Church Dogmatics* (Edinburgh: T and T Clark, 1960), III/2, p.278 and IV/2, p.745.

129 This is why the emotional impact of bereavement on staff should never be underestimated. The need both for adequate training and a commitment to on-going support for caregivers, at all levels, continues to be a pressing, and sadly often neglected, concern.

130 The 'death-denying' character of many modern Western attitudes towards life and death, described in chapter 1, means that withdrawal or 'distancing' from the bereaved has become a 'normal' social reaction as people attempt to avoid being confronted by the grief of others. A number of factors may help when bad news has to be broken. It is important that the setting is appropriate, ensuring as much privacy for the recipients of such news as possible. People need to feel 'safe', physically and emotionally, if they are to ventilate their feelings appropriately. Basic communication skills, both verbal and non-verbal are also essential, though all too often sadly lacking especially amongst some medical personnel. The avoidance of euphemisms and the giving of simple, clear explanations, avoiding technical phrases, helps to mitigate misunderstanding. Reinforcing the spoken word with written information can also be helpful since, as we have seen, the newly bereaved often fail to remember what has been said to them in the emotional turmoil of their grief. Above all, flexibility, a regard for the individuality of each situation, a willingness to be alongside, to listen empathetically, and to accept the emotions of the bereaved non-judgementally is that which is reported as most appreciated by the bereaved. For a brief discussion of breaking bad news see T.B. Brewin, 'Three ways of giving bad news,' *Lancet* 337 (1991), 1207-1209. What is critically important is that care should always be person-centred rather than problem-centred, as is so often the case when death and bereavement are medicalised. For David Thomasa, both the guiding motive of religion and medicine, and the grounds on which ethical norms are established, is respect of persons. ('The Basis of Medicine and Religion: Respect of Persons,' *Linacre Quarterly, 47* (May,1984),142-150.). Many hospitals now have particular rooms on the delivery suite for the labour of known stillbirths which offer a safe and supportive environment for the family, thus providing a less 'clinical' environment in which birth can occur and in which parents can remain for some time after it has occurred.

131 Penelope Wilcock writes, 'Medical professionals find ways to evade involvement, to retain detachment: but what medical care can hold at arm's length, spiritual care must embrace.' She adds, 'We all feel helpless... and there is a good reason for it, too: it is because we *are* helpless. Medicine can help with pain, nausea and other physical distress, but there is no bypassing or anaesthetizing the grief of laying down of life.' (*Spiritual Care of Dying and Bereaved People* (London: SPCK, 1996), pp. 3 and 5.).

132 This is indicative of the 'covenant of care' that is part of the true care-relationship, in which there is personal as well as professional (contractual) investment. See, W. May, 'Code, Covenant, Contract or Philanthropy,' *Hastings Center Report, 6* (1975).

133 On staff support groups, see chapter on neonatal death.

134 It is a telling omission that while society has a word for a person whose spouse has died (widow/widower) and a word for a child whose parent has died (orphan), there is no parallel word to denote a parent whose child has died.

135 One mother said, 'I shall always be grateful to those who said the right things: I have learnt to forgive those who said the wrong things; I shall never forgive those who said nothing.' Quoted in C. Hindmarch, 'Sudden Death,' in L. Hill, ed. *Caring for Dying Children and their Families* (London, Chapman & Hall, 1994), p.236.

136 ' Fear of death, the uncertainty about how to deal with it, and embarrassment, tells against the very sympathy which the bereaved need so badly.' M. Cullen and L. Young, *A Good Death: Conversations with East Londoners* (London: Routledge, 1996), p.160.

137 Organisations like the Miscarriage Association, The Stillbirth and Neonatal Death Society (SANDS), The Foundation for the Study of Infant Deaths (FSIDS) and the Compassionate Friends are all national, and in some cases international, organisations which work with and on behalf of bereaved parents. Most 'befrienders' in such organisations are themselves bereaved parents or grandparents. Alongside the larger scale organisations are more local groups, set up within communities by bereaved parents to support other bereaved parents in that particular locality. For a critique of such groups see Walter, *On Bereavement*, pp.185-204

138 Around 20% of women whose babies die in the perinatal period suffer a pathological outcome of their bereavement. M.T. Nicol, J.R. Tomkins, N.A. Campbell and J.S. Syme, 'Maternal Grieving Responses After Perinatal Death,' *Medical Journal of Australia, 144* (1986), 287-289.

139 L. Tolstoy (trans. R. Edmonds), *Anna Karenin* (Harmondsworth: Penguin Books, 1978), p.13.

140 F. Dominica, 'Reflections on Death in Childhood,' *British Medical Journal, 294* (1987),109.

141 Small, 'Masculinity and Loss,' in *Death, Gender and Ethnicity*, p.87.

142 Lewis, 'Mourning by the Family after a Stillbirth or Neonatal Death,' 306.

Chapter 4. Neo-natal Death

"What greater pain could mortals have than this,
To see their children dead before their eyes."

Euripides, *The Suppliant Woman.* (Trans.F.W.Jones)

"Dragons last forever, but not so little boys..."

Puff the Magic Dragon (final verse).

Introduction - Three questions

In the early months of 1978, a little boy called 'Dougy' wrote to one of the great pioneers of the twentieth century hospice movement, and author of one of the best known books on death and dying, Elizabeth Kübler-Ross. Dougy was nine years old and he was dying of cancer. In his letter to Kübler-Ross, he asked her three important questions, 'What is life?... What is death?... And why do young children have to die?'.[1]

The subject of this thesis is birth and death and all three of Dougy's questions lie firmly at the heart of this endeavour. In this chapter, therefore, we will explore some of the issues facing the parents of the dying baby and, consequently, facing those others who work with, and stand alongside, them on their painful journey. I shall examine the experience of families who have a child, born alive but facing death in the first hours, days or weeks of life. In large part, this will be focussed on families with babies in intensive care nurseries (ICNs), special care baby units (SCBUs) or paediatric intensive care units (PICUs).[2] I shall also examine a number of ethical and theological responses to issues raised by the dying child and, finally, set these in the context of the pastoral care of such families and, indeed, of those who work with them.

In the opening sentences of an article on the role of the hospice for the dying child, Frances Dominica notes,

> The moment at which you are told that your child is going to die is the moment at which your bereavement begins; you are bereaved of the

> future you had believed was your child's by right, bereaved of the future you had assumed you and your child would share. Hope and optimism die at that instant. Life will never be the same again.[3]

The experience of neo-natal death

A critically ill newborn baby is the worst fear of every parent. When a baby is taken from the delivery room to the intensive care unit instead of being put into the parents' waiting arms, it can leave parents shocked, bewildered and afraid. What is wrong with the baby? Will (s)he survive? What is being, or can be, done? are all questions that may rush through the mind in those early minutes, hours or days. If the mother has been sedated during the delivery, she may be struggling against the effects of anaesthesia; the father, if present, may often encounter feelings of powerlessness which may be so intense as to be at times even overwhelming. Especially if pre-natal diagnosis has failed to reveal any abnormality in the developing fetus, or the problem has been with the birth itself, parents may be ill-prepared and ill-equipped to deal with a baby born extremely prematurely or with an unexpected disability or disorder. As Borg and Lasker note,

> Because of the advances in modern medical technology and the continuing fall in the infant death rate, most couples begin their efforts to conceive with great confidence that they will have a favourable outcome. They feel they are largely in control of their future. Although they may have some fears during pregnancy, they expect to be among the great majority who give birth to healthy children. They are shocked when it turns out otherwise and frightened to discover that they have no control over what happens.[4]

Alongside the research being undertaken by clinicians and ethicists as the two-edged sword of new technologies in obstetric and neonatal medicine both offer new possibilities and pose increasingly difficult problems for those concerned with the care of the damaged newborn survivor, consideration also needs to be given to the theological and pastoral issues which surround the care of the dying baby.

Neo-natal deaths differs from those deaths covered in the preceding chapters, primarily in the fact that there is a live-born child whose life, for however brief a period, is independent of the womb. Although some philosophers like Michael Tooley, Peter Singer and John Harris maintain that birth *per se* has no logical moral 'value', the live-born baby nonetheless has a distinct legal status which does not adhere to the baby who dies *in utero*.[5] As Elizabeth Moltmann-Wendell says, 'Death makes all people equal but birth makes each person unique.'[6] The live but dying baby raises questions about the value of life and the nature of suffering in a particularly acute, although not exclusive, way which has a theological as well as an ethical and philosophical content and will almost always have pastoral implications for those working in the neo-natal environment, both clinicians and other healthcare professionals.

In the 1998 London Lectures in Contemporary Christianity, John Wyatt, a professor of neo-natal paediatrics, explores the ethical dilemmas of caring for the dying baby.[7] As a Christian, Wyatt is someone who takes a very different view of the newborn from that espoused by utilitarian philosophers who would argue, as Peter Singer does, that far from being a cause of moral outrage, the 'euthanasia' of the severely damaged or disabled neonate, regarded by Singer as a non-person, is both the logical and humane course in order to minimise suffering, although Singer does concede that in most circumstances choice should lie with the parents.[8]

As a clinician, Wyatt recognises all too well the issues raised and the problems posed by current technology in the management and care of the critical ill newborn. He writes, 'The effects of advances in medical technology... are nowhere more obvious than in the development of intensive care for newborn babies.'[9] Stanford Bourne and Emmanuel Lewis whose work in the field of perinatal deaths was ground-breaking in the 1970s, reviewing the last twenty-five years conclude that,

> (t)echnological advances have created fresh iatrogenic problems by enabling very tiny infants to survive. Families and professional staff are drained and tormented by the emotional and ethical problems that some cases pose. [10]

It is in the high-tech. environment of the neo-natal intensive care unit, then, that many of the moral issues raised by advances in medical technology are brought sharply into focus, and many of the theological and pastoral issues which are the subject of this thesis are daily worked out.

Charles Corr points out how, '(c)hanges in a society and in its healthcare system can... have a direct impact upon its experiences with death...'[11] In the high-tech environment of the intensive care unit, such changes have meant that death has become prolonged, professionalised, and institutionalised. Here we have a prime example of the way in which care for the dying, with all its implications for those who will be bereaved, has been marked by a shift from home to hospital and thus out of control, and even out of the experience, of the family.

The Intensive Care Unit - Who, or what, is being cared for?

' "What are you trying to save?" the pediatrician asked, looking over the Christian doctor's shoulder into the Isolette. "I don't know, Pete... but he's struggling to stay alive".'[12] Here, perhaps, is the nub of the problem, when is a *'what'* a *'who'* and does it make any difference? The answer to this question is not just of theoretical or academic interest but has direct practical implications for all those caring for dying babies and their families.

The birth of babies at 22-24 weeks gestation or with birthweights of <750 grammes is now commonplace, at least in major hospitals. The question is, however, whether attempts should be made to resuscitate or sustain the lives of *all* prematures babies, however immature. Such babies raise issues of care which have much in common with the resuscitation and care of the severely damaged newborn survivor (i.e. those babies born with severely life-threatening or fatal disabilities or disorders) and therefore they offer us a paradigm of care.[13] The question is, as a leading neonatologist asks, 'Is the expansion of neonatal intensive care driven by compassion for the vulnerable or by medical machismo?'[14] Although this is very much a

contemporary problem, the issues it highlights were prophetically recognised within a decade of the establishment of the first 'modern' neonatal intensive care units in the 1960s. Scott Hauerwas, writing in 1975, had this to say,

> Our longing to protect our children from death has built neonatal intensive care units; yet the very presence of these units creates problems which remind us how we must learn again when it is time for our children to die.[15]

Contemporary writing about the premature baby, in both the medical and philosophical literature, suggests that opinions about the moral and existential status of early human life fall along a continuum. At one end there are those who consider there to be a duty of care towards all babies, extremely premature or term, disabled or healthy. On this view, all babies are worth saving since all babies are persons, and therefore members of the human community, in their own right. David Thomasa has argued that '(t)he principle of respect for persons offers norms of moral activity for the healing profession.'[16] He sees this as underpinning the Hippocratic dictum, *primum non nocere*, and argues that clinical obligation is therefore so strong that it forms a bond of relationship of the kind that Paul Ramsey, and later William May, describe in terms of a canon or covenant relationship of loyalty.[17] Thomasa regards persons as possessing a sacramental character (i.e., since each person is loved by God, each person is sacred). He therefore argues that love, which reinforces but moves beyond the moral norm to do no harm, is the primary reason for acting in the best interests of each person.[18] Since it is argued that every person, of whatever age, reflects the *imago dei*, every person therefore possesses an intrinsic worth (a deontological approach).[19] Albert Outler, on the other hand, has argued that 'even normal neonates... are not yet decisively human (i.e. in the sense of 'person') in their neurological or social maturations.'[20] For Outler, personhood is 'the human organism orientated towards its transcendental matrix, in which it lives and moves and has its human being.'[21] Yet, he also reaches a very different conclusion to Singer (referred to earlier) since he sees 'personhood' as 'a divine intention operating in a lifelong process

that runs from nidification till death.'[22] Bonnie Steinbock has also argued that euthanasia of the defective newborn may, in some cases (e.g. an anacephalic infant), be morally acceptable, but, again, for different reasons to those put forward by Singer *et.al.*

> This is not because severely handicapped newborns do not have the same right to life as other normative persons. Rather, their right to life is not violated if they are genuinely better off dead.[23]

This position is clearly not the same as those who consider such severely damaged babies expendable, a kind of natural wastage, since they will never realise potential and attain full person status and are therefore not regarded as a part, and certainly not a full part, of the human community.[24] If such severely damaged babies should survive, it is argued, they would both lack quality of life and form a burden to others or to the state. The humane course, therefore, is to relieve them of their suffering, and others of the burden of their suffering, as swiftly as possible (a utilitarian approach).[25] Oliver O'Donovan characterises the distinction thus,

> The weak child, who is born less physically adept for the battle of life becomes in Christian society a claimant for compassion and care, while in the infanticidal community of natural man he is one who has not achieved the right to be human.[26]

An historical perpective

To understand either of these positions, or indeed those which fall between them, it is necessary to place the current debate in its historical perspective. The positions taken by those at either end of the continuum can be broadly characterised as those which, at one end, represent the position of classical antiquity and, at the other end, those which represent the position of the Judaeo-Christian tradition. In broad terms the classical Graeco-Roman world held that a child's significance lay in his or her value as a future citizen - in other words, the value of infants was essentially *potential* rather than *intrinsic* and therefore there was no protection offered, or rights conferred,

on the child simply by virtue of being born.[27] In the ancient world, the infanticide of weak or disabled babies was a commonplace. Both Plato and Aristotle, it appears, accepted the exposure of such infants as a moral act, and indeed a duty. Seneca argued that such practices were not to be considered acts of anger but acts of *reason*. He writes,

> Mad dogs we knock on the head; the fierce and savage ox we slay; unnatural progeny we destroy; we drown even children who at birth are weakly and abnormal. Yet it is not anger, but reason that separates the harmful from the sound.[28]

In sharp contrast to this view is the religious and moral tradition of Judaism and later of Christianity. Jewish Law, enshrined in the Torah, taught that all human life, even that of the newborn, was sacred since all life bore the divine image.[29] In this view, value, or worth, is *intrinsic*. Philo of Alexandria taught that infanticide was murder since what mattered was not the age of the person killed but that the human race had been interrupted or breached. The early Christian Church in its turn continued the Jewish condemnation of infanticide, with the Emperor Constantine issuing an Edict in 318 CE declaring the killing of a child by the father to be a crime. By the end of the 4th century CE infanticide had, ironically, come to be regarded as a capital offence in the Roman Empire.

The role of the doctor - curing and caring

If we conclude that all infants (indeed, all people) are of equal worth does this then mean that all newborns, whatever their condition, should, and indeed must, be treated with all the means available to modern medicine? The answer must sadly be that, when treatment would clearly be futile and would merely prolong the death of the infant with no benefit to the child, offering no gain in the quality of life, or indeed at the cost of increased suffering on the part of the child, this is not the case.[30] Under such circumstances, treatment ought to be withheld or, where it has begun, to be

withdrawn when it is clear that the conditions outlined above apply and that continued treatment 'at all costs' would not be in the best interests of the baby.[31] A genuine respect for human life sometimes entails us in the painful business of deciding when 'ordinary' treatment becomes unjustifiably 'heroic' and of 'letting go'.[32] Such a position in no way denies that such babies are either persons in their own right who may be known and loved for themselves alone, or that they deserve, and indeed demand, our care and compassion. It does not suggest that in them the divine image is any way reduced or occluded on account of their condition.[33] Indeed it may be argued that in the severely damaged newborn we see with particular clarity images of both 'incarnation' and 'broken-ness'. It is a reminder of the eternal continuity between the Jesus who is both the baby in the manger and the man on the cross, in whom God is revealed as an *embodied* person, fully human and capable of suffering, offering us a paradigm of humanness, and whose resurrection life patterns, and offers us hope for, our future.

We must recognise, therefore, that whatever the expectations of parents, and despite the abilities of modern medicine, the birth condition of some children may be overwhelming and ultimately incompatible with continued or sustainable life. Even such babies, however, should be regarded as full members of the human community and therefore as full recipients of the requirements of neighbour-love. Those who are beyond *cure* should, like their families, never be beyond *care* and care, as Paul Ramsey remarks, 'cannot fall short of universal equality.'[34] Hans Kung, too, offers a timely warning:

> Highly technological medicine... which provides therapy through apparatuses, must not lead to the terminally ill being left alone. The perfect clinic must not become a mere service station with maximal biochemical care and at the same time minimal human care... The patient orientated doctor knows that men and women are helped only by a total care which embraces both body and soul, and that a humane climate in the clinic and above all human conservation is important to the end.[35]

Stanley Hauerwas has argued that the instinct to care arises not out of philosophical notions of personhood but out of relational bonds. He writes,

> When people are dying we seldom decide to treat or not to treat them because they have or have not yet passed some line that makes them a person or non-person. Rather we care or do not care for them because they are Uncle Charlie, or my father, or a good friend. In the same manner we do not care or cease to care for a child born defective because it is or is not a person. [36]

David Smith, too, recognises that in cases of medical futility the fatally damaged newborn survivor should, with appropriate comfort and care, be allowed to die.[37] He would not, however, agree with Singer, Harris *et al.* that such babies should be actively euthanised. Ultimately, then, whilst we must not be simply sentimental, we have to ensure that we remain *person* rather than *procedure* centred in our decision making about the critically ill and dying newborn. Whatever our view, the newborn damaged survivor forms part of what Gene Outka describes as our 'moral landscape'.[38]

In the past, all that was possible for such critically ill or damaged survivors was that they should be kept warm and, if possible, fed until they died.[39] Today we have moved far beyond that position not only in what is possible in terms of pain and symptom control but in our ability to sustain, at times indefinitely, vital life-functions. Where problems are neither fully nor even partly correctable, the question of *appropriate* treatment for such infants has been, and continues to be however, in some cases, a source of controversy.[40] Since the newborn is unable to speak and is therefore unable to express an opinion or make a decision concerning his or her own future (i.e. he/she is neither *rational* nor *autonomous*), someone else (a *surrogate*), whether parents, physicians, or the courts, must make informed decisions on the child's behalf and act in the child's best interests. Part of the pastoral care offered by chaplains in such circumstances is to be both an informed resource and a support for decision makers, whether parents or clinicians.[41]

Ultimately, there is no simple formula that can offer easy answers in such circumstances. As William May observes,

> Most care for critically ill children and their families requires not recipe books for action but a cultivation of the virtues of discernment and fidelity, which those who profess something on behalf of someone must evidence if they would practice not perfectly but well.[42]

In practice, therefore, decisions fall between the two extremes. There may well be disagreement in individual cases about what constitutes the 'best interests' of the baby and it is important both that clear, simple, factual and accurate information is provided for the parents, that their feelings, beliefs, hopes and fears are allowed to be articulated and that there is a genuine dialogue among care-givers. While this will often require both time and patience, it is an essential component of care for the well-being of families as a whole and not just of their sick and dying infants who remain, nonetheless, the primary focus of care.[43] Nowhere it is more important to remind ourselves that, whatever technical skill or objective advice may be offered, parents are, and will under normal circumstances always remain, the primary care-givers and decision-takers for their children. The need to respect, support, affirm and empower parents in this role and so to give back to them some measure of control is crucial, especially at a time when they may be feeling powerless, inadequate, confused, bewildered and, very often, guilty because of their perceived responsibility for the condition of their child.[44]

The role of parents and their caregivers in the intensive care environment

Over the last twenty years there has been an increasing recognition of the role of parents in both caring for and making decisions about their babies. Irving Leon says,

> The statistically significant increase in well-being reported by parents who participated in the medical decisions or actual care of their terminally ill children versus those of parents who did not may be based on a greater sense of mastery in the situation as opposed to feelings of debilitating helplessness.[45]

In the early days of neonatal intensive care, parental involvement ended at the unit door. At this point, both care and decision-making passed into the hands of professionals. The modern neonatal unit is a very different place. Parents are actively encouraged to stay and to participate in the care of their child. Siblings and other family members are welcomed and physical contact with the baby is actively promoted in most cases. Thus, parents are encouraged to develop an emotional bond with their child and so to help establish the child as a 'real' person and themselves as parents.[46] Joanna Hawthorne Amick notes now the two elements of an 'open door' policy and a sense of both welcome and trust need to be held together.

> It is clear that opening the door to parents does not guarantee that they will feel at ease about visiting frequently. If they are made to feel welcome by the staff and given something to do for their baby when they visit, there are indications that they may visit more often.[47]

This is something which clearly has implications for parents whose babies subsequently die and is true for both mothers *and* fathers of critically ill newborns. Where death is anticipated, appropriate support and counselling can now be offered to the family and many neo-natal units have a designated member of staff trained in bereavement care. Increasingly staff working in areas of high mortality are being encouraged to avail themselves of training in this area.[48] Parents of the baby who is dying are encouraged to spend time with their baby, to name their child and to engage in appropriate ritual.[49] The importance of naming in acknowledging both existence and individuality discussed in earlier chapters, and the time spent with the critically ill newborn, indicates that, for most parents, even the most severely damaged newborn survivor is regarded as a unique and loved other, a person in their own right, with their own narrative, however brief.[50] Without the recognition of this by clinicians and other professionals, the grief which follows the death of such severely damaged or pre-term babies, and which is often frighteningly intense, will not be seen for what it is and will not therefore be legitimated.[51] Comments such as 'It's all for the best' may be small comfort to parents who are witnessing the death of a loved and wanted child.

Within a short time, the anticipated joy of the birth of a healthy newborn child is transformed by the shock of discovering that the long-awaited baby has life-threatening problems which may threaten not only his or her life but which may threaten the dynamics of both the new relationship and existing ones (i.e. between the parents and/or other siblings). One mother recalls with great clarity her distress after the death of her baby when she was asked how she wanted *'it', 'disposed of'*.[52] Such thoughtlessness and lack of care is unforgivable. It arises nonetheless from a dissonance in understanding between how parents view what has happened and about how professionals view it. In many cases such 'professional' views are themselves about 'emotional distancing'. This only serves to underline the importance of a genuinely dialogical approach to care that listens carefully to both what is said and is left unsaid. Most parents vividly recall, even many years later, the attitudes of others to them when breaking news or when their baby dies. Thus, how the news of disability or disorder is given to parents is of critical importance. This is why it is so important that every opportunity should be taken by care-givers to get to know the family and to build up relationships of mutual trust as soon as possible. A gentle and accepting honesty, both about their baby's condition and about their often confused and ambivalent feelings, is essential. It is particularly important that the sense of shock and numbness which often follows either diagnosis or death and the absence of expressed emotion (detachment) is not confused with 'coping well' or, indeed, with not caring. There is, however, much that can be done to mitigate the effects of this emotional 'blow', but it requires patience, sensitivity, gentleness, honesty, openness and respect on the part of caregivers and therefore depends as much on 'virtues' (the kind of people we are) as it does on skills (what we do).[53] Frances Young, writing about the birth of her severely disabled son, writes,

> I recognise now that there are no parents of handicapped children who have 'good' experiences of being told. It is so traumatic that there is bound to be anger and let down and resentment.[54]

And she adds, 'We all need to watch our words. Even the best professionals need to hear how vulnerable their clients are.'[55] Sensitivity as well as accuracy, then, is an essential element of good communication and this requires both time and effort. Too often parents have been rushed into decision-making for which they were not prepared and this may leave them with regrets or unresolved anger later on.[56]

Whilst much writing which regards the severely damaged survivor as a non-person suggests that they are to be regarded as disposable or 'replaceable' (the word is often used), the evidence of parents suggests that each child is regarded as unique and 'irreplaceable' even when there may be subsequent children. Despite the arguments of some philosophers, therefore, most parents would regard each child as having an intrinsic significance, even when they agree to withdrawal of treatment which is considered futile. Vigen Guroian, writing about the case of Baby Rena, an American baby dying of AIDS and heart disease, says,

> In light of the tragic story of Baby Rena, there is one practical point I would like to stress: biblical faith does make it possible for us to make reasonable moral judgements about when our primary obligation to a patient is not to do everything possible to extend her life but rather to care for her as if she is dying.[57]

Arguing for a 'care' rather than 'cure' approach in such circumstances, he concludes,

> Informed by a true biblical faith we will seek to navigate a course between an absolutist ethical vitalism on the one hand and a utilitarian ethic of 'quality of life', triage, and euthanasia on the other.[58]

When it becomes clear that a baby is dying it is important that the parents are given the opportunity to have the maximum amount of quality time with their infant, with as little medical 'impedimenta', which might act as a physical or a psychological barrier between parents and child, as possible. Care must be taken that it is not seen as 'isolating' the dying so that 'out of sight' becomes, 'out of mind'. It is a sad fact of modern medicine that, notwithstanding the immense strides made in the field of palliative care, we nonetheless tend to isolate those whose sufferings cannot be cured

and families are left feeling that their grief, like their dying child, is an embarrassment to others. Such feelings can be mitigated if time is taken to talk to parents and to ask what they would prefer.[59]

For many parents, grieving begins before death occurs (anticipatory grieving).[60] The first responses of denial (in which requests for other opinions are often made) may give way to distress, sometimes marked by anger (protest) and often by crying. Denial may recur but as the impending loss is gradually acknowledged, parents may begin to 'detach' (decathect) from the baby and some may withdraw, emotionally or physically, at this time. Much more common, however, is a temporary suspension of the bonding between the mother (or father) and the newborn baby.[61]

The critical medical condition of some neonates precipitates their immediate removal to an intensive care environment. This means that the parents' first glimpses of their child may be through the perspex wall of an incubator, perhaps being ventilated and 'wired-up' to various monitors. It is difficult under such circumstances, where holding the baby may not yet be possible, for normal parent-infant bonding to occur. Some parents may indeed initially refuse to visit a baby on the neo-natal unit either because they fear that they will be emotionally overwhelmed by the experience or, perhaps, because they fear getting to know a baby who might subsequently die. 'We'll wait and see' is often how this is articulated.[62] There are few parents who do not feel at least some ambivalence about being there. Such parents need a high degree of support and understanding. Criticism, implied or spoken, will only make it harder for them to return. The opportunity to hold and cuddle a dying baby is very important, both for the baby and for the parents. As one mother said, 'No baby should die alone, It was all the comfort I could give him, to hold him in my arms as he died.'[63] There is considerable evidence that holding the dying baby, like seeing and touching the miscarried or stillborn child, also helps the parents in the longer term resolution of grief. A mother's positive attachment to her dying baby in touching and holding the baby both before and after death, is therefore, as we have shown, important in assisting healthy grieving.

Whilst it was once thought that parents would quickly 'get over' the death of a baby in the pre- or perinatal period, it is now clear that such deaths can be both profoundly distressing for parents and have long-term, and even permanent, effects. Some would indeed suggest that the grief precipitated through the death of a child may be *more* severe and/or persistent than other bereavements.[64] In 1929, Sigmund Freud wrote to his friend Ludwig Biswanger,

> Although we know that after such a loss the acute state of mourning will subside, we also know that we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually this is how it should be. It is the only way of perpetuating that love which we do not have to relinquish.[65]

Freud wrote those words on the day his dead daughter would have been 36 years old.

A key factor identified in poor bereavement outcomes, identified in earlier chapters, is poor support, particularly from the husband or partner.[66] It has been shown that for as many as 50% of families affected by the death of a baby there are serious detrimental effects on the marital relationship.[67] Such families often feel that they are excluded from the normal circle of human relationships.[68] Bereavement support is therefore an important aspect of work at a time when the strength of the family unit is being severely tested. Early studies showed, however, that healthcare professionals on the whole provided a low level of support to families once a baby had died, arguably due to two factors - professionals' discomfort about death and their poor understanding of normal grief reactions.[69] Effective support, however, will always involve first and foremost a recognition of parents' grief and a willingness to share in it and to talk openly about it.[70] Good communication within families at this time can mitigate the isolation and loneliness of bereavement and, despite the increased stress, may in fact strengthen relationships. Parents can only help each other if they can recognise the other's needs and can both talk and listen to each other.[71]

When it is clear that a baby is dying, if not before, parents will be asked if they wish to see other, non-medical, members of the care team such as the social worker or chaplain. Often, relationships with parents will have begun to be built up from the time of their admission to the unit and good groundwork on the part of the team now pays its dividends. As Walker concludes, '(t)he response and intervention from the multidisciplinary team affects the immediate and overall grief response.'[72] It is important, for both staff and families, therefore, that chaplains should be seen on the unit each day in order to build relationships and to avoid the view that the only time a chaplain is seen on intensive care is when a death is imminent. The building of relationships is arguably the single most important dimension of pastoral care. Brief conversations over the period in which families are present on the intensive care unit, even a hand quietly rested upon a shoulder for a moment in passing, all help in communicating the faithful and dependable presence of a chaplain exercising a ministry of presence among and alongside the vulnerable and suffering which I have characterised as agape.[73] Presence 'alongside' another, whether expressed through speech, touch or silent being-there, is a powerful way of communicating 'connectedness' to those who are feeling alone and isolated or who are in despair.[74] As Manning says,

> We see the parents in heart-rending agony and want to do something that will ease their grief. There are no magic words but it is not so much what we say but whether or not we care. This always comes across. [75]

Henri Nouwen writes,

> It seems necessary to re-establish the basic principle that no one can help anyone without becoming involved, without entering with his whole person into the painful situation, without taking the risk of becoming hurt, wounded, or even destroyed in the process.[76]

This is, after all, the nature of love.

Good care of the dying infant and his/her family on the part of the chaplain consists, then, in being near enough to be readily available and to be seen to be supportive, yet far enough away not to be intrusive and so to allow parents and other members of the family to have the space they need to be with, and to talk to, their infant. This balance between nearness and distance is an important constituent element of good pastoral care as agape since it recognises the boundaries of both self and other, and displays a genuine respect for what Buber characterises as the 'I-Thou' relationship.[77] A chaplain may talk with parents, or simply to sit with them. He/she may, perhaps, hold the baby while parents stretch their legs, go to the toilet, have something to eat, or snatch some much needed sleep, and, by so doing, provide a re-assuring continuum of care. Parents may ask for a prayer or a blessing for their baby or for baptism at this time.[78] It is also important to be available to other family members who may feel particularly isolated or vulnerable such as siblings or grandparents.[79] Some research indicates that the grief response of families depends on the compassion and concern of caregivers more than on any other single factor and therefore that care for the bereaved should begin before death occurs.[80]

As we have seen in the preceding chapters, gender differences in grieving pose a challenge for the carer who seeks to care for each member of the family. Carers may be faced with the mother who wishes to remain with the child, whilst at the same time trying to support the father who may be more likely to wander along the hospital corridors on his own, unable to be present, perhaps for fear of losing control or frustrated because he fears that it is already lost.[81] While it is generally recognised that fathers find more difficulty in expressing their emotions than mothers, it is important not to fall into the trap of gender stereotyping (I have known fathers to sit with their dying infants while the mother is unable to bear the emotional strain of even being on the unit). Raj is correct, nonetheless, when he says that one role of the chaplain is often 'to draw the father into the intimacy of the situation' and so to 'provide him with the necessary opportunity to say goodbye to his child.'[82] His suggestion that fathers often evade these tasks by taking charge of the mother, staff

and family is only partly correct. As we have seen, part of the difficulty which fathers often have in expressing their emotions arises from the pressure to conform to social roles.[83] This is not just that 'big boys don't cry', but because fathers may be re-inforced in their 'coping' role by pressures from staff. Especially in the intensive care environment, they may be required to act as the link between hospital and family, to provide consent for treatment or its withdrawal and to sign post-mortem consent forms, 'so as not to upset the mother'. Thus there is often a failure to recognise the depth of a father's grief and bewilderment after the death of a baby because they are generally less open in expressing emotion than their partners.[84]

The role of the multidisciplinary team - Caring for the carers

The ability to offer whole-person care to the dying and their families has been greatly helped by a growing awareness of the need for professionals to operate in the context of a healthcare team, whether interdisciplinary or multidisciplinary. It is now widely recognised that a model of healthcare which sees the practice of medicine as something that is carried on only by individual doctors or other healthcare professionals working in isolation is one which is no longer appropriate. In the hospital setting in particular, an increasing dialogue and interdependence has developed between doctors, nurses, social workers, chaplains and other healthcare professionals over recent years. Thus, a team-based approach to care is now one which is widely implemented, and most hospital chaplains would regard themselves as being in some way part of a wider healthcare team. Ina Ajemin defines a team as 'a group of individuals with a common purpose' in which 'each individual member will have particular expertise and training and will be responsible for making decisions within his area of responsibility.'[85] For the chaplain or other pastoral care-giver this will find expression in a genuine care and concern for the patient as 'other', in the facilitating of the expression of feelings and beliefs and in the search for meaning and hope in a particular situation.[86]

Although Ajemin is writing in the palliative care setting what she has to say about chaplains and their role in the interdisciplinary team is also true in other areas of healthcare, including neonatal ICU. She says,

> A sympathetic Chaplain who is a good listener and able to meet patients as they are rather than where their particular religious tradition might suggest they should be, is a key team member. His presence provides a focus and a stimulus for airing of questions of meaning that are invariably present for patients and their families... The role of Chaplaincy is one of listening, facilitating past recollection, dealing with regrets, giving thanks for what has brought love and meaning, and growing in readiness for what lies ahead... In addition to spiritual counselling, the chaplain will often be used as a confidant and a source of support and encouragement; thus counselling skills are particularly helpful. A chaplain may be involved in discussion of ethical questions, or may be a facilitator to the team during times of stress or conflict.[87]

While this cannot serve as an exhaustive definition of the chaplain's role, Ajemian makes some pertinent comments. Similarly, J. L. Florell writes,

> Clergy are the professionals who demand nothing of the patient in the healthcare setting... Clergy often have an entree to the patient unavailable to other team members... People seem to go to clergy more than any other professionals for initial help with personal or emotional problems. One reason is that clergy provide a practical way for people to deal with crisis through the symbols and rituals of the Church. Whether a person is facing an operation or the loss of a loved one, when critical changes occur, religious belief can reassure, support, and give needed strength to face whatever difficulty comes. The religious professional provides this support for both patients and other team members... Clergy also report a significant amount of time listening to and supporting other team members.[88]

Whilst Florell is writing from the perspective of the United States, where the role of the hospital chaplain is, in some respects, different from that of chaplains in the United Kingdom, the underlying points which he is making are undoubtedly true. For members of the healthcare team, working in a high-stress environment, where anger, guilt or a sense of failure are often felt but seldom articulated, the chaplain can be an invaluable source of care and support. This is now being increasingly recognised in the professional literature of nursing and medicine. S. Burke and A. Matsumoto identify

seven key areas where the Chaplain can act as a supportive resource for other caregivers. These include (1) A creator of meaning, (2) a trustworthy listener, (3) a pastor away from home, (4) a calming presence, (5) a fellow sojourner in the land of bereavement, (6) a generator of ethical concerns and, (7) an educator. They conclude that the presence of the chaplain in the neonatal and perinatal environment has a vital role to play in mitigating stress since it, 'adds a dimension of respect and concern for each individual's well-being and each person's work on the staff.'[89]

Standing outside the hierarchical structures of the medical and nursing professions, the chaplain can be available to staff as a confidant or simply a shoulder to cry on.[90] Caring for staff, therefore, has a crucial role to play in the proper functioning of any team or unit, and therefore in the well-being of patients and their families. Conflicts between staff, or between staff and parents, can quickly undermine morale, increase stress, and reduce the capacity of staff to function well. The sensitive chaplain who takes time and effort to build relationships within the healthcare team can have a valuable role in affirming and validating the caring ministry of others in the intense atmosphere of the neo-natal ICU, and in addressing the real grief that is experienced by many staff when a baby dies.[91]

The role of the Chaplain - Virtues and skills

Caring has been variously defined as 'being with' another, becoming open to the other's reality (i.e., seeing the other as other) and giving the message that the other's experience matters to the one caring.[92] Caring is, therefore, as much about *virtues* - truthfulness, sincerity, fidelity etc., as it as about *skills*. Thus, neighbour-love (agape) is the underpinning quality of the care-relationship. If this is taken in the context of a holistic view of care, variously described as whole-patient or whole-person care, rather than an atomistic one, in which the focus is on the physical, medical condition alone, then such care does not polarise the physical and the spiritual. In terms of Christian theology, the doctrine of the Incarnation of Jesus links God and

the created world in such a way that negates a physical-spiritual dualism. For the Christian, therefore, the life, death and resurrection of Jesus are always paradigmatic of living, dying and post-mortem existence and shape both Christian teaching and pastoral care.

Standing outside hierarchical structures, chaplains have a unique perspective on care. Whilst professional in their approach to care, chaplains are not so professionalised in their care-giving that they are entirely detached from the recipients of that care. They can thus often play an important 'bridging' role between medical and nursing staff and the family. There are many, therefore, who resist the current trend in some quarters to 'medicalise' spiritual care, reducing 'spiritual distress' to a diagnosable and assessable phenomenon which takes it outside the inter-personal dynamic.[93] It is important to recognise that pastoral care, which includes spiritual care, is not simply a matter of psychological adjustment. As Jacob Firet says, 'Pastoral care is... an address to an equal... pastoral care means that she is addressed in the language of respect and dignity.'[94] As such, pastoral care is both social and relational. Kenneth Czillinger describes the role of being alongside the parents of a dying baby and the recognition that one has no final answers and can do nothing to change the situation as the 'helpless-helpless bond'.[95] Far from this being a negative role, Czillinger describes it in terms of a necessary self-awareness which enables ministry alongside others, not a 'fix-it' ministry but one of faithful companionship in the dark places, a ministry of presence, comfort and consolation.[96]

Gaylord Noyce argues that at times of medical crisis the role of pastoral care is three-fold, to serve (1) medical personnel (especially, for Noyce, those in the congregation), (2) those undergoing medical crises, and (3) the wider public as they reflect on issues of medical concern and of public policy.[97] Whilst I have described the first two of these in some detail, the third is also an important dimension of the chaplain's work and ought not to be underestimated or ignored. In order to be effective a chaplain must therefore be aware of his/her own strengths and limitations, including personal feelings about death. He/she must be secure enough not to feel that

he/she has to have all the answers or to 'defend' God.[98] The Chaplain must be skilled in practice and open as a human being with a genuine love and respect for others. Awareness of one's own need for appropriate support is also essential.

The death of a child as spiritual crisis

We have already noted that contemporary Western society does not deal well with death. When death comes at the beginning of life, the sense of outrage, so often felt at death today, is heightened. Such deaths can therefore become deeply threatening. They are considered to be un-natural, events in which the natural order of life has been breached, and in which life's most intimate connection, that between parent and child, is severed. Thus, the death of a baby provokes not only sorrow but often a deep existential *angst* as the world itself becomes, in a sense, inherently unsafe.

The shock of death may thus lie not simply in the 'loss' of a known and loved other, but also in that it affects the ability to rationalise the world, precipitating the bereaved into a chaos of meaninglessness as previously held world-views become, or are perceived to be, no longer tenable. Part of the role of the chaplain in such circumstances is to help the bereaved to discern meaning, not in the sense of explaining a particular death, but in helping the bereaved to re-orientate themselves to the world and its complex of relationships.

It has long been established that both peoples' understanding of death and the way in which they experience it has been shaped by religious beliefs and practices. On the whole, as we have seen, the practice of religion has been associated with better long-term outcomes after bereavement. This has usually been regarded as being the result of both having a system of beliefs which either attribute meaning to death by offering beliefs about death that render it less threatening, or which offer solace in its face, and with having a community which is able to offer support in times of crisis - generally, the greater the participation, the greater the support. Nonetheless, death, and the death of a child in particular, may challenge even the most fundamental of

beliefs and precipitate a crisis of faith leading sometimes to guilt and even despair. So, alongside the grieving for the dead child, we may have to set also the grief of lost or damaged faith. Here, anger and grief often go hand in hand, 'It's so unfair...', 'How could God let this happen?', 'Where is the meaning of it all?'. These are the questions so often asked by bereaved parents after the death of a loved and wanted baby, and which may form the context of care for the chaplain or other pastoral care-giver. For some, it must be said, blaming God is about finding a peg on which to hang blame in the rawness of grief and bewilderment, like blaming the doctor, or one's partner, or fate. For some, the chaplain may personify the God who has let such parents down and with whom they feel they will never be reconciled. One mother, whose child was dying, deliberately turned her back whenever I entered the intensive care unit where her child was being cared for. She did not wait to see if I was coming to see her. She was angry with God and she felt let down and I was his representative. If she could not physically turn away from God, she could physically turn away from the chaplain! Often, in the search for meaning, God is cast in the role of a tyrant, one who callously 'takes' the lives of children as a punishment for parental wrongdoing or, at best, stands idly by and does nothing when death comes to call. For some parents, their anger is as much at the apparent absence of God, as in any belief that God somehow caused, or permitted, their child to die.[99] It is a great mistake under such circumstances for the chaplain either to take such parental anger as a personal rebuke or to feel that he, or she, is there to 'defend' God and so to get drawn into unhelpful theological arguments on issues that ultimately will not be resolved in combative debate. For the Chaplain, or other pastoral care giver, a simple 'theology of presence' may be much more effective. The willingness to be alongside those who suffer, without the need to offer any easy solution or to provide any stock answer, as companion or accompanist in the dark places, will demonstrate another vision of God which may, in time, be glimpsed and embraced and the silence which goes beyond speech may speak more eloquently than those who feel the need to fill empty spaces with the sound of spoken words. N.A. Kirkwood, an Australian hospital chaplain says,

> In the hospital we do not suddenly put on a mantle that sets us up as an authority above all and all-knowing. Our task is to come up with our own frailties, imperfections and unanswered questions. We come as a fellow human being in all our humanness... To come with our tidy pack of "Here is the answer" cards is not the way to hear what they are asking and what the real problem is... In accepting and sharing the pain of others, we incarnate our faith in the God who stands with us in their suffering, sharing their burden... The love of God incarnate in us is seen by them... Where this love of God incarnate is seen, pastoral care is being received.[100]

For others the need to apportion 'blame' is focussed on the self. In this sense guilt is anger turned inwards but it is also part of the search for meaning and needs to be recognised as such. 'Why me?', 'What did I do?', 'Why couldn't I have a child that lived?' are all questions commonly asked by those whose babies die in infancy.

As with other forms of early-life death, self-esteem may plummet and women, in particular, will often use the language of 'failure' - failure to produce a well child, failing one's husband/partner/family/community, being failed by one's body, having failed expectations, are all common themes after the death of a baby or after the birth of a baby with a major disability, particularly as childbirth is so intimately linked with self and contemporary society raises such high expectations of the normality of childbirth. Self-worth is often intimately related to role and identity both of which are threatened by the death of a child.[101] In some cases this may lead to depression or even to self-destructive behaviour.

Blame, of self or other, may often become a destructive cycle, moving from one source to another - God, the doctors, one's partner, self, even the baby who has died for dying. Wherever such feelings are directed, the emotional and spiritual pain which is felt under such circumstances can often be so intense, that it may seem capable, at any moment, of overwhelming the sufferer.

In an article on the meaning of suffering, Stan van Hooft has agued that, as 'a spiritual phenomenon that strikes at the faith we can have in life,' suffering is 'contested at the level of discourse at which cultural meanings and visions of human

life are negotiated.'[102] Thus, the death of a child which I have described in terms of 'spiritual crisis' can be explored in terms of a number of different narrative perspectives, of which three examples follow:

Biblical perspectives

If, particularly in the Old Testament, there emerges, at times, a picture of God as one who dispenses blessings or curses as rewards or punishments for human actions there is also other material which, if not in direct contradiction to this, nonetheless betrays it as an understanding of God which is limited and ultimately not only unsatisfying but inadequate. Thus, over against the God who is portrayed in the Book of Deuteronomy and in some of the Wisdom literature as the dispenser of retributive justice, we have the God who, at the end of the Book of Job, hears, engages with, stands alongside, and ultimately redeems, the sufferer. What Job brings dialogically before God is *real* suffering, not just a matter of theological or philosophical speculation and abstraction. Such questions can, of course, be constructed theologically or philosophically but they are actually asked existentially (i.e., how human beings *actually* order their lives in relation to the supposed plenitude of God).

The notion of a punitive God who inflicts suffering on the innocent as a punishment for the sins of others is categorically dispelled by Jesus himself in St. John's gospel in response to the question, 'who sinned, this man or his parents?'[103] The answer is unequivocal, *'neither'*.

In the New Testament, the central motifs of the Cross and the empty tomb/resurrection-appearances stand as the symbol of the God who, through the incarnation, death and, above all, resurrection of Jesus, hears, engages with, stands alongside, and ultimately redeems, wounded and suffering humanity. As Austin Farrer says, '...God saves us not only out of suffering but by suffering.'[104] It is the image of the 'wounded healer', the suffering, death-bearing and ultimately death-defeating God which offers more hope to those who struggle with the anguish of what seems so

unfair and untimely form of bereavement than that of a punitive deity.[105] One father, whose child had just died said angrily, 'My child has died. How can God know what I'm going through?' When I said to him simply, 'How can he not? That is the story of the New Testament...' there was a long pause before he said simply, 'Yes, I suppose it is'. For that particular individual in that particular situation, that recognition was a real turning point. After all, it is often said by bereaved parents that the only ones who truly understand what they are going through are other bereaved parents. and there is an extent to which this is, of course, true. I could not offer him an answer to the question *'Why?'*, nor would I have tried to. All I could do was to point towards a shared experience and to offer him faithful companionship in his journey through grief.[106]

In this role the chaplain stands not just in his or her own right but as a representative of the covenant community of the Church which, especially for those who already belong to an ecclesial community, forms the context of on-going nurture and support.[107] It is by no means unknown for parents who have not previously had a history of Church attendance to start to go to Church after their baby's death. Such a momentous event can be a time when people radically re-evaluate their own lives and values and search for meaning and purpose in life. It must be remembered, however, that for others such traumatic events may also precipitate a spiritual crisis which can shake, and may even destroy, previously held beliefs and/or values. Such deaths profoundly challenge the image of God with which most people, if they believe in God at all, have been brought up. The question for many people at this time is not 'what ought I to believe?' but, 'what do I believe?' and for many the question uppermost is articulated as, 'How can I trust God again?' Non-judgemental openness and sensitivity are therefore crucial components of spiritual and emotional care after the death of a baby.

A social science perspective

In an article in the *Journal for the Scientific Study of Religion*, Judith Cook and Dale Wimberley use the social science models of exchange theory and phenomenology to explore the relationship between parental religious commitment and its role in the adjustment of such parents to the death of a child.[108] The article proceeds in two ways. It explores the relationship between religious commitment and post-bereavement adjustment and it examines the 'nature and effectiveness of theodices constructed by parents to explain their child's death.'[109] In the first part, they argue that religion offers 'compensation' to bereaved parents by providing meaning in the face of an otherwise bewildering event: while such parents can do nothing to restore the life of their dead child, they can go to church more regularly and cling more strongly to religious beliefs. However, they make a number of questionable assumptions. They assume, for example, that a belief in a personal, caring God and in a life after death are apt to be reassuring to a bereaved parent. Whilst those who continue to hold some belief in a post-mortem existence, however conceptualised, may undoubtedly draw some comfort from the thought that the death of their child does not mark a final separation, many bereaved parents, even those who have a religious commitment, will question or blame God for what has happened especially in the early period after a death.

Although Cook and Wimberley briefly acknowledge that for some, religious belief may lead to guilt 'when parents find the proffered explanation does not provide the comfort they had expected', they fail to recognise that, in the face of the death of a child, belief in a 'caring' God may also occasion a crisis of faith, whether temporary or permanent, that moves beyond guilt, as well as providing solace. It seldom, however, provides any 'meaning'.[110] Furthermore, they argue that, 'in order for religion to provide such compensation, some level of religious commitment must already exist.'[111] This, as we have seen, is not necessarily the case. For some parents, the death of a baby may prompt an examination of previously held beliefs, values or

lifestyle from which church attendance and the development of faith may arise.[112] The search for meaning may in fact therefore lead people to a discovery of faith which previously would have been unrecognised or denied. It is, nonetheless, true that both the presence of a personal faith and the support that can be offered by participation in an ecclesial community can offer real and valuable benefits to bereaved parents. This, however, is far more often in terms of helping people to live with their loss than in attributing meaning to it.[113]

In the latter part of their paper, Cook and Wimberley, more interestingly, draw on the work of Robert Wuthnow and his colleagues to construct a framework for considering post-bereavement adjustment.[114] They conclude that there are three specific types of bereavement theodicy which are most commonly articulated: 1) re-union with the child in an afterlife, 2) the child's death as serving a noble purpose, 3) death as a punishment for parental wrongdoing. Of these three, the first and the last are undoubtedly the most common. The last - death as a punishment for parental wrongdoing - has already been discussed both in this chapter and previous ones. In the first, solace is taken that the child has gone to a 'better place' and that parents will one day join the child there so that the physical parting of death is not seen as a final parting.[115] In the interval between parting and reconciliation such children are often described as being 'with Jesus' (sometimes with the child described as being an 'angel') or with other deceased family members, most commonly grandparents. Thus parents may feel reassured that their child is being looked after in this period.[116] Heaven is often conceived as a garden (sometimes with the children being described as 'flowers') or a playground in which the dead child is described as participating in those activities which have not been realised on earth (babies are described as 'running around', 'being mischievous' etc.)[117]

Belief in an afterlife, in which the deceased and the bereaved will one day be re-united, may also be used to mitigate some of the pain of present reality. Such beliefs may be articulated, not only by those who have some pre-existing religious adherence as an expression of faith, but by others who would neither describe themselves as

religious nor claim any particular belief in God. Whilst the question about what the child will look like at some point in the future when reconciliation takes place is not one which is often raised directly, there is a great deal of evidence that bereaved parents think of their children in an age-related way. I have known parents whose baby died five years previously to go and stand at the school gates in early September watching the new starters entering school because that would be when their child would also have started school. Though distressing, some have found that this has brought a peculiar kind of comfort.

A theological perspective

Glyn York observes the effects on some families faced with emotionally demanding decisions about the withholding or withdrawing of treatment from their dying baby. He noticed the tendency among some families to retreat into 'a harmful form of religious denial; the eternal belief in a miracle.'[118] Whilst York is writing from within the context of the American 'Bible Belt', some of the observations which he makes apply to the British situation, especially to those whose faith is of a more evangelical, especially fundamentalist, nature. For these parents, '(r)eligion becomes their motivation for denial rather than a source of comfort in accepting reality.'[119] This is very different from simply remaining hopeful even in the face of overwhelming odds since, from a Christian perspective, it is essential that hope is always based on truth.[120] It is important, then, that care-giving, whilst always offering and encouraging appropriate hope always remains truthful and does not re-inforce unrealistic expectations. To be truthful in such situations demands not only honesty but also a genuine openness and sensitivity to others. Telling the truth (veracity) in this way is not simply a stark and brutal imparting of facts but consists in a steadfastness in gently ensuring that those who are vulnerable and emotionally exposed always remain in touch with reality.[121] In this way, truthfulness can properly be described as an expression of love (agape). Such love is further demonstrated by loyalty, the

willingness of the caregiver to remain with the family in their time of need or crisis in an accepting way (i.e. without judgement).

York notes several common characteristics among parents who use religious-based denial as a coping mechanism in the face of bad news. These include: (1) the placing of all anxiety-provoking events in God's hands as a means of reducing the pain of the situation; (2) family support systems reinforce the denial due to their similar religious beliefs. Indeed, families may actively seek out others who share and therefore reinforce their views; (3) unrealistic expectations of modern medicine. This is often manifested in families who will only accept positive and not negative information or will seek to interpret negative information in a positive way; (4) the development of distrust towards staff whom they may consider as giving up hope too easily; (5) emotional and/or physical withdrawal from the neonatal unit which may be an issue about keeping 'control'; and (6) focus on the miracle rather than on the infant so that energy is expended on praying for the miracle rather than engaging with the sick or dying child.[122] The pervasiveness of such views can be seen in the theological college student, visiting a neonatal intensive care unit on which a number of babies were dying, as part of a placement in the 1990s, who said, 'If only everyone here had more faith then all these babies would live!'[123] Such religious-based denial can create difficulties not only for parents but also for staff who may find it difficult to communicate with them.[124] In such circumstances it is particularly important to take seriously the family as a whole as the context of care and not simply to 'split off' the dying baby as patient and to ignore or sideline the family, focussing only on the presenting medical problems. As Anthony Wright and his colleagues conclude, optimum care is given when 'the needs of the bereaved are integrated into the care of the dying.'[125]

In all of this the chaplain or other pastoral care giver may have an important role, both within the healthcare team and between the healthcare team and the family. What should be true in all circumstances is particularly important here - that in

communicating with the families of the dying we should always avoid euphemisms which protect us from using the words 'dead' or 'dying'.[126] When the baby dies, the effect of the death may be particularly acute on such death-denying families. For some, denial may persist and a miracle may still be looked for even after death (or it may be that the reality of the death itself is denied).[127] For others the sense of being 'let down' by God (where the blame lies with God) or of 'not having enough faith' (where the blame lies with self) may occasion great anger or feelings of guilt. Others may lapse into depression, despair and even contemplate suicide. Occasionally, such parents will adopt the position which is the second of Cook and Wimberley's categories - where the death of the child is seen as serving some higher purpose - and such parents may regard the death of their child as God giving them a way to witness to their faith to others. Although rare, this response is not unknown.

Reflection on suffering - 5 exemplars

In his article on suffering, van Hooft argues that suffering is one of 'the most profound and disturbing of human experiences.'[128] He writes,

> The very word *suffering* has a resonance that thus relates to our sense of life's meaning... It does not refer just to maladies, pains and difficulties with which we can and should cope. It involves crises and threats that constitute a degredation or alienation of our being. It is the spiritual dimension of our being... not only the bodily aspects of our selves, that is implicated in suffering.[129]

Thus, suffering does not simply mean experiencing pain, physical, mental or emotional, but the contextualisation of pain. The fact that we possess rational minds and have the ability to communicate with each other, means that we seek both explanations for our pain and ways of coping with it.[130]

The following section offers a brief perspective on the particular issues of suffering (in the sense suggested above) associated with the grief which follows the birth of children born with a condition which is life-threatening or terminal. All of the

authors considered below are theologians, three of whom have experienced the birth of a disabled or terminally ill child. The other two write from the context of personal involvement with a disabled or terminally ill child, who, although not their own, has profoundly affected their thinking and theological reflection. Their experience of grief and the questions which they raise, are not unique, but are echoed by many parents in a similar situation, although such parents do not, perhaps, articulate the issues with the same theological sophistication and acuity. Even for those whose children survive, though with varying degrees of disability, the grief over the loss of the anticipated (perfect) child mirrors that of those bereaved through a physical death and so these reflections are included here, since they directly address many of the emotions, feelings and questions which follow the death of a child, especially in early life.

Austin Farrer

At the end of *Love Almighty and Ills Unlimited*, Austin Farrer included a brief appendix entitled 'Imperfect Lives'.[131] Although he argues that 'the death of speechless infants, before they reach the stature of humanity' and 'the survival of imbeciles, who are incapable of attaining it' is 'a problem for medicine, not for theology', in two short pages, Farrer raises a number of complex issues for medical specialists and theologians alike.[132] For Farrer, the real issue is not that children are born damaged or disabled, that he accepts simply as a brute fact, but that, 'we do not know how we should relate to the mercy of God beings who never enjoy a glimmer of reason.' In a nutshell, Farrer asks, 'Are they capable of eternal salvation or not?'[133]

In one way, his answer is deeply unsatisfying, though nonetheless empirically true: '...there is no certain light on this painful matter; nor is there any honesty in dogmatising where we have nothing to go upon.'[134] While Farrer concedes that we treat such beings as human - 'We do not kill our imbeciles; we baptise dying infants, and give them Christian burial...' - on the one hand, he argues we do this out of a kind of 'natural piety' and a respect for the divine image in man; on the other hand, he

argues that we do so because we think in terms of a rational person being 'walled up' in a damaged body. This, Farrer considers an unjustifiable sentimental fallacy. Here Farrer's rationale reflects the received views of the 1960s in which the book was written and against which we have been arguing. He writes,

> Perhaps the greatest evil of infant mortality is parental disappointment. The grief may be as sharp as any, but scarcely as lasting. We do not sorrow in after years for children who have scarcely lived, as we do for hopeful boys and girls cut off in the midst of their growth. Children who attain no use of speech or reason at all remain to grieve our eyes; but it is not like having a clever child made imbecile by accident or sickness.[135]

Whilst, perhaps unusually, he concedes grief to be present, he considers it to be short-lived. In this, Farrer was simply wrong as later evidence has shown. On the eternal destiny of those babies who die, like that of the intrauterine death or abortus, though he recognises it will be little comfort to those parents whose babies die or survive severely damaged, Farrer refuses to speculate, saying only '...we may be sure that (God) loves and saves whatever is there to be saved or loved; if his love or power does not act, it is because there is nothing for it to act upon.'[136]

Frances Young

Like Austin Farrer, Frances Young writes from her own experience. *Face to Face: A Narrative Essay in the Theology of Suffering*, is therefore a book which is profoundly influenced by experience, as well as being informed by theory.[137]

Young presents her son to the reader as a person *both* objectively (Arthur in himself) *and* relationally (Arthur as part of a network of relationships). She writes with great love but also with remarkable honesty, recognising the frustrations and isolation of grief. She raises quality of life arguments and acknowledges her questioning of the aggressiveness of modern medicine in keeping children like Arthur alive, arguing that 'life at any price' is not an essentially Christian position but often 'the panic reaction of those who cannot face death because they have no hope in God.' which avoids the

moral responsibility of making appropriate judgements.[138] Young believes that in this sense medical advance has been ambiguous and has resulted in a flawed morality. She raises also the questions of theodicy explored above - how does one continue to believe in a good God in the face of the tragedy and evil of the world? In part, Young answers her own question when she says that she is satisfied that the cause of Arthur's condition was an 'accident'. Nonetheless she expresses her sense of feeling 'abandoned' by God, an 'inability to accept the existence and love of God at those deeper levels where it makes a real difference to one's life.'[139] It is, however, paradoxically, in the struggle and search entailed in abandonment that Young comes 'Face to Face' with God. In words resonant of Vincent Donovan's *Christianity Re-discovered*, she declares that in her search for God, '...I did not discover God. God confronted me.'[140] This confrontation has to it a Job-like quality in which honest protest is rewarded with encounter. But what of Arthur? Young eschews as fundamentally un-biblical the soul-body dualism of later Christian thought that allows for the concept of a 'soul' trapped inside a damaged body and appeals rather to a holistic view of the person as a psychosomatic whole. For her, '(t)here is no ideal Arthur trapped in this damaged physical casing.'[141] Arthur is Arthur precisely because he is how he is. Thus it can only be this whole Arthur who will both perish at death and who will be subject to whatever God wills in terms of post-mortem existence since 'salvation cannot be discontinuous with creation.'[142] Whilst she does not speculate on what Arthur's (or her own) ultimate destiny will be, she does believe that, despite a radically new order of existence, there will not be a dis-continuity between 'now' and 'then'. Hope is thus, for Young, an eschatological concept, something fundamentally Kingdom-orientated, which nevertheless contains within itself the pain of new birth. Thus she can later say, 'My afflicted son belongs to Christ, not because he can profess his faith in him, but because Christ has accepted him.'[143] Ultimately, no philosophical answer to the problem of suffering and evil proves satisfactory for Young and she adopts rather a doctrine of the Cross as the narrative of God's real presence in the taking of the evil and suffering of the world upon himself in the humanity of Jesus. It is important for

her, however, that Christian faith does not become so staurocentric that it occludes or misses what Christianity has to say about resurrection, however conceived, and therefore about hope for the future. As the Latin of the Roman Mass says, in death, *'vita mutatur, non tollitur'* - 'life is transformed, not taken away.'

David Pailin

A similar book, though not written from parental experience, is David Pailin's, *A Gentle Touch.*[144] The book centres around Alex, a premature baby with Down's Syndrome and multiple abnormalities. Within the first few pages, Pailin establishes clearly that he regarded Alex from the beginning as a person, an 'other', whose vulnerability called others into relationship and whose 'otherness' was the starting point of respect for his being. As Pailin says, 'Alex's worth is not a matter of having satisfied some external or internal goals. It is in his having been himself.'[145] Like Farrer and Young, Pailin questions the saving relationship between God and people who are considered severely 'disabled'. He asks, 'What in the divine memory of their lives establishes their worth?' and he concludes that 'we are of worth not because of what we contribute to God' (or we might add, to the world) 'but because of the value which God bestows on us' and therefore '(a)n understanding of faith in God which does not makes sense of the lives of all people... shows itself to be mistaken.'[146] Thus Pailin argues that belief in God as loving and the duty to love one's neighbour, whatever their particular needs, are inseparable at both the individual and corporate (community) level. Again, like Farrer and Young, Pailin then moves to a discussion of the nature of suffering, from which he draws similar conclusions to Frances Young - disability, however severe, even among those 'designated for death' is not a natural 'evil' and the finitude it places on the individual differs only in degree and not in kind from the finitude shared by all people.[147] Thus a moral problem, how we relate to the vulnerable, becomes a theological problem when we lose sight of the fact that we are 'not God'.[148] Pailin argues that the doctrine of the *imago dei* offers in fact 'no

material guidance towards determining what is and is not authentically human being.'[149] Later in the book, however, he offers a more profitable definition. He writes,

> To be in the image of God... can be held not to refer to some observable quality by which human beings may be discriminated from other beings, but to announce a status which belongs to persons simply by the accident of their being.[150]

Alex's value, therefore, consists in his being loved, embraced, cherished and valued by God simply for who he is at each given moment. Thus, those with severe and limiting disability become considered as a 'problem' only when others consider their own state as normative in judging human 'worth'. Reference to 'quality of life' does not, and cannot, of itself provide an adequate way of establishing the 'worth of a human life'. To do so is to propose an anthropocentric and not a theocentric notion of worth. Thus the question of the fundamental 'worth' or 'salvation' (as posed by Farrer) or 'finitude' of the severely damaged neonate is no more or less than the question of the worth or salvation or finitude of all people.[151] To have an authentic religious faith, then, is to grasp the ultimate nature of reality and to realise that neither life, nor death, *per se* are ultimate ends.[152]

Stanley Hauerwas

In the preface to *Naming the Silences,*[153] Hauerwas declares himself 'profoundly suspicious' of attempts to explain why God allows us to experience pain and suffering of the kind set out in Harold Kushner's *When Bad Things Happen to Good People*, a popular book which Hauerwas critiques.[154] Indeed, he says, 'I hope to show why this way of putting the question of suffering is a theological mistake.'[155] To do so, Hauerwas draws on Peter De Vries' novel, *The Blood of the Lamb.*[156] In it, De Vries argues for a God who suffers with us and, in so doing, redeems our suffering. This is a form of theodicy which Hauerwas believes gets it right. The issues

raised by the death of the novel's central character are questions which we have seen throughout this chapter. Of these, two are particularly pertinent. Firstly, why does the death of a child have such a particular effect that it challenges both our belief in God and in the world? Secondly, why, in some circumstances, would we rather subject them to prolonged suffering rather than face their deaths? To these, Hauerwas adds a third question, of why we place such faith as we do in modern medicine which, says Hauerwas, 'seems particularly puzzling when we realise that most of us know even less about medicine than we once did about God'.[157]

In an attempt to answer these questions Hauerwas asks whether there are different kinds of suffering that demand different sorts of answers or for us to construct different sorts of theodices. Ultimately, he concludes that, historically,

> Christians have not had a 'solution' to the problem of evil. Rather they have had a community of care that has made it possible for them to absorb the destructive terror of evil that constantly threatens to destroy all human relations.[158]

Furthermore, he admits to having no answer to the question of why children suffer because he challenges the presuppositions on which such a question is based. In short, while Hauerwas does not deny the reality of suffering or the pain it causes, he argues that there is no such 'thing' as 'suffering' which, as such, challenges belief in God. This he would see as his point of divergence with Kushner. His belief that human suffering derives, in large part, from 'our necessary experience of limits' means that death is 'part of God's good creation'.[159] Thus he concludes that '(t)here is no problem of suffering in general; rather the question of suffering can be raised only in the context of a God who creates to redeem'. Thus, 'What we must finally do in the face of the suffering... is to show a patience that does not try to discern any 'purpose' behind the suffering, but without in any way caring less for them.'[160] In the end, all that Hauerwas, like Farrer, Young and Pailin, can say is that there is no point in suffering but that those who suffer have a place in our lives and, ultimately in the life of God and we, like God, suffer because we love.[161] Thus, the presence of the sufferer encourages empathy and

builds the kind of relationships in which the narrative of the sufferer is heard and accepted.

Harold Kushner

The final book considered here is particularly popular with non-specialist readers. *When Bad Things Happen to Good People*, is Harold Kushner's account of the death of his son. Although written after Aaron's death, the book begins, like Frances Young's *Face to Face*, with that sense of disbelief which we have seen is so often the first reaction to the diagnosis of a fatal condition - 'This can't be happening. It is not how the world is supposed to work.'[162] Rabbi Kushner and his wife experience the bewilderment, questioning and anger so characteristic of those who have a child who is dying and come to question the goodness, even the existence, of God. The book explores, partly by an exegesis of the book of Job, partly through personal reflection, the theodices now familiar to us, the guilt-inducing belief that we get what we deserve, that such things come as the punishment for our sins; that God has reasons, part of a divine schema, for visiting suffering on people, reasons that the sufferer is in no position to judge; that suffering is educational or ennobling or is a test of spiritual strength. What all of these theories have in common is the assumption of God's ultimate responsibility for human suffering. Kushner rejects all of these and offers an alternative proposition, that God is not the cause of suffering but that 'He stands ready to help... us cope with our tragedies if only we could get beyond our feelings of guilt and anger that separate us from Him.'[163] Kushner argues that once we accept that there are some things God does not control a different relationship with God becomes possible.

> We can maintain our own self-respect and sense of goodness without having to feel that God has judged us and condemned us. We can be angry at what has happened to us, without feeling that we are angry at God. More than that, we can recognise our anger at life's unfairness, our instinctive compassion at seeing people suffer, as coming from God who teaches us to be angry at injustice and to feel compassion for

> the afflicted... Instead of feeling that we are opposed to God, we can feel that our indignation is God's anger at unfairness working through us, that when we cry out, we are still on God's side, and He is on ours.[164]

This Jewish response to suffering is very close to the Christian *theologica crucis* of Jürgen Moltmann and Dorothee Soelle, which allows the cross to be the cross in all its horror and speaks of a suffering God, who, through his suffering, stands alongside suffering creation.[165] Thus, the genetic mutations which mean that a baby is born severely disabled, or the accidents which happen at birth that leave the newborn badly damaged or dying, are random chance that come about simply because the world and life is what it is. Kushner, too, explores the often heroic (extraordinary) efforts of modern medicine and, like the other writers whom we have considered, concludes that, 'All we can say... is that vulnerability to death is one of the given conditions of life.'[166] Death is not the final evil it is so often portrayed as being and which, all too often, drives people to try to 'cheat' death or 'defeat' it.

It is not possible here to offer a full-blown critique of the books mentioned; they are rather used to flag up some of the questions, and some of the attempts at providing an answer, that arise when we are faced by the suffering or death of young children. I have suggested that, for those who hold theistic belief, the explanations (theodices) offered lie on a continuum from *'It's all God's fault'*, through, *'God is involved somehow but it's all a mystery'*, to, *'God can't do anything about suffering, it's the way the world is'*.

Meeting the needs of families after a death

In the post-bereavement period, the emotional and physical sequelae of grieving are well documented. As Giles had postulated in the early 1970s, whatever the received wisdom of the day which pointed in the opposite direction, women grieved for their dead babies as loved and significant others. The death of a baby was not something to be easily 'got over'.[167] In the early days after a perinatal death, as we

have noted with other early-life deaths, what bereaved parents want most is clear, simple, factual information, sensitively imparted and, above all else, a recognition of their grief and loss. The need to talk about what has happened can be great and someone who will simply listen to their tale can be their greatest support at this time, not least in reducing a sense of isolation and enabling the exploration and articulation of meaning. Genuine listening means being attentive to concerns, questions and feelings and thus enabling the parents in their talking.[168] Thus, flexibility of approach is essential in the care of the recently bereaved. It is often the case that, of all the members of the healthcare team, the chaplain or other pastoral care giver has the greatest amount of time and flexibility simply to 'be with' parents at this time and the value of this should not be underestimated especially as the intense emotions of grief ebb and flow (episodic grief). Many families will continue to sit with their dead baby, unwilling, or perhaps as yet unable, to accept that death has occurred. Such phrases as, 'She just looks as though she is asleep...' or "I keep thinking that he will just wake up...' are common. In this, disorganised, phase of grieving, death seems 'just like a bad dream'. Yearning for his/her return may be unbearably strong. As with other early-life deaths, the holding and cuddling that has happened before death often continues after death has occurred and can be therapeutic for parents. Parents should be encouraged to wash, dress and spend meaningful time with their child while they can, this is all part of saying 'goodbye' and of establishing memories of a baby who has died.[169] It is now common practice to photograph, and sometimes to hand or footprint, all babies who die on neonatal units. Some families will have taken their own photographs, especially if the baby has been in intensive care for some time but it is important that no families are left without a visible and physical record of their child or memories on which to focus both their grief and their future remembering. For families who do not wish to have the photograph in the early rawness of grief, the photograph is placed in their file to be made available later, if required. There is no reason why siblings should not be encouraged to see and touch the dead baby along with the parents.[170] This can help to reinforce the reality of the death and they should be allowed to talk about what has

happened and to ask questions about it. For too many children, dead siblings simply disappear! Frances Dominica says, 'I believe that the reality of seeing a dead brother or sister is easier to cope with and kinder to the child's sensitivities than the ordeal of experience by fantasy.'[171] The importance of seeing and touching the dead baby has been emphasised already, but it remains probably the most important way of validating a death and dispelling fantasies. As Beverley Raphael concludes, 'Painful as the reality of the dead body may be, it is important that it be incorporated into the death experience of the bereaved.'[172] Lack of focus is one of the particular features of early-life deaths - parents hardly have time to adjust to a new life, independent of the womb, before they have to deal with its extinction. As Jane Nichols says,

> caregivers are helpful and assist grief work when they seek to provide parents with opportunities to focus on reality. The reality is: they had a baby... the baby lived a while... the baby died.[173]

For parents who have watched their babies deteriorate over some time in the intensive care unit and who are emotionally and physically exhausted, there may be a sense of relief, or even euphoria, that it is 'all over' when they die - they may even have prayed that the death would come quickly before it happened. This is often accompanied by a sense of guilt that they have thought like this and reassurance that this is a normal feeling at a time of great physical and emotional stress needs to be gently communicated. As in other situations, bereaved parents need to be reassured that their grief, in all its intensity, is a natural response to loss and is not an abnormal condition. Where grief is denied or suppressed and mourning avoided, the risk of a pathological outcome is greatly increased. Low self-esteem and the sense of having 'failed' as parents may be predominant emotions at this time, and parents need firm but gentle reassurance that their baby's death is not their 'fault'. Most parents, nonetheless, feel 'diminished' by the death of their child. In the baby's death, something of themselves has also died.

In the case of babies who have lived independently of the womb, for however brief a time, the law requires that *both* the birth *and* the death be registered,

irrespective of the gestational age of the baby. This can be traumatic for parents, especially in the early stages of their grief, but may nonetheless itself be important in confirming the reality of what has happened. It is also important that parents continue to feel in control after their baby has died. Here, as with other deaths, doing things 'for' parents can sometimes be more about meeting the needs of carers, who may feel guilty that a baby in their care has died and who wish to 'protect' the parents, than about meeting the needs of the bereaved. Discussion with parents about their needs and desires can help in this and parents should be encouraged to do what they want, and are able to do and therefore to own both the reality of the death and their own grieving. It is sometimes possible to encourage care and control in ways that may not have been envisaged. I would, for example, offer parents, and particularly fathers who may be feeling especially powerless, the opportunity to carry their baby from the neo-natal unit down to the Chapel of Rest after he/she had died rather than leaving this to the porters. Many fathers appreciated the opportunity to do this and of having the opportunity to carry and cuddle their child in the process. The same is true of the difficult task of planning the funeral. The funeral may be arranged by the hospital or by the parents. For many couples, this may be their first experience of death and they are often bewildered by the legal procedures and unsure, or ignorant, of what options may be open to them.

Keeping the baby's identity band or other mementos of their life is an important way of preserving the memory of the child who has died as a real and independent 'other'. Even a copy of the post-mortem report can be useful in this way. A Certificate of Baptism or of the Blessing of a baby, or making an entry in the hospital's Book of Remembrance, may also, for many parents, be important reminders not only of their child's existence but also of the love in which they continue to be held.[174] Where such elements are lacking, grief and mourning can be made more difficult and grief may remain unresolved. If there are no pictures or other physical reminders of the baby's individuality and no place to return to to test the reality of what may, in time, come to seem like just a bad dream, parents may find themselves wondering who it is they are

mourning and why they are feeling as they do. This is often reinforced by others who, perhaps never having seen the baby who has died, cannot understand the depth or intensity of the parents' grief and often increase their sense of guilt at feeling as they do. Discounted grief is probably one of the most unique and damaging features of early-life deaths.[175] And yet, such grief can be intense, both emotionally and physically - fatigue is a common affect of grief, mothers in particular speak, quite literally, about 'aching arms' and bereaved parents may have vivid and persistent dreams or may 'hear' their baby cry and experience periods of restlessness (searching).[176] Pre-occupation with the deceased is well attested as an affect of grief but nonetheless the experience is often distressing.[177]

If family and friends fail to understand the grief of parents whose babies die in the pre- or perinatal period they are unlikely to understand why such grief may be protracted. They may expect the parents to return to 'normal' in a couple of months and may, indeed, become impatient with them when they do not. But the resolution of grief like this can take years, not months, and parents will often report that the second year is worse than the first. Each 'first' landmark re-opens wounds - the first birthday, Christmas, mother's (or father's!) day, anniversary of the death.[178] Sensitive bereavement support can help parents prepare for their return to the community but cannot, and should not, take away their grief or mitigate the painful journey which lies ahead. The most supportive people, professional or lay, are those who recognise that a baby's death is a significant, and tragic, loss and validate the parents' need to talk about their experience. Nonetheless, the pain of loss and grief both for the loved 'other' and for the loss of one's hopes, dreams and expectations can feel overwhelming at times and the suffering can be acute.

Conclusion

Ultimately, the lack of a worked-out theology of living and dying throws people back onto a fundamentally flawed 'life at all costs' view of medicine and of

human being. This is why, despite, perhaps because of, the achievements of modern medicine, so many people are deeply frustrated by the way things turn out. But the answer is not simply to do nothing. At the end of his article on the treatment of dying infants, David Smith concludes,

> In sum, loyalty is what the people of God owe defective babies. We owe them respect and hope, care and comfort for their body, fair play and due process. Sometimes this will mean we have to kiss them goodbye - but never without having made them welcome, never without a hug, never without regret.[179]

It is sometimes mistakenly believed that the 'resolution' of grief means that parents have 'got over' the death of their child and that moving on entails forgetting. On the contrary, parents whose babies die will tell you that the grief never ends, that there will always be sadness and regret that things turned out as they did, that forgetting would be a denial of the reality of their child and of the love in which he or she was held. But in the end most relationships *do* change and in time, and with the effort of grieving (grief work), for most people at least, life does go on.

At the end of her article, *Reflections of death in childhood*, Frances Dominica says this:

> Saying to parents whose child has died, "You'll get over it," is like saying, "One day it will seem as if he never existed." Nothing could be more hurtful. They don't want him written out of existence. But given time, given permission to be who they are, given reassurance to behave instinctively, given love and friendship, I believe that they will have the best chance to adjust to what has happened and grow towards healing and wholeness. Despite society's fear of death and ineptitude in the face of death, I believe that every individual has the potential within to meet death with a severe beauty which in no way denies grief. Being alongside such families you absorb some of their grief. But you also share some of the good things - learning to think of time in terms of depth rather than length; enjoying the swift growth of real friendship; by-passing the usual obstacles of class, creed, colour, age, education; having "all one's sensitivities heightened" as one father put it. And you begin to recognise and reverence the nobility and beauty in every man, woman, and child because tragedy lifts the mask of pretence and truth is revealed.[180]

How right she is.

NOTES:

1 E. Kübler-Ross, *A Letter to a Child with Cancer* (Escondido: Shanti Nilaya, 1979), p.1.

2 'The death of a child is now an uncommon event but the newborn period remains the most dangerous and death at that time tend to occur in a hospital ICU.' M.P.White, B.Reynolds and T.Evans, 'Handling of Death in SCUs and Parental Grief,' *British Medical Journal,* 289 (1984), p.167.

3 F. Dominica, 'The Role of the Hospice for the Dying Child,' *British Journal of Hospital Medicine*, October (1987), 338.

4 S. Borg, and J. Lasker, *When Pregnancy Fails: Coping With Miscarriage, Stillbirth and Infant Death* (London: Routledge and Kegan Paul, 1982), p.17.

5 M. Tooley, *Abortion and Infanticide* (Oxford: Clarendon Press, 1983); P. Singer, *Practical Ethics* (Cambridge: Cambridge University Press, 1993), chapter 7; J. Harris, *The Value of Life: An Introduction to Medical Ethics* (London: Routledge, 1985), chapter 2. Thomas Nagal holds the same view as Singer and Harris in seeing no logical significance in birth as the start of an individual *person*. T. Nagal, *Mortal Questions.* (Cambridge: Cambridge University Press, 1970). Rom Harre would go so far as to deny that personhood has any biological/physiological roots (such as sentience or neo-cortical function) at all. He says, 'For me a person is not a natural object but a cultural artefact. A person is a being who has learned a theory, in terms of which his or her experience is ordered.' R. Harre, *Personal Being: A Theory for Individual Psychology* (Oxford: Basil Blackwell, 1983), p.20. The current legal position faces us with the paradox that a 24 week premature neonate with severe, life threatening or fatal disabilities or disorders is afforded a greater legal and moral status and a higher degree of protection than a 30 week, healthy baby who is still *in utero*. An extreme example of this would be a failed abortion, especially a late abortion, where the abortus is damaged but born alive and is therefore placed on a resuscitator.

6 E. Moltmann-Wendell, *I Am My Body: New Ways of Embodiment* (London: SCM, 1994), p.87. This is, nonetheless, a somewhat clumsy statement. Clearly, Moltmann-Wendell isn't using 'birth' as a transitional moment on the trajectory to personhood in the way that Singer or Harris does. What Moltmann-Wendell is arguing is that birth, and life before it, has *moral* value, not just value. The un-born and newly-born child are objects of moral *concern*, even if they are not yet considered to be moral *agents*. This is so because such children are regarded as having *intrinsic* value, in other words, a value that is linked to their personal uniqueness (see below). It is my contention, however, that such value is not simply to be seen in terms of *moral* worth but that such life, whether before birth or after, has *theological* value (see chapter 2). This is an important point since it changes the significance afforded to such deaths and therefore re-configures bereavement.

7 J. Wyatt, *Matters of Life and Death: Today's Healthcare Dilemmas in the Light of Christian Faith* (Leicester: IVP, 1998). See Chapter 8, 'The Dying Baby: Dilemmas of Neonatal Care', pp.159-168.

8 P. Singer, *Practical Ethics* (Cambridge: Cambridge University Press, 1993), chapter 7. See also, P. Singer and H. Kuhse, *Should the Baby Live?* Singer and Kuhse argue that in accepting (i.e., legalising) abortion, we have already surrendered the

belief in 'sanctity of life'. See also J. Glover, *Causing Death and Saving Lives.* (Harmondsworth: Penguin Books, 1977). Glover also regards infanticide (whether by commission or omission) as an acceptable, even desirable, course of action in the case of the severely damaged newborn survivor, whether malformed or pre-term. Common to all these, and similar, arguments are the distinctions drawn between 'being alive' and 'having a life', 'killing' and 'letting die' 'persons' and 'non-persons' These continuing debates are both extensive and well documented in the philosophical and medical ethics literature.

9 Wyatt, *Matters of Life and Death,* p.159.

10 S. Bourne and E. Lewis, 'Perinatal Bereavement: A Milestone and Some New Dangers,' *British Medical Journal,* 302 (1991), 1167. Similarly, Daniel Callahan writes, 'For all its great triumphs, contemporary medicine does not know what to make of death. The end of life represents a troubling, and particularly recent, vacuum in its thinking.' D. Callahan, *The Troubled Dream of Life: In Search of a Peaceful Death* (New York: Simon and Schuster, 1993), p.14. By contrast, Hans Kung regards death from a Christian perspective, 'not (as) a final end but a consummation.' H. Kung and W. Jens, *A Dignified Dying* (London: SCM, 1995), p. 13.

11 C.A. Corr, 'Death in Modern Society,' in D. Doyle, G. Hanks and N. MacDonald, eds. *Oxford Textbook of Modern Medicine* (Oxford: Oxford University Press, 1993), p.29. Since attitudes towards death are so inextricably bound up with culture it is essential that bereavement care should always be sensitive and culturally appropriate. However, as Field *et.al.* note, 'While ethnicity, like gender, is an important source of identity which must be recognised and respected by those working with dying people there is little consensus about how to carry this insight into practice.' D.Field, J. Hockey and N. Small, 'Making Sense of the Difference: Death, Gender and Ethnicity in Modern Britain,' in D. Field, J. Hockey and N. Small eds. *Death, Gender and Ethnicity* (London: Routledge, 1997), p.19. The hospital chaplain can act both as a resource in enabling hospital personnel to act in culturally sensitive and appropriate ways and as an advocate for those whose cultural/faith perspectives may be overlooked.

12 R. Orr, D. Biebel and D.Schiedermayer, *Life and Death Decisions* (Grand Rapids: Baker Books, 1990), p.65.

13 The survival and care of the extremely premature baby has been one of the most significant developments since the early stages of neonatal intensive care in the 1960s. The effects of the rapid advancement of medical technology and the acute questions which it raises are seen nowhere more clearly than here. Over 2000 infants in this category are born in England and Wales each year.

14 J. Wyatt, 'Salvaging the Very Preterm Infant: Miracle or Madness?' in S. Bewley and R.H. Ward eds. *Ethics in Obstetrics and Gynaecology* (London: RCOG Press, 1994), p.268. The Hippocratic tradition of medicine clearly affirms that the practice of medicine must be 'for the benefit of the sick'. Sherwin Nuland says, 'The patient is every day less a human being and more a complicated challenge in intensive care, testing the genius of some of the most brilliantly aggressive of the hospital's clinical warriors.' *How We Die: Reflections on Life's Final Chapter* (New York: Knopf, 1994), p.149.. The American ethicist, Daniel Callahan describes this attitude of pushing the boundaries as 'technological brinkmanship'. *The Troubled Dream of Life,* p. 40.

15 S. Hauerwas, 'The Demands and Limits of Care,' *American Journal of Medical Science*, 269, 2 (1975), 228. Similarly, Daniel Callahan writes,

> A medicine that embodied an acceptance of death within it would represent a great change in the common conception of medicine, and might then set the stage for seeing the care of the dying not as an afterthought when all else has failed but as itself one of the ends of medicine.

(*The Troubled Dream of Life*, p. 229.). Alida Gersie suggests that protective urges of parents suffer a double blow when a child dies - firstly, the inability to protect the life of the child and secondly, the inability to accompany the child on the journey into death, which may be seen as a form of abandonment. (*Storymaking in Bereavement* (London: Jessica Kingsley, 1991), p.144.). This may well account for the feelings experienced by many parents that, after the death of their child, they, too, want to die. It may not simply be that life without the loved child appears to have no meaning any more, but a desire to be alongside the child, wherever the dead may be, in order to continue to fulfil the parental role of protecting and parenting.

16 D.C. Thomasa, 'The Basis of Medicine and Religion: Respect for Persons,' *Linacre Quarterly*, 47 (1984), 142.

17 P. Ramsey, *The Patient as Person* (New Haven: Yale University Press, 1970), pp.17-32. Ramsey uses the concept of 'person' as a Kantian counter-balance to medicine's tendency to maximise benefits, whether knowledge or life. W. May, *The Physician's Covenant* (Louisville: Westminster/John Knox Press, 1983), pp.116-30. See also, W. May, *Testing the Covenant: Active Euthanasia and Health Care Reform* (Grand Rapids: Eerdmans, 1996). May argues that, '(a) covenental ethic, above all else, defines the moral life responsively.' (p.52). For May, being human is fundamentally a matter of ontology (what we are) rather than function (what we do). The term 'human', itself, is open to ambiguity, sometimes being used to mean biological humanness and sometimes moral or personal life. Campbell, however, is right to remind us in this context that, '(d)eath is not always a harm, just as life is not always a good.' A.G.M. Campbell, 'Some Ethical Issues in Neonatal Care,' in G. R. Dunstan and E.A. Shinebourne eds. *Doctors' Decisions: Ethical Conflicts in Medical Practice* (Oxford: OUP, 1989), p.58.

18 Since love bestows value, Gene Outka similarly argues that 'love is not only the paramount attitude and principle in Judaeo-Christian ethics but it is finally the most adequate basis for any morality.' G. Outka, *Agape: An Ethical Analysis* (New Haven: Yale University Press, 1972), p.136.

19 David Atkinson argues that to be in the 'image of God' is a matter of ontology rather than function. It is, thus, the relationship to himself which God confers on us. (*Pastoral Ethics* (Lynx Press, 1994), p.204.). Even the defective newborn who is not regarded by others as a person, an 'other' (or, in Buber's terms, a 'Thou'), is therefore, nevertheless, so regarded by God. The value of such 'persons' lies, if not in human relationships, in being held in the divine memory and therefore inviolably in relation to the love of God. Neighbour love ('agape') towards those included in God's covenant promises, irrespective of biological development or functional capacity, therefore, places on us the responsibilities of covenant fidelity. Helen Oppenheimer thus describes the soul/human identity as a 'pattern of loveability'. H. Oppenheimer, 'Handling Life: Does God Forbid?' in D.R. Dunstone and E.A. Shinebourne eds.

Doctors' Decisions: Ethical Conflicts in Medical Practice (Oxford: Oxford University Press, 1989), p.207. This is not to say that personhood depends on actually being loved by others since 'an unwanted handicapped baby whose parents reject him, a senile old lady neither dear nor endearing, are well within the bounds of being persons.' (Ibid., p.211.).

20 A. Outler, 'The Beginnings of Personhood: Theological Considerations,' *Perkins Journal,* 27 (1973), 28-34.

21 Ibid., 28-34.

22 Ibid., 28-34. Whilst he argues against the search for a 'magic moment' at which 'the sub-human becomes human', preferring to see the whole human process as a unique 'slice' of being in which personhood is its 'longtitudinal axis', he nonetheless seems to draw a moral line with nidification

23 B. Steinbock, *Life Before Birth: The Moral and Legal Significance of Embryos and Fetuses* (Oxford: Oxford University Press, 1992), p.69. She argues, however, that the damaged newborn child 'is still part of a network of relationships which creates duties of care'. (Ibid., p.69). I am grateful to Neil Marlow, consultant paediatician at Bristol for the observation that a simple inversion allows us to be patient centred rather than problem centred in our language. Thus to talk of a 'baby with anencephaly' is preferable to speaking of an 'anencephalic baby', especially when talking to parents. (Personal conversation with JHP).

24 Such an understanding of potential in relation to personhood has severe limitations. Joseph Fletcher's suggests a 15 point checklist of qualities (later distilled to four - neo-cortical function, self-consciousness, relational ability and happiness) which one might require to be considered human. ('Indicators of Humanhood: a Tentative Profile of Man,' *The Hastings Center Report* 5 November (1972), 1 and 'Four Indicators of Humanhood: The Enquiry Matures,' in S.E. Lammers and A. Verhay eds. *On Moral Medicine* (Grand Rapids: Eerdmans, 1987), pp.275-277. Such an approach fails to take account of how such babies might nonetheless realise their own potential, however limited. This is not to suggest that no line be drawn. Clearly, babies born with conditions which mean they will never attain sentience (such as anencephaly) are problematic. Not only are such babies clearly human beings (i.e. belonging to the genus *homo sapiens*) but, by virtue of being born, they are afforded rights and legal protections which can only adhere to persons. This does not mean, however, in such cases of medical futility, that heroic efforts should be made to save and sustain such lives, irrespective of cost, personal, social or financial. The American Jesuit, Richard McCormick argues from the basis of 'relational potential' that any being incapable of minimal relationships cannot be described as human, i.e., a person.('To Save or Let Die: The Dilemma of Modern Medicine,' *Journal of the American Medical Association* 229 July (1974), 174.). There are few parents, however, who would not instinctively describe as 'relational' time spent with their dying baby, however damaged. Once again, we see here an understanding of value as *intrinsic* rather than *potential*. A.G.M. Campbell argues that resource allocation is as morally defensible as a decision to withhold treatment as refusal to admit when a unit is full or because of a lack of ventilators. (Dunstan and Shinebourne, *Doctors' Decisions*, p.64.). This view was reinforced in the 1990s by Alastair Campbell and his colleagues. See, A. Campbell, M.Charlesworth, G.Gillett and G.Jones, *Medical Ethics* (Oxford: Oxford University Press, 1997), p.106.

25 It is important to distinguish, by careful listening, exactly what is being said when people ask for euthanasia for others. Whilst this is often couched in terms of the sick and dying person being unable to endure their sufferings, what is often being articulated is rather the bystanders inability to bear the suffering of watching helplessly as another human being dies. Modern palliation now allows almost all physical pain to be relieved during the dying process.

26 O. O'Donovan, *The Christian and the Unborn Child* (Bramcote: Grove Books, 1975), p.12.

27 This is not to say of course that the weak or disabled infant had no intrinsic value to his/her parents and could not therefore be the object of love or affection.

28 Cited in J. Wyatt, 'Salvaging the Very Preterm Infant: Miracle or Madness?' in S. Bewley and R.H. Ward eds. *Ethics in Obstetrics and Gynaecology* (London: RCOG Press, 1994), p.271. The use of the word 'even' by Seneca, however, would suggest that he draws at least a rudimentary moral distinction between mad dogs, fierce oxen and disabled children!

29 Genesis 1:26-27, 5:1. Tacitus wrote that the practice of exposing weak or damaged infants was one which was unknown among the Jews since 'they regard it as a crime to kill any recently-born child' (Tacitus, *Histories,* 5,5.).

30 Quality of life in this context should not be taken to indicate levels of social utility but should certainly include reference to what parents consider to be in their child's best interests. Although some ethicists like Norman Giesler see quality of life ethics as 'a thinly veiled form of utilitariansim' (*Christian Ethics: Options and Issues* (Grand Rapids: Eerdmans, 1989), p.176), this is to miss the point. Quality of life, properly understood, is part of its sanctity and to take it into consideration is to show respect, and not disregard, for life. William May argues that since, in the theistic tradition, life is not an absolute good or death an absolute evil, '(m)aximal treatment is not always optimal care.' (*Testing the Medical Covenant: Active Euthanasia and Health Care Reform* (Grand Rapids: Eerdmans, 1996), p.14.), Even traditional Catholic moral theology has not argued that the concept of the inviolability of human life is something which is unlimited.

31 I do not take the principle of best interests to imply that it is always and under all circumstances better to be alive than to be dead. Although 'quality of life' may be considered a subjective criterion, there are cases which are clearly 'hopeless' (medical futility). Even in such cases, this is not to suggest a withholding or withdrawal of appropriate *care* or to suggest that appropriate analgesia should not be used to control pain in the dying infant. The withholding or withdrawal of hydration or feeding is a much more complex matter on which the BMA issued guidelines in 1999. Much more difficult is the withholding or withdrawal of treatment in cases where there is irreversible damage but where survival remains a possibility. The discussion of this lies outside the bounds of this thesis. The arguments are well set out in S.L. Cohen, 'Witholding and Withdrawing Treatment in the Dying Patient,' in S. Bewley and R.H. Ward eds. *Ethics in Obstetrics and Gynaecology* (London: RCOG, 1994), pp.298-304.

32 For examples of medical failure to let go in this way see the case of Samuel Linares (P. Singer, *Practical Ethics*, pp. 180-181) and of Andrew Stinson (T.L. Beauchamp and L. Walters, *Contemporary Issues in Biomedical Ethics.* (USA:

Wordsworth Publishing Co., 1982), pp.276-283). Both these controversial cases concern the selective treatment of infants. Letting go is often difficult not only because of the pain of separation which it often entails but because it requires both the recognition of painful realities and of the emotions which accompany them, and of the fact that we are not ultimately in control of life. Nevertheless, as one mother said, 'Letting go is not betrayal'. In theological terms, what is being respected is not just 'locked up' in individual human beings also includes relationality with God and others. (See footnote 20). Such an understanding of respectful care allows us to 'let go' since we are liberated to such deaths, as well as such lives, as being 'in God'. This frees us from the mistake of confusing attentiveness to a particular life with simply idolizing biological life (vitalism). As Vigen Guroian says, 'Christian ethics favours life over death always, even if that life is near its end. But Christian faith does not attribute ultimate value to human life.' (*Life's Living Towards Dying* (Grand Rapids: Eerdmans, 1996), p.xxv). He adds, 'The Christian ethic I embrace allows for careful moral calibration of the viability of a human life made in light of the best judgement of the physician.' (Ibid., p. xxvi). Similarly, Hans Küng has argued that, 'the fight for health is meaningful as long as healing is possible, but... a fight against death at any price is nonsensical: it is a help which becomes a torment.' (*A Dignified Dying*, p.16.). Thus, a theological perspective 'opens up' some views that are conventional in medicine but affords them a richer perspective.

33 Alexander Campbell says,

> In no way should care in (the) widest sense of comfort, concern and compassion be withheld or withdrawn from newborn infants. What is sometimes withheld or withdrawn are certain intensive treatments or procedures that while valuable, indeed life-saving for some infants, may be painful, cruel, meddlesome and futile for others.'

('Withholding Neonatal Care 1. A Paediatrician's View,' in D.R. Bromham, M.E. Dalton and J.C. Jackson eds. *Philosophical Ethics in Reproductive Medicine* (Manchester: Manchester University Press, 1990), p.107.). Care, therefore, goes beyond the simple provision of physical needs and extends, as Campbell suggests, to concern and compassion. This can be summed up as *respect* for life. It is this fundamental attitude which lies at the heart of, though is not limited to, a genuinely *Christian*, and therefore *agapeistic*, approach to care. Perhaps this is best summed up in the Rule of St. Benedict, 'Before all things, and above all things care must be taken of the sick, so that they may be served in very deed as Christ himself,' (Benedict, *Rule*, trans. J. McCann (London, 1976), chapter 36.).

34 P. Ramsey, 'Justice and Equal Treatment,' in S.E. Lammers and A. Verhay eds. *On Moral Medicine* (Grand Rapids: Eerdmans, 1987), p. 510. Whilst Ramsey always argues for a 'bias towards life', he, too, concludes that when treatment is no longer medically beneficial it becomes superfluous and so may cease. See P.Ramsey, *Ethics at the Edge of Life: Medical and Legal Intersections* (New Haven: Yale University Press, 1978), pp.146-148. The *imago dei* posits a flawed anthropology when it is taken as considering certain human lives as normative and sets up a false bench mark of normality against which other human lives are judged. A genuine theological anthropology regards all human life as bearing the *imago dei* in ways which are

always, to some extent, 'flawed'. Thus to be human is always to be in the process of becoming.

35 Kung and Jens, *A Dignified Dying*, p. 17. Kung rightly argues that human care and concern are also needed for family and friends in such circumstances.

36 S. Hauerwas, 'Must a Patient be a Person to be a Patient? Or, My Uncle Charlie is not much of a Person but he is still my Uncle Charlie,' *Conneticut Medicine*, 39 (Dec.1975), 280. Similarly, Vigen Guroian argues that, 'the Christian vision of death encompasses scientific definitions of death as the *terminus* of biological life, but it also embraces spiritual and eschatological dimensions of human personhood.' (*Life's Living toward Dying*, p.48.).

37 D.H. Smith, 'Our Religious Traditions and the Treatment of Infants,' in S.E. Lammers and A. Verhay eds. *On Moral Medicine* (Grand Rapids: Eerdmans, 1987), p. 514. Smith reminds us that loyal care of persons involves care for their bodies:

> Children...are not just personalities, nor bundles of potentiality; they are living, struggling bodies. It is through the body that we enter into relationships with others... There are no solitary beings. Every creature is in some way bound up with all other creatures and is dependent upon them. (Ibid., p.7).

Larry Kent Graham similarly sees the body as 'the primary basis... for generating our sense of selfhood.' (*Care of Persons, Care of Worlds: A Psychosystems Approach to Pastoral Care and Counselling* (Nashville: Abingdon Press, 1992), p.73.). See also K.T. Kelly, *New Directions in Moral Theology: The Challenge of Being Human* (London: Geoffrey Chapman, 1992) and A. McFadyen, *The Call to Personhood: A Christian Theory of the Individual in Social Relationships* (Cambridge: Cambridge University Press, 1990). Both Kelly and McFadyen see embodiment as a crucial dimension of personal being and relationality as a pre-requisite for personhood. William May argues that the concept of medical 'futility', which emerged in the mid 1990s, is a way of 'placing a limit on the physican's... medical covenant with a gravely ill patient' and therefore requires both *quantitative* and *qualitative* standards. (*Testing the Medical Covenant*, p.85.).

38 *Agape: An Ethical Analysis* (New Haven: Yale University Press, 1972), p.13. The phrase 'moral landscape' is, as Outka recognises, a phrase borrowed from Austin Farrer. See A.M. Farrer, 'An Examination of Theological Belief,' in *Faith and Logic* ed. B. Mitchell (London: George Allen and Unwin,1958), p.16. Alastair McFadyen similarly argues that 'regardless of age, sex, race or mental capacity there is no-one who does not call others to responsibility before her or him...'. (*The Call to Personhood*, p.180.).

39 Extremely premature babies lack the sucking reflex and often need to be fed via a nasogastric tube

40 See R.S. Duff and A.G.M. Campbell, 'Moral and Ethical Dilemmas in a Special Care Nursery,' *New England Journal of Medicine*, 25 October (1973), 890, C. Gillespie, 'Letting Die Severely Handicapped Newborns,' *Journal of Medical Ethics*, 9 (1983), 231, D. Morgan, 'Letting Babies Die Legally,' *Institute of Medical Ethics Bulletin*, May (1989), 13-18, P. Singer, H. Kuhse and C. Singer, 'The Treatment of Newborn Infants with Major Handicaps,' *Medical Journal of Australia*, 17 Sept.

(1983), A. Whitelaw, 'Death as an Option in Neonatal Intensive Care,' *Lancet*, 2, 1 (986), 328-331, *et.al.* Duff and Campbell disclosed that 14% of deaths in the nursery were the result of the withholding or withdrawing treatment. The publication of the article in 1973 provoked a storm of public protest that sick babies were being 'allowed to die'. They describe such early death as a 'management option.' (893). Robert Morison, writing in the same period, believed that in the face of technological advancements we were being driven back to the Graeco-Roman ethics of infanticide in the selective non-treatment of the severely damaged newborn survivor when such treatment was considered medically futile. R.S. Morison, 'Death: Process or Event?' *Science*, 173 (1971), 694-698. Campbell, who believes that the uncritical or universal application of intensive care runs the risk of being 'a new and pointless cruel form of child abuse', argues that the evidence of the early to mid 1980s showed that the number of neonatal deaths following decisions to withhold or withdraw life-support had risen to 82%. A. Campbell, 'Withholding Neonatal Care 1. A Paediatrician's View,' in D.R. Bromham, M.E. Dalton and J.C. Jackson eds. *Philosophical Ethics in Reproductive Medicine* (Manchester: Manchester University Press, 1990), p.113.While Duff and Campbell consider the parents as prime decision takers in decisions which affect the life, or death, of their child, the article provoked a sharp response from the ethicist Paul Ramsey who argued that parents facing 'oppressive burdens of care' are not capable of making 'the most morally sensible decisions about the needs and rights of defective newborns.' While he believes such decisions should lie with doctors he concludes, 'If physicians are going to play God... let us hope they play God as God plays God.' P. Ramsey, *Ethics at the Edge of Life* (New Haven: Yale University Press, 1978), pp.201-206. A similar view has been expressed by Baroness Warnock (personal conversation with JHP).

41 Since the intensive care environment is one which is so physically, intellectually and emotionally demanding, levels of stress, and even burnout, are high among those who work in this area. In the 1980s a colleague and I started a monthly 'support group' for medical, nursing, midwifery, and social work staff working in delivery, intensive care, special care, and accident and emergency at Bristol Children's Hospital and Bristol Maternity Hospital. The importance of this group was recognised and validated by the hospital management and time to attend the group was recognised and budgeted for. The group met outside the hospital but in recognised 'work' time. Attendance was entirely voluntary but the group became an important source of on-going support for many members of staff. A recent survey (1999) of staff support for those working in neonatal services in 25 hospitals reveals a wide discrepancy in the type and amount of support currently provided in this area, from regular, structured support available to all staff, through informal peer-support, to none at all, although the value of support was universally recognised. J.H. Pye and E. Crathern, 'Support in Neonatal Services: A Questionnaire,' *Leeds Bereavement Forum: Neonatal Death Special Interest Group*, 1999.

42 *Testing the Medical Covenant: Active Euthanasia and Health Care Reform* (Grand Rapids: Eerdmans, 1996), p. 98. Earlier May notes, 'We need to cultivate the virtues that allow us to live with mortality.' (p.44).

43 'Such knowledge and support lessen the parents' sense of isolation and sets up a therapeutic alliance for dealing with the future.' J.D. Baum, F. Dominica and R.N. Woodward, *Listen, My Child has a Lot of Living to Do: Caring for Children with Life-Threatening Conditions* (Oxford: Oxford University Press, 1990), p.80.

44 Daniel Callahan says, 'To have a choice is to have some control, even a choice to do nothing.' (*The Troubled Dream of Life*, p.18.). There are doubtless occasions when parents who may be emotionally overwhelmed by the condition of their baby are unable to understand the medical complexities of the situation and therefore the implications of treatment or non-treatment issues. Thus, notwithstanding issues of consent, the final decision making may have to remain with the doctors treating the baby. This does not, however, obviate the need for the widest possible consultation. In participating in such consultation the Chaplain can act in a traditional Christian role as advocate for the weak and vulnerable and for those who cannot speak for themselves and help to make sure that their best interests are kept clearly in focus.

45 *When a Baby Dies*, p. 42.

46 On the maternal-infant bond see M.H. Klaus and J.H. Kennell, *Maternal-Infant Bonding* (St.Louis: C.V Mosby Co. 1976). In a study of perinatal loss by Lewis, a major concern of her sample of bereaved parents was having their baby recognised as a 'real' person. H. Lewis, 'Nothing was said Sympathy-Wise,' *Social Work Today*, 110, 45 (1978), 2479.

47 J.H. Amick, 'Support for Parents of Babies in Special Care Units,' *Midwives Chronicle and Nursing Notes* June (1984), 170. Amick suggests 12 proposals for staff in supporting mothers with babies in SCBUs. These include trying to understand the emotional reactions of parents, enabling parents to be involved as far as possible in caring for their children, photographing the baby, ensuring good communication both between staff and between staff and parents, the provision of facilities for families and information booklets. All these are now considered good practice and, in most units, are in routine use. The 1980s, however, was a period when such ideas were being formulated and tested. For an example of similar guidelines in the UK, see P. Fleming, B. Speidel, and P. Dunn ed. *A Neonatal Vade-Mecum* (London: Lloyd-Luke Publishers, 1986), pp.245-246. In addition to the suggestions made by Amick, Fleming *et.al.* include, 'Do talk to your colleagues about your own reaction to the baby's death - to examine your own feelings does not diminish, but increases your professional usefulness.' (p.245).See also, S. Goodley, 'A Family Affair,' *Nursing Mirror*, 161, 9, August 28 (1985), 37-39. In this article Goodley describes the value of a family-centred neo-natal service. In 1987 I conducted some research into the use of protocols concerning neo-natal deaths (see RCOG Guidance Note 22:11, 1985). The evidence showed that there was great disparity amongst hospitals. Some units had no protocols and therefore what was done was very much in the hands of whoever happened to be on duty at the time of death; some units had protocols but either didn't know they existed or didn't know how to use them (i.e. what was important was simply ensuring that all the boxes were ticked rather than understanding why what was being ticked was important); some units had protocols, understood their purpose, and used them well in providing both continuity and a high standard of care. It is over-simplistic to suggest that units with protocols do 'better' than those without but protocols, nonetheless, do help to provide a baseline standard of care for all bereaved parents. See also Y. Brown, 'The Crisis of Pregnancy Loss: A Team Approach to Support,' *Birth*, 19, 2 (1992), 82-89.

48 Whilst the development of bereavement care has been a significant positive feature of the last twenty years, care must be taken that too easy recourse into intervention is not made. It is important that staff understand grief as a natural process.

Whilst support is always an important aspect of care, counselling is usually only necessary when grief becomes complicated or pathological. Sometimes, in the literature on bereavement, confusion arises over the use of terms. Worden, for example, uses the word 'counselling' to describe support through un-complicated grief, and uses the word 'therapy' to describe professional intervention in the case of complicated or pathological grieving. J.W. Worden, *Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner* (London: Routledge, 1992). Even where formal counselling/therapy is not used, counselling skills, such as acceptance, empathy and positive regard, are useful for those alongside the bereaved. The role of intervention is to encourage or facilitate the expression of grieving and to promote the mourning process. B. Raphael, *The Anatomy of Bereavement: A Handbook for the Caring Professions* (London: Routledge, 1984), p.368.

49 See chapter on Liturgy and Pastoral Care. Many rituals, as death approaches, are deeply personal enactments of love, care and goodbye.

50

> Some stories are far shorter than others, but even the life of an infant, a newborn, a stillborn, or a miscarried child is a life with a history that we can find meaningful and in which we have typically invested much hope. There is, consequently, a story to be told, heard and remembered, even in such seemingly limiting cases.

T. Attig, *How We Grieve: Relearning the World* (Oxford: Oxford University Press, 1996), p.179. Encouraging the telling, and re-telling, of stories is therefore integral to good pastoral care of the bereaved.

51 It is now universally accepted that where the significance of a death is not acknowledged or if grief is not legitimated it is likely to be suppressed and that the expression of grief is necessary before any degree of recovery can occur.

52 Martin Buber draws the distinction between a 'Thou' and an 'It' in which 'I-Thou' relationships are personal and 'I-It' relationships are impersonal. Although for Buber 'I-Thou' relationships are essentially mutual, reciprocal and symmetrical, I think that, even in the case of a dead baby, this offers a useful model of relationship insofar as it ensures that each person, dead or alive, retains their status as subject, which alone can be known directly, and are not reduced to 'objects'. For Frances Young, it is the 'I-Thou' relationship which offers 'the possibility of personal relationship even with one who seems a non-person.' (Young, *Face to Face*, p.51.). It is, of course, precisely this which is constitutive of personhood for those who take a relational view of persons. In this sense, personhood is something which is 'bestowed'.

53 'The competence, sincerity and consideration shown by... staff during the period of fatal illness establishes the atmosphere in which this crucial human experience occurs.' A.J. Solnit and M. Green, 'Psychological Considerations in the Management of Death in Paediatric Hospital Services,' *Paediatrics*, 24 (1959),106. From a theological and pastoral perspective, Paul Tillich observes that, 'we can speak to people only if we participate in their concerns; not by condescension, but by sharing...' P. Tillich, *Theology of Culture* (Oxford: Oxford University Press, 1978), p. 207.

54 *Face to Face: A Narrative Essay in the Theology of Suffering* (Edinburgh: T & T Clark, 1990), p.30. Later, Young describes anger as 'the dark side of love' without which there is no hope of change. (Ibid., p.158.).

55 Ibid., p.125.

56 It should be remembered that under such circumstances parents need to have time with (1) their baby, (2) each other, and (3) relevant professionals. Undue haste in any of these areas may have serious repercussions.

57 *Life's Living Towards Dying*, p.80. Baby Rena was adopted at four months by an evangelical couple who saw adopting this baby as a way not just of providing her with love and care but as a way of engaging in spiritual 'warfare' against AIDS. Their ultimate aim was to use prayer and faith to provide a miraculous healing.

58 Ibid., p.80. For the Orthodox Guroian both the community of faith and the narrative of death and resurrection are crucial elements in the healing process. Thus, even in the face of death, healing comes through our community with others, not least the communion of saints, and the churches' theology of death and resurrection form the ultimate context of care.

59 Similarly, it is important to discuss where mothers would like to stay if they need to remain in hospital. For some, being on a post-natal ward with other mothers and their babies whilst not having a baby of one's own to hold may be acutely painful. For others, being isolated may re-inforce notions of being a 'failed' mother or an embarrassment to staff (see previous chapters). Another valuable source of support for the parents of a dying baby, and one which has often been unrecognised or undervalued in the past, is the presence of other parents. Too often, a conspiracy of silence descends upon the unit when a baby is dying. Moving the baby, and hence the family, to a single cubicle or side room, while it certainly provides them with a much valued quiet space, can also have the effect of separating them other parents with whom they may have built a relationship however brief the time they may have been on the unit may be. It could be argued that the presence of a dying baby and parents who are upset could be distressing for other parents with babies on the same unit. In my experience, however, such parents offer each other valuable support at a time of strain. Few are fooled when a critically ill baby is suddenly moved to a side room any more than they are when a cot suddenly appears empty and no explanation is given. As so often, honesty is the best policy and there are few parents who are so self-absorbed that they do not have the time or energy to speak with parents whose babies are dying and to offer them support or consolation.

60 Some parents may even begin to plan the funeral in this period, partly because it gives them something to *do* at this time, and partly because it is a recognition of a painful reality - that their child is going to die. B.F. Friedman, P. Chodoff and J.W. Mason noted that the signs and symptoms of anticipatory grief may not be as well defined as in an acute grief reaction but that the emotional and somatic affects of such grief were nonetheless consistent with the findings of Lindemann. ('Behavioural Observations on Parents Anticipating the Death of a Child,' *Paediatrics*, 32 (1963), 610-625.) Bevereley Raphael notes that 'those who grieve in an anticipatory way may have a full gambit of emotions... when the death does occur then the reality is confirmed and further grief and mourning are set in train.' (*The Anatomy of Bereavement*, p.53.).

61 Over a century ago, Budin noticed that mothers who were separated from their infants eventually lost all interest in them if they no longer had to meet their needs. John Bowlby noted how infants, separated from their mothers also eventually lost interest and withdrew their attachment or transferred it elsewhere. J.H.Kennell and

M.H. Klaus argued that although bonding may begin early in pregnancy and is present at birth, it undergoes significant changes in the first few hours of life. This clearly has implications for parents whose babies are moved to intensive care immediately after birth. *Maternal-infant Bonding* (St.Louis: C.V. Mosby Co., 1976).

62 This attitude may also be seen in the reluctance to tell others that the birth has occurred. Parents may say, 'We've decided not to tell anyone about the birth until we know if he/she is going to live...'. Sadly, this approach often cuts parents off from a valuable source of support during a difficult or traumatic period in their lives.

63 Baum, Dominica and Woodward, *Listen, My Child Has a Lot of Living to Do*, p.105.

64 L.G. Peppers and R.J. Knapp argue that the 'shadow' of perinatal death may be a lifelong experience. (*Motherhood and Mourning: Perinatal Death* (New York: Praeger, 1980).). See also, J. Cullberg, 'Mental Reactions of Women to Perinatal Deaths,' in N. Morris ed. *Psychosomatic Medicine in Obstetrics and Gynaecology* (New York: Karger, 1972). It is remarkable that even in the late 1980s a paediatrician could write, 'Then one day... it occurred to me that a baby who was born dead or who died in the first few days after birth must have far reaching effects on the whole family.' D. Morris, 'A Paediatrician and Perinatal Bereavement,' *Bereavement Care*, 6, 2 (1987), 16. It is nonetheless true that it was only at this time that serious professional attention was starting to be given to the work of people like Emmanuel Lewis, Stanford Bourne of the Tavistock clinic and Pat Giles, an Australian obstetrician who had been writing on early life deaths since the 1970s. David Morris was one of the authors who produced the 1985 *Report of the RCOG Working Party on the Management of Perinatal Deaths* (London: RCOG). See also S. Bourne and E. Lewis, 'Perinatal Bereavement: A Milestone and Some New Dangers,' *British Medical Journal*, 302 (1991), 1167-8. Daniel Callahan argues that, because of its unfulfilled potential, 'the death of a young person... will trigger a different kind of grief not characteristic of the loss of life of an older person.' (*The Troubled Dream of Life*, p.176.).

65 Letter to Ludwig Biswanger, 1929. E. L. Freud (ed) *Letters of Sigmund Freud* (New York: Basic Books, 1961), p.386.

66 D.I. Tudehope, J. Iredell, D. Rodgers and A.Gunn, 'Neonatal Death: Grieving Families,' *The Medical Journal of Australia*, 144 (1986), 290-291. See also B. Raphael, 'Editorial: Grieving Over the Loss of a Baby,' *The Medical Journal of Australia*, 144 (1986), 281; G.I. Gilson, 'Care of the Family who has Lost a Newborn,' *Postgraduate Medicine*, 60 (1986), 67; M.T. Nichol, J.R. Tompkins, N.A. Campbell and J.S. Syme, 'Maternal Grieving Responses after Perinatal Death,' *Medical Journal of Australia*, 144 (1986), 291. There is no doubt that academic research being done into early life deaths in Australia the 1980s was in the forefront of work being done in this field. I valued the opportunity to discuss this, and subsequent, work with David Tudehope and his colleagues at the Mater Hospital, Brisbane in 1997.

67 G.C. Forrest, E, Standish and J.D. Baum, 'Support After Perinatal Death: A Study of Support and Counselling after Perinatal Bereavement,' *British Medical Journal*, 285 (1982), 1475-1479. See also, E. Standish, 'The Loss of a Baby,' *Lancet*, 1 (1982), 611-612; J. Rowe, R. Clyman and C. Green, 'Follow Up of Families Who Experience a Perinatal Death,' *Paediatrics*, 62, 2 (1978), 166-169; M.P.White, B. Reynolds and T. Evans, 'Handling of Death in SCUs and Parental Grief,' *British*

Medical Journal, 289 (1984), 167-169 and D.I. Tudehope, J. Iredell, D. Rodgers and A. Gunn, 'Neonatal Death: Grieving Families,' *The Medical Journal of Australia*, 144 (1986), 290. Frances Young notes that the birth of a severely disabled child may have similar consequences. (*Face to Face*, p.37.).

68 Such perceived social exclusion may also extend to the relationship with God. Feeling abandoned by God may lead to a disruption in the whole ecology of relationships.

69 Z. Smialek, 'Observations on Immediate Reactions of Familes to SIDS,' *Paediatrics*, 62, 2 (1978), 160.

70 The development of community-based counselling/support groups and self-help groups over the last twenty years has been an important element in mitigating the isolation and loneliness of many bereaved people. The Miscarriage Association, The Stillbirth and Neonatal Death Society (SANDS), Support After Termination for Fetal Abnormality (SATFA)/ARC (Antenatal Results and Choices), the Foundation for the Study of Infant Deaths (FSIDS), Compassionate Friends and Cruse are all national organisations. Alongside these are many locally-based support groups. The two types of support, counselling and befriending, should not be seen as competitive but complementary and many parents will benefit from both types of help. There is no doubt that the emergence of these organisations/groups has itself influenced professional attitudes to pre- and perinatal deaths over the last 25 years. As most people who experience grief after early-life loss are younger people, they may have little or no experience of death or grieving and so their grief may be particularly confusing or frightening. The presence of others who have experienced similar bereavements may therefore be particularly re-assuring. Not everyone, however, finds groups helpful. For some, individual counselling or family therapy may help at times of crisis.

71 See section on parental grief in the chapter on stillbirth.

72 J. Walker, 'Care in Bereavement,' *Paediatric Nursing*, (Oct. 1990), 17. In her study of PICUs, 80% were sending staff on bereavement study days.

73 For this reason I would regularly make calls to the SCBU, ICN, or ICU during the night shift. Some staff only work night-shifts and I considered it important that these staff, too, felt that the chaplain was there for them as well as for their patients.

74 The issue of touch is pastorally fraught. Touch, however, when sensitively and responsibly used in the therapeutic context can be communicative in ways in which, very often, words cannot. Elizabeth Moltmann-Wendell sees such touch as creative of community. She writes that 'to touch means to stimulate people in their whole existence... heal their brokenness and make them whole again, capable of contact, thought and experience.' (*I Am My Body*, p.65.).

75 H. Manning, 'Sudden Death,' *Nursing Mirror*, 18th. May (1985), 10

76 *The Wounded Healer* (New York: Image Books, 1979), p.72. Alastair Campbell describes this attitude towards pastoral care as, 'the medication of steadfastness and wholeness.' (*Rediscovering Pastoral Care* (London: DLT, 1986), p. 16.). In short, any pastoral or spiritual care worthy of the name will involve us wholly *as* persons, *with* persons. It is always, by definition, 'human', not 'mechanical'.

77 Cf. H.R.Niebuhr, 'Love is reverence: it keeps its distance even as it draws near; it does not seek to absorb the other in the self or want to be absorbed by it; it rejoices

in the otherness of the other...'. (*The Purpose of the Church and its Ministry.* (New York: Harper Row, 1956), p.35.). Karl Barth similarly argues that 'Christian love turns to the other purely for the sake of the other. It does not desire it for itself. It loves it simply because it is there as this other.' (*Church Dogmatics* IV/2. (Edinburgh: T and T Clark, 1960), p.733.) It is interesting to compare this with Kahil Gibran's piece on children in *The Prophet*, a piece which is often chosen to be read at children's funerals.

78 One mother said, as she passed her dying baby to me to hold, 'You go to your uncle Jonathan, he'll take care of you while mummy's away.' The use of the familial, 'uncle', was a poignant reminder of the depth of relationship that can be forged in a short period through attentive pastoral care which is built upon a genuine, agapeistic, love and care for patients and their families.

79 See chapter on children and death and sections on grief and families in previous chapters.

80 D.G. Benfield, M.A. Lieb and J.H. Vollman, 'Grief Response of Parents to Neonatal Death and Parent Participation in Deciding Care,' *Pediatrics*, 62 (1978), 171-177.

81 L. Raj, 'Caring for Parents When Their Child is Dying in the Intensive Care Unit,' *Ministry, Society and Theology*, 8, 2 (1994), 5-15.

82 Ibid., 14. There is, therefore, a need to be alert to non-verbal communication. Body language can be a valuable indicator of how people are feeling or responding. It is important that fathers are allowed to express their emotions, and even be given permission to do so. To see that carers will not be embarrassed by shows of emotion or intimidated by them is often an important element in allowing grief to be ventilated.

83 See previous chapters.

84 See section on parents and grief in chapter on stillbirth. Parents often have strong feelings and fears about post mortems. They may be eager to learn all they can about their baby's condition but nonetheless consider the post mortem to be a further violation of their child's body. Sometimes their fear is based on false information. One mother expressed her fear of picking up her baby to me after a post-mortem 'in case his arms or legs drop off'. In some cases there may be cultural or religious reasons why a post mortem is declined. It should be noted that, conversely, a post mortem, in some cases, may be required in law by the coroner. Communicating the results of the post mortem is very important. The natural, but sometimes un-spoken, corollary to the question, *'Why did it happen?'* is *'Will it happen again?'*

85 I. Ajemin, 'The Interdisciplinary Team,' in D. Doyle, G. Hanks and N. MacDonald eds. *Oxford Textbook of Palliative Medicine* (Oxford: Oxford University Press, 1993), p.18. Heije Faber describes the team as 'a task-centred group' and he says, 'like the specialist, the registrar, the analyst and others, the minister is a figure with his own role to play, and if he wishes to be accepted, he will have to make that role very clear.' (*Pastoral Care in the Modern Hospital* (London: SCM, 1971), p.73.). Above all, 'the minister must be interested in the work of the medical staff and in them **as persons** (my stress).' (p.94).

86 Derek Bacon writes, 'The sick child touches the child in us, and our world of meaning comes under threat of futility and emptiness when confronted with the child who is going to die,' and he concludes that 'part of what makes us human at all is the need to make sense of life by placing ourselves on a spiritual or cultural map.'

('Spiritual and Cultural Meanings: A Shared World of Meanings,' in A. Goldman ed. *Care of the Dying Child* (Oxford: Oxford University Press, 1994), p.133.). Death profoundly challenges the security we find in our life-map. Where we place ourselves on such maps frequently determines what people hope for in their lives as well as defining our identity.

87 I. Ajemin, 'The Interdisciplinary Team,' p.19.

88 J.L Florell, 'Interprofessional teams and relationships,' in R.J. Hunter ed. *Dictionary of Pastoral Care and Counselling* (Nashville: Abingdon Press, 1990), pp.593-594.

89 'Pastoral Care for Perinatal and Neonatal Health Care Providers,' *Journal of Obstetric, Gynaecological and Neo-natal Nursing*, 28 (1999), 138-139 and 141.

90 There is clear evidence that lack of support is still a real issue of concern for many staff working in the intensive care environment. J.H. Pye and E. Crathern, 'Support in Neonatal Services: A Questionnaire'. S.G. Wright and J. Sayre-Adams suggest that since stress and burnout still occur in those situations where support is provided, something is being overlooked. This, they suggest, is the emotional and spiritual cost of caring which can only be addressed by taking seriously the nature of caring relationships which, in turn, means that the spiritual as well as physical and emotional needs of caregivers need to be addressed:

> The objectification of health has led us to a point of great concern for healthcare and the carer. Some aspects of care, which do not lend themselves easily to measurement or evaluation, can find themselves excluded. This applies particularly to the 'softer' services such as some of the complementary therapies, counselling and chaplaincy.

(*Sacred Space: Right Relationship in Spirituality and Healthcare* (London: Churchill Livingstone, 2000), p. 37). See also, M. Cobb and V. Robshaw, (eds) *The Spiritual Challenge of Healthcare* (London: Churchill Livingstone, 1998) and D.Stoter, *Spiritual Aspects of Healthcare* (London: Mosby, 1995).

91 Bourne describes how staff are 'flung apart' by the death of a baby. S. Bourne, 'Coping With Perinatal Death,' *Midwife, Health Visitor and Community Nurse*, Feb. (1979), 59-62.

92 J. Dyson, 'Nurses' Conceptualizations of Caring Attitudes and Behaviours,' *Journal of Advanced Nursing*, 23 (1996), 1263.

93 'Spiritual distress' is now recognised as an official nursing diagnosis by the North American Nursing Diagnosis Association (NANDA). Scales and tools, such as the Texas Inventory of Grief, the Grief Experience Inventory (GEI) or the Perinatal Grief Scale, have therefore been created to help 'measure' spiritual well-being and spiritual distress. Many, however, including myself, remain sceptical of such a quantitive/qualitative approach to spirituality which often draws too little distinction between religious and spiritual needs. See, for example, R. Stoll, 'Guidelines for Spiritual Assessment,' *American Journal of Nursing*, 9 (1979), 1575-1577.

94 J. Firet, *Dynamics in Pastoring* (Grand Rapids, Michigan: Eerdmans, 1986), p.267.

95 K.J. Czillinger, 'Advice to Clergy on Counselling Bereaved Parents,' in T.E. Rando ed. *Parental Loss of a Child* (Champaign, Illinois: Research Press Company, 1986), p.466. Penelope Wilcock argues that in such situations, 'our helplessness is a

gift to the helpless,' which allows us to stay with them and is at the root of spiritual care. Such inter-relational presence affirms both identity and worth at the very boundaries of life and may be a deep form of communication, even, perhaps especially, where words are absent. (*Spiritual Care of Dying and Bereaved People* (London: SPCK, 1996), p. 5.).

96 Beverley Raphael writes, 'The most basic of human responses to those who are grief-stricken and distressed involve the offering of comfort and consolation.' (*The Anatomy of Bereavement*, p.353.). This is the attitude evinced by Jesus in John 14.

97 G. Noyce, *The Minister as Moral Counsellor.* (Nashville: Abingdon Press, 1989), pp.125-6.

98 Roland Riem says that '(t)he pastors' place is to witness humbly and fearlessly to God's grace and truth at work in human life. Their responsibility is not to protect the patient from judgement but to offer by their care a sign of God's unconditional love, which may finally be rejected.' (*Stronger than Death* (London: DLT, 1993), p.15.).

99 This response can be seen in Martha's response to Jesus after the death of Lazarus: 'Martha said to Jesus, 'Lord if you had been here, my brother would not have died.' John 11:21.

100 N.A. Kirkwood, *Pastoral Care in Hospitals* (E.J.Dwyer (Australia) Publishing Ltd., 1995), pp.213-214. When Kirkwood talks about coming 'as a fellow human being in all our humanness...' he is talking about an essential equality between care-giver and care-receiver. This is a theme taken up in detail by Alastair Campbell who describes what he calls 'the professional captivity of pastoral care'. A.V.Campbell, *Paid to Care: The Limits of Professionalism in Pastoral Care* (London: SPCK, 1985), chapter 3. Campbell insists that 'to offer oneself as an accredited helper is to impose limits upon the character of the relationship... ' (p.36). Lambourne similarly opposes professionalism in pastoral care, arguing that it should be 'lay, voluntary and diffuse in the community.' R.A. Lambourne, 'Professionalism and Pastoral care,' *Contact, 35,* June (1971), 27. For Lambourne professional pastoral care has sacrificed the principle of *koinonia* on the altar of peer-professional acceptance. Others writing in the pastoral care field, such as Howard Clinebell, for whom expertise in pastoral care is normative, disagree strongly.

101 Helen Vegoda, paediatric cardiac link worker at Bristol Royal Infirmary once suggested to me that 'guilt' might, in fact, be a necessary starting point. 'If they hang it on themselves first you can work with that, others are just angry and that's much harder to work with.' (Personal conversation with JHP, 26.2.91.). Frances Young, on the other hand, warns of the dangers of stereotyping. She was personally satisfied that her own son's disability was 'an accident and not my fault'. (*Face to Face,* p.44.).

102 S. van Hooft, 'The Meanings of Suffering,' *Hastings Center Report 28,* 5 (1998), 14.

103 John 9:2.

104 A.M. Farrer, *Love Almighty and Ills Unlimited* (London: Collins, 1962), p.172.

105 The theme of the isolation of pain and death in the cross is explored by a number of writers. See, for example, J. Moltmann, *The Crucified God* (London: SCM, 1974). Similarly, Gene Outka says, 'Love does not snatch us from the pain of

time, but takes the pain of the temporal upon itself. Hope makes us ready to bear the 'cross of the present'. It can hold to what is dead and hope for the unexpected.' G. Outka, *Agape: An Ethical Analysis* (New Haven: Yale University Press, 1972), p.179.

106 Two phrases which are almost universally unhelpful are *'It will be alright'* and *'I know how you're feeling'* The insensitive use of either of these phrases can precipitate a deep and abiding anger in bereaved parents since it *won't* be alright and most of us *don't* know how they are feeling! The uniqueness of meaning which is attached to each pregnancy is something which, as we have already noted, should not be underestimated.

107 For further on this see the chapter on the pastoral nature of liturgy.

108 J. Cook and D.W. Wimberley, 'If I Should Die Before I Wake: Religious Commitment and Adjustment to the Death of a Child,' *Journal for the Scientific Study of Religion*, 22 (1983), 222-238.

109 Ibid., 222.

110 'Meaning' can be used to denote both intention and life-orientation. In this sense, 'meaning' means more than simply the 'cause' of the death.

111 Cook and Wimberley, 'If I Should Die Before I Wake: Religious Commitment and Adjustment to the Death of a Child,' 223.

112 In this context, I particularly like Roland Riem's definition of faith. He says, 'Faith is not a religious commodity but the way by which truth may be found within human existence.' (*Stronger than Death*, p.20.).

113 Daniel McIntosh and his colleagues offer a timely caveat. In their study of 124 bereaved parents, they found that religious and spiritual beliefs were positively related to finding meaning in death, parents' perception of social support and, indirectly, to increased long-term well-being. D.N. McIntosh, R.C. Silver and C.B.Wortman, 'Religion's Role in Adjustment to a Negative Life Event: Coping With the Loss of a Child,' *Journal of Personality and Social Psychology*, 65, 4 (1993), 819.

114 R. Wuthnow, K. Christiano and J. Kuzlowski, 'Religion and Bereavement: A Conceptual Framework,' *Journal for the Scientific Study of Religion*, 19, 4 (1980), 408-422. Wuthnow *et.al.* argue that 'religion is likely to have an important bearing on the manner in which bereaved persons cope with their bereavement.' (p.408) and that religious organisations can be a valuable source of social support for their members.

115 See chapter on the pastoral nature of liturgy.

116 This may be related by some to the belief that life itself is a gift from God to whom that life is now seen to be returning.

117 Such descriptions of 'heaven' are long-standing and persistent. In the writings of the Desert Fathers, heaven is often described as a rich and luscious garden, not only reproducing the pre-fall conditions of paradise, but forming stark contrast to the barrenness and bleakness of their present, temporal, life. See B. Ward, *Lives of the Desert Fathers*. (London: Mowbray, 1980).

118 G.Y.York, 'Religious-Based Denial in the NICU: Implications for Social Work,' *Social Work in Health Care*, 12, 4 (1987), 31. To look for miracles of healing in this way is often a dangerous course to take since healing is most likely, in such circumstances to be equated with physical restoration or 'curing'. It is thus to take the short-term view of life and of the meaning of human being and, when death ensues the

crisis which it precipitates may be acute. Either the parents will blame God for not intervening and so 'answering' their prayer or they will blame themselves for 'not having enough faith...' or 'not being worthy...' to be listened to. It is often difficult for such people to grasp that death may, itself, be a form of healing in the sense that it brings a life to a conclusion or a wholeness. This is similar to the way in which Matthew uses the word, *teleios*, in Matthew 5:48. The word, often translated as 'perfect', also means 'made whole' or 'brought to completion'.

119 Ibid., 34.

120 An important element of ministry is confronting people with the truth (what Henri Nouwen calls a 'confronting service'), neither colluding with delusion nor offering false hope but standing alongside people with integrity in the reality of their situation, however painful, and therefore offering a genuine way forward.

121 'Reality', here, is not just in terms of what is going on in the world of experience but is akin to what Bonhoeffer describes in terms of God in Christ creating community in the one true reality (*Ethics* English translation (London: SCM, 1971).). George Pattison describes this as 'the really real'. (*The End of Theology and the Task of Thinking about God* (London: SCM, 1998).). Shakespeare offers us a piece of timely advice on pastoral sensitivity in relation to truth in *The Tempest*:

> The truth you speak doth lack some gentleness,
> And time to speak it in; you rub the sore,
> When you should bring the plaster.

W. Shakespeare, *The Tempest*, Act 2, scene1, 11.

122 'Religious-Based Denial in the NICU,' 34-35.

123 Personal conversation with JHP.

124 Staff may become angry or frustrated with such parents because of their inability to penetrate the parents' thought-world or beliefs and because they may feel that their efforts on behalf of the child are under-valued. The role of the chaplain in such circumstances may be to help maintain communication wherever possible and to act as a support for staff, allowing them to ventilate their feelings about the parents or about the situation and by acting in a non-judgemental way towards such families, however they may be acting. A key element of effective spiritual and pastoral care is the willingness and the ability to enter into alternative world-views non-judgementally.

125 A. Wright, J. Cousins, and J. Upward, 'Matters of Life and Death: A Study of Bereavement Support in NHS Hospitals,' *King's Fund Project Paper, No.77* (1988), p.10. The paper highlights the follow-up support offered by chaplains after bereavement as something particularly appreciated by the bereaved.

126 Such euphemisms might include phrases like, *'We're losing the baby'* or *'She's fading quickly'* or *'He's slipping away'*. As Corr so aptly says, 'In modern society, euphemisms tend to shy away from honest and straightforward speech by covering death with a linguistic shroud.' C.A.Corr, 'Death in modern society.' p.33. In 1965, Glaser and Strauss suggested that there were four basic types of communication, what they called 'awareness contexts', between the dying and those who surround them. While, like Elizabeth Kübler-Ross' *On Death and Dying* their work focuses on the dying person, like Kübler-Ross' work it can have a wider relevance and application. Their four categories are:

1. *closed awareness* - the dying person does not know that he/she is dying and staff, for whatever reason, do not disclose it.

2. *suspected awareness* - the dying person suspects that there is more going on than is being said.

3. *mutual pretence* - both the dying person and others know that the person is dying but neither side admits to knowing.

4. *Open awareness* - everyone knows the situation and is willing to talk about it.

B. Glaser and A. Strauss, *Awareness of Dying* (Chicago: Aldine Press, 1965). Clearly, the aim of caregivers should be to create the kind of environment where 'open awareness' is practised. Beverely Raphael notes how '(i)t is as though, by not speaking of it, the death may be reversible, untrue; and that the actual words somehow make it real, perhaps even make it happen.' (*The Anatomy of Bereavement*, p.34.).

127 One father, whose baby had died, said to me, 'Chaplain, we want you to say a prayer and then God will give us our baby back...'.

128 'The Meanings of Suffering,' 13.

129 Ibid., p.13.

130 Tom Driver describes suffering in terms of a social performance that expresses our search for meaning. T.F. Driver, *The Magic of Ritual* (Harper: San Francisco, 1991). Eric Cassell sees 'the test of a system of medicine (as) its adequacy in the face of suffering.' He distinguishes between 'pain' and 'suffering', seeing 'pain' as essentially a physical phenomenon and 'suffering' as psychological or spiritual. Thus, he argues that suffering is most likely when pain threatens the integrity of our personhood. See (*The Nature of Suffering and the Goals of Medicine* (New York: OUP, 1991), Preface, chapter 3 and pp. 103-104.). See also S. Hauerwas, *Suffering Presence* (Edinburgh: T & T Clark, 1988). Similarly, Job, whilst he does not get an 'answer' to his suffering, comes to see it from a theocentric perspective.

131 A. Farrer, *Love Almighty and Ills Unlimited* (London: Collins, 1962), pp. 198-191.

132 Farrer's writings on this theme, particularly in *Love Almighty and Ills Unlimited* was undoubtedly influenced, if not shaped, by the experience of his own daughter, Caroline, who, after a difficult birth, experienced learning difficulties as she grew out of infancy. See P. Curtis, *A Hawk Among Sparrows: A Biography of Austin Farrer* (London: SPCK. 1985).

133 A.M. Farrer, *Love Almighty and Ills Unlimited* (London: Collins, 1962), p.189.

134 Ibid., p.191.

135 Ibid., p.190.

136 Ibid., p.190. Elsewhere Farrer says of death and of our search for theological 'explanations' for its presence and meaning, 'God does not give us explanations; he gives up a Son...' ('The Country Doctor,' in *Austin Farrer: The Essential Sermons*, ed. L. Houldon (Cambridge, Mass.: Cowley Publications, 1991), p.204.).

137 (Edingburgh: T&T Clark, 1990). Arthur Young was born, brain-damaged, in 1967 with the condition microcephaly.

138 *Face to Face*, pp.43 and 156.

139 Ibid., p.53. Young recognises the links between these feelings and underlying emotional stress and argues that what Christian faith requires in response to the *'profound ambiguity'* of suffering is not 'blind' faith but an attempt to develop a coherent world-view.

140 Ibid., p.82. See V. Donovan, *Christianity Re-discovered* (London: SCM, 1982), p.63.

141 *Face to Face,* p.61.

142 Ibid., p.65.

143 Ibid., p.94.

144 D.A. Pailin, *A Gentle Touch: From a Theology of Handicap to a Theology of Human Being* (London: SPCK, 1992). Although published only two years after *Face to Face*, Pailin curiously makes no mention of it.

145 Ibid., p.10.

146 Ibid., pp.13, 14 and 15. Again, we can see here the contention that worth or value, that which makes 'persons' persons, is something which is bestowed by being loved and, ultimately, by being held in the divine memory. In short, we are loved because we 'are' and we 'are' because we are loved.

147 The phrase 'designated for death' first appeared in English law in the case of Jodie and Mary, conjoined twins, born in Manchester in 2000. The phrase was used to describe the situation of Mary, the weaker twin, who, it was judged by the Court of Appeal, would die whatever course of action was undertaken. The phrase originated in a rabbinic ruling, also concerning conjoined twins, a decade earlier, in the United States. See Case No: B1/2000/2969 A (Children) in the Court of Appeal (Civil Division) on appeal from Family Division.

148 Vulnerability can itself be an important pastoral tool, representing both the vulnerability of the pastor alongside the vulnerability of the bereaved, making companionship a genuine sharing of the journey into darkness. This is, of course, entirely different from a simple identification with the sufferings of the bereaved - often patronizingly articulated as 'I know what you're going through'. It is important, then, that the uniqueness of each person's suffering is recognised whilst genuinely 'being with' them in that experience. This balance between intimacy and distance is a key notion in the writings of Alastair Campbell. See, A. Campbell, *Rediscovering Pastoral Care* (London: DLT, 1981), A. Campbell, *Moderated Love: A Theology of Pastoral Care*. (London: SPCK, 1984) and A. Campbell, *Paid to Care: The Limits of Professionalism in Pastoral Care.* (London: SPCK, 1985). Campbell argues that the pastoral caregiver is able to mediate healing precisely because he is able to convey 'as much by presence as by the words used, both an awareness and a transcendence of loss.' (*Rediscovering Pastoral Care*, p. 42.).

149 Pailin, *A Gentle Touch*, p.52.

150 Ibid., p156.

151 This is, of course, the question posed by Psalm 8:4.

152 Pailin's view of post-mortem existence concurs with that of Young described above.

153 S. Hauerwas, *Naming the Silences: God, Medicine, and the Problem of Suffering.* (T and T Clark: Edinburgh, 1993).

154 London: Pan Books, 1981. Harold Kushner's son, Aaron, was born in 1963 with the degenerative disease, progeria. He died in 1977.

155 *Naming the Silences*, p. ix. Hauerwas regards suffering as part of all human lives and is profoundly suspicious of any simplistic attempt by people to relate their suffering to the suffering represented by the cross. See, S. Hauerwas, *Suffering Presence: Theological Reflections on Medicine, The Mentally Handicapped and the Church* Notre Dame: University of Notre Dame Press, 1986).

156 P. De Vries, *The Blood of the Lamb* (Little, Brown and Co., 1969).

157 *Naming the Silences*, p.36. Later he poses this in the form of the question, 'Given our boundless expectations of medicine, how can we ever set limits on medical care?' (p.101) This is a question that Hauerwas had been exploring since at least the mid 1970s. See, for example, S. Hauerwas, *Truthfulness and Tragedy* (Notre Dame: University of Notre Dame Press, 1977), chaps. 10-13.

158 *Naming the Silences*, p.53. The concept of the community of care is one which is particularly important for Hauerwas. In 1977, Hauerwas had explored the moral dilemmas of neo-natal intensive care in *Truthfulness and Tragedy*. He argues that the creation of a truly human community, from which defective or dying newborns are not arbitrarily cut off by reason of their defects, allows us to regain the perspective, lost as a result of modern medicine's emphasis on cure over care, to love and care for *all* children as being 'destined for death.' (p. 178). For Hauerwas this view provides a middle axiom which means that we will neither necessarily strive to keep all children alive, whatever their condition, nor to kill some (or, at least to allow them to die), because they do not conform to a norm, or ideal, of the 'good' life. Hauerwas thus believes that there are *limits* to the care which is owed, morally, by parents, or others, to their children. To believe otherwise, he argues, would be to subject them to 'a mercy grown overwhelming by technology' and in which care becomes 'synonymous with manipulation.' (p. 182).

159 *Naming the Silences*, pp.74 and 75.

160 Ibid., pp.79 and 89.

161 Ibid., pp.95 and 150. Elsewhere, in a discussion on living with the handicapped, Hauerwas argues that although we may feel that, in some cases, it would have been better if such people had not existed, nonetheless, their presence among us imposes a duty of care. Moreover, since such people *do* exist we ought to delight in their presence within the human community. (*Sanctify Them in the Truth: Holiness Exemplified* (Edinburgh: T and T Clark, 1998), pp. 143-156.).

162 *When Bad Things Happen to Good People*, p.11.

163 Ibid., p.38.

164 Ibid., p.53. This is very close to the position which Elie Wiesel adopts in *All Rivers Run to the Sea*, and which stands in stark contrast to the protest atheism of writers like Primo Levi. Daniel Callahan describes compassion as a virtue, 'the capacity to feel with and for another.' Callahan, *The Troubled Dream of Life*, p. 94.

165 Kushner writes,

> Christianity introduced the world to the idea of a God who suffers... I don't know what it means for God to suffer. I don't believe that God is a person like me... But I would like to think that the anguish I feel when I read of the sufferings of innocent people reflects God's anguish and God's compassion, even if His way of feeling pain is different from ours.

Ibid., p.93. Like Moltmann *et.al.*, Jon Sobrino argues that the scandal of the cross is not eliminated by the resurrection but rather that 'it elevates it to a mystery...' (*Christology at the Crossroads* (London: SCM, 1978), p.187.). On the concept of mystery, I am grateful to Rev.Dr. Roy Yates who drew my attention to the correspondence between Gerard Manley Hopkins and Robert Bridges in which Hopkins says, 'You do not mean by a mystery what a Catholic does. You mean an interesting uncertainty... But a Catholic by mystery means an incomprehensible certainty.'

166 *When Bad Things Happen to Good People*, p.79.

167 P.F.H. Giles, 'Reactions of Women to Perinatal Death,' *Australia and New Zealand Journal of Obstetrics and Gynaecology*,170, 10 (1970), 207-210. See also, Forrest, Standish, and Baum, 'Support After Perinatal Death,' 1475-1479. Contrast this with H. Deutsch,*The Psychology of Women: A Psychoanalytic Interpretation*, vol.2. (New York: Grune and Stratton, 1944), p.263. Deutsch argues that grief following a stillbirth or neo-natal death is *not* the same as that following the death of a loved person but is the *'non-fulfilment of a wish fantasy'*. (see Chapter 1). Many parents find that relationships with relatives or friends become strained after the death of a baby. People avoid talking about the subject when talking about what has happened is what many parents most want to do. This is often seen as a reluctance to validate their grief or to recognise the reality of the baby who has died. Friends with babies and children tend to stay away and the isolation created by bereavement can be intense and painful in itself. Frances Dominica says, 'I believe that the pain of bereavement is greatly intensified when society expects you to get over it quickly and you are left feeling stranded because you are a long way from complete recovery.' ('Reflections on death in childhood,' 109.).

168 Communication between staff, especially between hospital and community, is also important when a baby dies. It is distressing for parents whose babies have died to have a Health visitor call to 'check up on the new baby'. Owen Hagan, a senior social worker at Liverpool's Alder Hey Children's hospital, says, 'Experience has taught us that good terminal care does not simply happen; it is the product of careful thought by, and good communication between, experienced staff.' (Personal communication with JHP, 1987). Parents who feel that they cannot tell their story or that they are boring others, will often withdraw from contact with others and internalise their grief. Failure to grieve adequately can have catastrophic long-term consequences.

169 It is important for parents to be able to spend time with their baby as and when they wish. Grieving takes time and cannot be hurried. Most hospitals have a chapel of rest where parents can sit with their child. Parents should be told that, over time, the look of the child will change. Good communication is particularly important where a post-mortem has taken place. Beverley Raphael underlines the importance of seeing and touching the baby. She writes, 'The experience of seeing and saying goodbye to the dead person makes it possible for the bereaved to develop an image of the person

as dead, different and altered from the living image.' (*The Anatomy of Bereavement*, p.36.).

170 As Elizabeth Moltmann-Wendell says, 'In touching we experience the world and one another.' *I Am My Body*, p.62.

171 'Reflections on Death in Childhood,' 108. See chapter on children and grief for an account of siblings and bereavement.

172 *The Anatomy of Bereavement*, p.23.

173 'Newborn Death,' in Rando, *Parental Loss of a Child*, p.153.

174 It is important to remember that, for many families whose babies die on a neonatal unit, the hospital is the only home that their baby ever had. The hospital can therefore become a significant place since it forms the backdrop to parents' memories of their child. They may therefore continue to visit for some time and a sensitivity of welcome and acceptance is important.

175 Jane Nichols suggests that one reason for the tendency to discount, or negate, such grief is the comparative rarity of early-life deaths in contemporary western society and therefore the lack of rituals of behaviour for the occasion. In others words, faced with the death of a baby many people simply don't know how to act and therefore avoid acknowledging the situation. ('Newborn death,' in Rando, *Parental Loss of a Child*, pp.145-157.).

176 One of the strange things about neo-natal intensive care is often its silence. Premature babies do not yet have lungs that are developed enough to allow them to cry and many babies are intubated.

177 J.H, Kennel, H. Slyter and M.K. Klaus, 'The Mourning Response of Parents to a Newborn Infant,' *New England Journal of Medicine* 283 (1970), 344-349. Preoccupation may include not only the need constantly to talk about the dead baby but may involve hallucinations, such as 'hearing' the baby cry.

178 Anniversary reactions can be particularly acute and may persist for many years. Some families mark such occasions ritually, visiting the grave, lighting a candle, looking at photographs; others may find the pain of such days incapacitating. Anniversary reactions are a well documented phenomenon. See J. Bowlby, *Attachment and Loss, vol. 3* (Harmondsworth: Penguin, 1981), p.159f.

179 'Our Religious Traditions and the Treatment of Infants,' p. 515.

180 'Reflections on death in childhood,' 110. From a theological perspective, N. P. Harvey distinguishes between the negative view that bereavement is something to be 'got over' and the view that, though painful, bereavement may, in fact, provide an important point of growth for the bereaved. (*Death's Gift: Chapters on Resurrection and Bereavement* (Grand Rapids: Eerdman's, 1995), p. 15.).

Chapter 5. Children and Grief

"Am I Still a Sister?"

Alicia Sims (Age 11)[1]

Introduction

In 1986, I was sent a copy of a little book written by an eleven year old girl named Alicia Sims. Alicia's 13 month old brother, Austin, had died of a rare form of brain cancer. In a collection of letters to her dead brother Alicia struggled to express the bewilderment, anger and frustration that Austin's death had brought for her. They deal for the most part with the ordinary things of life and Alicia's sadness that Austin is no longer there to share them. Her biggest question, however, as it is for many bereaved children, is one of identity, encapsulated in the book's title: *Am I Still a Sister?*[2] The book is a poignant and moving account of one child's journey through the experience of sibling bereavement. In Alicia's case, the process was helped both by the fact that Alicia was old enough to be literate and to have a maturing understanding of death and its consequences, and because she had parents who recognised her need to grieve, and encouraged and facilitated the therapeutic exercise of writing down her feelings.

For the child whose sibling has died, struggling to come to terms not only with the death of a brother or sister, but also with his/her own identity and with his/her relationships with those who surround him, both the living and the dead, bereavement can be a frightening experience. Many such bereaved and vulnerable children still lack both the experience and the critical apparatus to reflect adequately on their situation and death may raise many troubling or even frightening questions.[3] Not least among these, is the question, 'Who am I?'[4] It is a sad fact, however, that in the pain and bewilderment that surrounds the death of a child, surviving children and their grief are often marginalised or ignored.[5] Such children become the invisible victims of the 'dark land' of bereavement, forgotten mourners whose deepest needs are frequently overlooked in the aftermath of a death.[6]

Do children grieve?

The question of whether, and at what age, children are in fact capable of grieving is a subject of long-standing contention. Martha Wolfenstein, for example, argued that children cannot properly be said to grieve until there has been a complete formation of identity, when the individual is fully differentiated, which she places towards or at the end of adolescence.[7] At the other end of the scale, Piaget and Bowlby suggest that children of less than one year may grieve from the time when 'object constancy' and 'person permanence' become part of the infant's experience.[8] The psychotherapist, Irving Leon has suggested that, in many cases, 'much of a child's unresolved mourning is probably attributable to the failure of his family to assist grieving rather than innate inability to mourn.'[9]

At whatever age grieving may be said to begin, however, the nature of contemporary society which conspires to silence over death and which so easily therefore withholds from people, adults or children, vital information about the dead and dying, often suggests very early on to the child that a denial of death and its reality is, in fact, the norm.[10] Frank Wright, who was himself bereaved as a child, describes this 'evasion' as 'a sort of blind unwillingness to weave the experience of death into any coherent pattern of living.'[11]

Such withholding of information may, however, have a number of causes. The parents may be too distraught to talk about the death or may lack the emotional energy to do so; they may themselves feel that it is something not to be talked about. They may consider that the child is 'too young to understand' - and it may not be clear even to the parents whether it is the child or themselves that they are protecting. They may not want to talk to the child because they are still, themselves, at a stage of denial. They may doubt their own capacity to continue to be 'good' parents to their surviving children or they may simply not be able to find the words to describe what has happened.[12] The end result, however, remains the same. Difficult feelings which need to be owned by the child by asking questions about them are, instead, all too

often buried and remain un-asked. It is important to note that such questioning is not just about formulating propositions about death (i.e. it is *more* than simply linguistic). Such questions may come in highly disguised ways, through altered patterns of behaviour, for example. Thus, clinginess may ask the question, 'Am I still loved?' or naughtiness, in testing the limits of acceptable behaviour, may ask the question, '*How much* am I still loved?' It is important to recognise that children may need to play (often literally!) with the answers as well as the questions in order to assimilate them into their experience. Where questioning is discouraged or answers are not forthcoming, a child who, from the time of birth, has turned to his parents for protection in times of vulnerability or for the answer to difficult questions may now feel abandoned, cut off from the protection or the knowledge which up until now has seemed to him an inalienable and unassailable right. Harriot Sarnoff-Schiff, in her now classic book, *The Bereaved Parent*, describes how such children may come to see, perhaps for the first time, their parents as powerless to help them - 'They see them overwhelmed by death and they too are overwhelmed. They expect solace from people who themselves need consoling.' [13] Fiona Cathcart in an article on talking to children about death also quite rightly relates the grief of children to the grief of the adults around them, 'The ability of the child to cope with a bereavement', she says, 'is related to the ability of parents to cope with loss'.[14] A similar view is expressed by Irving Leon, who concludes that a parent who is able to mourn a peri-natal death will be one who is, in turn, much more able to help the surviving siblings. Thus, he argues that, in the first instance, the best way to 'help' a grieving child is to 'help' the grieving parent.[15]

Whilst it is my contention both that grief is a *natural* process, part of the fabric of what it means to be human, and that unless there are exceptional circumstances (e.g. mental illness or a history of abuse against the child), the parents are always to be regarded as the primary givers in respect of their children, where professional intervention after a bereavement is warranted, a systemic approach is usually the most appropriate. The family unit needs to be enabled *as a family*,

whatever else may be necessary for its individual members. However much a death of a child may affect individual family members, adults or children, the death changes the configuration of the family system irrevocably.[16] It would be as inappropriate and unhelpful for a parent to have to divert all their emotional energy and resources into helping their children to deal with their grief at the expense of their own (parental) grieving, just as much as it would be inappropriate and unhelpful for them to ignore the child's grieving altogether. Where parents divest themselves of their own grief in order to meet the emotional needs of their children, the grief of the adult may well be 'buried' or avoided and thus the parent may also become disabled in their own grieving. This may, indeed, become a stratagem for avoiding the pain of facing one's own grief at a time of emotional distress.

It is also important to remember, however, that a child's grief is both like and unlike that of adults in just the same way that a child is both like and unlike an adult, not least in the way in which they experience and respond to the world around them. Children are much more dependent on those around them than adults, to provide a model for their grieving (though this, of course, is still true for adults, especially today when many people will not experience the death of a close relative until at least early middle-age); their periods of sadness may be much more episodic than the more sustained sadness of the adults (children will generally intersperse their times of sadness with periods of play when the death may seem to be forgotten or put 'on hold'). What we do, therefore, with children must always allow them to *be* children. In other words, when we are confronted with a bereaved child we must learn to see the child first and their 'status' as bereaved second.[17]

The two key points to make at this juncture, and which will be important for what is to follow, are, firstly, that children grieve, and, secondly, that bereaved children need to integrate their grieving into a developing spirituality of the 'self'. In what follows, therefore, I shall attempt to give a brief outline of responses or stages in the emerging death-consciousness of children. I will examine the particular issues surrounding sibling death in the prenatal, perinatal and infant period, suggesting that

family context shapes and conditions children's responses. I will then describe one particular therapeutic model from my own work with bereaved siblings, before finally making some observations on the development of spirituality in children and its implications for the care of the bereaved child.[18]

The child's awareness of death

Children's awareness of death is a subject that is now well documented and has been the subject of much discussion since the seminal work of Maria Nagy was first published in 1948.[19] Much of the early work in this field, however, was concerned with the child bereaved through the death of a parent. The subject of a child's grief after the death of a sibling developed only later in the literature and research and still remains of only secondary importance in many cases.[20] All of these works, furthermore, continue to draw on the principles enunciated in the late 1940's on whether, and if so from what age, children are capable of feeling or expressing grief at the death of a significant other in their lives.

From the very moment of birth, developing human beings struggle with change and with the experience of attachment and separation.[21] Even for the newborn baby in the first weeks of life, as the experience of attachment to the mother or primary care-giver grows stronger, so does the intensity of the experience of isolation or abandonment when the care-giver is absent even for a short period of time.

From the age of about six months to around two years the child will not only cry out for its mother but will search/ask for her when she is absent. If the mother (or other primary attachment figure) does not re-appear, the child will protest and may eventually lapse into despair, becoming withdrawn and apathetic if the separation continues. Finally, if the separation goes on long enough, the infant will detach from the 'lost' person and begin to build a new relationship with a substitute. While the child's memory store is increasing, permanent or stable memories may well, at this

stage, be few. We may hesitate, therefore, to describe what is happening as 'grieving', and recognise the absence of a concept of death; nonetheless, a *process*, similar to that of grieving (crying out for... searching for... despairing for... and eventually resolving), can nonetheless be seen to be developing. It is important to recognise that experiencing this process is, in itself, as important as being able to conceptualise death. Thus, Beverley Raphael concludes that,

> the child in the 2-5 age range may experience much of the grief and mourning that adults also bear. But others may not perceive his responses as bereavement; he may lack the capacity to put into words his feelings and memories as such; and because others find his recognition of death and his painful mourning intolerable, they may deny him his feelings and their expression....[22]

Others have concluded that children below the age of five years tend, on the whole, to ignore death or to treat it almost casually, since death and separation or absence have the same practical meaning for them. Nevertheless, in Rochin's study of children in the three to five years age group, even here a developing awareness and interest in death and its causes is noted.[23] Bowlby describes how children in this age group also begin to 'fantasize' about death, often working out their experience through play and so giving expression to experiences for which they may lack any concept or developed language/vocabulary of feelings.[24] It may be very difficult for parents, especially grieving parents, to see a child exploring death and articulating his or her grief by re-enacting or playing out the death of someone for whom they cared, and therefore for the adult to 'allow' the game to continue without sanction or interruption. However, play is the child's natural means of expression and of exploring this inner world, and so is a vital resource in coming to terms with bereavement and grief. Children may also 'invent' poems or songs about dying or dead babies which they may sing to themselves or want to share with others as part of this process.

Above the age of five years, children appear to become increasingly aware of death and to be intrigued by it.[25] From the age of four to nine years, children may already have some experience of death. Seeing a dead bird in the garden or by the

roadside may increase their interest and experience and they may even experience the death of a family pet.[26] At around eight years of age children are maturing quickly and beginning to develop a relative understanding of time - with a consequent idea of what 'past' and 'future' means and so phrases like, 'Billy won't be living with us *any more...*' or 'You won't see Suzie *ever again...*' begin, for the first time, to make sense. Hence, the questions which may be asked by younger children like, *'When do you stop being dead?'* or, in the context of sibling death, *'When is the baby coming home again?'* gradually diminish with increasing age.[27] Children's questions are, however, often asked time and time again as the child begins to assimilate the experiences which have befallen them. It is important to remember in all of this that, alongside the 'actual' loss of a brother or sister, are other, no less real, losses which are being experienced (e.g. a loss of innocence, or of a sense of security). As the death is integrated, the experience of death as a reality that can, and does, touch everyone, means that the world is consequently no longer the 'safe' place which it once was.[28]

As mental and cognitive ability increase, so 'magical thinking' (about which I want to say more later) decreases or diminishes. The real danger with this age group, however, is that they are also getting 'better' at hiding their feelings. The child who outwardly appears to be coping well with the death of a sibling, therefore, may well be denying or hiding their own feelings of insecurity which the death of a sibling often precipitates (e.g. that I might die too...).[29] My own experience suggests that the feeling 'that I, too, might die...' is also experienced by children as young as four or five years old who have been brought into contact with a death through family experience, as the following example shows.[30] A four year old sibling survivor of a cot death, who had appeared to cope 'well' with the death of his brother just before Christmas (a good example of the under-fives' 'matter-of-fact' approach to death), began to show marked anxiety at the same time the following year. He became very 'clingy' and insecure and was easily distressed. When his mother questioned him gently about how he might be feeling, he responded by asking, *'Is it my turn to die this year, mummy?'* In this case, he had associated a particular time - Christmas - with dying. What had

happened to his sibling could equally well happen to him! With reassurance that the approach of Christmas did not make anyone any more likely to die and that he was not therefore at risk, the anxiety rapidly diminished and was replaced by a more appropriate sadness that the baby brother, whom he had adored, was no longer alive.[31] Clear, open, honest information coupled with the reassurance that the death was not the fault of anything that the child thought or did and the assurance that the child is, and will continue to be, loved will do much to mitigate anxiety in the bereaved child.[32]

In general, then, we may say that children between the ages of about five and eight years are increasingly able to grasp the *reality* of death, though they may not yet be able to work out its implications in the way that older children can (i.e., that death is something which is natural, final, inevitable and irreversible).[33] It is at this age also that guilt may become a powerful emotional factor and both withdrawal and (so-called) 'bad' behaviour, may reflect a child's assumption that he or she has somehow caused what has happened. If grieving and mourning are allowed to happen then these feelings will, however, ultimately be resolved.

Another factor affecting the responses of children in this age-group is the fact that they will now be at school where peer status and the sense of being like (in the sense of not being different from...) other children becomes increasingly important.[34] The child whose sibling has died may feel themselves no longer a part of (if not actually excluded from) the 'club' of those who have brothers or sisters. He or she becomes once again, in a sense, an 'only-child' with a consequent re-drawing of the peer-group map.[35]

Above the age of eight and into early adolescence we find that the child's maturing understanding and awareness of death evokes responses, in both type and duration, that are very much equivalent to those of adults (as described by Parkes, *et al.*[36]). Nonetheless, they may continue for some time to think primarily in concrete terms and so concepts, such as 'heaven' or an 'after-life', may still be difficult to comprehend - as, indeed, they may well be for many adults too.[37] It is important to

note that phrases like '...gone to heaven' or '...gone to be with God/Jesus' may be used (albeit misguidedly) by adults when talking to children to soften the impact in communicating the news of a death (being considered less 'blunt' than the phrase '...has died') rather than to communicate a religious belief.[38] This is as unhelpful for many children as phrases like 'gone away'. Where religious belief and practice is part of the structure of family life, however, the use of religious language and imagery will be an appropriate way of articulating both feelings and emotions and of expressing a belief in a post-mortem continuation for the baby or child who has died. Nonetheless, as I have noted above, it may be difficult for children, especially younger children to understand phrases like 'gone to heaven' in non-literal ways.[39] Parents in families where there is a shared faith structure may want to read passages of scripture or appropriate religious texts and to pray with their children. Shared symbolic acts, such as going to church or lighting a candle can help to recognise and communicate that grief is being shared as a family and that surviving children and their feelings are not being excluded. Many parents greatly appreciate the opportunity to talk with a hospital chaplain or with their own minister about how to communicate with their surviving children about subjects such as the afterlife.

Children in the older age-group are often particularly shocked as well as saddened by the news of the death of a sibling. Now aware of their own vulnerability, the death of a brother or sister may awaken in them the realization described above that they too, one day, will die.[40] As such children are in the process of naturally 'taking' or 'accepting' independence at this age, there may also be some reluctance to reveal their vulnerability to adults for fear of being treated once again as a dependent child. Adolescence itself brings with it new emotions of attachment and separation and these may also make bereavement something particularly difficult for the teenager to bear. Once again, questions of personal identity may prove particularly problematic.[41]

Issues with younger siblings

With death through pre-natal, peri-natal or infant death, the predominant sibling age-group is that of the younger child. With the death of a first child there is no sibling survivor; with a second there is generally a relatively small age gap (<5 years) between the children; with a third, the age gap between the first and the third increases, and so on.[42] It is, therefore, to children of the younger age group that I now turn in more detail.

In his study of bereaved children, Yalom argues that bereavement can form an understanding of death in children as young as four or five years old, a conclusion well borne out in my own work with bereaved siblings.[43] Such children are, as we have seen, amongst the most emotionally vulnerable. Whilst their need to grieve may too easily be written off by adults who consider them 'too young to understand...', they are, nevertheless, often acutely aware that something is happening to which they are a party even when they cannot verbalise or define it. The child of this age occupies a world that is largely egocentric. He/she characteristically believes that everything that happens is somehow related to, or directed towards, them. If parents or other adults are distressed or sad, the child asks first, 'What have I done?' If a sibling dies, the child asks, 'How did I do that?' Many children often fear that 'bad' or resentful thoughts about a brother or sister, 'wishing the baby away', have somehow caused the sibling to die. This is the phenomenon commonly described in children of this age as 'magical thinking'.[44] The realisation of such imagined potency can be the cause not only of great guilt but also of considerable fear and insecurity. How is this power to be controlled? Will it be the occasion of punishment? Could it affect the child's parents, thus leaving him/her abandoned and alone? Did it cause the death of the sibling? Could it happen again? All these are questions that may run through the mind of the bereaved child. If parents then seek to 'protect' the child, or indeed themselves from the child and his/her questioning, by sending him or her away to stay with relatives or friends, this may easily be interpreted as punishment, even banishment, and reinforce the

delusion of 'magical' thinking. This is why, for the egocentric child, an immediate simple, informative, age-appropriate, explanation of the death, without resort to euphemism, explaining how it happened and what is going to happen next (not least to them...) is so vitally important.[45] As Pip Leitch says,

> We cannot alter the tragedy of a death but some of the awfulness and anguish can be reduced and avoided in respect of long-term problems if bereaved children are helped immediately following the death....[46]

At a time when they may, quite understandably, be pre-occupied with, or even overwhelmed by, their own grief, parents will often need advice, not only about how to deal with their own very powerful emotions, but also about how to deal with those of their other children. This, however, is seldom given. Simply to say, 'It was nobody's fault' would seem to be a good starting point with young children, who will be content with answers that are simple and, as far as possible, factual. Parents should be encouraged, then, not simply to *talk* to their children, which, though painful, may well be as therapeutic for the parents as for the children, but they should also be encouraged to *listen* to them and their fears, however irrational to the adult mind these may be, and to *include* them in their grieving as a family.[47]

After a baby has died, there is no reason why siblings should not be involved in handling, washing and dressing the baby or in spending time with the baby so that they are not left with only ignorance and confusion to fall back on.[48] The opportunity to see and touch the body may be both helpful and appropriate for children as well as parents in testing the reality of the death in a concrete and experiential way, especially where the death has been sudden and unexpected.[49] It also affords the child an important opportunity to say 'goodbye', itself an important ritual, whether or not later codified through a funeral or other religious rite, and perhaps to leave a parting gift.[50]

For too many children, however, the dead sibling either remains unseen or simply 'disappears' without explanation. Small wonder, then, that such children are often left confused and afraid in the conspiracy of silence that so often follows a death,

unable to ask questions or express their fears or needs.[51] Knowing, or feeling, that there is a secret from which the child is excluded effectively re-draws the boundaries of relationship for the child. Those who are party to the secret are 'in', those who are not are 'out'. For the bereaved child, therefore, silence may be a particularly powerful sign of exclusion, however unintentional, from the family group.[52]

It is my central contention that children, of whatever age, whose brother or sister has died are also bereaved people and therefore need to be treated as such. We must avoid seeing children simply as 'extras' in the drama of bereavement, and learn rather to see them as principal 'players' in what is happening around and to them. They are not simply spectators but are intimately involved in what is happening, even when they do not necessarily show any outward emotion or may be unable to articulate how they are feeling. It may be desperately hard for the child who has looked forward to the arrival of a brother or sister, and who has already adopted the new role of big brother or big sister in the family, to understand that, although they may always *be* the big brother or sister, the longed-for baby will no longer be with them in any physical sense and the family map has to be re-drawn.[53] In losing a sibling through death, a child loses not only a playmate, companion and audience, real or imagined, but also part of his/her own identity. Thus, the grief of children is both like and unlike that of the adults around them, not least because the child is a child and not an adult.

Since the child's understanding of the grief experience is, at least in part, age-related, it is critical that grief-work is also age-appropriate, taking account not only of the child's chronological age, but also their background, emotional maturity and previous life-experiences.[54]

> Children do not exist in a vacuum. They are dependent on families which exert powerful influences on them and which, in turn, are influenced by them. Families have histories and are embedded in cultures which have helped to shape their values and their attitudes and feelings towards life and death and illness.[55]

Many of the bereavement and grief issues already raised with reference to adults also apply to children. Whilst, as we have seen, grief after pregnancy loss or death in the early *post-partum* period does not proceed along a neat gestational curve there are, nonetheless, specific issues which relate to deaths through, miscarriage, stillbirth and neo-natal deaths.

Sibling bereavement 1: Miscarriage

Where death occurs through miscarriage there are a number of factors in the event itself which can affect the grief of surviving siblings. In those circumstances where the child has not yet been told about the pregnancy, the trauma of miscarriage of a planned pregnancy can be communicated to the child as undisclosed distress. Where the parents decide not to tell the child the cause of this distress - that there has been a pregnancy which is now ended - the child may, as we have seen, fantasize about the cause of the parents' emotion. It makes little difference whether the child sees the parents visibly distressed or whether there is an attempt to 'hide' emotion from the child. Most children have an uncanny ability to sense when there is something 'wrong'. In the absence of explanation, they will provide their own. For children at an age where 'magical thinking' predominates, such fantasized explanations are often the source of great guilt as self-blame for acts, real or imagined, are made the source of the parents' grief and distress. Once again, the reassurance of a simple statement such as 'It's not your fault...' can make all the difference to the emotional well-being of a child.

Where the pregnancy has been disclosed to the child, other issues may now come to the fore. First, 'mummy is going to have baby', then she is not. Where has the baby gone? What made it go away? These are common questions asked by children whose mothers have miscarried. Where the pregnancy has been described in terms of, 'You're going to be a big brother/sister...' the questions of identity discussed earlier in this chapter will very likely be important. If the miscarriage is threatened or the mother

requires a period of hospitalization, separation anxiety can be a real issue for the surviving child or children. Such anxiety focuses not only on the well-being of the mother but the implications of her well-being for the child. 'Will mummy come back?', 'Who will look after me?' are both real, and often very threatening, issues for the sibling survivor. Where death follows a miscarriage, there has been no real or visible 'sign' of the impending sibling and now the mystery is compounded (the question, 'where did the baby come from?' may be just as puzzling to a child as 'where did the baby go?'). Furthermore, the reality of the event is hard to 'test'. Although attitudes are changing, it is still relatively unusual in the United Kingdom for parents to be offered the opportunity to see an early miscarriage and the inclusion of children in this is almost, if not entirely, unknown, certainly in the hospital context.

Sibling bereavement 2: Stillbirth

When death occurs later in the pregnancy, expectations of the impending arrival of a new baby brother or sister are often raised. Talk about the new baby and about the child's new 'status' as brother or sister is common. The child may have been encouraged to feel the baby move after quickening or involved in the preparations for the new baby, buying new things or re-decorating a bedroom. If the baby dies *in utero*, the mother may be hospitalised for a time (see above on separation anxiety) and there may be a pervading sense of grief or despondency in the family. If the stillbirth is fresh or unexpected, the sense of shock and the consequent trauma is inevitably communicated to the surviving siblings. As the pregnancy reaches its expected climax, the baby is suddenly 'snatched away'. It is still uncommon for children, especially young children, to be present at a birth and so the news of the stillbirth is most frequently communicated by the father or by another relative, often themselves still in a state of shock. Distance from the event (i.e. the fact that the children are at home and not at the hospital) can often heighten the sense of unreality and disbelief for other children in the family.[56] Whether surviving children subsequently see the stillborn

child very much depends upon the attitude of the family to the event. Parents who instinctively wish to see and hold the dead baby are, in my experience, generally more likely to include other family members, including children, in their time together. Even where parents see the baby who has died, there is sometimes the fear that this may somehow be a 'damaging' experience for a child. Reality is seldom, however, as damaging as fantasy. An excluded child runs the risk of far greater emotional and psychological threat to their well-being by the fact of their exclusion.[57] Seeing and touching the dead baby is an important way of testing the reality of the event both for parents and their surviving children

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Sibling bereavement 3: neo-natal deaths

When the baby is born seriously ill or malformed or dies in the neo-natal period, other factors may also be brought into play. Siblings may see their sick or dying brother or sister and may have the opportunity to touch or to hold the baby in the intensive care or neo-natal unit.[58] There is often, in such circumstances, a sense of 'suspended reality' on the part of some parents, while outcomes for the baby are as yet unknown or unassimilated. This is seldom the case with children, however, who generally begin to bond with their sibling straightaway, even when it may not be possible to touch the baby who is on a ventilator or in a humidi-crib. The child may wish to bring a present for the new baby and should be included, as far as possible, in any ritual acts such as blessing or baptism. Once again, it is important that surviving children should not be made to feel unwelcome interlopers in the grief of their parents but should be involved, physically and emotionally, in what is going on. When the dying process is protracted over a number of days or weeks, it is also important that siblings should be made to feel welcome visitors to the neo-natal unit and not ignored or made to feel that they are somehow in the way. Children whose parents are investing time in being with a dying baby or infant may feel that they have to vie for their parent's attention. A. Cairns and M. Clark make the following observation,

> Many parents may not recognise the siblings concern... siblings feel very isolated from their parents and from other family members and friends. The sibling know that the parents' time and attention... are directed towards the patient rather than towards their own needs. The parents in their distress, postpone attending to the need of their other children.[59]

Though children are often not as intimidated by the intensive care environment as many adults and as some of the literature suggests, they will be well aware of the heightened emotion of parents, family and friends at this time.[60] Where death is inevitable it may be helpful to talk to siblings about the fact that the baby is going to die before the death occurs.[61]

The world of the bereaved child

John Stephenson observes that, '(g)rief is a process that begins when a loss is recognised.'[62] It used to be the generally held view that the death of a child affects the parents to a much greater degree than it does siblings.[63] Undoubtedly there are differences between parental grief and sibling grief but I would argue that these reflect a difference in the nature of the relationship and it is wrong, therefore, to see such differences simply as a matter of degree. To do so, once again, minimizes and marginalises the grief of children over the death of their sibling.

So much of what has been said, however, depends on the capacity of the family as a whole to deal appropriately with the death.[64] In some families, the need to find someone to blame after a death may be very strong. Halpern's study of cot death survivors noted that,

> the discovery of the dead or moribund infant by the mother is a trauma that is often shared with an older child who may become the immediate target for the distraught mother's initial reactions...When blame and guilt cannot be tolerated by the parent who discovers the crib death, one way out may be found through the use of projection, with the focus on the conveniently available older child.[65]

For such families, 'It's your fault...' becomes a key theme.[66] There is often little recognition of the needs of grieving children in such circumstances. Indeed, for such children there may only be criticism as the parents vent their frustration at the sibling's death and the child may be left feeling guilty even for being alive.[67] For some families it may simply be that 'closeness' or emotional warmth is not the norm and so is not encouraged even in a time of crisis. In such families there is often little physical expression of feelings or relationships in terms of touching or cuddling generally and so when grief and distress are experienced or expressed they are quickly covered up and the child, who may be confused and bewildered by his/her own emotions and their intensity, learns to cover them up also.

Other families deal with the death 'better'. There will be talking, questions are answered (and even encouraged). Some parents will give their children books to read which deal with the subject of death, and some will actually go so far as to read them with them![68] Often, in such families, there will be plenty of cuddling and reassuring, the child will be drawn into the grief of the family as a whole and enabled to express their feelings in a supported way.[69]

Like adults, children may display a wide range of emotions at the time of bereavement - confusion, sadness, denial, anger and guilt may all, to a greater or lesser degree, be present as much in children as in adults. Where these emotions may not necessarily be verbalised - either because the child has picked up the signal that these are not deemed appropriate, or because the child lacks the requisite verbal skills to express adequately how they are feeling - such emotions may manifest themselves somatically, behaviourally or through changes in the child's social interaction. Withdrawal, regression, bed-wetting, sleeping problems, temper tantrums and crying are all well-documented symptoms shown by the bereaved child.[70] The child may, for example, feel guilty (even if they may not understand *why* this is so), they may be angry at their parents for being 'let down' and it will be deeply hurtful for the parent whose child says to them in a blaming way, *'Everyone else can have a baby*

brother/sister, why can't I?' or even *'I hate you...'*. In such circumstances 'bad' behaviour may not simply be about testing the limits, a 'let's-see-if-you-really-love-me' response, but a way of 'punishing' the parents for what they have 'done' or, as described earlier, invoking punishment for an imagined crime (e.g. 'making the baby die') on the part of the child. Anger may also be directed towards the baby who has died. *'Why did the stupid baby have to go and die?'* is a not uncommon question by frustrated and bewildered siblings who may feel deserted and abandoned by the baby who has died.[71] There may be real fear that what has happened to their sibling could also happen to them. Feelings, including rage, that are internal need to be externalised and ventilated. The intensity of such emotions, especially if not experienced before, may be frightening for both child and parent and children need to be re-assured both that such intense feelings are perfectly normal and that they will, in time, pass.

It may, however, be much more difficult for parents to recognise the emotions of the child whose behaviour changes go the other way. The child who is un-naturally 'good' after a bereavement may often be thought to be 'coping' well, whereas the reality may well be of a child who is afraid that if they do not 'conform' by being good or achieving, a similar fate may befall them as 'befell' their brother or sister. It may be especially difficult for parents to allay such fears as they may actually be very close to their own unspoken fear that such a tragedy could, in fact, happen again.[72] Such acting-out behaviour, both 'naughtiness' and being un-naturally 'good', may find their expression in school performance and behaviour in the school-age child.

One model of intervention

I said earlier that the experience of both seeing and touching a dead sibling may help the bereaved child and I want now to return briefly to this theme. For many children the events surrounding the death of a sibling are shrouded in mystery. First, the brother or sister is there - in the pre-birth period, 'in mummy's tummy' (and as the pregnancy continues the child may be increasingly encouraged to feel the baby kick,

etc.); *post-partum*, as a differentiated 'other' who can be seen and touched - then they are not.[73] Seeing the baby and being able to talk about what has happened, however, may very well mitigate at least some of the trauma'. Frances Dominica who has great experience in working with the siblings of dying children at Helen House in Oxford says, 'I believe that the reality of seeing a dead brother or sister is easier to cope with and kinder to the child's sensitivities than the ordeal of experience by fantasy...'.[74]

In Bristol, from the mid-1980s, all SIDS babies were brought to the Royal Hospital for Sick Children rather than to the city mortuary. For their families, as for families whose children were stillborn or who died at, or shortly after, birth, the hospital Chapel became the place where they could be together, to spend time, to talk, to grieve. Families were encouraged to grieve together and were supported through the often difficult process of communicating with each other. Parents were thus encouraged to involve siblings in what was going on and counselled about the needs of their surviving children as part of the supporting process. With encouragement, parents were helped to allow even very young siblings to express their natural curiosity and, in some circumstances, to satisfy it in an experiential way. For some, this involved what was then a novel, if not a controversial, approach, at least in the United Kingdom.

Children learn, quite naturally, to relate to a new sibling by experience. If you touch the baby, it is warm and moves; if you poke the baby, he/she may wriggle or cry. The baby moves his/her eyes and waves his/her arms and legs. It may suck its thumb. It is generally 'interesting' while attention span lasts or until something more 'interesting' distracts the child's attention. In this way a 'map' of the new baby is built up. If the baby dies, this too needs to be assimilated and to find its place on the 'map'. Although the cognitive skills of the child may be limited and 'death' as a concept may have little or no meaning, the surviving sibling may still draw experiential conclusions. If the child is permitted to see and to touch the dead sibling, he/she may be able to note that something has happened and the baby is now, in a sense, 'different'. He/she is cold to the touch, does not move or respond to stimuli (such as touching or

prodding), does not open their eyes. They may, therefore, ask questions, about the baby's 'new' state and, when these are satisfied, move on to other things. Touching comes naturally to children and children generally have little inhibition about touching the body of a dead sibling since the experience is usually one of curiosity rather than of distaste and/or fear.

An example of how this process can be facilitated is as follows: A rug is spread on the Chapel floor on which are placed some age-appropriate toys. There are chairs for the parents to sit on, or they may opt to sit on the rug too. The baby who has died is also present, either in a low crib or carry-cot or also on the rug, just as he or she might be during 'play' times at home. When the surviving sibling arrives (s)he is encouraged to explore the surroundings and to feel at home in them. He may look at and touch whatever he wishes. He may play with the toys and will often quickly settle down to play with an interesting one. He is not reminded of the baby's presence or encouraged to engage with him or her. When the child moves his attention to the baby, this is allowed to happen. Again, he may look and touch. Questions are answered, simply and honestly, by parents, if they feel able to do so, or by a member of staff who will have been present throughout - *'Why is the baby cold?', 'Is he/she hungry?', 'Why doesn't the baby move?', 'Why are his/her eyes closed? 'When will the baby wake up?'* are all questions which recurred among children involved in this approach.[75] When the child is satisfied, he or she will return to playing with the toys or ask to go.[76] Throughout, it is the child who has determined both the agenda and the timescale. The child may, like the parents, want to say 'goodbye' or simply to depart at the end of the session. Many children who are involved in this way will show little *visible* emotion but cuddles and reassurance are readily given as appropriate and are encouraged, thus affirming the parent as the primary care-giver. The grieving of others is recognised and shown not to be threatening to the child's well being. Further opportunities to talk and to question and to spend time with the baby will be offered. The family will be encouraged to continue to talk and be offered appropriate support and reassurance in their time of grieving and, hopefully, beyond it.

As already noted earlier in this chapter, play (with younger children) and painting, drawing and writing (with older children) are all ways to help children to come to terms with strong and often frightening feelings which they may lack either the vocabulary or language skills to express. C. Schultz offers a number of guidelines for talking to children about a death. These include talking to the child at eye level (neither adults nor children can effectively respond if 'talked down' to); always backing up words with touch (though in today's climate the issues of touch, with children and adults alike is a minefield for the care-giver); letting the child know what to expect (clear, simple, age appropriate explanations are a vital part of helping the bereaved child); and giving the child meaningful tasks to perform (my own experience is that, on the whole, it is more a case of giving a child 'permission' to undertake those tasks which occur naturally to them such as leaving a toy with the baby or making a card/painting a picture).[77]

What is clear in all of this is that children's grief needs to be both recognised and allowed by parents and professionals alike and there needs to be an environment in which the child can explore his/her feelings in safety and in which they can participate in the family's loss. Children need, just as adults do, to be able to talk about crises in their lives or to express them in other, perhaps non-verbal, ways and to have their questions answered immediately, simply and directly. In addition, children need a continuing relationship on which they can rely. Parents whose baby has died need to be encouraged to spend time with their surviving children, talking to them, offering them support in their own journey through grief, affirming their continued place within the family and involving them in family ritual and mourning. Such companionship of the bereaved child is itself agapeistic and enables the child to develop as a person.

Only when this happens will children be able to face the three major tasks which confront them as much as they confront their parents - (1) to come to terms with the meaning of death in an age-appropriate way; (2) to grieve for their loss; and (3) to resume the normal development of their personality.[78]

Children and spirituality

Discussions about the developing spirituality of bereaved children must take place in parallel with discussions about their developing death awareness, and it to this that I now turn in more detail.[79] The educationalist, Rebecca Nye, notes how '(c)ontemporary developmental psychology rarely acknowledges the existence of the spiritual domain in childhood.'[80] Similarly, Jacqueline Hawkins notes how,

> (r)especting children as human individuals in their own right is still a novel idea. The idea that children may have deep spiritual awareness before they are taught a religious faith is only now starting to be acknowledged.[81]

Robert Coles, one of the few medical writers to acknowledge this, argues in his book on the spiritual life of children that,

> (c)hildren try to understand not only what is happening to them but why; and in doing that, they call upon the religious life they have experienced, the spiritual values they have received, as well as other sources of potential explanation.[82]

In other words, reflecting on their experience is an important dimension in the spiritual development of children.[83] Coles believes that death, or its possibility, can be something which evokes spiritual questions and exploration in children, just as they can in adults. Indeed, he goes so far as to suggest that, 'the entire range of children's mental life can and does connect with their religious and spiritual thinking'.[84] It is certainly true to say that death, actual or impending, can occasion reflection on the meaning of life and/or on the existence or nature of God, as much in children as it can in adults. They may wonder about their own future and that of their dying or dead sibling, and so engage in a spiritual quest.[85]

Children for whom religious practice is part and parcel of their everyday life at home will talk about spiritual/religious themes much more readily, though not exclusively, than where this is not the case. Thus, children who have been taught to pray or for whom prayer is part of the fabric of their home life, will pray or 'talk' to

God more readily than where this is not so and will more readily seek out religious understanding for what is happening in their lives. It is important, however, that adults who engage in such conversations with children should use language that is appropriate to the age and development of the child and this, on the whole, means avoiding theological abstractions as far as possible.[86] The parents' own faith-approach to their situation may provide a model for that adopted by their children, although this is not always the case.

Conversations with God often feature in conversations with dying children and their siblings or friends. Such conversations may be independent of parental or familial attitudes especially if the views of parents conflict.[87] They too, after all, may be undergoing a radical re-appraisal of their own spiritual or religious attitudes and beliefs at this time. Children from agnostic or atheistic homes will seldom, however, naturally use religious language or turn to religious themes at such times although the language of some children may reflect influences other than those of their parents, such as school or grandparents.[88]

It is important that religious beliefs, values, understandings and language are not used inappropriately or introduced by care-givers without the permission of the parents, or indeed of the child. Professionals working with the bereaved family, therefore, need to take great care to understand the culture or belief system of the particular family with whom they are involved since culture and belief shape not only how people view mortality but how they face bereavement and give it meaning through shared ritual and action. Many children, and not a few adults, from many different cultural backgrounds have, nonetheless, a primitive tendency to regard God primarily as the dispenser of rewards or punishments, though this is not universally the case.[89]

In older children and adolescents this may raise the question of the problem of evil and/or suffering and of God's response to it.[90] God (or Jesus) may sometimes take on the role of a 'friend' especially if children are, for whatever reason, finding it difficult to communicate with the significant adults in their lives or are excluded from

the emotional experiences of other family members. At other times, God may be seen, especially by younger children, as a threatening figure who has the capacity to 'take children away'. Coles' conclusion about the developing spirituality of children is that (psychologically) God can take on almost any shape for children. It is thus important to listen to what each child has to say and to take our cue from them and from the family context not least in taking up religious themes or using religious language or explanations in the presence of death.

It may be very helpful for children, who may find it hard to verbalise either their feelings or beliefs, to participate in symbolic or ritual acts, whether religious or non religious, at the time of the death. The inclusion of children in baptisms or blessings and in the planning for and attendance at funerals or memorial services (see chapter on the pastoral nature of liturgy) can be both helpful and important, not least in enabling the child to test the reality of the death, provided that the child is adequately supported through the event.[91] As Young and Papadatou say, 'Shared mourning practices are as important for children as they are for adults.'[92] Indeed,

> Children are constantly being formed by what they observe from adults. The attitudes and patterns they see in us form them in habits of ritual behaviour, and even more importantly, in the habits of the heart that our ritual behaviour signifies. At funerals, children discover and are formed in what we believe about death.[93]

The bereaved child has his or her own grieving to do and needs to come to terms with the death of a brother or sister in an appropriate way for them. Older children are often curious not only about death but about the rituals which surround death. By puberty and adolescence the spiritual implications of both death and the rituals which surround it generally become more pronounced. I believe that it is important for surviving children's wishes to be taken seriously by adults and for them to play as full a part as they may wish or are able in any ritual or symbolic act. Such inclusion not only recognises and validates the child's grief but it affirms the child as someone of value in

the life of the family. The 'doing' as much as, if not more than, the 'saying' element is important for children, and to give them the opportunity to participate in family ritual can be important in making them feel a part of what is going on as well as in dispelling inappropriate fantasies. Thus, meaning (or sense) is created not given.[94] Elizabeth Kübler-Ross, who has played such a major role not only in working with the dying and the bereaved but in opening up the subject of death to public discourse, says in her book on children and death,

> There are still too many families who wonder if the surviving children should be taken to a wake and a funeral. My question is "Why not?". Wasn't it their sister or brother who died? Why should they be excluded from this final farewell ritual which serves as the only sort of closure and beginning process of "letting go". The funeral is a public acknowledgment that a person significant in our lives has died. It is a ritual that signals acceptance of this reality and puts the physical body in a final place that can be visited later on, in order to make the separation gradual. The wake and funeral serve important purposes in the grief process, and those who are excluded from them feel that they are not an important member of the family. [95]

As Kübler-Ross implies, it is also important that children's involvement does not end with the funeral itself, but that children are taken to see the baby's grave and involved in any anniversary rituals.[96] This is an important part of the follow-up support needed by the child who has attended the funeral of a sibling. Even when a child has been excluded (for whatever reason) from attending the funeral itself, there is no reason why they should not subsequently be taken to the grave-site. In this way the child is able to 'locate' the dead baby and to dispel any inappropriate fantasies about where it might be as well as making the process of separation more gentle and gradual.[97]

When a baby is miscarried or stillborn, or dies in hospital, the hospital chaplain will often be asked to take the funeral, especially if the chaplain has already been involved with the family during their time in hospital as part of the co-ordinated team approach to their care. With fewer families having their 'own' priest or minister, the funeral is increasingly devolved onto the chaplain who acts as the focal pastoral carer for the family and its needs at this time. Where parish or local church clergy are

already involved with the family, it is appropriate that, where there is a pre-existing relationship, they should take the 'lead' role. Where no local clergy were involved, I would ask the family's permission for me to contact a local priest or minister to enable follow-through care to happen in the community in which the family lived. With the high turn-over of admissions to hospital and a wide geographical catchment area, adequate pastoral through-care over an extended period, not least for children, is just not a possibility for most hospital-based chaplains.[98]

It is important to see that, with appropriate sensitivity, all those in or with the family can be an important spiritual resource for the family members, adults or children at the time of bereavement. The primary role of the hospital Chaplain or of the family priest or minister may be one of sensitive support for those who are closest to bereaved children. We will need to struggle with the hard questions like that posed by the little girl who said to me, *'If God wanted my brother, didn't he know how much I wanted him, too. God isn't being fair!'*. How hard it is for surviving children when they are told things like, *'God wanted the baby...'* or *'God took him/her because he/was special...'*. Such a God appears not as a loving carer but as a capricious power who has the capacity, and apparently the will, to snatch away. I have always resisted the tendency to describe the dying or deceased child as 'special', a tendency not only among parents but also in many books, especially those emanating from the United States which deal with the dying or dead child. The implications of this for surviving children are two-fold. Either it means that surviving children see themselves as somehow not 'special' (or, at least, less special) to their parents or others, or, if they are told, *'but, of course, you're special too...'* they run the real risk of fearing that, being special, they too will die.[99]

Conclusion

How adaptive then, are children, to the death of a sibling? A number of studies have been carried out in this area. The majority of them, however, are studies of children whose siblings have died of paediatric cancer or following a sudden infant death.[100] A child health study in Canada in the late 1980s concluded that siblings of sick children were twice as likely to develop emotional disorders as compared to siblings of healthy children.[101] Irving Leon devotes a chapter of some fifty eight pages in his book, *When a baby dies,* to what he considers a possible, 'destructive childhood stressor, potentially contributing to serious emotional disturbance.'[102] There is no doubt, however, that supportive families who function well as a family reduce the risk of disordered outcomes in their surviving children. Conversely, poor family dynamics, lack of communication and poor parental adjustment all predispose surviving children to poor mental and emotional outcomes. The study by Pettle and Lansdown, however, highlights a number of factors which surviving siblings have found helpful in their adjustment. These included already having experienced the death of a pet or a relative (prior death experience), having the opportunity to say goodbye properly (including seeing the dead brother or sister), and attending the funeral (involvement in family ritual).[103] In short, children who are actively included in the family's grief are less likely to be disturbed by the death in the longer term. It is important that, however much the dead baby is 'missed', surviving children are not made to feel that they have to 'fill the gap' or 'make up for' the dead child. Affirming the surviving child's *own* identity is important for the mental and emotional well-being of parents and child alike. A high proportion of children in Pettle and Lansdown's study suffered from low self-esteem in relation to their dead sibling especially when parents referred to their dead children as having been 'very special'.[104]

The experience of the death of a sibling, though undoubtedly a major event in a child's life, can, nonetheless, act as a catalyst for emotional and spiritual growth for the bereaved child where grief is accepted and the child supported through the

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The experience of the death of a sibling, though undoubtedly a major event in a child's life, can, nonetheless, act as a catalyst for emotional and spiritual growth for the bereaved child where grief is accepted and the child supported through the

mourning rituals and adjustment of the family. The bereaved child's appreciation of love as something to be both given and received may be deepened and their own sense of worth, self-knowledge and self-value enhanced. The bereaved child, like bereaved adults, has the capacity to grow both emotionally and spiritually through what is an un-looked for and un-wanted experience. It is simply not the case that all, even most, bereaved children are so traumatised by their experience of death that they will never recover. Even those who will carry their sadness over the death of a brother or sister for the rest of their lives may find themselves and their relationships, both present and future, strangely enriched by what they have shared within their families. Most of them, in short, will never need professional intervention, just the love and understanding of those around them. Those who have experienced pain are not necessarily scarred by it and, whether adults or children, they may also experience healing, whether mediated through others or through a deepening sense of the transcendent in their lives.

However much they may want to, parents cannot grieve *for* their surviving child or children. Each person has to grieve in their own way and in their own time. But, support is essential. Taking the time to listen to the bereaved child, to answer their questions, to talk with them and to show them (as well as to tell them) that emotions do not need to be hidden away or denied and that feelings can be shared will pay its own dividends for the future. The benefits for the child who learns, from such a show of love, that grief and grieving are normal after a death, and who are encouraged, therefore, to grieve, will be enormous in their development as whole persons. As Fiona Cathcart in her article on 'Talking to Children about Death' so aptly concludes, 'Learning to deal with death may be a process that begins in childhood but it continues to the end of our lives...'.[105]

NOTES:

1 A shorter version of this chapter under the title, 'Sibling Survivors' was originally given as a paper at a professional Study Day organised by the Foundation for the Study of Infant Death at the postgraduate centre, Hull Royal Infirmary, May 1994.

2 A. Sims, *Am I Still a Sister?* (New Mexico: Big A & Co., 1986).

3 Reflection, however, is not just a cognitive process. It can also be engaged with through play, acting out behaviour or painting and drawing, for example. Reflection is thus a process one step removed from the experience itself and is the way of either making sense of the situation or simply assimilating experience. What many younger bereaved children lack is the capacity to engage in *cognitive* reflection. It is a too frequent misconception that children are simply the passive recipients of what happens to them, not least in bereavement.

4 The question, 'Who am I?' like 'Why am I here?' is a question commonly asked of parents by their children. Such questions may be seen as part of a child's developing spirituality. When asked in the context of the death of a brother or sister, therefore, they may also be spiritual as well as existential questions.

5 Jillian Tallon, the National Secretary of the Compassionate Friends rightly observes, 'When a child dies, it is the parents - and, sometimes, especially the mother, - who are the main focus of care, but it is tremendously important to include the wider family, and most particularly the sisters and brothers.' ('The Compassionate Friends: Mutual Support by Bereaved Parents,' in J.D. Baum, F. Dominica and R.N. Woodward eds. *Listen, My Child has a Lot of Living to Do* (Oxford: Oxford University Press, 1990). p.152. Rosemary Mander recognises 'the serious deficit in research-based knowledge into the effects of perinatal loss on siblings...' R.Mander, *Loss and Bereavement in Childbearing* (Oxford: Blackwell Scientific, 1994), p.21.

6 Paradoxically, children in the late twentieth century are (potentially) exposed to 'graphic' death almost every day through television and video. Such death is, however, 'second-hand' and this may make it harder still for the child to interpret. Faced with images of death on the television news after a mortar attack on a village in the former Yugoslavia, my daughter, then aged about six, asked the telling question, 'But is it *real*?'. Children in previous generations would have been much more aware of death, if generally less violent, as 'an event in life'. Grandparents would often have died at home and the bodies laid out in the parlour, in the 'public' gaze. Similarly, with much higher levels of infant mortality, and with birth still predominantly home-based until the late 1950's, the experience of the death of a sibling was much more commonplace.

7 'How is Mourning Possible?' *Psychoanalytic Study of the Child*, 21 (1966), 93-123.

8 J. Piaget, *The Child's Construction of Reality* (London: Routledge & Kegan Paul, 1955). J. Bowlby, *Attachment and Loss.* Vol.3, Loss, Sadness and Depression (London: Hogarth Press, 1980).

9 *When a Baby Dies: Psychotherapy for Pregnancy and Newborn Loss* (New Haven: Yale University Press, 1990), p. 135.

10 Irving Leon suggests that '(b)ecause understanding the facts of perinatal death requires confronting probably two of the greatest taboos within the family - sex and death - it is not surprising that the bereaved child is left to imagine what has occurred.' (Ibid., p. 139.).

11 *Pastoral Care Revisited* (London: SCM Press, 1996), p.108. In the process models of grieving, this would be regarded as the stage of *resolution.*

12 B. Raphael, *The Anatomy of Bereavement* (London: Routledge, 1984), chap.3.

13 London: Souvenir Press (E&A) Ltd., 1979, p.91. Sarnoff Schiff, herself a bereaved parent, goes on to argue that, '(a)t the time a child dies, surviving children must become the uppermost concern - almost beyond a parent's own grief.' (p.96). This, I think, overstates the issue. For a parent to put the grief of their surviving children before their own grief carries its own inherent dangers, not least that the adults' grief will be suppressed or avoided in ways which may ultimately be unhelpful or detrimental to their emotional well-being or mental health. It is, nonetheless, true that, in the upheaval and trauma of grieving, a bereaved parent may have little or no physical or emotional energy left to invest in caring for the needs of others, including their surviving children. Whilst, on one level, it seems to make sense for them to let their surviving children stay with grandparents or with aunties and uncles, this removes the bereaved child from the source of support on which he or she most depends at a time of extreme emotional vulnerability. Even if it not verbalised, most children will interpret such actions as exclusion and attach their own meaning to it. As one woman who had faced just such a situation as a child said,

> I was angry with them because they made me feel I was being shoved aside just when I needed them most. I see now that they were incapable of giving me any more than they did.' .

(Ibid., p.84.).

14 'Talking to Children about Death,' *New Generation* Dec. (1990), 8. See also, B. Davies, 'Responses of Children to the Death of a Sibling,' in D. Papadatou and C. Papadatou eds. *Children and Death* (London: Hemisphere Publishing, 1991). Sula Wolff also argues that it is only when parents are helped to deal with their own feelings and emotions about death that they will be able to help their children. (*Children Under Stress* (London: Penguin Books, 1969).).

15 'The Invisible Loss: the Impact of Perinatal Death on Siblings,' *Journal of Psychosomatic Obstetrics and Gynaecology,* 5 (1986),10. Traumatised by an event which they have not yet, themselves, processed, parents find it much more difficult to help their child find meaning in what has happened and to integrate that meaning. Under 'normal' circumstances, parenting involves journeying with a child into territory which the parent knows well. In bereavement, parent and child may often journey into mutually unknown territory making it more difficult for the parent to support the child in, and through, the experience.

16 It is always important for carers to do their best to understand the dynamics of a particular family, which will often fall short of the 'ideal', and to work with the family and its own particular dynamics as it is and not as we expect, or would like, it to be. It is important to note that in advocating a 'systems' approach, we recognise the individuality of grieving of family members within the system. Advocating a systems approach is *not* to suggest that the needs of the individual should be subsumed or

considered to be of only secondary importance but rather to recognise that grieving is not simply an internal, psychological, process but a *social* one.

17 I believe that it is important for children to be allowed to laugh and play, not least in the early stages of bereavement and, indeed, for this actually to be encouraged. Play, for children, can be an important way of assimilating what is happening in their lives, especially 'new' experiences. Some children may need permission to laugh after a death although it is also important to affirm that sadness is alright and that it is permissible to cry. Both these things can be taught as much by example as by telling the child that this is so! Above all, children need to have hope for the future and part of that is the re-discovery of childlike ways of being.

18 The death-consciousness of children is described here in an age-related way. Whilst this is the most common methodology used by those who write about children and death, it is important to note that age is only one factor in the child's emerging death-consciousness. What is said, therefore, should be taken as a common, developmental, indicator of how children come to a maturing understanding about death and not as a benchmark.

19 'The Child's Theories Concerning Death,' *Journal of Genetic Psychology,* 73 (1948), 3-27. In her study of Hungarian children, Nagy outlined three phases in the developing death-consciousness of children. Under five years of age children are unable to conceptualise death as something permanent - death is considered more like sleep, a transitory phase. Between five and nine years the awareness of death as a fact grows, but death is still not regarded as something universally applicable. In particular, in this stage there is little understanding of what 'my death' might mean. From the age of ten onwards, children's understanding of death approximates to that of adults. Death is a natural process which will happen to everyone, including me. It is final and irrevocable. In a paper on disease-related communication, J.J. Spinetta surveys a number of objections to talking to children about death ('The Dying Child's Awareness of Death: A Review,' *Psychological Bulletin,* 81, 4 (1974), 256-60.). The issue of the awareness of death in the dying child is dealt with in a number of books and articles, e.g., Myra Bluebond-Langner, *The Private Worlds of Dying Children* (Princeton: Princeton University Press, 1978) and Dorothy Judd, *Give Sorrow Words: Working with a Dying Child* (London: Free Association Books, 1989).

20 A notable exception to this is A. Cain, I. Fast, M. Erikson and I. Vaughan, 'Children's Disturbed Reactions to their Mother's Miscarriage,' *Psychosomatic Medicine,* 26 (1964), 58-66. The study emphasised, however, the child's reaction to the grief of the mother rather than addressing the child's own grief at the death of a sibling. It is still a common misconception that the grief reaction of young children is predominantly related to the fact that the parents, and others, are upset rather than being an expression of the child's own sense of loss and bereavement. What Cain and his co-workers correctly emphasise, however, is the important fact that the child's grief is directly related to and influenced by the way in which the family unit as a whole interacts and communicates. See also, A.C. Cain, I. Fast, and M.E. Erickson, 'Children's Disturbed Reactions to the Death of a Sibling,' *American Journal of Orthopsychiatry,* 31 (1964), 741-752. It is interesting to note, however, that two of the most significant early works on caring for bereaved children, E.A. Grollman's, *Explaining Death to Children* (Boston: Beacon Press, 1967.) and I. Moriarty's, 'Mourning the Death of an Infant: The Sibling's Story,' *Journal of Pastoral Care,* 32 (1978), 22-33, were written, not by doctors or by the then rapidly emergent body of

professional counsellors, but by clergy - one Jewish and one Christian. Following on from these, Elisabeth Kübler-Ross published her book, *On Children and Death*, in the 1980s. This was aimed at a general readership rather than at professionals. She describes it on the cover as a book, 'about how children and their parents can and do cope with death.' (New York: Collier Books, 1983). Since then the number of books, for both parents and professionals, has proliferated. Books for children which can help communication between parent and child by making talk about death less threatening and which help children to see that others, too, have similar feelings and experiences to their own, have been supplemented by a wide range of work and activity books as well as by books on interventions with children for professionals, whether teachers, counsellors or clergy, e.g., B. Ward, *Good Grief - Exploring Feelings, Loss and Death with Under-11s* (London: Jessica Kingsley Publishers, 1989), (second edition 1995); S.C. Smith and M. Pennells, *Interventions with Bereaved Children* (London: Jessica Kingsley Publishers, 1995) and A. Dyregrov, *Grief in Children: A Handbook for Adults* (London: Jessica Kingsley Publishers, 1991). The Liverpool Children's Project, which closed in June 1998, also produced an excellent resource guide for those working with bereaved children. See, P. Barnard, I. Morland and J. Nagy, *Children: Bereavement: Trauma* (Liverpool: The Children's Society, 1998). This valuable resource, provided free for information and research, is now no longer available.).

21 See, J. Bowlby, *Attachment and Loss*, 3 vols. (London: Hogarth Press, 1980). Separation anxiety is a common manifestation of grief in children.

22 *The Anatomy of Bereavement*, p.95. Nonetheless, as Raphael herself acknowledges, such early relationships are mostly, 'of the interaction, the here-and-now'. (Ibid. p.75). See also, E. Furman, *A Child's Parent Dies* (New Haven: Yale University Press, 1974). Furman argues that even from the age of two years a child has a fundamental understanding of what the word 'dead' means. It is generally felt, however that children under five years old have difficulty in attaching permanence to the term. E. Burns, J. House and M. Ankenbauer concluded that even in children as young as two years old, the grief-time pattern shown was very similar to that of adults and reported that the grief of over 50% of the children in their sample lasted for more than a year. ('Sibling Grief Reactions to Sudden Infant Death Syndrome,' *Pediatrics*, 78, 3 (1986), 458-87.).

23 G. Rochin, 'How Younger Children View Death and Themselves,' in E.A. Grollman ed. *Explaining Death to Children* (Boston: Beacon Press, 1967).

24 *The Making and Breaking of Affectional Bonds* (London: Tavistock, 1979). Maureen Hicham says, 'Children are capable of having feelings that come from a place so deep down inside that they find it impossible to put them into words, not talking even when the need or want to.' ('Direct Work Techniques with the Siblings of Children Dying from Cancer,' in S.A. Smith, and M. Pennells eds. *Interventions with Bereaved Children* (London: Jessica Kingsley Publishers, 1995), p.29.). Similarly, J. McWhirter, N. Wetton and A. Hantler argue that 'children cannot suddenly, especially when experiencing a traumatic loss such as death or divorce, develop a language with which to articulate their confused range of feelings.' ('Preparing Children for Loss and Bereavement,' in R. Weston, T. Martin and Y. Anderson eds. *Loss and Bereavement: Managing Change* (Oxford: Blackwell, 1998), p. 200. Where appropriate language is absent, play fulfils an important role.

25 S. Anthony, *The Child's Discovery of Death* (London: RKP, 1940); *The Discovery of Death in Childhood and After* (Harmondsworth: Penguin Press, 1971).

26 There is a clear distinction here between 'death' and 'loss'. The child who sees a dead bird or animal by the roadside may use this to extend their understanding of what death *is* (e.g. not moving, not breathing, decaying etc.). They may even feel sad about it and experiment with, or question, such feelings. Such an experience, however, will not be such as to evoke a feeling of loss. With the death of a pet it may well be very different. Whilst the experiential components of death (i.e. what death *is*...) are present, so also is a sense of loss, and thus of bereavement. The death of a pet, therefore, will involve the child in a greater 'learning curve'. Likewise, it is important to distinguish between a developmental interest in death and the development which comes through the actual, lived experience of the child whose brother or sister has died.

27 Note here the distinction between *general* questions about death and *specific* questions about *this* death, in particular. Ian McEwan describes a conversation between two children, aged seven and four, facing the funeral of their grandmother. In response to the four year old's assertion that the grandmother won't 'like' being buried, the seven year old retorts, 'She's dead, stupid. Stone cold dead. She doesn't know anything about it...' and when he raises the question, 'When is she coming back?' he replies, 'Never ever ever ever...' (*Black Dogs* (London: Picador, 1992), p.63).

28 Peta Hemmings says, 'A bereaved child has knowledge beyond her years... the world has become a fearful and a dangerous place.' 'Communicating with Children through Play,' in S.A. Smith, and M. Pennells eds. *Interventions with Bereaved Children* (London: Jessica Kingsley Publishers, 1995), p.9.

29 In some extreme circumstances this may lead to 'splitting' - the psychological distancing that may be unconsciously employed to protect the self (ego) from difficult or painful emotions. 'Splitting' may become a learned response and may be carried over into later life where its use may persist. In such circumstances, individuals may appear emotionally 'cold' or detached from the situation surrounding them. It is important, however, to distinguish this from denial which is generally much more transitory.

30 Yalom would also agree that such feelings may exist in much younger children. See, I.D.Yalom, *Existential Psychotherapy* (New York: Basic Books, 1980).

31 This example underlines the importance of listening to children's fears with sensitivity. For many bereaved children, the fear that they, too, will die is often the result of the fact that they are unclear about the causes of death and so are much more likely to draw false inferences about death. A good example of an association of death with a *place* rather than with a *time* is of a child in hospital who had been taken to another hospital for more specialised treatment. In the first hospital, children who died were described by (some) staff as having 'gone to the thirteenth floor'. Unfortunately, the second hospital actually had a thirteenth floor and when the child was in the lift and was told that they were being taken to the thirteenth floor they immediately became hysterical. No child whom they could remember having been taken to the thirteenth floor had ever come back! Small wonder, then, that the child should fear for its own safety and well-being under such circumstances. Borg and Lasker cite the example of a three year old about to visit an aunt's new baby a few months after his own mother's stillbirth saying, 'Let's go now before the baby dies...'. S. Borg and J.

Lasker, *When Pregnancy Fails: Coping with Miscarriage, Stillbirth and Infant Death* (London: Routledge and Kegan Paul, 1982), p.102.

32 John Bradford argues that a child's need to experience love, like his/her need for security, creative experiences, affirmation and a sense of belonging can also be described in terms of love, peace, wonder, confidence and relatedness. (*Caring for the Whole Child: A Holistic Approach to Spirituality* (London: The Children's Society, 1995), p.4.). These categories are described by Bradford as human-spiritual needs, spiritual needs which every child may be said to have irrespective of any religious affiliation or belief. Deprivation in the human-spiritual needs of children may often be evidenced in the aftermath of bereavement. Bradford also argues that nurtural damage of the child's spirituality may be caused both by disruptive changes in home circumstances and by exclusion from family or community gatherings. (Ibid., p.11). The disruption caused by the death of a child and the exclusion of children from funerals or other family rituals is a prime example of where such damage may be caused.

33 See, R. Kastenbaum and I. Aisenberg, *The Psychology of Death* (New York: Springer, 1972).

34 This is something that comes across very clearly in Alicia Sim's book, *Am I Still a Sister?*

35 The Compassionate Friends leaflet, *'When a Child in Your School is Bereaved'*, deals with supporting the bereaved child in the school environment. Many bereaved children are sent back to school as soon as possible after a bereavement in the belief that re-establishing a normal routine will provide a distraction from, or mitigate, the pain they feel.

36 C.M. Parkes, *Bereavement: Studies of Grief in Adult Life* (London: Tavistock, 1972).

37 Nonetheless, the idea of heaven as a *locational*, rather than a theological, construct may be strong. In one study, 74% of children, bereaved through the death of a parent, located the deceased by describing them as being 'in heaven'. (P.R. Silverman and S.L. Nickman, 'Children's Construction of their Dead Parents,' in *Continuing Bonds: New Understandings of Grief* (London and Boston: Taylor and Francis, 1996), pp. 73-86.

38 There are many variants on this theme. Amongst the most common, even in 'non-believing' families, is the idea that the dead baby has 'gone to be an angel'. This theme is remarkably persistent and can be found in many Victorian accounts of infant death (though seldom there of the child who dies in the pre-natal period) and on many Victorian funerary inscriptions. A revealing collection of such inscriptions can be found in the now dis-used Beckett Street Cemetery in Leeds. The persistence of particular imagery through to the late-twentieth century is remarkable and the inscriptions on Victorian tombstones often have uncanny parallels in the contemporary memorial books of maternity and children's hospitals. These are a relatively late development which began in the 1980s as a result of an initiative taken by the Miscarriage Association. The predominant images, even in the midst of the scientific rationalism and scepticism of the twentieth century are of children as angels or flowers who have gone to be 'with Jesus/God'. A much more difficult concept, though exceedingly common, is that such children have been 'taken' by God. Two particularly recurrent phrases in this context are, *'God wanted him for an angel...'* and *'Jesus picks*

all the best flowers...'. Whilst these can be ways of expressing the 'value' and importance of such children to their parents (and therefore, by implication, to God), it can be as frightening for children to be left with the idea that death is an 'idealization' (the idea that children who die are 'special' children), as for them to be left with the idea that death is a form of 'punishment' (the idea of being 'sent away'). On children who have died as 'special' children and on the problems of idealisation see later in this chapter. Richard Lansdown notes, however, that even today, there are 'remarkably few children under the age of about 8 or 9 years (who) do not have some notion of an afterlife, even if there has been no teaching of religion at home.' R. Lansdown, 'Communicating with Children,' in A. Goldman ed. *Care of the Dying Child* (Oxford: Oxford University Press, 1994), p. 97.

39 I know of one child who, after his father died, ran away from home on several occasions. On each occasion he was found trying to get to the local airport. His association with heaven being 'up in the sky' was worked out in trying to be re-united with his dead father. Another child associated heaven with helicopters since his dying sibling was taken to hospital, from which he did not return, by air ambulance. He believed thereafter that the role of helicopters was to take the dying/dead to heaven. Children may be particularly concerned with where the dead person is 'located'. They want to know where heaven *is* and what people eat there. It can be important for them to construct a picture of where the baby is and they may seek to do this primarily through drawing. I am reminded nonetheless of Austin Farrer's dictum that, 'it is useless to speculate on either the furniture of heaven or the temperature of hell.' (*Saving Belief* (London: Hodder and Stoughton, 1964), p.140). For many bereaved children, however, (as for many adults) the idea of a dead baby who is 'lost', or not 'located' somewhere, may be a frightening concept. The theme of locating the dead has been a central one in many anthropological accounts of grief from Van Gennep onwards and is one of the functions of death rituals. See later chapter.

40 H. Turnbull, *The Concept of Death in Bereaved and Non-bereaved Latent and Adolescent children, Related to Attribution and School Performance.* Master's thesis, University of NSW, Australia, 1980. A.L. Wainwright, *Children's Perception of and Affective Responses to Death.* Master's thesis, University of NSW, Australia, 1980.

41 The death of a baby whose parents are in the adolescent period can thus prove particularly problematic. Caught between childhood and adulthood, such parents often lack the emotional maturity for parenthood, let alone for the demand of being bereaved parents. The emotions surrounding the death of their child may be compounded by other sorrows, perhaps less recognised, for a lost childhood in which others could 'make things better' or by a sense of failure by those so newly trying to make their way as adults in a 'grown up' world.

42 One important exception to this is the 'second' family. With increasing numbers of second relationships where there are already children from the first relationship, the age gap between siblings will often be greater.

43 Yalom, *Existential Psychotherapy.*

44 'Magical Thinking' has tended to focus on the potential *rivalry* between siblings. It is important to remember that the dead sibling is also regarded as a potential playmate, companion, friend and audience. Positive thoughts about the baby need to be taken into account at this time just as much as any negative ones. Where

positive and negative thoughts about the baby conflict, this is described as 'ambivalence'.

45 I believe that this is important not only for children, but also for adults who may feel that, whatever the circumstances, they are somehow to blame. It is important for parents whose baby has died to be given clear, simple information as quickly as possible, not only about what has happened but what will happen next, in enabling them to regain some degree of control in their lives (see previous chapters). I am a strong advocate of using the words 'died' and 'dead' as opposed to, 'gone away', 'gone to be with God/Jesus/Grandma...', 'been taken...', 'become a star...' or other variants on these. The use of euphemisms serves only to compound confusion and mis-understanding rather than 'softening' the impact of death. Not only is what is said important, *how* it is said is important, too. A child who hears the whispered message that his parents have 'lost' the baby can easily fear that he may be the next victim of such parental carelessness!

46 'Children and Bereavement,' *Community Paediatric Group Newsletter*, Spring (1990), p.4.

47 Earl Grollman, whose early ground-breaking work with bereaved children is now over thirty years old says,

> Death is a crisis which should be shared by all members of the family. Children are all too often forgotten by grieving adults. Silence and secrecy deprive them of an important opportunity to share grief.

('Grieving Children: Can We Answer Their Questions?' in K.J. Doka ed. *Children Mourning: Mourning Children* (Washington DC: Hospice Foundation of America, 1995), p.17.). Susan Foster, a headteacher, says, 'Children should be encouraged to talk freely about being born and about dying and death. They need to express their fears and fantasies to someone who can listen.' ('Explaining Death to Children,' *British Medical Journal*, 282 (1981), 540-542.). As Maureen Hitcham says, 'Inside every child there is a story waiting to be told, but when that story involves difficult issues such as death and dying it is neither easy to tell nor is it easy to listen to.' ('Direct Work Techniques With the Siblings of Children Dying from Cancer' in S.A. Smith and M.Pennels eds. *Interventions with Bereaved Children* (London: Jessica Kingsley Publishers, 1995), p.24.). Dorothy Judd in her work as a psychotherapist with dying children questions whether children have an innate fear of death or whether this is something which is learned from adults. (*Give Sorrow Words: Working with a Dying Child* (London: Free Association Books, 1989), p.4.).

48 Handling, washing or dressing the baby are not simply tasks to be undertaken but form part of a complex ritual of acknowledging the baby and of his/her relation to the family (see previous chapters). Such actions are thus symbolic as well as practical. It is important that children are included in such family rituals.

49 The first of William Worden's 'tasks' of mourning is 'to accept the reality of the loss'. J.W. Worden, *Grief Counselling and Grief Therapy* Second edition (London: Routledge, 1991), p.10.

50 Such gifts are usually 'intimate' gifts. Rather than being something bought specially for the baby, the significance of the gift often lies primarily in its significance to the giver. A much loved teddy bear or a favourite toy car, however old or worn, may carry a much deeper significance in its being 'given' to the sibling as something of real 'value' than something bought especially for the occasion. Such giving may have a

real 'sacrificial' quality about it and may form a significant expression of the child's relationship with their dead sibling and needs to be affirmed as such. It can also be important for children to have something of, or from, the baby, perhaps a photograph, which they can 'own', a tangible reminder of their siblings existence and importance. It is also important to note that, where death occurs in the pre- or perinatal period, saying 'hello' is as important a part of what is going on as saying 'goodbye'.

51 Even as early as 1959 A.J Solnit and M. Green, uncharacterstically for this period, remarked on the importance of talking to children about the death of a sibling:

> Silence is often interpreted as the fact that the mother has something dreadful to hide such as the murder or rejection of the baby and therefore in consequence they are markedly concerned about their own future.

('Psychological Considerations in the Management of Death in Paediatric Hospital Services,' *Paediatrics*, 26 (1959), 106-112.).

52 Integration and exclusion are themes explored more fully in the context of abuse in A. I. McFadyen, *Bound To Sin: Abuse, Holocaust and the Christian Doctrine of Sin* (Cambridge: Cambridge University Press, 2000), Chapter 4.

53 J. Culbertson, H. Kraus and R. Bendell eds. *SIDS - Medical Aspects and Psychological Management* (London: Edward Arnold, 1988). See also, R. Rabkin and L. Krell (1979). 'The Effects of Sibling Death on the Surviving Child: A Family Perspective,' *Family Process*, 18 (1979), 471-77.

54 See, Charles Corr, 'Children's Understandings of Death' in *Children Mourning: Mourning Children* pp.3-16. Charles Corr demonstrates how cognitive development in children is conditioned both by the child's previous experiences and by the culture in which they brought up.

55 J. Cadranell, 'Talking About Death - Parents and Children,' in L. Hill ed. *Caring for Dying Children and their Families* (London: Chapman and Hall, 1994), p.40.

56 Even very young children may display the commonly described characteristics of bereavement. There may be shock or disbelief, anger (however displaced) and sadness, though varying considerably in degree dependent upon such factors as the child's age, emotional maturity, expectations of, or involvement with, the pregnancy, or even the number of other siblings.

57 Exclusion is, as we have seen, often equated with punishment or even with banishment and may be interpreted either as a sign of parental displeasure or as a sign of the removal of love for the child even though this is seldom the case.

58 On the place of the sibling child in the intensive care unit see chapter on neo-natal deaths.

59 'Adaptation of Siblings to Childhood Malignancy,' *Journal of Paediatrics*, 95, 3 (1979), 484-87.

60 On the SCBU at Bristol Maternity Hospital a room was set aside as a 'play room' for children whose siblings were on the unit. This not only made the visit to the unit a more attractive proposition for siblings, whose attention span on the baby would inevitably be limited, but also provided a useful diversion for children to allow their parents much-needed time with the sick child. Observing the play of such children in the play room could be an enlightening experience. Children would often tell the dolls

or teddies how they were feeling and how they perceived what was going on. An old telephone switchboard excellently facilitated 'pretend' conversations. As Chaplain, I always tried to spend some time with children in this room listening to them play and engaging them in conversation when this was appropriate.

61 I. Martinson and G.D. Armstrong suggest that the cause of death may be confusing for siblings when their brother or sister dies in hospital (i.e. some children may fear that it is the hospitalisation rather than the illness which was the cause of death). ('Home Care for Children Dying of Cancer,' *Paediatrics*, 62, 1 (1978),106-13.). Zoe Smialek also underlines the need for good, age-appropriate explanations to avoid confusion and misunderstanding in the bereaved child. ('Observations on the Immediate Reactions of Families to SIDS,' *Paediatrics*, 62, 2 (1978),160-165.).

62 'Grief of Siblings,' in T.A. Rando ed. *Parental Loss of a Child* (Illinois: Research Press Company, 1986), p.329.

63 See, for example, Raphael, *The Anatomy of Bereavement*, 'The child will grieve the death of a sibling... just as surely (as that of a parent) but by no means as intensely...' (p. 113). The evidence for diminished intensity in grieving after the death of a sibling is by no means conclusive.

64 The following section owes its structure, in part, to the work of Beverley Raphael in, *The Anatomy of Bereavement*, Chap.3. 'The Bereaved Child'. Section on, 'The Influence of the Family', pp. 114-119. Raphael's work is paradigmatic of much that has been written on age-determined responses to death in children and on the impact of the family system on children's grief and grieving although her section on the grief of children following miscarriage, stillbirth or neonatal death is itself slight and inconclusive. The work of P.R. Silverman and J.W. Worden on the significance of the family is also of importance here. See, 'Children's Reaction to the Death of a Parent,' in M.S. Stroebe, W. Stroebe and R.O Hansson eds. *Handbook of Bereavement: Theory, Research and Intervention* (Cambridge: Cambridge University Press, 1993), pp.300-316. They argue that, 'the child's social context (provides) a frame of reference for the experience of mourning' and that this is determinant of grief outcomes in children. (p.311).

65 W.I. Halpern, 'Some Psychological Sequelae to Crib Death,' *American Journal of Psychiatry*, 129, 4 (Oct.1972), 58f.

66 Raphael notes that in such families a high or extreme expectation of 'good' behaviour is often placed upon surviving children. Such expectations may be persistent and last for many years 'Your brother (or sister) would never have done that...' becomes the un-spoken or spoken criticism - a burden for any child for whom competing with an idealised sibling can be an unattainable goal.

67 I have known such guilt to precipitate a suicide attempt in a child as young as eight years old. G. Pollock describes such guilt in terms of 'survivor' guilt although I think that the impact of such thinking, more common in grandparents (*'I've had my life, why couldn't it have been me that died...)* is here overstated in relation to siblings. ('On Siblings, Childhood Sibling Loss, and Creativity,' *The Annals of Psychoanalysis*, 6 (1978), 443-481.). There is no doubt, however, that children can suffer from depression following the death of a sibling that is, at times, acute.

68 The range of books now available is extensive in both number and quality.

69 Deborah Davies sees four of the critical factors in determining how children in the family respond to the death of their baby as: 1. Their level of understanding about death; 2. Their relationship with the baby; 3. Their reactions to the parents' grief; 4. The support and reassurance they receive. (*Empty Cradle, Broken Heart: Surviving the Death of Your Baby* (Colorado: Fulcrum Publishing, 1991), p.123.). See also, B. Monroe, 'It is Impossible Not to Communicate - Helping the Grieving Family,' in *Interventions with Bereaved Children*. Barbara Monroe also says that children need help in four main areas: 1. information, 2. reassurance, 3. the expression of feelings and, 4. an opportunity to be involved in what is happening. (p.89).

70 In the study by F. Mandell, E.H. McAnulty and A. Carlson, 'Unexpected Death of an Infant Sibling,' *Pediatrics*, 72, 5 (1983), 652-57, which looked at 35 SIDS surviving children, 69% experienced disrupted sleep patterns, changes in patterns of social interaction or changes in eating habits. A headache or tummy-ache may express emotional as well as somatic distress.

71 Children may also 'cover' their feelings by feigned disinterest or even callousness. It may be hard for parents to understand that a child who says, *'well I wanted my room back anyway...'* is not necessarily simply being cruel or un-caring.

72 In some circumstances this fear that tragedy might strike again leads parents to over-protect their surviving children. This may sometimes, itself, become a source of conflict and of anxiety in the child. Conversely, the belief that God takes 'good' children may predispose a surviving child to naughtiness as a survival strategy.

73 Whilst Raphael correctly suggests that the child's reaction to the death of a sibling will be influenced by the prior relationship between them, her view that powerful feelings are likely to be less intense than when a parent dies is not necessarily correct. As for the parent, this will depend on the meaning of the sibling for the child. Particularly for a first child, for whom the new baby may represent not only a companion or playmate but a new status among his or her peers, the death of a baby may be overwhelming. For younger children, especially prone to 'magical' thinking, the guilty feeling that they may somehow have 'caused' their sibling's death may, for some children, be almost too much to bear. I would contend that while the feelings that accompany the death of a brother or sister are undoubtedly *different* from those which accompany the death of a parent (e.g. in terms of separation anxiety), they may be equally as intense and their affects may well be the same.

74 'Reflections on Death in Childhood,' *BMJ*, 249 (1987), 109.

75 Other questions, which may be asked at any stage may include questions like, *'where has the baby gone?', 'who will look after her?', 'will I die?', 'will you die?', 'how long do you stay dead for?'*. Such questions my be both 'intellectual' (i.e how the child understands death as a concept) and 'experiential' (i.e. how does this 'thing' called 'death' relate to me?). In 1974 Gerald Koocher of the Children's Hospital Medical Centre in Boston interviewed a group of 75 children between the ages of six and fifteen years about their understanding of death and, in particular, about how they understood the possibility of their own death. In the study the children were asked four questions, (1) What makes things die?, (2) How do you make dead things come back to life?, (3) When will you die? and (4) What will happen then? Koocher's research showed that the older the child the more likely they were to be able to handle abstraction. He concluded that there should be no 'unspoken barriers' since children are remarkably capable about talking about death and indeed may be quite willing to

do so. It is important to note, however, that Koocher's research was done with children on a variety of summer camps and not with children facing the immediacy of death either in themselves or others. ('Talking With Children About Death,' *American Journal of Orthopsychiatry*, 44, 3 (1974), 404-411.).

76 In the study by S.M. Krasnet and H. Beinart, 'The Monday Group: A Brief Intervention with the Siblings of Infants who Died from Sudden Infant Death Syndrome (S.I.D.S),' *ACCP Newsletter* 11, 4 (July, 1989), 11-17, the children naturally dictated when a particular line of questioning was concluded by all going to the toilet.

77 'Grieving Children,' *Critical Care Update*, 9, 2 (1982), 26-32.

78 It is important to note that such an approach is not applicable in every situation. It can be emotionally demanding for parents and professionals alike and careful preparation and consultation needs to be undertaken between the family and those others who are to be involved if this approach is to used. Some nursing staff with whom I worked, initially found such an approach too demanding and did not wish to be further involved. Some parents could not face this process in the rawness of their own grief and so other techniques were used instead.

79 Defining what is meant by words like 'spiritual' and 'spirituality' is notably difficult. I warm to Becker's definition of spirituality as 'a code word for the depth dimension of human existence.' W. Becker, 'Spiritual Struggle in Contemporary America,' *Theology Today*, 51, 2 (1994), p. 257. Thus spirituality has an irreducible relational component as well as being descriptive of the experience of transcendence. David Aldridge sees a major aspect of spirituality as 'a way of becoming, engaging a challenging world through a developing self.' (*Spirituality, Healing and Medicine* (London: Jessica Kingsley, 2000), p.48.). It involves also, therefore, the search for, and, ultimately, the attribution of, meaning.

80 'Childhood Spirituality and Contemporary Developmental Psychology.' in R. Best ed. *Education, Spirituality and the Whole Child* (London: Cassell, 1996), p.108.

81 J. Hawkins, 'Foreword,' *The Spirituality of Children.* The Way Supplement, 86 (1996), p.3.

82 *The Spiritual Life of Children* English edition, (London: Harper Collins, 1992), p.100. Robert Coles served his residency at the Massachusetts General Hospital in the 1950's where Erich Lindemann was chief of the psychiatric services. The influence of Lindemann's psychoanalytic approach is evident throughout the book, although Coles is careful to guard against a purely psychological or psychiatric perspective in his work. See especially Chapter 5, 'Young Spirituality: Psychological Themes,' pp.98-128. The reference to the religious life which the child has experienced and to the spiritual values which they have received is what Bradford would describe under the category of devotional spirituality as opposed to human spirituality (i.e. it describes something experienced or learned within the context of a shared faith rather than as an inherent quality). In such circumstances the religious beliefs and affiliations of the child's parents are a part of his/her own identity. (J. Bradford, *Caring for the Whole Child*). Bradford has a third category of spirituality which he describes as 'practical' spirituality which is evidenced through the child's capacity for affection and resilience and through the capacity for both enquiry and reflection through which self-confidence and an appreciation of community (and one's own responsibility to others within than community) can grow. He argues that it is practical spirituality which gives

the child 'the capacity for coping constructively with difficulty and dissonance.' (Ibid., p.27).

83 An important contribution to the debate about faith/spiritual development, although primarily geared towards adults, is to be found in the work of James Fowler. See *Stages of Faith* (San Francisco: Harper Collins, 1976). Fowler owes much to the psychological 'stage' theories of development of Erikson, Piaget and Kohlberg. The second of Fowler's seven stages of faith development, the intuitive-projective, may be seen to parallel the position of the young child who is influenced by the example of the adults around him/her. God is often imagined as an adult figure and the child may copy the religious practices of adults without understanding their significance. In the mythic-literal stage (3), the child begins to internalise, and therefore to own, religious beliefs, while in the synthetic-conventional stage (4), the child, often in early adolescence, begins to question the religious beliefs or practices of the family or group.

84 Coles contends that, '(m)oral attitudes, including emotions such as shame and guilt, are a major psychological and sometimes psychiatric side of young spirituality'. (*The Spiritual Life of Children*, p.108).

85 Heinrich Brückner, a German paediatrician, describes such experiences as being 'on the edge of transcendence' (*an der Grenze zur Transzendenz*). ('Kinder Zwischen Naiver Und Intellektueller Religiosität,' *Religiösen Gesellschaft der Freunde* (1996), p.8.). He argues that scientific/ psychological models are inadequate to account for a child's experience. Such experiences are, he says, 'mystical' (*mystischen*) or a form of continuing revelation, a concept he finds in the writings of Martin Buber.

86 Children process information differently at different ages. The younger the child, the more limited their vocabulary and the more concrete their thinking. This is important not only in talking *to* children but also in understanding what a child may *really* be saying or asking in their talk about the death.

87 For example, one parent may have a religious faith that is not shared by their partner or, even where there is a shared faith, the death of a child may impact upon the adult's faith in very different ways. One may turn to his/her faith for solace and comfort, the other may find their faith in a good and loving God shattered and therefore, either temporarily or permanently, untenable. To hear one parent say that God is 'looking after' the baby while the other is saying that God does not exist can be profoundly disturbing and deeply confusing for their children. Conflict between parents can be carried over into the way in which they relate to their other children in many ways. See, R. Krell and L. Rabkin, 'The Effects of Sibling Death on the Surviving Child,' *Family Process*, 18 (1979), 471-477.

88 In 1974, Gerald Koocher made the following observation,

> While no data were gathered on church affiliation or parental theism, it seems a bit surprising that little in the way of detailed religious concepts of death and its concomitants was elicited. In fact, only seven percent of children in the study used the word 'god' in answering the questions. Another 21% referred to this somewhat indirectly, mentioning heaven , hell, or some unearthly afterlife, but still this may seem rather low.

('Talking with children about death,' *American Journal of Orthopsychiatry*, 44, 3 (1974), 410.). Koocher concludes that this may be because the influence of media portrayals of death, including cartoons and television, on American children gave minimal weight to religious views or content. Even in 1974, however, he suggested that this absence of reference to God and/or an afterlife might also be due to 'the growing disillusionment with religion as a mode of coping with death.' (411). In contrast, in the study by P.R. Silverman and J.W. Worden, also conducted in America, of 125 children interviewed, 92 children (74%) believed in a 'place' called 'heaven'. The study concluded that in these children there was no statistical relationship between the children's expressed beliefs and their religious background. ('Children's Reactions to the Death of a Parent in the Early Months After a Death,' *American Journal of Orthopsychiatry*, 62 (1992), 93-104. A revised version of this paper was published by Silverman, Nickman and Worden as 'Detachment Re-visited: The Child's Reconstruction of a Dead Parent,' in Doka, *Children Mourning: Mourning Children*, pp.131-148. See also, R. Lansdown, 'Communicating With Children,' in A. Goldman ed. *Care of the Dying Child* (Oxford: Oxford University Press, 1994), pp.93-106. Richard Lansdown contends that, '(r)emarkably few children under the age of about 8 or 9 years do not have some notion of an afterlife, even if there has been no teaching of religion at home.' (p.97). It is important however that if belief in an afterlife is shared, the physical finality of death is also acknowledged as many younger children, especially those in two to eight years age range see death as life continuing but under different or changed circumstances. For some children, their very literal interpretations can lead to anxiety that the baby is still alive somewhere else and unable to return.

89 As we have seen, the tendency to see God in terms of the dispenser of rewards and punishments is one which is deeply rooted. Miscarriage, stillbirth or neo-natal deaths are often interpreted as being 'punishments' for past 'crimes', real or imagined. A miscarriage where there has been a previous termination of a pregnancy (abortion) even many years previously is often interpreted as a 'punishment' from God for killing a prior baby. It is not hard to understand the roots of such belief and very early on in their lives children are taught that things that happen to them have a cause.

90 Elizabeth Kübler-Ross suggests that human beings have four developmental *'quadrants'*. The first, from birth to one year is what she describes as the *physical* quadrant. The second, from one to six years is the *emotional* quadrant. This is followed from about the age of six years by the *intellectual* quadrant, with the fourth quadrant - which Kubler-Ross describes as the *spiritual/intuitive* developing from early adolescence. (*On Children and Death* (New York: Collier Books, 1983) Chapter 5, 'The Natural way to Prepare Children for Life,' pp.60-76.).

91 Whilst most workers in the field of death studies consider the attendance of siblings at the funeral to be beneficial to the grieving processes of the child there are, nonetheless, voices who sound a warning. D. McCown, for example, questions the benefit of funeral attendance in young children since he believes that many, if not most, parents fail either to prepare their surviving children for the emotional act of the funeral or to explain to them what will happen. ('Funeral Attendance, Cremation and Young Siblings,' *Death Education*, 8 (1984), 349-363). It is crucial that, if a child is to attend the funeral of a brother or sister, then they are both adequately prepared and adequately supported through the experience. Harriet Sarnoff Schiff says of her own experience, 'My daughter, then four, did not attend the funeral... She is resentful even

after all these years that she was cheated of the experience.' (*The Bereaved Parent*, p.14.).

92 B. Young and D. Papadatou, 'Childhood Death and Bereavement Across Cultures,' in C.M. Parkes, P. Laungani and B.Young eds. *Death and Bereavement Across Cultures* (London: Routledge, 1997), p. 200. This view is endorsed by Earl Grollman: 'Death is a crisis which should be shared by *all members of the family* (my stress)... silence and secrecy deprive them of an important opportunity to share grief.' ('Grieving Children: Can We Answer Their Questions?' in Doka, *Children Mourning: Mourning Children*, p.17.).

93 K.Hughes, *Saying Amen: A Mystagogy of Sacrament* (Archdiocese of Chicago: Liturgy Training Publications, 1999), p.176.

94 See, M. Kavanagh, 'Spiritual Care,' in L. Hill ed. *Caring for Dying Children and their Families* (London: Chapman and Hall, 1994), pp.106-122.

95 Kûbler-Ross, *On Children and Death*, p.6.

96 Anniversaries are often important 'markers' for bereaved siblings. Questions like, *'How old would the baby be if it were alive now?'* are commonplace. It is important to remember, however, that anniversaries can also be times of great emotional strain.

97 In my conversations with mothers whose babies had been miscarried and who had not been involved with the disposal of the remains, there was a high incidence of anxiety about where the baby might 'be'. Some women were disturbed by thoughts that the dead baby was *'in a kind of limbo'* or *'just floating around'*. The importance of the funeral lies not just in the disposing of human remains but in locating the deceased in a 'safe' place. Going to see a grave or the spot where ashes have been scattered may help siblings to dispel unhelpful and errant ideas about graves or graveyards which may have been gleaned from cartoons, comics or videos. See, P. Aries, *The Hour of our Death* Trans. Helen Weaver (Harmondsworth: Penguin Books, 1981); D.G. Davies, *Death, Ritual and Belief* (London: Cassell, 1997); P.C. Jupp and T. Rogers ed. *Interpreting Death: Christian Theology and Pastoral Practice* (London: Cassell, 1997). This may be particularly important for children who have difficulty in conceptualising the permanence of physical death and who may similarly think of the baby continuing to exist elsewhere.

98 I believe that the referral to local clergy by the hospital chaplain in terms of their pastoral or spiritual care is both important and is analogous to the consultant's referral of the family to their local GP. Such referral should, however, only be made after consultation with those involved and with their express permission. Such referral is particularly important in terms of the care of siblings and/or other family members since the focus of the chaplain's care, though it should always strive to encompass the family as a unit, is inevitably primarily with the person who is 'in' hospital. Where children are involved I would suggest that parents inform the school, play-group, or other groups with which the child is involved about what has happened. Some children try to 'protect' their families from their grief (just as parents may try to 'protect' their children) and so may use other appropriate and trusted adults such as teachers, youth-group leaders or clergy as their confidants. It is also important to note that, where there are other siblings, they may be a source of peer-support. In my experience it is unusual for bereaved children, particularly younger children, to use other children who are not family members (e.g. friends) as a source of support. *'They wouldn't*

understand' is a frequent response in such circumstances although it is generally felt that peers are of great importance in fulfilling roles that cannot generally be filled by other adults. An exception to this is the support which can be offered, usually in the group setting by other similarly bereaved children. A description of one such group-based project, 'Camp Winston' can be found in Smith and Pennells, *Interventions with Bereaved Children*, pp.172-192. 'Winston's Wish', a grief support programme for children was first set up in Gloucestershire in 1992 as a non-pathological service and deals with factual, emotional and spiritual questions in a non-threatening atmosphere using a variety of verbal, play, drama and experiential techniques. It is important, I believe, to distinguish clearly between groups which offer support and groups which offer therapy. Camp Winston is an example of the former type.

99 This again underlines the danger of using phrases like 'special' children, 'gone to sleep', or 'you'll be the death of me...' with children whose understanding of such phrases may be, 'I'm not special', 'I'll die if I go to sleep', 'I could cause mummy to die too'. There is, of course, the danger that the dying or dead child *will* actually be regarded as special and idealised by the parents. It is hard for children to have to compete with an idealised sibling who can never be naughty or fail to live up to parental expectations. Some children struggle for many years, if not for the rest of their lives, to escape from the shadow of an idealised dead sibling. Such idealisation can be the cause of deep and long lasting resentment on the part of surviving siblings. This phrase, 'someone special' even appears in the title of a publication for children of no less an organisation than St.Christopher's Hospice at Sydenham in London. Department of Social Work, St.Christopher's Hospice, *Someone Special Has Died* (London: St. Christopher's Hospice, 1989).

100 See, for example, N.U. Cairns, G.M. Clark and S.D. Smith, 'Adaption of Siblings to Childhood Malignancy,' *Journal of Paediatrics*, 95 (1979), 484-7. M. Pettle and R.G. Lansdown, 'Adjustment to the Death of a Sibling,' *Archives of Disease in Childhood*, 61 (1986), 278-83. S.M. Krasner and H. Beinart, 'The Monday Group: A Brief Intervention with the Siblings of Infants who Died from Sudden Infant Death Syndrome,' ACCP Newsletter, 2, 4 (July 1989), 11-16.

101 D. Cadman, M. Boyle and D.R. Offord, 'The Ontario Child Health Study: Social Adjustment and Mental Health of Siblings of Children with Chronic Health Problems,' *Developmental and Behavioural Paediatrics*, 9 (1988), 117-21. This study was predominantly of siblings who had long-term chronic illnesses and did not specifically address outcomes of children whose siblings died in the peri-natal or infant period.

102 *When a Baby Dies*, p.131.

103 Pettle and Lansdown, 'Adjustment to the Death of a Sibling,' 278-83.

104 See earlier in this chapter on idealisation.

105 F. Cathcart, 'Talking to Children about Death,' *New Generation*, (Dec.1990), 8.

Chapter 6. Liturgy and Pastoral Practice

"You say 'goodbye', I say 'hello'..."

The Beatles

"Death is like being born backwards."

Philip (Aged 8)

Introduction

For those who take a predominantly functional view of ritual, the linking of liturgy with pastoral practice may at first seem a puzzling move. Even though those rituals within the Christian tradition concerned with the end of life are sometimes described as 'pastoral' offices, they remain in the eyes of some a means to an end. They are seen primarily as a way of disposing of human remains and, secondarily, of enabling transition or the symbolic re-integration of the bereaved, stigmatised by death, back into the community of the living. This view is particularly prevalent amongst anthropologists and sociologists.[1]

Beverley Raphael notes how ritual helps people make sense of the experience of death. She writes, 'Human society from its earliest times, has involved ritual and myths in its attempt to give meaning to death: the mysterious, fearful and unknown.'[2] But she also notes how '(o)ut of his fear of death man builds many futures for himself.'[3]

If we are to understand how the death of a baby affects individuals, families and their social networks we need to listen, not just to what people say in and through their grief but also to how they shape, enact and give expression to what they are thinking, feeling, believing and experiencing through those rituals which are themselves both part of their grief and part of its healing. That is so even if we admit that, for some, in line with much current thinking in contemporary grief theory, this grief may never ultimately be resolved.[4]

Thus, whilst most death ritual marks the transition of the deceased from the place of the living to the place of the dead (and here the removal of the body to the

burial plot or crematorium has both an actual and a symbolic role), it also marks the transition of the bereaved to a new place within human community. The funeral, therefore, as the primary event in which the dead person is mourned and public expression is given to grief, both effects and declares a resultant change in status for both the deceased and the bereaved.

This view of ritual accords with the seminal work of the anthropologist, van Gennep which has been influential in shaping the way in which ritual has been understood in this country over the last forty years. Van Gennep argued that all rituals which mark a passage from one state to another share a common threefold structure. Such 'rites of passage' involve and effect *separation*, *transition* and *incorporation* with various rites giving dominance to one or more of the three elements.[5] Whilst this influential view of ritual is important, a consideration of liturgy as pastoral act suggests that there are other functions for liturgy which it neglects. In fact, liturgy, its formation, its use by communities of faith and its role *vis a vis* the individual is far more complex than has hitherto been allowed and the pastoral dimension of liturgy therefore merits more detailed attention.[6]

The practice of ritual is something which is deeply embedded in human experience.[7] From earliest times, human beings have expressed their relation to themselves, to others, to the community, to the world around them and to the transcendent through ritual acts often associated with religious practice. Such rituals often include reference to a deity or deities who frequently not only have a place in personal and social history but who also have the capacity to affect and shape both the present and the future. Ritual has thus been used from the very beginning of human history in both a human (human:human) and a sacral (human:divine) way and has been used, not least, to mark the great, and often transitional, moments of human being including birth, puberty, marriage and death.[8] In enabling the individual to relate to the divine, to the community and to the self as well as expressing the nature of relationship to both other and self, ritual is therefore both connective and expressive.[9] Ritual acts

within the Christian tradition, not least those surrounding the key boundary events of birth and death, also reflect this pattern within the context of Christian beliefs about the creative and salvific acts of God and about human purpose and destiny.[10] There are those, however, who believe that much contemporary liturgical practice, particularly in the area of death, has neglected or down-played such key Christian beliefs and is therefore insufficiently theologically earthed.[11]

Ritual is articulated and enacted not only through the use of words, but also through the use of signs, symbols, gestures and actions which are often stylized. Thus, through the use of ritual, people are enabled to express themselves, not just at a cognitive level, but with the whole of their being.[12] Since ritual has the capacity not only to express what we think or feel, but also to change us, and is therefore 'transformative', the development of rituals, both to express and to interpret human belief and experience, must be similarly holistic. Tom Driver, who sees ritual in this holistic way, says, '...(H)uman lives are shaped not only... by the ideas we have in our minds but even more by the actions we perform with our bodies.'[13] Ritual is 'above all a pattern of action'.[14] In the Christian context, the performative utterances and actions of ritual expression involve both vertical (human-divine) and horizontal (human-human) elements.[15]

Thus, whilst 'no good rituals are disembodied' (since they are enacted by human beings), it is also true to say that, 'at the same time there are no good rituals without spirit' (since in all Christian ritual God is both addressed and perceived as being involved).[16] Ritual, then, is never an end in itself - this would reduce it to mere theatricality - but is a process, ideally enabling and enacting transformation and change.[17] Whilst this is perhaps most clearly seen in eucharistic and baptismal liturgies, it is also an essential element in many other rites and especially, as we shall see in more detail later, in the rites which are to do with birth and death.[18]

It is interesting to note at this stage, however, that whilst there has been a strong movement over the last thirty years to re-instate and re-locate baptism within the context of the gathered, worshipping community, making its enacted narrative a

shared event - few baptisms now take place on a Sunday afternoon in an empty church - much late twentieth century funerary practice, even amongst practising Christians, has gone in the opposite direction. The funeral rite has been removed from the Church to the crematorium or graveside where 'private' cremations/burials serve to keep, or even exclude, grief from the public domain.[19] Thus, in a sense, death is removed, or 'sequestered', from public view and is rendered 'safe'.[20] In a Christian context, death is always a dying 'in the Lord' in order that we may share in his resurrection. Such rites are therefore properly rooted both in an understanding of the nature of Christian community and of the paschal mystery.[21]

In this chapter, I shall examine some of the rites associated with birth (or pre-birth) and then go on to examine those associated with the death (or anniversary of the death) of a baby. Whilst the parts of the chapter are distinct, the areas of overlap which occur when a child dies in the pre- or perinatal period are unique and it is important, therefore, to consider 'birth' and 'death' rites together and not in isolation. Some of the rites examined form the 'official' liturgies of the Church, the 'common' prayer of the ecclesial community. Others represent the growing number of unofficial, but nonetheless increasingly public, liturgies which are now available either commercially or in private circulation. Yet others represent individual and personal expressions, through stylized words and actions, of the beliefs and feelings which surround the experience of the loss through death of a particular child.[22]

Birth and death are major, perhaps the most major, events of human experience and none of us are left unchanged by their touch. Indeed, for many, if not all of those who are touched by the death of a loved and wanted child, such changes are often permanent and irrevocable.[23] Rituals offer the opportunity to understand the significance, acknowledge the importance, and test the reality of what has happened. Roger Grainger reminds us that ritual and its symbols 'enable us to come to terms on an intuitive level with facts whose literal meaning we cannot yet deal with.'[24] As such,

ritual and its place in human life and experience needs to be taken seriously by those who deal with the bereaved, including clinicians, pastoral carers and other healthcare professionals.[25]

In the past, liturgical or ritual expression in this country was often limited to the authorised or established rites of a particular ecclesial community. This perhaps mattered little when the majority of the population belonged to a Church and ritual would have been experienced within a Christian frame of reference which was more familiar then. Today things are very different. Only a minority of people in the United Kingdom now attend Church or describe themselves as having any religious affiliation or even faith. Even among these, there are still, nonetheless, many for whom there is an expectation that the Church will provide appropriate rites to mark the great transitional moments of human life and who therefore buy into the Christian narrative at times of crisis or change.[26] Wesley Carr argues that the key to understanding such ministry 'comes from seeing that the church and the minister are available for ministry because of the way in which they interact with their environment'.[27]

Contemporary society generally is, it is argued, much more 'consumer led' and this trend is also increasingly being reflected in the Church. Why should this be so? Has the Church learned to be more flexible than it might in earlier times have appeared to be, particularly with the increased involvement of the laity, not least in liturgical revision? Is it simply that those who request such rites, whether Church members or not, are now cast increasingly in the role of consumer (or at least may cast themselves in such a way) and therefore make particular demands that exceed what the traditional rites of the Church can deliver?[28] Is it that such rites no longer affirm what people actually believe, or what resonates with their experience at an emotional level, and they now have the confidence to articulate this? Or, is it that whilst such rites may still represent what at least some people may believe, the form in which it is expressed is no longer considered appropriate?[29] Such beliefs may themselves be pre-existent or may indeed emerge from the experience of the loss through death itself. C.S. Lewis,

following the death of his wife, expresses well how, for better or worse, belief may be shaped and altered by experience:

> Not that I am (I think) in much danger of ceasing to believe in God. The real danger is coming to believe such dreadful things about Him. The conclusion I dread is not 'So there's no God after all,' but 'So this is what God's really like.'[30]

An important role for ritual may, then, be in challenging belief as much as in affirming it. This involves recognising that beliefs filtered through the lens of particular, and often painful, experiences may need to be balanced by, and tested against, received tradition and the experience of the community. Thus, ritual may challenge and re-shape people's view of God as well as meeting their immediate human needs. Ritual may also, however, have a stabilising role, providing a sameness in a time of crisis or change which becomes the safe context in which the new and the 'un-safe' can be explored and shared.[31] It is in the holding together of sameness and difference, stability and change, continuity and immediacy, that the ritual of liturgy can be most meaningful and most pastorally creative.[32]

I shall argue, therefore, that the role of liturgy, as more than ritual of transition, is not simply to express or articulate what is believed or experienced, but to set those beliefs or experiences in the context of the traditions and faith of the Church. I shall argue further, that liturgy may thus be about challenging and stabilizing as well as affirming and this, not least, is part of what is meant by its 'pastoral' role. Whilst this aspect of pastoral care is necessarily both personal and individual, nonetheless the context of such ritually expressed care is that of community. Thus ritual may also likewise affirm (or even create), challenge and stabilise communities and community values as well as individuals and this, too, should not be ignored.[33] One of the roles of ritual as described by anthropologists and sociologists is, after all, to strengthen or re-inforce group ties. Liturgy may thus help the bonds of relationship to be maintained or even re-drawn. When a child dies before, at, or shortly after the time of birth, liturgy can help not only in affirming the identity of the child who is the cause or focus of its

enactment or in letting go of the child who has died but in revealing to the group how such losses are understood.[34]

In the case of official liturgies, therefore, I shall examine the rite both as expressing the faith/belief of the ecclesial community and as pastoral act. In the case of unofficial liturgies or liturgical acts I shall explore what it is that such rites are seeking to express or touch in terms of structuring belief or experience, which their authors do not find, or perhaps find to be inadequate, in the official rites of the Church above and beyond the attempt simply to create a liturgy that is 'personal'.[35] In each case the questions, *'Who is this rite for?'*, *'What purpose does it fulfil?'* and *'Who are the principal players in the rite?'* will be of primary importance. It will be necessary to explore, in this context, the tension between what the church understands itself to be saying through its rites and what those who engage with them understand those rites to be saying, since these may not be the same. I shall argue that the move towards writing one's own liturgies expresses not just the desire to personalise the service but a desire to express those feelings, intuitions or experiences which the more formal, received liturgies of the Church may fail to touch in a meaningful way. Where time is taken to do this, meaningful, and ultimately transformative, rites may well emerge and this, too, is part of pastoral engagement with the bereaved.

Part I Rites concerning the beginning of life

Introduction

The term 'rites concerning the beginning of life' as opposed to 'birth rites' or 'rites at the time of birth', is used here since not all children are carried to term and those whose pregnancies come to an end very early on in the gestational life of their child may also wish for or request a rite which both recognises and affirms the life (as opposed to the death) of their child, however brief. This is the case even when that child did not have a life which was independent of the womb.[36] In thinking about the

range of such rites available to meet the variety of circumstances of the baby who dies in the pre- or peri-natal period we may consider two main sub-groups: those where baptism is not an option (where the baby dies before birth) and those where it is an option (where the baby is born alive and the rite may be performed before death occurs). In the latter group, it is important to note that, just as for any other child, the parents may not wish for, or request, baptism, but may nonetheless require a rite of welcome and/or recognition, of blessing or of naming. This may be irrespective of any religious belief or practice they hold and sensitivity is needed in exploring what may be an appropriate expression of the parents' wishes or intent.[37] Simply for the sake of clarity, we will consider such rites in progressive order of gestational age.

It is generally true to say that, as far as 'official' Church rites are concerned, the earlier the death occurs, the harder it is to find rites which affirm or give recognition to the intrauterine life of the child.[38] Historically, this may have a number of causes. High rates of infant mortality in the past meant that many more children died in the pre- and peri-natal period than today. Far from leading to the development of rites to deal with this, the very commonness of the occurrence meant that, since it was much more taken for granted that some children would not survive to term or beyond the early months of life, the emotional impact and effect of such loss was perhaps considerably less on society than it is today when the expectations of survival are so much higher.[39] Children who were stillborn, or who died before baptism, could not be buried in consecrated ground and were therefore excluded from the churchyards of England and buried in unconsecrated or 'common' graves.[40] The persistence of this practice is reflected both in the refusal of some clergy to inter the unbaptised remains of an infant in a Churchyard, and in the struggle that was encountered in persuading secular cremating authorities to accept the remains of non-viable fetuses (i.e., those babies who died at less than 24 weeks gestation) for cremation.[41]

As we have noted, it was only after the technology which led to the birth of Louise Brown in 1978 had led to a deeper understanding of early intrauterine life that

things began to change at all. The debates about abortion of the 1960s which had culminated in the Wade vs. Roe judgement in the United States Supreme Court, had also thrown open the debate about the moral status of the unborn human, especially that of the early embryo or fetus. Further developments in technology, including the development of the high resolution ultrasound scan (which has meant that putative parents have 'fixed' their image of their unborn child at increasingly earlier stages of gestation), and the ability to sustain premature babies of increasingly early gestation outside the womb, has changed the early life parent-child relationship irrevocably. Thus, pastoral necessity has meant that many hospital Chaplains, especially those specialising in maternity services, have developed or adapted rites to meet the needs of parents whose babies have died in such circumstances.

Amongst the rites developed and used at Bristol Maternity Hospital are a *Service of Baptismal Desire for Bereaved Parents*, a *Service of Blessing for a Baby Miscarried or Stillborn* and a *Service of Blessing for the Child of Bereaved Parents.* These services merit some detailed description as examples of rites which evolved in the context of specific liturgical and pastoral practice and relationships and not least since they were written in the early 1980s, at a time when little, if any, other liturgical material of this sort was available for use.

It is important to distinguish in these rites the elements which are to do with recognising and affirming the life of the child and those elements which recognise and acknowledge death (what may be described as the 'hello...goodbye' elements). Such a use of ritual, in externalising the reality of the death and therefore in a sense making it public, is also a powerful and valuable reminder of reality.[42] As Beverley Raphael notes in regard to ritual, 'One level of denial is relinquished when the dead person is accepted as dead.'[43] Peter Berger describes this role of ritual as one which keeps people 'reality-orientated'.[44]

A rite which exemplifies this is the *Service of Baptismal Desire for Bereaved Parents*:

Service of Baptismal Desire for Bereaved Parents

Minister:
It is the Church's understanding that not even a sparrow shall fall outside the knowledge and love of God our Father. And the concern of Jesus for children is one of the striking moments of St.Mark's Gospel in which we read:

They brought children for him to touch. The disciples rebuked them; but when Jesus saw this he was indignant and said to them - 'Let the children come to me; for the Kingdom of God belongs to such as these. I tell you that whoever does not accept the Kingdom of God like a child will never enter it.' And he put his arms round them, laid his hands upon them, and blessed them.

Yet in the frailty of our minds, the mysteries of life and death are hidden from us. It is therefore necessary and right, on such an occasion as this to show both our sadness and our trust. So let us speak to God of both, in thought, and prayer, and action.

(Here the minister shall light a candle, hold it during the following prayer, and hand it to the parent(s) before the second prayer.)

Minister:
Lord Jesus, we have followed your command and sought baptism for this our dearly loved child N... In the mystery of your will, his/her life returns to you. May our desire that he/she should be a member of your body (the Church) be granted.
May this candle symbolise your light in our saddened lives, and his/her incorporation into the body of your faithful people, who with the Father and the Holy Spirit draw us all to your everlasting life.
Amen.

(The minister hands the candle to the parent(s)).

Lord God, we meet at this moment in sadness and regret. But we thank you for making us aware of the value of life. The pain we feel is a measure of our love for N... our child. Out of the pain of Christ's death for us make us aware of the love in which you hold us; and over the coming months grant us the strength to bear our loss and the wisdom to know that the life of our child is now in your care, through Jesus Christ our Lord, who through life brought us love and through death gave us hope.
Amen.

Let us commend ourselves and our loved one(s) to God, in the words our Saviour taught us...

Our Father...

> The grace of our Lord Jesus Christ be with you this day and always. Amen.[45]

This service, whilst one which expresses the parents' desire for their child's baptism, is clearly and consciously distinct from any baptismal rite which might be used with a live-born child. It is used where a baby, of whatever gestational age, has died *in utero* or where a liveborn baby has died before baptism and the parents wish to acknowledge that, had their child lived, they would have sought the Christian rite of baptism. Although there is a reading from Mark 10:13-16, which speaks of Jesus' concern for children, a reading which is contained in many baptismal rites, there is no reading either of passages which refer to the baptism of Jesus (e.g. Mark 1:9f.) or the dominical injunction on baptism (as in Matthew 28:18f.,) although this is implicit in the prayer after the lighting of the candle which begins with the words, 'Lord Jesus we have followed your command and sought baptism for...'. There is no confession, epiclesis over water, promises or profession of faith according to a credal formulary although the belief that the faithful are incorporated into the body of Christ (the Church) is a dominant feature of the rite. The complete absence of any water-based action and/or baptismal formulary underscores the fact that this is not, and should not be confused with, a baptismal rite. Baptism, notwithstanding its strong death-resurrection motif, is essentially a rite for the living, not those who have died, although the lighted candle given to the parents as part of this rite reflects contemporary baptismal practice. The candle symbolises both the 'incorporation' of the child into 'the body of Christ's faithful people' and the 'light' of Christ in the 'saddened lives' of the parents.[46] Note also that the element of naming is similarly excluded from the rite. Although opportunity to use the child's name is explicitly given, the name itself is not 'given' in the context of this service. The death of the child is seen as being within the will of God, which, nonetheless, remains a 'mystery'. The fact that the child's 'life' returns to God affirms their pre-birth life. The inclusion of the child as a member of the body of Christ (literally, incorporation) is asked for. The service recognises the

'sadness and regret' which form the context of this rite, whilst thanking God 'for making us aware of the value of life.' Although this is not spelt out, the implication is that this awareness is both of the value of life in general and of the life of this child in particular. The service suggests that the emotional pain felt by the parents is in direct proportion to the measure of love for their child and relates this to the passion of Christ as a sign of the love of God for us. The prayer concludes by asking both for the strength to bear the loss and wisdom to know that the life of the child who has died is in the care of God. The commendation of both self and others to God is made through the saying of the Lord's Prayer and the service ends with the grace.

In summary, this service:

- *is a semi-official rite*
- *is primarily parent-orientated*
- *can be used in hospital, church or home (usually hospital)*
- *does not include a naming element*
- *includes a commendation*

This service bears many similarities to the *Service of Blessing for a Baby Miscarried or Stillborn.*[47] This latter service lacks any reference to baptismal desire, focussing rather on the commendation of the miscarried or stillborn baby to the care and keeping of God. Whilst the *Service of Baptismal Desire* is a rite that affirms the value of life, therefore, the main thrust of the rite is the transference of care for the child from the parents to God. Any rite where this is the case makes sense only in a context where the living participants in the rite share a belief in some form of post-mortem existence. Does this, however, mean that such rites collude in the death-denying orientation of much contemporary Western culture and thus avoids fully acknowledging the pain of grief, even where there are references to 'sadness and regret'?

Clearly, what parents believe happens to their baby after death is pastorally important in the capacity it has to affect the course of the grieving itself. Those within the Christian tradition who maintain some form of belief in post-mortem existence

appear to divide between those for whom belief in the resurrection of the body is predominant and those for whom belief in the on-going survival of the soul in separation from the body predominates.[48] Walters contrasts the holistic, biblical view of human being which, notwithstanding the hope of future bodily resurrection ('corporate' in both senses!), faces the fact of death as a reality, and therefore recognises death as a source of human grief, and the post-Augustinian body-soul dualism with its roots in Greek philosophy which, with its emphasis on the (individualistic) immortality of the soul, appears to deny, or at best suppress, the reality of death. If death is not real then, ultimately, we are left with nothing to grieve for. Walters argues that both views continue to be held among Christians today but he regards the ambivalence created by the immortality model as the source of 'the discomfort that many Christians feel about grief and the sense that it is unworthy of true faith'.[49]

Walters argues that it is far from clear in the minds of many contemporary Christians whether they should be sad because a loved one has died or glad because that loved one is now with God and therefore in a 'better' place. The former position is characterised as consonant not only with the biblical tradition but with much contemporary psychological theory about grieving, the latter as the legacy of patristic thought derived from Plato *via* Augustine and often a source of guilt.[50] Despite the overall decline in beliefs in life after death, the body-soul model has persisted as the way in which most people who hold a belief in some sort of post-mortem continuance would describe what happens after death.

Perhaps the situation is not as bi-polar as Walters suggests. Grief is a complex and often ambivalent phenomenon that may well include elements of both joy and sorrow, particularly for those whose present grief is tempered by faith in a loving God whose will it is to bring each person to share in the joy of heaven. In Christian terms it is that for which we are created and therefore grief, from a Christian perspective, however painful an experience on the human level, is always tempered by hope and a balanced Christian view of life is neither death-focussed nor death-denying.[51]

Service of Blessing for a Baby Miscarried or Stillborn

THE LAMB who is at the throne will be their shepherd and will lead them to springs of living water; and God will wipe away all tears from their eyes.'
REVELATION 7.17

PSALM 23

The Lord is my Shepherd, I shall not want;
He makes me lie down in green pastures,
He leads me beside still waters;
He restores my soul;
He leads me in the paths of righteousness for his name's sake.
Even though I walk through the valley of the shadow of death,
I fear no evil;
For thou art with me;
Thy rod and staff, they comfort me.
Thou preparest a table before me in the presence of my enemies;
Thou anointest my head with oil,
My cup overflows.
Surely goodness and mercy shall follow me all the days of my life,
and I shall dwell in the house of the Lord forever.

READING from PSALM 139 verses 13 - 18.

'You created every part of me;
You put me together in my mother's womb.

I will praise you because you are to be feared;
all you do is strange and wonderful.
I know it with all my heart.

You saw my bones being formed,
carefully put together in my mother's womb,
when I was growing there in secret.

You saw me before I was born.
The days that had been created for me
had all been recorded in your book,
before any of them had ever begun.

God, how difficult your thoughts are for me;
how many of them there are!

If I counted them, they would be more than the grains of sand. When I awake, I am still with you.

In the frailty of our minds, the mysteries of life and death are hidden from us. It is therefore necessary and right, on such an occasion as this, to show both our sadness and our trust. So let us speak to God of both, in thought, and prayer, and action.

A candle may be lit, to symbolise God's light in our saddened lives.

Let us commend this child to the love of God our Father.
HEAVENLY Father, by your mighty power you gave us life, and in your love you have given us new life in Christ Jesus. We entrust this baby to your merciful keeping, in the faith of Jesus Christ your Son our Lord, who died and rose again to save us, and is now alive and reigns with you and the Holy Spirit in glory forever. AMEN.

PRAYERS for bereaved parents

Heavenly father, you alone can heal broken hearts and wipe away tears that well up inside us; you alone can give us the peace we need and the strength to carry. We ask you to be near to (parents' names) whose time of joy has been turned to sadness. May they be aware of your presence and encouraged by your strength. May our love for one another be deepened by the knowledge of your love for us. Lord, amid all our questions, help us to trust you. In our time of darkness, shine into our lives with the light of your presence, through Jesus Christ our Lord.
AMEN.[52]

Father in heaven, you gave your Son Jesus Christ to suffering and to death on the cross, and raised him to life in glory. Grant us a patient faith in time of darkness, and strengthen our hearts with the knowledge of your love; through Jesus Christ our Lord. AMEN.

THE LORD'S PRAYER

Jesus taught us to call God our Father, and so in faith and trust we say:
Our Father who art in heaven, hallowed be thy name, thy kingdom come, thy will be done on earth as it is in heaven. Give us this day our daily bread and forgive us our trespasses as we forgive those who trespass against us. lead us not into temptation, but deliver us from evil. For thine is the kingdom, the power and the glory, for ever and ever. AMEN.

THE BLESSING

May the love of the Lord Jesus draw you to himself,
the power of the Lord Jesus comfort you in your sorrow,
the peace of the Lord Jesus fill your hearts, and the blessing of God Almighty, Father, Son and Holy Spirit be upon you and those you love, now and through to eternity. AMEN.[53]

The service begins with the reading of Revelation 7:17, the final verse of the song of victory concluding a passage in the book of Revelation which refers to the post-mortem fate of those who have been martyred for their faith.[54] This is followed by Psalm 23, whose references to passing 'through the valley of the shadow of death' have close associations with the funeral service or other services for the dead, and some verses from Psalm 139. The use of this psalm is particularly significant. These verses establish the pre-natal identity of the unborn child and therefore affirm his/her existence as something of value not only to the parents but to God. The reference to one's created days being recorded 'before any of them had ever begun' might raise questions about the purpose of God creating a child whose days would end before birth. This is probably due to the fact that, in the ancient world, human origin was not located simply in the human womb but often in the earth as mother, from whose 'womb' the human race ultimately 'came'.[55] The sense here, therefore, is of God's knowledge reaching back to the point of ultimate origin. In fact, such a question of divine purpose was never raised in this context with me by bereaved parents, even though the apparent futility of a life ending before it had, in any independent sense, begun was a frequent issue in conversation. Secondly, the verses affirm as real the state of confusion felt by many parents and they recognise the difficulty which many find in making sense out of the apparent senselessness of their child's death. The verses do not say that there is *no* point to the life/death but that what point there is, or may be, remains hidden from us. This is not, however, simply to attribute a direct causality between God's will and individual deaths, although this, too, is a subject frequently raised by bereaved parents. Such causal connection might be framed in a number of ways: Asking *'Why did God do this?'* or *'Why did God take my/our baby?'* or making statements which, in terms of the language used, may seem strange or bizarre, but reflect the underlying struggle of parents to discover meaning in death and to articulate the sense of worth felt for the child who has died: *'Jesus wanted him/her for an angel'* or *'Jesus picks all the best flowers...'*. These attribute divine purpose to the life/death that has been experienced and establish the worth of the life that has been 'taken'. It is

something that is 'precious' and therefore of value and, if of value to the parents, then also to God, in whose presence the child is seen now to be.[56] Any sense of the 'unfairness' of the world, manifested in the death of a child, is ultimately seen as being compensated for by their life in 'heaven'. Parents may also talk of a dead child being 'cared for' or 'with' other relatives who have died, predominantly grandparents. Thus, ties of kinship and familial care are maintained beyond the present.

The verses from Psalm 139 are then followed by a section identical with the *Service of Baptismal Desire.*

> In the frailty of our minds, the mysteries of life and death are hidden from us. It is therefore necessary and right on such an occasion as this to show both our sadness and our trust. So let us speak to God of both, in thought, and prayer and action.
>
> A candle may be lit, to symbolise God's light in our saddened lives.

Here, thought (including both memory of and hopes for the child who has died), word (in the language of the rite) and action (in the lighting of the candle) are brought together.

This is followed by a prayer of commendation, entrusting the baby to the merciful keeping of God and expressing faith in the death and resurrection of Jesus Christ as paradigmatic for the post-mortem fate of those who die 'in the Lord'. There then follow two prayers for the bereaved parents. Note how here again there is recognition that such deaths may be the occasion of spiritual crisis marked by questioning.[57] The first prayer recognises the grief of the parents with its reference to 'broken hearts' and to 'the tears which well up inside us' and the transition from joy to sadness which is so often the hallmark of the emotions of those whose children die. It recognises the profound questioning such deaths may raise and asks for an awareness of the presence of Christ in their shattered lives. The second prayer begins by relating the present suffering of the parents to the suffering and death of Jesus: 'Father in heaven you gave your Son Jesus Christ to suffering and to death on the cross...' It then

points beyond physical death to new life: '...and you raised him to new life in glory'. It asks for patience in faith and the strengthening of our hearts 'by the knowledge of your love'. The service then concludes with the Lord's Prayer and a blessing.

In summary, this service:

- *is a semi-official rite*
- *is primarily child-orientated*
- *can be used in hospital, church or home (usually hospital)*
- *does not include a naming element*
- *includes a commendation*

The third rite used at Bristol Maternity Hospital, which also bears similarities to the two rites described above, is the *Service of Blessing for the Child of Bereaved Parents.* The title of this service is itself interesting. Combining elements of the titles of the preceding rites, it establishes that the primary focus of the service is the child who has died, although the latter part of the title incorporates the parents and affirms their status both as parents and as those who have been bereaved.

Service of Blessing for the Child of Bereaved Parents

> THE LAMB who is at the throne will be their shepherd and will lead them to springs of living water; and God will wipe away all tears from their eyes. REVELATION 7.17.
>
> READING from Mark's Gospel showing the love of Jesus for children. MARK 10. 13 - 16.
>
> WE LIGHT a candle for to symbolise God's light in our saddened lives.
> Let us commend this child to the love of God our Father.
> HEAVENLY Father, by your mighty power you gave us life, and in your love you have given us new life in Christ Jesus. We entrust to your merciful keeping, in the faith of Jesus Christ your Son our Lord, who died and rose again to save us, and is now alive and reigns with you and the Holy Spirit in glory forever. AMEN.
>
> The candle is handed to the parents.

LORD GOD, we meet in this time of sadness and regret. But we thank you for making us aware of the value of life. The pain which
feel is a measure of their love for , their child. Out of the pain of Christ's death for them make them more aware of the love in which you hold them: and over the coming months grant them the strength to bear their loss and the wisdom to know that the life of their child is now in your care, through Jesus Christ our Lord, who through life brought us love and through death gave us hope. AMEN.

LET us commend ourselves and our loved one(s) to God in the words Jesus himself taught us.

Our Father.

MAY the love of the Lord Jesus draw you to himself, the power of the Lord Jesus comfort you in your sorrow, the peace of the Lord Jesus fill your hearts, and the blessing of God Almighty, Father, Son and Holy Spirit be upon you and those you love, now and through to eternity. AMEN.[58]

Like the *Service of Blessing for a Baby Miscarried or Stillborn* the service begins with Revelation 7:17. Whilst no psalm is included in this service, unlike the *Service of Blessing for a Baby Miscarried or Stillborn*, like the *Service of Baptismal Desire for Bereaved Parents* there is a reading from the gospels. The reading is from Mark 10: 13-16 which the service describes as 'showing the love of Jesus for children.' It is significant that this reading is one which is frequently included in the rites of baptism for children. As with both the *Service of Baptismal Desire for Bereaved Parents* (where the primary focus is on the parents) and the *Service of Blessing for a Baby Miscarried or Stillborn* (where the primary focus is on the child) the lighting of a candle 'to symbolise God's light in our saddened lives' is included. Again, whilst there is no sense of giving a name to the child in the context of the service, where the child has been given a name it is assumed that this name will be used here. The giving of the lighted candle to the parents is followed immediately by the commendation used in the *Service of Blessing for a Baby Miscarried or Stillborn* and the prayer which begins with the words, 'Lord God we meet at this time of sadness and regret...' from the *Service of Baptismal Desire for Bereaved Parents* although the phrase, 'the pain we

feel...' becomes, 'the pain which _____ feel...', where the parents' names are inserted into the rite. The remainder of the prayer is similarly transposed from the first person to the third person plural. This prayer is followed by the Lord's Prayer, through which we 'commend ourselves and our loved one(s) to God'. The service concludes with the grace.

In summary, this service:

- *is a semi-official rite*
- *is primarily child-orientated but with a strong acknowledgement of the parents*
- *can be used in hospital, church or home (usually hospital)*
- *does not include a naming element*
- *includes a commendation*

After each of these services the parents would be given some form of card or certificate as a tangible reminder that an act of significance and value had taken place.[59] Where such cards are used, they have usually been designed and produced locally. The one used at Bristol Maternity Hospital was a simple buff-coloured folded card entitled 'The Blessing of your baby'. Inside were the words:

The Blessing of your baby

---

on .....
by .....

The Lord bless you
and keep you
and give you peace.....
and the Blessing of God Almighty
Father, Son & Holy Spirit
rest upon you
& upon those who love you
now & through eternity.

As noted in earlier chapters, for parents who do not have a baby to take home with them when they leave the hospital, any tangible reminders of their baby's brief time

with them physically (a card or certificate, a photograph, a footprint or handprint, a name band, even a copy of the pre-natal scan or post mortem report) are valuable mementos which help to affirm and 'anchor' in reality the baby who has died. In this context, I found the practice of foot or hand-printing to be particularly valuable. Though photographs are important in reminding parents how their baby looked, they lack the immediate and very personal intimacy of a footprint or handprint. They also have the advantage, unlike taking a lock of hair, of being non-invasive'.[60] Such physical reminders may be used later in the context of a rite as a point of focus in the absence of a physical presence.

The simplified funeral service used at Bristol Maternity Hospital, *The Funeral of a Child*, followed the pattern of the three services described above with minor variations. Romans 8: 38-39 replaces Revelation 7:17 as the introductory sentence and Psalms 121 and 23 are included, the latter being followed by the gloria. A reading from Isaiah 25: 8-9, which is resonant of the passage from Revelation 7, with its reference to the wiping away of tears, is included and is followed by the gospel, Mark 10: 13-16. The Lord's Prayer is followed by the prayer for the parents beginning, 'Lord God, we meet at this time of sadness and regret...' and prayers of both commendation and commital. A blessing concludes the service.[61] This order of service would be used by the Chaplains when conducting the funeral service of a baby or child who had died at the hospital.[62]

In summary, this service:

- *is a semi-official rite*
- *is primarily child-orientated*
- *can be used in church, crematorium or at the graveside*
- *does not include a naming element*
- *includes a commendation and committal*

Each of these rites was developed within a specific pastoral context - that of a maternity hospital in which both birth and death occurred and in which both needed to be recognised and acknowledged. The lack of suitable liturgical material at the time, especially in dealing with those situations where death precedes birth, meant that the attempts to provide appropriate material were attempts to bring together the teachings and traditions of the Christian Church and the realities of human experience. In order to do this, we not only had to be true to those experiences but. also to go back to the tradition to develop a way of speaking which was also true to the Christian narrative.[63] In so doing, we were undertaking a task which was simultaneously liturgical and pastoral in a way which strove to be genuinely agapeistic. In other words, it both listened to, and was attentive to, others as 'other', thus affording them genuine respect, whilst also listening to, being attentive to, and respecting the self and the tradition which we, as Chaplains, embodied. Thus, the liturgical task would not have been possible without a genuine commitment to the pastoral task of 'being alongside' others and adopting the kind of dialogical approach which took seriously Tillich's observation that, 'we can speak to people only if we participate in their concerns; not by condescension, but by sharing...'.[64] Thus, as far as possible, we produced rites which were *expressive*, *affirming*, *challenging* and *stabilizing* and which, therefore, both Chaplains and the bereaved could use with integrity.

One criticism which may be levelled at each of these rites is one which may also be levelled at many other received rites of the Church. Although the emotions of 'sadness and regret' are openly acknowledged in the text, there is little or no reference to either anger or guilt. This may be because these emotions are more 'difficult' to acknowledge or own. If this is the case, however, then all the more reason for them to be addressed in ritual as well as in psychological ways. Liturgy needs to be truthful, recognising both what is the case and allowing it to be owned, drawing people beyond present experience into a greater truth. After all, anger and guilt are, as we have seen, emotions which are both well-documented in bereavement literature and are emotions

particularly prevalent after early life deaths, whose apparent futility can provoke intense reaction. If ritual is authentically to represent human experience as well as belief then it is important that such experiences and their concomitant feelings are adequately recognised and validated. The message that *'it's OK to be angry'* and the recognition that anger is itself an expression of relationship needs to be made explicit if people are genuinely to engage with such rites. They need, in short, to be true to experience.

'Permission' to be angry often needs to be granted to the bereaved, and its normality in grief affirmed, particularly in the ritual context. In bereavement, people may feel angry not only with other people (including the person who has died!) but also with God. Whilst this may be said in the context of the rite, it is, too often, invisible in the text.[65] Liturgy has to trust itself, therefore, to allow people to effect the move from one place to another (transition), since good liturgy does not simply communicate where we should be but recognises where we are, signposting the work to be done and enabling it. Anger, therefore, does not need to be regarded as a necessarily negative emotion, still less a 'bad' one. Such expressions of anger in bereavement may be no less than an expression of love. The more the person who has died is loved and cherished, the greater the potential for anger at their death. Such anger may well indeed both be reflected in, and be a reflection of, the anger of God. Such an understanding would act as a useful corrective to an image of God who 'takes' the life of a child, either as a punishment for previous wrongdoing or simply on a whim. Rather, it recognises such deaths as a scandal, not only to those who grieve in human terms, but also to God, and the suffering of the bereaved as the suffering of God.

Two further rites were used at Bristol Maternity Hospital. These were *An Order for Emergency Baptism* and *Thanksgiving for the Birth of a Child.* Whilst the *Service of Blessing for a Baby Miscarried or Stillborn* was primarily used, as the name suggests, following a miscarriage or stillbirth and the *Service of Blessing for the*

Child of Bereaved Parents after a neo-natal death, with the *Service of Baptismal desire for Bereaved Parents* used either after a miscarriage or stillbirth or when a liveborn baby died before baptism could be conferred, *An Order for Emergency Baptism* would be used where a baby was liveborn, but where death was imminent. This rite also merits more detailed discussion as part of the liturgical 'package' used at Bristol Maternity Hospital.

An Order for Emergency Baptism

> In St.Matthew's gospel we read of the risen Christ commanding His followers to make disciples of all nations and to baptise men everywhere and in the Acts of the Apostles we read of St.Peter preaching in these words:
>
> 'Repent and be baptised in the name of Jesus Christ for the forgiveness of sins and you shall receive the gift of the Holy Spirit. For the promise is to you and your children and to all that are afar off, everyone whom the Lord calls to Him'.
>
> Almighty God, whose Son Jesus Christ was baptised in the River Jordan; we thank you for the gift of water to cleanse and revive us. We thank you that through the deep waters of death you brought your Son, and raised him to live in triumph.
> Bless this water, that your servants who are washed in it may be made one with Christ in his death and resurrection, to be cleansed and delivered from all sin. Send your Holy Spirit upon them to bring them to new birth in the family of the Church, and to raise them with Christ to full and eternal life.
> For all might, majesty, authority, and power are yours, now and forever. Amen.
>
> ..... I baptise you in the name of the Father and of the Son and of the Holy spirit. Amen.
>
> I sign you with the Cross, the sign of Christ.
>
> Jesus taught us to call God our Father, and so in faith and trust we say together:
>
> Our Father who art in heaven, hallowed be thy name, thy kingdom come, thy will be done on earth as it is in heaven. give us this day our daily bread, and forgive us our trespasses as we forgive those who trespass against us. Lead us not into temptation, but deliver us from evil. For thine is the kingdom, the power and the glory, for ever and ever. Amen.

> We pray for all in this place, for all children, their parents and families, all doctors, nurses and staff and for this child.
>
> Lord Jesus Christ you took children in your arms and blessed them. Draw near to this child and hold him/her in your love. Restore him/her to your health and fill him/her with your peace for your name's sake. Amen.
>
> The Grace of our Lord Jesus Christ, the love of God and the fellowship of the Holy Spirit be with us all evermore. Amen.[66]

The rite begins by using a shortened form of the optional introduction to the Ministry of the Word of the service for the Baptism of Infants in the *Alternative Service Book* of the Church of England.[67] It makes reference to the dominical injunction to baptism of Matthew 28:19 and cites Acts 2:38-39, part of Peter's speech to the crowd on the Day of Pentecost. This is followed by a similarly shortened version of the introduction to the Baptism in the *Alternative Service Book*.[68] It includes the reference to the baptism of Jesus, omitting the reference to the Exodus with its motif of crossing from slavery to freedom, from the old life to the new. Any credal formulary is omitted and the rite moves directly to the baptism with water in the name of the Trinity and the signing of the baptised with the Cross. This is followed by the Lord's Prayer, with prayers for the hospital and its staff and for child, for whom restoration to health and peace are asked, interposed between the Lord's Prayer and the Grace with which the rite concludes.[69]

In summary, this service:

- *is a semi-official rite*
- *is primarily child-orientated*
- *can be used in hospital (in extremis)*
- *includes a naming element*

Emergency Baptism - Theological and pastoral practice

The use of emergency baptism raises a number of issues for Chaplains and other hospital staff. For many parents, baptism is a public and tangible way of affirming the reality of their child as someone who is loved and cherished, however brief their life might be.[70] Where one, or both, of the parents are practising Christians, it is a sign of their child's inclusion into the wider, visible family of the Church and a sign that their love is part of the wider love of God, freely given, for their child.[71]

In a seven year retrospective review by Salter and Watkinson of families of babies who had received emergency baptism in a neonatal unit in the West Midlands, the role of emergency baptism and the expectations which surround it are examined.[72] The aim of the study was to 'understand better which babies were being baptised, the timing of baptism and the effect of baptism on the parents.'[73] When it is considered that a baby is unlikely to survive, parents will usually be asked whether they wish the baby to be baptised, blessed or named. Some parents, particularly those who are practising Christians, will often take the initiative themselves and ask for such a service, although this may mean recognising the severity of their infant's condition, perhaps for the first time. At the other end of the spectrum, those who are convinced atheists are unlikely to ask for, or assent to, baptism or other associated religious rites, though naming may still be an important secular rite for such parents. As Salter and Watkinson recognise, however, the vast majority of parents fall in between these two poles.

Of those parents in the study whose babies had been baptised, whether or not the baby had subsequently survived, none regretted having their babies baptised. This representative sample provides a figure largely in line with, or just above, the percentage of those whose children are baptised in the wider community.[74] The study singles out three groups of parents for particular attention - Roman Catholics (for whom baptism operated on two levels, *emotional* and *sacramental*); those whom the study describes as 'pragmatists' (those who did not express 'any real religious faith but

saw baptism as a way of ensuring that everything possible was being done to help their sick child'[75]); and those who retrospectively felt that baptism had been the right thing to do. In respect of the second group, Salter and Watkinson make an interesting observation which they fail to develop when they say that, in addition to the family 'feeling stronger' after the baptism, the occasion caused the entire immediate family to gather and support the parents'.[76] One important, though often neglected, aspect of ritual is that it is, of itself, often creative of community both by affirming (and often strengthening) existing bonds/relationships, and by creating new bonds or relationships which are founded upon, or built around, a particular event.[77]

Whilst Salter and Watkinson's ensuing discussion is superficial, they nonetheless raise a number of points which merit comment or expansion. They rightly comment that, within the Christian Church, there is a range of attitudes towards baptism. Not only is there a distinction between paedo-baptist churches and those who believe that baptism is contingent upon profession of faith, but there is a distinction between those who take a firm stand against 'indiscriminate' baptism and those who take a much more liberal or 'open' view of the sacrament. Few hospital Chaplains, in my experience, would refuse baptism to a child *in extremis* either because the child could not make a profession of faith or because the parents were not deemed to have the requisite faith.[78]

One group which is neglected by Salter and Watkinson, but which is encountered by hospital Chaplains working in maternity or a neo-natal environment is comprised of those parents who request baptism for a child who has already died. This situation may pose particular problems for Chaplains in ministering to a particularly vulnerable group of parents. There are few who would not argue that baptism is a rite which is necessarily contingent upon the child being alive at the time when the sacrament is administered. Nonetheless, usually on what are described as 'pastoral grounds', there are many who would also argue that, since it is often difficult to pinpoint the actual moment of death, baptism in the period immediately following death is an acceptable practice. It is difficult not to see this as a predominantly parent-

orientated rather than child-orientated decision. Consequently, however, there is a variety of practice among Chaplains and other ministers on this issue and there is, in such circumstances, always a struggle to balance theological or ecclesial teaching and tradition with pastoral sensitivity. I have known stillborn babies to be baptised 'on pastoral grounds' by ministers of all denominations, including Baptist ministers and Roman Catholic priests, even though baptism is universally regarded as a rite administered to the living rather than the dead. In some non-paedobaptist churches, ministers have also found themselves at variance with the theological position of their churches when they have acted in response to pastoral need and have baptised live but dying babies, when baptism has been specifically requested by the parents. Such ministers have at times been subject to severe criticism and even censure by denominational colleagues for their actions.[79]

The application of the rite of baptism to children who have already died is, however, a problematic issue which cannot easily be sidestepped. Nonetheless, attempts may be made to sidestep the issue in either of two directions. On the one hand, those who administer the rite of baptism uncritically in what are often emotionally charged situations, sidestep on what, as we have noted, are argued to be 'pastoral grounds' - *'If that's what the parents want, then that's what we should do...'*. On the other, it may also be sidestepped by those whose refusal to administer the rite, whilst in strict accord with ecclesial law or rule, is also often uncritical (and too often unexplained) - *'Since the baby has already died, baptism is no longer an option...'*.

Two articles in the Australian journal, *Ministry, Society and Theology* highlight some of the issues involved here. In the first, Judith Ford states unequivocally that,

> (o)n occasions we have baptised dead babies. Sometimes Christian parents are anxious as to where the baby will go and have asked that their child be baptised. The baby is then baptised, at their request, **to ease their minds**. (my stress).[80]

Ford clearly sees herself and her colleagues as acting justifiably, on pastoral grounds. The aim of the rite here is to offer comfort or reassurance to the bereaved parents. Rather than challenging the (often un-spoken) belief that the unbaptised child will be excluded from heaven (or even, go to hell!), Ford's approach is to sidestep the issue by administering baptism to the dead child (simply) to give the parents peace of mind. She does not state whether she regards the act or the rite as being in any way efficacious for the dead child on whom such baptism is conferred.

In the same journal, Paul Dalzell offers a more theologically and pastorally thoughtful approach in his article, 'Being Christian, Being Pastoral, and Baptismal Practice'.[81] Whilst he argues against a simple sidestepping in the other direction - an uncritical refusal to administer the rite on the grounds of its invalidity or unlawfulness - he does, nonetheless, criticise the practice of simply acceding to whatever parents may ask for or demand, even on pastoral grounds. He therefore offers a strong challenge to the view that *'what the family wants the family should get'*.[82] This, however, leaves him with a dilemma which he articulates thus:

> The difficult aspect of the situation is this: Many people are not aware of the options they have when it comes to the liturgical possibilities for commemorating or expressing before God what we feel over the death of our child. Often they hold an overly punishing view of God, and believe that the baby will go to hell if it is not baptised. To accede to the request does nothing to challenge this horrible picture of God. The difficult work which faces me in this situation is to hold the relationship open, while discovering what other possibilities there are for action. Otherwise to say "Baptism is not proper for your situation" is heard as saying "I do not care about you".[83]

Dalzell's approach is therefore one which is open and dialogical, an approach which neither dismisses the request of the bereaved parents, nor simply accedes to it without challenging the pre-suppositions which may underlie that request. It is his contention, then, that sometimes 'an aversion to asking... hard questions, or not exploring what is really going on, **masquerades** as 'pastoral sensitivity' (my stress).[84] Dalzell argues that what the Church has to say on the subject of baptism needs to be heard too, and

that sometimes people simply do not know what they want, since their knowledge of what options may be open to them are, at best, limited. Thus, exploring options openly and sensitively rather than simply acceding uncritically or unquestioningly to what is asked for, or meeting such requests with a blank refusal, is itself part and parcel of the pastoral task. The simple acceding to demands, he believes, serves in the long run only to make the Church and its rites less credible.[85]

The key to good practice therefore, which Dalzell's article exemplifies, is the adoption of a genuinely open, agapeistic and dialogical stance which recognises the otherness and integrity of the bereaved and which therefore opens the way for the building of a meaningful pastoral relationship. Such a stance neither simply states a doctrinal position nor simply dismisses it as irrelevant and is therefore more genuinely respectful of both the bereaved and their needs, as well as of the rites of the Church, than either of the other two options. As a result, the bereaved may perceive themselves as being genuinely cared for even when their original request is not acceded to, whilst the integrity, value and meaning of the sacrament of baptism is maintained. Dalzell's conclusion that 'chaplains have a responsibility to take courage and to offer what alternatives there are, and to invite the suffering ones into the company of God in a way that they themselves might not have envisaged'[86] offers a way of pastoral and liturgical engagement that *both* meets pastoral needs *and* preserves liturgical and doctrinal integrity.

This practice was one which was well established at Bristol Maternity Hospital by the early 1980s. The wishes of parents were carefully listened to although, since alternative rites were available and were explained to parents, it was often possible to use an appropriate alternative to baptism (such as prayers for the child, rites of blessing or of naming, or rites such as the *Service of Baptismal Desire* outlined above). In such circumstances, neither the minister's theological conscience nor the rites of the Church would be compromised by simply acceding to requests, nor would the possibility of a pastoral relationship be compromised by simply refusing to accede to a request for baptism. In the vast majority of cases, taking the time to explore other

options paid its own rewards and revealed more appropriate and meaningful rites to parents whose request for baptism was based on an ignorance of what else might be available for them and for their child.[87] An open and dialogical approach, respecting the parents as the primary care-givers seeking the best for their child but respecting also the Christian tradition in which the rite of baptism is grounded, therefore helps to maintain the integrity of all parties. Taking whatever time might be available to explore with parents their wishes and feelings and genuinely listening to what they have to say is itself pastoral engagement and an important step on an on-going contiuum of care.

The practice of baptism *in utero*, particularly where the child is alive but dying, or where there is a real possibility of imminent death, is rare but extremely problematic. I have known it to be practised by a small number of older Roman Catholic Chaplains who have, nonetheless, been hesitant about talking about this practice. Although the Roman Catholic Church does *not* teach that the unbaptised child is excluded from eternal life, there is still widespread folk-belief that this is the case, which can lead to great distress for those whose children are dying.[88] Even as late as 1997, Harold Ter Blanche and Colin Murray Parkes, both experienced writers in the field of bereavement studies (though neither of them Roman Catholics!), could write of Roman Catholicism, 'Baptism is important, and a child who remains unbaptised may not receive eternal life...'[89] This is counter-evidenced by current Roman Catholic rites.[90]

The pastoral problems involved in the use of Emergency Baptism or other rites conducted *in extremis* are increased if baptism is requested by the father (or other family members) when the mother is anaesthetised or heavily sedated, or if there is a conflict of religious belief or practice between the parents.[91] If it is possible to wait until both parents (and, where appropriate, other significant family members or friends including siblings of the dead child) can actively participate both in decision-making and in the rite, then this is advisable. It may not always be possible, however, and the window of opportunity between birth and death may be very small indeed.[92] In such circumstances, careful pastoral through-care for the family is essential. Similarly,

where preparation for baptism is restricted or precluded by time, parents may not be adequately prepared. It is possible, nonetheless, to convey key information quickly and simply, such as: entry into heaven (however conceived) is not dependent upon the rite of baptism, nor are unbaptised children excluded from God's love. It is important for parents to understand that God's love for their child similarly does not begin at the point of baptism, but is a part of God's on-going concern for all creation. It is also important that parents understand that baptising a sick child before an operation or other procedure is not, to put it crudely, a way of 'stacking the odds' in the child's favour.

It is understandable that parents who are often under great stress and facing a bleak and uncertain future for their child will want to do all that is possible for that child and to enlist any help which might be available. To allow such an 'insurance' view of baptism to go unchallenged may, however, raise unrealistic expectations, and may be the cause of disappointment, disillusionment or crisis if the child subsequently dies.[93] Such parents may feel 'let down', or even betrayed, by God and any pastoral relationship may be undermined or frustrated. The gentle assurance of God's love for their child, pre-existent of any rite, is critical, as is the parents' need to 'do' something significant, in which God may, to a greater or lesser degree, be a part. The rite of baptism under such circumstances may be a powerful sign and reminder of God's love and mediate much comfort to those who then feel 'held' in the love of God as well as welcoming the child into the life of Christian community. Where possible, any such rite, however speedily enacted, is a significant moment for all those concerned.

If circumstances permitted, I would wear alb and stole (practice in this matter varies according both to circumstance and to the ecclesiology of the minister concerned) as a sign that the rite was both seriously and joyfully undertaken and to help create positive memories of the occasion in the minds of those present.[94] Usually, a small trolley, such as an instrument trolley, would be made ready by the nursing staff. It would be covered with a white cloth and the small font kept in the hospital for such purposes would be placed on it along with a small wooden cross. Some nurses would

add a small posy of flowers. With the consent of the parents, as many family members or significant others who were present would be included, as would appropriate members of the nursing or medical staff who might be invited to read one of the short readings or to say a prayer. The invitation to say the Lord's Prayer together often creates a sense of community and avoids those involved feeling like bystanders in the drama being enacted before them. Even those with little prior involvement with the Christian community often find themselves able to join in with the Lord's Prayer. Where possible, one of the parents would hold their child, as free as possible from technological impedimenta, and a photographic record of the event would be made. In short, my practice was to ensure that any such rite, whilst always mindful of the circumstances, was made as 'normal' as possible - 'as if' parents had taken their child to their home or local Church.[95] Time permitting, it is preferable that where families have their own priest or minister, his/her involvement is often of great importance. In such circumstances, the Chaplain's role may be as a facilitator. In the majority of such circumstances, however, shortness of time and the fact that a decreasing number of people have a pre-existing relationship with any member of the clergy, means that such rites are most often exercised by the hospital chaplain or, *in extremis*, by a member of the medical or nursing staff. Details of baptism are always entered into the hospital's Register of Baptisms and a Certificate of Baptism is always given to the parents. In circumstances where the baby lives, such proof of baptism may be important later; where the baby dies, it may be one of the few tangible reminders for the parents of their baby's existence and a sign that their child is remembered and cherished by others. Where a baptised baby subsequently dies, it is often the case that the hospital Chaplain is asked by the parents to conduct or participate in the funeral. Even when families live at some distance from the hospital, it is important that, wherever possible, this should be respected, since the context of the funeral liturgy is as important pastorally as its content.[96]

Before moving on to consider funerary rites we shall consider a number of other rites which may occur before, or even instead of, a funeral. The American *United Methodist Book of Worship*, under 'Healing Services and Prayers', includes 'A Service of Hope after Loss of Pregnancy'.[97] This is unusual among 'official' liturgies although there are similarities with a number of the Bristol Maternity Hospital Services outlined above and so the text is included here.

A Service of Hope after Loss of Pregnancy

This service may be held in a Church, hospital or home. Any of the scriptures and prayers may also be used by themselves.

Any of the acts of worship suggested at the death of a child (161-63) or in A Service of Death and Resurrection for a Stillborn Child (170-171) may be included or substituted.

GATHERING

WORDS OF GRACE *One or more of the following*:

Blessed be the God who consoles us in all our affliction,
so that we may be able to console those who are in any affliction
with the consolation with which we ourselves are consoled by God.
(2 Corinthians 1:3a,4)

Thus says the Lord:
A voice is heard in Ramah, lamentation and bitter weeping. Rachel is weeping for her children;
she refuses to be comforted for her children, because they are no more.
(Jeremiah 31:15)

The Lord is merciful and gracious,
slow to anger and abounding in steadfast love.
As a father shows compassion to his children,
so the Lord shows compassion to the faithful.
For the Lord knows our frame, and remembers that we are dust.
But the steadfast love of the Lord
is from everlasting to everlasting upon the faithful,
and the righteousness of the Lord- to children's children,
to those who keep his covenant
and remember to do his commandments.
(Psalm 103:8, 13-14, 17-18, *UMH* 824-25)

PRAYER *One or more of the following:*

Life-giving God,
your love surrounded each of us in our mothers' wombs,
and from that secret place you called us forth to life.
Pour out your compassion upon *mother's Name*.
Her heart is heavy with the loss of the promise
that once took form in her womb.
Have compassion upon *Names of father and/or other family members.*
Their hearts are also heavy with the loss of promise.
They grieve the death of the hopes *they* (*she*) anticipated,
the dreams *they* (*she*) envisioned, the relationship *they* (*she*) desired.
Give *them* (*her*) the courage to admit *their* (*her*) pain and confusion,
and couple that confession with the simplicity to rest in your care.
Allow *them* (*her*) to grieve, and then to accept this loss.
Warm *them* (*her*) with the embrace of your arms.
Knit together their (her) frayed emotions,
and bind *their* (*her*) heart(s) with the fabric of your love from *them* (*her*).
In the strong name of Jesus we pray. **Amen.**

Lord, we do not understand why this life,
which we had hoped to bring into this world,
is now gone from us.
We know only that where there was sweet expectation,
now there is bitter disappointment;
where there were hope and excitement, there is a sense of failure and loss.
We have seen how fragile life is,
and nothing can replace this life, this child, whom we have loved
before seeing, before feeling it stirring in the womb,
even before it was conceived.
In our pain and confusion we look to you, Lord,
in whom no life is without meaning, however small or brief.
Let not our limited understanding confine our faith.
Draw us closer to you and to one another.
Lay our broken hearts open in faith to you
and in ever greater compassion to one another.
So raise us from death to life; we pray in Christ's name. **Amen.**

Ever loving and caring God,
we come before you humbled by the mysteries of life and death.
Help us to accept what we cannot understand,
to have faith where reason fails,
to have courage in the midst of disappointment.
Comfort *mother's Name*, who has lost a part of herself,
and *Names of father and/or other family members.*
Help *them* (*her*) to see the hope of life beyond grief.
Through Jesus we know that you love all your children
and are with us always.
Let us feel that presence now as we seek to love in faith,
through Jesus Christ our Lord. **Amen.**

SCRIPTURE *Suggested lessons:*

2 Samuel 12:15*b*-23	David and the death of his child
Isaiah 25:6-9	God will wipe away the tears.
Psalm 23 (*UMH* 754, 137)	The good shepherd
Psalm 42 (*UMH* 777)	Longing for God's presence
Psalm 90 (*UMH* 809)	God's eternal presence
Psalm 103 (*UMH* 824)	The steadfast love of God
Psalm 118 (*UMH* 839)	God's love endures forever.
Psalm 121 (*UMH* 844)	From where will my help come?
Psalm 130 (*UMH* 515, 516, 848)	Out of the depths I cry.
Psalm 139 (*UMH* 854)	Where can I flee?
Romans 14:7-8	Living or dying, we are the Lord's
1 Thessalonians 4:13-18	Do not grieve as those who have no hope.
1 John 3:1-2	See what love the Father has given us.
Matthew 5:1-12	The Beatitudes
Matthew 11:25-30	God revealed to babes
Matthew 18:1-5,10-14	Children are greatest in God's kingdom.
Mark 10:13-16	Let the little children come to me.
John 14:1-6*a*	Do not let you hearts be troubled.

WITNESS

Pastor, family, and friends may briefly voice their feelings and Christian witness.
Signs of faith, hope and love may be exchanged.

PRAYER *One or both of the following may be used:*

Lord God, as your Son, Jesus,
took children into his arms and blessed them,
so we commit this child *Name* into your loving care.
Grant us the assurance that you have received this life, which you gave,
and grant that when we stand before you
we might be as innocent and trusting as little children. **Amen.**

Compassionate God,
soothe the heart(s) of *Name(s)* and enlighten *their* (*her*) faith.
Give hope to *their hearts* and peace to *their lives.*
Grant mercy to *all members of this family* (*her*)
and comfort *them* (*her*) with the hope
that one day we shall all live with you,
through Jesus Christ our Lord. **Amen.**

Here or elsewhere in the service a familiar and beloved hymn of comfort may be sung.

THE LORD'S PRAYER *See 29.*

BLESSING *See 31-32.*

This is a service with a great deal of liturgical and pastoral sensitivity and may be used after a loss of pregnancy at any stage. It begins with words of scripture including, significantly, Rachel's lament in the Book of Jeremiah with its specific reference to the death of children.[98] Like the Bristol services, the prayers recognise the intrauterine life of the unborn child and affirm God's love for the life which is called forth by God. The first prayer makes specific reference to the death of a baby as a 'loss of promise' for both parents. The separation of the father and mother and the relegation of the father's place to being one among 'other family members' may, however, be seen as inadvertently re-inforcing the commonly held view that pre-natal deaths are primarily a source of maternal rather than parental grief. The prayer recognises that such deaths are not just of an individuated other but of anticipated hopes, envisioned dreams and desired relationships, that such losses are both painful and confusing and that grief is the natural consequence of loss.[99] 'Frayed' emotions (note the nice poetic touch here about 'knitting together' and 'binding with the fabric of your love') are characteristic of bereavement and especially of the feelings and emotions which follow the death of a child. Such raw feelings can be the source of much disharmony in a relationship and individuals may often feel isolated and alone in their grief. God's companionship, expressed through his warm embrace, is seen as the supportive antidote of the loneliness of grieving and active in the healing of fractured relationships. Similarly, the Bristol *Service of Blessing for a Child Miscarried or Stillborn* asks that 'our love for one another be deepened by the knowledge of your love for us'.

The second prayer also begins with sentiments similar to those expressed in the *Service for a Baby Miscarried or Stillborn* that '(i)n the frailty of our minds the mystery of life and death is hidden from us'. In the American Methodist rite this is expressed as, '...we do not understand why this life, which we had hoped to bring into this world, is now gone from us.'.[100] Like the prayer which precedes it, it acknowledges that such deaths have the effect of turning wanted emotions on their heads so that disappointment replaces expectation, and hope and excitement are

replaced by a sense of failure and loss. Thus painful, and well-documented, emotions are recognised and acknowledged in the context of the rite and the power of the rite lies in its honest dealing with the painful nature of reality.[101] Like the Bristol rites, which similarly pray for 'those whose time of joy has been turned to sadness', it recognises the frailty of life but then adds a section which is not explicit in other rites. The phrase, '...nothing can replace this life, this child, whom we have loved...' is a powerful counter to those who argue that a child who dies in the pre-natal period can somehow be 'replaced' by a subsequent pregnancy. The prayer also acknowledges that such children are loved before they are seen or movement is felt. Here, the identity of the 'child' who dies before birth is structured as a relational identity brought into being by those who love him/her so that a wanted child can be 'loved' even before conception! Whilst the pain and confusion of bereavement is very much a part of this prayer, there is also a turning to God in whom all life, however small or brief, finds its meaning. This section is reminiscent of the phrase in the Bristol rite, '...we thank you for making us aware of the value of life' with its view that the pain felt by the parents in their loss is also both an expression and a reflection of their love for their un-born child. Unlike the Bristol rite, however, the United Methodist service does not explicitly link the pain of the parents, faced with the death of their child, to 'the pain of Christ's death for us' which makes us aware of the love in which we are held by God. The prayer ends with the Pauline sentiment that we might, like Christ, and through his death and resurrection, be raised from death to life.

The third prayer in the trilogy begins from the premise of God's un-failing love and care and, like those which precede it, recognises the mysteries of life and death.[102] In the presence of such mystery, there is, again, the request that we might be helped 'to accept what we cannot understand'.[103] This is made explicit in the call for faith 'where reason fails' and for courage in the midst of disappointment. The purpose of God's comfort is to help the bereaved 'to see the hope of life beyond death'. This prayer expresses the faith that God's love is both ever-present and extends to all.

The prayer concludes with the request that we might 'feel that presence now as we seek to live in faith.'

These introductory prayers are followed by a selection of readings, some of which, such as Psalm 23 and John 14, are redolent of the funeral service, whilst others are specifically related to the place of children. The inclusion of 2 Samuel 12:15*b*-23 which speaks of David's grief on the death of his child is an interesting addition to the list. The passage is one of the few stories in the Bible which deals specifically with parental grief, especially of a young child, yet the story is one which is theologically difficult, since the child's fatal sickness is described in penal terms as being 'caused' by God. Whilst sparing David's life, God punishes his sin, and therefore his contempt for God in causing the death of Uriah the Hittite, by taking the life of the child born of David and Uriah's wife, Bathsheba. The narrative implies that the child becomes the innocent victim of God's act of punishment on David. Whilst this accords with the Old Testament doctrine of 'an eye for an eye', it raises important questions about the justice of God *vis a vis* the child. It also neglects to take into account the effect of the child's death (which remains unaccounted) on his mother who, through no fault of her own, has now suffered the death of both her husband (Uriah) and her child. Whilst this is an illuminating passage in terms of its psychologically accurate description of anticipatory grieving, the passage, nonetheless, also appears to lend weight to the often articulated belief that the death of a child is divine punishment for parental sin. Its inclusion here is therefore of doubtful value since the criterion for inclusion seems to rest more on the simple fact that there is both a child and a death involved in the story than in the underlying theology which the story elucidates.[104]

Following the scripture reading, opportunity is given for the articulation of feelings, for Christian witness and for the exchange of signs of faith, hope and love.[105] This is a particularly valuable inclusion as those who are present on such an occasion have a real need to ventilate the emotions which they feel and to put those feelings, however painful, into words. Whilst it is clearly anticipated that this will be an occasion for Christian witness and for faith, and as such is an important articulation

of the importance of community, such expression may also include the valid articulation of the confusion, anger and frustration as well as the sadness, felt at the death of the child, acknowledged in the preceding prayers.

The service ends with an act of committal, transferring the care of the child who has died from the parents to God, referenced by Jesus' taking and blessing the children in Mark 10:13-16, an assurance that God has once again received the child's life, a prayer for the parents and other family members focussed on the hope of future re-union with the deceased (expressed through 'the hope that one day we shall all live with you'), the Lord's Prayer, and a Blessing.

It is interesting to note, however, that despite the undoubted pastoral sensitivity and awareness of this rite, it is included in the section, 'Healing Services and Prayers' and *not* under 'Services of Death and Resurrection'. Whilst this service is clearly not a funerary rite it is, nonetheless, concerned with death and is the only such rite in that section.[106]

In summary, this service:

- *is an official rite*
- *is primarily parent-orientated*
- *can be used in hospital, church or home*
- *does not include a naming element*
- *includes a committal (although this is not a funeral rite)*

A Service of Death and Resurrection

The United Methodist *Service of Death and Resurrection for a Stillborn Child* has a similar structure to the rite outlined above. It opens with a Word of Grace (a biblical sentence), a greeting and prayer. The prayers suggested are similar in content and structure to those used in the *Service of Hope After Loss of Pregnancy*. They express sorrow at the fact that a loved child has been 'taken from us so soon' although the

phrases used in the *Service of Hope After Loss of Pregnancy* are preferable since they talk about the 'loss of promise' and about the life which is now 'gone from us', rather than suggesting that the child's life has been 'taken away'. Words like, *'taken'* should be avoided, since they either (often inadvertently) objectivise death, casting death as the 'grim reaper' ever waiting to snatch life away, or they present God as one who capriciously takes away with one hand what he has given with the other. Both views, whilst historically common, are nonetheless, as we have seen, both pastorally and theologically unfortunate. The second prayer offered is preferable, then, since it states with both simplicity and clarity the reality of what the bereaved parents have experienced - 'Expecting the life of a child, we have witnessed his/her death'.[107] Both prayers, however, express the belief that God is ever-present in Christ to console and to heal those who grieve. The list of readings, and the alternatives suggested, omit the 2 Samuel passage about David's grief at the death of his child (although this is included in the suggested lessons for use at a 'Service for a Child'[108]). Space is given for a Sermon which is followed by a Prayer of Commendation although this is clearly a prayer which commends the bereaved and not the deceased to God,[109] a Prayer of Thanksgiving and, where it is part of the service and not at the final resting place, the Committal. The service concludes with the Lord's Prayer and a Dismissal with Blessing. This service is clearly a funerary rite.

In summary, this service:

- *is an official rite*
- *is primarily parent-orientated*
- *can be used in church, crematorium or at the graveside*
- *does not include a naming element*
- *includes a commendation and committal (although the commendation is of the bereaved not the deceased)*

Human Rites is a book of liturgies which the compilers describe in their Introduction as being '...a collection of services and rituals that demonstrate liturgy 'from the

ground up'.'[110] Whilst some of the liturgies clearly rely on existing denominational rites for their basic shape and, indeed, some of their content, others are genuinely 'experimental' in nature and in the pastoral services there is no attempt to 'polish' the material so that the 'rawness' of emotion is preserved. This is particularly true of those services which are concerned with birth/death rites. This book serves as a good example of liturgical material which lies outside the official denominational liturgies but which acts as a resource both for clergy in planning funeral or memorial services, or those who are planning their 'own' services. This genre of material stands, therefore, as a bridge between 'official' liturgies and individual rites which are person and context specific. Its importance lies as much in the fact that it offers people 'ideas for ways of structuring rituals' as in the specific material which is offered.[111] Two rites will suffice here to exemplify this 'bridging' role, *Liturgy at the time of choosing whether or not to have an abortion* and *Rituals for abortion* both by Vienna Cobb Anderson.[112] Whilst the first of these implies an element of choice, it is nonetheless a rite that could equally be used in the context of both elective and therapeutic abortions.

Liturgy at the time of choosing whether or not to have an abortion.

Gathering in God's name

The woman, family and friends gather in God's name. This is a very intimate service. It may take place in a home or a chapel in a church. If there is not a sensitive priest known to the woman facing the abortion, then a friend or mother may take the role of the leader.

LEADER Blessed are you,
loving God, Mother of all.
PEOPLE Holy is your name,
Now and for ever.

LEADER Eternal Womb
from whence all came,
PEOPLE We lift our hearts to you.
Heal our wounds.

LEADER Mother of the world,
bless us.

PEOPLE Hear our cries
and grant us peace.

LEADER Let us pray
Loving God, all hearts are open to you, all desires known, and from you no secrets are hid. Cleanse the thoughts of our hearts that we may love you, and praise your holy name with our acts this day and for evermore. Amen.

The Word of God proclaimed

One of the following readings from scripture is read as well as any passage that is particularly meaningful to the woman.

Revelation 21.1-5 *(Behold I make all things new.)*
Mark 14.1-9 *(She has done what she could.)*
John 1.1-5 *(In the beginning was the Word. An inclusive-language text is essential.)*

Response to God's Word

If the woman has chosen to have an abortion, a letter to a dead child written by the mother may be read by her or by someone of her choosing. The letter may express her feelings, her thoughts about the abortion, what she would have liked to say to the child.
If the woman has chosen not to have an abortion and to keep her child, a letter expressing her hopes and dreams for her child may be read.

Prayers for one another

LEADER Mother of all,
we ask your blessing upon _____
PEOPLE Hear our prayer, O God our Mother.

LEADER Bless all who face the choice of abortion. Grant them wisdom to make their choice, courage to act upon it, and the knowledge of your love.
PEOPLE Hear our prayer, O God our Mother.

LEADER Grant unto all women the support and love that we offer unto _____ this day and always. Bind us close in your love and keep us faithful in our friendships.
PEOPLE Hear our prayer, O God our Mother.

LEADER Let us ask God's mercy and forgiveness upon all our lives.

Confession

Hear our prayer, O God our Mother. Forgive us our sins as we forgive those who have sinned against us. Forgive us our passivity, our doubts, our guilt,

and our shame. Empower us to forgive ourselves that we may receive the fullness of your forgiveness and grace; in Jesus Christ's name we pray. Amen.

Absolution

Loving God, you have given power to your priests to pronounce absolution; give to this your daughter _____, your love to absolve her guilt, remove her fear, heal her wounds, and make whole her body, that she may live her life reconciled to you and to her child, with the opportunity to begin a new life sustained by your Holy Spirit, now and forever. Amen.

Act of Dedication

The mother makes a dedication in the name of the child and asks for the community's support to keep her vow. The promise should be personal, specific, and attainable.

Example:
'In the name of my child, I promise I will give $___ every month for the coming year to support a homeless child...'

'In the name of my child, I promise I will plant a garden on the street where all who pass by may see the abundance of God's grace.'

The laying on of hands

PEOPLE We lay our hands upon you in the name of our Savior, Jesus Christ, beseeching God to uphold you and to fill you with grace, that you may know the healing power of God's divine love. We give you our love, promising to stand by you through this decision and in the days to come. Amen.

The Peace

LEADER The peace and love of God be with you this day.
PEOPLE And also with you.

The people exchange the peace with hugs. It may take as long as necessary.

If the woman has chosen to have an abortion, it is suggested that the letter that she has written be burned and the ashes buried in a suitable place. This helps to give a tangible sense of letting go and of burial.

The service may conclude here or the people may make Eucharist. It is appropriate to use homemade bread. If the Eucharist is celebrated, the following prayer may be used afterward.

Post-Communion Prayer

PEOPLE Most loving God, you are the source of life and our defender in the hour of death. We thank you for feeding us with the spiritual food of the body and blood of Jesus Christ. May we be strengthened to meet

the days ahead with hope and newness of life. Grant that we may serve others in your name and to your glory. Bless our sister, _____, and her child; give to them peace in the unity of your love. All this we ask through Jesus Christ. Amen.

Benediction

CELEBRANT

The blessing of God,
the creator of life
be with you this day.

The blessing of God,
the redeemer of abundant love
be with you always.

The blessing of God,
the sanctifer of all,
send you as a blessing to others.

ALL So be it.
Alleluia.
Amen.

This is clearly a very woman-centered rite. No mention is made of the father of the child, nor does he have any apparent role in the proceedings. The language of the rite is similarly woman-centered with the imagery of God as Mother and of womb as dominant motifs. If the text of John 1 is read, the directions make it clear that an inclusive-language text is not simply desirable but essential, though the rite itself is gender specific rather than gender inclusive! The prayers are open, empathetic and non-judgemental and the confession is particularly powerful with its call for empowerment, particularly the empowerment '...to forgive ourselves that we may receive the fullness of your forgiveness and grace'. Self-blame and poor self-image are frequently present after pregnancy loss, often compounded by real or perceived complicity in the death. The use of the absolution is a priestly act, and one cannot help wondering if, within the context of this rite, an act of forgiveness conferred by the group would not be more consistent. The act of dedication following the absolution has more a feel of restitution than dedication to it and, whilst there is a stress that any such act should be 'personal, specific, and attainable', one cannot help feeling that

there is an air of imposition and duty here, rather than a spontaneous and free act. The laying on of hands and the peace are both tactile acts of affirmation and support, offered in a situation where feelings of isolation are common. The burning of the letter, and the burial of the ashes, enact a physical letting go, closure and symbolic burial of the child. It is important to note that, throughout the rite, the abortus is clearly seen as a child, as the post-communion prayer makes explicit, 'Bless our sister, _____ , and her child'. The inclusion of a eucharist underscores the healing role of the rite and the specific reference to the appropriateness of homemade bread is consonant with the tenor of the rite as a whole, although the priestly/ministerial acts of absolution and eucharistic presidency detract somewhat from the strongly communal feel of the rite.

In summary, this service:

- *is a non-official rite (commercially available)*
- *is mother-orientated (with no mention of the father)*
- *can be used in hospital, church or home*
- *may include the Eucharist*
- *does not include a naming element*
- *does not include a commendation or committal*

The companion rite, *Rituals for abortion*, forms a useful corollary to this rite and its text is therefore included here.

Rituals for abortion

There are three parts to this ritual

Before: Preparation; the need for courage
During: Friend; the need for support
After: Guilt; the need for forgiveness

Before

Friends gather with the woman at her home prior to the abortion. It could be the night, or the morning before the surgery. They share a simple meal together as a sign of friendship.
After the meal the friends gather in a circle around the woman and lay hands upon her. They may express their feelings and prayers in their own words or say the following together:

We lay our hands upon you in the name of our Savior Jesus Christ, beseeching God to uphold you and to fill you with grace, that you may know the healing power of God's divine love. We ask God to fill your heart with strength and courage and we give you our love, promising to stand by you through this decision and in the days to come. Amen.

The friends then greet one another with hugs.

During

A friend goes with the woman to the place of abortion and stays with her as long as permitted. Prior to leaving, the friend takes oil, which she has brought with her, and anoints the woman.

On the head, saying: We support your decision.

On the hands, saying: We hold your hands in solidarity and love.

On the womb, saying: We bless you.

The two women hug as a sign of peace between them and all the friends who gathered earlier.

After

Friends gather once again with the woman at the time of her choosing. They gather in a circle.

Water is poured from a pitcher into a bowl in front of the woman.
FRIEND We wash you with water as a symbol of the tears of mourning, the forgiveness of guilt, and the beginning of a new life for you.

One by one the friend come to the woman, put their hand in the water and place water on her head, her hands, her face, or her feet.

At the end the friend greet one another with hugs, the sign of friendship and peace.

Rituals for abortion has a strongly trinitarian shape and offers non-judgemental support throughout the pre-abortion, abortion, and post-abortion period. It recognises the need for preparation and courage, friendship and support; it

acknowledges guilt, and recognises the need for forgiveness, which together form a strong emotionally-supportive framework for the woman who is undergoing the abortion. Whether intentionally or not, however, the gathering together for a shared meal before the event has an eerie 'last supper' feel to it. It may need to be remembered that, when a general anaesthetic is to be used, the woman herself may be precluded from eating anything for some time before her operation. The encircling of the woman by her friends and the laying on of hands has both a healing and affirmative role. The prayer which follows is identical to the one used in the preceding rite with the inclusion of the words, 'We ask God to fill your heart with strength and courage...'. The greeting with hugs is a familiarly tactile element of these rites.

During the abortion, or at least in the final pre-abortion time, the woman is accompanied by a friend. This sense of 'being journeyed with' or accompanied is both affirmative of the woman and may help to mitigate the sense of aloneness which, as we have seen, often accompanies both abortion and grief. Once again, the rite appears to preclude the presence of the woman's husband or partner or the father of the child, or at least to assume that he will not be present! There is an assumptiveness about this which sits uneasily with those who are aware that partners and fathers may be very much involved in the decision-making or share in a sense of grief, guilt and powerlessness at this time but whose needs are not just marginalised here, but are positively ignored. This seems to be an 'all-female' experience from which men are *ipso facto* excluded.

The anointing with oil accords with the practice advocated in James 5:14, although in James it is the *sick* who are anointed. It is unclear whether the words, 'We bless you' when the womb is anointed are a blessing on the woman or the child who is to be aborted. It may well be that the ambiguity here is intentional.

In the rite which follows the abortion, sensitively at a time of the woman's choosing, the friends gather in a circle to wash the woman with water. The purpose of the water is threefold: to symbolise the tears of mourning; the forgiveness of guilt;

the beginning of a new life for the woman. There is a great deal of pastoral perceptiveness in this which demonstrates well the symbiotic relationship of pastoral care and liturgical action which is advocated in this chapter. The recognition that there may be mourning after an abortion is something which needs to be underlined.[113] All too often it is assumed that as abortion carries with it, in most cases, an element of choice, the woman has, at best, made a free choice which it is up to her to live with and, at worst, that she has brought the situation upon herself. Women who undergo abortions, especially, though not exclusively, elective abortions, report that those around them are often unsympathetic to their grief and grieving, dismissing the aborted child merely as a termination. This can be both deeply distressing and deeply damaging to healthy grieving.[114] As in baptismal liturgies, the water also symbolises forgiveness and, as already noted, guilt is often a strong emotion in those who have, either by choice or necessity, sought or consented to the termination of a pregnancy. Finally, also as in baptism, the water symbolises a new life beginning for the woman, in this case, post-abortion.

In summary, this service:

- *is a non-official rite (commercially available)*
- *is mother-orientated (with no mention of the father)*
- *can be used in a combination of hospital, church or home*
- *does not include a naming element*
- *does not include a commendation or committal*

Whilst these are sympathetic and empathetic rites, there is nonetheless a strongly and politically 'feminist' feel to them which may not always be appropriate and which, in some cases, may be wholly inappropriate. They stand, nonetheless, almost alone in their brave recognition that abortion, so often the cause of controversy and polemic within the Christian community, is something that can be, and needs to be, drawn within the orbit of a pastoral caring. Here it is given a powerful symbolic and liturgical setting.

Human Rites also includes a number of other rites including *The blessing of a dead baby* and *On the death of a child* adapted from prayers from *A New Zealand Prayer Book.*[115] There is also an *Order of Service for the funeral of a two-day old baby* by Alec and Linda Balfe-Mitchell whose son, Nicholas, died in 1991; a *Dedication and funeral of a stillborn baby* by Clare Edwards and *A service of commemoration and healing after abortion,* a service prepared for a young woman who had chosen to have an abortion after rape by her boyfriend.[116] Two rites after miscarriage, a service for a stillborn child and a water-based rite of blessing for a deceased baby by Ingrid Kohn and Perry-Lynn Moffitt complete the rites offered in this volume.[117]

Part II Rites concerning the end of life

Introduction

At the end of life, rituals perform a number of complex functions with regard to both the person who has died and those who have been bereaved. It is in this context that the questions *Who is this rite for?* and *Who are the principal players?* are perhaps at their most pertinent. For the deceased, such rites are often seen as both marking and effecting their transition from the world of the living to the world of the dead. For the bereaved, such rites also mark or effect a transition, a transition both in their relationship with the person who has died and with the commuity of the living.[118] This, however, is not the whole story. The use of the stylised language of ritual within the context of the rite may allow fragile and vulnerable human beings to name or say those things in a safe and boundaried context, which they might otherwise not dare face and therefore to let them 'move on'. This is a role which is both psychological *and* theological/pastoral. It is a mistake all too commonly made to see these two aspects as mutually exclusive.[119] It is important, therefore, to recognise that rituals at the end of life, and funerals in particular, have an important, if not on

occasions pivotal, role to play in the grief process itself. Thus while a 'good' funeral can help grieving, the opposite is also true, that a 'bad' funeral can hinder or even damage it.

Historically, the effect of the Protestant Reformation of the sixteenth century in England, by outlawing prayers for the dead and repudiating the doctrine of purgatory, effected a shift in the role of the funeral from addressing the needs of the departed to addressing the needs of the bereaved.[120] Henceforth, the role of the funeral was to provide consolation for those who remained and not to affect the post-mortem fate of those who had died. Even in contemporary liturgy where the focus has ostensibly once again shifted back towards the deceased, it has done so in terms of 'celebrating' or giving thanks for their past life, rather than praying for their future happiness. Thus, once again, any perceived 'benefit' is conferred on the bereaved rather than the deceased.

In this section, we will look at two forms of end of life rites: funerals and memorial services. The former have as a central, though not exclusive, element, acts of disposal; the latter focus primarily on remembering. Both, however, can be powerful reminders of reality. Once again, a distinction will be drawn between 'official', semi-official, and self-written rites.

In terms of funeral rituals there are an increasing number of 'official' liturgies which can be used either in their entirety or as the basis for a more personal service either in Church or at the crematorium or graveside.[121] The sense of the personal is an important element for consideration. One of the criticisms levelled at the rites of the Church, especially when conducted in crematoria, is that they are too impersonal.[122] Opportunity may be offered at certain points in the rite to refer to the deceased by name, but personal touches may be minimal where rites are used without appropriate adaptation (which should not be confused with alteration!) and sensitivity to context. This is especially so in the case of the funeral of babies or infants where the need to affirm those who have died as 'persons' is often particularly acute. Susan Hill

underlines the importance of the involvement of parents in planning the funeral, both to give a sense of 'ownership' to the rite and also to ensure that it is a positive experience. She cites the advice which was given to her, 'you should make it your service, for your child. It should bear your mark upon it'.[123] I believe that this is actually most effective when the funeral liturgy itself is robust and is least effectively achieved when people, including clergy, simply 'do their own thing'. Such services are too often un-rooted and instead of being funeral services which are deeply personal, they can become vague and sometimes purposeless 'pick and mix' rites, whose only role is to recall the deceased in an often rather sentimental way. In order to be person-orientated Christian funerals do not have to cease to be God-centered![124]

Most books of 'common' prayer (i.e., those which form the received and authorised text of a particular ecclesial community) contain rites for the disposal of the dead. Historically, before the advent of cremation in modern Western society as a legal and acceptable alternative to burial, in a Christian context these were almost exclusively burial rites.[125] When cremation became an option in the nineteenth century, alternative forms of words allowed for differences in disposal at the committal.[126] For the funeral of a child, most service books offered either supplementary prayers or a simplified form of the adult service. In later rites, directions allowed for the adaptation of rites to allow for the burial or cremation of stillborn children. Since those children who die at less than 24 weeks gestation have no legal status, no specific liturgical provision is made for them, although the *Methodist Worship Book* offers *A Funeral Service for a Stillborn Child* in which it states: '(t)his service can be adapted for use after a miscarriage or neo-natal death'.[127]

The Alternative Service Book of the Church of England offers *Prayers after the Birth of a still-born Child or the Death of a newly-born Child.*[128] No mention is made here of early miscarriage and, while the directions say that, 'these prayers may be used in church, in hospital, or in the home; and where appropriate they may be used at the burial or cremation of a still-born or newly-born child', the service is described as

'Prayers' and not as a funeral. Although the service contains a commendation, there are no readings (apart from an optional selection of verses from the Psalms after the commendation) and there is no committal. The role of the father is seen as secondary and references to him are put in parenthesis. A separate service, *Funeral Service for a child dying near the time of birth'*, was produced by the liturgical commission of the Church of England in 1989 which offers a more context specific funeral rite.[129]

Common Worship, published in 2000 as the successor to the *Alternative Service Book*, offers a flexible *Outline Order for the Funeral of a Child.*[130] The outline provides a framework for both eucharistic and non-eucharistic rites, and includes the elements of gathering, a ministry of the word, prayers, commendation and farewell, commital and dismissal. While there is no separate rite for miscarriages, stillbirths or neo-natal deaths, a section on *Resources for the Funeral of a Child*, includes prayers for 'an older' child, 'a young child', and also 'A baby', 'Stillbirth', and 'Miscarriage':

4. **A Baby**
To you, gentle Father,
we humbly entrust this child so precious in your sight.
Take *him/her* into your arms
and welcome *him/her* into your presence
where there is no sorrow nor pain,
but the fulness of joy and peace with you
for ever and ever.
All **Amen.**

5. **Stillbirth**
God of compassion, you make nothing in vain
and love all you have created;
we commend to you *N* and *N's* child *N*,
for whom they poured out such great love,
for whom they cherished so many hopes and dreams.
We had longed to welcome *him/her* among us;
grant us the assurance that *he/she* is now encircled
in your arms of love,
and shares the resurrection life of your Son, Jesus Christ.
All **Amen.**

6. **Miscarriage**
God of compassion,

you make nothing in vain,
and we love all that you have created;
we commend to you *N* and *N's* child *(name child if appropriate)*
for whom they poured out such great love,
for whom they cherished many hopes and dreams.
Grant them the assurance that their child,
though not seen by us, is seen and known by you,
and will share the risen life of your Son, Jesus Christ.

All **Amen.**

Several points may be noted here. While the first prayer makes no mention of the resurrection life, the second and third do so, but with significant differences. The prayer for a stillborn uses the present tense - 'shares'; that for a miscarriage, the future - 'will share'. The only conclusion that can be drawn, other than poor liturgical revision, is that the text intends a different post-mortem chronology in each case. In both cases, however, the stillborn and the miscarried are referred to by the use of the word 'child' and therefore their moral and personal status is affirmed. Thus, the tense change is liturgically and theologically curious. The preceding line in the prayer for a stillbirth, furthermore, asks for the assurance that the child (*he/she*) 'is **now** encircled in your arms of love...' (my stress). Does this suggested that there was a time when the child was *not* thus encircled? Furthermore, while both these prayers begin in the same way - 'God of compassion, you make nothing in vain...' the stillbirth prayer continues, 'and love all you have created'; that for a miscarriage says, 'and **we** love all that you have created' (my stress). Again, does this suggest a more than verbal difference? Can it really be that while the prayer acknowledges that both the miscarried and the stillborn are created by God, only the latter is loved by God - or, at least, that it is unclear whether there is anything in the former state to be so loved (although if there is enough there to be loved by us, why not by God?).

That there is an ambivalence here, is borne out in the *'Theological Note on the Funeral of a Child Dying near the Time of Birth'* by Oliver O'Donovan, included in the text of *Common Worship*.[131] O'Donovan asks whether it is 'right to regard an unborn child as a human person, with the capacity for life after death.'[132] If, indeed, the person-status of the unborn is doubted in either respect, the rationale for holding a

funeral at all is called into question. 'If we cannot speak of a stillborn child as a human being, then we cannot speak of a stillborn child at all.'[133] O'Donovan makes no mention of a miscarriage. It is unclear whether he is using the terms 'stillbirth' and 'stillborn child' as a paradigm that implicitly includes the miscarried, or whether he is suggesting that the person-status of the miscarriage is so much in doubt that nothing can be said about it. Secondly, O'Donovan questions whether it is right to speak of a 'sure and certain hope' in the case of someone (sic) who has not lived outside the womb, and has not been baptised.[134] While O'Donovan does not refer either to the stillborn or the miscarried specifically, he concludes that '(w)e are right to be cautious about a *particular* assertion of the individual child's resurrection.'[135] Is O'Donovan implying here that sharing in the resurrection life is contingent upon baptism? Certainly the text of *Common Worship* stops short, as O'Donovan recognises, of asserting with confidence 'that this individual will be raised on the last day' although the hope that this will be so is held onto.[136] Thus, O'Donovan takes us no further in discovering the theological intent of the text of *Common Worship* on these issues. He does little more than assert, as Austin Farrer had done at the end of *Love Almighty and Ills Unlimited*, that God will save whatever there is to be saved but that what there is to be saved is not known to us. Certainly, his theological note sheds no light on the theological curiosity of the text.[137] Ultimately, then, we are faced with a resource which, however good its pastoral intention, is ultimately liturgically unsatisfactory.

The Uniting Church in Australia's, *A service to follow the birth of a still-born child or the death of a newly born child*, says in the notes to its version of this service, 'It should be clearly understood that this is not a funeral service and is necessarily brief. A quite separate funeral service will be held in due course'.[138] The service acknowledges the grief and pain of the parents, setting the rite in the context of both 'the mystery of life and death' and of the Passion of Christ. After some short verses from scripture and prayers for the family, the focus of the rite shifts from the bereaved

to the child who has died. The presiding minister places the sign of the cross on the child and may invite the parents to do the same. The accompanying prayer affirms that Christ 'has welcomed N/this child into his eternal Kingdom'.[139] The service concludes with the Lord's Prayer and a blessing.

Similarly, the Iona Community's brief *Liturgy for a Stillborn Child* is a liturgy and not a funeral rite.[140] The word 'for' in the title is ambiguous, but it is clear from the text that this is primarily a rite 'for' bereaved parents. The rite begins with words of comfort for the bereaved parents and offers thanks for the child whose intrauterine life is acknowledged and affirmed. There is a nice use of zeugma, acknowledging that the child has been 'carried' in both the mother's womb and the father's heart, thus establishing the death as a parental loss which affects both partners equally, though in different ways. The rite acknowledges the sadness, questioning and, significantly, the anger of the parents. The fact that the anger is, 'that a life promised has been taken...', however, again suggests an inappropriate doctrine of God. There is an acknowledgement of the feelings of guilt and failure which are so often a hallmark of such early-life deaths and, whilst no readings are included, space is given for parents and others to articulate their feelings in words or symbolic actions. After a period of silence there is a prayer of commendation or 'letting go', said by all. There is no committal and the service ends without a blessing or grace.

Until the mid-1980s, in the UK the only provision made for the disposal of a baby who died before the legal age of viability was with other hospital 'waste' either in the hospital incinerator or, later, elsewhere under contract. Such babies were simply regarded as POC (product of conception) or NVF (non-viable foetuses) and, since they lacked any legal status, needed neither registration (of birth or death) nor rite. For some women and their families this was not a problem (or at least it was not articulated as a problem). For others, who regarded the conceptus as being a baby, the lack of significant ritual and the apparent indignity of disposal could seem shocking, brutal and a denial of the value and reality of their child. When faced with a direct

question - 'What happens to the baby now?', most staff would be faced with trying to 'fudge' the issue by saying things like, 'the hospital takes care of all that...' or 'they go to a special place in the hospital...' If the question, 'How?' or 'Where?' followed, then ethical issues of truth-telling and the right to access to information became acute. Although legally the property of the hospital, the question, 'What happened to *my* baby?' demands an answer. Gradually, more and more hospital Chaplains working in Maternity services began to seek an alternative to the hospital or commercial incinerator.[141]

From the mid-1980's, babies in Bristol who died *in utero* before legal viability were taken to South Bristol Crematorium on a monthly basis where *'a short but dignified service'* was conducted by a hospital Chaplain.[142] Initially, there were a number of obstacles. Some crematoria officials or employees were uncertain or even antagonistic towards these new moves which some considered un-necessary (although they were often unclear *why* they felt it un-necessary). Though there was no legal requirement for either the registration or funeral, permission for cremation/interment was required by the Crematoria and Cemeteries Department.[143] There now existed three options. The hospital could deal entirely with the matter of disposal with the parents opting to know no details; the parents could consent to cremation of remains with a 'short but dignified service'; or, the parents could contract directly with an undertaker to provide a funeral, including burial or cremation of remains. A small number of parents asked about a fourth option - that they should have the remains of a non-viable baby to inter at home. Legally, this was an option that could be pursued but the pastoral and psychological implications were often poorly thought out, if at all.[144] The first option involved no rite, the second option usually involved the Bristol Maternity Hospital rite, *The Funeral of a Child*, described above, with no distinction being drawn as to the intrauterine age of the child, the third option usually involved local clergy rather than hospital Chaplains, the former tending to rely more heavily on 'official' funeral rites, adapted to a greater or lesser extent according to circumstance.[145]

Parents at Bristol Maternity Hospital were always offered information about all available options, and, in the case of a hospital arranged service, informed when the service for their child would take place, in order that they could attend the service if they so wished. Some parents opted neither to attend nor to know when the service would be taking place; others would want to avail themselves of both options. It is true to say, however, that, generally, the earlier the loss, the fewer people would attend the cremation. It was sufficient for many parents simply to be re-assured that a dignified disposal would take place. Often the immediacy of the trauma of the loss of a planned and/or wanted pregnancy would deter many parents from being involved in the rite after a miscarriage and for these parents in particular the option of a later memorial service was seen as a more appropriate and welcome option. Nonetheless, even in such circumstances, funerals may have an important role in granting permission to grieve by affirming the reality of the situation and validating the miscarriage as a 'real' bereavement.

With a stillbirth, where there is more often a clearly formed body which has been seen and/or held by the parents, a funeral is more common. The birth/death of the child is registered and a stillbirth certificate issued. Once again, either burial or cremation is an option. Unlike miscarried remains, which are often casketted in a small plywood box, stillborn babies, like those who have died in the neo-natal period, often have a recognisable coffin of the traditional shape. Such coffins are appropriate to the size of the baby who has died and are, unlike their adult counterparts, often white, usually being covered in a white fabric. Such coffins also bear the name of the baby who has died and the date of birth/death.[146] Such funerals are frequently deeply touching and significant rites for all concerned. The baby who has been miscarried or stillborn will, in all probability, never have been taken home. Into the funeral are channelled, therefore, all that the parents might have hoped and wanted to do for their child and often all that they might have hoped for themselves in a future shared together. A significant part of the funerary rite, therefore, is the transfer, or at least

extension, of care which the parents had hoped to show for their child to God and the re-location of the child from the orbit of human relationships to that of 'heaven'.[147]

Peter Speck has suggested that, after a stillbirth, parents may feel the world to be so inherently 'unsafe', and themselves so incapable of 'caring for' their child, that they cannot contemplate another pregnancy. In such circumstances, he maintains, the funeral and associated rites facilitate the grieving process and help the bereaved to make the necessary re-investment in life, in surviving children, or in future pregnancies.[148]

The funeral of a stillborn child, whether in Church, crematorium or cemetery, is always a sad and moving occasion. Very often, one of the parents, usually the father, would be invited to carry the coffin and to place it on the trestle or catafalque. The sight of the tiny, white coffin being cradled by the grieving parent was itself a cause of emotion for many people. Such services are often permeated by a deep sense of futility and powerlessness. The fact that the baby will probably not have been seen by the majority of those present, may lend an air of unreality to the occasion. Whilst there are few memories on which to draw, not discounting the importance of memories of the preparation for and of the pregnancy itself, the hopes, aspirations and dreams of the parents and others form the emotional core of this service as they do for services which follow miscarriages and neo-natal deaths. The role of ritual, not only in affirming faith but in validating experience and in the creation of a sympathetic and empathetic community of care, should not be under-estimated. Perhaps most significantly such ritual can help affirm the identity of the child as a person, rather than a 'thing' to be disposed of. This is why the use of the child's name in this context is so important. As has been argued in preceding chapters the way in which miscarried or stillborn infants are regarded needs to reflect how those most closely connected with the experience relate to who/what is the focus of the ritual. It is no longer acceptable (indeed, it never was acceptable) to treat extinguished human life, whether or not it is yet regarded as a person, as no more than hospital 'waste'. Douglas Davies reflects how,

> (p)erspectives like this express an underlying medical model ignoring deep facts of existence, whether existential experiences lying at the heart of life, or religious experiences at the centre of faith.[149]

I include here some examples of rites which may be used, or adapted, in such circumstances.

A Funeral Service for a Still-Born Child[150]

Words in **bold** type are said by all

Prayer:

> Almighty Father, who in your great mercy made glad the disciples with the sight of the risen Lord: give us such knowledge of his presence with us that we may be strengthened and sustained by his risen life, and serve you continually in righteousness and truth; through Jesus Christ our Lord.

Brief introduction, including a reference to the name N. that has been given to the child.

Prayer:

> Father in heaven, we come to you as your children: We come in sorrow that *N.* has been taken from us so soon; but also we come in peace, for your Son has promised that all your little ones shall look upon your loving face for ever.
> We come to you in prayer for ***his*** parents (mother), who have (has) had so little time to care for ***him***; We thank your for their (her) love, which surrounded ***him*** as he grew, and for your love for us all, that gives us strength.
>
> Father we thank you that you have created all things and made us in your own image:
> That after we had fallen into sin you did not leave us in darkness, but sent your only Son Jesus Christ to be our Saviour;
> That by his death and resurrection he broke the power of evil;
> And that by sending the Holy spirit you have made us a new creation.

We thank you that *N.* is, with us, an heir of all your promises, sharer with us in the humanity that you redeemed in Christ, and in the eternal life which you have revealed to us through him.

We welcome our brother N. into the flock of Christ in the Name of the Father and of the Son and of the Holy Spirit.

Amen.

Psalm 23

Reading:

Perhaps from Matthew 18: 1-5, 10; Matthew 11: 27-30; 2 Corinthians 1: 3-7.

Prayers: Let us Pray.

Praise and honour, glory and thanks be given to you, almighty God, our Father, because in your great love for the world you gave your Son to be our Saviour, to live our life, to bear our griefs, and to die our death upon the Cross.

We praise you because you have brought him back from death with great power and glory, and given him all authority in heaven and on earth.

We thank you because he has conquered sin and death for us, and opened the kingdom of heaven to all believers.

We praise you for the great company of the faithful whom Christ has brought through death to behold your face in glory, who join with us in worship, prayer and service.

For your full perfect and sufficient gift of life in Christ all praise and thanks be given to you for ever and ever.

Amen.

Prayers:

For parents;
For brothers and sisters;
For attendant medical team, whether attending the funeral or not

Commendation: Let us pray.

Merciful God, you have made us all and given your Son for our redemption. We commend our ***brother*** to your perfect mercy and wisdom for in you alone we put our trust.

Amen.

Our Father...

Blessing of Choice

Nunc dimittis,

while leading the coffin and procession, or after committal in case of cremation.

Committal:

Forasmuch as this child is in the care of Almighty God, we therefore commit *his* body to the ground, earth to earth, ashes to ashes, dust to dust (OR, to the elements, ashes to ashes, dust to dust), in sure and certain hope of eternal life,
through our Lord Jesus Christ.

Amen.

Prayers:

Most ministers will probably prefer to pray *extempore* here.

This rite was written as a response to a perceived pastoral need some ten years after the *Methodist Service Book* was printed in 1975.

The service begins with a clear affirmation of the Easter faith of the Church which sets the service within the context of the death and resurrection of Jesus Christ. The 'brief introduction' allows for a personalising of the rite, particularly through the use of the child's given name. It is important to note that the name is not given in the context of the rite. This is particularly important since a little later in the service the prayer is used which begins, 'Father, we thank you that you have created all things...' which is the Baptismal Prayer said together, at the font, by the Minister and congregation in the rite for *The Baptism of Infants.*[151]

Before that prayer, however, is a context-specific prayer expressing sorrow over the death of the child. Unfortunately, this rite also uses the phrase, 'who has been taken from us so soon...' which suggests a capricious 'taking' of children by God, even though there is the balancing suggestion that, in the mercy of God, 'all your little ones will look upon your loving face forever.' Against the reference to the child's parents,

for whom those gathered for the funeral pray, the word 'mother' is put in parenthesis with the accompanying 'their (her)' throughout underlining the fact that, as so often after intrauterine or inter-partum deaths, the role of fathers can be down-played. The prayer recognises, the brevity of time which the parents had to care for their child and, importantly, it recognises, both God's love and 'their (her) love, which surrounded him as he grew...' thus affirming the intrauterine life of the child. There then follows the prayer from the rite for The Baptism of Infants (see above) and the affirmation that, with us, the child is 'an heir of all your promises, sharer with us in the humanity that you redeemed in Christ and in the eternal life which you have revealed to us through him.' The child is then welcomed 'into the flock of Christ' in the name of the Trinity. This section has clear resonances with the rite of baptism though it is in no way a baptismal or quasi-baptismal liturgy. In this section, belief is heavily overlaid with function, in other words, it not only affirms the faith of the Church that the child is thus 'welcomed into the flock of Christ' but actually effects it through the liturgy.

The reading from Psalm 23 clearly anchors the service as a funerary rite and the suggested passages include the passage about the calling into the midst of a child[152], the easy yoke of Christ[153] and Paul's thanksgiving to God in time of trouble.[154]

The readings are followed by the Thanksgiving from *The Burial or Cremation of the Dead*[155] and intercessions for family members, including siblings, and for the medical team. This is an important and sensitive recognition of the place of the medical attendants and of the 'ripple effect' that such deaths often have. The rite ends with the Commendation, Our Father, Blessing, *Nunc dimittis*, Committal and *extempore* prayers. In the committal, it is interesting to note that the reference to the resurrection is notably absent saying simply, 'in sure and certain hope of eternal life'. The absence of the three words, 'the resurrection to' before 'eternal life' is an indefensible omission.

The service, however, is very much a rite of its time. It appeared in the mid-1980s when recognition was growing of the needs of stillborn children and their families but resources, especially official liturgical resources, were scant.

In summary, this service:

- *is an official rite*
- *is primarily child-orientated*
- *can be used church, crematorium or at the graveside*
- *does not include a naming element (but makes specific reference to the child's given name and includes elements from the Service of Baptism)*
- *includes a commendation and committal*

Whilst the *Funeral Service for a Stillborn Child* which appears in the new *Methodist Worship Book* has a number of similarities with its predecessor, it is no mere revision. The 1999 rite has a number of significantly new features.

A Funeral Service for a Stillborn Child

NOTES

1 This service can be adapted for use after a miscarriage or neo-natal death

2 If the child has been given a name this should be used: otherwise it is appropriate to say 'this child'

3 If there is a coffin it may be brought into the building before the service

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GATHERING

1 The Minister says:

We meet in God's loving presence
to acknowledge our loss of one so young.
God knows and loves this child
*(whose **parents A and B (A)**,*
__have given her/him the name N__).

We ask for God's grace
that in our pain we find comfort:
in our sorrow, hope;
in our questioning, understanding;
and in the experience of death, resurrection.

2. Let us be silent and make our own prayers.

Silence

Lord, you love us and watch over us;
you have known us from the very beginning;
and nothing is hidden from you.
Help us now as we entrust *N* to you,
knowing that *she/he* is safe in your care;
In Jesus' name. **Amen**.

THE MINISTRY OF THE WORD

3. Let us hear the words of Holy Scripture, that from them we may draw comfort and strength.

One or both of the following Psalms may be read.

Psalm 23 (*the full text is included in the rite*)
Psalm 139 vss.1,13-18(*the full text is included in the rite*)

4. One or more of the following....

Matthew 18: 1-5 (*the full text is included in the rite*)
Matthew 11: 27-30 (*the full text is included in the rite*)
2 Corinthians 1: 3-7 (*the full text is included in the rite*)

5 A short address or reflection

COMMENDATION

6 Let us pray

Silence

Loving God,
we praise and thank you that *N* is, like us
an heir to all your promises:
sharing with us in the humanity
that you have redeemed in Christ,
and in the eternal life revealed to us through him. **Amen**.

7 All stand

Let us commend *N* to God.

Heavenly Father,
we thank you for *N* and commend *her/him*
to your perfect mercy and wisdom,
for in you alone we put our trust. **Amen**.

8. When the whole service takes place in a crematorium or at the graveside, the service continues from no.11. When there is to be no Committal the service continues from no.12.

9. Otherwise the minister says:

The grace of our Lord Jesus Christ,
and the love of God,
and the fellowship of the Holy Spirit,
be with us all evermore. **Amen**.

---

10. The Minister, going before the body into the crematorium or to the grave, may say one or more of these sentences:

Blessed be the God and Father of our Lord Jesus Christ,
the Father of mercies and the God of all comfort, who
comforts us in our affliction.

'As a mother comforts her child, so shall I myself comfort
you,' says the Lord.

Like a shepherd he will tend his flock and with his arm
keep them together.

COMMITTAL

11. All stand. The Minister says:

Gracious God,
You have made nothing in vain
and love all that you have made.
We therefore commit N's body
to be cremated/to the elements/to be buried,
earth to earth, ashes to ashes, dust to dust;
in sure and certain hope of the resurrection to eternal life,
through our Lord Jesus Christ,
to whom be glory for ever and ever. **Amen**.

PRAYERS

12 The minister may say such parts of the following prayers as are appropriate or some other prayers.

A Holy God,
you are like a loving parent to all your children.
Although the burdens of life overwhelm us,
we still put our trust in you,
knowing that you are with us always;
through Jesus Christ our Lord. **Amen**.

B God and Father of all,
comfort *A* and *B (A)*
together with *their families*,
in *their* grief,
uphold them with your love,
through Jesus Christ our Saviour. **Amen**.

C Gracious God,
may your loving arms enfold us in our grief.
Support *N's* mother *B*,
who with love has carried her/him to birth.
Uphold *N's* father *A*,
who has watched and waited.
Be with them now
in their emptiness and pain;
through him who bears our griefs
and carries our sorrows,
Jesus Christ our Lord. **Amen**.

D Grant us, O God,
in all our duties your help,
in all our perplexities your guidance,
in all our dangers your protection, and in all our sorrows your peace;
through Jesus Christ our Lord. **Amen**.

The Lord's Prayer

EITHER

We say together the prayer
that Jesus gave us:

Our Father in heaven
hallowed be your Name
your kingdom come,
your will be done
on earth as in heaven.

OR

As our Saviour taught his
disciples, we pray:

Our Father, who art in
heaven,
hallowed be thy Name;
thy kingdom come;
thy will be done;

Give us today our daily
bread.
Forgive us our sins
as we forgive those who
sin against us.
Save us from the time of
trial
and deliver us from evil.
For the kingdom, the
power and the glory
are yours,
Now and for ever. Amen.

on earth as it is in heaven.
Give us this day our
daily bread.
And forgive us our
trespasses,
as we forgive those who
trespass against us.
And lead us not into
temptation;
but deliver us from evil.
For Thine is the kingdom
the power and the
glory,
for ever and ever. Amen.

EITHER

A The peace of God
which passes all understanding,
keep *your/our* hearts and minds
in the knowledge and love of God
and of his Son, Jesus Christ our Lord;
and the blessing of God,
the father, the Son and the Holy Spirit,
remain with *you/us* always. **Amen**.

OR

B Christ the Good Shepherd
enfold *you/us* with love,
fill *you/us* with peace,
and lead *you/us* in hope,
this day and all *your/our* days;
and the blessing of God,
the Father, the Son and the Holy Spirit,
be with *you/us* evermore. **Amen**.

Unlike its predecessor, this rite starts with an affirmation of God's loving presence rather than of Easter faith (which comes in the last line of the first prayer), but affirms God's knowledge of the particular child. While the starting point is with both parents, designated as *A* and *B*, the rite allows for the use of the mother's name alone, designated as *(B)*, again underscoring the maternal predominance of this and other rites. The opening prayer asks for God's comfort for the parents and also, rightly,

acknowledges the element of questioning. After a period of silent prayer, the rite affirms that God has known us 'from the very beginning' and that 'nothing is hidden' from God. In line with Psalm 139, 'beginning' probably means before conception, rather than simply from the point of conception onwards (see above). Psalm 23 retains its traditional place in the funerary rite and is accompanied by verses from Psalm 139.

Like its Methodist predecessor, the rite includes the two readings from Matthew's gospel - the setting of the child in the midst and the easy yoke - and the reading from 2 Corinthians 1 - Paul's thanksgiving to God in the midst of trouble. The Commendation reproduces the prayer that in the previous rite precedes Psalm 23 and is followed by the Commendation and the Grace. The verses which precede the Committal reflect a contemporary awareness of, and sensitivity to, gender inclusive language with the reference to God's comfort being like that of a mother. The Committal is in the traditional form and the words 'the resurrection to', omitted in the 1984 rite, are restored. In the prayers which follow, specific references to any siblings are omitted as is any reference to medical and nursing staff. The third prayer mentions both mother and father by name, although the statement that the father has simply 'watched and waited' posits an overly passive role to the father, implying he is a mere bystander in the process of creation. Two versions of the Lord's Prayer are offered and two blessings, the latter one echoing both Psalm 23 and John 10 with its reference to the Good Shepherd.

In summary, this service:

- *is an official rite*
- *is primarily child-orientated*
- *can be used in church, crematorium or at the graveside*
- *does not include a naming element*
- *includes a commendation and committal*

Patterns and Prayers for Christian Worship, published by the Baptist Union of Great Britain, also offers a short service *'For a Still-Born or Newly Born Child'*.[156] The rite,

in a section titled 'Additional material for situations of particular pastoral need', is preceded by an explicit note which states that,

> (i)n the funeral for a baby it is important to recognise and express the belief that the baby was a person. Even if he or she never lived outside the womb, he or she was a loved child who has died.[157]

Although the note does not spell out how such intrauterine personhood might be constituted, the care of the parents for their child is nonetheless thus affirmed. A relational theory of personhood would see this, of itself, as constitutive of personhood and, in the Christian context, would also regard the holding of the child in the divine memory as similarly constitutive.

The service begins with a sentence of scripture affirming the presence of God. Suggested texts include Lamentations 3: 22-23, Psalm 55:22, Hebrews 13:5 and, as in other similar services, Revelation 7:17. Suggested Scripture readings include Psalm 139, Mark 10: 13-16, John 1: 1-5 and Ephesians 3: 14-19. Although the book dates from 1991, the language of the rite (which the prayers describe as 'these last offices of love...'), is traditional. The prayers are bible-centred and affirm that God is bringing 'him/her and us to undying life with Jesus Christ our Lord'.[158]

In summary, this service:

- *is an official rite*
- *is primarily parent-orientated*
- *can be used in church, crematorium or at the graveside*
- *does not include a naming element (but places particular emphasis on the individuality of the child)*
- *includes a commendation*

These familiar themes are found also in the *Common Order of the Church of Scotland.*[159] In the *Order for the Funeral of a Stillborn Child*, the introduction acknowledges that '(o)ur minds are filled with questions to which there appear to be no answers: so many things we do not know; so many things we do not understand...'.

The rite then goes on to affirm that 'there are some truths we do know...'. It spells out that 'the God who made us, loves us; that he loves us always, that through his Son Jesus Christ he has promised never to leave us nor forsake us.'[160]. The suggested passages of scripture include Isaiah 40:11, Psalm 23, I Corinthians 13: 4-8, 12-13, Hebrews 13:5-6, Matthew 18:14, Mark 10:13-16 although there is no passage from Revelation. Five sets of brief prayers are offered which repeat the themes already noted in other services - an affirmation of the love of the parents for their child and of God for all, an acknowledgement of grief, the assurance that the child is now in the care and keeping of God, a request for peace and the strength to bear loss. The prayers are followed by the Lord's Prayer, an act of committal and a blessing.

In summary, this service:

- *is an official rite*
- *is primarily child-orientated*
- *can be used in church, crematorium or at the graveside*
- *does not include a naming element*
- *includes a commendation and committal*

In England, while the United Reformed Church has no separate service for the funerals of stillborn babies (or, indeed, other children) the *Service Book* includes appropriate prayers in an Appendix.[161] By contrast, the Presbyterian Church in Cameroon offers a complete rite for *The Burial of an Unbaptised or Stillborn Child.* This service includes a complete ministry of the word, commital and blessing.[162] The Salvation Army, *Salvation Army Ceremonies* also contains prayers and guidance for the funeral of a child which includes stillborn and newly-born babies in a final section. This, too, affirms that '...this dear child (baby) is now in the loving care of God his/her heavenly Father'.[163]

Most denominational rites which do not include material specifically related to pre- or peri-natal deaths include rites for the funerals of children which may be used or

adapted in the case of pre-birth or early-life deaths. These rites are, however, usually little more than a shortened form of the funeral service for adults, sometimes with the addition of a context-specific reading (such as Mark 10:13-16) and a supplementary prayer. *The Funeral of a Child* in the *Alternative Service Book* of the Church of England begins with Revelation 17:7, moves directly into the reading of Psalm 23, followed by a reading of either Mark 10:13-16 or Ephesians 3:14-19. The prayers consist of the *kyries* and the Lord's Prayer followed by a commendation and committal with verses from Psalm 103 as an optional reading at the graveside or crematorium. Jude 24:25 acts in the role of a blessing.[164] The *Methodist Service Book* simply offers emendations to the adult rite offering John14:1-6, 27 and Mark 10:13-16 as readings. Revelation 17:7 is read at the committal and two alternative or additional prayers are offered after the committal.[165]

The successor to the *Methodist Service Book*, the *Methodist Worship Book* offers a more context specific rite in *A Funeral Service for a Child* (as well as *A Funeral Service for a Stillborn Child*).[166] After the scripture sentences and a hymn the intention is stated:

> We meet in God's loving presence
> to give thanks for the life of *N*,
> the *daughter/son* of *A and B (A)*;
> to commend *her/him* to God;
> and to uphold and support those who mourn.[167]

Thanksgiving for the child's life, the commendation of the child to the care and keeping of God and the support of those who have been bereaved are the aims of the service. The introduction to the prayers also makes explicit their purpose:

> As we seek the strength and comfort of God,
> let us in silence bring our confusion and sorrow,
> our anger and pain,
> and lay them before God.[168]

One of two prayers follow this and precede the readings from scripture. Once again the readings offered are Psalm 23, Mark 10:13-16, John 14:1-6, 27 with the addition of Revelation 21:1-5a. Provision is made for a sermon and the commendation includes

context-specific prayers. The service proceeds at the crematorium or graveside with a committal, after the sentences of scripture, which includes a reference to Revelation 17:7. The intercessions are more extended than in previous services and have a high degree of pastoral sensitivity, recognising the grief of the parents, family and friends, asking for God's support and forgiveness and for the healing of painful memories. Reference is included to Mary and her place at the Cross witnessing the death of her son, and a plea is made for the confidence of a resurrection faith. The Lord's Prayer is followed by a reading of St. Patrick's breastplate and a blessing. A similar service, both in length and content is offered in the *Book of Common Order of the Church of Scotland.*[169]

The Roman Catholic *Order of Christian Funerals* devotes a massive one hundred and thirty three pages to funeral rites for children.[170] Part II of the *Order of Christian Funerals* provides rites that can be used with infants and young children including those who are of early school age. The general directions suggest that the most appropriate rite should be chosen by the minister in consultation with those concerned according to the particular circumstances. The directions also clearly establish the purposes of such rites, which correspond to the tri-partite purposes found in other funeral liturgies:

> In the celebration of the funeral of a child the Church offers worship to God, the author of life, commends the child to God's love, and prays for the consolation of the family and close friends.[171]

These rites, however, are notable also for their sturdy attempt to reflect the death and resurrection emphases characteristic of early Christian funerals.

The Roman rite, unlike other rites (with the exception of the Presbyterian Church in Cameroon), draws a clear distinction between the baptised and un-baptised child. Thus, while these funeral rites may be used for children whose parents intended them to be baptised, but who died before baptism, those elements of the rite which are reminders of baptism, such as the pall and the holy water, are not used in such

circumstances. Alternative wordings are offered in the text to distinguish between the baptised (where the dominant motif is that the child already enjoys eternal life in God's kingdom), and the unbaptised child (where the faith of the parents and the entrusting of the child to the love of God becomes dominant). In the prayers for the bereaved there is a strong sense of the mother and father, and any brothers or sisters, being held and remembered together as a family by the community. In the seven forms of the rite of committal provided, the *'Rite of Final Commendation for an Infant'* may be used with appropriate adaptation for a stillborn or miscarried child as well as for an infant who dies shortly after birth.[172] Once again, the dominant motif is that of the frailty of human wisdom and understanding in the presence of the mysteries of life and death. Thus, the rite maintains that 'in the face of death all human wisdom fails'.[173] It is interesting to note that the prayer of commendation begins with the words, 'Tender shepherd of the flock, N. now lies cradled in your love.'[174] In other rites in the *Order of Christian Funerals* this phrase is used for children who have been baptised and alternative prayers are offered in the case of the unbaptised child. In the case of a miscarried child, opportunity is given to name the child if the parents so wish: 'Lord, you formed this child in the womb; you have known it by name before time began. We now wish to name this little one N.: a name we shall treasure in our hearts for ever'.[175] Somewhat surprisingly, rather than coming at or near the beginning of the service, this option is part of the prayer of commendation and comes immediately before the blessing with which the rite concludes.

In summary, this service:

- *is an official rite*
- *is primarily child-orientated*
- *can be used in church, crematorium or at the graveside*
- *distinguishes between baptised and un-baptised children*
- *may include a naming element*
- *includes a commendation and committal*

A theology of funerals

Throughout the examples given some clear messages emerge: that whilst recent liturgical revision has become increasingly sensitive to the needs of a previously marginalised group among the bereaved whose pastoral circumstances are amongst the most difficult and challenging, this trend needs to continue if people are not to be alienated from the Church and what it has to offer, liturgically and pastorally, to the bereaved; that even the best liturgies need to be used sensitively and creatively since there can be no off the shelf, one-size-fits-all, rite which can adequately meet the needs of each individual family; that where these needs are not met, families turn elsewhere, either appropriating rituals which *do* meet their needs, or constructing their own in which the formalities of traditional liturgical convention may have little place. One thing is clear, what bereaved parents are looking for above all else are rites which a) are context-sensitive and recognise and affirm the individual identity of their child at whatever age, before or after birth, that child dies, b) validate the grief of such parents in a genuine and accepting way, taking account of the wide range of feelings and emotions which such experiences may elicit, c) provide the context for the expression of those thoughts, feelings and experiences which form the mental and emotional framework of their lives, d) allow for appropriate sharing with others and with God (however named) of a continuing love for and concern about the child who has died.

Where such issues are ignored or 'fudged', confidence in both the ritual and those who are its traditional 'keepers' is eroded and ultimately compromised. Margaret Saunders, writing on peri-natal death, says,

> If parents are given the opportunity to be as involved as they wish in the funeral, the funeral can provide a containment for their grief and their endeavours to care for their child whom they have loved and from whom they are parted too soon. Clergy and chaplains have a pastoral, liturgical and interpretative role at these crucial times.[176]

If this is to be effective then the process of creating good liturgy will always involve mutuality and partnership. The time spent with the family before the funeral will be of

critical importance if the funeral service is to be meaningful and relevant and is not to be based on an unequal power dynamic in which the bereaved are cast in the role of the passive recipients of the rite rather than as active participants in it.[177]

An example of how this may be achieved can be seen in the funerals of a number of babies who had died in the Bristol neo-natal intensive care unit (NICU) from congenital heart abnormalities in the early-mid 1980s. By and large these babies were ones who had been transferred straight to an intensive care environment from the delivery suite because of the severity of their condition. Although much can now be successfully achieved by way of corrective surgery such babies clearly form a high risk group. For some of these babies surgery, or other medical procedures such as angioplasty, are not a viable option. Some will die before intervention and some will die during or shortly after it. It is this group with which we are concerned here. In many cases, contact between the families of these babies and the Chaplains had already been established before death occurred.[178] For some, baptism or other appropriate rites (see above) had been performed and a pastoral relationship had begun. For some families, talking about, or even planning, the funeral had already begun prior to the baby's death.[179] Since the baby could not be taken home the number of people outside the immediate family who had had the opportunity to see the baby was often very limited, especially if the baby had been transferred in from outside the area.[180]

The time before the death, where appropriate, and the period immediately following it was a period for the Chaplain to be alongside the family, listening and sharing with them as they explored the meaning of what was happening to them.[181] During the time in NICU families often took photographs of their baby, as with any new baby, and gathered precious memories in their time together, where possible holding and cuddling the baby or stroking his/her skin. All these experiences can be valuable when it comes to planning and taking part in a funeral. As part of my conversation with these families a number of points began to emerge - How could others understand what they wanted to say when so few of those who would come to the funeral had even seen the baby? What could be said that could even begin to

explain how much their brief lives had meant to their parents? When memories, though intense and precious, were so few and memories that could be shared with others outside the immediate family were almost non-existent, what could be said that represented the joy of having these particular children, even though the time spent with them was so short? How could joy and sorrow be held together in a meaningful way? What place was there for expressing other feelings: frustration, anger, guilt? How could the wonder of a new life and the tragedy of untimely death co-exist so closely?

In the hours and days which followed such bereavements listening attentively to oft-repeated stories formed a core part of pastoral care. Talking, openly and honestly, about life and death and the Church's understanding about the nature of God and the reality, often so deeply painful, of experience helped slowly to shape a meaningful rite that could meet, as nearly as possible, the criteria of a good rite outlined above. With some families I employed a story-boarding technique.[182] We would sit down with photographs, cards, poems, scissors and glue and I would encourage the parents to tell the story of their child through words and pictures. These were mounted on card and were placed in the foyer of the Church so that people could see them as they arrived for the funeral. Thus, many who had not had the opportunity even to see the baby and therefore had no idea of what he/she looked like could be drawn into the narrative. One of the things which well-handled liturgy can achieve is the creation of a 'community of care' around the bereaved. This can happen through the gathering of people together and through the establishment of a shared narrative which can be achieved by using techniques like story-boarding, as much as through the words of the liturgy and what is said and done within it. Such services could be deeply personal and moving events. I regarded my role as the presiding Minister not as one enacting a narrative with the congregation as onlookers, but as a facilitator enabling all present fully to enter into the rite as both event and process.[183]

In any such rite, the silence is as important, and sometimes more important, than the words, creating sacred space to hold memories, dreams, feelings and beliefs

and experience together. Sometimes one or both of the parents would say something during the service - fathers often talking about what had happened, about the experience, and sometimes, wonderfully, about their feelings; mothers often reading a poem or a letter which they had written to their child. At such moments the silence could be palpable as others were drawn into a narrative of love and support. The use of the child's given name throughout is a reminder that the child was known and loved as a person in their own right and not just as someone who might have been. Others, friends or relatives, might be asked to read a lesson or to speak briefly. If all those who are present are accepted with the radical openeness of neighbour-love, irrespective of any faith, professed or otherwise, permission can be given to acknowledge, to own, and to explore the whole range of emotions and feelings which such occasions may precipitate, in a safe and boundaried environment. It is possible, with sensitivity and without any sense of proselytising to proclaim within this, the central truths of the Christian faith. It is important for any Christian Minister when conducting such rites to remain true to the tradition in which he/she stands, as well as validating the experiences of others, if integrity is to be maintained. As Penelope Wilcock has noted, 'Problems commonly arise over the mismatch of the needs of the mourners and the expectations of the minister'.[184] To this I would add, 'and their expectations of the Minister...'.

It has sometimes been argued that for religion to provide support and comfort in such circumstances some prior commitment to faith must already exist.[185] I would argue, however, that such experiences can also be the source of faith, rather than simply providing support or comfort to those who have it.[186] It may occasion reflection on the meaning of life or a re-appraisal of previously held beliefs, values or practices which may lead to a change in belief, practice or lifestyle. Whilst achieving this is not an aim of the funeral service it is not unknown for it to happen and such people may subsequently become part of a new or extended community of support and care.[187]

Before moving on to consider Memorial Services, both individual and collective, I include one more rite found in the sources used to exemplify rituals which surround the birth/death of a baby. This significant rite is found in *The Glory of Blood, Sweat and Tears: Liturgies for living and dying*, published by the Australian Joint Board of Christian Education.[188] In a slim but excellent volume of liturgies a rite entitled, *'Grieving the Child: A service for those whose child has a disability'* is included.[189] The rite sensitively recognises the disappointment of those whose child is born with, or acquires, a serious disability. Such parents are indeed, 'bereaved' of the 'perfect' child which is every parents' hope and of the dreams and ambitions which they may have held or nurtured for themselves and for that particular child. Indeed, I would go so far as to argue that until the grief for their 'loss' of the child-who-will-never-be is expressed, it may well be difficult for many parents to 'own' the less-than-perfect child who actually 'is' and to recognise that all human beings are, in their own ways, 'imperfect' beings. The rite recognises a weeping both for self and for other, the pain of recognising that the child is less than perfect (and indeed, for some, the pain of recognising that their image of God is less than perfect), and an affirmation of hope. The rite concludes with this moving section:

THE NEW CHILD

Leader: The child we expected is not the child we have.
In this moment let us farewell the old child.

(Period of silence)

If it is appropriate, the child is brought into the centre and surrounded by the people who lay their hands upon her/him.

Leader: Here is the child we have,
the new child,
the precious one that belongs to its parents and to all of us for sacred safe-keeping all the days of his/her life.

People: **We welcome this child with love.**
We will watch over this child

and hold it surely within our community of hope.
The life of this child
is a slender golden thread among us.[190]

The rites outlined in this chapter provide a representative cross-section of rites currently in use both in the United Kingdom and elsewhere. They demonstrate the historical emergence of such rites from the early-mid 1980s as a response to an increasing sensitivity towards those whose babies die before, at, or shortly after, birth and a willingness on the part of at least some of those working with them to engage with difficult theological as well as pastoral issues. The increasing number of 'non-official' rites, whether published or not, demonstrates a growing confidence among the bereaved to re-claim death and its accompanying rituals from the hands of professionals without necessarily denying them a role. There are many who would support this move.[191] Jane Littlewood, for example, writes,

> 'Perhaps the best that can be hoped for is that people who have been bereaved may begin to consider new ritual expressions of grief appropriate to themselves and their mourning group in greater numbers...'.[192]

Some rituals at or around the time of death are more informal, though no less important, acts. They make take place in the hospital or, more frequently, later at home with perhaps a small circle of closest family and/or friends in attendance. Where a Chaplain or other minister has been invited, it is most often in the role of friend - someone who because of their involvement already with the baby and his/her life/death is seen as part of an intimate circle of those who have 'known' the child - rather than as a leader or president at the rite. The sense is of all those present acting as 'celebrant' and the setting is usually informal. Although each act is individual, there are recurrent themes or motifs and therefore such ritual acts are perhaps best described by means of a fictitious example.

John and Mary's first child miscarried at 18 weeks. Although the parents were informed of the funeral details by the hospital neither, at the time, felt able to attend the service which was conducted by the hospital Chaplain and held at the local crematorium. After a month Mary and John felt the need both to acknowledge and to say goodbye to their child in a symbolic way. They talked about what they wanted to say and planned a short ritual together. On a Wednesday evening, the same day as their baby had miscarried, they gathered a few close friends together in their flat. Included in this small gathering was the hospital Chaplain who had been with the family during Mary's short stay in hospital and had spent time talking with her and John. After a glass of wine, John explained the short 'service' which was about to take place and said something about why it was important to him and Mary. The 'guests' sat around the room, on chairs or on the floor, and in the middle of the room was a small, low table on which had been placed several items - a hard-copy of the ultrasound scan, a small posy of flowers, a pair of knitted bootees and a lighted candle. After a short time of silence Mary explained the meaning of each of the items on the table - the scan, John and Mary's first 'glimpse' of their unborn child; the flowers, because it was early springtime when Mary had become pregnant and when their child had died; the bootees, a symbol of what they had longed and hoped for; the candle, given to them at the hospital as part of a short service of baptismal desire conducted by the hospital Chaplain. Then, Mary read a poem which she had written in the days after her baby had died. Although the post-mortem report had indicated the sex of the baby, John and Mary instinctively used the 'pet name' which they had had for their unborn child during the short pregnancy - 'Bump'. The poem expressed both the hope of the pregnancy and the sadness of loss. Those who were there listened quietly and attentively to what was being said. John then spoke about his feelings and about how dads were parents too. He had found a poem in a book by Kahlil Gibran called *The Prophet.*[193] It was from a section about children, which spoke about the mystery of life. He read it out loud. After the reading one or two of the others present spoke a few words about their own feelings of sadness and then John played a tape of a song that had a special meaning

for him and Mary while each person present could say their own quiet goodbyes to 'Bump'. It was a song that had been playing in the cafe where John and Mary had first met as students. At the end of the song, there was a silence broken only when Mary blew out the candle. Slowly limbs were stretched and people began to rise. Spontaneously people embraced each other, speaking words of love to John and Mary. Mary tidied away the items on the table, putting the copy of the scan back on the mantlepiece with the posy of flowers. She folded the bootees into her hands as the guests quietly departed.

This description of such an intensely personal moment highlights several important features of these rituals. Firstly, there is the need to make some sort of gesture which 'closes' an intense emotional and physical experience. Such ritual acts seldom, in my experience, come within days of a death but rarely go longer than a month. There is a gathering of friends and of those who are felt to understand what the parents are feeling, who form a community of care and support. There is a sense of intimacy about the rite and a sense, too, of belonging without any sense of leadership by any one person and, while the short time together has a definite shape, it is not so tightly knit that it does not allow spontaneity within it. There is a point of visual focus - the table with its symbolic items, each carefully chosen for a particular reason. The words, which are few, are either written by the parents or chosen because they 'speak' to the individual about their own, very personal, situation. There is the music, once again chosen because of personal significance; the extinguishing of the candle which signifies not simply the conclusion of the ritual but also, too, in a sense, the letting go of the baby; the embrace which reminds the parents both of the love in which they are held and their continued inclusion in the community of the living.

For many bereaved parents, writing has a particular cathartic significance and may continue for some time, even several years after the baby has died. Poetry, as a stylised form of writing, is a particularly powerful medium for ventilating emotions and of creating a 'record' of feelings which may continue to have significance for their

author for many years. Such writings may be shared with significant others and, in some cases, have been published for wider use. Thus parental writings may fulfil a dual role, both in ventilating private grief and in making public the child who has died.

Memorial services

Another form of ritual act which occurs at some distance from the birth/death event is the Memorial Service. Once again these may be personal affairs arranged by a family or they may be more corporate occasions.[194] What follows is a description of the development of an annual Memorial Service for the families of babies, of whatever age, who had died at either Bristol Maternity Hospital or Southmead Hospital. This was among the first of its kind in the United Kingdom and was held from the mid-1980's onwards.[195]

SANDS (The Stillbirth and Neo-Natal Death Society) had been particularly active in promoting recognition of such early-life deaths in the 1980s. Consequently, conversations were held between the Chaplains of the two major hospitals providing maternity services in the City of Bristol, Bristol Maternity Hospital and Southmead Hospital, and local representatives of parent's organisations such as SANDS, the Miscarriage Association, SATFA (Support After Termination for Fetal Abnormality), Compassionate Friends and FSIDS (Foundation for the Study of Infant Deaths). At this stage, the planning of the service was very much Chaplain-led, although this was to change somewhat in later years.[196] Since bereaved parents come from a variety of religious traditions or, indeed, no religious tradition at all, great care was taken over a title for this memorial act. It was decided to call it *'A time for sharing our memories, our sadness and for offering each other sympathy and support'*.[197] The Service was held at Cotham Parish Church, close to Bristol Maternity Hospital on St.Michael's Hill. As the Order remained stable, with only minor variations, over the first few years, one example will suffice.

The service opened with a word of welcome from one of the Chaplains and a hymn, in this case, *Lord of all hopefulness*, by Jan Struther, sung to the Irish folk melody 'Slane'. This was followed by a reading of verses from Psalm 139 and a reading of a poem, written by a member of SANDS, with the dedication, *For Sam and Ben* and entitled *Maybe....* I include the text of the poem here as it has already entered and been used in the public domain. The poem is representative of much parental writing after the death of a child.

Maybe.....

Maybe in the morning
When the sun comes up,
They'll tell me I've been dreaming -
And offer me a cup
Of sweetly smelling tea,
to take away the taste
of the nightmare that's not ending
with any speed or haste.

Maybe in the morning
when the birds begin to sing,
they'll tell me you're still living
and the things that I should bring.
A babygrow, some nappies,
a shawl, maybe a toy,
Collected over several months
for you our baby boy.

Maybe in the morning
things will not look bleak.
And you'll be coming home soon,
Maybe in a week,
to see the room that waits for you,
that Daddy decorated.
To do the things we've wanted to,
The things for which we've waited.

Maybe in the morning
the pain won't hurt so much.
The urge that I should hold you,
to feel your gentle touch
Will lessen without warning,

and we can return home
as if nothing ever happened -
and you have yet to come.

Maybe in the morning,
When life must carry on,
We'll begin to live again,
knowing that you're gone.
You'll never be forgotten,
of that you can be sure.
Your Mum and Dad will miss you,
No-one could love you more.

Sue Thomas.[198]

There followed a brief Reflection by a member of the medical staff and a hymn set to the tune of *Morning has broken.* As the words of this particular hymn do not appear in any hymn book, I reproduce them here. I am unable to locate the author and source of this hymn which may have been written specifically for this occasion:

Fleeting known, yet
ever remembered,
These are our children
now and always:
these whom we see not
we will forget not,
Morning and evening
all of our days.

Lives touched by their lives,
tenderly, briefly,
Now in the one light
living always:
Named in our hearts now,
safe from all harm now,
We will remember
all of our days.

As we recall them,
silently name them,
Open our hearts, Lord,
now and always:
Grant to us grieving,
love for the living:
Strength for each other
all of our days.

Safe in your peace, Lord,
hold these our children;
Grace, light, and laughter
grant them each day:
Cherish and hold them
till we may know them
When to your glory we find our way.[199]

Three readings followed the hymn - a poem read by a member of FSID, a reading from *Matthew 18: 1-4, 10*, read by a member of the Miscarriage Association, and another poem, read by a member of the Bristol Bereavement Support Group. The readings were followed by a Reflection by a Chaplain and a time of stillness during which flowers, in remembrance of the babies who had died, were brought up and laid on and around the altar.[200] After a period of silence, the hymn *One more step along the world I go* by Sidney Carter was sung to the tune, Southcote, and the service concluded with a final prayer.

After the service, families gathered together for tea and biscuits and a time of informal conversation. Although we had 'advertised' the service through the parents' support groups we had no idea, on the first occasion, how many people would turn up. On the day we were overwhelmed by the response. We had certainly expected at least some families whose babies had died at Bristol Maternity Hospital or Southmead Hospital in the preceding year to attend. In the event, many others also came, including older women, many of them now grandmothers, who had experienced an early-life loss sometimes twenty or thirty or more years previously but who had never had the opportunity to give such public and open recognition to their losses. For them, too, the service marked a significant step on the journey through bereavement. Many families brought small children with them, siblings of those children who had died. Some were older children; others, children born subsequent to the death of the sibling or siblings who were being remembered. The service was also attended by members of the nursing and medical staffs from both hospitals for many of whom this was also a significant experience.

It was to prove to be the case that some families would come to the memorial service for a number of successive years after their babies had died and found comfort both in a renewed act of remembering and in the presence of other bereaved parents. This is partly what made the Memorial Services so significant and resulted in their becoming so widespread. The opportunity to publicly remember a baby who has died, in the presence of others who have experienced a similar loss, in a 'safe' environment, is very important. Where this is denied - as it was for so many people prior to the mid-1970s in terms of the recognition of the emotional and psychological impact of pre- and peri-natal deaths, and prior to the mid-1980's in terms of the recognition of the importance of the public validation of such feelings - there is often much 'catching-up' to be done since not recognising such feelings does not mean that they are not there, still less, with the passage of time, does it mean that they will simply have 'gone away'.

Conclusion

The use of ritual, then, is a powerful pastoral tool in working with the bereaved at any stage in the life cycle. In circumstances where all too often neither the loss nor its accompanying grief has been validated, it can be a critical element in the resolution of complicated grieving. The inclusion of children, particularly siblings, is an important element in any of the rites surrounding the birth/death of a child. Children have been described as the 'forgotten mourners' after a death and recognition of them both as children and as bereaved is paramount in any ritual which would extend pastoral care to the child and take seriously their grieving.[201] Both language and ritual action need to accommodate children, taking account of their age, culture, emotional maturity, and relation to the deceased as well as intellectual and spiritual development. For children who may be feeling particularly vulnerable, and even excluded, after a death, their inclusion in ritual may communicate and affirm their continued inclusion in the life of the family and its social networks.

Effective rites will be those which are inclusive, recognising that death seldom affects a single individual but that its effects ripple through the family and extended family networks and out into the wider community.[202] Like all pastoral care in bereavement, pastoral care focussed in the liturgy needs to be systemic in its appeal, meeting the needs of all concerned, including those who have been marginalised in the aftermath of a death. Just as we need flexibility, skill and patience in listening to people in order to help them (if help is necessary) to express their grief in their own way, so we must also exercise flexibility, skill and patience in listening in order that the ritual expression of grief in all its diversity reflects the diversity of human need as well as the truths and traditions of the Church.[203] Emmanuel Larty, is thus correct when he concludes that, in creating a constructive dynamic of holistic care, '(p)astoral carers and liturgists need to be close partners'.[204] This means engaging in a creative dialectic as faithful accompanists, a task which, in the chaos of grief, is often as much about 'being' as it is about 'doing'. Such attentive and faithful presence lies at the heart of both good pastoral care and good ritual.

NOTES:

1 See J. Littlewood, *Aspects of Grief: Bereavement in Adult Life* (London: Routledge, 1992); D.J. Davies, *Death, Ritual and Belief* (London:Cassell, 1997). Therese Rando argues that, '(r)ituals can provide powerful therapeutic experiences that symbolise transition, healing and continuity,' and she adds, 'rituals can be particularly helpful in assisting an individual or family to successfully resolve grief, **both prior to and after the death**.' (my stress). T. Rando, 'Individuals and Couples' Treatment Following the Death of a Child,' in T. Rando, ed. *Parental Loss of a Child* (Illinois: Research Press Company, 1986), p. 402.

2 B. Raphael, *The Anatomy of Bereavement* (London: Routledge. 1984), p.19. Similarly, Judy Tatelbaum argues that, '(t)he meanings we ascribe to life, to suffering and to death are often the keys to how well we survive the pain and how we restructure our lives after a loss.' *The Courage to Grieve* (London: Cedar Books, 1993), p.86.

3 Raphael. *The Anatomy of Bereavement*, p. 21. Malinowski argued that all religion is grounded in the need to control death. B. Malinowski, 'The Art of Magic

and the Power of Faith,' in *Theories of Society,* ed. T. Parsons (New York: Free Press, 1961).

4 See D. Klass, P.R. Silverman, S.L. Nickman, eds. *Continuing Bonds: New Understandings of Grief* (Philadelphia: Taylor & Francis, 1996).

5 *The Rites of Passage,* (Chicago: University of Chicago Press, 1960).

6 In an article on the ASB funeral service Christine Worsley argues that funeral liturgies are perceived by the Church of England as 'channels for pastoral care'. C. Worsley, 'In Some Foreign Tongue... The ASB Funeral Liturgy and the Bereaved,' *Contact,* 115 (1994), 26. It is often argued that acceptance of those who request the rites of the Church, and the same is said of baptism as of funerals, opens the way for pastoral care of families in the future. Such a view fails to recognise the role of the liturgy as a pastoral act in itself and sees it only as a means to an end. While we need to recognise the limitions of any liturgy, it should be seen as part and a parcel of an on-going commitment to pastoral care and not simply as a means of getting a foot in the door. What is important, is the acceptance offered to those who seek it in reponse to the gospel imperative of neighbour-love. The words of Clebsch and Jaekle sound a timely warning to pastoral carers, 'Pastoral care must either rediscover from its great tradition the appropriateness of ritual to its ministrations, or it may forfeit ritual to the other helping professions.' W.A. Clebsch and C.R. Jaekle, *Pastoral Care in Historical Perspective* (New York: Harper, 1967), p. 73.

7 An excellent overview and account of the complex development of ritual can be found in C. Bell, *Ritual: Perspectives and Dimensions* (Oxford: Oxford University Press, 1997).

8 I would also include in death rituals, anniversary and memorial rituals, both personal and communal. For a comprehensive historical survey of such rituals see P. Ariès, *Western Attitudes towards Death: From the Middle Ages to the Present* (Baltimore: John Hopkins University Press, 1974), and P. Ariès, *The Hour of Our Death,* (Oxford: Oxford University Press, 1981). Ariès argues that, at least until the increasing privatisation of death in the late twentieth century, death was regarded as a social experience which therefore evoked a communal response expressed through shared rituals. The idea of ritual effecting transition within community is described by van Gennep as 'liminality' in which previous social relationships are de-structured and relational boundaries and connections are re-drawn. Significant rites are those which mark the transition from one state or stage to another (e.g. wife to widow). Van Gennep regarded funeral rituals therefore as rituals that essentially had more to do with transition than with separation. *The Rites of Passage.*

9 Jane Marie Lamb OSF, an Australian working with ritual after the failure of a pregnancy, says,

> 'Rituals provide the means for persons to enter into experiences and express emotions in a way that is not available outside the ritual moment. Rituals are symbolic of behaviour; using words, gestures and objects to enable those who use them to give meaning to the important events of life... Rituals are in important part of each of our lives.'

Cited in B. Brown, 'Ritual in Pastoral Healing,' *Ministry,* 7, 3 (1997),13.

10 Some would argue that birth *per se* is not in fact marked by Christian liturgy, e.g., D.H. Tripp, 'Worship and the Pastoral Office,' in C. Jones, G. Wainwright and E. Yarnold, eds. *The Study of Liturgy* (London: SPCK, 1978), pp. 510-532. Tripp makes the point that both Churching and Baptism are predominantly rites of passage - rites of inclusion (or, in the case of Churching, re-inclusion) rather than birth-rites.

11 See P.C. Jupp and T. Rogers, eds. *Interpreting Death: Christian Theology and Pastoral Practice* (London: Cassell, 1997), p. xiii and G. Walters, *Why do Christians Find it Hard to Grieve* (Carlisle: Patermoster Press, 1997), pp. 150-1.

12 Roger Grainger notes how the experience of bereavement affects people in the totality of their being. He says, 'The world of the bereaved person is not only emotionally disrupted, it is cognitively shattered.' R.Grainger, *The Message of the Rite: The Significance of Christian Rites of Passage* (Cambridge: Lutterworth Press, 1988), p.29.

13 *The Magic of Ritual* (Harper: San Francisco, 1991), p.79. In using ritual, people are thus acting out how they *are* and not just expressing what they *think*. Ritual therefore gives a *lived* expression to experience and belief which goes beyond simply 'talking things through' or 'having the right ideas'. This theme of lived, or narrative, 'perfomance', taking place in a defining context is also taken up by David Aldridge in *Spirituality, Healing and Medicine* (London: Jessica Kingsley, 2000), p.13ff.

14 T. Jennings, 'On Ritual Knowledge,' *The Journal of Religious Education* 62, 2 (1982), 111.

15 On 'performative utterances' see J.L.Austin, *Philosophical Papers* (Oxford: Clarendon Press, 1961), p.220.

16 Driver, *The Magic of Ritual*, p.84.

17 Sometimes this transformation may involve an affirmation or re-affirmation of those sources of support, natural or supernatural, which may sustain the individual in times of need or of crisis. In this way ritual may be a way of helping the individual, and indeed those around them, to re-orientate their lives.

18 D.J. Davies describes such 'performative utterences' as 'words against death', part of the adaptive process which both transforms the status of the living to that of the dead and of the bereaved to a new state of being from which the deceased is absent. See *Death, Ritual and Belief*, p.1.

19 70% of funerals in the United Kingdom today involve cremation rather than burial. The strict allocation of time 'slots', especially in busy city crematoria (which is also where the large hospitals tend to be located) means that those who officiate at services which take place wholly at the crematorium are constrained by the limited time which they are allocated. While Geoffrey Rowell is right, therefore, to maintain that 'no liturgy ought ever to be mechanical, skimped or dis-engaged', the context works against those who seek to work within a framework of pastoral sensitivity. ('The Role of the Clergy in Funeral Arrangements: Options For Change,' in *The Future of Funerals: Options for Change* (London:National Funerals College, 1997), p.19.). H. Sarnoff Schiff says that, in the context of the funeral of a child, '(t)o voluntarily remove oneself from caring people by holding the private funeral seems only to heighten a pain that is nearly unbearable.' *The Bereaved Parent* (London: Souvenir Press, 1979), p. 12.

20 . The idea of the 'safe' death is developed by Philippe Ariès in his concept of 'tamed death'. See, Ariès, *Western Attitudes Towards Death,* Chap.1. Ariès argues that until recent times death was always regarded as a social rather than personal or private matter, which meant that it produced a communal response, enacted and given expression through shared rituals bringing the community together. The professionalisation of the organisational aspects of death (laying out the body, the funeral etc.), taking the person who has died out of the hands of the family (and therefore out of the hands of the community), and the decline in numbers of those who engage in public religious practice and ritual has meant that death has become an increasingly private affair and one which leaves many people unsure how to deal with it in the absence of the shared rituals which previously boundaried mourning. Perhaps it is not so much that late twentieth century death is a taboo subject, but that its sequestration has left the bereaved confused and unsure how to act. See T. Walter, *The Revival of Death* (London: Routledge, 1994); 'Modern Death: Taboo or not Taboo?' *Sociology, 25* (1991), 293-310; P.A. Mellor and C. Shilling, 'Modernity, Self-Identity and the Sequestration of Death,' *Sociology, 27,* 3 (1993), 411-431. Neil Small argues that late twentieth century ritual focusses more on the 'private tragedy' than on the 'social event' of death. ('Death and difference,' in D. Field, J. Hockey and N. Small, eds. *Death, Gender and Ethicity* (London: Routledge, 1997), p.206.).

21 Romans 6:3.

22 Alice Lovell commends this process. She writes,

> I suggest that culture thrives and can be enriched by adding fresh ideas which relate directly to human experiences. Individuals and groups within and outwith religious traditions are writing new prayers and creating their own rituals which can complement rather than compete with existing belief systems.

('Death at the Beginning of Life,' in *Death, Gender and Ethnicity*, p. 47.).

23 This must be the caveat of so many grief theories which argues that the goal of grief, whether conceptualised as work, stages, or wound, is its eventual resolution. Many, and particularly those who are bereaved through the death of a child, will never ultimately resolve their grief. At best they may learn to live with it, at worst it may overwhelm them.

24 *The Message of the Rite,* p. 30. As such, 'liturgy is a confrontation with the underlying truth of human being.' Ibid., p. 37.

25 How clinicians, as much as 'ritual specialists', treat or refer to the subjects of early life deaths is therefore important since its impact upon those who are most closely affected by such deaths can be profound, affecting both the grieving process and, indeed, their future physical, mental and spiritual health and well-being.

26 What is considered 'appropriate' is, however, open to question. There can be no doubt that the increasingly secular nature of contemporary Western society and the consequent decline in established mourning customs has made bereavement more difficult to deal with by taking away a cultural context in which grief and other personal experiences can be interpreted and communal support offered. Such rites now have to meet both different needs and different expectations among the bereaved. Tony Walter has argued that, '(t)hough the business of dying in the West has been

profoundly influenced by Christianity, it is today very largely a secular affair.The reference point in death, as in life, is no longer God but man...' ('Secularization,' in C. M.Parkes, P. Laungani and B.Young, *Death and Bereavement Across Cultures* (London: Routledge, 1997), p. 166).Wesley Carr, however, argues that liturgies associated with the central rites of passage of human life, especially those concerned with birth and death are ones which belong to humanity in general and not simply to the Church. See W. Carr, *Brief Encounters: Pastoral Ministry Through the Occasional Offices* (London: SPCK, 1985), p.38. Roger Grainger says that the human need for ritual at crucial moments, 'presents the church with a tremendous opportunity for evangelism in the widest and deepest sense of the word.' *The Message of the Rite,* p.8.

27 Carr, *Brief Encounters,* p.11. On p.14, Carr argues that '(t)he person requesting some such rite comes to a church or minister which is believed to be handling not only the realities of existence but also the meaning of life itself and its ultimate significance'.

28 The National Funerals College offers *The Dead Citizens' Charter* and The Institute of Burial and Cremation Administration (IBCA) a *Charter for the Bereaved* (both first published in 1996).

29 Cullen and Young argue that, 'If there is to be any large revival of ritual around death. it will, in an ecological age, need to echo the cycle of birth and death... and it will also need to relate the individual to the whole more convincingly than it does now.' M. Cullen and L. Young, *A Good Death: Conversations with East Londoners* (London: Routledge, 1996), p. 193. It is important to recognise, however, that, 'Our contemporary understanding of dying,death and disposal is one that has been powerfully shaped by what the Christian faith has had to say about death and the hope of a life beyond death.' G. Rowell, 'Changing Patterns: Christian Beliefs about Death and the Future Life,' in Jupp and Rogers, *Interpreting Death,* p. 17.

30 *A Grief Observed* (London: Faber and Faber, 1961), p.9.

31 'Rituals are repeated, normative, symbolic and functional behaviours often associated with religious expression'. R.J. Hunter, ed. *Dictionary of Pastoral Care and Counselling* (Nashville: Abingdon Press, 1990), p.1088. Thus rituals represent culturally standardised ways of expressing the values of that culture through words and/or actions and therefore provide a boundaried context for the exploration of experience.

32 It needs, however, to be noted that this creative tension can also be destructive if mis-used or used badly. Liturgical blundering can do far more harm than good and so utilizing the pastoral dimension of liturgy needs both sensitivity and skill.

33 Tony Walter argues that, '(b)y rupturing human bonds, death threatens social solidarity; by affirming social bonds, the rituals of mourning reconstitute society.' (*On Bereavement: The Culture of Grief* (Buckingham: Open University Press, 1999), p. 21.).

34 Rituals before, at or around the time of birth/death of a baby may be a way of parents saying to others, 'This is how we regarded the one who has died - not simply as a conceptus or 'product of conception' but as a distinct and loved 'other', a being in their own right...' thus helping others in the community of the family or the wider community to know how to relate both to what has happened and to those to whom it

has happened and to affirm or strengthen their relational ties. In this way ritual may also be described as communicative.

35 It is not possible within the constraints of this chapter to conduct an exhaustive survey of all rites which may be used. In the absence of other pastorally appropriate liturgical material many hospital chaplaincies devise their own rites which may be authorised, as appropriate, for local use. Those which I have selected represent, therefore, a sample of rites from which I have drawn, or to which I have contributed, in my own practice. (The need to develop such rites and to extend their availability is well indicated by the fact that, in a one week period during which this chapter was being drafted in 1998, I had three telephone calls for guidance or advice on rites and their use, or for liturgical material, from places as far apart as Scotland and South East England and involving issues concerning the termination of pregnancy, neo-natal death and SIDS!).

36 The word 'child' is used in this context to refer to all stages of gestation as well as to life outside the womb. Jackman, McGee and Turner's study of the management of fetal remains after early pregnancy loss shows that whilst most women in their study neither saw their miscarried baby (85%), nor knew what had happened subsequently to the remains (93%), all wanted to be actively involved in the decision-making process. ('Maternal Views on the Management of Fetal remains following Early Miscarriage,' *Irish Journal of Psychological Medicine 10*, 2 (1993), 93-4.). Other studies include, D. Morris, 'Disposal Arrangements for Second Trimester Fetuses,' *British Journal of Obsterics and Gynaecology 95* (1988), 545-546 and C. Jackson, H. McGee, and H. Turner, 'The Experience and Psychological Impact of Early Miscarraige,' *Irish Journal of Psychology* 12 (1991), 108-20.

37 Often parents will ask for baptism for a sick baby, either because they do not know that other (sometimes more appropriate) rites or liturgical actions are available or because the word 'baptism' is used simply as a blanket word to describe a significant rite or action concerned with children at, or shortly after, birth.

38 Alice Lovell says, 'There are gaps in scripture and other religious texts surrounding all these losses. These omissions mean that the needs of bereaved parents, from a range of religious backgrounds and cultures, are often overlooked.' ('Death at the Beginning of Life,' in *Death, Gender and Ethnicity*, p. 29.). Those modern service books which contain services for use at the funeral of stillborn children generally affirm the intrauterine life of the child. The fact that these may be 'adapted' for use with the miscarried baby suggests that what is believed of the intrauterine life of the stillborn may also be applied to the miscarried baby, although whether this is intended is not always clear. Writing from a feminist perspective, Lovell believes that, whilst 'rituals invest death with meaning' and 'the major belief systems teach that there is some form of continuity after death and provide comfort to the bereaved by helping them to make sense of loss,' nonetheless, 'very little is said about babies.' She concludes, '(t)hese spaces in the scriptures and religious texts, texts written by men, go some way to explaining why these losses have been, and continue to be, overlooked.' (pp. 33, 43). For more on this, see later in this chapter.

39 Jane Littlewood argues that '(o)ne of the factors which complicates any appreciation of the supportive role of rituals in connection with bereavement is that of the general mortality rate in the community'. (*Aspects of Grief*, p.32.). I do not suggest that the grief felt over each individual loss through death was less acute but rather that

increased expectations of pregnancy outcomes has changed our perception of infant mortality and its impact on both the family and society. Whilst it is beyond the scope of this chapter, it should be remembered that not only was the rate of infant mortality much higher in previous generations but so was the rate of maternal mortality.

40 The persistence of this practice has led to much confusion. The setting aside of part of a graveyard for stillborn infants and babies is still common practice. Such ground is generally in an unconsecrated area and thus any grave is referred to as a 'common' grave. Sometimes this is mis-interpreted as meaning a 'mass' grave (i.e., one holding more than one person's remains). This is never the case. When the remains of non-viable fetuses (i.e those of <24 weeks or, before 1992, <28 weeks) were disposed of locally, such remains were simply consigned to the hospital incinerator as 'waste'. When the cremation of such remains was transferred to local cremating authorities, remains were individually casketted and named, as with stillbirths and neo-natal deaths. After cremation of such early remains no ash was available for collection. Where burial took place, remains were similarly casketted and named for interment. Andersson Wretmark notes how, in Nordic Law, while unbaptised infants were excluded from burial in consecrated ground, those who had been blessed but not baptised occupied a 'between' position. Whilst not entitled to a funeral in Church they could sometimes, nonetheless, be buried on the edges of churhyards. (*Perinatal Death as a Pastoral Problem* (Bibliotheca Theologicae Practicae. Stockholm: Almquist and Wiksel, 1993).).

41 How deep the resistance to such practices ran can be seen by the fact that although the crematorium gave the Chaplains the 9.00 a.m. slot for the funerals of babies who had died at either Bristol Maternity Hospital, Bristol Children's Hospital or Southmead Hospital, when, on one occasion, a family, whose baby had been born alive but had then subsequently died (i.e. this was a live birth infant whose birth and death had been legally recorded) asked for a later time so that relatives travelling from a distance could attend, were told that this was not possible because the rest of the day was taken up with *'proper funerals'*. Although this was the response of one individual and did not reflect the views of the the cremating authority, the fact this could be said as late as the 1980s reflects how deeply ingrained the view that such deaths are insignificant could be.

42 Testing the reality of the death is often very important especially after early life deaths. See earlier chapters on the importance of post mortems etc. in helping to do this.

43 *The Anatomy of Bereavement* (London: Routledge, 1984), p.37. Raphael writes, 'The experience of seeing and saying Goodbye to the dead person as a dead person makes it possible for the bereaved to develop an image of the person as dead, different and altered from the living image.' (p.36). Raphael recognises the importance of the ritual of saying 'goodbye'. She writes, 'The farewell represents a setting in place of life and the relationship, a recognition of the departure from both.' (p.27).

44 *The Social Reality of Religion* (Harmondsworth: Penguin, 1967), p.33. A somewhat different interpretation of the role of ritual, including religious ritual, is given by Zygmunt Bauman who suggests that death is so problematic for contemporary society that the role of ritual is to keep the impact of its pervasive reality to a minimum. (*Mortality, Immortality and Other Life Strategies* (Cambridge: Polity Press, 1992).).

45 Bristol Maternity Hospital, *Service of Baptismal Desire for Bereaved Parents.* This title was suggested by Peter Firth, then Bishop of Malmesbury. The liturgy was written to provide a rite that was pastorally sensitive and theologically defensible when parents requested baptism for a child who had already died. It has been printed in the September 1991 issue of *The Hospital Chaplain.*

46 Many parents would subsequently light this candle on the anniversary of their child's birth/death as a symbolic reminder of the love in which that child continued to be held.

47 Bristol Maternity Hospital, *Service of Blessing for a Baby Miscarried or Stillborn.* This rite was constructed for use at Bristol Maternity Hospital by the then Anglican Chaplain, Rev.Charmian Mann. Concern was being expressed by many Chaplains at this time about the absence of appropriate rites within the Christian tradition and much creative thinking was being done at this time by Chaplains working in Maternity Services including Charmian Mann at Bristol Maternity Hospital, Sue Giles at Southmead Hospital and Barbara Richards at Swindon. The theological and liturgical contribution of Peter Firth, Bishop of Malmesbury, was also significant.

48 Many contemporary writers, however, argue that belief in an after-life has declined almost to the point of non-existence. N.P. Harvey, for example, writes, 'even the majority of professing Christians have at best a purely notional belief in an after-life.' (*Death's Gift: Chapters on Resurrection and Bereavement* (Grand Rapids: Eerdman's, 1995), p. 3.). Whilst this may be true in abstract terms, those who are faced with the death of a loved person seldom see them as passing out of existence after death, however hesitant they are in articulating the *form* of post-mortem existence. The necessity of the Church's need to say something meaningful on this subject as part of pastoral care of the bereaved led the Methodist Church to establish a Faith and Order Working Party on Life after Death in 1998. The Working Party, of which I am the Convenor, is due to report in late 2001. While Harvey argues that, 'pastoral concern with bereavement continues to be dominated by the social welfare mentality,' (p.4), I will argue that liturgy, as a particular expression of pastoral care, provides an important counter-balance to this.

49 G. Walters, *Why do Christians find it Hard to Grieve* (Carlisle: Paternoster Press, 1997), p.4. The alternative view, which argues *for* a soul-body dualism, from an evangelical standpoint, can be found in J.P. Morland and S.B.Rae, *Body and Soul: Human Nature and the Crisis in Ethics* (Illinois: InterVarsity Press, 2000).

50 For Augustine the body as the locus of personhood is problematic. His vision of heaven appears to suggest that it is a purely 'spiritual' place and it is only in his later writings that he allows for the possibility of some sort of 'body' which enters into the beatific vision. The resurrection body is nonetheless a significant feature particularly in Augustine's later writings, particularly his *City of God* and by this time (late 5th. century) he represents the Christian tradition as being committed to *both* belief in an immortal soul *and* to a bodily resurrection. Particularly important in the current context is his belief that in the case of babies who had died, a 'sudden and strange power of God shall give them a stature of full growth'. Augustine, *City of God, 22:4.* While he was more ambivalent about what would happen to an aborted fetus, he nonetheless considered it possible that they, too, would be provided with bodies. See Augustine, *City of God, 22:13.*

51 The element of hope, both present and future, is particularly clear in the theology of St.Paul. See, for example Romans 8, a passage included in many funeral liturgies in which Paul affirms his confidence in the abiding love of God from which the Christian cannot be separated even by death.

52 This prayer is taken from the *Order for the funeral of a stillborn child.* Church of Scotland (1994). *Common Order of the Church of Scotland.* Edinburgh: St.Andrew's Press, pp. 319-325.

53 Bristol Maternity Hospital *Service of Blessing for a Baby Miscarried or Stillborn.*

54 In this passage those who are martyred for their faith clearly enter into heaven immediately after their physical death (although this appears to be at variance with Revelation 20:4 where the martyrs are seen as among the first to be resurrected at the millenium whilst others had to wait for their resurrection until the millenium was over).

55 See also Job 1:21, Ecclesiasticus 40:1.

56 Such phrases, as we have noted, are redolent of many Victorian funerary inscriptions. The similarities between Victorian funerary inscriptions and the entries made by parents in hospital Books of Remembrance are striking, with imagery of flowers and angels providing a common motif. While such imagery is avoided in most liturgical settings, it is used to excess in a Dominican publication, *Funeral Liturgies,* which likens a baby who has died to a flower that dies before it has had chance to bloom. Thus the liturgy focusses on what the child *might* have been rather than the actual child who really *was.* (F. McCarthy, *Funeral Liturgies* (Dublin: Dominican Publications, 1994), p.15). The same rite speaks, in an indigestable plethora of images, of tiny sparrows falling to earth before they could get airborne, acorns contained in oak trees and apple blossoms lying on the ground. There is a real danger here that the dead child will be unhealthily idealised. For this reason I resist all talk of children who, at any age, die as 'special' children, not least in the context of a rite, since it carries the implication that surviving children are in fact less 'special' than their dead siblings. This is discussed in more detail in the chapter on children and grief. In a Scandanavian study which also encompasses English and American rites, Wretmark discusses how important it is that the parents see their child *as* a child and notes how slow the churches have been 'in catching up with the ritual needs which have been expressed by bereaved parents and by hospital staff.' (Wretmark, *Perinatal Death as a Pastoral Problem,* p.229.).

57 David Aldridge reminds us that, '(s)piritual meanings are linked to actions, and those actions have consequences that are performed as prayer, meditation, worship and healing.' and that 'distress can be manifested that finds no immediate resolution in a healthcare setting.' (*Spirituality, Healing and Medicine,* pp.15, 20.).

58 Bristol Maternity Hospital *Service of Blessing for the Child of Bereaved Parents.*

59 It was my practice to offer parents such a 'certificate' after any form of prayer or blessing, however brief.

60 While some hospitals offer parents a lock of hair or even finger nail clippings as mementos, and whilst these are undoubtedly valued by some people, others feel that cutting their dead baby's hair 'violates' the child's body. If parents want a lock of hair I think it is valuable either to let them cut it themselves or, at least, to be present whilst

this is being done. In my opinion, non-invasive procedures such as foot or hand prints are equally 'personal' (and indeed unique!).See chapter on Stillbirth.

61 This service will be referred to later but is included here to show its familial similarity to the three services under discussion.

62 Wherever possible, where local clergy already had a relationship with the family, we encouraged the participation of those ministers at as early a stage as possible. Where pre-existing pastoral relationships existed, such a practice both respected the on-going relationship and helped to provide longer-term pastoral support. Parents would, however, often say things like, 'You were the only person who knew him/her...' and relationships built over a very short (and often very intense) period could have a significant impact on parents. Sometimes, services would be shared between local clergy and particular Chaplains. On funerals see later.

63 Thus for families who were asking those who stood alongside them for rites which both recognised and said something meaningful about their experience, the response of the Chaplains was to enter into a dialogue *both* with those families *and* with the Christian tradition in order to produce rites which both reflected the reality of present human experiences and the reality of the experience of God as witnessed to in Christian history and tradition. Only by doing so could rites emerge which were genuinely respectful and mindful of the realities which were being addressed but which were also true to the faith context which was the root and ground of our shared being.

64 P. Tillich, *Theology of Culture* (Oxford: Oxford University Press, 1978), p.207.

65 Two notable exceptions are the *Methodist Worship Book* (1999) and the Iona Community *The Pattern of Our Days: Liturgies and Resources for Worship* (1996) both of which explicity recognise and name anger as an emotion felt following the death of a child. Mark Sutherland, writing in the mental health context, notes that,

> maturity brings the awareness that life will never be conflict free, only conflict managed. However, it is the management of conflict which is the raw material for wholeness.

('Pastoral Care, Theology and Mental Health: Relationship, Discernment and Wholeness,' *Contact, 123* (1997), 17).

66 Bristol Maternity Hospital *An Order for Emergency Baptism.*

67 Central Board of Finance of the Church of England (1980). *Alternative Service Book*, Cambridge: CUP, section 45, p.244.

68 Ibid., section 52, p.246.

69 The inclusion of prayers for restoration of health and peace for the sick child does not preclude the child's death as part of this. Indeed, since this rite is used *in extremis*, the death of the child is, in fact, expected.

70 Roger Grainger describes baptism as, 'participation in a particular kind of personhood; not a sign of participation but participation itself.' It is, in other words, a taking of Christ's personhood 'whose name confirms us in personhood because it establishes us in our true life...' (*The Message of the Rite*, p.19.).

71 It is increasingly uncommon, although by no means unknown, for parents to request baptism for their child out of fear that an unbaptised child will be excluded from heaven or even condemned to hell. For this reason, however, all parents are assured that neither the ultimate salvation of their child nor the provision of a Christian funeral are affected if the child dies in an unbaptised state. It is also sometimes necessary to remind some parents that baptism does not, of itself, affect the outcome of any medical prognosis and that a baptised child is as likely to die as one who remains unbaptised. Prayers for healing do not preclude the possibility that death will occur. On issues of religious denial and the dying child, see chapter on neo-natal death.

72 C. Salter and M. Watkinson, 'Emergency Baptism on a Neonatal Unit: First Blessing or Last Rites?' *Crucible* (1994), 123-132.

73 Ibid., p.124. Statistics were drawn from the neo-natal Unit's Register of Baptism. Such a register is held on every neo-natal unit, SCBU or ICN.

74 28% of children who died in the neo-natal period were baptised in the hospital in which they were born, compared with a national average of 27.5% baptised into the Church of England in the same period.

75 Salter and Watkinson, 126.

76 Ibid., p.126.

77 Attentive listening is essential here since it is important to recognise where each person is in relation to the event. This may be as much the case when only the parents are present as with the gathering of a more extended group. Liturgy therefore needs to be inclusive, true to where each person is, and its dialogue needs to engage with everybody involved, in order that what it offers does not reflect just one person's perspective, thus leaving others marginalised.

78 One child, facing complex heart surgery and with a poor prognosis, was, however, refused baptism by parish clergy on the grounds that the parents were not married. The child was baptised by me prior to surgery and a pastoral link between the parents and the wider Church was thus re-established.

79 I would argue that where a baptism is conducted under such circumstances, whilst it may be regarded as irregular, it should not be considered invalid.

80 J. Ford, 'How Shall We Comfort Them?' *Ministry, Society and Theology, 8, 2* (1994), 17.

81 D.P. Dalzell, 'Being Christian, Being Pastoral, and Baptismal Practice,' *Ministry, Society and Theology 8, 2* (1994), 24-31.

82 It is this *engagement* with familes, including the element of challenge, which is genuinely 'pastoral' not the simple acceding to what people want.

83 Dalzell, 'Being Christian, Being Pastoral, and Baptismal Practice,' 25.

84 Ibid., p. 26.

85 Dalzell similarly challenges an article in *Journal of Pastoral Care* (47,3, 1994) entitled, 'Theological Reflections on Baptism by a Jewish Chaplain' where the underlying assumption appeared to be that 'one religious person in a ward is as good as another'. He concludes that it is less than truthful to deny differences under the guise of being 'pastoral'. Ibid., p.28.

86 Dalzell, 'Being Christian, Being Pastoral, and Baptismal Practice,' 31.

87 In some traditions the practice of Anointing may be used as an acceptable pastoral alternative to baptism.

88 Tony Walter has argued that, '(u)nderstanding the spiritual meaning of bereavement... has to take seriously the afterlife, relationships with the dead, the supernatural and both official and folk religious traditions.' Walter, *On Bereavement*, p. 60.

89 H. Ter Blanche and C. M. Parkes, 'Christianity,' in *Death and Bereavement Across Cultures* ed. C.M. Parkes, P. Laungani and B. Young (London: Routledge, 1997), p. 136.

90 See later in this chapter.

91 The variants on this are, of course, many. One of the most common, however, are inter-generational differences. Grandparents who have religious beliefs may try to influence or pressurise their children into acts which, whilst significant and meaningful within the grandparents frame of reference, have little or no meaning for the parents. In the heightened emotional context of the death of a child, conflict may be easily precipitated as the dynamics of interpersonal relationships come under threat or are compromised.

92 Such rites may take place in the delivery room, intensive care unit or even in the operating theatre. In such circumstances the hospital chaplain clearly has advantages over the visiting minister or even the family's own ministers. He/she will be more used to procedures in what may, for some, be intimidating or even frightening circumstances and will be more likely to have the confidence of medical or nursing staff with whom he/she, hopefully, has a good working relationship.

93 Equally, if the child then survives, parents may attribute this to divine intervention and unrealistic expectations may be reinforced.

94 Others would not see this as significant. Robin Lapwood says, '...I personally do not waste precious moments putting on robes and vestments - most Special Care Baby Units are tropically hot anyway.' (*When Babies Die* (Nottingham: Grove Books, 1992), p.13.). Barbara Kimes Myers talks about the importance of rituals as meeting places where the role of 'ritual elders' is 'to invoke sacred space - a space laden with expectation, transcendence and mystery'. (*Young Children and Spirituality* (London: Routledge, 1997), p. 78.). Such space is the space we enter when we move from the known to the unknown. The appropriate use of the visual and other senses allows for both creating and communicating a sense of the sacred. For many parents, the use of vestements plays a similar, though subsidiary, role to the use of water and the symbol of the cross in invoking and creating sacred space and is not, therefore, for them, a waste of time.

95 Although a greater understanding of the value of interdisciplinary and multi-diciplinary teams has allowed a greater freedom over recent years, the predominance of the medical model and medical practitioners in the hospital setting has 'shaped' the context and environment of care. As Peter Bellamy notes, 'The medical personality is at the heart of the hospital and exerts considerable pressure on both staff and patients to conform to medically perceived values and beliefs'. ('Medicalised Ethics or the Context of Medical Ethics,' *Contact*, 85, 4 (1984), 5.).

96 See later on the role of ritual in the creation or affirmation of community. Many writers on bereavement regard the funeral as an important stage in the resolution of grief. See, for example, J.W. Worden, *Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner* (London: Routledge, 1991), p.61.

97 United Methodist Church. *The United Methodist Book of Worship.* (The United Methodist Publishing House: Nashville, Tennessee, 1992), pp.623-626.

98 Rachel was the ancestress of the Northern tribes of Ephraim, Mannaseh and Benjamin. Jeremiah portrays Rachel as weeping for her children, taken from her into Exile. With perhaps more relevance here, this reference is taken in Matthew 2:18 in the context of Herod's massacre of the innocents, the slaughter of the boy children under two years of age after the birth of Jesus. Such a massacre, however, is not recorded in any contemporary source.

99 The phrase '(a)llow them (her) to grieve, and then to accept this loss.' reflects the now well-established view that the end point and goal of grief is the acceptance of the loss when the dead person is internalised and the bereaved person is able to move on, not without the deceased but with the deceased properly located. See, for example, Worden, *Grief Counselling and Grief Therapy*. The fourth of Worden's Four Tasks is 'to emotionally relocate the deceased and move on with life.' (p.16).

100 Later, the prayer further asks that our 'limited understanding' might not 'confine' our faith.

101 Whilst liturgy can, and should, be part of a healing process in such circumstances, it should never be used as an anaesthetic against the pain of reality. Thus the pain of the event of the death of child needs to be liturgically recognised for what it is, whatever may then lie beyond it.

102 Implicit in this phrase about the mystery of life and death is, I would argue, something about the mysteriousness of human being and becoming (i.e., what it means for us to be human and therefore mortal and finite in our being).

103 There is an implicit danger here of setting acceptance over against feelings of anger which parents may feel on the death of their child. Denying parents the opportunity to express their anger, or suggesting that such anger may be inappropriate, may have far reaching consequences for healthy grieving.

104 The view that miscarriage is a 'punishment' for a previous 'sin' whether specified (such as having an abortion) or not, is particularly common. Parents who suffer the death of a child will frequently ask, 'What did *I* do that has made this happen?' Such bereaved parents will often scrutinize their past lives in order to find a reason for, and therefore to rationalise, the death of their child. Such a course of action is frequently the source of mis-placed guilt.

105 1 Corinthians 13:13.

106 The section contains the following rites:

A Service of Healing I
A Service of Healing II
A Service of Hope After Loss of Pregnancy
Ministry with Persons Going through Divorce
Ministry with Persons Suffering from Addiction or Substance Abuse

Ministry with Persons with AIDS
Ministry with Persons with Life-threatening Illnesses
Ministry with Persons in Coma or Unable to Communicate
(*The United Methodist Book of Worship*, pp.613-629.).

107 Ibid., p.170.

108 Ibid., p.162.

109 All-loving and caring God, Parent of us all,
you know our grief in our loss
for you too suffered the death of your child.
Give us strength to go forward from this day,
trusting, where we do not understand, that your love never ends.
When all else fails, you still are God.
We thank you for the life and hope
that you give
through the resurrection of your Son Jesus Christ.
We pray to you for one another in our need,
and for all, anywhere, who mourn with us this day.
To those who doubt, give light; to those who are weak, strength;
to all who have sinned, mercy; to all who sorrow, your peace.
Keep true in us the love with which we hold one another.
And to you, with your Church on earth and in heaven,
we offer honor and praise, now and for ever. **Amen**.
Ibid., p.171.

110 H. Ward and J. Wild, *Human Rites: Worship Resources for an Age of Change* (London: Mowbray, 1995), p.1. The compilers attribute the title of the book to the 'wish to encourage the humanizing of our religious rituals.' (p.3).

111 Ibid., p.3.

112 Ibid., p.148-152. I would also draw attention to June O'Conner's account of the ritual recognition of abortion in Japan. See L.S. Cahill and M.A. Farley eds. *Embodiment, Morality and Medicine* (Dordrecht: Kluwer Academic Publishers, 1995), pp.93-111. See also, D. Brown, T.E. Elkins and D.B. Larson, 'Prolonged Grieving After Abortion: A Descriptive Study,' *The Journal of Clinical Ethics, 4* (1993), 118-123.

113 In Japan, ritualised mourning after abortion (which has been legal in Japan since 1949), called *mizuko jizo*, involves the use of small figures which represent the aborted fetus. Parents name the baby and openly acknowledge its loss. The primary aim of this ritual, however, is to alleviate ill-will on the part of the abortus towards the mother. The rite is unusual, however, in dealing openly with abortion.

114 See chapter on Miscarriage.

115 Ward and Wild, *Human Rites*, pp.209-210.

116 Ibid., p. 210-219.

117 Ibid., pp.219-225.

118 See above.

119 This would also be true for other human circumstances as well as death. In the context of a healing service, for example, the victim of sexual abuse may be enabled to

name the source of their pain (i.e., their abuse) in a way which, outside the rite, may simply not be possible. Such naming of human terrors, whether abuse or death, may in itself actually effect healing.

120 Prayers for the dead, whether private or public, have been very important in shaping and expressing Christian attitudes towards death. Their repudiation by the Protestant Reformers marked the shift in focus from the deceased to the bereaved as the focus of funeral ritual. Michael Perham concludes that '(i)n the end praying for the dead is more about affection than influence'. ('Anglican Funeral Rites Today and Tomorrow,' in Jupp and Rogers, *Interpreting Death*, p.160.).

121 It is increasingly being recognised that such liturgies can also be adapted to serve the needs of other pre-natal deaths such as miscarriage. For liturgies after an abortion, however, it is still necessary in most cases to look outside the authorised liturgies of the Churches.

122 As Jennifer Hockey remarks, 'When priest and liturgy, deceased and bereaved, are meeting for the first time, the resulting lack of personal significance felt by survivors may cause their grief to deepen into a more pervasive sense of loss as 'meaning' itself becomes questionable.' J. Hockey, *Experiences of Death: An Anthropological Account* (Edinburgh: Edinburgh University Press, 1990), p. 29.

123 *Family* (Harmondsworth: Penguin, 1989), p.243. Anthony Gardiner says of miscarriage, 'You cannot dismiss miscarriage as a gynaecological accident. This was a real bereavement, as the baby lost was a real child, already the object of love'. ('Confronting the Abyss: The Relationship between Bereavement and Faith,' in Jupp and Rogers, *Interpreting Death*, p.124.).

124 Similarly, it is a mistake to regard 'non-traditional' rites as those which are person-centered rather than God-centered. This shouldn't follow, but it is a commonly made mistake.

125 The only alternative rite was that which allowed for burial at sea. Cremation, of course, had been common in the ancient world but with the adoption of Christianity as the official religion of the Roman Empire, burial, following Jewish custom, became the norm.

126 Cremation, though still at this stage opposed by the Church, was legalised in England in 1884 and provision for the disposal of the dead by cremation by local authorities was authorised by the Cremations Act of 1902.

127 The Methodist Worship Book p.489, note 1. As a member of the Faith and Order Committee of the Methodist Church during the period of the writing and compilation of the new service book I argued for the inclusion of miscarriage and neo-natal death, although I would have preferred to see the term 'can be used after...', whilst still allowing for appropriate adaptation of the rite according to individual circumstances. The use of the phrase, 'may be adapted' still suggests that miscarriages (or neo-natal deaths) do not warrant a rite of their own. Although the 1974 Methodist Service Book did not include a rite for stillborn children, offering either a service for *The Burial or Cremation of the Dead* (MSB F1-F19) or *The Burial or Cremation of a Child* (MSB F20-F21) the Methodist Conference of 1984 authorised *A Funeral Service for a Still-Born Child* in the same format as the Methodist Service Book but as a separate pamphlet (Peterborough: Methodist Publishing House, 1984). Although it was not included in later editions of the book but was kept as a separate pamphlet, it

was nonetheless to be seen as a supplementary rite that carried the full status of an official rite and not simply as a secondary resource.

128 Central Board of Finance of the Church of England, *The Alternativie Service Book* (London: SPCK, Cambridge: CUP, Clowes, 1980), pp.322-323.

129 In the 1960s the Church of England Liturgical Commission asked the question 'What ought we to be doing at a burial service?' It came up with a five-fold answer which has informed subsequent Anglican liturgical thinking in this area:

(a) to secure the reverent disposal of the corpse
(b) to commend the deceased to the care of our heavenly Father
(c) to proclaim the glory of our risen life with Christ here and hereafter
(d) to remind us of the awful certainty of our own coming death and judgement
(e) to make plain the eternal unity of Christian people, living and departed, in the risen and ascended Christ.

Cited in P.Speck, 'Bereavement and belief: An Anglican Persepective,' in Jupp and Rogers, *Interpreting Death*, p.101.

130 Church of England. *Common Worship: Services and Prayers for the Church of England.* (London: Church House Publishing, 2000).

131 *Common Worship*, pp.316-317.

132 Ibid., p.316.

133 Ibid., p.316.

134 This question has been dealt with in greater detail earlier in this chapter.

135 *Common Worship*, p. 317.

136 Ibid., p.317.

137 O'Donovan's suggestion that parents might be asked 'to profess that they would have brought the child to baptism had they been able' (p.317) is addressed by the Bristol Maternity Hospital liturgy, *'A Service of Baptismal Desire for Bereaved Parents'* addressed earlier in this chapter.

138 The Uniting Church in Australia National Commission on Liturgy (1994). *A service to follow the birth of a still-born child or the death of a newly born child.* Produced and printed by the Wesley Hospital, Brisbane.

139 Ibid., p.8.

140 K. Galloway, ed. *The Pattern of our Days: Liturgies and Resources for Worship* (Glasgow: Wild Goose Publications, 1996), pp.2-23.

141 The Stillbirth and Neo-natal Death Society (SANDS) produced a leaflet in 1992 offering guidelines for good practice in this area. See, N. Kohner, *A Dignified Ending: Recommendations for good practice in the disposal of the bodies and remains of babies born before the legal age of viability* (London: The Stillbirth and Neo-natal Death Society, 1992). The Bristol Maternity Hospital Chaplains had negotiated this by the mid-late 1980s.

142 BMH Protocol. Bereavement Record Sheet, Section 1.

143 Two forms of Form F were required to be used. One was a consent form, signed by either or both of the parents, formally requesting cremation or interment for

their baby and was forwarded to the Cemetaries Manager and Registrar; the other was the Certificate of Medical Practitioner in respect of Non-Viable Foetus which was forwarded to the medical referee of the City Council. The receiving authority also required that remains had to be individually casketed and named.

144 See chapter on miscarriage.

145 Since most local church or parish clergy have little experience of conducting the funeral of a baby, many tend to be 'conservative' in their approach and to use existing funeral rites adapted according to circumstance.

146 Many parents report that it was seeing the coffin that finally brought home for them the reality of the death.

147 Few parents would see the funeral simply as a rite of disposal. The movement from one sphere of relationships to another is often expressed in terms of 'going to be with Jesus', or 'going to be with Granny' even among families who would not claim to have any religious beliefs and for whom beliefs about heaven, however conceived, would appear to be meaningless. In other words, there is a transfer, or extension, of care from the parents to another significant carer (since babies, dead or alive, cannot care for themselves). Parents will often express some confusion about how to keep the dead baby within the orbit of the family system, If asked how many children they have, if they have, say, one surviving child, do they say, 'two' or 'one' or 'two but one is dead' or 'we had two but now we only have one'. Often the fear is that they will appear macabre to others or embarass them by reference to a child who has died. This problem is exacerbated in the case of a miscarriage where there may already be an ambivalence about whether such a child could be said to have 'existed' or 'lived' at all. Persistence in talk about 'heaven' (however conceived) remains strong after the death of a child even though belief in some form of 'afterlife' has generally declined over the course of this century. One reason for this may well be that the concept of heaven, according to Roger Grainger, addresses three key existential problems, (1) the world demands to be understood; (2) its sufferings must be lessened; (3) the unfairness of things that happen in it must be countered. (R. Grainger, 'To be dead is not enough'. In Jupp and Rogers, *Interpreting Death* p.31). These problems may be particularly acute after the death of a baby. Furthermore, many rituals look two ways - back to the life which has been lived and forward to a 'life' to come. When a baby dies, especially at or before birth, rites can only be primarily uni-directional.

148 'Bereavement and Belief: An Anglican Perspective,' in Jupp and Rogers, *Interpreting Death*, p. 105.

149 Davies, *Death, Ritual and Belief*, p.52. Many of these issues have re-surfaced in 2001 in the Redfern Inquiry (Organ Retention).

150 Methodist Church, *A Funeral Service for a Still-Born Child* (Peterborough: Methodist Publishing House, 1984).

151 Methodist Church, *The Methodist Service Book* (Peterborough: Methodist Publishing House, 1975), p.A8.

152 Matthew 18:1-5, 10, parallels Mark 9: 33-37; Luke 9: 46-48.

153 Matthew 11: 27-30

154 2 Corinthians 1: 3-7.

155 Methodist Service Book F1-F19.

156 Baptist Union of Great Britain, *Patterns and Prayers for Christian Worship* (Oxford: Oxford University Press, 1991), pp.157-159.

157 Ibid., pp.158-159.

158 Ibid., p.159.

159 Church of Scotland, *Common Order of the Church of Scotland* (Edinburgh: St.Andrew's Press, 1994), pp.319-325.

160 Ibid., p.319. Prior to the publication of the *Common Order* in 1994, the Church of Scotland Panel on Worship produced a booklet offering both pastoral guidelines and a funeral service for use after stillbirth or neo-natal death. See, Panel of Worship of Church of Scotland, *Pastoral Guidelines and a funeral service for a child dying near the time of death* (Oxford: Oxford University Press, 1986).

161 United Reformed Church, *Service Book* (Oxford: Oxford University Press, 1989).

162 Presbyterian Church in Cameroon, *Book of Divine Offices* (Germ: Verlagsdruckerei, 1984.), volume 5, pp.40-43. It is interesting that the title of this volume is *Ministry to the Dead* (my stress).

163 Salvation Army, *Salvation Army Ceremonies* (London: International Headquarters of the Salvation Army, 1989).

164 The Church of England, *Alternative Service Book* (Cambridge: Cambridge University Press, 1980), pp.318-321. Similarly contracted rites can be found in the liturgies of the Anglican Church in the USA, Canada, South Africa, New Zealand and Australia, although the latter offers an alternative rite for intrauterine deaths.

165 *Methodist Service Book*, pp.F20-F21.

166 Methodist Church, *The Methodist Worship Book* (Peterborough: Methodist Publishing House, 1999), pp.478-488. See also, *Prayer Book of the Methodist Church of the Caribbean and the Americas* (Peterborough: Methodist Publishing House, 1992).

167 Ibid., p.478.

168 Ibid., p.479.

169 The Church of Scotland, *The Book of Common Order of the Church of Scotland*, pp.305-317.

170 The Roman Catholic Church in Great Britain, *Order of Christian Funerals.* (London: Geoffrey Chapman, 1991), pp.220-363. Geoffrey Steel describes the over-arching vision of these rites as 'integrating ritual support, pastoral care and practical assistance...'.('Celebrating our Journey into Christ: The Roman Catholic *Order of Christian Funerals*'. in Jupp and Rogers, *Interpreting Death*, p.171.).

171 *Order of Christian Funerals*, p. 220, note 332. The act of commendation is, once again, functional and effective rather than a simple statement that the child is now with God.

172 Ibid., pp.358-363.

173 Ibid., p.359.

174 Ibid., p.361.

175 Ibid,. p.362. It is unfortunate that this otherwise pastorally sensitive rite uses the impersonal pronoun, *'it'*, at this point, rather than the personal, *'he/she'*.

176 'Peri-natal Death'. in Jupp and Rogers, *Interpreting Death,* p.150.

177 I would frequently say to parents that my role in the funeral service and its preparation was to create a meaningful ritual *with* them rather than *for* them. Careful listening and genuine negotiation can enable rites which all parties can genuinely engage in with integrity.

178 This contact would be established either in the course of ward or unit rounds, as a result of a request from the family to see the Chaplain or through my regular conversations with the paediatric cardiac social worker.

179 Whilst for some families denial that their child might, or was going to, die could be particularly strong at this stage, for other families this was part of their acceptance of the reality and gravity of the situation and became part of their anticipatory grieving. See chapter on neo-natal deaths.

180 Bristol is a regional centre for neo-natal heart surgery and so some babies may have travelled from as far as Cornwall or South Wales.

181 On the role of the Chaplain in the intensive-care environment, see chapter on neo-natal deaths..

182 As far as I am aware, this story-boarding approach is unique. I have not heard of it being used by other chaplains or clergy in this context.

183 I would often be asked to take, or share in, the funerals of babies who had died at the hospital both, I hope, because of the pastoral relationships which had been built during that time, and because I represented that small circle of people, family, medical and nursing staff and others who had 'known' that particular child.

184 'Non-Standard Funerals'. In Jupp and Rogers, *Interpreting Death*, p.145

185 See J.A. Cook and D.W. Wimberley, 'If I Should Die Before I Wake: Religious Commitment and Adjustment to the Death of a Child,' *Journal for the Scientific Study of Religion, 22* (1983), 223.

186 In some circumstances those with a prior religious commitment can find their faith challenged or even destroyed by the experience of the death of a child. Such people find it no longer possible to reconcile belief in a good and loving God with the reality of their experience. For more on this see the chapter on neo-natal deaths.

187 I have known families to start coming to Church as a result of the funeral of their child and to find there both faith and meaning for their future lives. Sometimes families for whose children I have conducted a funeral have come back later to ask me to baptise a subsequent baby.

188 D. McRae-McMahon, *The Glory of Blood, Sweat and Tears: Liturgies for living and dying* (Melbourne: The Joint Board of Christian Education, 1996), pp.117-120.

189 This rite was written by Dorothy McRae-McMahon, a liturgist and minister of the Uniting Church in Australia, after her son, Christopher, was brain damaged as a result of a polio vaccination.

190 *The Glory of Blood, Sweat and Tears,* p120.

191 These would include, the sociologist, Tony Walter, author of, *Funerals and How to Improve Them* (London: Hodder and Stoughton, 1990); Sr. Frances Dominica, editor of the resource book, *Just My Reflection: Helping parents to do things their way when their child dies* (London: Dartman, Longman and Todd, 1997).

192 *Aspects of Grief*, p.36.

193 K. Gibran, *The Prophet* (London: Heinemann Ltd., 1926).

194 John Bowlby gives the example of the Kota people of India who hold two 'funerals' - the Green and the Dry. The Green is held soon after the death and only close friends and relatives attend. At this ceremony the body is cremated. The Dry is a communal ceremony held a year or two later to commemorate all the deaths that have occurred since the last Dry funeral. Bowlby, *Attachment and Loss, 3*, p.130f.

195 Although such services are now commonplace, the Bristol Service was in the vanguard of such public recognition of pre- and peri-natal deaths. It was certainly novel enough at the time to attract the attention of the media and a News at Ten item was devoted to it.

196 This was, in fact, to be problematic for the Chaplains. Whilst it was desirable that the service was 'owned' in a very real way by those who were its major participants, the strength of particular personalities meant that there was a danger of bias towards parents whose babies had died at a certain stage. The Chaplains had, therefore, to ask some very searching questions - Was it right to 'hand over' the service, its planning and execution to the parents' groups entirely or should the Chaplains retain some measure of control, and even of sanction, in order to ensure that a balance was maintained? In short, was this to become a parents' service or was this a service offered by chaplains to and for parents? In the end it was decided that the latter option should remain the case, as indeed it had been in the first instance, although the participation and input of parents' groups remained high and was an essential feature of the service.

197 This title itself has since been taken up by other hospitals offering a similar service to bereaved parents.

198 The poem, written by Sue Thomas after the death of her sons Sam and Ben, is reproduced here as it was printed in the Order of Service on Saturday 11th May 1991. I was the attending Chaplain at the death of both Sam (in 1989) and Ben (in 1990). Douglas Davies argues that 'the power of poetry to console and to elevate in funerary rites remains strong' as 'words against death'. *Death, Ritual and Belief*, p.63.

199 No author is given in the Order of Service. The text is reproduced here as it was printed in the Order of Service on Saturday 11th May 1991.

200 Each person who came to the service was given a flower on arrival. These were brought forward at this point in the service and laid down as an act of remembrance. In other years candles, which were lit from a central flame and were then left on the altar, fulfilled this role. This act of remembering has been incorporated into the annual University of Leeds Medical School Commemoration Service, *A Time of Remembering and of Thankgiving for those who have donated their bodies to Medical Science and for Medical Education.* This service was first introduced in Leeds in 1994, as a result of my work with the Bristol Memorial Services, and has been well received. For a comment on this service see 'New Lives After Death,' *Guardian*, Wednesday, April 5th., 1998, pp.2-3.

201 See separate chapter on children and grief.

202 The social significance of death and the 'shared' nature of grief are important factors in any consideration of the nature of ritual.

203 Penelope Wilcock rightly observes that '(f)or too long the Church has tried to preach a humble Christ with an attitude of arrogance, demanding that people come to us, speak our words, submit to our constructs'. ('Non-Standard Funerals,' in Jupp and Rogers, *Interpreting Death*, p.147.).

204 E. Larty, 'Liturgy and Pastoral Care: A Response,' *Contact, 115* (1994), 16.

Conclusion

'In order to arrive at what you do not know
You must go by a way which is a way of ignorance...
And what you do not know is the only thing you know'
(T.S.Eliot, *Four Quartets.*)

'He alone is truly wise who knows how much he does not know.'
(Aristotle)

To say that the provision of bereavement services for the families of children who die in the pre- and peri-natal period is better now than it was thirty years ago, is to state what can only be acknowledged to be true. The evidence presented in this thesis traces the development of both understanding and practice in pre- and peri-natal bereavement care in what has, generally speaking, been in the right direction. Nonetheless, as we enter the twenty-first century, to assume either that we have now got it 'right', or that we now know all that there is to know, or that the needs of all bereaved families are now being met to the best of our abilities, is to delude ourselves. Indeed, as the staff of the Alder Centre, the first dedicated centre for bereaved parents in the United Kingdom, acknowledge, 'The more we provide the service, the more the need becomes apparent.'[1]

As the capacity to treat a variety of once life-threatening or fatal conditions in intrauterine and early post-partum life continues to develop, we must not become blinded to the needs of those who, all too often, are simply regarded as failures. Too often, as we have seen, an uncritical application of the medical model in isolation, despite the model's undeniable successes in the advancement of curative practice, encourages us to leave behind such 'failures'. Such an approach will always be, at best, limited and partial, at worst, it will sacrifice compassion and care on the altar of progress and a scientific dogmatism. We must always remember, therefore, that '(b)irth and death, illness and injury are not simply events that the doctor attends. They are moments in every human life...'[2] What is needed, then, is the kind of theologically informed, holistic approach to care, both clinical and pastoral, not least in bereavement, that is advocated in this thesis. Such care, because it is born out of compassion, will always recognise - and therefore respect - the other, as 'other'. It will

always be dialogical in its approach, eschewing the arrogance which can so easily lead to paternalism, however benevolent.[3] This means that:

> to provide good care after loss at any stage of pregnancy, professionals must be able to listen and respond, as sensitively as they are able, to the feelings and needs of individual parents' experiences of loss and grief; the care and support they give should be determined by parents' particular needs. This means they must be prepared to work openly and flexibly, to communicate honestly with parents, to avoid assumptions and judgements, and, sometimes, to risk making mistakes.'[4]

Because of this, theological reflection and pastoral practice needs to be both robust and rigorous. Practitioners, in whatever discipline, will need to be virtue-led as well as technically proficient. Only thus will they be other-orientated, whether to individuals, to families or to their colleagues, and therefore exemplify that approach to others that has been characterised in this thesis as 'agapeistic'. Though he does not use the word, such an approach is well characterised by H.R. Niebuhr:

> 'Love is reverence: it keeps its distance even as it draws near; it does not seek to absorb the other in the self or want to be absorbed by it; it rejoices in the otherness of the other; it desires the beloved to be what he is and does not seek to re-fashion him into a replica of the self or to make him a means of self-advancement.'[5]

Just as 'the impulse for compassion is at the heart of Christian ethics',[6] so too, such compassionate 'other-orientation' is at the heart of both theological reflection and pastoral practice.

The underpinning belief expressed in this thesis, therefore, is that 'there are no solitary beings,' but that, '(e)very creature is in some way bound up with all other creatures and is dependent on them.'[7] Consequently, 'The meaning, substance, and consummation of life is found in human relationships.'[8]

Such relationality forms the basis, as we have seen, not only of care in practice but is pivotal in our understanding of the way in which human identity, or personhood, is constructed and understood. Thus, I have argued for a fundamental

orientation towards being-in-relationship. This is especially important in the current context in which, as we have seen, it may be difficult to define with any certainty when human personhood has begun. Ultimately, as Oliver O'Donovan concludes:

> Unless we approach new human beings, including those whose humanity is ambiguous and uncertain to us, with the expectancy and hope that we shall discern how God has called them out of nothing into personal being, then I do not see how we shall ever learn to love another human being at all.[9]

For bereaved families, the recognition of their loss in appropriate ways - a recognition for which they, themselves, consistently plead - is the cornerstone of person-centred, compassionate care.[10] Above all, the willingness to stand alongside the bereaved not simply in a care-giver: care-receiver relationship but in genuinely human encounter means that creative healing will be enabled not primarily what we do but by our willingness to 'be' in relationship with another. We cannot - indeed, we ought not to - take away the pain of grief. Nonetheless, we can be hope-bearers who sustain the bereaved by our faithful presence in the midst of their painful experiences. As Gene Outka says, 'Love does not snatch us from the pain of time, but takes the pain of the temporal upon itself. Hope makes us ready to bear the cross of the present...'[11] It is this willingness to be alongside, to listen and act empathetically, that Frances Dominica, from her wide experience with the dying and bereaved, believes offers the best way forward in our companionship with the bereaved.[12] Drawing on a wide range of material, particularly from the last thirty years, and from across the disciplines who are most closely involved in the care of bereaved parents and their families, I have argued that best-practice in such care is therefore person-centred, rather than problem-centred; holistic in its understanding of human being; inter-disciplinary and co-operative, rather than parochial and competitive, in its approach; and, above all, genuinely agapeistic. Furthermore, since it is grounded in love, such faithful presence before the other both creates and sustains genuine community.[13]

The members of this community are no less, for each of us, than our neighbours, not patients, or clients, or cases:

> The bereaved are normal people who have experienced a terrible event. They are not to be pitied or shunned. They come from every social class, ethnic group and religious faith. Every personality trait is represented, every quirk and failing; the broadminded and the bigot, the depressed and the cheery, the silent and the ebullient, some embittered and others constructing new meanings and purpose. They are our colleagues and our neighbours... In some respects their needs are simple and are felt in differing ways, at certain times in life, by all of us: the space to dwell on the person who is absent and express the depth of pain being felt, to be listened to and to be allowed to speak, to obtain what information there is about why and how the circumstances have occurred. What separates out the experience of losing a child from other traumas is, perhaps, the depth of despair in those left to grieve, the fear of being overcome and destroyed by the enormity of it all.'[14]

For those who operate from within a Christian framework there are, however, those beliefs and values which sustain us in our work and which shape our relationships and orientates the care we offer to others in the darkness, pain and loneliness of bereavement; beliefs and values which are communicated in our willingness to be as we are, with others as they are. Such beliefs and values, and their application in the context of early-life loss, are well summed up by Tom Paris:

> Life is not only a gift and a task, it is also a journey. We are on a journey from God back to God, and death is part of that journey. Death is not the victor, it is a transition state, not a final state. What within Christian tradition is the significance of life? It is that life is destined for God. It's ultimate goal is the restoration of the fulness of the kingdom. Thus it is eternal life and not life itself which is ultimate. For the Christian who believes in the life, death and resurrection of Jesus, death has been overcome. It is not the final victor, and all those who believe and accept that message likewise have overcome its defeat.[15]

The starting point of this thesis was the recognition that bereavement after intrauterine and post-partum death is a genuine bereavement experience, and of such a specific type that it demands not only recognition, but the sort of specialised attention that it

has long been denied, and which is advocated and modelled in this thesis. While I have argued that grief is a 'normal' experience - and have warned of the dangers of pathologising grief - this thesis has put forward a perspective on the care of the bereaved after pre-natal, peri-natal and neo-natal death that has major practice implications for all those involved with such families. Thus, the lessons to be learned from the collation and analysis of relevant medical, nursing, social science, philosophical, theological and pastoral literature offered here, which is reinforced and built upon from an informed practice perspective, offers concrete, and innovative, ways forward not only for pastoral caregivers and liturgists but for medical and nursing practitioners as well. Such an economy of care, which has been explored from the perspective of individuals, the family matrix, carers, and the wider community, offers a genuinely person-centred, holistic approach which, while theologically grounded, has real practice implications which are now increasingly being recognised in medical and nursing, as much as theological, education. Thus, this thesis, whilst written from a predominantly pastoral and theological perspective, has important implications for the multi-disciplinary team, to whose care the bereaved are entrusted, and on whose sensitivity in informed practice, the well-being of those who are among the most vulnerable in our communities may well depend.

NOTES:

1 'Helping Parents Cope with the Loss of a Child,' *Social Work Today* (1989), 26 Jan., 8.

2 P. Ramsey, *The Patient as Person* (New Haven: Yale University Press, 1970), p. i.

3 'The most useful theological reflection takes place in dialogue with practice.' G. Noyce, *The Minister as Moral Counsellor* (Nashville: Abingdon Press, 1989), p.21.

4 N. Kohner, 'The Loss of a Baby: Parents' Needs and Professional Practice after Early Loss,' in D. Dickinson and M. Johnson ed. *Death, Dying and Bereavement* (Milton Keynes: Open University Press,1993), p. 287.

5 H. R. Niebuhr, *The Purpose of the Church and its Ministry* (New York: Harper, 1956), p.35. This definition also highlights the delicate balance between intimacy and distance that Campbell describes as 'moderated love' that allows professionalism and care to co-exist.

6 A. Outler, 'The Beginnings of Personhood: Theological Considerations,' *Perkins Journal*, 27 (1982), p.34.

7 E. Moltmann-Wendell, *I Am My Body: New Ways of Embodiment* (London: SCM, 1994), p.7.

8 R. McCormick, 'To Save or Let Die: The Dilemma of Modern Medicine,' *Journal of the American Medical Association*, 229, July 8 (1974), 172-176.

9 O. O'Donovan, *Begotten or Made?* (Oxford: Clarendon Press, 1984), p. 66.

10 'This awareness, experienced by parents, that there is 'someone' to relate to even though the human is unborn, reinforces from an experiential viewpoint the Christian understanding of the value of the unborn human.' Methodist Church, *Status of the Unborn Human* (Conference Report, 1990), p.32.

11 G. Outka, *Agape: An Ethical Analysis* (New Haven: Yale University Press, 1972), p.179.

12 F. Dominica, 'The Way Forward,' in J.D. Baum *et al.* ed. Listen, My Child Has a Lot of Living To Do, p. 171.

13 'Actions are loving when they create and sustain community...' G. Outka, *Agape: An Ethical Analysis*, p.42.

14 O. Hagen, 'The Alder Centre: Counselling for all Those Affected by the Death of a Child,' in J.D. Baum *et al.* ed. *Listen, My Child Has a Lot of Living To Do*, p. 150.

15 John Paris, 'Terminating Treatment for Newborns: A Theological Perspective,' *Law, Medicine and Healthcare*, 10 (1982), 120-124.

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