

**Family Practices during
Life-threatening Illness:
Exploring the Everyday**

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Abstract

This thesis explores the experiences of individuals living in a family where a member is dying or has a life-threatening illness. It focuses in particular upon how families are actively produced in the everyday 'doing' of day-to-day family life (Morgan, 1996) in circumstances of severe ill-health and when facing death. Using an ethnographic approach combining informal, in-depth interviews with 9 families and participant observation on a hospice ward, the research provides insight into how families experience themselves as family in the 'here-and-now' of their daily lives. It will be argued that in both popular culture and theoretical work there is a pervasive tendency to associate death with crisis and that the more ordinary, everyday and mundane aspects of dying experiences are less well understood. Therefore, the analysis of family lives presented here moves away from the more familiar model of emotional crisis and rupture in relation to severe ill-health and dying, to ask new questions about the 'everydayness' of people's feelings and experiences during this time. A more nuanced picture of living with life-threatening illness and dying is provided as the data chapters explore the everyday and mundane in relation to families' experiences. Analysing empirical data about various aspects of day-to-day life - including eating practices, spatial dynamics and material objects - the thesis shows how ill-health and dying are not discrete ontological experiences existing outside and separate from everyday life. Rather, in paying attention to the 'doing' of being a family day-to-day, this research brings more squarely into view, the everyday as a lived experience (Felski, 1999) *within* which families come to 'know' their experiences of illness and dying.

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Foreword: The extraordinary and the mundane...

In the wards of Mayday Hospital people just disappeared, they were not remarked upon, they were mostly working-class people and - like my father - they simply vanished. The buses continued to run, the shops stayed open and life continued without them.

(Les Back, 2007:3 writing about his feelings at the time of his father's death).

In all her excursions into unreality, Mam remained the shy, unassuming woman she had always been, none of her fantasies extravagant, her claims, however irrational they might be, always modest. She might be ill, disturbed, mad even, but she still knew her place.

(The playwright Alan Bennett, 2005:7 writing about his mother's mental illness- cited in Silverman, 2007:34).

'... And I went next door and said, 'you'll never guess what, Joyce (neighbour), - Percy's only dead on the bathroom floor' ...'

(My grandma re-telling the story of the day she found my grandad after he had died).

But ethnography is not only about seeing remarkable things in every-day situations. It also asks us to see the *mundane* elements of *remarkable* events and contexts.

(David Silverman, 2007:18 suggesting something I came to realise in producing this thesis).

Chapter 1

Introduction: the study context, aims and beginnings

This thesis explores the experiences of individuals living in a family where a member is dying or has a life-threatening illness¹. It focuses in particular upon how families are actively produced in the everyday 'doing' of day-to-day family life (Morgan, 1996) in circumstances of severe ill-health and when facing death. The project also has a temporal-experiential focus and examines family experiences over a sustained period of time within the illness process. By conducting repeat in-depth interviews with 9 families, a more continuous picture of their family life was gained². In addition carrying out participant observation on a hospice ward provided an opportunity to explore what family life is like and how it gets done, when a family member is 'actively' dying³ and nearing the end of their life.

Therefore using an ethnographic approach combining informal interviews

¹ In this thesis I use the phrase 'life-threatening illness' to refer to the experiences of the individuals and family members I worked with, as this term was used by the hospice where I recruited participants for the study.

² The 'families' I interviewed included married couples and other relationships that are commonly considered to make up part of a larger family network. However, I use the term 'family' to refer to them all. Thus, although not all members within a particular family took part in the research, how the participating individuals identified and considered them within their narratives of family life meant that the research did have an essentially 'familial' (in its wider sense) focus. Moreover, using the term 'family' to describe these various relationships was also important given that the central theoretical framework of the thesis is Morgan's (1996) concept of 'family practices' which is about the *quality* of family relations - how individuals produce themselves as 'family' - rather than rigid notions of form and composition.

³ Throughout the thesis I use the phrase 'actively dying' to refer to the more 'terminal' stage of an individual's dying experience. Michael Ashby, a professor of palliative care, explains that for most palliative-care services 'terminal' means 'dying this week rather than next' and therefore 'actively dying' is used to denote those cases where individuals were more perceivably, visibly 'dying' (2009: 79).

and participant observation, the research provides insight into how families were experiencing themselves as family in the 'here-and-now' of their everyday lives.

In this introduction I outline the central arguments which are to be made over the course of the thesis and introduce my rationale for conducting the research. I begin by defining *family practices* as a key theoretical concept which underpins my methodological and analytical approach, and point to a lack of practices-based analysis of dying experience in the death studies literature. Briefly, I then discuss context and the particular 'kinds' of dying experienced by families in the research before moving on to argue how 'family' as a concept has a symbolic potency in relation to death. This discussion is then followed by a more personal account of how my own experience of spending time with dying people and their families shaped my initial interest in doing the study. Finally, I conclude by outlining the research aims that guided the study and provide an overview of the thesis structure.

Theoretical Framework

Morgan's (1996) seminal work on family practices is central to the theoretical framework of this thesis. To escape constraints inherent within a static notion of *the* family, Morgan's concept of family practices is a theoretical description of the active construction of family life in everyday diverse family contexts. In other words, practices are 'often little fragments

of daily life' which are essentially the actions and interactions undertaken by people as they '*do*' being a family day-to-day (1996: 189). However more recently the concept of family practices has been developed further to encompass the *interconnected* ways in which people *feel* and imagine themselves as related (Smart, 2007). Smart (2007) explores how thinking about and imagining relationships can create feelings of being embedded emotionally and materially in the lives of others, and she suggests these more interior processes are *entwined* with family practices and the 'doing' of family. In her own words she explains:

I wanted to move out of the flat world of most sociological accounts of relationships and families to incorporate the kinds of emotional and relational dimensions that are meaningful in everyday life... Although, following David Morgan (1996), I acknowledge that family is what families do, I also think we need to explore those families and relationships which exist in our imaginings and memories, since these are just as real (2007: 3-4).

The above conceptual ideas which suggest that 'family' is performed, imagined, felt, achieved, created and produced rather than simply 'is', underpin the theoretical view developed in this thesis. Thus I draw on the approaches of Morgan and Smart to provide an important insight into the neglected area of practices (as assemblages of doing, thinking and feeling) in relation to pre-death experiences.

Filling the Pre-death Practices Gap

Whilst there have been a number of insightful studies about post-death practices which sustain relationships after death in bereavement⁴, practices have rarely been used as a lens through which to view the time leading up to death and to understand how relationality is negotiated and achieved between family members while the dying person is still living. Therefore by taking this situated and practice-based approach, the thesis makes an important contribution to understanding the relationship between mundane everyday life, relationality, and experiences of severe illness and dying. Furthermore it also realises Morgan's (1996) intention that family practices should not be studied in isolation. Rather, he drew on the analogy of a kaleidoscope, to propose that family practices are most analytically revealing in terms of the *overlap and linkage* they find with other areas of modern social life. In bringing together insights from various bodies of literature in the areas of death studies, the sociology of illness, palliative care, everyday life and family studies, this thesis puts Morgan's suggestion effectively into practice.

As a review of the death studies literature in Chapter 2 will show, everyday matters related to *doing* family life in the context of terminal illness and dying, have received inadequate attention. Consequently theoretical frameworks tend to neglect the everyday in favour of a more spectacular, crisis-based model of death and dying which carries powerful connotations

⁴ For instance memorialisation practices such as tending to ashes (Kellaher *et al.*, 2005), the uses made of material objects related to the dead person (Gibson, 2008) and verbal forms of memory-sharing (Walter, 1996).

of rupture and emotional intensity/ distress. Whilst I do not deny that negotiating dying and the prospect of death is difficult at times for families (indeed some of my fieldwork experiences were testament to this), the central focus of the thesis will be to provide a more comprehensive view of the ways in which family experiences of illness and dying are made meaningful as lived experience through an immersion within everyday life and mundane practices. In other words to foreground the *very ordinary* in relation to how families feel about (emotions), make sense of (imagination and thought), and go about (doing) being a family when they are faced with severe illness, dying and the prospect of death.

What ‘Kinds’ of Dying?

And so my thesis underlines the importance of acknowledging diversity as it is inherent in dying experiences (Kellehear, 2009a; Lawton, 2000). Lawton has argued that literature in the field of death studies ‘tends to build its theoretical paradigms upon assumptions of homogeneous categories such as ‘the dying patient’ and ‘the dying process’ (2000: 146). Suggesting that the more everyday aspects of dying have been neglected in theoretical work on dying experiences, my thesis will challenge the reductionist and generalising tendencies of ‘grand’ theorising highlighted by Lawton. My analysis will therefore explore particular instances of living and dying with cancer through the experiences of families who were situated within specific familial histories and social contexts. This made their experiences unique, though perhaps not ‘exceptional’ in the sense that the majority of families were encountering a common cause of death in western societies (cancer)

and many of the ill, or dying individuals in my sample, were in their later years of life⁵. Indeed, within industrial societies cancer is the second 'biggest killer' after heart disease (Howarth, 2009) with recent UK statistics for 2008 highlighting that, 'around three quarters of cancer deaths (77%) occur in people aged 65 years and over' and that 'death rates rise with increasing age' (Cancer Research UK). However, caution is required when assuming comparability in dying experience between individuals with 'similar' dying trajectories or life-threatening disease. In other words, whilst in the developed world in particular, cancer may be a major *cause* of death, this 'cannot easily be mapped onto the *experiences* of dying' (Howarth, 2009: 100 my emphasis added).

Finally, I suggest that in certain ways the families 'shared' a similar habitus system and cultural experiences (Bourdieu, 1979), as many appeared to be 'typically' working class in terms of their ethos and values, and all the participants were white British.

The Symbolic Efficacy of 'Family' in Death

I have not failed to consider the challenging nature of what I argue in this thesis. Making a case for how family experiences might not always be about the momentous and extreme, and suggesting that my data indicates

⁵ Whilst the majority of individuals I met did have a 'terminal' diagnosis, one interviewee was without active disease at the time she participated in the study. Frequently the ill participants were over 65 years of age. 7 of the 9 ill individuals involved in the interviews were aged over 65 years and a large proportion of patients admitted onto the hospice ward were also in their 60s and often older.

ways in which they can be rather more mundane and interlaced with aspects of benign everyday life, has felt at times a difficult argument to make, given the pervasive and emotive associations of death as a most disruptive and difficult experience. Furthermore in a similarly pervasive way, there are certain qualities associated with '*the family*' which contribute to the establishment of family as a normative concept with virtues that are implicitly understood to be self-evident and beyond question (Bernardes 1997; 1985; Morgan, 1996). Gillis (1996) discusses the discursive power of the families we *live by*. He argues that irrespective of the increasing diversification that characterises the western families we actually *live with*, there remains a commitment to sustaining through ritual, myth and image an ideological investment in notions of nurture, cooperation, loyalty, and protection that are naturally associated with the image of families we *live by*. Morgan also suggests that family practices embody *moral* dimensions, and that these can be especially apparent when the matters with which the practices are concerned map onto aspects of 'the common currency of human experience' - such as dealing with a death (1996: 195).

And so, one might argue that the qualities of security, comfort and caring associated with familial relationships, take on a powerful resonance in the context of death which gives 'family' a kind of moral and symbolic efficacy⁶ in these circumstances. For instance this symbolic power can be identified in the idea of 'accompaniment' during the dying experience

⁶ I use this phrase in the same way as Verdery argued that dead bodies have a particular symbolic power and effectiveness - they act as 'symbolic vehicles' to embody and convey meanings about 'culturally established relations to death' (1999: 27-28).

(Seale, 1995). The family clustered at the deathbed has become a symbolic image in the history of western death culture, where a 'good death' could be orchestrated through the opportunities it presented to say goodbyes and to allow the dying person to put their affairs 'in order' (Strange, 2009). This idea of keeping a presence around the dying person also appears in recent empirical work on the dying process where nurses and care staff explain how in the absence of family members, they 'look in' on dying people regularly to avoid a lonely death (Komaromy, 2009: 74) or feelings of 'abandonment' (Olson *et al.*, 2000-2001: 302). As Seale argues, professionals feel that to achieve a 'good death' maintaining presence - 'a community of care and concern' - around the dying person is important (1995: 376). Often the message conveyed by this model of the good death is that relatives need to ready themselves to be 'of optimal therapeutic value' and to learn how to be there for the dying person during the final stages of life (Samarel, 1995: 103; Burham Jones, 1979). Citing the pioneering work of psychiatrist Elisabeth Kubler-Ross, Seale explains how the hospice movement champions this idea of presence and trains professionals and families 'in the arts of accompaniment' (1995: 377). Indeed, Kissane and Bloch exemplify the embedded nature of family within the good death discourse when they argue that:

Achieving the 'good death' depends substantially on the family's competence in offering support, facilitating preparation for dying and affirming the patient's dignity, as well as saying farewell' (2002: 1).

Moreover, highlighting explicitly that there *is* a moral dimension to end-of-life family relationships, Raunkiær explores the construction of 'normative

settings for acceptable behaviour on the part of dying people and their relatives' (2009: 325). This Danish research reveals how normative standards are applied by professionals who assign the roles of 'villain' or 'victim' to patients and relatives, so as to define what constitutes being a 'good family member' and 'doing the right thing' in circumstances of home care for the terminally ill.

More generally, how a society approaches death and cares for its dying is considered as 'a measure of [the] society as a whole' (End of Life Care Strategy, 2008: 10), and a reflection of its humanity (Kellehear, 2007; Seale, 2004; Kubler-Ross, 1969). Thus often the experience of dying is ascribed this sense of 'bigness' which interlaces with the perception of it as an 'ultimate', 'emotional' and 'extraordinary' experience (Vivat, 2008; Foster, 2007). In this context, the idea that anyone should experience a social death⁷ and die alone is morally objectionable and it does not fit with the principles of what is a 'good death' (Seale, 2004; 1995). Given that dying is a morally 'loaded' issue related to accompaniment and care, families are clearly implicated within this discourse of the lonely death and its avoidance. However, it is argued at both popular and theoretical levels that as lifestyles increasingly become more individualistic, modern western families become further fragmented and diverse (Beck and Beck-Gernsheim 2004; 1995, Beck, 2000; Giddens, 1992). Although empirical evidence suggests individuals remain embedded within relationships and continue to

⁷ For thorough discussions of social death, see Mulkey (1993), Sudnow (1967) and Glaser and Strauss (1965).

feel connected to others (Smart, 2007), the popular and theoretical influence of individualisation theories raises questions about the extent to which care of ill and dying people might happen less and less within family contexts⁸. Furthermore, the idea that modern families are somehow bereft of ways to deal with death due to the sequestration of death-related experiences and a reliance on 'expert' guidance is increasingly pervasive (Walter, 1994).

Therefore in light of what I discuss here, I suggest that 'family' has a symbolic power in the context of dying and in matters concerned with *caring for* the dying person in particular. This is perhaps reflected in the fact that 'much of the research effort has focused on carer's experiences and views', which means that there is a lack of empirical understanding of the experience of dying from the dying person's perspective (Kellehear, 2009a: 1). This also suggests however that where family members are the subjects of empirical interest, it has often been in their capacity as 'carers' or in relation to their views about care provision first and foremost. Therefore one of the main reasons I wanted to conduct this research was to consider family experiences as just that very thing and to step aside from the more care-based analysis which, for the reasons I plotted out above, has perhaps been considered as a more pressing area for enquiry. Rather, I wanted to approach ill people and their relatives as people who experience feeling

⁸ 'Family' is linked to debates at the more macro, structural and policy level in terms of the demographic 'burden' of care *vis a vis* an ageing population in the west. Family is implicated in discourses of care-giving as wider social changes - for instance increased geographical mobility and generally more individualistic lifestyles - are understood to reduce the likelihood that ill people will be cared for within the family (see Clark and Seymour, 1999; Anderson and Bury, 1988). In this context it is possible to reflect further on the emotive and moral discourses around responsibility and 'abandonment' which might be at work in considering family in the context of care and dying experiences.

'related' in their daily lives and to ask how this is achieved via family practices. In other words, I did not want to assume the illness would be all-defining and to think of families only in terms of patients, their carers and how it was that they managed, or did not manage, to cope⁹. Therefore my thesis presents insight into family experiences which lay outside the dominant care-centric ways in which families have been considered in relation to dying experiences.

Research Beginnings: some personal reflections

It was a beautiful day as I stood on the steps of the hospital mentally going over what might happen in this introductory encounter. I felt that I would have to be very careful in what I said. All of the rules about meeting someone for the first time seemed irrelevant. Even such an innocuous subject as the weather would be taboo since I was the healthy one able to enjoy the day, whereas this man whom I did not know would most likely never be able to do so again (Burnham Jones, 1979: 353).

In the above quote the author - a trained counsellor - is reflecting on what it was like waiting to meet a dying man for the first time. In many ways what Burnham Jones seems to be getting at about the 'bigness' of death, reflects dominant ideas about dying as the 'ultimate' and most extraordinary of experiences. The trepidation, as it appears in his account, is pervasive and informs the idea that dying is an experience which exists outside of the 'usual' rules of engagement and everyday matters of ordinary life. His

⁹ I realised that these were not unimportant issues or somehow separate from other family experiences; my intention was however to start from a place of asking what it means to be doing family at this time - rather than to ask specifically about 'coping'. Though, as I discuss in Chapter 8, this did inevitably interlace with conversation about doing everyday family life.

words are in many ways aligned with a crisis, rupture-based model of death and dying and they make me reflect on my own experiences of spending time with dying people when I worked as a hospice volunteer for 5 years prior to beginning the fieldwork for this research¹⁰.

Recalling my time volunteering on the inpatient ward, I can remember one patient in particular. This is perhaps not least of all because he had a daughter who was of a similar age to me at the time - in her early twenties. I remember one occasion when I encountered the daughter crying in the hospice foyer - on that day I had not known what to say to her and the inadequacy I felt was upsetting. I also recall my experience of sitting alone with him as he was dying - holding his hand and watching his breathing. At the time I was moved by the experience of watching life slipping further and further away and have since thought about the young daughter this man left behind. Indeed, the moments I describe here were clearly emotional for me, and they do underline the pain that can accompany experiencing the death of a close family member. In certain ways my early thoughts about doing this research were informed by these feelings and by the emotions I imagined I would experience when I placed myself in the shoes of families I might observe on the ward. I did wonder how *I* would 'manage' if someone I loved was dying and the lurch I felt (and still feel) in my stomach was not unlike something I might describe as a 'rupture'. Thus, I had experienced in my own sadness how dying could be difficult for families, whilst a

¹⁰ This hospice became the research site for the study on which this thesis is based. Over 5 years I worked at different times as a volunteer on the inpatient ward and on the reception desk, whilst I also provided bereavement support - again on a voluntary basis - to people in the own homes.

familiarity with popular and academic constructions of death- as-crisis did have some influence in shaping my initial ideas around doing this research¹¹.

However, when I came to reflect more deeply on what it was that interested me about family life in this context, I realised that during the time I was a volunteer, families also drank tea, talked about innocuous things and organised aspects of their day-to-day lives outside and beyond the hospice walls - in other words, perhaps there was something more 'ordinary' about their experiences than a purely crisis-based model might suggest. This led me to consider how dying experiences interrelate with how families continue to 'be' families and do 'ordinary' things day-to-day, and to wonder generally how familial relationships and identities are negotiated over the illness and dying process and during time spent on the ward. As my ideas developed through looking at different literature, I decided I wanted to learn about if, and how, families could manage to 'be' families and *do* family-like things at what is so often assumed to be such a difficult and disruptive time or indeed whether illness and the prospect of death induced some kind of intensification of family interactions. As I have already explained, Morgan's (1996) notion of family practices encouraged me to find out what families were actually *doing* over the dying process, and in many ways applying this concept to dying experiences was the first stage in questioning dominant assumptions about families and their experiences of dying as

¹¹ During the time that I was volunteering I became familiar with key concepts in the death, dying and bereavement literature as I completed modules about death and about health and illness as part of a sociology degree course. I also produced a dissertation which examined the social construction of bereavement experiences.

largely being about crisis and rupture. The very fact that modern disease trajectories are often protracted (Green, 2008; Field, 1996; Kellehear, 1990) suggested that families continued to *do* something and experience themselves somehow as families - day-to-day - across this time. Ultimately I decided I wanted to ask - what did living with life-threatening illness and dying mean for having an *everyday* family life?

Aims of the Thesis

I have described how the project developed from my experience of seeing families in a hospice ward environment and since wondering how they could reconcile, on a daily basis, the interlacing of everyday, mundane family concerns - putting the bin out on the correct day, picking children up from school, remembering to walk the dog - with the experience of being around a family member who is dying. And so I began to plan a study which could help me to understand how families experience, understand and 'do' being a family when they are faced with the seemingly inevitable 'bigness' of death and dying. As a review of the literature in the following chapter will show, given the theoretical and empirical neglect of familial perspectives (as *family members* first and foremost) on doing everyday family life during dying and life-threatening illness, I wanted to explore these experiences in a non-retrospective way with families. This became the central concern of the research and the following statements sum up what the broad aims of the research were as they reflected this central focus:

- To explore how everyday family life is pursued when someone in the family has a life-threatening or terminal illness. To ask what families are *doing* at this time.
- To examine how relationships, family practices, familial identities and everyday family lives are experienced, understood, affected *and* effected (brought into being or made). Particularly how they are *sustained* and/or *changed* when families encounter illness, dying and death.
- And to also consider how family lives are experienced in a less everyday and familiar context, by asking what might be significant about a hospice inpatient ward as a setting for family life during the illness process and especially nearing the end-of-life.

Thesis Structure

In the next chapter, I review literature which has helped to develop the theoretical focus and analytical approach that has shaped my thesis. The chapter is divided into four parts with the first exploring key ideas in death studies to argue that there has been a theoretical tradition of aligning death with omnipotent themes of the spectacular and extraordinary. In Part 2, I examine the concept of family practices more fully by considering its place within the field of family studies and exploring its theoretical and empirical links with literature on everyday life and mundanity. The focus in Part 3 is upon conceptual work in sociology of health and illness where I discuss how although the everyday has sustained a more analytical foothold here,

the theoretical frameworks of crisis and rupture have been nonetheless pervasive when conceptualising illness experience. And finally in Part 4, I return to the area of death studies to provide an overview of empirical work about families and the experience of dying. Here I conclude the review by arguing that the theoretical and empirical picture is limited in terms of understanding the everyday lives of families facing life-threatening illness, death and dying.

Next I provide a reflexive account of the research process which incorporates a focus on the ethical, emotional and embodied aspects of doing research with severely ill and/or dying people and their families. The purpose here is to explore my decision-making and experiences at various stages of the study, as well as to explain how the data was generated using in-depth interviews and participant observation.

Chapters 4-8 contain my analytical arguments and show how these are grounded in empirical data about family lives¹². In Chapters 4-6 there is a more explicit focus on the doing of family life, starting with an in-depth case study of one family practice in particular - food and eating. The following chapters explore experiences of continuity (Chapter 5) and change (Chapter 6) in everyday family life during life-threatening illness, whilst in Chapters 7 and 8 my focus shifts to consider more closely the imagined, felt

¹² When presenting spoken data from the interviews and on occasions when I use a participant's *own* words in my analysis, these conversations and phrases will appear in italics. My field notes are not italicised, however; they are enclosed within single quotation marks and identified as observational data or interview field notes on each occasion I refer to them.

and discursive aspects of family and everyday life. Thus essentially, the order in which the chapters progress is intended to reflect my theoretical and conceptual approach to family practices as assemblages of doing, thinking and feeling as it has been informed by the work of Morgan (1996) and Smart (2007).

In Chapter 9 my concluding chapter, I retrace the contours of the thesis argument and consider how my analysis fills a gap in the wider picture of theorising about dying experiences. It also outlines the broader implications of the study, and suggests this work might be usefully extended to other areas of death and illness-related research in the future. Finally, some brief reflections on how the research is relevant for practice in hospice and palliative care settings are also offered.

Chapter 2

Literature Review

Introduction

The aim of this review is to highlight how considering a variety of literatures enabled the theoretical rationale of my thesis to take shape. I begin in Part 1 by showing how a focus on practice and the everyday in relation to dying experiences is neglected within a theoretical tradition that aligns death with omnipotent themes of the spectacular and extraordinary. In Part 2, the concept of family practices is outlined fully and considered as an area of useful overlap with literature on everyday life and mundanity. Because individuals were dying for relatively prolonged periods of time in the families I encountered, these families were also *experiencing illness* and therefore Part 3 considers dominant conceptual ideas in the sociology of health and illness. Finally, Part 4 returns more squarely to death and dying and provides an overview of work about families and the experience of dying. I conclude that the empirical picture is limited in terms of informing knowledge about the *everyday* lives of families, and that therefore my thesis can begin to fill this gap.

Part 1 - Death and Dying: the spectacular and the extraordinary

It is curious how sometimes the memory of death lived on for so much longer than the memory of the life it purloined. Over the years, as the memory of Sophie Mol... slowly faded, the loss of Sophie Mol grew robust and alive. It was always there. Like a fruit in the

season. Every season... (Roy, 1997: 16 cited in Hallam and Hockey, 2001: 87).

Introducing Omnipotent Death

As this extract from Roy's novel *The God of Small Things* demonstrates, in the public imagination and popular culture death is often considered to have a powerful omnipotence that can overshadow the life that precedes it. In this review I will be arguing that conceiving of death in this way places it conceptually at a distance from the everyday and mundane. To take another example, W.H. Auden's popular poem entitled *Funeral Blues* conveys this in its opening verse:

Stop all the clocks, cut off the telephone,
Prevent the dog from barking with a juicy bone,
Silence the pianos and with muffled drum
Bring out the coffin, let the mourners come.

(Auden, 2009 [1940]: 36).

The line 'stop all the clocks' in particular evokes notions of rupture and a sense that in death everything stops and life is disrupted and changed forever.

Sociological work concerned with representations of death in the media (Mcinerney, 2009; Pickering *et al.*, 1996; Walter *et al.*, 1995; Kearl, 1989) show how popular culture is involved in generating pervasive discourses of death and dying as dramatic and extraordinary. Whilst further examples include death's association with the supernatural (see Hockey, 1999a

regarding haunting in domestic spaces) and its centrality in religious themes.

About Christianity in particular Davies explains that:

Since the end of the last Ice Age about ten thousand years ago, one hundred billion people have died. Death would therefore seem to be fairly common and indeed benign... Yet Christianity... has never been able to regard human death as normal (let alone benign!) and has placed the death of the individual right in the middle of great doom-laden cosmologies and fates... (1996: 47).

He proceeds to talk about the doctrine of judgement and the relationship between death and sin in religious ideology which incorporates a host of extreme and extraordinary images of unknown fates and spectacular after worlds - namely heaven, hell and the liminality of Purgatory.

Thus, these examples highlight how the representation of death within culture as something of enormity and omnipotence, has inherent associations with the spectacular and the extraordinary. And whilst some of the work I have referred to does address more 'non'-ordinary experiences, for example murder representations in the media (Walter *et al.*, 1995), it is at a more general and discursive level that I argue death as the ending of life *per se*, is predominantly represented in terms of the extraordinary. This is a conceptualisation which is made more vivid by some of these 'extreme' representations of death, but I argue that the idea of death as something extraordinary exists independently of these nonetheless.

Moreover, as I am about to explore, theoretical work in the area of death studies has helped shore up associations between death and the

extraordinary. For instance, the point is made by Kubler-Ross in her seminal work on the dying process that the unconscious mind cannot perceive its own death - which implies a view of dying as something particularly extraordinary in its fearfulness and need to be denied (1969: 14). Whilst I do not disagree that dying can at times be an extraordinary, emotional and difficult experience for individuals and their families I challenge the theoretical generalisation of death-related experiences in these terms. In doing so I argue that an all-pervasive association of death with crisis obscures and neglects its ordinary and mundane aspects and that it is these that are less well understood and integrated into perspectives in the literature.

Death the Intruder: theories of rupture, emotional crisis and fear

Theoretical models which inform service provision in the area of dying and bereavement generally associate these experiences with emotional challenges and difficulties. They tend to identify emotion 'work' to be done, stages to be passed through or tasks to be completed with the aim of recovering emotional stability (see Walsh and McGoldrick, 2004a; Kissane and Bloch, 2002; Parkes, 1975; Worden, 1982; Kubler-Ross, 1969).

Sociologists argue that these approaches also psychologise death-related experiences, producing normative ideas about 'healthy' and 'unhealthy' emotional responses (Walter, 1999; Prior, 1989) and a preoccupation with examining the individual and their inner psychological worlds (Small and Hockey, 2001; Hockey, 2001; Hockey, 1996). Studies of bereavement counselling services (Anderson, 2001; Arnason, 2001) and professionals

involved with supporting bereaved people such as members of the clergy (Hockey, 1993) also point to the centrality of a need to regulate death-related emotions, and a professional view of emotions as dangerous forces requiring careful management. Conceptualising death as an extraordinary event that brings about intense and extreme emotional experiences is therefore resonant in these theoretical, clinical and professional approaches.

Furthermore, in stage theories of grief *and* dying experience, Prior (1989) argues that the goal is also to reach a state of emotional stability so reintegration back into a more usual condition of mind and social order is possible¹³. For example, in her work on dying experiences, Kubler-Ross (1969) suggests that patients initially experience shock and numbness in response to the unexpected intrusion of illness and death into their lives. Similarly this notion of death as a rupture to the everyday is evident in Ellis' (1995) autobiographical work where she discusses meeting a friend with AIDS and being unable to talk about his dying.

I realize now that my encounter with Peter had been riddled with intersubjective failure. I did not want to take Peter's consciousness as my own... He was unprepared or unwilling to expose his inner world to me. Why should he? How could he? Is it ever really possible to overcome denial and connect the world of living to the world of dying? (1995: 81)

In keeping with my focus on interiority and emotions, Ellis' narrative speaks about a gulf between two mental worlds where as a healthy person she cannot connect meaningfully with the experience of the dying man she

¹³ See Copp (1998) and Samarel (1995) for reviews of stages theories of dying.

considers a friend. Tacitly, the notion of undertaking an emotional *journey* which the idea of progressing through dying stages implies (Kellehear, 2009a), places the dying individual at a distance from the everyday as they are perceived to be engrossed in an inner emotional world.

Predominantly then, theoretical work on dying represents it as an extraordinary, dramatic experience of rupture. The following explanation illustrates the pervasive nature of understanding death in marginal, dramatic and mysterious ways:

It is possible to conceive of human experience as being divided into a day side and a night side... The night side contains experiences that are uncanny, sometimes terrifying, and which put in question the firm reality of everyday life. It is the world of dreams, of visions, of those twilight experiences of other possibilities of being... The human experience most obviously belonging to this night side is the experience of death - which not only terminates the world of everyday life for whomever passes through it but which, for those who are witnesses of the death of another, appears as the ultimate threat to whatever is firm and lucid in everyday life (Berger and Berger, 1976: 354).

Although Berger and Berger explain that old age, illness and death 'are experiences *in everyday life*' their understanding of death as an experience of limits and borders and as 'a threat to the structure of ordinary living' suggests some inevitable semantic separation from the everyday (1976: 355 emphasis in original). This idea is central to many accounts of how death is the ultimate threat to social stability and meaningfulness in life (see also Berger, 1969). Because death is considered as profoundly threatening, it has led many to argue that human beings and societies protect themselves by denying the reality of it. Becker, for instance argued that the universal

'terror' of death is a psychological and emotional response so 'all-consuming' that human beings have to deny the prospect of dying (1973: 25). Becker then suggested that whole societies may 'adopt this maladaptive psychological response', although Freud's (1940) original work around denial as a psychological defence against traumatic experience was the foundation upon which variations of the denial thesis built (Howarth, 2007a: 31-32). Howarth (2007a) argues that the 'denial of death thesis' emerged during the 1950s and 1960s and was driven mainly by psychologists but was also supported by sociologists exploring behaviour and attitudes towards death at the societal level. It was argued that in an attempt to minimise the threat of disruption to social life, modern societies deny death (Aries, 1981; 1976) and consider it a taboo subject (Gorer, 1965). Later, drawing particularly on the idea that death has the omnipotent potential to make everything meaningless, Bauman (1992) claimed that making culture is a mode of repression created by humans to symbolically defeat their fears of mortality.

The explanatory value of denial is problematic and, as a psychological concept, its applicability to *societal* (e.g. institutional and organisational) responses to death has been challenged (Walter, 1991; Kellehear, 1984). Thus focusing more on social responses, Seale (1998) and Walter (1991) consider how death is hidden or sequestered in modern societies; a view which suggests the *removal* of death and its associated experiences from *everyday life*. A quote from Aries clearly shows how a theoretical focus on

the sequestration of death leads to the consideration of it as a dramatic 'other' located in the domain of the spectacular.

In the modern period, death, despite the apparent continuity of themes and ritual, became challenged and was furtively pushed out of the world of familiar things. In the realm of the imagination it became allied with eroticism in order to express the break with the established order... Thus death gradually assumed another form, both more distant and more dramatic, more full of tension (1976: 105-106).

Here, death is conceptually understood in terms of its distance from ordinary, everyday life. As Clark and Seymour note, the 'profound alteration' of societal attitudes towards death which is identified by Aries suggests that in modern times 'death loses its 'everyday' quality and becomes that which is mysterious, meaningless and feared' (1999: 90).

More specifically then, the sequestration thesis considers how contemporary, western societies professionalise death and privatise experiences surrounding it, as a way to contain fear and to manage the threat it poses (Mellor and Shilling, 1993; Giddens, 1991; Elias, 1985). Mellor and Shilling have argued that the traditional strategies (e.g. religion) that people previously used to manage the crisis posed by death, have become 'increasingly precarious and problematic in the conditions of high modernity' (1993: 411). They focus on how individualised lifestyles leave people ontologically insecure about their place in the world (Giddens, 1991). As a strategy to manage this, following Giddens, they highlight the significance of self and bodily identity, as sites for reconstructing ontological stability. However, drawing on Elias' (1985) thesis of a lonely death, Shilling (2003) explains how dying bodies undermine the self-

securing 'body work' modern individuals do by revealing the body's ultimate vulnerability (see also McNamara, 2001), and that therefore this makes the sequestration of dying in modern societies so necessary. Lawton (2000) gives a particularly graphic account of dying with an unbounded body and describes how its deterioration can betray the self and lead to sequestration in a ward side room. Observing patients' experiences of dying in a hospice Lawton discusses the isolation and social death experienced by those with fungating tumours for example, whose unbounded, (spectacularly) leaky bodies, mark them out as problematic in terms of achieving the hospice ideal of living as a social person until death. As Hockey (2001) has argued, this is important work which has sought to ask what sequestration might mean for people who are dealing with death in their everyday lives. However at the theoretical level where it pervades conceptual thinking about death and dying, sequestration and its analogous notion of social death, like the denial and fear thesis, aligns death with discourses of crisis and the extraordinary. To support this argument it is useful to consider a contribution made to the sequestration thesis by Willmott (2000).

Following Bauman's (1992) argument that the making of culture provides a means to deny death, Willmott discusses the relevance of mortality for the study of social action and human social organisation more generally. He argues however, that the fear of death is a *socially constructed* response; a consequence of the dominant western worldview of the individual self as a separate and bounded entity rather than part of a larger collective energy

field. His work takes an alternative approach to the dominant interpretations of denial and sequestration identified above which represent death as a spectacular, problematic intruder. In a critique of the self-fulfilling nature of this understanding of death Willmott suggests:

Sociological studies that illuminate modern strategies for coping with death *also* contribute to its sequestration as they routinely naturalise the contemporary commonsense understanding of death as something negative that must be coped with. The (negative or morbid) representation of death, it is argued, should be re-cognised as a social product, not reproduced in sociological studies as something that is seemingly innate to the human condition (2000: 649).

Thus he challenges the dominant discourse of death as crisis and points to how sociological theory has privileged the extraordinary and crisis in relation to death experiences¹⁴.

The Modern Hospice Movement: spectacular in its 'ordinariness'?

Challenging the idea that modernism *per se* equates to a cultural denial of death, the *modern* hospice movement is renowned for being an institution that faces death openly (du Boulay, 1984). In particular, hospice is an interesting institutional context in which to consider the representation of death as extraordinary because implicit in its rhetoric is the idea that death is natural and ordinary. A passage written by Cicely Saunders - considered by

¹⁴ Also, see Kellehear (2009a: 19) for discussion about a lack of understanding about the positive aspects of dying as these have been over-shadowed by 'problem-based concerns' in palliative and medical literatures on the dying experience.

many as the founder of the modern hospice movement¹⁵ - clearly shows some of the more routine and ordinary aspects of life on hospice wards.

Much of the communication at St Christopher's may at first sight look superficial. Visiting students find themselves busy serving meals and giving so much practical care that they do not feel they can sit down and have the *long talks* they somehow thought would make up their experience. But the part of life before death is like the rest, it is full of *ordinary* and exasperating things. Feeding a person who cannot even manage to get a spoon to his mouth can be a chore to the worker and a humiliation to the patient; it can also be a social occasion when the worker can just come as a neighbour. We all feel clumsy at times and must often say the wrong or hurtful thing, but as we keep coming for such *simple* errands we have the opportunity for a new beginning, in the endlessly repetitive and insignificant. A true meeting between two people is a gift coming unbidden into the midst of such action (1977: 164-165 my emphasis added).

Writing about a hospice in London which she founded in 1967, Saunders points to the significance of ordinariness in hospice care whilst also acknowledging that it is not what is expected of a place for dying people. She suggests that students anticipate taking part in 'long talks' and implies that when caring for dying people there is the implicit assumption that deep emotionality and meaningful conversation - elements of more 'extraordinary' experience - will be to the fore. Indeed the prevalence of this expectation is supported by empirical work with hospice nurses in Scotland (Vivat, 2008) and with hospice volunteers in the USA (Foster, 2007). Adopting the role of a volunteer befriender to conduct her research, Foster reflects in conversation with another volunteer that:

"I'd always framed this work as something that I couldn't do because it was emotionally overwhelming. It's a big surprise to me how human and ordinary this work is - what we do and the things we talk about..." (2007: 107).

¹⁵ See du Boulay (1984).

Interestingly Foster concludes her study with the realisation that relationships at the end of life are actually about 'finding the magic in the mundane' (2007: 208). Thus Foster echoes what Saunders discusses above - both suggest that the mundane and ordinary is relevant to dying experiences but that this is also a site for making relationships at the end of life special or 'true' - to use Saunders' term. In a sense these interpretations 'elevate' ordinariness into something else - something special or 'magical' - via its association with dying as an authentic or transformative experience - and I will return to this point again at various places throughout this review.

Despite affirming the more ordinary aspects of dying, hospices are often referred to as 'extraordinary' - for instance, as special and romanticised spaces (Lawton, 2000) - whilst the movement itself has religious and spiritual origins (Clark, 2001; 1998; Bradshaw, 1996). Moreover, as institutions, hospices have been associated with the management of boundaries between life and death and therefore ascribed sacredness in a theoretical sense as liminal spaces (Froggatt, 1997). However, hospice as an extraordinary place is perhaps reinforced most clearly by the movement's revolutionary or 'anti-modernist' roots (Lawton, 2000: 12). Pioneering the hospice concept during the 1950s and 1960s, Saunders declared that her purpose was to establish 'a reaction against the impersonal medical city' (cited in du Boulay, 1984: 137). Philosophically the movement determined an *alternative* view that death 'could be natural and dignified instead of a daunting and dehumanising process' (Young, 1981: 1). However, it is

ironic that in considering death as natural and in more 'ordinary' terms this actually gave the movement its 'alternative' and 'extraordinary' status.

More recently, as the scope of palliative care has broadened into further fields of health care, a cautionary view which bemoans the loss of the original *special* value of the hospice ideal has been established (Clark and Seymour, 1999). Some argue that hospices have become increasingly rationalised, bureaucratic and somewhat '*disenchanted*' (Weber, 1930) and that the erosion of the movement's spiritual foundations means hospices risk becoming more like the modern, medical institutions they were originally trying to provide an alternative from (Bradshaw, 1996). There is also a concern that the overly-prescriptive notion of the 'good death' embedded within hospice culture and the field of palliative care, is problematic because it sets up certain expectations of death which are not always achievable (Masson, 2002; Clark and Seymour, 1999). As Lawton argues, the movement 'glosses over' bodily realities which interrupt the romantic notion that death can be the ultimate point of self-expression - such as when 'non-negotiable' physical deterioration impacts adversely upon selfhood (2000: 16). She suggests the movement propagates disembodied ideas about dying that are premised on 'problematic 'rhetorics of individuality'' which present death more as a psychological, rather than a bodily process (Lawton, 2000: 16). In other words, the more (mundane) bodily experience of dying is 'overridden' - at a conceptual level within hospice philosophy - by the emotive idea that facing death is an (extraordinary) opportunity for

'authenticity', self-development and growth. I will return to consider this point further in the following section.

From Death Ritual to Ritualisation: conceptualising practices

Latterly I pointed to a breakdown in aspects of so-called hospice 'tradition' and the more 'enchanted' or spiritual discourses associated with the origins of the movement. Thinking also about the loss of 'tradition', Hockey (1996) explores death rituals and describes how contemporary deathways are considered impoverished by their nostalgic comparison with more elaborate rituals of previous eras and other cultures (see also Bradbury, 1999). Such ritual comparisons have been intrinsic to the effectiveness of establishing the aforementioned themes of fear and denial as central theoretical discourses in relation to death in modern, western societies. For instance, Aries (1981; 1976) identified greatly with the idea that modern societies do not acknowledge death in daily life and lack the social means to mourn as a community. His is a particularly bleak assessment of the state of modern day responses to death and it made a significant contribution, along with the work of Gorer (1965), to the thesis which suggests that modern societies deny and sequester death as they no longer have the collective rituals to manage it. When compared with classic anthropological accounts of death rituals in other cultures, such as those produced by van Gennep (1960 [1909]) and Hertz (1960 [1907]), the implication is that the inevitable threat posed by death as an intruder into everyday life is problematic in modern western societies because it cannot be functionally integrated into

community, familial and social life generally. However Rosaldo is critical of traditional anthropological studies of death in other cultures for 'seeing' death purely in relation to formalised ritual events which neglect the significance of bereavement as it is experienced (with *emotional* intensity or 'force' as he argues) in 'informal settings of everyday life' (1989: 14).

Although Rosaldo does seem to suggest that anthropology has been concerned with the *less* spectacular or intense aspects of death experiences, having factored-out the emotionality of bereavement, he *also* nevertheless points to the absence of analytical focus on the *everyday*. To give a brief example of this absence, the concept of liminality developed in van Gennep's (1960 [1909]) work on *Rites of Passage* and mentioned above in relation to hospices, is a time of ambiguity following death where rituals are used to negotiate status transitions. So for instance, bereaved people are separated from the 'normal modes of social action' and the 'secular structure of wider society' and enter the limen to occupy a marginal position *vis a vis* 'normal', everyday society (Froggatt, 1997: 125). This suggests that liminality is a particular sacred and ritualised period of social experience which occurs symbolically and actually, at a *distance* from the usual flow of everyday life. And so, whilst the concept has made an important contribution to theorising social and ritual responses to death (Huntington and Metcalf, 1979) - for instance in studies of boundary maintenance between life and death in institutions managing the dying experience (see Komaromy, 2009; Froggatt, 1997; Hockey, 1990), it can be argued it has also contributed to a theoretical association of death with extraordinary, non-everyday experience.

However, returning to focus on the matter of contemporary western death practices, there are two arguments which challenge the idea that these are actually impoverished - revivalism and diversity - and I shall consider each of these in turn. Firstly revivalist approaches suggest that death is increasingly publically acknowledged and that individuals are seeking, in the absence of what was once a firmer belief in traditional narratives of religion and modern medicine, ways to 'do' dying and grieving in the private realms of their daily lives (Walter, 1994). The neo-modern reflexive self has an active role in trying to find meaningful ways to manage death in a society where it is talked about more and more, making it increasingly difficult to think of death as denied or a taboo subject (Walter *et al.*, 1995; Walter, 1991). Thus there is now a renewed interest in how to 'do' death which necessarily complicates the adage that contemporary death culture is impoverished. Having said this, it is significant that Walter should ask just how free modern individuals are to choose their own deathways.

The trouble with putting dying people in the shoes of the postmodern consumer, of course, is that they have never died before... and don't necessarily know how to die or what they want... This means that the truly postmodern strand, letting people do it their way, alternates with the late-modern strand, with experts and those with experience of the field letting dying and bereaved people know what is the best way... (1994: 44).

Indeed, there is a close alignment between reflexive projects of the self (Giddens, 1991) and therapeutic/ counselling discourses concerned with privileging a confessional self. These reflect a curious mix, as Walter suggests, of doing it 'my way' but in line with guidance from an authoritative other. Since in contemporary society people are experiencing

protracted terminal illness trajectories (Green, 2008; Field, 1996; Kellehear, 1990) individuals have more time to work out how to 'be' in their dying (Walter, 1994). I will now discuss empirical and theoretical work that draws on themes of the individualised self in relation to people living with terminal illness. I suggest that while they do bring the everyday into analytical view, it tends to slide out of the picture when the analysis provided is concerned with transformations of self in the face of death.

Interested in the everyday lives of people who have HIV/ AIDS, Heaphy (2000) refers to how modern individuals are deskilled in relation to their abilities to manage the incorporation of facing death into their daily lives. Following Bauman (1992) and his notion of 'collective deskilling' as a characteristic of the 'emotional impoverishment' of modernity, Heaphy echoes Walter's suggestion that we do not know how 'to be' in the face of death which is now an individualised and private 'problem' (2000: 164). The suggestion is that in modernity we have 'lost the sacred' which may once have offered guidance about how to manage death, and that therefore individuals are involved in processes of 'reskilling' (or working out how to do death) as a way to manage living with dying. These processes of creating 'new meaning and value through the project of living with contingency' can 'also provide the context for being transformed through it' (Heaphy, 2000: 174). Importantly, here 'reskilling' is aligned with a process of *transformation* which perhaps also mirrors a recapturing of the sacred deemed necessary to manage death. Further, although Heaphy suggests that therapy is problematic because it affirms that death is a

problem for the individual, self-help groups are considered to overcome the issue of individualisation because they share a concern for a collective problem and involve relating to others in day-to-day life. Sharing narratives about facing death are considered as a way to reskill by listening to others.

In telling their stories - in private and in public - individuals and collectives are generating resources for making sense of living and dying now. In listening to these we can understand that it is possible to live with radical contingency - and to be *transformed* through it (Heaphy, 2000: 175 my emphasis added).

Thus, although this work is about facing death in everyday life, its theoretical frame moves away from the mundane, since reflexive self-making and reskilling become aligned with notions of seeking transformation. And this, as I discuss in Part 2, can represent a transcendence of the mundane and everyday rather than a situation within it.

Similarly, and bringing me more squarely back to a focus on ritual, Seale has argued that mortality poses problems at both the societal and individual level and to manage this people constantly engage in 'resurrective practice' to 'reorient themselves towards life in the face of death' (1998: 50).

According to Seale, who also considers narrative by suggesting that talk is a mediator of social bonds in the face of death, conversation represents 'everyday talk-as-ritual' - an important resurrective practice which defends against death (1998: 50). Focused very much on the everyday Seale argues that 'resurrective practice restores a sense of basic security fractured by death, but is also a routine feature of daily life' (2001: 107). However, whilst acknowledging the centrality of the everyday, this approach can align

death with notions of the spectacular via an emphasis on ritual as transformative practice in everyday life¹⁶. The idea of being transformed echoes Heaphy's approach and both seem to highlight more extraordinary possibilities for refashioning self when faced with death. As Seale writes:

Psychological and other revivalist discourse can help people, faced with the fateful moments of death and loss, to restructure narratives of self identity and transform the event of death into a positive experience (2001: 108).

Later, after outlining his work on media representations and cultural scripts for 'doing' death, he discusses heroic dying using the example of a television interview with British playwright Dennis Potter who was at the time dying of cancer.

...I demonstrate the construction of the aware dying role as a *drama* of inner adventure. In this discourse certain rhetorical devices - such as the juxtaposition of opposites - are routinely used to generate an authoritative voice, based on the demonstration of *special status* as a *liminal* being, as well as *transforming* the experience of dying into an opportunity for *growth*. The parallels with symbolic *transformation* of death into fertility in mortuary rituals are evident (2001: 109 my emphasis added).

Thus, whilst these are examples of important work that represent attempts to understand more about the experience of facing death and dying, once again the mundanity of everyday life slips out of focus. Notions of drama, having special status, liminality, transformation and growth, all appear in Seale's analysis of Potter's reflexive making of the aware and heroic dying self.

Although he suggests this might all happen in the flow of everyday life as

¹⁶ However, Seale's (1998) focus on food (Chapter 7) does clearly represent an engagement with aspects of the more 'mundane' in this work.

resurrective (ritual) practice, death as an everyday and *mundane* experience is not to the fore, and once again death's alignment with aspects of the spectacular is asserted. Thus having started to explore ritual practice, I now consider the matter of diversity in death-related experiences which challenges the idea the modern western death rituals are necessarily impoverished (Howarth, 2007a).

It is important to recognise that despite the various models and schemas devised to try and represent the dying process, it remains the case that in comparison to bereavement and other death-related matters, *dying* has been neglected and 'distinctly under-theorised' (Kellehear, 2007: 5; 2009a).

Indeed, this can be seen in how understandings of the dying process have not deepened as perhaps they might have, given the significant theoretical shifts in the area of bereavement studies over the last 10-15 years, and particularly since the publication of Klass *et al.*'s (1996) work on continuing bonds. In this key publication the contributors undermined the dominant psychological premise upon which grief in western societies had been understood and described instead how rather than searching for a way to 'move on', bereaved people engage in processes of 'altering and then continuing their relationship to the lost or dead person' (1996: xviii).

The *diverse* nature of responses to death and sentiments associated with the continuing bonds thesis can be found in media representations of how 'everyday' families manage the death of a member. An episode of the BBC2 comedy series *The Royle Family*, screened at Christmas 2006,

featured the death of the much-loved character, Nana. The episode closed with the family and their friends gathered in the living room of the family home with Jim, Nana's son-in-law announcing to the gathering that Nana should get pride of place in the home. The camera then pans to towards the corner of the living room and follows Jim as he places Nana's ashes majestically on top of the TV. For those familiar with the series, this gesture has clear relevance for my concern with death experiences in the context of mundane family life. The family are archetypal television addicts and much of the humour is based around their sedentary evenings in front of the TV. Placing Nana's ashes on top of an object which is so central to family life represents the family's way of negotiating a continuing place for her within the family. The ritual/ habitual act of remembering Nana when the family gather to watch TV suggests the diverse nature of death practices and how modern families relate to death and dying in the context of their *daily lives*. Importantly there are empirical studies that reflect this example from popular culture and which have focused on similar practices, rituals, habits and memories in material and spatial everyday life to understand bereavement experiences (see Gibson, 2008; Hockey *et al.*, 2007a; Kellaher *et al.*, 2005; Bradbury, 2001; Francis *et al.*, 2001; Hockey *et al.*, 2001). There has not however been the same attention paid to mundane practices (doing) or material culture in empirical work on living with dying.

In this discussion I have used the terms 'do' and 'doing' to describe the performance of 'rituals' which, following Seale and Walter, relate to active undertakings of individuals to find ways of 'being' with death in revivalist

culture. In Part 2 the active construction of social life via practices - performance and *doing* - will be discussed and more fully explained. The term *practices* although it cannot be straightforwardly interchanged with the notion of ritual, does have a degree of semantic overlap with the latter and thinking about the two in relation to one another provides a useful place to begin moving theoretical emphasis more firmly towards the mundane in everyday life.

Whilst *ritual* has been extensively associated with death (mostly in relation to managing it), and *practices* can also refer to enactment and performance, this latter concept has a particular association with *doing* in everyday life (see Morgan, 1996). The two concepts have, however, been used together in the exploration of material culture in relation to death where an emphasis is placed upon the active role of individuals and their memories as 'embodied in ritualised practices' (Hallam and Hockey, 2001: 179).

Moreover, despite her claim that death rituals have transformative and existential dimensions, Bradbury suggests that the 'customs and rituals of our society are almost invisible and, for many, taking part in them can be a comfortable, almost *mundane*, experience' (1999: 190 my emphasis added).

So, it is possible to plot out conceptual linkages between the more spectacular notion of ritual as something that helps to transcend death, and the concept of practices explored in studies which show how bereavement has mundane material and spatial qualities as part of *daily life*.

A final theoretical point is helpful to include here as a means of outlining my argument more clearly. Seremetakis (1991) provides an important challenge to the theoretical assumption in anthropology that death ritual is a bounded experience existing at the margins of everyday life. Instead she conceptualises ritual in more fluid terms as a process of *ritualisation* and actually uses the term practices in relation to it.

Ritualization here is defined as the processual representation of death in a variety of social contexts and practices that do not have the formal status of a public rite. The concept of ritualization moves the analysis of death rites away from performances fixed in time and space and resituates it within the flux and contingency of everyday events... The ceremonialization of death emerges gradually from the background of everyday social life and never fully fades back into it (1991: 47).

Importantly this approach does create a conceptual location for death more centrally in the context of everyday life, despite, as is the case with death studies more generally (Kellehear, 2007) Seremetakis' focus is on bereavement and mourning rather than dying. In Part 2, I now outline the concept of everyday practices more fully and configure its significance for theoretical work in relation to family experiences of living with *dying* and life-threatening illness in day-to-day life.

Part 2 - Conceptualising Family and Everyday Life

'Family': embeddedness or individualisation?

It has been suggested that over the last decade theorising about the family and personal relationships has acquired a sort of 'street cred' not historically

associated with family based sociological research (Smart, 2004: 1043). Indeed, there have been a number of accounts dedicated to exploring emergent, diverse and negotiated modes of family and personal relationships (Smart *et al.*, 2001; Weeks *et al.*, 1999; Simpson, 1998; Finch and Mason, 1993). These studies and others like them, point to the plurality of modern family forms and represent what Seymour and Bagguley (1999) suggest are the individual and collective processes of 'creative construction' involved in maintaining personal relationships. However, it is also argued that, the diversification of family forms in particular, reflects the individualism characteristic of late-modernity where strong familial bonds and grand-narratives of marriage and the nuclear family have been weakened and are no longer upheld as the dominant ideological norm (Beck and Beck-Gernsheim 2004; 1995, Beck, 2000; Giddens, 1992). Beck's idea that the family has become a 'Zombie Category' encapsulates his feeling that we do not necessarily know what the family is anymore (2000: 37).

Importantly, the extent to which this is actually reflected in the lived reality of people's everyday lives is contended by accounts which underline the continued importance of personal relationships (Gabb, 2008; Smart, 2007; Smart and Shipman, 2004; Mason, 2008; 2004). Thus, these suggest that people continue to feel embedded in webs of interdependent relationships and that to understand relational experiences we need to explore what is happening for people and how they think and feel about family, in their everyday lives (Smart, 2007).

Family Practices: new conceptual windows on 'doing' family life

To 'get at' and understand the day-to-day lives of families there has been a conceptual shift in family sociology where the idea of '*the family*' is challenged and instead researchers ask - in what ways are people *doing* being a family? In his work introduced in Chapter 1, Morgan (1996) outlined the important idea of 'doing family' to represent a multitude of active relational possibilities and to challenge the traditional idea of *the family* as a static 'unit'. In doing so he altered the conceptual base and analytical character of family studies profoundly. Whilst accepting that ceasing to use the term 'family' is practically and conceptually impossible Morgan stressed that:

... terms such as 'family' should be seen as topics to be explored further, in all their useages and ramifications, rather than as resources to be drawn upon uncritically... the terms that people use, including the terms sociologists use, become part of the social reality in which we live (1996: 11).

By acknowledging how people think with words and the conceptual possibilities these create, Morgan was able to deconstruct *the family* as noun or thing and encourage more fluid and dynamic ways of understanding relationships, identities and family life by using the concept of *family practices*. As the intention here is to escape some of the constraints of a static notion of *the family*, family practices can be understood as the theoretical description of the active construction of family life in everyday diverse family contexts (see also Morgan, 2004 and 1999). Put simply, practices are 'often little fragments of daily life' which are characteristically open-ended, fluid and convey a sense of regularity; essentially they are the

actions and interactions undertaken by people in the course of their lives as they 'do' being a family (1996: 189). And so the 'doing' is very important as it reflects Morgan's intention that family is what happens - for instance caring practices, gender practices or eating practices - in the day-to-day routines of family life. It is individuals doing things in an embodied way with one another, *together*, which creates family.

Building on Morgan's concept of practices, Smart acknowledges the importance of the contribution of 'doing' to our understanding of what families are, yet she develops this analysis further 'to explore those families and relationships which exist in our imaginings and memories, since these are just as real' (2007: 4). Thus Smart problematises the duality of thinking and doing and indicates how the two are entwined in people's experiences of relatedness and connection in their everyday lives. She argues:

Relationality is then a mode of thinking which not only influences decisions and choice, but also forms a context for the unfolding of everyday life. But it is not just a state of mind, it requires action. This brings me back to... the distinction between mind (thought) and body (practices)... thought and action permeate one another. Family practices do not occur without thought, however ritualized some of them may become (2007: 49).

This important work explores how emotions and thought practices related to our imaginations, memories and biographies can provide another layer of richness to the complex construction of connections in personal and family life. An empirical example of the importance of imagination can be found in Simpson's (1998) study of divorce where he identifies how relationships with former partners *continued* in the imaginations of his interviewees.

This, he argued, reflects a complex process of mental intermeshing where

absent ex-partners appear in an ongoing dialogue of relationality that shows the way couples remain implicated in each other's biographies after, and in spite of, separation. More recently we can also see recognition of the role of the imaginative in the negotiation of relationality in Mason's (2008) work on tangible affinities which she argues represent different ways people are engaged with thinking about kinship and how they create, sense and retain familial connections¹⁷. Mason refers to these as *tangible* affinities 'not because they are all literally tangible but because of their resonance in lived experience and their vivid and palpable (or almost palpable) character' (2008: 29).

Thinking in a more 'grounded' sense about 'props' that might facilitate imaginative relational work, Smart (2007) discusses the importance of material culture, considering how objects retain a sense of connectedness and carry complex relational meanings. Similarly, Finch (2007) explores the significance of material objects such as photographs in everyday domestic life for the purposes of *displaying* meanings of 'family-ness'. In this work Finch is also building on Morgan's notion of family practices, arguing that we need to include the importance of 'displaying family' alongside the doing of family life:

By 'displaying' I mean to emphasise the fundamentally social nature of family practices, where the meaning of one's actions has to be both conveyed to and understood by relevant others if those actions are to be effective as constituting 'family' practices... to be understood by others as carrying meaning associated with 'family'... and thereby confirm[ing] that these relationships are 'family' relationships (2007: 66-67).

¹⁷ An example Mason discusses is family resemblances.

Finch's argument echoes the earlier work of Gillis (1996) introduced in Chapter 1, where he describes the mythological 'ideal' family pervasive in contemporary North American and European culture. Thus he explains how:

We not only live with families but depend on them to do the symbolic work that was assigned to religious and communal institutions: representing ourselves to ourselves as we would like to think we are' (1996: xv).

Indeed Finch herself argues that evidence from recent empirical studies such as those discussed in the previous section indicate that in contemporary UK society it is the fluidity which characterises family composition that makes the practice of displaying family particularly important. There are, she suggests, now fewer people able to easily answer the question 'Who constitutes my family?' (2007: 67). Consequently how family is connected needs to be actively worked out by the individuals involved and displayed or demonstrated to others to receive validation and acceptance that yes, this is 'a family'.

And so to summarise, 'family' as constituted by family practices (incorporating doing, thinking, feeling and displaying) is *an active process* of constructing relationality and expressing family connections undertaken by individuals themselves in their everyday lives. In the following section I consider how matters associated with family life are often taken-for-granted as they are embedded in the flow of everyday life. In other words they are considered in many ways under the rubric of the everyday, ordinary and mundane (Morgan, 2004). However I will show how it is precisely this, the

illumination of the mundane, which gives family practices such conceptual importance.

Seeing the Mundane: families and everyday life

It is evident from Morgan's discussion of family practices as 'little fragments of daily life' that practices are inextricably tangled up with the everyday and constitute our experiences of it (1996: 189). His emphasis on the doing of family resonates closely with the definition of everyday life as a series of sites or situations 'in which people do (perform, reproduce, and occasionally challenge) social life, day-to-day' (Scott, 2009: 1)¹⁸. In fact writing about the fluidity of modern day life, Bennett and Silva argue that Morgan's conceptual view of institutions like the family as 'the active processes of human creation through ordinary interaction' has made a significant contribution to everyday life 'enjoying something of a renaissance in contemporary social thought' (2004: 1). Indeed Morgan (1996) stresses the links between practices of individuals and their families and the wider societal structures and processes of social change. The idea that one can see patterns of reproduction, organisation and resistance to dominant discourses in the mundane routines and embodied practices of people's lives importantly highlights 'the political processes that go into the construction of the "mundane"' (Schaffer, 2000: 5)¹⁹. In other words everyday life is far from insignificant and unimportant as 'like any

¹⁸ Also, see Goffman (1969).

¹⁹ See Hockey *et al.* (2007b) for a discussion of heterosexuality and Felski (1999) for a discussion of gender.

analytical term, it organises the world according to certain assumptions and criteria' (Felski, 1999: 15).

This is not however the usual conclusion which is reached when thinking about the everyday. Assumptions about its natural triviality imply the concept needs no further explanation. As Chaney suggests it is 'the forms of life we routinely consider unremarkable and thus take for granted' (2002: 10). Therefore it can be said that the everyday and '*the family*' share a taken-for-granted quality which belies their conceptual and experiential complexities. Whilst seminal works such as those produced by Lefebvre, de Certeau, and Goffman point to a more long-standing sociological interest in the everyday (Crow and Pope, 2008), contemporary theorists argue for a more empirically grounded knowledge of the everyday (Bennett and Silva, 2004; Highmore, 2002). That is, one which explicitly engages with the benign and the boring (Moran, 2005) and has a focus on the very ordinary and habitual nature of everyday life (Felski, 1999).

Transcending the Everyday: making the 'ordinary' spectacular

Habit, is indeed a further way in which family and everyday life are aligned. They are both commonly associated with domestic life and the mundane routines of going to bed, mealtimes and shopping which are produced and reproduced here (Morgan, 2004). Discussing the experience of researching family life Morgan points to the common and pervasive association of family with the mundane:

Family researchers are sometimes asked by the people they interview: 'surely you don't want to hear about this?' Family, after all, is related linguistically to the 'familiar'. Family practices are organised around the regular deployment of bodies, time and space and material culture. These constitute the routines of family living... (2004: 40).

However, Moran's (2005) point about studies of everyday life needing to engage more explicitly with the benign and boring suggests that like the research participants Morgan refers to above, analytical approaches tend to 'under rate' the habitual and mundane. Indeed, Lefebvre in his classic text 'Everyday Life in the Modern' (1971) discusses *breaking out* of the routine of daily life to find more *authentic* ways of being in the world (Bennett and Watson, 2002). Having been firmly influenced by the work of Marx, Lefebvre was highly critical of the everyday as an opaque structure which represented all that was 'left over' from the 'distinct' and 'superior' activities of life (Highmore, 2002: 115). This notion is reiterated in Featherstone's (1995) point that the everyday appears to be 'a residual category into which can be jettisoned all the irritating bits and pieces which do not fit into orderly thought' (Featherstone, 1995: 55, cited in Highmore, 2002: 19). Highmore argues that this implies that the everyday and the rational are mutually exclusive. He suggests that to apply a scientific, rational discourse to explore the everyday - an experience more akin with the domain of sensory experience and aesthetics - is essentially to lose what one is looking for. As he explains:

How often is the particularity of the everyday lost as it is transformed in the process of description and interpretation? As rationalist discourse expands to cover areas of life that are non-rational, that do not follow patterns of logical reasoning, what is lost (as these aspects of life are transformed into suitable objects for

attention) is the very 'stuff-ness' that made them urgent problems in the first place (2002: 20).

Therefore Highmore conceives that analytical processes of *transformation* are problematic when trying to understand the 'stuff' of the everyday. This is because they signify an interest in the everyday only when it is transformed from 'its status as 'mere' sensation living in the lowly realms of the everyday', rather than considering how to represent the everyday in ways which attend to its experiences more appropriately (2002: 20-21). However as Bennett and Watson point out, a 'politics of transcendence' - the idea that 'the mundane and banal cycle of everyday life might one day be transcended' - was very much at the heart of classical European schools of thought, as is the case with Lefebvre above (2002: xix). Indeed, as Moran (2005) has argued about contemporary cultural studies which built on this earlier critical discourse, the dominant reading of the everyday is either in relation to ritual 'as symbolically charged practices' (Ries, 2002: 732, cited in Moran, 2005: 9) - essentially seeking to find the extraordinary in patterns of the ordinary - or through consumption practices as an everyday form of cultural resistance and power. Thus, Moran reflects how ultimately 'the banal is usually turned into something else, made interesting and significant by acts of subaltern resistance or semiotic reinvention' (2005: 12).

This separation of the everyday from the more 'spectacular' occasions and aspects of social life, or the reduction of its usefulness to providing a backdrop against which the important, notable and significant can be

recognised discussed and theorised, resonates with my argument that death and dying has been constructed through discourses of the spectacular as the antithesis of the everyday. And so, echoing the discussion around spectacular death and an emphasis on crisis, rupture and self-transformation which I identified in Part 1, Bennett and Silva argue that we need:

... not to abandon the everyday as a field of study and political engagement but, rather, to retrieve its analysis from the search for the exceptional and *ruptural possibilities* that has characterised the critique of everyday life. And this means... being concerned with how social changes comes about in and through the ways in which political issues are worked through in the context of the mundane dynamics of everyday life rather than seeking a generalised transcendence of the everyday, seen as a one-dimensional realm of social stasis and repetition, to be effected by some singular and exceptional social force (2004: 6 my emphasis added).

Similarly Highmore (2002) problematises this idea of the everyday existing as something separate from the extraordinary and he suggests that a contradiction and paradox of the everyday is that it is both ordinary and extraordinary. His central argument is that there needs to be a shift in how the two are contrasted against each other where:

Instead of picturing the world as a drama of significant (and exceptional) events and people, set against a backdrop of everyday life, the relation between foreground and background needs to be reversed (2002: 27).

In relation to Highmore's point, Robinson's (2008) work is useful here. In her recent study of masculinities and the extreme sport of rock climbing Robinson uses the concept of 'mundane extremities' to reflect the co-existence of the mundane and extraordinary in the everyday lives of the climbers she interviewed. As both the sporting and the domestic or

relational aspects of the men's lives encountered various transitions over time, Robinson found that in the men's experiences 'the extreme continually shaded into the mundane' and that therefore following Chaney (2002) she argues:

...we need to be aware of the boundaries between everyday life and the extraordinary and how they are negotiated... for a more complex understanding of how the extreme and the mundane are inextricably bound together (Robinson, 2008: 116).

This research and a study undertaken by Hockey *et al.* (2007b) on mundane heterosexualities are important examples of empirical work which complicate dualisms around the everyday and the extraordinary. Similarly, Silverman's (2007) suggestion that the value of ethnography is that it enables the observer to see the mundane in the most remarkable events and contexts and vice versa, also provides a useful consideration of the *intersection* between mundanity and the extraordinary²⁰.

However, finally, I refer once again to Morgan (2004) who is also able to provide a less dualistic way of approaching everyday life and other so-called more 'extraordinary' events (see pages 38-39). Writing about everyday life and family practices, he considers the relationship between 'life events' (including illness and death) and daily family life and describes how these experiences affect us all at some point during our lives. They are therefore, part of the character of everyday life in the way that they become 'talk-

²⁰ Mattingly (1998) provides an insightful empirical example of this in the context of occupational therapy in a US hospital. She discusses how the mundane tasks which often constitute therapy interweave with 'profound discussions' and 'become invested with symbolic meanings' (1998: 51). The study explores the connections between narrative and experience in clinical encounters, and Mattingly, an ethnographer, explains how this work 'plunged' her into the world of occupational therapists where 'the existential and the commonsense traveled side by side' (1998: 52).

about-ables’ - essentially the essence of ‘what life is all about’. Regarding these ‘talk-about-ables’ Morgan points out:

Further, and more importantly, it is not the events themselves which are significant, but the way in which they are shaped and *given meaning in everyday life* through talk, ritual and cultural representations (2004: 39 my emphasis added).

Therefore, he situates our understandings and experiences of such events within the context of doing everyday life. However, at the same time, Morgan does suggest that as personal experiences - the death of *my* dad, the birth of *my* child - we cannot play down the importance of such events.

And so, viewing the everyday and more seemingly ‘extraordinary’ experiences such as illness, as mutually exclusive is problematic for families where illness is not a temporary visitor, but is a part of how life has to continue to be. Ultimately then, there is a need to consider explicitly how the mundane routines, habits and ‘stuff-ness’ of day-to-day life co-exist with the prospect of death and the experience of severe ill health in the context of the everyday without assuming the everyday will be somehow eclipsed or transcended in the process. How illness has been studied and theorised as an everyday experience is the subject of analysis in the following section.

Part 3 - Experiencing Illness: conceptual and theoretical approaches

Illness and Everyday Experience

It appears that the sociology of health and illness provides a more explicit focus on the everyday than has been the case in death studies. Writing in 1988, Anderson and Bury claim that from around 1965 a variety of work in the field of health and illness addressed questions about managing illness in everyday life - though much of this appears to relate more specifically to chronic illness conditions²¹. Furthermore, responding to the inadequacy of Parsonian functionalism to account for experiences of illness from which people would not recover, interpretive branches of the illness literature have given more extensive attention to daily life as the context within which illness is *experienced* and made sense of (Lawton, 2003; Pierret, 2003; Williams, 2000; Conrad and Bury, 1997; Bury, 1991).

In their own volume that sought to reflect the diverse experiences of living with chronic conditions, Anderson and Bury (1988) provide an 'insiders' view of illness and include attention to both the 'patient' and their family, suggesting that 'the handicap of chronic illness may fall as heavily on the family as on the patient, in terms of problems created for daily living and family life' (1988: 7). Bury's (1988) own chapter in the volume focuses on the experience of uncertainty and how meanings (such as about the future)

²¹ Lawton (2003) points out that this has been the case with the vast majority of articles published in the eminent journal *Sociology of Health and Illness* since its establishment in 1978.

are placed 'at risk' for individuals living with rheumatoid arthritis and their relatives. Whilst his account (and the volume generally) appears problem-focused²², it clearly places the sufferer in their wider familial context. And although it seems to take a patient-out approach (starting mainly with the ill-person's standpoint and taking in family experience in relation to this), it explores how relationships are 'threatened' in daily life, referring to how the illness is understood and negotiated by both the sufferer and their relatives. Furthermore, these negotiations are placed within the context of *mundane* activities as they are experienced in the unfolding of daily life - so matters such as housework, bag carrying and the inability to operate simple household fixtures such as kitchen taps are identified in participant accounts.

Perhaps more unusually, Bluebond-Langner (1996) takes an *explicitly* family-focused perspective in her work on cystic fibrosis (CF). Exploring everyday family life in the context of managing a condition which is considered to be chronic but yet also ultimately life-threatening/ limiting, she considers the experiences of well siblings and parents *foremost*.

Although Bluebond-Langner found that having a child with CF meant that some difficulties and burdens were experienced by families, she also recognised 'that families appear, at least for long periods of time, very much like other families' (1996: xiii). She reflects:

²² Although, in Bury (1991) he explicitly encourages sociologists to also consider the ways in which people manage and respond positively to dealing with their illnesses, rather than focusing only on the problems that they face.

I realized that understanding the impact of CF on well siblings does not come from searching for something wrong in their lives, nor does it come through the identification of some form of pathology or from the discovery of abnormal behavior caused by a trying situation (1996: xiii).

Her sense that it was necessary to focus upon how families were living with CF without assuming a position of 'crisis' from which to begin looking is important and underscores the need to consider the *everyday* aspects of family life to understand how illness is *experienced*. Again, as Bluebond-Langner explains:

...I could discuss the well siblings' views of the disease and their relations to their ill siblings and parents only by placing them within the context of everyday family life. Documenting and analyzing the changes in the everyday lives of these families were necessary, for this is the context from which the knowledge and experience of the well sibling derives (1996: xiii).

In terms of linkages between chronic illness and life-threatening or terminal illness, the experience of living and/or dying with cancer as a disease more readily associated with death (McNamara, 2001; Diamond, 1998; Ball *et al.*, 1996; Sontag, 1991) does make it a qualitatively different experience from having a more 'typically' chronic condition. That is, one without such an immediate - or perhaps even longer term - threat to life²³. This is in spite of the fact that having cancer also undoubtedly incorporates many aspects of chronic illness experience and requires social adjustments in everyday life to accommodate these (Kellehear, 1990). Indeed, some sociological studies of chronic illness involve people with cancer in their samples - see for

²³ See Armstrong-Coster, (2004), Grinyer, (2002), Costain Schou and Hewison, (1999), Ball *et al.* (1996) and Kellehear, (1990) for empirical accounts of experiencing - living and dying with - cancer. See Stacey, (1997) and Frank, (1991) for autobiographically influenced accounts.

example Charmaz (1991) and also Macdonald's (1988) chapter about rectal cancer in Anderson and Bury's volume. As a quick glance at the web pages of the World Health Organisation will show, cancer is listed there as chronic illness. Thus it is recognised that one can experience chronic illness complaints not only as a result of the cancer itself, but as a side-effect of its various treatments²⁴.

Anderson and Bury define chronic conditions as characterised by 'some long-term influence upon the lives of sufferers' and suggest that consequently emphasis for care in these circumstances is 'more on enhancing and sustaining the quality and fullness of life than on reordering the disease process' (1988: 2). In fact, this is a definition which resonates with the philosophy of the hospice movement as a 'living idea' (see Saunders *et al.*, 1981) and the notion that individuals who have an imminently limited life can continue to live it with some quality. However, while the association between cancer and death is now less readily assumed than it was when Sontag was writing about cancer in the 1970s (James and Hockey, 2007), having a diagnosis of malignancy still involves an inherent, and in many ways imminent life-threatening possibility (McNamara, 2001). Therefore whilst I draw on concepts, ideas and evidence taken from the literature on chronic illness precisely because it has an important focus on the experiential and the everyday, this is a thesis which features the experiences of many terminally ill people and is ultimately about living with

²⁴ Although, sociological accounts concerning *lived experience* of cancer have been described as 'scarce' with Thomas arguing that such analyses have only a marginal presence in work on chronic illness and disability within the medical sociology literature (2008: 424).

the knowledge that death is likely to occur sooner rather than later. I now want to explore some areas of conceptual overlap between theorising about death and dying and theorising about chronic illness experiences.

Biographical Disruption: a return to rupture?

Bury's (1982) seminal idea of chronic illness as a *biographical disruption* has been extremely influential in shaping the nature of qualitative inquiry into illness experiences (Lawton, 2003; Pierret, 2003; Williams, 2000).

Describing his concept Bury explains:

My contention is that illness, and especially chronic illness, is precisely that kind of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others (1982: 169).

Bury suggests three elements to the disruption caused by chronic illness.

The first is disruption to things taken for granted such as behaviours and bodily states, which in illness are more consciously experienced. The second disruption is to the ill person's biography and their sense of self and who they are. And the third is how resources are mobilised as a way to respond to the disruption experienced. Whilst the term *biographical* does indicate that it is the ill *individual's* experience which is of central concern,

Bury does also state that biographical disruption in illness:

...brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support. The growing dependency involved in chronic illness is a major issue here (1982: 169).

Thus, there is an acknowledgement within this framework that illness will bring disruption not simply to the individual's worldview and everyday life, but that it will also have an impact on relationships with significant others²⁵. Moreover, the association of relationships with dependency which Bury mentions here implies a link with crisis and coping-based discourses. In this work he draws closely on Giddens' (1979) notion of a 'critical situation' which, as Bury explores, describes as an occasion when everyday routines and settings are disturbed. Therefore, having been influenced by this concept where the use of the term '*critical*' has dramatic overtones, the notion of biographical disruption is inherently associated with the problematic and a sense of crisis.

Nonetheless, biographical disruption as a concept has contributed useful insights into the experiential, contextual and individual 'realities' of illness. Furthermore it recognises that there are diverse and active ways people approach their chronic illnesses and that there are many 'positive actions people take' to manage the problems they face (Bury, 1991: 451). However, due to its association with the problematic aspects of illness, as Williams (2000) has pointed out, it assumes that illness is inherently experienced as a disruption in the first instance, which may not always be the case.

²⁵ Although it is interesting to note that as Lawton (2003) observes (in a footnote), from 1978-2003 the Journal Sociology of Health and Illness did not publish any articles that made an 'obvious attempt to extrapolate' Bury's massively influential ideas regarding 'biographical disruption' to understand the experience of 'caregivers' (2003: 37).

In an important paper that 'provides a critical assessment' of the idea of chronic illness as biographical disruption and its usefulness as a theoretical and empirical framework in late modernity, Williams discusses the contextual issue of 'normal' crises and suggests these can occur throughout an individual's life where they experience 'general adversity and material deprivation' (2000: 50). To build his argument Williams refers to Cornwell's (1984) study of stoic residents in the East-End of London. In this study Cornwell used ethnographic methods to investigate how residents understood and talked about matters of health and illness and she argued that 'the relationship people have to health and illness is governed by commonsense ideas and values which are grounded in their way of life' (1984:203)²⁶. Drawing on Cornwell's work, Williams claims that for some, illness is simply something to be expected and health as seen from this view point leads him to suggest that:

...the biographically disruptive nature of illness is perhaps most keenly felt amongst the privileged rather [than the] disadvantaged segments of society. Biographical disruption, in other words, carries particular class- and age-related connotations, as well as gender and ethnic dimensions, which remain, at present, under-played and under-researched (2000: 50).

To provide some further empirical support, Williams draws on a paper by Pound *et al.* (1998) where the wholesale applicability of biographical disruption as a framework to understand illness is challenged by the experiences of stroke survivors. Pound *et al.* explain how 'stroke is

²⁶ See also, Rory Williams' (1990) study with older Aberdonians (people living in Aberdeen in Scotland) towards death and illness. He considers the influence of religious and economic legacies and how these are intertwined in the lives of those studied, shaping their attitudes towards illness and death. This work will be discussed more explicitly in Chapter 8.

popularly conceived of as an illness which shatters lives' and that this 'discourse of shattered lives' is actually 'articulated more generally within the sociological literature on chronic illness as "biographical disruption"' (1998: 189). Reviewing the stroke stories they had collected the authors were left asking; 'Why were we failing to uncover the dramatic stories we had anticipated? Where was the 'biographical disruption?' (1998: 491). Instead this study provides a different perspective on the conceptualisation of illness as an interruption to the everyday. Importantly, as the authors explain:

Ten months after the acute event, the stroke appeared to have been accepted with resignation and pragmatism, not as something which could be bracketed off from the continuous ebbs and flow of their lives, but which was fundamentally part and parcel of it (1998: 498).

They conclude that although stroke was experienced as a crisis in the lives of the people they spoke with, it did *not* 'suddenly disrupt a previously unproblematic life' because essentially 'crises were not unusual in these peoples' lives' (1998: 497). They underline how factors such as age, social class and life experiences can mean that there is something normal about the experience of stroke - for some it can be understood as a 'normal crisis'. Similarly Faircloth *et al.* (2004) echo these findings and suggest that biographical disruption is not an appropriate framework for understanding all illness experiences - it must be recognised that they are affected by age, previous illness knowledge and co-morbidities. Ultimately they consider 'biographical flow' a more relevant concept for some illness experiences and argue that:

Suggesting... there is a definitive split between self and body after a stroke, resulting in biographical disruption, is too generalist and must be placed in more specific context (2004: 258).

Similarly, Williams' (2000) analysis points to the importance of biographical continuity in certain illness experiences. Thus, there are, it would seem, other illness experiences and perspectives which do not neatly fit into a framework of biographical disruption.

And so, the concept of biographical disruption has helped to emphasise the everyday ways in which illness is experienced, and it also - via a focus on coping, strategies, styles of adjustment and the mobilisation of resources - enables a focus on the *active* ways in which people manage living with their illnesses in positive ways (Williams, 2000). However the conceptualisation of disruption and its general application to *all* illness experiences is problematic because it assumes that illness is an *a priori* major intrusion into everyday life, and in this regard the concept has many semantic parallels with the death as crisis and rupture discourse which I discussed in Part 1.

Illness Narratives: repairing the rupture

It was in taking up the second of Bury's aspects of disruption - the disruption of identity and self-concept - that work 'concerning the narrative reconstruction of illness... provided new insights into the meaning and experience of chronic illness' (Williams, 2000: 43). It was argued that following the profound disruption thought to be caused by the onset of

illness, the individual undertakes the task of putting their self back together again by telling their illness story and re-negotiating a new identity and stable sense of self. So 'narrative reconstruction' is:

... an attempt to reconstitute and repair ruptures between body, self, and world by linking up and interpreting different aspects of biography in order to realign present and past and self with society' (Williams, 1984a: 197 cited in Pierret, 2003: 10-11).

Here Williams' conceptual use of the term *ruptures* is particularly important because it resonates directly with the dominant death-as-rupture discourse mentioned previously.

Moreover, there are powerful accounts in the literature which describe the significance of narrative and story-telling as part of illness experience (Frank, 1995) and within medical and clinical contexts (Brody, 2003; Mattingly, 1998). In particular some suggest that centralising a place for narrative within health care can directly facilitate healing (Brody, 2003). Brody (2003) argues that story-telling as a healing process enables patients to produce meanings through talking about the illness which helps them to create (with the co-presence of the clinician) a coherent story about what has happened to them. In this work there is a clear resonance with the discourse of illness as biographical disruption, and stories are understood as a means through which to do 'story work' that will enable the ill person to heal the rupture and to 'construct a modified life story that carries on within the realities and constraints forced by the sickness' (Brody, 2003: 17).

Using language particularly evocative of disruption, Mattingly writes about how narrative 'plays a variety of roles' in the 'grim terrain' of negotiating

the death of self in illness and the 'recreation of some new self' that is required (1998: 1), whilst Frank proposes that 'stories have to repair the damage that illness has done to the ill person's sense of where she is in life, and where she is going' (1995: 53).

However, some argue that an over-emphasis on illness narratives can be problematic. Despite the interest shown in how experiences of illness affect day-to-day life in the sociology of illness literature, Lawton (2003) has recently argued that more needs to be done to focus on the very *mundane* matters that make up and shape people's experience²⁷. She draws on Bury's (2001) concern that because researchers have relied predominantly on research interviews and narratives to understand illness experiences, there has been a much greater focus on *talk* and how *meaning* gets repaired for individuals, rather than on the 'mundane aspects of experience' (Bury, 2001: 283 cited in Lawton, 2003: 35). Indeed, this important point provides further context for the work of Heaphy (2000), and Seale (2001) which was discussed in Part 1. Thus, whilst the idea of biographical disruption and the subsequent reintegration of a 'workable' self using narrative relates to a crisis-based discourse, it also has resonance with the idea of transforming or resurrecting the self in the face of adversity (Seale, 2001; 1998). Indeed, as Stacey (1997) has suggested regarding dominant cultural narratives about having cancer:

²⁷ Lawton is particularly concerned about the neglect of bodies and mundane matters related to managing bodies in health and ill-health in the sociology of health and illness literature. However, Frank's narrative theory does consider the embodiment of illness stories - 'how they are told not just about the body but through it' (1995: 3)

If the person with cancer has lived to tell the tale, the story is often of a heroic struggle against adversity... These are often stories of transformation in which the negative physical affliction becomes a positive source of self-knowledge (1997: 1).

Thinking more specifically about individuals who are actually dying, Holloway (2007) writes about the positive view of death and acknowledges, following Heidegger (1962), that facing death can give renewed meaning to life. She also explains that:

... achieving potential, even personal growth, through facing death has been popularised among the counselling community through the work of Elizabeth Kubler-Ross (2007: 53).

It is possible to see how transformation via personal growth and achievement in the face of adversity fits comfortably with the idea of working towards healing the self via illness narratives. For instance, Grinyer (2006) discusses written narratives about experiences of illness and dying and suggests that we exist in a 'confessional culture' where autobiographical writing has therapeutic value. A clear indication of the pervasiveness of this 'confessional culture' can be seen in the numerous autobiographical accounts of 'public dying' (Small, 1998), illness and bereavement experiences²⁸. Importantly though, as Holloway points out, there is clear overlap between the idea of reflexive personal growth - of achievement and transformation - and the discourses used in therapeutic practice. Indeed, this point is linked to my argument in Part 1 about how discourses of transformation and self-development divert attention from the everyday and mundane in relation to illness and dying experiences.

²⁸ For examples see Didion, (2006), Diamond, (1998) and Picardie, (1998).

However, the question also emerges as to whether there is a class issue to consider here. That is, one relating to 'articulation' or talk as an important source of identity-making within a particular habitus system (Bourdieu, 1979) that is embedded within what are arguably middle class values more analogous with the idea of 'therapy', and the confessional self (Allen, 2007; Howarth, 2007b). As noted above in the work of Pound *et al.* (1998) and Williams (2000), different class-based lives and lifestyles shape illness experiences and these may not always fit neatly with the idea of repairing a ruptured self. The notion of engaging in a particular 'level' of introspection required to realign a repaired or transformed self does seem to lend itself to being a rather middle class (by virtue of more readily having the cultural resources/ disposition to do so) approach. Seale makes a similar point when he discusses the confessional, heroic dying of playwright Dennis Potter:

The resurrective practice which Potter performs in the face of his own death draws on revivalist scripts to place himself at the forefront of an imagined community, in which personal insight is valued... Potter is claiming an heroic place within this community through this public performance of his own dying, and no doubt has contributed to the aspiration of others to die in a similar fashion...It represents a particular mode of dying, preferred by people in higher social classes as a sign of distinction, and particularly characteristic of death from cancer... (2001: 113).

And so, whilst work on illness narratives contributes significantly to bringing an important agency-perspective to theoretical understandings of illness (James and Hockey, 2007), as transformation of the self becomes an established way of interpreting and conceptualising illness and dying experiences, this does seem to key into a more extraordinary discourse about illness and dying. Ultimately these may then theoretically 'over-ride'

the more mundane and everyday aspects of how these experiences are lived out in ordinary family life.

Part 4 - Families Facing Death: the empirical picture

Having outlined key conceptual ideas and arguments central to the thesis, in this final part of the review I consider what the empirical literature tells us about family experiences of living day-to-day whilst a family member has a life-threatening illness. Providing a brief overview of key themes within the literature, the majority of the work I refer to draws on deaths that are more directly relevant to the family experiences considered in this thesis; so deaths arising from periods of living with terminal and life-threatening illness - usually cancer²⁹. Therefore empirical work which explicitly deals with the experiences of families in more critical, acute and sudden dying situations (for instance Seymour, 2001) will not be included.

Studies of Family and Dying: a brief overview

In Chapter 1 I noted that the experience of living with dying has been empirically and theoretically neglected in comparison with other death-related matters such as bereavement or mortuary rites (Kellehear, 2007).

Kellehear (2009a) argues that little is known about dying from the perspective of those actually experiencing it, and that the limited knowledge

²⁹ This is with the exception of the general discussion of family systems theory in the second section.

we do have reflects the concerns and views of carers - both professional and informal. And so, whilst in this sense the perspectives of family members have been explored, often they have been considered in limited ways - such as when providing proxy and retrospective accounts of their relative's dying experience (Grande and Ingleton, 2008). Studies which focus explicitly on the experience of dying as it happens in the context of everyday family life and not from a concern with caring and care provision remain uncommon³⁰.

There is surprisingly little that stands out as 'seminal' in the sociological death literature in terms of focusing primarily and explicitly on family or relational experiences of dying³¹. Families are sometimes considered in work which attempts to understand other, or more general, aspects of the illness/dying process³² and in relation to individual or specific dying experiences in particular³³, but less so as the primary focus of empirical study. For example, Kellehear (1990) asked 100 dying people how living with terminal cancer affected their significant relationships. This was part of a wider study which aimed to understand the social behaviour and experiences of individuals who had less than 12 months to live - he

³⁰ Moreover, it is reported that within palliative care, studies which explore the experiences of family care-givers *foremost* are limited. Thus there is a lack of understanding about family care-giving roles and about the perceptions family members have regarding their involvement in caring (Smith, 2001), whilst their contributions to cancer care and their individual needs are also relatively under-explored (Thomas *et al.*, 2002).

³¹ However as was noted in Part 1, in terms of social studies of bereavement and the establishment of the continuing bonds thesis (Klass *et al.*, 1996), families and relationships are often more central to analysis in this work which explores how practices help to maintain bonds after death.

³² For examples see McNamara (2001), Lawton (2000) and Kubler-Ross (1969).

³³ See for instance, Bluebond-Langner (1978) regarding terminal illness in childhood and Grinyer (2002) on cancer in young adults. Also see Armstrong-Coster (2004) and Kellehear (1990) for accounts provided primarily from the dying person's perspective.

concluded that for many their relationships continued positively. Thus, whilst this work gave an important voice to dying people themselves, to gain a more situated, broader familial perspective of relationships during severe ill-health, further empirical work is required. For example, Grinyer's (2002) narrative-based work does have a familial perspective and it considers how cancer in young adults affects parents and well siblings by providing parental accounts of family life during this time. However, it perhaps finds its 'niche' more as a title which explores the under-researched area of cancer in young adults primarily, and as the research focuses on the perspectives of parents, the young adult's own voices - as a part of the family - are absent, or presented through their parents' eyes.

Family experiences also appear in chapters or are considered in studies about something else substantially associated with death, such as care patterns and needs (Cartwright *et al.*, 1973; Seale and Cartwright, 1994) or the closely related area of what makes a 'good death' (Young and Cullen, 1996). Moreover, families also feature (or are implicated) within wider theoretical arguments, as has been the case with some very influential work in the area of death studies. For instance, in Glaser and Strauss' seminal work on awareness contexts (1965) and dying trajectories (1968) consideration is given to how families 'manage', or they need to be 'managed' by professionals in situations of institutional dying (see 1968: 156-157 for example). However, in general, there is little in the sociological literature that focuses primarily and explicitly on everyday experiences of family life and mundane practices over the dying process.

In the palliative, nursing and therapeutic literatures, whilst there is work involving relatives and the dying process being undertaken, few studies seem to take the experience of everyday family living as the prime focus of investigation. Again, family is often conflated with care-giving and *vis a vis* provision of care and care services, with literature focussing on relationships with health care professionals and the perceptions and experiences of family care-givers in life-threatening/ terminal illness contexts (James *et al.*, 2009a; Phillips and Reed, 2009; Smith and Skilbeck, 2008; Thomas *et al.*, 2002; Smith, 2001)³⁴. A systematic review of literature in the CINAHL and Medline databases from January 1999 until February 2004 (Andershed, 2006) focused on the *situation* of relatives and their *needs* in end-of-life care and highlights the centrality of care issues in work related to families. The review concluded that the analytic evidence accrued from the 94 papers reviewed indicated that good patient care, communication and the attitudes of professionals are of most importance to relatives. Importantly, the author Andershed, points out that although 'family' was a key word used in the literature search and the notion of a 'family unit' is central within palliative care, none of the studies found 'were *based* on the family' (2006: 1166 my emphasis added).

Finally, in work relating to families the aim is often to help professionals to support or 'manage' relatives of patients who are dying in institutional settings (Main, 2002; Virdee, 1990) - to provide insight and guidance, for

³⁴ However, see footnote 30 regarding concerns about a lack of knowledge surrounding family carers' *own* needs, perceptions and experiences, which suggests a more general requirement for further research to explore familial dimensions of dying and life-threatening illness experiences.

instance, around matters related to communication (Kehl and Gartner, 2010; Macpherson, 2005). Therefore, within the medical literatures, everyday family life is also somewhat neglected in relation to understanding dying experiences.

Family Systems: another return to crisis and rupture

In opposition to the approach taken by Morgan (1996), discussed in Part 2, in practitioner or clinical-based literature, conceptualising the family as 'a unit' of care is generally accepted and is now quite firmly established as a key principle in family systems nursing (Bell, 2009). More extensively it has been foundational as a core principle of holism in hospice care since its earliest days (Lattanzi-Licht and Connor, 1995). As Kissane and Bloch suggest, relatives are not only seen as carers, but also as 'second order patients' in hospice and palliative care contexts (2002: 2).

Thinking about family in this way reflects the wider field of family systems theory where family experiences are understood in terms of functionality and the affects illness and death have upon roles within families and stability. Much of this work seems to refer to bereavement (Moss and Moss, 2001 is an example) and is interested in understanding how the kind of loss - sudden, expected, violent and so on - affects the family system (Murray *et al.*, 2005; Walsh and McGoldrick, 2004a)³⁵. There are a number of key components of the family systems approach to death, including a

³⁵ See Davies *et al.* (1995) and Rolland (2004) as exceptions of Systems Theory work which does focus on the dying process in families.

concern for how the 'whole', multigenerational family is affected by the experience which is understood to have 'far-reaching reverberations for every member and all other relationships' (Walsh and McGoldrick, 2004a: 3). Principally death is understood as a natural part of family life and a life cycle approach to contextualise it as organic is used, creating semantic links to surviving it as a means for families to grow (Wedemeyer, 1986). The very idea of circularity in life and the same circularity in families as systems supporting life reflects the conceptual links systems theory has with psychology and developmental stage theories. From the systems perspective there is also a concern with life stages which have certain developmental tasks associated with them and, whilst some theorists and practitioners accept that differences do exist among families, generally the timing of a death in relation to these stages and other 'life stressors' is considered important in terms of how it will affect a family's ability to adjust to change functionally (Cook and Oltjenbrums, 1998). Not only is the timing important in how a family responds to death, but depending on who it is that dies and where they are in the life cycle this also has implications for how the family's functionality will be impaired or its 'equilibrium' disturbed (Bowen, 1976). Finally it is considered that after death (and during dying) there is work to be done or 'adaptational tasks' to be completed in order to adjust to change, regain functional balance and orientate the family system towards the future (Walsh and McGoldrick, 2004a: 9).

Ultimately then, this approach aligns itself with the 'death as crisis' and 'death as rupture' discourse and through the somewhat mechanical representation of family as a system, the implication is that it is prone to breaking down and will need to be fixed. This is a functionalist perspective that defines family in terms of the reproduction of stability and which tends to represent family as form - as in 'the family unit' - and it therefore presents a rather static, rigid view of family life. Whilst some family systems theorists do acknowledge death as a process rather than an event and they consider families as relational and dynamic (Murray *et al.*, 2005), the over-arching theory acts as a conceptual container or constraint which considers interactive family processes as shifting cycles within a pre-given structural frame which is the system. As Rosenblatt (1994) argues, there are a series of core metaphors for family systems and the idea of the family as a machine and a container are both foundational in systems theory.

Significantly, he points out that the metaphors of family as an entity and as a system neglect to represent the unboundedness and fluidity of families and what goes on 'in' them. Here we can see the value of Morgan's (1996) agency-perspective which underlines the active construction of family through practices.

Furthermore, whilst many of the family systems theorists argue that differences between families are expected and accepted and a systems approach to death is not about pathologising certain familial responses (Walsh and McGoldrick, 2004a), there remains the implicit (and in some cases more explicit where medical terminology like 'symptoms' is used -

see Bowen, 1976) assumption of what makes a functional and dysfunction family system. Referring to findings from research undertaken with families, Walsh and McGoldrick explain how contrasts are drawn between functional and dysfunctional families:

...very dysfunctional families show maladaptive patterns in dealing with inevitable losses, clinging together in fantasy and denial to blur reality and insisting on timelessness and perpetuation of never-broken bonds (2004a: 8).

The authors go on to suggest how practitioners should direct their therapeutic interventions to assess the lifecycle experiences of families to aid them to 'struggle well' and 'cope actively'. Indeed, much of the family systems literature is written with intervention and therapeutic practice in mind³⁶, and has a direct relationship with reality-making processes which are grounded in discourses of what is 'healthy' for families (Rosenblatt, 1994: 9). Death and loss are considered the most painful challenges families will face (Walsh and McGoldrick, 2004b) and therefore systems theory works on the premise that death is often most likely to be experienced as a crisis at some level.

For example, in 'Family Focused Grief Therapy' (Kissane and Bloch, 2002) which takes a systems-based, therapeutic approach to families facing grief, there is an aim to identify families who may experience psychosocial morbidity and distress. As the authors explain:

³⁶ Walsh and McGoldrick's (2004) edited volume which aims to guide practitioners to facilitate family healing has a section devoted entirely to family therapists' reflections on personal losses and how these intersect with clinical experiences and practice.

Specifically, we offer an account of a treatment for the relatively vulnerable family in palliative care and one that is extended into bereavement as a preventive therapy, reducing the morbidity that may otherwise follow loss. The thrust of this book is on authentic living, yet we recognize that periods of transition are inevitable across the life cycle, that sadness, loss and tragedy occur, and that people need to mourn to restore creativity and happiness (Kissane and Bloch, 2002: 1).

Furthermore, this quote also conveys the structural conception of families inherent in the systems approach when it refers to a cyclical view of life. Arguing that the concept of the life cycle is inadequate for representing the fluidity characteristic of social processes, Hockey and James critique the developmental model as essentially too rigid and 'mechanical' (2003: 5). Therefore, in systems theory, the active negotiation of practices undertaken by family in their everyday lives becomes less of a focus for understanding how families 'do' being families facing illness, death and dying. Instead, the concept of the life cycle as it was used in traditional anthropology to 'explain the maintenance of society's stability and equilibrium' (Hockey and James, 2003: 35) is pervasive, and death is understood to be the ultimate threat to the family's functional equilibrium.

Thus, whilst it is not my intention to suggest that family systems theory is an entirely rigid, pathology-based model, it can be argued that its affinities with the therapeutic and psychological disciplines mean that it does little to challenge the dominance of thinking about death in more extraordinary, rupture-based terms. It is therefore limited in helping to bring the mundane and everyday into analyses in the area of families and death. A quote from 'Fading Away - The Experience of Transition in Families with Terminal

Illness' by Davies *et al.* (1995), reveals some of the thinking behind this approach. In the introduction to their one very short chapter on living day-to-day, the authors offer the following explanation for its brevity.

Two reasons account for a briefer description of this component of the transition versus others. First, not all people with a terminal illness reach this point, and therefore fewer data exist. Second - and more important - although this component of the transition addresses painful, difficult tasks, it does not entail the same agonizing, soul-searching struggle... When people have found some meaning and can put the situation into perspective, they experience less turmoil. They see more clearly the need to live day-to-day and make the most of the time they have left (1995: 49).

Here it appears that emphasis is placed upon a theoretical need to understand the spectacular in dying - on the agonizing and the soul-searching and the need to struggle and to find meaning. Seemingly the assumption is also made that terminally ill people have to transition towards a point which is the everyday; as though since they became ill they have somehow existed separately from it. Thus, this clearly resonates with what was discussed previously regarding illness and its association with the disruption or transcendence of everyday life.

Dying and Everyday Family Life

In 1990, Kellehear wrote that there was a lack of 'formal work on the recreational side of the dying person's social life', and he suggested that the popular image was limited to 'articulate' personal and professional accounts which may be unrepresentative of most dying people's everyday experiences (1990: 106). His own work summarises aspects of day-to-day experience - pointing out the tendency for dying individuals to take up more

passive recreational activities such as watching TV, whilst also providing a brief outline of how many were involved less, or not at all, in household chores. Thus this work does consider the more mundane and taken-for-granted aspects of daily life and provides an important starting point. There remains a need however, for further work to flesh out these experiences in more detail and to have a focus on the everyday that is more central to its aims and analysis, whilst also taking a wider familial perspective.

Therefore, this final section considers the empirical work available about *everyday* family life in the context of severe ill-health and dying, to see how these experiences are conceptualised.

The taken-for-granted nature of everyday life and the discourse of crisis which surrounds death, means that sometimes researchers are surprised to find mundane things are important in maintaining relationships at the end of life (Foster, 2007). Or they unexpectedly discover just how routine even the most seemingly extraordinary of experiences - such as the uncertainty of being a child living with cancer - can become (Stewart, 2003). Thus sometimes the everyday creeps into an analytical picture, even though it was not originally the focus of the research. For instance, Bluebond-Langner's (1978) ethnographic study of the private worlds of dying children discusses how topics considered to belong to the domain of everyday life are used to structure 'safe' dialogue between children, staff and parents with the intention of keeping up mutual pretence as the dominant awareness context.

Thinking more about work concerned explicitly with family, two studies - although not primarily about mundane matters - do consider everyday family life (James *et al.*, 2007; Milberg and Strang, 2003)³⁷. Milberg and Strang's (2003) analysis is limited to stating that retaining everyday life was important to families. James *et al.* (2007), on the other hand, provide a family case study of how beliefs affect daily life and explain how the family believed death could be held at bay whilst also living alongside it. Thinking about, talking about and focusing more on everyday things (for instance cooking and eating were important) became, they suggest, a tactic used by the family to live with the knowledge of impending death whilst holding it more at a distance. The participants spoke about getting used to dying in the context of their everyday lives and mention that they spoke about everyday things even when the final dying hours came.

As noted above, Bluebond-Langner's (1996) anthropological study of the experiences of well siblings in families dealing with Cystic Fibrosis does take an explicitly family-based approach. It provides an in-depth view of the everyday family realities of living with a chronic (though ultimately life-threatening) illness as it progresses through its different stages.

Highlighting the strategies parents use to preserve a 'normal way of life for as long as possible' the study reveals how it was important to families to maintain a sense of normalcy and continuity - to have some control - in the

³⁷ One article is concerned with meaningfulness for 'next of kin' in palliative care (Milberg and Strang, 2003) and the other explores a particular family's beliefs about cancer and dying (James *et al.*, 2007).

face of disruption or intrusion into daily family life (1996: 13). Thus, as I noted above on page 55, everyday life is a primary focus in this work.

Similarly, as previously discussed, Grinyer's (2002) study of cancer in young adults also considers the impact of life-threatening illness on family life. Interestingly, in a small section towards the end of her account, she refers to the 'trivial nature of everyday life' as an 'affront' because in some narratives doing 'normal' things such as worrying about what to wear or planning for Christmas angered parents who were facing the possibility that their child might die (2002: 150-152). Nonetheless, as 'normal life' was reflected on by these parents, it suggests that aspects of the everyday were important for how they tried to manage and contextualise their experiences. Thus, given the quite specific nature of the accounts in both Grinyer and Bluebond-Langer's research, this poses the question of how the everyday might be experienced differently in families where life-threatening illness is occurring later in life, and at what is considered a more expected, and therefore perhaps more 'ordinary' time in the life course.

An ethnographic study conducted by Staton *et al.* (2001) provides some insight here by documenting the last months of life as they were experienced by nine terminally ill American adults and the family members caring for them. The authors, who define the study as 'unique' and describe it as having a focus on participants' everyday lives, are committed to challenging the emphasis placed on clinical perspectives and a tendency to focus on the dying individual as 'distinct from family, friends and

community' which has dominated research into end of life care (2001: xv). They consider the interwoven experience of dying people and their 'care-givers' to be 'an invisible aspect of dying' (2001: xvii). Significantly then, the authors dedicate an entire chapter to 'daily life and meaningful activities' because professionals hardly ever see 'the mundane, everyday activities that absorb the lives of terminally ill patients who are dying at home' (2001: ix). The authors use Seale's (1998) theoretical argument about participation in embodied, daily activities as essential for retaining a place in culture and expressing sociality, to suggest that their participants continued with such activities to assert their identities and their continued existence as social people. Aside from this theoretical framing there is otherwise little analytical contextualisation of the actual mundane, everyday practices people spoke about, as the data are presented mostly as stand-alone descriptive lists of participants' everyday activities and daily routines. Furthermore, the everyday in the context of death and dying is once again linked to the 'spectacular' when the authors suggest that 'small routines and rituals... take on *cosmic* significance as one approaches death' and they claim that the daily life data could easily have been presented in their chapter on 'personal growth, meaning and spirituality' (2001: 136 my emphasis added). The similar idea that dying people find a greater appreciation of the mundane aspects of life is considered by Armstrong-Coster in her narrative-based work with individuals dying from cancer and their carers (2004: 5). Thus whilst it appears that the more everyday aspects of living with dying are sometimes considered, the mundane is also represented in terms of its *transformative* and *transcendent* possibilities, or

as Armstrong-Coster puts it ‘a heightened emotional appreciation’ of things which were previously taken for granted (2004: 5). Predominantly thinking about the everyday in this sense can mean, however, that the actual mundane aspects of daily life during dying are somewhat displaced as an analytical focus. Nonetheless, these are important contributions to the literature as they focus on the empirical experiences of dying and take account of the everyday as part of this. Indeed, in the case of Staton *et al.*'s (2001) work, these authors explicitly attempt to start from the premise that crisis and coping cannot adequately define, family experiences during these times³⁸.

Summary

So to recap, in Part 4 I have considered how family systems and ‘coping’ frameworks, which are influential in practice-based fields and represent a particular way of thinking about families *vis a vis* death, suggest that theoretically and conceptually there is a tendency to marginalise the everyday and mundane aspects of family lives. Thus a discussion of this served to underscore, once again, the centrality of crisis and rupture as their theoretical dominance across various death and illness literatures considered in Parts 1 and 3 of the review, had already suggested.

³⁸ In addition to ‘academic’ attempts to explore everyday life in the context of death and dying, there are also more reflexive, personal and familial narratives of living with terminal illnesses. When these appear within anthologies of death-related work which includes theoretical contributions they represent a more clear consideration of the mundane (see for example Jaffe and Jaffe (1977) and Dickenson and Johnson (1993) Open University collections) but on the whole, they do not seem to have prompted a serious theoretical re-think in terms of death, dying and the everyday.

More generally, in this final part, I have underlined how experiences of dying are less frequently explored empirically in death studies, whilst it has also been established that family, as a specific focus in relation to dying, is relatively neglected beyond the view of family as care-givers or care-receivers. Finally, although I highlighted some work which does consider the everyday in relation to family experiences of dying, both in this final part and throughout the review a case has been made for an explicitly practice-based approach (Smart, 2007; Morgan, 1996) - as outlined in Part 2 - to explore the *mundane* in relation family experiences of severe ill-health and dying.

Ultimately, I conclude that there is an empirical gap in our understanding of the mundane, daily lives of families at this time. There is also a need to make the ordinary a prime focus of theorisation in a way which does not transcend its everydayness in the process of trying to analytically understand its significance for families facing death. In the following chapter I now outline how the study I designed and conducted was able to achieve this.

Chapter 3

Methodology and Research Experience

Introduction

In this chapter I provide an account of my decision-making and experience at various stages of the research process and discuss the felt and embodied aspects of conducting research with severely ill and/or dying people.

Structured in three parts the chapter begins by introducing the study and provides a brief overview of the research approach alongside a discussion of my methodological position. Moving on to explore the research context more fully, in the next section I introduce the study settings and the places and people involved in the research. The final section gives a detailed picture of how the data were generated using in-depth interviewing and participant observation, and it includes a discussion of ethical issues and the data analysis process. This section ends with a reflexive consideration of the role of my 'self' in the research process where I provide an auto-ethnographic account of how the generation of my analytical ideas interlaced with my situated, embodied and emotional involvement with the fieldwork. In doing this I provide a more nuanced understanding of how key ideas in the analysis chapters emerged from data generation phases of the research.

The Research Approach: a methodological overview

In Chapter 1 I explained that the motivation to undertake this study stemmed from my experiences as a hospice volunteer. It developed through observing families and wondering about everyday family concerns and their relation to dying experiences. Given the lack of empirical research on doing everyday family life over the dying process, I wanted to explore this and what daily life meant for families in a more immediate, non-retrospective way as it was being experienced³⁹. Considering how meanings are essentially emergent through family practices as assemblages of doing, thinking and feeling (see Smart, 2007) and understanding these processes as inherently fluid (Morgan, 1996), my theoretical perspective implied a 'methodological position that would not expect to unearth a unified family reality' (Warin *et al.*, 2007: 122). Instead I anticipated that I would be dealing with differing realities as well as consensus regarding family understandings of their situation. And so, ultimately, this research was concerned with *understanding* - something which 'lies at the heart of the qualitative inquiry enterprise' (Schwandt, 1999: 451). It was in families' own words and through their own interpretations and understandings which I wanted to learn about everyday family life.

Thus, as the following discussion will show, a broadly phenomenological approach fits epistemologically with how I wanted to know about everyday family life in the following ways:

³⁹ See Page 14-15 for specific aims that guided the study.

- As sequences or assemblages of family practices (Smart, 2007; Morgan, 1996).
- As a process - thinking about the fluidity of the illness journey and experiences over time.
- As lived, felt experiences.
- In family accounts/ stories/ narratives that provide a representation of their everyday lives.

To explore these family experiences, the research involved conducting 39 repeat in-depth interviews with members from 9 different families. In each family a patient attending a hospice day care service was recruited and asked to invite their family members to be involved in the research. In total 9 patients and 14 family members participated in the interviews which were conducted over a 12 month period. During the same fieldwork year and over a period of 7 months, I conducted participant observation on a hospice inpatient ward where I performed the duties of an inpatient volunteer and participated in informal conversations with patients, their relatives and different staff members. The families I encountered here were not involved in the interview element of the project, though I did visit some of my interview participants when they were admitted onto the hospice ward. Although ideally it would have been beneficial to conduct a more longitudinal piece of research where I was able to follow the 9 interview families over the entire course of the illness experience and incorporate ward-based work into a longitudinal account of their stories, practically this

was not possible. Due to time and funding limitations as well as the unpredictability of cancer disease trajectories, having the different family populations in interview and observation data was necessary to achieve my aims of understanding family life at home and in the hospice, within the timescale available.

Nonetheless, by using these different approaches to explore with families their experiences of living with severe ill-health, I was able to consider how everyday family life is undertaken at this time. Sometimes this happened at an individual level when I listened to individuals sharing their stories. However in many cases I also gained an insight into the shared biography of a family by either considering the individual narratives as a whole, or by conducting joint interviews with family members. I was also able to observe families interacting together and talking about their experiences collectively in the hospice ward setting. Additionally the project had a temporal-experiential focus in the sense that it aimed to know about family experiences over a period of time in the illness process. Therefore by conducting repeat, sequential interviews, I gained a more sustained picture of family life and not just a 'snapshot' and this has enabled me to present family experiences as in-depth case studies in some sections of the thesis. On the other hand the participation observation allowed me to explore what family life is like towards the end of the illness process and when someone is in the very end phases of their life.

However, before I actually started the research, the thought of encountering the everyday social worlds of seriously ill people and their families was a daunting prospect. Indeed, knowing where to start was a challenge and so to help with this I sought advice from literature that discussed doing research in palliative care. The key authors I referred to also shared my sociological understanding of illness and dying and this encouraged me to feel heartened by their enthusiasm for doing qualitative research with dying people (Payne, 2007; Seymour, 2007). My research which combined narrative-based interviewing and participant observation as a research strategy constitutes a broadly ethnographic approach. Although narrative methods have played a limited role in research with dying individuals, recently the value of narrative-based interviewing in this context has been asserted and explored (Thomas *et al.*, 2009; Thomas, 2008). Furthermore Seymour has suggested the following about the pivotal role of ethnography in research with dying people:

A great deal of our knowledge about palliative care... stems from a relatively small collection of ethnographic studies... Ethnographers provide an in-depth understanding of sensitive issues that are difficult to address using other research approaches (2007: 211).

Importantly 'ethnographers are concerned with meaning as embedded in the *practices*, language, contexts, ideas, and events of a culture as well as the subjective meanings of the individual within that culture' (Foster, 2007: xvi my emphasis added). In other words it can be described as a process of searching out 'the patterns of meaning and emotions that make up culture and how these make sense of actions in everyday life' (Kristjanson and Coyle, 2004: 139).

Also, because I used qualitative methods, my research was guided by an interpretive philosophical tradition. This basically refers to finding ‘meaning in an action’ or a ‘process of interpreting or understanding’ (Schwandt, 2003: 296) that is more generally explained as the desire to see the world through the eyes of the people being studied (Avis, 2005; Bryman, 2001). A particular way of gaining interpretive understanding is through phenomenological epistemology which locates the *everyday* very much at the heart of its approach (Schwandt, 2003) and ‘revolves around the problem of how we make sense of the everyday world’ (Seymour and Clark, 1998: 127). It also privileges the felt, experiential aspects of the ‘lived body’ and understands human perception and knowledge to be essentially embodied (Nettleton and Watson, 1998). Moreover, phenomenology provides a methodological framework that is ‘sensitive enough to allow subjective experiences to be elicited with compassion, whilst at the same time conforming to expectations and principles of scientific rigour’ (Seymour and Clark, 1998: 127). Therefore, given the sensitive nature of my research, this approach was the most appropriate. Not only did it enable me to explore meanings, experiences and interactions in everyday life, but the qualitative methods were also especially suited to conducting research with potentially vulnerable people (Liamputtong, 2007). They enabled participants to have more control as in-depth interviews do not impose a rigid interview structure upon personal narratives (Seymour and Clark, 1998), whilst participant observation can ‘capture naturally occurring events with minimum research interference’ (Seymour and Clark, 1998: 128).

Qualitative research methods are also appropriate in research which aims to explore social processes (Bryman, 2001). As the study did have a temporal dimension, my methods enabled me to explore ‘the processes by which families create, sustain, and discuss their own family realities’ in the context of the evolving illness experience (Daly, 1992: 4). Indeed, it is argued that there is a ‘fit between qualitative research and characteristics of families’ and that these methods provide a holistic picture of families and family life because they can reveal ‘the individual and collective phenomenological experiences of family members’ (Daly, 1992: 4).

Finally, as qualitative research is based on exploring social worlds and phenomena from the perspectives of the people who are being studied, it ‘encourages researchers to view social reality as *constructed* out of different social perspectives’ (Avis, 2005: 9 emphasis in original). This is useful to consider in relation to Morgan’s (1996) view that families and therefore family experiences or realities are constructed by individuals in their everyday domestic lives via family practices. This perspective relates to the ontological position of constructionism which argues that the idea of social ‘reality’ as one observable, knowable truth existing separately from human action, intention and meaning is problematic. Furthermore it suggests that how we come to know ‘reality’ is a socially, culturally and historically contingent process (Schwandt, 2003). This matter often divides proponents of the qualitative research tradition into different camps with some suggesting that there is *no actual* social reality which can be investigated (Avis, 2005). For the sake of clarity I cannot delve too deeply here. I

simply want to point to the basic principle of constructionism that social phenomena are constructed by humans via 'the application of social norms' (Avis, 2005: 9), and to suggest that not only has this informed my thinking about how families do, maintain and create family life, but it has also influenced how I understand the matter of interpretation and representation in my research. I see myself as a *co-constructor* of the family stories and experiences that I represent in this thesis and I consider these to be a product of my *engagement with* the interpretive research process⁴⁰. An acceptance of the role played by researchers in establishing research relationships and the subsequent knowledge generated from these is something that feminist research claims as a central and ethical component of the research endeavour (Oakley, 1981). It also informs work in the area of auto-ethnography and autobiography in the social sciences⁴¹. Whilst I am not producing an explicitly autobiographical account, I recognise that my past encounters as a hospice volunteer and the relationships I have with my own family implicitly enter into the sense I make of my research experiences and the stories I represent here.

Searching for terms to explain my relationship to the research encounter I find Mason's (2002) critique of the idea that researchers are miners digging to extract information from participants, especially useful. She argues that

⁴⁰ See Schwandt (2003) for in-depth discussion of how traditional phenomenological approaches argue the interpreter/ researcher remains external from and unaffected by, the interpretation process. In other words, that there are 'original' meanings which can be recovered without being transformed and re-interpreted via the interpretative process.

⁴¹ See as examples Carel, (2008), Ray, (2008), Oakley, (2007), Letherby, (2000) and Ellis and Bochner, (1999).

if we believe that ‘the phenomenon under research does not have a static decontextual and therefore uncoverable existence’, then this undermines the interview’s purpose as a method of ‘excavation’ and shifts focus onto understanding it as a site of ‘construction’ (2002: 227). Logically, the same can be said for conversations held in the course of participant observation. Thus I acknowledge the involvement of my subjectivity in the interpretations I make about families, illness and dying from both the observation and interview data.

The Research Context: places, spaces and people

Interview Families: family at home

The people who took part in this research lived in a town in the north of England. Its ethos and character can be described as generally working class - owing in large part to the fact that it was once a strong-hold of heavy industry. Following the decline in industrial manufacturing in the UK the town has suffered economic hardship, with one council commissioned report published in 2005 describing how the area had ‘high’ levels of multiple deprivation ‘mainly driven by Income, Employment, Health and Education and skills deprivation’. It concluded that ‘[the town] ranked among the most deprived 20% of Districts in England on these domains’.⁴² Despite this, generally my interview participants appeared to be living fairly comfortably, with 5 of the 15 homes I visited situated in what are

⁴² To avoid revealing the hospice location, the reference details for this data about the town are omitted from the thesis on the grounds of maintaining confidentiality and anonymity.

considered more 'affluent' or desirable areas of the town. Nonetheless, a number of participants did speak of financial hardship or times of struggle in their lives, and based on what I learnt about them I would hesitate to describe any of the families as materially 'wealthy'. Thus many of the people who feature in the pages of this thesis were either 'working class' in a structural, economic sense otherwise they possessed or had some kind of link with what can be described as 'typical' working class values and attitudes⁴³.

In terms of the ages of my participants, the ill interviewees ranged between 51 and 78 years, whilst the age spread for family members was between 13 and 76 years. None of the individuals living with cancer were in paid employment, though two were of a typical working age - in their 50s. Of the 9 family members (from a total of 14) who were of usual employable age all were in employment - paid and unpaid.

Regarding the relationship between the ill person and the other participants in the study, I recruited in total, 1 husband, 3 wives, 1 son, 6 daughters, 1 sister, 1 granddaughter and a close friend, who was described by the ill person as, 'like a daughter' to her (see appendix 1 and 2 for further participant information). These relationships were important because I approached ill participants as family members first and foremost, and

⁴³ I realise that such classifications are inherently complex and problematic. What I offer here are *my* impressions of class-based practices and cultures based on my own experiential, as well as academic knowledge of how class intersects with identity.

considered them within a family dynamic rather than seeing their experiences and those of fellow family members as separate.

Family: a metaphor for hospice care

Over the course of my fieldwork year, I was invited into the homes of the families I described above. During this time I was able to explore and observe in a situated way, how 'family' and family practices are 'done' - how they are achieved and managed - during a time of life-threatening illness. However as I stated in the study aims on page 15, I also wanted the research to explore family practices outside of the more familiar home environment and to consider the hospice ward as 'home' in perhaps another sense. Therefore using participant observation based at the same hospice from which I recruited interview families, I was able to explore how families recreated or (re)negotiated doing family here.

Writing about the conflicting relationship between medicine and families in a US context, Lindermann Nelson and Lindermann Nelson (1995) argue that families *should* matter very much to health care as they are the primary site for identity formation, protection and care. The authors suggest that medical institutions neglect the importance of families despite the role they play in '*domesticating*' illness by 'overcoming the alienation we experience when we can no longer take for granted the smooth functioning of our bodies' (1995: 45). Field and Johnson (1993) explain how hospices differ from other formal organisations because they rely heavily on voluntary

labour. They suggest that the unpaid physical and emotional labour which underpins care provision in hospices, has led many to adopt the metaphor of hospice as family, 'in an attempt to describe its style of care' (1993: 203). Similarly Froggatt (1997) discusses the twin ideals in hospice philosophy of 'holism' and 'hospice as family'. Because a patient is understood to have holistic needs they are 'perceived as an integrated whole, a social being with previously established social relationships which cannot be ignored' (Froggatt, 1997: 130). Consequently the patient and their family are considered as a unit of care to be welcomed into their new 'family'- the hospice, whilst staff members are encouraged to provide the kind of care to patients they would give to members of their own family (Froggatt, 1997).

Therefore by having 'family' as a metaphor that underpins philosophy and practice hospices demonstrate that, in principle at least, families and domesticity are valued and central to their 'management' of the illness and dying experience. As I show in the following section, spatially there was an interlacing of discursive influences within my hospice site, where the organisational and philosophical model of the family and an emphasis on holism gain material expression in the *domestication* of space and reveal aspirations of *homely* comfort for patient experience. In a leaflet for prospective patients it states that the inpatient ward aims 'to provide a welcoming and *homely* environment to all', whilst Cicely Saunders herself describes the care provided at St Christopher's hospice as 'given to hospitality' (1977: 163). Nonetheless symbols of modern biomedicine complicate these attempts to domesticate the setting with an example from

my own fieldwork being the floral-patterned catheter-bag covers which nestle over bulging bags of urine. And so this complex intersection of death, family and domesticity makes the hospice a particularly rich site for observing family experiences of severe ill-health and dying and also for considering the distinction between home and 'home-like' spaces for the negotiation of family life.

Spring House Hospice

Spring House⁴⁴ is a relatively small, self-contained hospice centrally located in the northern town where my participant's lived, and it provided me with a space within which to observe how family and family life was achieved by participants outside of the home environment. It provided a number of services including hospice-at-home care, though its main facilities were day care and an inpatient ward. The inpatient ward (or unit as it was often called) provided 24 hour care for dying people, patients with specific symptom-control needs related to their life-threatening condition and occasional emergency respite provision. The day unit supported approximately 75-80 patients, with up to 15 patients attending each day. The referral criteria for this service stipulated that attendees must live in the town, be over the age of 18, be living with a life-threatening illness and have palliative care needs. Eligible patients usually attended on the same day each week for as long as they wished and their need of the service

⁴⁴ For the purposes of anonymity I use the pseudonym Spring House to refer to the hospice where I was a volunteer for approximately 5 years and then transitioned into the role of researcher and conducted my fieldwork.

remained appropriate, or as was often the case, until they became too ill and/or died. Day care provided an opportunity for family members to have a break (some from caring) whilst patients could receive complementary treatments, socialise, do craft work, play games, have a meal and get advice on medication or any symptom problems related to their disease.

Day care and the inpatient unit were based at opposite ends of the building and were reached via the main entrance which opened out into a reception area with seating, a TV, tea bar, merchandise stalls and a reception desk.

The hospice was on two floors with admin and fundraising offices, a seminar room and staff room on the lower level beneath the reception area.

Spring House also had its own gardens and a conservatory attached to the day unit which looked out over the garden view. In day care there was an activity room for crafts, and a small unit for complementary therapies and hairdressing. The walls of the unit were often decorated with craft work completed by patients and the decor appeared 'homely' with a number of easy or recliner chairs and a wooden dresser for cutlery in the dining room where day patients ate a home-cooked lunch.

Throughout the hospice generally, some items of furniture or fittings did not always 'match', which was in part attributed to the fact that over the years the hospice has relied on donations to buy new goods and therefore some items had been purchased at different times or had been donated from

various sources⁴⁵. Consequently in certain ways the hospice had a 'lived-in' feel similar to that of a domestic home where the identities and biographies of its occupiers lead to idiosyncrasies in how the home appears materially as a space (Miller, 2008). Indeed the hospice space differed somewhat from the 'clinical' appearance of hospital wards - for instance it was carpeted throughout all patient accessible areas - and therefore there seemed to be a deliberate attempt to create an environment that felt domesticated, despite it being an institution and a public space (Hollows, 2008; Hockey, 1999b).

The inpatient ward was approximately 15 metres from the main reception area and its entrance was marked by a set of double doors. It was reached via a corridor which led to a number of offices and a couple of 'quiet rooms' - one was quite large and the other somewhat smaller. The ward itself was fairly small, comprised of 4 single bedrooms, all with en-suite facilities, and 3 with small balconies. In addition there was a 4-bedded communal area which also has its own balcony and shared bathroom. This communal bedded area was always occupied by patients of the same sex and when I was there, depending on referrals and patient numbers, there was often jiggling around to try and accommodate as many patients as possible. In total there were facilities to care for up to 8 patients at any one time.

⁴⁵ A hospice trust is responsible for meeting running and maintenance costs for Spring House. The trust owns the building and at the time of my fieldwork although the hospice's clinical care was delivered by NHS Primary Care Trust staff and the service was partly funded by the NHS, Spring House was an independent charity substantially reliant on charitable donations and fund-raising to keep it afloat financially.

Single room



Communal 4-bedded area



The nurses' station and a surrounding small communal area had once again, a rather 'homely' feel, as it was furnished with easy chairs, bookcases, a wooden dresser for crockery (which also acted as a food serving station), a fish tank and a fridge for patients. This area was at the centre of the ward and was most frequently occupied by staff; though relatives and patients, who felt well enough, did sit out in the easy chairs occasionally.

Behind the nurses' station where staff prepared notes, took phone calls and dealt with the administrative side of patient care, there was a mini-kitchen area with a fridge, sink and tea and coffee-making facilities. Again the style appeared 'homely' with the wooden cupboard doors giving the space a domestic kitchen 'feel'. Often plates of food sat on the sides waiting to be heated up when staff took their breaks, and goodies brought in by staff or donated to the ward could also be found here. Furthermore, much like the 'family memos' which might be tacked to a kitchen fridge at home, this space acted as a site for communication between staff about social events

and training days, with various messages and sheets of paper stuck to the kitchen units.

Finally, in the remainder of the ward there was a small sluice room, a linen cupboard and a large bathroom with a specially adapted bath for patients with mobility difficulties. To give a more complete impression of how the ward appeared spatially, there is a sketch which provides a bird's-eye view of the inpatient unit at Spring House in appendix 3.

Access and NHS Ethical Approval

Although Spring House was owned by a hospice trust rather than the National Health Service (NHS), because my research involved the recruitment of NHS patients, I was required to submit an application for NHS ethical approval before I could make contact with potential participants⁴⁶. I was aware that when doing research in palliative care contexts, researchers face ethical challenges and have to justify the value of their work against a backdrop of 'perceived cultural sensitivities associated with palliative care' (Seymour *et al.*, 2005: 170)⁴⁷. As I have already explained, I did not want to start from the assumption that families would be experiencing emotional crisis, and yet I did recognise this was a possibility and that therefore my participants would be defined by many as 'vulnerable'

⁴⁶ I would like to acknowledge the guidance I was kindly offered by Melanie Hall - a fellow PhD student who had already experienced the NHS ethics process - whilst I was putting this application together.

⁴⁷ See also, Sheldon and Sargeant (2007) and Lawton (2001).

(Liamputtong, 2007) and the research area considered 'sensitive' (Johnson and Clarke, 2003). Initially I was worried that the committee would reject participant observation as a method due to concerns they might have about families feeling 'spied' upon at such a potentially difficult time. Fortunately my committee were open to the merits of qualitative research, though in the literature there are some accounts which document difficult experiences of gaining NHS ethical approval (Lockyer, 2005; Pearce, 2002). Similarly others have expressed concern about the appropriateness and extent of ethical regulation given the low risk of 'harm' posed by social science research (Dingwall, 2006). It has been argued that as the governance of social research continues to expand, it threatens to make certain areas of social life less accessible, resulting in a homogenised and narrowed field (Haggerty, 2004). Indeed some have questioned whether it can ever be morally justifiable to conduct research with individuals who are dying (de Raeve, 1994). However, denying people who are dying the choice to participate in research could lead to their further marginalisation within a society which some argue, struggles to talk openly about personal experiences of death (Grinyer, 2002; Walter, 1994).

Recognising this and drawing on the consensus amongst researchers in palliative care that it 'is not a special case and that the usual methods for protecting research participants... therefore apply' (Addington- Hall, 2007: 5-6), I presented my case to the ethics committee. As an inexperienced researcher based in a non-clinical academic department, the application process was especially challenging. Although the committee were helpful, I

realise how it can be a disadvantage for sociologists applying within a system that recognises a predominantly biomedical model of research (see Brown, 2002). When completing the ethics form, in places it was apparent that it was not designed for someone planning to conduct ethnographic research. Often it intended the applicant to state in advance specific details about matters such as the number of participants to be recruited and the length of time they would be engaged in the research. I could not say with certainty how aspects of the research would develop and I found the unpredictability of what *might* happen in the field became a source of anxiety, rather than something to be accepted (and valued) as an integral part of my methodology. To some extent the legacy of this quite rigid approach was evident in the field when the spontaneity and flexibility characteristic of ethnography felt at times curtailed by stipulations I had made to the committee; for instance, being restricted to certain modes of recruitment. On the whole however, I *was* able to practice sufficient flexibility, though the emotional burden I experienced managing this was challenging and at times a source of distraction from immersion in the field. Having experienced the formalised, linearity of the governance process, it made the ‘messiness’ of doing research feel particularly stressful.

However, in spite of the difficulties I have reflected upon here, once ethical approval had been secured prior to the commencement of any fieldwork⁴⁸, I

⁴⁸ I was required to make only minimal changes to the application I submitted - the committee made stipulations regarding the storage of personal details and insisted I make hospice ward staff formally aware of my relationship with the Day Unit Sister (mother and daughter). No changes were requested regarding research methods or procedures for recruitment etc.

was fortunate that working with a small number of gatekeepers, I faced none of the usual concerns surrounding institutional politics and resistance to my presence in the setting. In fact it was just a matter of days before recruitment for the study began⁴⁹; a process which worked differently for the interviews and the observation. I shall now describe these methods in turn, outlining the recruitment procedures undertaken for each at the start of their respective sections below.

Doing the Research

In-depth Interviewing: how it happened

To try and work with families where the ill person had less advanced disease and was likely to live for a length of time which was conducive to participating in repeat interviews over a period of at least 3-4 months, I approached the day unit team for help with recruitment. After a pre-recruitment meeting with the day unit sister (my mother) and 2 members of the occupational therapy team, a procedure for approaching patients was agreed. It was decided that I would not approach patients directly, but that staff would do so on my behalf. They would mention the research to patients whom firstly they felt were well enough and would not be adversely affected by taking part, and secondly that fit the research criteria in terms of having regular face-to-face involvement with family members. To keep the

⁴⁹ I had a number of contacts at Spring House due to my voluntary work there. I also had more informal connections with the institution as my mother had been a nurse in the Day Unit there for a number of years. Consequently I was able to gain support in principle to do the research at this site, prior to submitting an application for ESRC funding or NHS ethical approval.

family focus of the research I stipulated that by 'family' I was referring to blood relatives or individuals connected to the patient by marriage or partnership. By suggesting that these individuals should be 'close' to the patient, I tried to ensure that relatives interviewed would have a reasonably in-depth involvement with the ill person, if not always daily contact. After a member of the day unit recruitment team (nearly always the day unit sister) made an initial approach and handed over information packs⁵⁰ (see appendix 4a-d), families who were willing to take part returned reply slips to the hospice and it was at this point that I would make contact to discuss their initial interest. Therefore patients acted as gatekeepers with regard to the recruitment of family members and had initial control over the decision to participate⁵¹. Out of a total of 14 patients approached, 5 declined to participate either directly or by never returning their reply slips.

Initially I had intended to recruit approximately 5 families. However overall, fewer family members were willing to take part (or had been asked by their ill relative) within each family than I had hoped, and so I increased the number of overall families in the sample to ensure I could hear enough

⁵⁰ Packs included a generic information sheet for patients and family members. There was also a different cover letter depending on whether the participant was a patient or a relative. In addition there were reply slips and a guidance sheet referring to the participation of children and young people (not included in appendix). I encouraged the involvement of young people and prepared information sheets appropriate for different age groups (age 9-12 and 13-16). I forwarded this material when it was requested by one family (see appendix 4d for aged 9-12 information booklet).

⁵¹ Although I ideally wanted to interview the ill person *and* their family members, in the information sheets I suggested that if a patient did not want to participate but they were happy for their relatives to do so, that I would still like to work with the family. I felt it was important to explain this so that patients who felt too ill to participate did not feel any pressure to take part if other family members had expressed an interest in the project. Furthermore, I realised that it may be difficult to recruit families in the time-frame available and that I therefore needed to be flexible about recruitment.

stories to produce an account of requisite depth⁵². In the end I recruited 9 families from which I had a total of 23 interview participants with various relationships to each other⁵³. Although the number of participants might still appear small at 23, qualitative, interview-based projects only require a small number of people (often less than 20) to ‘facilitate the researcher’s close association with the respondents, and enhance the validity of fine-grained, in-depth inquiry in naturalistic settings’ (Crouch and McKenzie, 2006: 483). I interviewed these 23 participants over the 12 months designated for empirical work completing 39 interviews in total across the 9 families. Families were recruited at staggered stages across this time to avoid having too many schedules to manage at once. Ultimately, I inevitably fell into closer relationships with certain families and therefore interviewed particular families and family members more often than others, sustaining varying levels of contact over the 12 months of fieldwork⁵⁴.

In-depth interviews were chosen for this project because they aim to produce narratives, accounts and stories about experience, and therefore this method is most appropriate for finding out about peoples’ situated understandings of their everyday family lives. Drawing on the work of key sociologists such as Goffman (1959) and Garfinkel (1956; 1967) Orbuch has suggested that ‘accounts and other related concepts, such as stories and

⁵² When participants did share with me the reasons why certain members of their family were not able to be involved, on a couple of occasions I sensed that ill-relatives wanted to ‘protect’ certain members from talking about the illness, but more generally being too busy or having ‘too much on’ were cited as reasons for non-participation.

⁵³ See Participant Profiles in appendix 1 for information about the families interviewed for the research.

⁵⁴ See appendix 2 for a table showing varying levels of contact with families.

narratives, represent ways in which people organize views of themselves, of others, and of their social world' (1997: 455). Referring to Garfinkel, she reminds us of his belief that accounts are a 'general aspect of social life' and 'a regular day-to-day experience' (1997: 457). Therefore inviting families to give their own accounts about everyday life in unstructured, in-depth interviews allowed members to reflect upon and articulate particular understandings of the illness experience. It enabled individuals to share their experiences and understandings, but it also created opportunity to express views about the experiences and understandings of fellow family members and to consider how the family more generally goes about everyday life in the context of life-threatening illness. Moreover returning to re-interview families and to enquire about everyday life as it was actually happening, allowed me to engage with feelings and experiences infused with a sense of immediacy. So for instance asking about what was current and important in the family at that time or what plans a family had for the next month, gave the research a very immediate focus which was grounded in the everyday matters of daily life. This concern with everyday experience and the production of accounts or stories to represent it was at the heart of the interviewing phase of the research.

And so, when I invited people to talk about their experiences, I shared the view held by narrative theorists that 'people structure experience through stories, and that a person is essentially a storytelling animal' (Sparkes, 2005: 191). Although my research is not concerned with close examination of narrative *form*, it is informed by a *thematic* approach to narrative where

there is still a sense of keeping the overall story in mind and having a strong case (or participant) centred commitment, despite looking for themes across the dataset (Reissman, 2008). Reissman argues that narrative interviewing has more in common with ethnographic approaches than mainstream, structured interview approaches and she acknowledges that narratives ‘come in many forms and sizes’ (2008: 23). So although my interviews may not have always produced long narratives in the form of uninterrupted dialogue (though sometimes they did), and they did at times have a strong conversational form with lots of interchange in dialogue between participants (in joint interviews) and between participants and myself, I did see them as ‘narrative occasions’ (Reissman, 2008: 23). Thus the principles of an in-depth narrative approach applied in terms of the occasions being open, fluid, unstructured, participant-led and characterised by informality to create a ‘non-pressurised’ environment conducive to exploring and co-creating stories.

When I first met my interview participants, I explained that I would like to re-interview them over the course of a few months and gave the figure of 3 interviews as a benchmark. Everyone was happy to speak to me again, though unfortunately this did not always happen. Working with terminally ill people, the disease process can be highly unpredictable and poses challenges for arranging contact with participants (Armstrong-Coster, 2004; Raudonis, 1992). Sadly some of my participants died before 3 interviews or even a second meeting could be arranged. More generally the disease, in terms of how it made participants feel, the treatment regimes it dictated and

the appointments with various medical agencies it required, meant that negotiating interview times involved great sensitivity and flexibility.

Therefore the time between interviews varied according to different family circumstances. On my part, I was often conscious of wanting to leave enough of a gap to gain greater insight into changes over the illness process and to have different things to talk about in the next interview, but in many ways it was a balancing act as I was aware that people could become gravely ill very suddenly. Indeed this did happen on a couple of occasions and understandably I was not invited to interview people at this time.

Therefore I did struggle to gain direct insight into 'big' changes in terms of how family life was affected when the illness shifted into a more 'actively' dying period. However by conducting post-death interviews with two family members from different families where the ill participant had died, I managed to gain some understanding of the more protracted effect on family practices when the ill family member was dying, and also when they had actually died.

Therefore, given the potentially sensitive nature of the interviews, location and context was an important consideration. Consequently I suggested in the information sheets that it was down to the individual families to decide how and where they would like to be interviewed. Ultimately all opted to be interviewed in their own homes, apart from one person who I interviewed at their place of work, and whilst I had anticipated that some individuals may wish to speak to me on their own, all the married couples in my sample requested to be interviewed together. This was also the case for two sisters

who were living together, for a mother and daughter who were both well and for another mother who was ill and her well daughter⁵⁵. Perhaps this arrangement meant that these individuals did not always talk so openly because they were reluctant for the other person to hear, but essentially the project was not concerned with secrets in this sense. Moreover, in actual fact many of the shared interviews *did* feature frank discussion of 'difficult issues' or moments of tension. Whilst it was useful because it gave me the opportunity to see how family members interacted with one another and how they co-constructed through moments of agreement, disagreement, frustration, affection, humour, butting in and/or finishing each other's sentences, an understanding of their family experience. Importantly it also abated a concern I had that talking to participants separately might induce feelings of anxiety or uncertainty for particular family members about what others were feeling or saying (Morris, 2001).

When I arrived for my first interview with a participant/s, at the beginning of the session I intended to discuss the research aims generally and then the participant/s role in the project more specifically. Mostly, it was also at this point that I explained the consent process (see appendix 5a-b) and asked participants to sign a consent form (see appendix 6a-c). I found that some participants were less concerned about informed consent than I was primed to be. And therefore on some occasions people launched into their stories before I had chance to complete the 'formalities'. In these instances the

⁵⁵ See Morris (2001) who discusses a similar finding in her study with cancer patients and their close carers.

most sensitive approach was to allow them to continue and consent was negotiated at a later point in the session, usually as the interview was coming to a close. Following this, except for on one occasion when the participant was satisfactorily reassured, no-one chose to retract what they had said or became concerned about something they had shared.

To conduct the interviews I used guides which listed areas of everyday family life to probe around, and some broad questions about family life and the illness (see appendix 5a-b). This acted as a prompt, but generally the research was participant lead. At the initial interview I was more concerned with scene-setting; I wanted to get acquainted with the family and to hear an overview of the illness story - for instance how it came about, current prognosis and what the general approach in the family was towards it. I aimed to explore broadly anything salient about the family's past, any general feelings and experiences of family life in the present (especially related to the illness) and to a lesser extent but where appropriate, I sensitively probed around understandings regarding the future. Then the purpose of any further interviews was to encourage the participant/s to describe their experiences of doing family life, day-to-day, at this time and to follow up on some of the issues which were discussed in previous interviews. In terms of asking about death, for reasons of ethical sensitivity (see Young and Cullen, 1996 and Kellehear, 1990) I only tended to ask specifically about dying using that term, if and when the issue was raised in a quite open way by the participants themselves.

The interviews varied in length with the shortest recorded session approximately 35 minutes and the longest 3 hours and 40 minutes. On two occasions when scheduled interviews which should have involved the ill participant and their spouse together were impossible because the ill family member was too unwell or in hospital, I spent time chatting with the well family member and I actually took the wife of the hospitalised participant to visit him there⁵⁶. Details relating to these occasions were recorded as interview field notes. I also made similar, though less extensive field notes for the other interviews where tape recordings were made, to note important contextual details and record my own immediate impressions and feelings regarding my visits. The interviews were transcribed almost verbatim⁵⁷, and I did this personally once the interviewing had started to come to a close. As the fieldwork year was so intense and occurred alongside teaching and other intermittent commitments that tend to interrupt immersion in fieldwork experiences (Shaffir and Stebbins, 1991), it was impossible to transcribe interviews in time for the next session. I did however, ensure that I listened to the recordings and made notes in preparation for returning to a family to do a further interview. I found that in doing this I could work iteratively and was able to ask about issues which seemed significant from previous interviews, in later meetings I had with families.

⁵⁶ I had to 'play it by ear' regarding the interviews sometimes. When I arrived in these instances I was unexpectedly presented with someone who was ill in bed and someone who was in hospital. This reinforced for me how unpredictability was a part of the daily lives I was trying to understand.

⁵⁷ Occasionally I made a decision to omit some (limited) dialogue from transcription if a passage of conversation was more general 'social chat', or clearly not relevant to the research aims.

In between interviews, I also made telephone contact with many of the participants and I found that the same iterative process occurred when I was able to probe around something that had been mentioned in a telephone conversation when I returned to re-interview people. Practically this contact was a means to make arrangements for face-to-face interviews, but it was also an opportunity to be updated about how things were going day-to-day. Chatting in this way between interviews was often rather brief (a couple of minutes) but on a few occasions I did speak to people for longer and doing this allowed me to build up a fuller picture of the immediate concerns and daily realities of family life⁵⁸. It also helped to forge a closer relationship and greater familiarity with particular participants and enabled me to make the research process feel more inclusive and to keep participants informed, so as not to leave them feeling that their stories have been 'used' (Grinyer, 2002). In addition, making notes about the nature of these conversations and any changes in family circumstances or disease progression provided an events-based commentary that acted as a memory device for managing my contact with the different participants more sensitively.

Ultimately, the nature of these conversations did depend very much on the individual participant and whilst I have not systematically coded the content of the phone conversations, due to the amount of data I had, the details I recorded as a telephone log informed my general impression of the families. What is noticeable from this information is that some participants shared in phone conversation a similar level of disclosure to that I encountered with

⁵⁸ I spoke with a relative for 14 minutes on one occasion.

them during face-to-face interaction. For example, two participants spoke candidly about how the illness had shifted in recent weeks and that they now anticipated the death of their parent. Patients themselves would sometimes give detailed accounts of any changes in their physical condition such as symptoms experienced, pain and personal care issues, appointments attended, various tests and scans completed as well as results they had received and were awaiting. Less often, small comments over the phone would reveal nuances in how someone felt about another family member. In terms of my reactions to the content of these conversations, my notes revealed my own emotional labour in terms of trying to read tone, mood and how well someone was feeling from their voice. The telephone log shows how I became emotionally involved in the lives of my participants, often experiencing 'contact anxiety' (Johnson and Clarke, 2003: 425). For instance, I would deliberate over when to call, whether the calls would be experienced as intrusive, about the ethical appropriateness of my work and if I was providing 'adequate' responses of comfort when it seemed necessary. More generally the feelings I had about researching gravely ill people - seeing them in pain or breathless for instance - was something which I did find difficult at times⁵⁹.

Finally, in terms of informing the project's focus, phone calls did reveal aspects of participants' daily lives as they were happening in 'real time'.

What I mean by this is that calling participants and encountering them in the

⁵⁹ See Morse (2000) for a broad discussion of how researching illness can affect the research process and have emotional ramifications for the researcher - especially those less accustomed to ill-health.

middle of a bout of acute pain or being asked to call back in 10 minutes as someone is in the middle of their 8pm night routine which involves some tricky negotiations with an unruly catheter bag, demonstrated powerfully how the temporality of everyday life is shaped by illness.

Experiencing the Interview: encountering the flow of everyday life

As my reflections about telephone contact have indicated, I became quite involved emotionally with certain families. With some a warm familiarity built over the research process and I was sometimes taken aback by the informal nature of the time I spent in people's homes. Testimony to this is the fact that over the course of the research I was introduced to family pets, attended church events, met neighbours, was the very willing recipient of specially bought cream cakes, took someone to hospital and attended funerals. Surprised by the lack of control I had over the interviews sometimes, I came to reflect more deeply on what I was actually *doing* that constituted 'research'. Often the more formalised interview encounter felt like an inaccurate description of what happened when I went to people's homes and I was subsumed within the flow of their everyday lives. What was I doing, I wondered, when we spied on their neighbours, looked through photo albums, played with pets, nosed around a new kitchen or inspected progress being made with an ongoing dolls house project? Reflecting on this with my supervisor Jenny Hockey, we discussed my concern that I was not doing 'proper' interviews. Ironically in her own work she explores the converse and more frequent concern that in their familiar British environment, researchers worry they are not doing 'proper'

ethnography (Hockey, 2002a). Whilst I was concerned that interviewing should feel reasonably organised and be, even in unstructured sessions, goal-orientated in the sense that there is a fairly clear focus around which interviewer and interviewee talk, as Hockey (2002a) explains, conversely ethnographers fear not achieving an 'authentic' field experience of deep immersion. In fact in some sessions and with one family in particular, I felt very much at the mercy of established routines and the idiosyncrasies of their usual afternoon conversation. In many ways I experienced that very 'ethnographic immersion' as I encountered the flow of their daily life. Hockey challenges the hierarchal relationship between participant observation as 'gold standard' and interviewing as somehow less authentic in ethnographic methodology. Instead she argues that 'we need to question the distinction between interview data and 'what really happened' and acknowledge parallels between interviewing and 'real life' (2002a: 210). Resonating with my own sense that I was 'visiting' people rather than simply interviewing them, Hockey encourages us to consider that interviews are not occasions 'abstracted from the temporal flow of the life-course' (2002a: 214). They are actually *spatialised* and *embodied* performances of doing and being in 'real life'. The following extract from my field notes with the particular family I refer to above, illustrates my point.

'When the neighbour arrived - she let herself in and there was no sense of discomfort on Hugh and Dot's part - it was like I was part of the furniture; not really an issue or source of awkwardness that she had called during the interview. I immediately stop the tape and leave it off for a while until I can assess what will happen. The neighbour... sits herself down on the sofa next to me and it soon

becomes apparent that she isn't just popping her head in. Hugh starts to joke around with Dot about dying of thirst and gets her to go and put the kettle on. The neighbour is having a drink also and tells Dot to shout her when they are ready and she says she'll carry them through. I chat to Hugh whilst the 2 women are in the kitchen and ask if I can turn the recorder back on - when I realise the neighbour could be here for a while I decide I need to try and salvage the session and opt to record whatever I can and then think about the very natural, everyday setting I am witnessing with the family. When the neighbour returns I explain to her what I am doing and about the tape and I assure her that I won't be mentioning any names and that she can't be identified. She seems happy with this. She asks me if I am training to be a nurse. From this point on the session felt very much like PO [participant observation] - I felt strangely frustrated that I struggled more than usual to keep the conversation on lines which roughly help to explore illness specific aspects of life and yet at the same time it was a great opportunity to gain an insight into very mundane, daily life for this couple. I felt like I witnessed life how it is lived for them, but just left the session feeling a bit confused as to how I was going to understand the significance of all the chat which didn't immediately feel directly relevant to the research. I suppose I ultimately felt quite powerless as well; it was like I wasn't clear of my role, they hadn't interpreted the session as something quite formal and factored time in as such for it - it was like I arrived during their daily time and went with the flow - it wasn't set out for me exclusively'.

In reflecting on my role or position *within* the research experience in this example I demonstrate how 'data are influenced through the mutual positioning, the power play and the developing human relationship between the researcher and the interviewee' (Warin *et al.*, 2007: 125). This also relates to the emotion I felt at being 'involved' in people's lives over the

research process, and the subsequent insight that I gained from thinking about how this informed data analysis. I felt many things which differed from what is perhaps more expected when doing research, such as confidence when an interview goes well or frustration when someone cancels at the last minute. For instance I felt accepted and liked when I was instructed to '*park over our drive next time*', and then cared for when I was walked to the gate by another participant to ensure I was not parked too far away. I was also sad and preoccupied for most of the day after interviewing a participant with whom I had cried when she told me that what she found most difficult about dying was the realisation that she will miss important occasions in her daughters' future lives. And so my emotions were not always maintained privately, they were intermeshed with the emotions of my participants and the experience of being *within* the interview experience. As I am about to explore further in the following section, the felt and embodied nature of doing this research was also apparent in my experience as a participant observer in the hospice ward environment. Before I discuss this matter in detail, I begin by outlining more generally how the observation took place.

Participant Observation: how it happened

Over the 5 years that I was a volunteer at Spring House the inpatient service changed its focus of care in the sense that bed space priority was increasingly given to patients nearing the very end of their lives and those requiring urgent symptom control. At the time of the fieldwork, admissions for respite were significantly reduced and referrals only received in

emergencies. Therefore many of the families visiting the inpatient unit were 'doing' family life in end-of-life circumstances and observation of the ward provided a rare opportunity to gain access to this experience as it was happening, rather than having to rely on retrospective accounts sought after death had occurred. Given that the research had a temporal focus, it was important to generate data which reflected family life during the latter stages of life. And so, I spent time on the ward at Spring House, fulfilling the role of an inpatient volunteer whilst also conducting participant observation.

In terms of recruiting participants, my approach was perpetually in progress and often rather informal. I approached patients and family members to explain the research and to ask for their consent to observe and chat to them. Prior to this, family members received an information sheet usually from a volunteer receptionist as they arrived at the hospice or, if on weekends and at other times when the desk was not staffed, I would approach the relatives myself with this information (see appendix 7a-d⁶⁰). I also offered patients an information sheet when I talked with them about their consent to be involved in the research (see appendix 8). However, often they were happy to just discuss the matter and preferred not to take one. I felt that in the ward setting it was both inappropriate and impractical to ask participants to sign consent forms. I did however where possible, return to the issue of consent and periodically reminded patients and relatives of my role to

⁶⁰ I did prepare age-appropriate materials (8-12 and 13-16 years) for children and young people visiting the ward and handed these out on a couple of occasions to young people in families I was observing (see appendix 7c-d for aged 8-12 information booklet).

ensure that consent was negotiated over the course of my involvement with a family⁶¹.

The majority of the patients had terminal cancer and many did die on the ward, with some going home for a while before then being re-admitted and dying following further deterioration. Overall I spent 175 hours engaged in observation, changing the times and days of the week that I was present, hoping to see varied aspects of ward life and family routines. This included fieldwork on weekends and evenings and also visits on special days such as Christmas Eve, Christmas Day, New Years Day and Mother's Day.

Although I did stay late into the night on a couple of occasions - and on one I actually stayed through the night - families most often went home and when they did stay their general lack of activity meant that this was not always an especially useful time to observe. The ward was open to family and friends to visit patients at any time between 10am and 10pm other than during daily rest hour (1.30pm to 2.30pm) where visitors were encouraged to leave, unless a patient was seriously unwell or dying. Similarly with overnight stays, generally it was when someone was close to death that relatives stayed the night, sleeping in recliner chairs in the patient's bedroom, or on a camp bed which staff erected in the large quiet room down the corridor⁶².

⁶¹ To maintain the family focus of the research as far as possible, I tried to identify non-family members who were visiting and tended not to focus my attention on these cases.

⁶² There were no designated family facilities at Spring House.

My relationship with many of the families I met during the observation differed from the more involved relationships I had with some interview participants, as often contact was fairly fleeting⁶³. Due to my observation timetable and the length of time patients tended to stay - sometimes only days - it was often the case that I would meet a family one week and then they were not always there on the days I returned next time. There were nonetheless, certain families and patients who I got to know in a more sustained and in-depth way, and therefore it is generally these families that form the main bulk of my observational notes and analysis. On four occasions I spoke informally with family members in another room away from the ward where I asked them about their lives at that time. I managed to record two of these conversations (with a son and a daughter from different families) and made field notes regarding what was discussed in the other two. My more substantial field notes which corresponded to each observation period were often made in stages utilising hand written notes made during available moments on the ward and then further detail was added afterwards if necessary. Sometimes I also used Dictaphone commentaries which I would make in the car after leaving the ward. I then used these notes and commentaries to type up my field accounts and assigned participants pseudonyms. On the ward I often found time to sit and record notes. This did not appear so odd because staff also sat in the same places as I did - at the nurses' station or in one of the easy chairs in the communal area - and they similarly made notes or completed paperwork. A

⁶³ Although this was not always the case, as one particular family obviously felt sufficiently involved with the research to text me after I had left the ward to say their mum had died peacefully.

few weeks into the observation I had a meeting with my supervisor where we discussed field notes and she shared some examples from her own field work to help with my analytic note-taking and to indicate the contextual, mundane details which can help to flesh out a fuller perspective of a setting and enable one to 'see' the taken-for-granted in the everyday world (Silverman, 2007). Silverman suggests that, 'in making field notes, one is not simply recording data but also analysing them' (2001: 65). In other words the participant observer makes two types of notes - descriptive and analytic. To this I would add the researcher's own subjective reflections about being in the field and their relationship with the process (Okely, 1996). I found it useful to write up these different kinds of observational notes in the same fieldwork log so I could easily identify how they each interlaced and related to the specific circumstances, families and issues I was encountering at any particular time on the ward.

Before entering the field I did not have a framework for making observations and notes. I did however ascertain that the purpose of the observation was to collect data about how family life is conducted on the ward and that therefore I would be primarily observing family routines and any significant moments such as deaths or where there appeared to be shifts in family dynamics and interactions. I devised the following questions to prepare myself for what I might find useful to make notes around:

- What do family members do/ talk about when they visit?

- How do they arrange themselves around their relative's bed/ bedroom space?
- What items do they bring to the ward? Do any of these symbolise family life or are they involved in its facilitation/ recreation?
- Are there any changes to observe when different family members enter the space and then leave?
- Who in the family does what?
- How do families understand their 'place' within the hospice space and its routines?

It was so I could be more involved in ward life and interact with the patients and their families to explore these questions, that I adopted the participatory role of a ward volunteer. I managed this with relative ease as I had already received the necessary training and was known to the hospice. I did however wear an identification badge which clearly showed I was a researcher and my role as such was explained to participants who became involved in the observation. The various tasks I performed included making drinks for patients and their relatives, serving food to patients, washing pots and generally tidying around. I sometimes answered the phone and took messages if no one else was available or gathered meal orders from patients ready for the kitchen staff, whilst I also sat with a couple of patients to assist them with eating.

And so in summary, because my study aimed to explore how family is constituted by family practices - *an active process* of constructing family undertaken by individuals in their everyday lives (Morgan, 1996) - I needed to see families interacting and 'doing' family together. Therefore participant observation in a setting where families are more overtly negotiating the illness and/ or dying experience of their relative, was chosen as it allowed me to explore, 'the *routine* ways in which people make sense of the world in everyday life' (Hammersley and Atkinson, 1983: 2 my emphasis added). Because the researcher is actively immersed in the environment and interacting with people there through talk as well as observation, informal and opportunistic conversations also play an important role in data generation (Hammersley and Atkinson, 1983). It is through this interactive process of observation and conversation that the researcher builds knowledge of the issues they are exploring. Indeed, participant observation is being used with increasing frequency in medical and health care settings (Savage, 2000) and as important examples have shown, ethnographic work can both inform and challenge our understandings of death and dying (see Komaromy, 2005; Seymour, 2001; Lawton, 2000; Hockey, 1990; Bluebond-Langner, 1978; Sudnow, 1967; Glaser and Strauss, 1965; 1968).

Experiencing Participant Observation: embodied knowledge

By adopting a participatory approach to observation the researcher can gain experiential knowledge of an issue/ setting because they recognise how their *embodied* immersion in the field is involved in the production of data and

their understandings of the situation (Okely, 2007; Savage, 2000). This can help the researcher to go beyond describing happenings in a setting and enables them to develop analytic ideas, to make the process of interpreting and understanding people's experiences deeper and more reflexive. Indeed, having been a participant observer, I can relate to Okely's point that fieldwork is 'a dramatic contrast to the private, sedentary and academic demands of university existence' (1996: 41). Elsewhere Okely (2007) provides a key example of why this is the case, pointing out the deeply *embodied* nature of fieldwork and highlighting how different sorts of skills might be required of the researcher in order to 'pass' successfully in the fieldwork environment. Often these are practical and manual skills of great value in the fieldwork setting, but less familiar in the usual, daily life of an academic researcher (Okely, 2007). Although Okely is primarily discussing anthropological fieldwork undertaken in distant places and different cultures to those most researchers are accustomed too, her argument still applies to fieldwork closer to home where one is expected to draw on a different set of skills to negotiate a setting which is not usually part of one's daily life. So for me this involved demonstrating confidence in my own body and its closer than usual proximity to others I did not know so well. For example feeding patients felt like an intimate form of interaction involving not only physical closeness but technical bodily-based skills in terms of knowing, for instance, how much food to place on the spoon and what angle to enter the mouth at. As my use of the term 'intimate' suggests, embodied experiences are also closely, and intrinsically, related to emotional experiences as the researcher shows and feels emotions as part of the research experience by

using their bodies (Dickson-Swift *et al.*, 2009). My feeding experiences also demanded emotional skills, such as knowing how to tactfully wipe drips from someone's chin without embarrassing them or myself.

Precisely because there is this potential to be embarrassed, to be caught out or found wanting, and yet there is equally the chance to succeed and to become adept at new skills, Okely suggests participant observation can have an impact upon the researcher's sense of self that 'can be both shattering and exhilarating' (1996: 42). I can relate to Okely's point here when I recall feeling dejected when a perfectly well-meaning relative observed me trying to portion out meals (clumsily) from the dinner trolley one tea time. '*We can tell you're an academic*', she joked and I laughed along publically whilst privately I felt like hiding somewhere dark and quiet. In a moment of complete over reaction I felt my inadequacies exposed. I realised I wanted to be perceived as a 'good', capable, dependable hospice worker and not just as a 'clever' but ultimately detached academic who was clueless about the hands-on stuff. It felt like I had been 'found out'; my practical skills exposed as cumbersome and unnatural as my lack of a steady hand and purposeful manner marked me out from the more skilful staff members. Perhaps this can also reveal something about how social categories were constructed and negotiated within the setting, with people, bodies and experiences divided into the different categories of dependent and dependable.

Indeed, Okely explains how adapting and using these embodied skills in less familiar contexts produces a form of bodily knowledge about matters of *difference*:

Moving and living beyond the familiar by engaging with other cultures, groups and societies, however, entails learning about difference in all aspects: economic, political, religious, ideological *and* bodily (2007: 65 emphasis in original).

Interestingly, although perhaps not the kind of 'places' or 'cultures' Okely had in mind, Sontag refers to the experiences of being sick and being well using geographical metaphors; 'the kingdom of the well' and 'the kingdom of the sick' (1991: 3). Similarly Lawton's (2000) concept of the unbounded, dying body which behaves in ways that feel foreign to the person inhabiting it, let alone those inhabitants of the 'kingdom of the well', might suggest that for a well researcher to gain an understanding of the 'distant culture' of the sick, bodily knowledge will be important. I can identify with how the embodied feelings I experienced in the ward environment provided an experiential knowledge about what it might feel like for well family members to interact with a sick relative. Most notably this came through in my notes about feeling uncomfortably perched on chairs and leaning into the side of beds or standing over patients who were lying down and becoming aware of power imbalances in the way our bodies were positioned. These are bodily experiences which helped to focus my understanding of the nuances of interactional dynamics as these are expressed in the positions between bodies within space, and how these might relate to relational dynamics for families. I found that as Dickson-

Swift *et al.* suggest, emotional, embodied responses to doing research ‘are markers of meaning from which researchers can learn’ (2009: 68).

Intrusion and Ethical Issues in Family Research

As my discussion of the emotional nature of carrying out this study suggests, conducting research with gravely ill people is considered ethically problematic and sensitive (Liamputtong, 2007; Sheldon and Sargeant, 2007; Seymour *et al.*, 2005; Johnson and Clarke, 2003; de Raeve, 1994; Raudonis, 1992). However, as Kellehear (2009b) argues, the ethical issue of *intrusion* is of utmost importance when conducting research with dying people, yet it does not receive the same attention as more familiar and frequently cited concerns relating to consent and confidentiality. Whilst I recognise that justifying the need to take time from dying individuals to do research is ethically challenging (Barnett, 2001), in my case any ‘intrusion’ experienced by individuals and their families involved in the research was ‘weighed up’ alongside the potential this work had to inform theorists and professionals alike, about the social and relational aspects of dying experiences. In other words, there is simply not enough existing data which is rich enough in its focus on the everyday, lived experiences of families dealing with life-threatening illness to add a much needed critical ‘balance’ to the predominantly ‘problem-based’ concerns embedded deeply in the death and dying literature (Kellehear, 2009a). Thus it is possible to understand the undertaking of this research as having an ethical imperative in the sense that it reflects efforts to provide a more comprehensive representation of dying experience.

Furthermore, whilst not wishing to undermine the importance of attending sensitively to the matter of intrusion in regard to justifying the undertaking of any research, there are publications which point to the therapeutic benefits of the qualitative research experience (see Corbin and Morse, 2003). Indeed, some argue that participants themselves claim to derive feelings of altruism and comfort as a result of being involved in research about sensitive issues such as health conditions, bereavement and terminal illness (Peel *et al.*, 2006; Grinyer, 2004; Barnett, 2001). Thus there is evidence to suggest that sensitivity should not be a barrier to including ill people in research, however when the project involves working with families, there are further ethical matters to consider. Aside from representational issues regarding multiple narratives and whose story the researcher is ultimately telling (Warin *et al.*, 2007), there are difficult issues pertaining to confidentiality and anonymity to contend with, as well as the general concern that the researcher's presence might alter dynamics within the family which could have adverse effects for relationships and how the illness is managed. For example, on occasions during the interviews, potentially sensitive comments were made by certain participants about people in their family and deciding how to manage this disclosure and subsequent reassurances that fellow family members would not find out was challenging. In an effort to try and offer participants realistic assurances regarding confidentiality I did explain that when researching in a family context, given the familiarity that exists between participants, anonymity can be trickier to ensure (Daly, 1992). I reassured participants that appropriate anonymisation would take place and that I would not discuss

with others in the family what particular participants had shared. However I did point out that although it was unlikely, there was still the possibility that in a publication one family member may be able to recognise the contribution of another. I hoped such a forewarning would enable participants to decide in a more informed way what they chose to disclose. To ensure that participants understood how contributions provided in qualitative interviewing are often represented in academic work, I showed them a health-based sociological text and suggested that their own words would be presented in a similar way⁶⁴.

Regarding anonymisation more generally, not only did I have the family aspect to consider but, due to the small number of interview participants in the project the anonymisation process was very important. Therefore, to maintain anonymity and confidentiality, aspects of my data have been anonymised to disguise individual participants. In terms of the observation participants, some data has also been changed to preserve anonymity. Furthermore, whilst it is an ethical strength of observational methods that they are less intrusive than other methods which demand more in terms of time or prolonged commitment from participants (Darlington and Scott, 2002; Lawton, 2001), they nonetheless bring ethical challenges which once again feel heightened in the context of ill-health and death. Whilst my familiarity with the hospice helped with negotiating gatekeepers and navigating my way around the hospice in the early days, it did not reduce

⁶⁴ See appendix 5a-b and appendix 6a-c for more information about informed consent and the interviews.

regular feelings of uncertainty and anxiety which persisted on and off throughout the fieldwork (Shaffir and Stebbins, 1991). Many of these anxieties related to matters of ethical conduct and in some ways my familiarity with the setting posed its own challenges in this regard. As Lawton (2001) also recognised in her ethnographic work in a hospice, ensuring that patients and others in the research setting remain aware that you are there primarily to conduct research, can be tricky when the researcher takes on the role of a volunteer. Reinforcing the nature of my 'true' role in the setting was made even more difficult due to my previous voluntary work there. For instance on one occasion a member of staff introduced me to other professionals as someone doing research - but mainly in my capacity as a long-term volunteer. In spite of this, and trying to be as transparent about my presence as I could, I often reminded patients and families of my role as an observer. Even so, as Lawton (2001) also found, the main difficulty I experienced was generally around informed consent and assessing if, and how, this remained valid over the research process. As some patients lacked capacity to give consent to participate this was a complicating factor and advice was sought around the Mental Capacity Act (2005) which at the time was in the process of being applied to cover participation in research. Sometimes I spoke to staff to help with this matter, and a useful way of managing these difficulties was to always be sensitive and to ascertain the views of family members to utilise their knowledge about a patient and what their likely feelings would be.

Also when conducting the observation, I was faced with the practicalities of being within a naturalistic environment. To try and ensure that as many people as possible knew about the project I wore the aforementioned identification badge and tried to give all visitors (except professionals and clinical staff) a copy of a participant information sheet which clearly explained an opt-out method of consent. Visitors were instructed to inform either the hospice staff or myself directly that they did not wish to be observed for the research; though in all the time I was there no one actually did this. I realise that there were a number of people who perhaps did not read the material so carefully, and so to ensure participants were as fully informed as was practically possible, I also tried to speak directly to visiting families face-to-face, once they had had time to digest the material. The result of this was that by having direct conversation and assessing more closely with individuals their feelings about participation, it helped to focus my observations on particular families. For instance where my approach was received warmly and without any sense of trepidation I naturally felt more comfortable spending time around these families and therefore they became more closely involved in the research. So ultimately whilst I endeavoured to stick to the protocol I had outlined in my ethics application and was very anxious to do so, I used my own moral and emotional sensibilities (Ellis, 2007) to read situations and responses, and based my ethical and more practical observational decisions on these as well. As Guillemin and Gillam (2004) argue, although formal ethics protocols provide an opportunity to enhance the likelihood that research will be broadly ethical, there are many day-to-day ethical issues which arise in the

course of actually doing the research that cannot always be clearly anticipated. These require a reflexive approach on the researcher's behalf and recognition of the everyday quality of 'ethics in practice' (Guillemin and Gillam, 2004). An example of this from my own research related to the spatial constraints imposed by the ward layout. These meant that to observe families in any depth I had to be invited closer; which was especially the case with patients in private rooms. Therefore needing to be proactive to observe families had to be weighed up against maintaining a respectful privacy for those families. Doing so was something I found challenging, as the temptation was to err on the side of caution and to stay at a distance so I did not feel that I was imposing. Again this is something which I experienced in embodied terms when I was aware of my discomfort at hanging awkwardly around door frames which led to privately deliberating about what was the 'right' thing to be doing.

Finally, my relationships with ward staff also created ethical issues which mainly related to confidentiality. Whilst initially I had been keen to observe staff handovers where both patients and their families were discussed, after doing so once I only attended on one more occasion after this, as I felt uncomfortable knowing information about patients and their families which they had not given to me themselves. I also felt that hearing staff views on family dynamics might affect my own interpretations about what I was observing. Although it was impossible to avoid hearing staffs' views during normal day-to-day interaction in the setting, avoiding the handovers seemed the most ethical way of containing the influence this may have. My

approach to confidentiality more generally was to not repeat what patients and relatives shared with me unless it was a matter of medical urgency; a situation which did not arise during the fieldwork.

The Data Analysis Process

Towards the end of the fieldwork year I have described above, I became aware of an interaction in my data between what families were *doing*, what they were *thinking* about, and how they were *feeling* regarding being a family and their illness situation. In other words, I was acquiring an interconnected and multi-faceted picture of family practices (see Smart, 2007), all of which helped generate the experience of ‘being’ a family facing life-threatening illness and death. And so as I started the post-fieldwork analysis I was influenced by the idea of family practices as assemblages of *doing, thinking and feeling*, which had developed whilst I was transcribing my interviews, discussing my thoughts in supervision, and considering the data in relation to important conceptual ideas in the literature (namely Smart, 2007)⁶⁵. These ideas consequently informed the coding process when I began to work more closely with the data.

As a result of listening to the interviews once they had been conducted and making notes about salient themes and further questions I wanted to ask in future interviews, I did manage to work iteratively over the fieldwork year.

I also re-read some sections of my observation field notes to begin to build

⁶⁵ Refer to Part 2 of the Literature Review to revisit Smart’s conceptual development of Morgan’s (1996) family practices.

familiarity and to consider emerging themes. And so prior to moving into the more focused, post-fieldwork analysis that began once all the data had been 'collected', I had started to note down ideas which related to themes emerging from having listened to the interviews and as a result of my general interaction with the data during the fieldwork. Broadly these were themes around, food, time and routine practices, 'everydayness', stoicism and continuity and change. Once I moved into the more in-depth analysis phase, I started to keep a coding/ analysis diary and created 'code thoughts' documents to note down any ideas and links within the data. Starting with the interview transcripts I completed very detailed interview summaries for just over half of the interviews conducted, looking for further emergent codes and any subthemes that related to the earlier themes I noted above⁶⁶. I found this process useful because the task was a more involved, less 'passive' way of re-reading the transcripts and it therefore contributed to working in an 'immersed' way with the data. It also helped to ensure that for those interviews that I did summarise, I was keeping in mind a focus on the 'whole' narrative and with the finished summaries I essentially had documents providing interview details, at my 'fingertips'. After the summaries I then re-read the observation field notes and marked up sections of the data under the broad categories of methodology, family-specific observations and other significant themes which seemed to emerge - such as displaying photos and food routines. There were also themes which related to those that had started to emerge from the interview summaries - for

⁶⁶ I stopped summarising interviews at this stage, as similar themes had begun to emerge and useful directions for more close analysis and sub-coding had started to take shape.

instance the dualisms of being in/ out (of spaces), with/ without (one another) and staying/ leaving.

Having done all this, I discussed these emergent ideas with my supervisor and I then felt ready to work more closely at coding the data. At this stage I transferred all the field notes - from interviews and participant observation - into Nvivo, along with the 41 interview transcripts⁶⁷. I then began to code, using a single coding frame for the different bodies of data, around the following themes which had emerged from the processes I outlined above:

- Planning and routine
- Descriptions of movement across space (general space and between home and hospice) - in and out; staying and leaving; being with and being without
- Food/ eating practices
- Thinking about mundane things
- Uncertainty
- Time
- Things continuing/ things changing
- Silence and 'gaps' in family relations
- Pragmatism/ acceptance

⁶⁷ 39 from interview families, 2 conducted with family members on the ward.

- Dying/ life on ward - mundane and emotional elements intersecting

As I wanted to address over-arching questions about 'doing' family and everyday family life, it felt important to code the different sets of data within a single frame to avoid artificially separating the experiences of families interviewed at home, and those observed on the ward⁶⁸. Working through the data again in Nvivo allowed me to create more specific sub-codes from the ideas I had already started to build by doing the interview summaries and broad coding of the observation data. Thus I was able to further refine my themes and arrive at a final coding frame for organising the data as a representation of families' experiences (see appendix 9).

The Emotional Mundane: fragments of auto-ethnography

Producing copious amounts of field notes, transcribing hours of interview material and performing detailed analysis, was an emotionally tiring process. In many ways it reminded me of Smart's (2009) suggestion that social researchers have to 'live with other people's lives' as they find themselves 'haunted' in certain ways by their data. For me 'haunting' was rather an apt term, given that the analysis actually involved 'working with the ghosts' of my dead participants (Komaromy, 2005). Hearing their voices in recorded material or recalling time spent with them on the ward, made the responsibility of producing an account of their experiences even

⁶⁸ Although, I did create a couple of codes within the frame which were specifically for data which revealed the situated, contextual experience of being within the ward environment - and I also did the same for data relating to how families 'were' and how they interacted in, their home spaces during interviews (see appendix 9).

more overwhelming. Smart (2009) suggests these feelings of responsibility are central to developing a 'sociological conscience' which she describes as the intersection of a researcher's personal life with the practice of doing research. To explain this further, Smart (2009) also referred to Back's (2007) invitation to social researchers to *truly* practice the 'art of listening'. Here Back argues for the need to 'pay attention to the fragments, the voices and stories that are otherwise passed over or ignored' (2007: 1). Interestingly he acknowledges sociology's 'enchanted obsession with the spectacular' and makes a point about the *ethics* of 'thinking with all our senses' to be able to 'notice more and ask different questions of our world' (2007: 8). His work helps me to consider some of what was involved in 'hearing' the mundane in my families' accounts.

Essentially, what both Back and Smart suggest encourages thought about the role of emotions, ethics and the self in research. In a memoir about how her research relationship with a much older participant became a personal and intimate one, Ray (2008) explains that her motivation for telling this story is to offer a 'narrative for social change'. She argues that this involves:

...telling countercultural stories about aging and old age, celebrating the unexpected and the inexplicable in these stories, engaging as researchers and writers in the critical self- reflection and self-reflexivity needed to work through our own age anxieties, and, in the process, changing not only how we and others *think* about aging but also how we *feel* about it (2008: xi-xii emphasis in original).

What she suggests here about changing perceptions of later life resonates with my interpretation of dying in terms of mundane/ ordinary experience which is a somewhat countercultural narrative to the dominant discourses of death as rupture and crisis. Furthermore, Ray's publication provides useful insight into the felt and emotional aspects of doing social research on sensitive topics, which is something I have pointed out regarding my own research experience throughout this chapter⁶⁹. However as Lee-Treweek suggests:

...where they are mentioned, emotional issues are often objectified into the more easily identifiable and clearly defined reflexive bit in the 'methods section'. In order to be useful to other researchers, emotional accounts need to be discussed *as data* and in relation to the generally unspoken emotion rules of the setting under investigation (Lee-Treweek, 2000: 114 my emphasis added).

Considering my emotional experience of being *within* the research *as data*, the following auto-ethnographic reflections are offered as a way to show how my embodied presence in the research settings became analytically important.

(In an interviewee's home...)

'I asked them if they had any plans for today... Mary said that Ellen would be taking her to buy some flowers to take up to the cemetery to visit her sister who would have been 58 today (my bid to move the interview into 'safer' territory failed!) Mary then started saying that she did not want her ashes putting in the ground; she didn't care where she was as long as she was in the house with the family. The

⁶⁹ For further examples which discuss the emotional nature of conducting sensitive social research, see Dickson-Swift *et al.* (2009), Woodthorpe, (2007), Rager, (2005), Johnson and Clarke, (2003), Hubbard *et al.* (2001), Lee-Treweek, (2000), Rowling, (1999) and Cannon, (1989).

girls responded to this with humour - Ellen saying that Mary would be put on the settee and her sister shouting up from round the corner that she will end up, up the hoover. Mary herself said she didn't mind if they put her under the stairs - as long as she wasn't in a hole in the ground. I felt awkward because of the immense sadness I imagined Mary must be feeling; I don't know if I've succeeded in asking questions which will get me anywhere near understanding this - to know she won't be there and life will go on. I was glad they brought in humour though - it made things easier for me - though I wasn't sure how to respond to the hoover remark - was this their private family joke to make sense of the fact that materially Mary won't be here for much longer - it seems like a weird thing to joke about to those outside the situation - I wasn't sure if I was in or out of my research role - was it appropriate to laugh at this? In the end I think I just did'.

(Observing on the ward...)

'When somebody dies the nurses light a candle and place it on the nurses' station so everyone is aware that a death has occurred. It's so very strange when this happens - everything just carries on. The staff continue to chat, to laugh, the housekeepers hoover around and we lift our feet so they can do under the chairs. Glasses clink as teas are made and water poured - I wonder how this feels for the family. Do they even notice?'

(Driving home from an interview...)

'In the car driving home I felt strange - subdued and numb, but also a little tearful. It made me sad to think about what Malcolm and Tracey are facing and I also began to feel troubled about putting the thesis together. I get mixed feelings - sometimes feeling bad for having a numb and detached feeling and not being overwhelmingly

burdened by the circumstances I find people facing. And yet perhaps their ability to just get on and do makes me able to be saddened but not paralysed by distress. But then I do feel compelled lately to reflect on my own life and the time I have and how I use it... time is passing quickly and studying dying is magnifying the importance of maximising it. I feel so guilty because I imagine I ought to be more committed to the thesis and not have to struggle to sit down and work on it. And yet I'm aware that the sheer enormity of the task is overwhelming - I feel lost for ideas - not sure of what I want to say about any of this. Could this explain the numbness and detachment - the lack of motivation? Of course, feeling indebted to the families who have spoken with me is an added burden - I feel like I'm struggling with getting themes to emerge - I'm feeling the 'ordinary' yet specific life worlds of individual families and am starting to wonder if illness experiences within families are just different and what more can I say than that? If I simply re-tell their stories how am I doing anything they couldn't? Ultimately the work seems trivial... imagining Malcolm's isolation [due to deafness] makes the thesis feel small, like nothing - like it couldn't do anything to touch the magnitude of what that experience must be like - yet the mundane comes in as the everyday world keeps on ticking over. What can I say about this?'

As this final extract from my interview field notes shows, I was troubled by any 'mundanity' in my own approach to, and reflections about, the research. Whilst this suggests I felt ambivalent about generally being able to get on and not always feeling overwhelmed, it also points to difficulties I was having *analytically* in working out how to make sense of the everydayness in my data. In this process of considering my own emotions, I began to see I was also struggling to formulate an analytical perspective on how the everyday and the mundane intersected with the more extraordinary and

emotional experiences associated with death and dying. For instance, in the other extracts above, the mundane - making tea, hoovering, the cupboard under the stairs - interlace with emotionally challenging feelings and situations and sit together in the same experiential frame (see Robinson, 2008 and 'mundane extremities'). As Hockey *et al.* have suggested about the taken-for-granted and implicit concept of heterosexuality, researching what appears very ordinary and mundane can be challenging because it is both 'everywhere and nowhere' (2007b: 4). Furthermore, assumptions regarding the intensity and drama of death meant that constructing an account that gave voice to the mundane and everyday present in families' stories was challenging both analytically and emotionally as I felt in danger of trivialising such a 'momentous' issue.

However, despite this challenge, the following five chapters represent my analysis of how the mundane and everyday appeared significant as part of family experiences. They will demonstrate, as my own fieldwork experience has shown, that mundane and more emotional/extraordinary experience can co-exist in a *dialectical* relationship where there is a 'unity of opposing tendencies within the domain of human activity' (Foster, 2007: 157). The order in which the chapters progress reflects my theoretical and conceptual approach to family practices as assemblages of doing, thinking and feeling as it has been informed by the work of Morgan (1996) and Smart (2007) (see Chapters 1 and 2).

Chapter 4

Food and Eating: a family practice in focus

Introduction

As I discussed in Chapter 2, everyday matters related to '*doing*' family life in the context of terminal illness have received inadequate attention in the literature. Consequently theoretical frameworks have tended to neglect the everyday in favour of a more spectacular, crisis-based model of death and dying. Taking an alternative approach, and using family practices as a lens through which to consider the '*doing*' of family, this chapter begins my thesis' exploration of the everyday by providing an in-depth case study of one 'mundane' practice in particular - food and eating. Because food has an especially 'everyday' quality, eating practices are a powerful example of how mundane family practices are (re)negotiated during life-threatening illness. They can therefore provide nuanced insight into the '*doing*' of being a family at this time.

Thus it is within day-to-day family and domestic life where cooking practices, food preferences, emotive food associations and eating-related behaviours are acquired, and experienced (Hollows, 2008; Coveney, 2000; Valentine, 1999; Morgan, 1996; Lupton, 1996; 1994). Moreover, studies have shown how food practices - having a 'proper' meal composed of certain foods and eating together as a family - can shape, sustain and essentially 'make' family (James *et al.*, 2009b; DeVault, 1991; Charles and Kerr, 1988; Murcott, 1983). Indeed, Hollows (2008) describes the domestic

routine of cooking as ‘a particularly rich example of how everyday household tasks produce the very experience of home and family’ (2008: 62).

However, as my data will show, in circumstances of severe ill-health the food choices and eating habits of an ill relative as well as those that have been established within the family more generally, can be affected in different ways. Exploring these circumstances, I argue that changes in eating-related practices during severe illness are *relational* processes that can be used to understand how families experience themselves as families dealing with life-threatening illness. Moreover, in examining the relational nature of food at the end of life, this chapter makes a timely contribution to palliative care literature where the *social* and *experiential* significance of eating has recently been identified as an important, but neglected, area of research (Strasser *et al.*, 2007; Poole and Froggatt, 2002)⁷⁰.

I begin my analysis by describing how food routines shaped life on the hospice ward, and point to some of the symbolic meanings food can embody in an environment where growing thin often presages death. In particular, I note how ‘food talk’ and monitoring food intake helped families to make sense of and to negotiate, transitions between states of being more or less well or sick, over the illness process. I also draw on my interview data to explore how food and eating interlaced with assessments of wellness and

⁷⁰ Interestingly, both papers cited here suggest that there is evidence to indicate that observing someone losing weight and having difficulties with food is more distressing for family members than it is for the dying person.

sickness in day-to-day life, and use this analysis as a basis for the following section which considers how negotiating change in food practices as a result of illness, is *also* about (re)negotiating familial identities.

Finally, I examine how these processes can be challenging for families as they go about dealing with food in day-to-day life. Thus the last section discusses how food-related matters created instances of disagreement, power struggle and conflict between family members. These seemed to occur as tensions between maintaining established or accepted eating practices, and incorporating food-related changes, were being negotiated within families.

Noticing the Mundane: food on the ward

The following extract from my field notes refers to what was only my second day of observation. It shows how eating, despite being ‘perhaps one of the most mundane and taken-for-granted parts of our everyday life’ (Valentine, 1999: 491), was something which demanded to be viewed more sharply in the ward environment.

‘I knew patients would be poorly but I don’t think I expected them to be as disengaged as they are. There is very little activity; they are mainly dozing and with one exception, they cannot get about independently. Mealtimes appear to be a struggle as well - little food is eaten and it’s hard to watch them gingerly chasing food around the plate and being barely able to raise the cutlery to their mouths...’

The struggle I observed when patients were trying to eat was poignant and these notes reveal my discomfort in watching the vulnerability it exposed, implying that my own association of eating with wellness influenced how I felt about what I observed. Moreover it is ironic that in a setting associated with death, a mundane practice such as eating demanded to be more closely observed in its complexity. Indeed, I was soon able to see how food - ordering it, delivering it, eating it or not eating it - was a primary feature of routine life on the ward.

At Spring House patients had three meals a day - breakfast, lunch and an evening meal. For lunch, and in the evening, there was a homemade hot meal with three courses generally available if a patient chose to have soup, a main and then a dessert. There were also alternatives such as sandwiches, and the catering staff did try to provide whatever a patient fancied or felt they could manage. Lunch and evening meal were served at the same time each day (around 12pm and 5pm) and patients were asked during the day what they wanted to order from the menu. Sundays were a bit different, with a traditional Sunday roast at midday⁷¹ and then a cold buffet available with soup and dessert in the evening.

However, what was particularly interesting given that typically in institutions like hospitals food preparation is managed in 'back stage' areas and arrives with the intended eater in its finished form, this was not the case

⁷¹ See Charles and Kerr, (1988) and Murcott, (1983) regarding the pervasiveness of this event in British family life.

at Spring House. Although the meals were presented to patients on trays, the actual dishing up of the 'main meals' happened on the ward in full view of everyone within the communal space. Therefore serving up was very much a 'front stage' activity (Goffman, 1969) and there were various 'props' which helped to facilitate the performance of food service, such as the ward's traditional wooden-style dresser. This sat beside the plug socket where the trolley which brought food down from the kitchen was connected to keep the food warm. Cutlery, crockery and salt and pepper pots were also stored within the dresser, whilst beside it sat a plastic tub filled with trays and place mats. The act of taking these items from the dresser and making up the trays (like laying the table at home) was part of the activity which preceded meal times on the ward.

Heated trolley



Dresser and trays



Although it was perhaps not as intentional as Goffman suggests many aspects of 'front stage' presentation can be⁷², the way food on the ward was publically awaited, prepared for and then spooned out, gave the occasion a homely 'feel'. I observed this process many times and participated in the serving up myself. The fact that this took place on top of the heated trolley where there was very little space and uneven surfaces to contend with, made it reminiscent of a scene from a domestic kitchen with items scattered about the place. Watching the serving up of meals, I noted an endearing 'non-showiness' in the sense that the process worked, but it was not 'polished' or uniformly perfect, which again represented distance from the typical practices of protocol and standardisation associated with institutional life. Since the food was also 'home cooked', this added to the enactment of domesticity because as Hollows suggests:

Home cooking is central to many people's very understanding of the meaning of home: unlike commercially produced food, home cooking is understood to be personal and laced with intimacy and warmth provided by the cook (2008: 63).

The way in which food on the ward could be observed being 'handled' (spooned out etc.) by individuals involved in care work added to this sense of personalisation and intimacy, which Hollows identifies is bound up with notions of homeliness. However, markers of institutional life were clearly evident in the provision of hot meals for family members which was somewhat hap-hazard because staff members applied their discretion differently. Generally I understood the 'official line' to be that relatives

⁷² In a practical sense, dishing food up on the ward allowed staff to ensure patients were given the items and amount of food they wanted - or what they themselves felt patients could manage.

could be offered a hot meal if they were staying for lengthy periods of time⁷³. This ultimately referred to instances where someone was either very poorly and/or in the latter stages of life and that therefore a 24/7 family presence on the ward was more expected and considered appropriate by the staff.

More generally food played a notable part in life on the ward. For instance, 'treat' items (usually chocolates) were frequently received as gifts from families, and so goodies were rarely in short supply. I certainly experienced the temptation of food available on the ward - though in the following reflective notes what is interesting is my sense of ambiguity about how I should have felt eating it.

'Today was the first time during the observation that I had taken up the offer to have a pudding. I 'pinched' a Yorkshire pudding from the trolley after declining a full dinner but decided I would have a lump of jam sponge and custard. Donna [support worker] gave me a right dish full and said she hated to see food go to waste. I stood round in the alcove by the nurses' station and felt really self-indulgent as I ate. It was odd to be eating such a delicious pudding when the patients could hardly [manage] anything. I felt a bit awkward and would have preferred to be in my own company as I ate the dessert'.

It has been argued that food and eating practices can create socially significant categories (Douglas, 1975), and in this instance I experienced

⁷³ These meals were always provided free of charge, though collection tins for donations were available around the hospice for those that wanted to 'pay' in this sense. I did see some visitors making donations during my time on the ward.

this in an embodied way when I was tempted to eat a delicious pudding after on previous occasions declining similar invitations to have food from the trolley. After accepting the sponge and custard, I then experienced feelings of self-indulgence and self-consciousness as I enjoyed eating it. In particular I felt ambiguous about sharing the same food which patients could also eat, but I knew many would not. On previous occasions I believed I had declined offers of food out of politeness, but having experienced this demarcation of difference between my own unproblematic relationship with food (I could eat it whether hungry or not) and that of the struggling patients, perhaps it was more a sense of social differentiation which was actually contributing to my feelings of unease with eating. Indeed, on the ward there was this strange sense of juxtaposition where food on the one hand was symbolic as a treat and was plentifully available, and yet at the same time this contrasted uncomfortably with the mountains of food that were wasted and scrapped from patients plates after mealtimes.

Wellness and Sickness: making-sense of illness using food

I have started to show how, beyond the significance of routine, food and eating pervaded life on the ward in other symbolic ways. It also provided a focus around which interactions between patients, their families and staff members took place, and these often involved negotiations around how ill or well somebody was. For example, one patient's wife explained to me that she had sent a text message to her son that morning to wish him happy birthday, but also to say that his dad was ok and had eaten something.

Another time I observed a different patient's wife arrive on the ward and

enquire if her husband had managed to eat anything. After she had gone to be with her husband in his room the nurse turned to me and said 'you see?' - referring to the fact that she had had a frank chat with the family recently about a decline in food intake and dwindling interest in eating as a part of his illness process, but that it did not seem to make much difference.

And so, 'food talk' happened between different actors I observed in the ward environment - including myself who I noticed became increasingly reliant on food questions and eating-related comments as a means to interact with patients and to assess how they were feeling. In doing this I was perhaps emulating what I had seen from some ward staff who talked about patients in terms of what they could eat or what they liked, saying things like '*oh he's a lovely eater*' or making ironic statements such as '*they are all on diets*' when patients were not eating much. The nurse who made this wry comment went on to say '*I've dished out my semolina nicely and they don't want it; I think they are too lazy to feed themselves*' and although expressed in a humorous, almost dismissive way, the sight and sound of left-over, hardly touched food being scrapped into the waste tub has a symbolic potency in the ward environment where patients were often precariously teetering on a boundary between sustaining themselves and 'tipping' towards death. Even in my own mind the relationship between food and wellness became pervasive, as I note on one occasion my surprise at learning a particular patient had died whilst I had been away from the ward.

‘Keith sadly deteriorated and died. I was a bit surprised about this and I find myself saying to the staff member who told me - but he was eating well and everything wasn’t he?’

Food talk and food monitoring also took place in interactions between family members and patients on the ward where explicit or implicit reference was often made to food intake and the aim of increased wellness. Mike, a younger patient in his 50s, was visited by his brother who explained to me his concern that Mike needed to eat more.

‘As dinners are about to come around he [brother] tells me that they are concerned to get some food down Mike - he has never been a *‘heavyweight’* but he is especially thin at the minute. At one point Mike says he doesn’t know what’s wrong with him and he asks his brother if he knows. His brother replies that he has no lungs left. When the nurse asks Mike if he would like his soup in a beaker or a bowl he can’t decide for a while. His brother says - *‘decisions, decisions’*. Eventually Mike opts to give a bowl a try.’

There were other occasions when I witnessed relatives willing patients to muster the appetite to eat the food placed before them. Indeed, various interview participants and families I met on the ward associated eating with being a positive step and it was something which appeared to reduce concern relating to the illness. Relatives often felt it was their task to try and ‘tempt’ patients to eat; something which Seale has referred to as using certain foods as ‘temptations to life’ (1998: 164). A conversation with Mabel, a patient’s wife, sums up the relief that can follow a sick relative eating.

'Mabel was overjoyed about this and the fact that he's had a FULL (emphasis was placed on this) breakfast. She tells me that he hasn't been eating a thing and how worrying this has been; she has been making him jellies and buying ice cream - anything to try and 'tempt' him, but he hasn't been interested. Mabel grew emotional when she told me that it's been awful; the worst thing being watching him get ill and being so poorly and not being able to do anything'.

What these experiences imply, is that there is an implicit or hidden moral dimension to the act of eating. That is, ill people should try and eat whilst relatives ought to encourage or tempt them to do so. Although not writing specifically about the moral implications of eating within families dealing with severe ill-health, Coveney (2000) has outlined how food and eating practices have deeply moral meanings and implications. Following Foucault, he argues that family food and eating practices produce parents who 'construct themselves as subjects of the government of food choice' and that by examining family mealtimes we can see 'how nutrition opens up a number of possibilities for the discipline and training of family members' (2000: 169-170). For instance, exploring the role of children as family participants via the negotiation of food in everyday life, James *et al.* (2009b) argue that in some families eating the same food together as a family 'takes on the form of a moral crusade whereby children *should* learn the value of 'family' through the consumption of family food' (2009: 45 emphasis in the original). Therefore, given that food practices contribute to the constitution of 'family' as an experience it can be argued that food, morality and power

are intermeshed in significant ways in the construction of family life (Lupton, 1996; DeVault, 1991; Charles and Kerr, 1988).

Considering this interdependency between food and family life, it is hardly surprising that watching someone not eating can be difficult for relatives of a terminally ill person, and that there is a latent sense that dying people have a moral (relational) responsibility, to try and eat. In other words, to *do one's best* to slow down the dying process and thereby relieve distress for the family. Indeed, it has been argued that for dying people usual mealtime structures can disintegrate and at times be replaced by instances of eating motivated by 'the dying person's will to please others' or 'the desire to hang on to life, [as it] is translated into the effort to eat or drink' (Seale, 1998: 162). Extending my point about morality, Parson's (1951) idea of the legitimate patient - one who accepts the benefits of a temporary sick role in exchange for the moral requirement to get well as soon as possible - is instructive. In cases of terminal illness and in relation to eating, it seems that the moral implication works in reverse in the sense that people are legitimately expected to die as slowly as they can to maintain a sense and appearance of social integration for as long as possible. Eating has, of course, frequently been associated with sociality, social participation and a sense of belonging to the wider social body or collective which means it can be of particular symbolic importance during the dying experience (Seale, 1998). Thus, not eating might signal a decline into social death; or perhaps what should be more accurately termed 'social *dying*' (see Mulkay, 1993) as the *process* of struggling with eating and altering eating patterns and

practices, complicates the idea that the social death it might precipitate is a discrete, fixed category. The moral implication to eat in a bid to die as slowly as possible shows how the ill person can control (or it is implied they should control) the process and temporality of their dying - in both a bodily and a social sense.

This analysis underscores the *relational* context of eating. An example which alerts us to the pervasive social and symbolic dimensions of food across cultures comes from a study conducted in Fiji. Becker (1995) argues that the western idea of the individual body/self is less recognised in this society where:

A body is the responsibility of the micro-community that feeds and cares for it; consequently crafting its form is the province of the community rather than of the self. And because the individual body is the locus of vested efforts of its community, the individual's own efforts are directed back toward the community (1995: 57).

Although a rather different cultural context was obviously at play for the families I observed, Becker's analysis has resonance with literature which indicates that food and feeding practices within western families are inextricably intermeshed with the construction and experience of being a 'collective' and a part of something greater than one's self - i.e. 'the family' (James *et al.*, 2009b; Lupton, 1996; DeVault, 1991; Charles and Kerr, 1988; Murcott, 1983). These different empirical studies highlight the universal significance of food above and beyond its nutritional value, and help to explain why for some families experiencing severe illness the act of taking

food into a single, 'failing' body appeared to be part of a wider picture of 'nourishment' that involved the wellbeing of the family 'body' as collective.

And so, witnessing or learning that a sick relative had eaten brought relief for families. In a joint interview with her sister Vera, Helen talks about Vera's fluctuating appetite and explains that it was '*wonderful*' when she was able to eat.

Helen: *Well when she was diagnosed at first she had no appetite at all*

Vera: *No*

Helen: *her appetite was terrible, it was, I was at my wits end I was trying to think up things that would treat her to eat and things that she would maybe like a little bit of fish and toast or - and then they put her on these steroids that's wonderful she'll just eat anything and that's great, absolutely great*

Vera: *So I'm a big fat woman*

Helen: *But she just wasn't eating and she was losing weight er wasn't well at all. But you are much better; you are much healthier now that you are eating*

Vera: *Oh sure*

The same sentiment is shared in another interview when Tracey, Malcolm's wife, is '*over the moon*' with his desire to be engaged in food practices and preparation:

Tracey: *No but generally speaking you have been doing better.*

Malcolm: *Oh yeah*

Tracey: *Definitely cos you would never have managed that would you? You wouldn't have managed to make your drop scones er your*

Julie: *Rock buns?*

Tracey: *No, your rock buns and*

Malcolm: *No*

Tracey: *Would you?*

Malcolm: *No I wouldn't have been able to stir the mixture*

Tracey: *I'm absolutely over the moon I am - cos it's wonderful really.*

Malcolm: *What's more important is I eat em*

Tracey: *Well yes and you can tell cos you are getting (cute voice) little cheeks there aren't you? They are beginning to get chubby again.*

In this last extract it is Malcolm who notes the significance of actually being able to eat the rock buns he makes, whilst Tracey's gushing response and playfulness indicates her joy at seeing Malcolm's face filling out again and the weight creeping back on⁷⁴. Seale discusses how the wasting body can be especially problematic for relatives to see; it having particularly graphic associations with the dying body (1998: 164-165; see also Hopkinson *et al.*, 2006). Indeed when the eating prospects for an ill relative were poor, the concern and demoralisation some families experienced was evident. On one occasion I was involved with an exchange that took place between Rob a patient in his 60s, and his wife Mabel, introduced above. We were all sat around Rob's bed and Mabel had recently arrived for her usual afternoon visit when the following conversation occurred.

⁷⁴ In fact, her 'cute' voice mimics the parental perspective Coveney (2000) refers to in his work cited above.

'I ask Rob how he is and the consensus is not too good - he has been feeling sickly. I sense tension between them as Mabel - his wife - tries to ask what Rob's eaten today. We tell her that he's eaten some meat and potato pie - Rob adds that he didn't have any meat though because it's too rich. Mabel informs me that Rob ate minced beef for tea a couple of nights ago and he thinks that's what set him off being sick. She asks if he ate all the pie and Rob says not. She also asks about pudding and learns that he hasn't had any. There is a bit of a silence and she concludes that he hasn't had much again then - making a dry comment about him aiming for the catwalk and then clarifying what she meant by explaining he was trying to get to a size zero. Beneath the banter and the brave face it is easy to see how worried Mabel is about Rob'.

From her questions it is apparent that Mabel was trying to gain a picture of what Rob had eaten whilst she had been away. There was tentativeness and gauging present in her dialogue which suggests that for Mabel, this gave an indication of how Rob was doing, what kind of day he was having and perhaps ultimately, some understanding about where they were in terms of the disease and its progression. Her somewhat frustrated comment that he was trying to get to tiny supermodel proportions (a euphemism for his wasting body) reveals the feelings of powerlessness food can create for families when a relative is not eating - something which I discuss more fully below. However, this exchange may also have involved a 'metaphorical move' in the sense that Mabel expressed her frustration and complaint in a displaced, more socially acceptable way. In other words by referring to the topical critique of 'size zero' models, she did not have to state overtly that

her 'complaint' might be have been that Rob not eating represented a move closer to his death.

Meanwhile, food *tastes* can also be a gauge for wellness, and this cropped up in another conversation with an older couple on the ward. John was a quiet man and I sat with him and his wife as she explained what she thought John would be like at home having had the chance to recuperate in the hospice. I noted the following about the conversation.

'His wife tells John that she thinks he'll be alright now - now he has seen some improvement. I was struck when she said that his bottle of whiskey will last him beyond Christmas - when a few weeks ago she didn't think he would make it till then. Again John didn't comment'.

Here the whiskey symbolically embodied, or was associated with, John's wellness and the possibility of a return from the ward to the couple's more everyday life. It was a way of thinking meaningfully about the time John's wife felt he might have left and, as with the previous examples, it reveals something about how eating (and drinking) become important for families negotiating and trying to understand the illness process. However, what these examples also suggest is that knowing about a relative's eating practices is a source of *relational* knowledge acquired and embedded within everyday family life which is also symbolic of the familiarity that characterises being part of a relationship/ family. Thus John's penchant for whiskey seems significant in his wife's assessment of their situation but it also implies how certain foods/ drink can be a part of a person's identity and

how others 'know' them to be, in daily life. I shall now examine the relationship between food and identity in closer detail, to consider how severe ill-health affects and changes this within families.

'Eater Identities': food and who you are in your family

Indeed, it is widely acknowledged that food preferences and practices can act as a site for individual and group identity production and maintenance (Scholliers, 2001; Valentine, 1999; Caplan, 1997; Fischler, 1988).

Furthermore, it has also been argued that certain foods and eating practices make up categories which are used to order and structure social life and that these embody various social meanings (Douglas, 1975). Douglas (1975) writes in particular about the significance of 'the meal' and the symbolism of its various components which indicate the culturally specific notion of what constitutes a 'proper' meal (see also Charles and Kerr, 1988 and Murcott, 1983 in a family context). This is then something which operates to give order to social and family life and provides a sense of belonging through being able to participate and eat according to culturally mediated food-related practices. Not conforming to these socially recognised eating norms - such as in circumstances of ill-health - can mark someone out as 'different' and have consequences in terms of their identity and how others perceive them. Malcolm had particular eating difficulties due to an illness and some resultant surgery he had some years before his cancer diagnosis. He spoke about his experience of gendered eating identities as they are implicitly recognised in a 'couple' situation.

Malcolm: *And I've had to leave the table a few times because food has started sticking I just can't, I've had to give up erm so I do get, I still get embarrassed to a degree, not as much as I used to at a restaurant when they come and I'll often say to the lady that serves me 'now look I'll be leaving some of this but that's no reflection on your chef it's just that I can't' - 'oh that's alright'. But I like them to know... Asda's of course you can have a small meal*

Julie: *Yeah in their cafe*

Malcolm: *We have been to Asda's once and Tracey ordered what she wanted and I ordered what I wanted and one was the small meal and they naturally gave Tracey the small meal and I said 'no it's the other way round'. And she looked at me and I said 'that's a first for you int it?' - (laughter in voice) she said 'yes'.*

Like Malcolm, on the ward often patients would not have a 'full' or 'standard' size meal - they sometimes specified certain items to be left off the plate or to have a small amount of each. It was quite usual for really poorly patients to order soup (for some it was actually ordered for them), or just a simple pudding - usually ice cream. One patient in particular became almost synonymous with their preferred food of choice - bananas - and I noted that it became something of running joke that most meals had to incorporate these.

However, despite patients often not wanting a 'full' meal, the dinner trolley with a mountain of food - all the right portions to make a 'proper' meal - consistently rolled up to the ward and although staff did comment on what a shame it was that so much got wasted, the symbolic importance of the meal patients *might* eat seemed pervasive. Bearing in mind Douglas' analysis of the social functions of eating and empirical evidence demonstrating the

importance of a 'proper meal' for 'producing' family (Charles and Kerr, 1988; Murcott, 1983), the food dying people eat - the kinds, combinations and amounts - may have implications for their closeness to being a social person. As Seale explains:

The symbolic meanings of food, then, are maintained as people die, so that changes in feeding practices, alterations to the type of consistency of foodstuffs, a decline in appetite and eventual cessation run closely in parallel with a decline and eventual extinction of life itself... This mirrors the decline of the body and of self-control, leading eventually to the withdrawal of the self in a final fall from culture (1998: 165).

Thinking about matters of *identity* as they intersect with Seale's focus on sociality and culture, Fischler suggests that 'food makes the eater: it is therefore natural that the eater should try to make himself [or herself] by eating' (1988: 282). This implies the centrality of food to one's identity and suggests that if someone stops eating, or their eating practices change significantly, elements of selfhood might also change. And so when an individual is forced by illness to eat differently - whether it be different foods, in different places, using different utensils - it is important to note that not only is there a physical, bodily adjustment process, there is also a need to negotiate the transition in terms of how it affects the social self and a person's 'eater identity'.

Furthermore, this is a transitioning process which is negotiated and shared with the significant people around the ill and/or dying person. Jenkins (1996) writing about identification, reminds us that identity and feelings of

selfhood are a dialectic process where significant others are required to reflect back to us a sense of who we are for us to have an understanding of our own identity. For instance, Lupton (1994) argues that individual eating choices can only be explained by considering the interplay between food, subjectivity and family relationships, whilst Caplan explains that we need to understand eaters as social beings who 'continu[e] to use food to express significant relationships' (1997: 25). Morgan (1996) describes food as a family practice which is involved in 'producing' family and considers how as a site for 'specialist' *knowledge* - regarding for example, preparation, technique and family members' needs/ preferences - it can shape (notably) gendered power dynamics within the family (see also DeVault, 1991 and Charles and Kerr, 1988).

However, food knowledge also has a further relational significance, in the sense that having specific knowledge about the food preferences of others gives relatives a privileged knowledge about the 'eater identity' of others within their family and is something that might create a sense of 'us-ness' and belonging. I am referring here to different ways families might identify a member through, for example, their least favourite vegetable and how this becomes unequivocally family 'in-knowledge' and synonymous with whom that person is and how they are known to others in their family⁷⁵. To take an example from the ward, the mother of a patient who was having difficulties consuming food and liquids became the subject of a discussion I

⁷⁵ I am thinking about well-versed family stories which through their re-telling become familial 'in-knowledge' and tell for instance about how a particular individual is known within their family for their hatred of sprouts say, or of cabbage.

had with one of the nurses. Recounting a conversation they had had, she explained how the mother had found it difficult to understand why her child had recently refused what had been one of their *favourite* foods - chicken soup. Providing this example for my benefit the nurse then spoke more generally about how often families feel a strong need to continue to see their relative receive nourishment even when it is physiologically inappropriate (see McClement *et al.*, 2003). Thinking about the relationship between food and identity, it seems that the knowledge this mother had about her child's bodily deterioration was in conflict with the child's previous eater identity and how their food preferences were a part of who they were, and how they were known to her. What was happening at this point in the patient's illness may well have provoked the mother to recognise the imminence of death evoked by her child's withdrawal from food. However the 'change' in food preference she witnessed might *also* have involved further important relational implications that were firmly sited within the family's history and the implicit, mundane knowledge they shared of one another as family.

For Eddie Cox, an interview participant who had stomach cancer, food and eating practices were particularly significant in his day-to-day life and that of his family. During my first encounter with the Eddie and his wife Kathleen I was made aware instantly of the physical changes a lack of appetite and difficulty eating had made to Eddie's appearance. Following my visit I wrote:

'Before I am barely into the living room after removing my boots in the hallway, Kathleen has taken an unframed photo from the fireplace and shows it to me. It is a picture of Eddie some months or

may be a couple of years ago and Kathleen tells me she likes it, she is going to get it framed. It reminds her of Last of the Summer Wine [TV programme] as Eddie is leaning up against a country-style brick wall. She draws my attention to his rounded belly and I look up from the image to see Eddie rubbing the same spot which is now somewhat less rounded and his physique is skinny. I joke and ask if the belly in the photo is a beer-belly and Kathleen says she doesn't think so - telling me that she thinks it is a food belly and I briefly wonder about the significance for the couple of a change in Eddie's eating practices. She takes the photo back and props it up again on the fire place'.

Later as I interviewed the couple I learnt more about the complexities of food practices within families and how these relate to ideas of familial identity, associating individuals as particular kinds of eaters and by the type of appetite they once had.

Eddie: I hate em at all - all mealtimes I can't - the days are alright bar for the mealtimes

Kathleen: Yeah

Eddie: I can't stand meals

Kathleen: And he can't abide the cooking smells can you?

Eddie: But I have got to have something, I've got to have something

Kathleen: Yeah

Julie: And did you used to like your food Eddie?

Eddie: Oh aye I was always a big eater

Kathleen: Yeah! He used to have platefuls - he loved his dinner - he won't touch Yorkshire pudding anything like that [now] - bacon and egg

Eddie: *I'd have 2 or 3 dinners me (pause) but not now it takes me all my time trying to get one down now*

That Eddie was known within his family as being a 'big eater' is also something both his daughters identified with. Laura, the eldest daughter explained:

Laura: *Yeah cos at Christmas to be honest I mean I didn't think he'd be here at Christmas but there were nine of us and we had got two tables in there (dining room) and I says to him 'if you don't want to sit with us' you know I says 'you can have yours later'. But he did, he sat and had his dinner and he only had a right little bit but I mean like now its soup... then he were being able to eat little bits of things... it's odd because when you have... always known him to be a big eater and like now... he's so thin now.*

Similarly Claudia noted the cruel irony in how Eddie's inability to eat drew a sharp contrast with the kind of eater he was:

Claudia: *And it's weird me dad's thing in life were food; he'd eat owt me dad. I mean some of the meals me mother has produced you needed an iron stomach I mean she's not the world's best cook do you know what I mean? But erm and he never [complained] - 'it were lovely that, it were lovely that' - she could have put in horse manure with gravy on and he'd have eaten it! 'Lovely that'*

Julie: *So food was a massive part of who he was?*

Claudia: *Oh yeah, yeah he'd eat owt*

However for this couple it was not only Eddie's identity as a 'big eater' which had changed. As Morgan points out 'in many cases, the provision of proper food, in all the complex and negotiated sense of the term, may be closely bound up with a sense of self and feminine identity' and it serves as 'a key aspect of caring work' (1996: 160-161). In these terms the

intersection of intimacy, identity and knowledge became quite complex when Kathleen's place within the family as food provider was undermined, made uncertain and perhaps even displaced in certain ways by Eddie's difficulties with eating. The following discussion I had with their eldest daughter, Laura, suggests this.

Julie: ... Cos obviously eating is like quite an important part of your day isn't it? How's that for you, you know if you go around for tea or anything you know?

Laura: Well all he can have is soup and erm me mother kept ringing me up and 'he's not eating, he'll not have anything I make him, he's not eating it' and erm so I says to her 'why don't you make him some soup?' And me mum's one of these traditional people, she makes - I mean there was one day I went down and he looked shocking and she had made him some fried liver because he were anaemic so they said give him liver and I said to me mother like erm - she's old fashioned that she thinks everything should be fried. And erm I said to her 'why didn't you do him a liver casserole and do it in the oven?' and erm she didn't seem to get her head round it but then he's saying he didn't want any meat so I do this - in fact I'm cooking one at the minute - I do this erm parsnip soup and I made some and I took it him down and he right enjoyed it so I gave her the recipe and virtually that's what he's living on now...

It seems Kathleen's familial food knowledge may have been undermined by the appetite of her husband which she could no longer recognise or feed. Her 'traditional' fried approach was displaced by the seemingly more 'appropriate' practice of oven-cooking or preparation of soup suggested by her daughter. The significance of these changes for Kathleen's sense of who she was within the family were made more apparent in Claudia's and her daughter Joanna's reflections on how Eddie's eating had affected Kathleen's food practices. Once again the idea of having a 'proper' meal was pervasive and one which interlaced with Kathleen's identity as a

'traditional' food provider for her family (Charles and Kerr, 1988; Murcott, 1983).

Julie: *Do you have to; when you go up your nan and grandad's then do you have to worry about what you are eating then?*

Joanna: *No*

Julie: *You are alright, he doesn't seem to mind if you eat?*

Joanna: *I mean Saturday night I usually just go up there and have a sandwich or something don't I?*

Claudia: *Well before grandad got really to like how he is now like you go up and me mum would say 'oh I have saved you some Shepard's Pie Joanna'*

Joanna: *Well I mean she still saves me some like Yorkshire puddings and veg and stuff*

Claudia: *But it's not very often that she does that now it is cos she's not making it... but whereas me mum religiously it didn't matter if it were 100 degrees outside there was always a cooked dinner on the table whereas with now*

Joanna: *[A] proper cooked dinner*

Claudia: *Yeah*

Joanna: *Sunday dinner, proper Yorkshire puddings, beef, veg - proper*

Claudia: *It were like meat, potatoes and veg that's me mum, that's what me mum's always done - do you know what I mean? Like she'll er say for example our Kevin (Kathleen's son-in-law) - 'he comes home from work, he's worked all them hours and he comes home from work for a blooming salad! That's never going to fill him up that'. It's me mum's era. You know what I mean it were 50s housewife weren't it? How to look after your husband erm*

Julie: *It must be terribly difficult now when that role's not there or its causing such conflict?*

Claudia: *Yeah, it is, the root of evil is now food.*

Furthermore, ill relatives also shared examples of how food practices shaped how *they felt* about themselves and therefore it was not simply a matter of food being significant in terms of how it related to disease progress *per se*. It was also about how it affected processes of relationality and doing, or achieving being a relative, to particular others within the family. As I noted previously in the example on page 153-154, for Malcolm being able to maintain his energy levels to bake *his* rock cakes was very important. Later in the interview he made a link between baking rock buns and his relationship with granddaughter Paige and associated being able to *share* his method of preparing the cakes with having fun and being an *active* grandparent to her. In the following extract Tracey and Malcolm were negotiating the ambiguity that his bursts of being active brought to their identities and the care dynamic between them.

Malcolm: *But there are plenty of times you, Tracey will offer to make my supper but quite frankly I don't think it's right she's had a hard long day and everything and if I can do something*

Tracey: *You feel at the moment you'd be able to do it don't you?*

Malcolm: *I like doing it. I like, it's I don't know have you ever made rock cakes?*

Julie: *My grandad used to make rock cakes I haven't made them but he used to make them*

Malcolm: *They are dead easy to bake you know fifteen minutes and they are done. But I'm as proud as punch when I've made rock cakes (laughs a little) so occasionally I make some rock cakes*

Tracey: *It's lovely to see him doing it though*

Malcolm: *or I'll make some cheese straws or something you know it's I'm as proud as punch.*

Tracey: *You are*

Malcolm: *It's just something*

Tracey: *Then I feel bad it's a strange feeling because I feel bad cos he's doing it and yet really I should be glad that he's doing it you know what I mean?... And then sometimes he'll go down again but erm its when, when he starts doing things like that then I, I start to feel you know I should be doing that for you (giggles) and erm but I should let go really and let him do it and enjoy the fact that he's doing rather than thinking I feel bad because I'm not doing it.*

Malcolm: *Well I want to get practiced at doing things so that when Paige (granddaughter) comes I can do some baking with her and they're dead simple but she'll think they are wonderful (chuckles)*

In terms of Morgan's (1996) family practices, it appears that Malcolm felt he could achieve being grandad (and therefore having the identity of grandad) through 'doing' something active with Paige and he used the preparation of his rock cakes as an example. And so in revisiting what the different families shared with me or I observed about their time on the ward, I am reminded of Morgan's (1996) observation that:

In providing food, the provider is not merely undertaking a series of tasks or chores, although they may seem like that, *but also handling past, present and potential future expressions of emotion* (1996: 161 my emphasis added).

Although not always in the role of food provider (for instance particularly when their relative was in the hospice), in interactions around food, families were involved in negotiations of various temporal sorts. They were negotiating past memories about who the ill-person was in relation to their eater identity, they were dealing with (at times difficult) transitions in food preferences as a result of the disease in their present day-to-day lives, and as the extract from Malcolm and Tracey shows, food and food-related practices

could also embody potentialities for who the ill person might be in the future. Each of these temporal scenarios relate to processes of identification of individuals within the context of everyday family life and them being known as a particular person within a family.

Thus this data shows that changes in eating practices and food preference are about negotiations of identity and relationality and that cessation of appetite is not only salient for family experiences of terminal illness as an ominous precursor of movement towards death. Its routine, 'knowable' qualities and how these shape family life and relational dynamics, indicates once again how the mundane practices involved in the 'doing' of family life can reveal some of the emotional and practical complexities of relating as a family at this time.

Tension, Power and Conflict: the strain of food for families

As I have shown so far, despite having a taken-for-granted quality food is not as Morgan identifies, 'an emotionally neutral subject' (1996: 161). And whilst 'the giving of food and drink to the sick has long been used to symbolise compassionate care' (Seale, 1998: 160) when food represents the enemy or, as Eddie's daughter Claudia commented above, it becomes '*the root of evil*', there is scope on the part of both parties - provider and receiver - to feel frustrated and for tensions to ensue.

Because Eddie had stomach cancer, food was especially problematic for him and his family, but it was also something which seemed to create tensions within the Fielding family. For Anna's daughter Sue in particular, food was a source of deep concern and caused conflict between her and her mother.

About her worries that Anna does not follow her advice, Sue explained:

Sue: But you can't tell her, you know (laughter in voice) you can't sort of

Julie: Advise?

Sue: yeah. I've tried cos, I know she, she was being right sarcastic one of the days on phone to me about it and it really annoyed me because she were like trying to be clever and I thought well I'm only doing it cos I'm worried about her you know, but cos like you know I think I've sort of spent, I've had sleepless nights worrying about, thinking she's not eaten anything and she's not you know, she's not eating properly and things like that and but erm, (slight pause) like I've took meals up and things like that and half of the time she doesn't want em or she'll like if I phone and say do you want a bit of Sunday dinner - 'no don't fetch me anything I don't want anything', you know but. But I've found sometimes if you do take it take things up, then she will tend to eat them if they're there you know...

Similarly for the Mullins, Hugh's decline in appetite caused friction between himself and his wife Dot as it became an issue in the sense that it interrupted what were habitual, expected, routine eating patterns that had built up over the years.

Dot: We have always got biscuits - the other day, on Thursday I got a half a box of er biscuit barrel full of biscuits and I threw em in the dustbin cos they had been there that long, they had been there a fortnight - nobody had touched em

Julie: Why's that then?

Dot: Cos he doesn't bother now

Hugh: *I'm not bothered about*

Dot: *and I don't eat a lot. We waste more stuff don't we?*

Hugh: *No*

Dot: *If we get a loaf on a Monday you can guarantee it's still there on Thursday (laughing) so that goes in the bin*

Hugh: *Many a time. It isn't a lately because I have been having toast every morning*

Dot: *Well yeah you've not done too bad - yeah but when you've had toast you don't have nowt no more and unless I decide to cook*

Hugh: *I know it's getting you to cook now and again*

Dot: *No it isn't its getting you to eat it, int it? I'm going to start and get some tins of soup in I've got some in*

Hugh: *I don't want soup; I'm not a soup fan I never have been!*

Dot: *I know you're not*

Hugh: *Well I don't want soup*

Dot: *I mean I have got a freezer full of meat in there, joints of meat I've chucked, today I have thrown half of one away I cooked other day*

Hugh: *Beef aye*

Dot: *Big piece of beef; I cook it and it just gets thrown away. On a Sunday I always cook one on a Sunday, he'll have one piece I have about the same and the other goes in the bin. Dustbin gets more than us*

It becomes apparent in this exchange between Hugh and Dot that his cancer shaped the eating practices of the couple, as Dot seems to be lamenting something more than the loss of Hugh's appetite as an indication of his decline towards more serious ill-health and death. She seems frustrated, as her comments about stocking up on soup despite Hugh's objections imply.

Somehow soup - ambiguous as a food stuff due to its 'reduced-to-liquid' form - seems to symbolise the resignation Dot feels about there being no point in doing 'proper' cooking now. The couple were unhappy about the amount of food they were wasting but this also seemed to represent a change in how they once knew one another via their predictable eating patterns - a change which appeared to be taking some getting used to. Lately, as Dot wryly comments - the '*dustbin gets more than us*'. This small comment and use of '*us*' suggests powerfully that it was not only Hugh's eating practices that became a key focus; it was the relational aspect of how they ate as a couple which was also important. Thus, as Morgan argues, within families eating is a collectively produced affair.

Particular diets and food controls are conventionally administered or monitored through family relationships... Individuals who go on diets, for medical, political or cosmetic reasons, have to consider the question as to how these diets are to be woven into other eating practices within the household' (1996: 167).

Although Eddie Cox did not 'go on a diet' as such, his different eating patterns became a 'diet' of sorts - one of food-avoidance - and this had an impact upon the eating practices of his wife Kathleen. The couple explained how it caused strain and tension around food preparation in their home as often Eddie could not stand the smell of food cooking because it made him feel incredibly sick. At times this led to Kathleen avoiding cooking food for herself and the couple's children spoke separately about being worried that their mother was doing too much. It seemed that for Claudia and Brian in particular, their worries coalesced around what she was or was not eating. In an interview where her own daughter Joanna was also present, Claudia

described her concerns regarding Kathleen's food practices and how at times it caused (rather public) conflict between them.

Claudia: ... I don't know with me mum... she's got to like give herself energy and by her not eating she's going to be the next one that's going to be poorly I can see it

Julie: Is there a plan in the pipeline then to try and get her to eat? Or who's got to keep

Claudia: Well... last night I had a go with her in Tesco and I gave her the shock tactic; I'm probably you know it weren't, I was just annoyed... and I weren't in the best mood anyway cos someone were what do you call it - playing [up] (meaning Joanna her daughter)... we went shopping and I'd put my food on first and then me mum came to me so I put the divider between us and I were picking stuff up but prior to this me mum had asked me dad for some money for shopping cos they go halves like - so he went 'I don't know why I should give you bloody money' he says 'cos I'm not eating owt'. So like he like threw this £20 at me mum and er like me mum picked it up and he says 'and I want some bloody change from that'... So... like I say... I'm putting it on and it's like soup, soup, soup yet more soup, more soup, more soup, more soup, more soup

Joanna: And etc

Claudia: er what else were there? He's got a sweet-tooth at the moment er erm waffles, er erm

Joanna: Bread

Claudia: what else were there? Erm scones, cake, more soup, more soup, pop, milk, loaf of bread, more soup and then there were a chicken on the end. And I were packing and I looked and I went 'you've been shopping haven't you?' So she (Kathleen) says 'course I've been shopping what are you on about?' So I says 'this is all for me dad this' I says 'what are you going to eat?' 'Oh don't worry about me'. So I says 'what is there here mum where's your fruit, where's your veg?' I says 'where's a meal here?... I could see I were flustering her and I just looked at her and I said it like it weren't busy Tesco but I said it loud enough and I said it abruptly and I went 'mum at the end of the day it's me dad with stomach cancer that can't eat - not you'. And she looked and she like - she put her head down and I went 'you have got to start eating'... our Brian (brother) keeps going on at her about eating... And I mean last night she came

here and I says to her 'do you want me to make you some chips?' 'No I haven't got time I'm going to have a prawn cocktail when I go up home er I have got to get back for your dad'. And the only time really that she eats is when she goes out on a Wednesday er erm - she goes out with my Uncle - they go for a meal and she goes to the pub... whereas I've caught her having them supplements of me dad's... it's like me and our Brian have said to her today at the end of the day me dad is being selfish now with me mum even, he can't eat if its making him feel sick the smell of it he's got to appreciate me mum's got to eat

Claudia's 'no-nonsense' approach to being critical about how both her parents were managing the situation and her realisation that the mundane trials of daily life meant she was not in the best of moods, provides a gritty, 'honest' view of the way families continue to be imperfect, frustrating meshes of human relations despite the threat of death. It appeared that the siblings were closely involved with the day-to-day problems food was causing in their parent's home - Claudia in particular, because she lived only minutes away and called in most frequently. In fact due to her living in such close proximity she felt the pressure from her sister to try and be active in facilitating Kathleen's eating by providing her with an evening meal. Claudia seemed to resent this as she told me the following:

Claudia: And I mean it's like our Laura says to me the... other week... 'why don't you start cooking for me mum?' and I went 'Laura I haven't got a problem cooking for me mum I says 'but' I says - me mum's like religiously dinner's been on the table like between 1 and 2, I says 'I don't eat like that Laura' I says 'I work just like you work'. When I come in from 3 o'clock, say I get home at half past 3 quart to 4 then for me to make a dinner for me to like cook the meat it's like 6 well its 7 o'clock it can be sometimes 8 o'clock for me to cook a proper dinner its time consuming do you know what I mean? I says 'and I have asked me mum if she wants dinner' I says 'I have even offered to plate it her up but she won't

have it warmed up' I says... 'to cook like that it means me eating late and me mum won't eat late'.

The tensions experienced by the Cox family regarding food are embodied in spatial and temporal aspects of daily family life - for instance, in Claudia's frustration that her dad could (but does not) move into upstairs space in their home to avoid cooking smells that would allow Kathleen to have her food without worrying about precipitating Eddie's nausea. She also seemed irritated by her sister's lack of consideration that cooking for Kathleen would entail re-organising the temporality of eating within her own home to fit around the rigid ideas about when food should be prepared, and how it should be eaten (i.e. not warmed up), that were held by their mother.

Claudia concedes that this made Kathleen particularly difficult to monitor in terms of her eating.

Indeed, it appeared there were various layers of food monitoring ongoing within the wider family, from Claudia scrutinising the items in Kathleen's shopping trolley, to her reporting practices back to her brother Brian. The Cox siblings talk very much in terms of a discourse of care when discussing their concerns for Kathleen's eating-related well-being, and interestingly

Morgan reminds us that the:

...rights to control or monitor the eating practices of others clearly follow along generational lines. In a variety of ways, therefore, age and generation, as well as gender, are constructed in sites where family and food practices meet' (1996: 164).

Morgan focuses specifically upon the hierarchical relationship between parent and child in defining age-appropriate foods and eating practices (see also Lupton, 1996). In the case of the Cox family this dynamic seemed somewhat inverted, with Kathleen's children discussing, monitoring and deciding what was best for her. This point was made even more explicit by another participant, Sue, when she discussed her difficulties in trying to get her sick mother Anna to eat more.

Julie: Yeah, you know if your mum's not eating is that where there might be conflict between you and if you are trying to encourage her to get things (in the supermarket) and she doesn't want them or, how does it

Sue: Erm (pause)

Julie: or do you tend not to say anything, do you know?

Sue: No, not so much in the supermarket so much really I think cos she is buying food in the supermarket it's just when we are at home and when she's not got much food in and you know and I'll, like when I do give her her dinner or whatever she'll, she'll eat, well she does eat, she'll eat the rubbish off it generally she'll eat the roast potato and Yorkshire pudding (laughter in voice) you know

Julie: Yeah

Sue: that's about it. But then she'll leave most of the other things so there's, so she's eaten like the tiniest little portion of food and that's like when I start thinking God she didn't eat nothing there you know and I start worrying about her then. (Laughter in voice) I suppose it's like having a child in it? You know you are sat there

Julie: (overlapping with Sue) yeah it's like role reversal

Sue: sat worrying about what your kid's eating, yeah. But erm I mean she has eaten a bit of something you know but it's just I can see that she's so thin and you know... It's very, very hard (laughter) you know...

The way Sue talks about her mother's desire to eat 'rubbish' sounds like the archetypal parent scolding a child who only wants to eat sweets or leaves their dinner in favour of what is coming for dessert. In a separate interview, Sue's sister Cindy also noted the reversal of generational roles in the dynamic between Anna and Sue where food was concerned, and this implied that the tension was observed throughout the family as other members were aware of it. Cindy used her alternative approach to her mother's eating to show her competence and how she considered herself more able to understand Anna's situation than Sue. In the broader context of my impression of the family this is interesting, because in a more general sense there appeared to be tension between the siblings regarding who did what to most appropriately support Anna with her illness.

Cindy: ...it makes me laugh cos I thought yeah she's (Sue) swapped her daughter for my mother if you understand...

Julie: I think I do yeah

Cindy: yeah she's like apparently when people have got children and they leave home this that and the other you feel useless because you have got nowt else to do or, she's never expressed this me sister but obviously I've analysed, tried to analyse the situation cos me mum keeps saying 'our Sue won't leave me alone, she won't leave me alone, she doesn't realise what I eat'... you get to learn what me mum can eat erm I mean she's been through all these dieticians and things, but I do feel sorry for our Sue cos she is right hard and she is right trying you know and I think yeah I agree with our Sue she does need to eat more but our Sue needs to think hang on a minute she'll not be able to digest that... Alright she's not getting all the vitamins she needs but I just think while she's poorly let her eat what she wants - a bacon butty with tomato on it or something you know whatever erm but our Sue's trying to shove all these noodles and things down her (laughing)

Julie: Is that causing a bit of conflict then?

Cindy: It does actually with my mum yeah. It causes a hell of a lot of conflict (laughing) cos me mum's like 'will you stop; I'm not a child!' And our Sue's saying 'no I know you're not mum but you need to eat these things' and my mum knows she does but it won't sink into our Sue's head it's as if it's a mission

The fact that Cindy defined the conflict between Sue and Anna as a 'mission' on Sue's part reveals some of the mundane intensity (Robinson, 2008) which food can bring to daily family life. It also suggests that symbolic battle-lines had been drawn and that positions of power and powerlessness were being played out through the medium of food.

A rather different example of this dynamic was at work between Hugh and his wife Dot when the matter of Hugh having a meal whilst he visited the hospice day unit created tension, and what appeared to be, feelings of rejection on Dot's part. During one interview the following conversation took place:

Hugh: They only give you a course (of steroids) as a booster to pick you up. But yet there's talk of putting me on a lower dose permanent see

Julie: Yeah

Hugh: So I don't know whether they will do or what. I hope they do cos it gets me eating and keeps me eating see

Julie: Hmmm

Hugh: and there's no arguments over snap (food) - she can cook a meal and she knows I'm going to eat it

Julie: Hmmm so was that was a source of

Dot: Yeah

Julie: a lot of the friction between you a little bit then?

Hugh: *Well this is it she's always onto me I mean she's had a go at me today - 'you are eating that food up at the hospice you won't eat what I'm cooking' (Julie and Dot laugh) See*

Dot: *But he doesn't eat a lot do you?*

Hugh: *I don't get a lot up at the hospice*

Dot: *That's what I say but you used to you started eating a lot*

Hugh: *I know*

Julie: *Does it make you feel a bit because you like to care for Hugh and that does it make you feel a little bit?*

Dot: *I like to cook me own you know for em and er I think well he's going out and he's eating other people's - I know he's got to - and he knows they'll make him*

Hugh: *They won't make me love I have what I want up there if I don't want it up there I can have a sandwich or owt up there. If I say, if she brings the menu I say 'no there's nowt I fancy there love and I'm not hungry for owt like that' I could have a sandwich or owt you know they'll do a sandwich or owt*

Dot: *Oh that's why you keep asking me for sandwiches then when you are not*

Hugh: *No*

Dot: *Cos you never used to did you? You always had a big meal*

Dot's idea that the hospice as an institution could exert power over Hugh to *make* him eat, is particularly telling when considered alongside what appear to be her feelings of powerlessness. She interprets her lesser ability to make Hugh eat as a matter of him not *having* to eat for her, but ironically fails to understand that Hugh feels under *less* pressure to eat a 'proper' meal at the hospice because, as he points out, he can choose to have something more manageable there - a sandwich. Dot's response appears almost like an accusation of sorts - as though Hugh had been 'caught out' - when she

reflects that this was why he was always asking her for sandwiches. What she implied was somehow interlaced with a sense that Hugh was betraying their home cooking by bringing less familiar practices into their usual way of having meals and eating. The fact that Dot felt the hospice had more influence than her is conveyed in her final statement that Hugh never used to eat sandwiches - he always wanted a 'big' (by implication 'proper') meal. Although there was laughter between the couple during the exchange and the conversation was not heated as such, some tension was evident. Hugh's mimicking of Dot having '*a go*' at him about eating food at the hospice but not eating what she prepares at home, gives a clear indication of the discussions which were on-going between the couple day-to-day, as food became a source of conflict and misunderstanding between them. Dot's responses implied her feelings of rejection as well as relative powerlessness in the situation. Her established way of liking to '*cook me own*' expressed something of the unity cemented between the two of them in Hugh's consumption of the food she had prepared for them both. Indeed, the sense that eating in their household was a shared pursuit was made clear when Dot explained she felt less like eating when Hugh was not having much.

Dot: (Laughing) I mean there's only 2 of us. Well we haven't been eating it have we? (meat they have bought)

Julie: Has it made, have you felt, being eating less then as Hugh eats less? Does it make you not want to eat as much?

Dot: I don't bother when he doesn't want nowt

Hugh: Well she's not cooking for herself see

Julie: Yeah

Hugh's comment suggests that there is little point in doing proper meals - cooking (see Murcott, 1983) - for just one person, and this was also the case for Kathleen Cox, who admitted that feeding herself got 'put off' because Eddie was no longer always eating the same meals and she was preparing separate food for him.

Kathleen: ... but if I were cooking a Sunday dinner and I were doing potatoes he'd have just a little bit of Yorkshire Pudding as it is cut up in bits yeah but the potatoes I mash em well and then I cut a bit of meat up and put em in and mix em altogether so it grates all the meat up

Julie: Yeah

Kathleen: but you see he's getting now he doesn't want meat at all

Julie: Hmmm

Kathleen: So I'm making for him separate

Eddie: What is it a vegan?

Julie: (Julie laughs a little) Yeah a plant-eater

Kathleen: Yeah but what it is I mean I'm not a big eater myself I have always liked me dinner

Julie: Hmmm

Kathleen: Me dinner is me main meal - he used to go mad cos I wouldn't have breakfast in a morning but I've started having a slice of toast now in a morning but er with seeing to Eddie and that I keep putting myself off

Julie: Yeah

Kathleen: I'll get something later, I'll get something later and that later never comes do you know what I mean?

Julie: Hmmm

Kathleen: So I have had to put me foot down with a firm hand because I know if I'm no good he's going to be no good

Julie: Yeah

Therefore, these latter examples suggest that for some families food-related tensions stem from the frustration of having experienced eating as constitutive of family life and feeling like a 'family' (DeVault, 1991; Charles and Kerr, 1988) - of a sense of 'relatedness' (Smart, 2007: 46-49) - rather than an individualistic pursuit. As I discussed in the previous section on familial and 'eater identities', how families relate to and 'know' one another as a result of food practices, means that the relational nature of eating and its involvement in the production of family life, makes it significant for understanding how families negotiate experiences and changes - which can be challenging as this last section has shown - brought about by life-threatening illness.

Conclusion

The data I have drawn on in this chapter show how mundane practices constitute complexity and provide insight into the production of everyday family life (Morgan, 1996). In particular I have used family data to explore food as a key site for understanding family experiences of illness and dying more comprehensively, precisely because of its *everyday* qualities. What I have argued suggests that examining eating practices can go beyond the obvious equation between a decline in food consumption and deterioration towards death, and provide a more nuanced understanding of how the prospect, and experience of dying, is lived with day-to-day.

More specifically, drawing on empirical evidence which has demonstrated how food is constitutive of family, a specific case has been made for the identification of food and eating as *relational* in the context of severe ill-health and dying. Firstly I explored how day-to-day practices involve food monitoring as a process of sense-making for families regarding the illness trajectory, and then I considered how this intersects with the renegotiation of familial identities. I then went on to consider data which suggests that changes in food and eating practices can create tensions within families that, whilst becoming a part of day-to-day living with severe ill-health, can also necessitate a renegotiation of the experience of relatedness or being a 'family'.

Finally, having examined how eating practices are negotiated by families, this chapter has begun to explore how families experience change as a result of life-threatening illness. In the following two chapters I develop my analysis of transitions and change further, and use my data to explore how families experience both *continuity* and *change* in day-to-day life during the illness/ dying process.

Chapter 5

Day-to-day Living: continuity and routine in family life

Introduction

The family experiences I discuss in this chapter make additional and important contributions to understanding the relationship between mundane everyday life and experiencing illness and dying. As in the previous chapter, whilst my analysis does suggest that negotiating dying and the prospect of death can at times be difficult for families, here I focus specifically upon experiences of *continuity* and consider how these are negotiated by families through an immersion *within* everyday life and its routines and mundane practices.

'Modern' dying in western societies often takes the form of an extended process where, due to early diagnosis of life-limiting conditions, terminally ill individuals and their families live with the knowledge of impending death over a variable, but often protracted period of time (Green, 2008, Field, 1996, Kellehear, 1990). It seems unlikely, therefore, that for many families the 'extremities' of more existential processes such as spiritual soul-searching⁷⁶, emotional 'crisis' and emotive communication surrounding the issue of death, would be their *only* focus over this time. Yet even in families where this might predominantly be the case, the *extended* nature of

⁷⁶ Asking 'why us?' for example.

these intense processes would make the experience one of *mundane intensity*, and necessitate a rethink of how extreme and intense experience intersects with mundane, domestic life (Robinson, 2008). Therefore, it can be argued that these more 'intense' processes often associated with dying, do not provide a comprehensive picture of daily life during contemporary dying. And this then begs the question of what families are *doing* over the illness/dying process in its less intense moments.

Providing some insight into this question is the purpose of this chapter as it draws on Highmore's (2002) problematisation of separating the everyday from what are considered life's more extraordinary or significant experiences. Arguing that there should be a shift in how the two are contrasted with each other, Highmore suggests the everyday should be brought more to the fore, rather than remaining relegated as an insignificant backdrop. As the data in this chapter will show, this can enable a more situated understanding of family experiences of illness and dying. Drawing primarily on two family case studies, it will show how mundane, daily life is integral to understanding the ways in which families are produced and can maintain a sense of continuity during circumstances of impending death. My analysis focuses in particular upon how the families understand their relationships with each other, and their experiences of routine, day-to-day life. Consequently I argue that individuals and their families come to know their *lived experiences* (Felski, 1999) of life-threatening illness through their on-going negotiation of, and reflection upon, everyday life and their engagement in mundane family practices.

Revisiting Emotion and the Mundane

Chapter 3 highlighted the complex intersection of emotive and mundane moments in my fieldwork experience. It is possible to identify the same complex interlacing at work in the following accounts of my time on the ward which appear to involve the symbolism of mundane objects to understand emotional transitions brought about by the experience of terminal illness. About a conversation with May, an older patient in her 70s, I noted the following.

‘She is happy to talk and I mention to her about the research. She places the sewing on the bed and squeezes her hands. She explains that the nurses have told her she ought to leave off with the sewing for a while - but she wants something to do and cheekily implies she’ll see what she can get away with. She tells me that she orders the cloths (which appear to be tablecloths) from Wales because the linen is so hardwearing and will last a lifetime. She is stitching colourful flowers onto the fabric and explains that she has made loads in the past and that she gives them as gifts to her daughter-in-laws - something they can keep. This one is for one of the nurses. May says that she is going to have to stop doing them soon because they don’t look neat anymore - they have to be neat. She makes a remark about how she’ll not be around when the time comes for one of her daughter-in-laws to iron a particularly large cloth she has made for her. I take this to mean that she will have died. We were discussing what a pain they can be when it comes to ironing them’.

The understated way in which May expresses an awareness of her impending death is contextualised by her routine practice of embroidery. Her manner is pragmatic, and acknowledgement of her transition towards

death comes not in overtly emotive dialogue, but from the realisation that she will not be around when the mundane task of ironing the tablecloth is undertaken by her daughter-in-law. On another occasion a patient's son explained what preparations his family were making at home for when his dad, Don, was discharged from the hospice. He mentions moving a particular sideboard in Don's home and what he discusses suggests how the emotional transitions brought about by the illness are embedded within the materiality of family life.

'When he told me that he and his family were staying at his mum and dad's he laughed and said the kids loved playing around on their grandad's electronic bed now that he was not there to sleep in it. We spoke a little about the significance of changes made around the home due to illness and he told me that currently they were trying to sort out how to make a clear walk-way for Don so he could get from his bedroom to the bathroom. This has involved a sideboard having to be moved - one which he believes holds emotional attachment/significance for Don as it is where he has always kept his golf clubs'.

I began this chapter by revisiting this intersection of the mundane with the emotional aspects of living with life-threatening illness, in order to underline the importance of foregrounding what might otherwise be taken-for-granted data about mundane daily life. As the following exchange between Eddie, a hospice day care patient, and his wife Kathleen so poignantly makes clear, the most mundane of acts are significant experiential sites for negotiating how families continue to be, and

understand themselves as 'related' (Smart, 2007), in the context of terminal illness.

Julie: So are you, do you need a lot of support with things Eddie at the minute? Or are you

Eddie: No I mean I don't rely on anybody for owt do I?

Kathleen: No, he never complains, he showers himself but I'm always here in case he falls out of the shower... er he can dress himself er

Eddie: I have a shave; I can shave myself and things like that

Kathleen: Yeah if he's up before me he'll fetch me a cup of tea up to bed... which he has done for 50 odd years when he used to be on shifts I always had a cup of tea in bed and if he's up before me now I get a cup of tea in bed - it might take him half an hour to get upstairs with it and it might be a bit on the chilly side when you get it, but you get it.

Kathleen's morning cuppa might now be a cold one, but the significance of the fact that she still receives this drink which she suggests has become a ritual in how the couple 'do' being husband and wife, seems to define something between them. It allows her to tell me about how they continue to be that couple in spite of Eddie's illness. Therefore, following Highmore (2002) and Felski (1999) I suggest that the very ordinariness of this data is important, as it can enable a more situated understanding of family experiences.

To flesh out more clearly the role of mundane, everyday life in families' lived experiences as a anchor-point from which to make sense of illness and death, I present the following family case studies. Here I draw specifically

upon how ordinary, taken-for-granted aspects of daily life expressed in interview data reveal ways in which families are engaged in processes of doing family and relating to each other.

Daily Life for the Bakers

Malcolm, his wife Tracey and their daughter Karen were one of two families in my interview sample who had been living with long-term chronic illness within the family, in addition to the diagnosis of Malcolm's leukaemia. Since the very first months of his marriage to Tracey 30 years ago, Malcolm suffered serious and at times life-threatening illness, meaning that for long periods he was unable to work and experienced chronic tiredness which restricted aspects of daily living. The fact that Malcolm also had difficulties with his sleep pattern meant that the tiredness he experienced as a result of his condition and poor-health was particularly problematic. He also had difficulty eating and digesting food which was caused by a previous illness that had resulted in surgery to his stomach. At the time that the family were involved in my research, Malcolm was once again unable to work and Tracey had reduced her working hours to just two days a week to provide care for him. On one of the days when Tracey was at work, Malcolm attended the hospice day unit and on the other sometimes - and especially when Malcolm was less well - their daughter Karen would come round to the house to do tidying up and spend time with her dad. Although the couple explained that Malcolm's capacity to prepare his own meals and to 'potter' around or pop out in the car varied, most often it appeared that Tracey was responsible for running their home, for preparing

meals and generally looking after Malcolm's welfare. She was in charge of Malcolm's medication routine and dealt with family budgeting matters. Once a week, in the evening, she made the journey without Malcolm to visit their son, his wife and their granddaughter who lived outside of town. The couple acknowledged that due to Malcolm's waning health and excessive need to rest he was missing regular contact with their granddaughter. He could, however make shorter trips, usually in the morning, to church or the supermarket.

Malcolm and Tracey's home was in a more affluent area of the town and they appeared both materially and culturally, to be one of the few families from my sample that I could define as 'middle class'⁷⁷. Their home was fairly large and traditionally decorated. Despite being in the process of redecoration, the house was always tidy and when I arrived for interviews I was served tea or juice on a tray with cakes or biscuits. Generally the family had traditional ideas about 'family' and the fact that daily life did not always mirror these seemed to be the result of Malcolm's illness, rather than choice. So, for instance, Malcolm spoke about the importance of having a male breadwinner in the family and how it had taken him many years to come to terms with the fact that he could not work to support his family and that Tracey had had to perform roles which otherwise would have fallen to him. Their daughter Karen was extremely close to her parents and held them both in high regard for the way they had done all they could to give

⁷⁷ Though from our conversations it seemed that Malcolm in particular came from a more 'working class' background.

her a happy childhood despite Malcolm's poor-health. Karen had a very busy work schedule and she was married to Tom. They usually visited Malcolm and Tracey's home on Sundays for lunch.

And so, whilst the illness experience was nothing new to the Baker family, they did concede that the life-limiting nature of Malcolm's cancer meant something qualitatively different from previous illness occasions, with time especially after his initial diagnosis, feeling finite. They considered themselves to manage nonetheless, and stated frequently how their Christian beliefs were of paramount importance in how they dealt with the illness and life generally. Interestingly, at times, they referred to this in rather mundane ways, stating that God was simply a part of their everyday lives and existential matters such as going to heaven (as they all believed Malcolm would) was something they considered alongside daily concerns such as trusting in God that Malcolm would be okay whilst out in the car. Talking about a recent incident where he got stuck in a traffic jam, the couple explained the role of God in managing their day-to-day lives.

Malcolm: So that, the sort of pressure that Tracey's talking about was not on me but it was going through my mind... I hadn't got my mobile on me and I thought oh poor Tracey she's going to be worried she'll be thinking something has happened to me.

Julie: Yeah

Tracey: Shouldn't really you know. We shouldn't do that - we should not be worried.

Malcolm: Well I know we shouldn't (laughs) but we do.

Tracey: No

Malcolm: *Perhaps our faith isn't as much; as good as we (laughing) reckon it is.*

Tracey: *Hmmm, well that's it really we shouldn't should we?*

Julie: *Is that because you think that you know, whatever has occurred God will be*

Tracey: *Yes*

Julie: *there and he will be*

Tracey: *Yeah, we have to trust, I mean at moments when we are worried then we should, we send out with a prayer - Lord undertake, look after him - and then we should trust that he is doing. But you see typical human beings.*

This notion of relational time and structure - of being expected home at a certain time and being acutely aware of each other's movements in space - indicates concern about Malcolm's fragile health, but it also reflects a wider preoccupation with routine and predictability which was integral to the couple's account of their daily life. As Malcolm explained:

Malcolm: *But I think when you are poorly this, this routine business is er you know its lord and master almost of your life (pause)... I think when you are poorly it does and your medication and your sleep and your meals and everything else it does govern your life... and it's difficult for Tracey because Tracey has to fit into that routine whereas other times she sort of 'oh ok you know it's whatever time it is, I'll go up... and do the shopping and I'll have a late lunch' you know - which you do sometimes*

Tracey: *Hmmm*

Malcolm: *you go sometimes*

Tracey: *But that causes you a problem then, doesn't it, cos you are thinking I should have had my lunch before this and*

Malcolm: *Well it can do erm, it can do*

Tracey: *It does - you don't like it do you?*

Malcolm: *No I don't like it*

Tracey: *No*

Malcolm: *I've got to this stage where I am in this routine and I like me dinner about one-ish or twelve, one-ish whatever - erm but like you the other day... I didn't get back - that's right I'd been to the church and then I'd gone looking for this printer thingy stuff and... there'd been this accident so it was about half past three when I got in and you'd only just finished your dinner and erm about an hour later I'm sort of pottering around looking and moving pots and pans cos I want me tea (Tracey laughs). 'I've only just had my dinner' (imitating Tracey).*

As this conversation demonstrates, Malcolm's very rigid sense of mealtimes was, on occasions in tension with Tracey's more fluid approach and this marked out and reinforced an awareness of separation between the couple that was understood by Malcolm in this instance through his clattering of pots and pans that needed to be re-organised to accommodate the two different schedules. The way he describes the dynamic between the two of them suggests perhaps he was shuffling items around the kitchen and 'looking' and 'pottering' as a way of hinting at and asserting his own 'clock time'. The indirect way he goes about this implies, as Tracey states above, that it can be a 'problem' when one routine clashes with another. This notion of discord between the couple and a need to negotiate each other's daily movements was a reoccurring theme throughout their interviews. Here Malcolm explains that even on a special occasion, his need for routine leads to a failed attempt to do something together socially, as a family.

Malcolm: *I found it you see the break in routine can affect - you get into this routine and it can affect you I went to the Christmas fair which was what six o'clock was it?... Cos normally I'd be in bed... but I was sat there and it was a huge din in these things (hearing*

aids) just echoes so much and nothing I did with these helped and that and the fact that I was just sat waiting for everything to start and everything I just got too much didn't it? And I just I had to go. So I went home and came back again and picked them (Karen and Tracey) up. But so that was unfortunate but there are things like that you know and you do you get as a patient or whatever you get yourself into this routine and it's like a medication almost 'oh please don't change it I've just got right on it' and you get yourself into this routine and you don't want that routine to change and its, it's a problem...

Again Malcolm identified that his desperate need for this routine was experienced as a *'problem'*, a view shared by Tracey who spoke often about the strange family life they all experienced as a result of Malcolm's *'routine'*. The sense that the couple were living in separate *'clock times'* became evident when they talked about being on holiday and, as they put it, there was a *'carry off'* involved in getting to sleep. Although Malcolm had difficulty sleeping generally, on this occasion the *'queerness'* of this behaviour (as Tracey describes it) is more apparent because they are in a different place and Malcolm's usual routine practices of sleep management (e.g. staying up and watching TV) are displaced.

Malcolm: Well I've braved up a bit recently that if we are in a hotel or something I just get in my dressing gown and I go downstairs and sit in their lounge and read some magazines and blow it if somebody comes in that's their hard cheese (laughs)... But erm at other times you know you just kind of er well I've known that I have gone and sat in the toilet and read the paper you know because I didn't want to put a light on or whatever but other times we've had some, a really decent room and er I can sort of, there is an easy chair and I can put a little light on and read you know but it's, it's not easy.

Tracey: It seems a queer carry off though with us doesn't it?

Although the difficulties experienced as a result of Malcolm's sleep pattern are magnified by the spatial constrictions of a hotel room, bedtimes were a key focus for Tracey, where Malcolm's extensive tiredness and the routine this necessitated '*mixed up*' their whole life more generally. In one interview Malcolm explained that he tends to sleep in short bursts and therefore goes to bed a few times throughout the day and evening, leaving Tracey alone for much of the time.

Tracey: You see your whole life is, is (pause) is mixed up with regard to his sleep... you find at the moment that you go; you like your routine as well don't you?

Malcolm: I have problems sleeping... I have medication for it but I've had problems for donkey's years and the only way I can cope with it generally is the medication and a strict routine how it works for me... I am, some people are morning people and some people are evening people but I'm a morning person I'm awake... and then I wind down during the day and some of the other complaints that I have means that I can't eat much... so it has to be small and often... and I get just so sleepy its crazy. And that's how I am and I sort of up for me dinner and sometimes I go to bed after that but then up again and then (pause) go to bed for me tea and I have a couple of hours or so in bed... and then I get up and I come down and Tracey is off to bed (Malcolm and Tracey laugh). And I'm there watching TV til 1 o'clock 2 o'clock in the morning until I can just feel myself going and then either sleep on the settee or whatever. The situation now is I'll get up onto that bed (double bed in the interview room), er so

Tracey: Yeah I find it a bit lonely sometimes

Malcolm: So you need Russell (dog) don't you?

Tracey: Erm you know the mornings really are the only times when we can be together and then, and then it's you are either in bed; well you are just in bed aren't you - usually? Erm (slight pause) so I think evenings are the worse because you go to bed so early and you are shattered anyway sometimes afternoons you are shattered and you are in bed aren't you?

Talking about how this affected their relationship, they both referred to themselves frequently as like *'ships passing in the night'*. However Tracey seemed to express more overt regret and dissatisfaction with the situation, and Malcolm, despite at times conceding routine could be a problem, made attempts to *'normalise'* their discordant *'life clocks'*.

Tracey: *It is like caused a separation hasn't it... in that sense?*

Malcolm: *But some people live like that. I mean some husbands and wives they have different jobs different you know social things and erm they, they that's their lifestyle anyway*

Julie: *But would you say that this style that you're in is because of the illness pretty much?*

Tracey: *I think so*

Malcolm: *Oh yeah, yeah [it] wouldn't happen we'd be doing everything together - well practically we would still have our friends or whatever and still do things separately but it would be a life that we'd live together we'd have meals together, we'd have sleep together in the same room, probably go to bed at the same time. I don't know about that actually*

Tracey: *What go to bed at the same time? (Laughs)*

Malcolm: *Well you have always been a late bird and I've always been an early. It was instilled*

Tracey: *But don't you think though that it would have affected me if you were going to bed at half past ten then I would go to bed at half past ten if it was a proper carry on?*

Malcolm: *It might have been*

Tracey: *But I tend to be later now cos you are getting up!*

In their conversation here it is clear that Malcolm and Tracey are reflecting on their own family practices but they also suggest that there is such a thing as *'a proper carry on'* and they have an idea or a model of how couples

should 'do' being a couple. In Gillis' (1996) words, they have an idea of family that they are living *by* and which is made meaningful via the identification that this is something different to the family they live *with*. Malcolm suggests that had it not been for his illness they would have conducted their lives in ways that more closely reflected the idea of 'proper' family life. The couple acknowledged here the difficulty they had sometimes in 'doing' what it takes to be 'a family' because of the illness.

Notably in the above conversation, Tracey also explains how recently Malcolm had been able to get up again in the evening and come downstairs for a while; and so to spend more time with him she pushed her own bedtime back even further. Not only is this something which perhaps moves them closer in their imagination of themselves as a couple towards having a 'normal' family life, I also realised that it was an indication of Malcolm's increased 'wellness' and it was therefore more generally significant for the family. In fact, as I got to know the Bakers over a period of about 10 months, Malcolm's cancer-related health had reached a plateau and actually seemed to steadily improve in some respects. This created a feeling of cautious hopefulness which was suppressed and moderated to ensure hopes were not falsely raised. However, towards my final meetings with the family the accuracy of Malcolm's 'terminal' status was being tentatively questioned. More generally the family reminded me throughout their accounts of daily life that they were required to negotiate *not* what they had anticipated would be a steadily progressing and linear deterioration in Malcolm's health, but periods of going up, going down and plateau. This

was understood and given meaning via processes of negotiation and re-evaluation in everyday family life of the activities Malcolm was able to do. I discussed this in my second interview with their daughter Karen.

Karen: Yeah, yeah everything's good at the minute. Erm I was thinking it's not really a massive case study for you really cos you haven't really seen a lot of difference kind of since last time.

Julie: But that's the reality of your situation and I think that's useful for me because... there are families that are living a really quite prolonged period of time

Karen: Yeah

Julie: with this thing but then like you say it's very much day-to-day things have to keep going and you have to, not always keep adapting to a constant degeneration but also adapting to positivity and getting better in some instances... in that it's not necessarily that families are preparing for somebody sort of losing independence and worse, it actually might be adapting to - ok well he's better now so like you say, we'll have to feel ok about him driving!

Earlier in the interview Karen spoke about Malcolm's driving and explained that this was something she and Tracey had talked about, as they were worried that he might not be fit enough to take this up again despite a recent 'upturn' in health. In a separate interview the couple raise this matter themselves as we are discussing Malcolm's improvement since I saw the family last. Talking more generally about how facets of their relationship - trust and reassurance - shift in line with ups and downs in the illness, the couple explain clearly how decisions that make daily life happen become a site for negotiation which shapes their awareness and experience of the illness as a non-linear process.

Tracey: What I was going to say, it has made me realise though that I mean it took a bit of telling me that time didn't it? 'You've got to

bank it; you've got to bank it' (Malcolm's advice about family finance matter). Erm since Malcolm's illness especially latterly, I've not found it as easy to trust his judgement as I did before.

Malcolm: *Hmmm*

Tracey: *Erm probably because of the illness (pause) that you because I know that you are not grasping things the same*

Malcolm: *No*

Tracey: *or you are not erm you know understanding things and everything as well as you used to do because at one, I mean you were always very bright and capable and one of the things that really attracted me to him was the fact that he, you know he was erm straight and you sort of felt you could trust his judgement and erm you know er very (sighs) what can I say? (Pause) capable right ok, so it is more difficult when somebody's poorly like that to you know to trust that they have judged correctly - or grasped everything and so you tend to not be quite as erm... You tend to be a bit more wary of his judgement and therefore and you know at one point I would not have questioned it and I'd have felt right he knows what he's doing that's it you know, but (laughs a little).*

Malcolm: *... when you have sort of been ill and you've had to hand a lot of responsibility to someone else to your wife shall we say and then perhaps you pick up and get better and you want to take those in to your own hands but your wife has learnt over the years over the long period that you've been ill how to handle these things herself and to make her own decisions then you have got a problem because Tracey has got one set of decisions and I've got coming back into it make another set of decisions; neither set of decisions can be right or wrong it doesn't really matter it's like whether you go the long route or the short route... it doesn't really matter you get there in the end but you can find that frustrating and I think I do sometimes find that frustrating that Tracey has got a will and whereas once she would have deferred to me she's 'oh I can sort this one out I know what I'm doing' (laughs) and I'll say, it's very much like that if we are sat in the car and we're deciding where to go (laughs) and which route to get and 'oh I know where' and I'm like 'oh that's not the way to do it' you know and then I've thought oh shut up and leave her alone.*

Tracey: *Yes*

Malcolm: *she's the one that's driving (Tracey laughs)*

It appears neither their daily life nor the illness was experienced by the family in static, linear or 'given' ways, but as shifting and fluid processes which required negotiation and gave mutual meaning to each other. As Kellehear (2009a) has argued, although dying is often represented as a 'journey' or in terms of linear stages, many dying experiences are characterised by 'oscillation'. He writes:

Dying, as an identity and as a physical experience, is not always an uninterrupted trajectory of decline. Dying can be, and often is, an intermittent experience determined by disease process and the social roles and circumstances that prevail in end-of-life situations (2009a: 8).

Notably Kellehear mentions identity and social roles. This is something which resonates with how Malcolm's status within his family *vis a vis* his 'doing capacity' is changeable or oscillates rather than irreversibly declines. It is also an inherently relational process where his status or identity as 'doer' is monitored and ascribed in the flow of daily life by those close to him (see Jenkins, 1996).

In the data I have presented here, this family clearly show how they drew on instances from their day-to-day lives to express how they understood their relations with one another in the context of Malcolm's terminal illness. As the latter example shows, neither the illness process nor the family's everyday life could be separated out into discrete experiences; rather they give mutual meaning to each other. Moreover it can be argued that for this family, at times, the momentous and existential - 'the big matter of death' - were lived out through mundane material things and everyday routines. So,

whilst Malcolm and Tracey were ultimately faced with a separation that would be forever, they focused and perhaps made sense of this bigger separation through more preoccupying separations in everyday life, as these were experienced in their sleep, eating and pottering routines.

Daily Life for the Kennys

Jackie Kenny also talked in great detail about the routine aspects of her daily life with husband Clive. Having enjoyed a few years of good health after her retirement and leading what she described as an active and healthy lifestyle, when I first met Jackie, she was spending longer periods of time in her home due to pain and symptom management problems related to her cancer. She had already had some surgery and one cycle of chemotherapy before I met her and during the time I was in contact she did have another round of treatment, although her condition had advanced considerably by the time of the second cycle and it was not long after receiving this that she died in the hospice. Despite at times feeling fed up with bouts of persistent pain and discomfort, Jackie was not at all resentful about her situation and told me that *'it wasn't such a bad existence'*. Indeed the couple seemed to live fairly comfortably and Jackie was content in their home. Although Jackie did talk about a bit of decorating she had thought about doing, between my first and second interview she had decided that a different mirror and a couple of new ornaments would do the trick nicely and this gave her something different to look at from her usual place which was her chair by the living room window. Messing about with more extensive redecoration was something that she just could not be bothered about

anymore. Their home was not very large, but it had a nice-sized plot of land at the back and a small garden area at the front of the property which Jackie liked to maintain (when she could), and potter around in. Prior to Jackie's illness the couple tended to walk to places or use public transport - they had never owned a car - and at the time I met them it had become Clive's task to bring their food and household shopping from the town centre. Although Jackie described how, since her diagnosis, Clive had practically '*taken over*' the running of their home - something which she had been almost solely responsible for before - she also made a point of explaining that when their two children were young and she worked shifts, Clive had prepared meals for Johnny and Emma - and when she worked on weekends he did the family shopping. However, more generally and in terms of managing finances, making routine phone calls - for instance to renew his prescription - or dealing with bills, making out cheques and similar household matters, these tasks had always been Jackie's responsibility. And so in some respects she was able to view her cancer as having - in her words - '*some good come out of it*', in the sense that it made Clive take more responsibility for their day-to-day living which she felt in turn had increased his confidence.

Although Jackie's husband did not wish to take part in the interviews, he was very welcoming and when I first visited their home he finished up the pots he had been washing in the sink and came to sit with us for a while to tell me about how Jackie's health had deteriorated over the last couple of years. Later, after he left to spend a couple of hours with friends in a local pub, Jackie explained that Clive was insecure about himself in certain

situations and that he often found it easier to hide his emotions away. Jackie was a calm, pragmatic woman with a soft, reflective humour and stoical approach to her illness. Routine for Jackie did not seem to be such a problem; providing somewhat of a contrast to the Bakers. Yet whilst routine appeared to be experienced differently by the two couples, its importance in both cases was nonetheless evident. Jackie presented the routinisation of her life very much in terms of synchronicity - mundane tasks and exchanges which bound Clive and herself together into predictable actions and dialogue. The changes to daily life necessitated by her illness seemed to have brought the 'life clocks' of the couple closer. Jackie appeared to find the fact that her life was so carefully patterned somewhat amusing and she laughed about the intricate ways in which the husband she used to 'carry about' and do everything for, now anticipated and was aware of her most mundane needs. Describing a typical day she told me the following:

Jackie: Well we normally have breakfast... about quart to 10 as I say we get up and then Clive fetches the paper first and er I go in the kitchen... while he goes to the shop. What he does he has porridge Clive every (laughs) every morning he has porridge and I usually have some cereals of some description and I tend to have some figs or some prunes or some Albran... well they are all kept in a cupboard in the kitchen which is a bit low down actually er and at one time I couldn't get, I couldn't get stuff out so there again he's got into the habit of getting it out so now you see he goes to the shop, he'll say 'I'm just going for the paper I've got stuff out' and he gets it all out ready all his things and the pan for his porridge and then I make it you see - by the time he comes back his porridge is ready but then he washes up after breakfast and then like we'll have a coffee mid-morning or something and then when it gets to lunchtime we usually just have a sandwich, most days we have like a snack - today he's had some porkpie and that but I go and prepare it then again he washes up and then at evening time well it's not very often I eat a proper dinner but Clive does he'll have every day he'll either have a pork chop and some potatoes and vegetables or some stewing steak

or steak and kidney pie or fish and peas and potatoes and that and he'll go in and he'll say to me like 'what we having?' and he'll get it out of the freezer whatever cos see he knows where everything is he's in charge, he's put everything away he knows where it all is, he'll get it out earlier in the day... and then he'll say 'how many potatoes do you want?' and I'll say 'oh I don't think I want any potatoes tonight' or if I do I'll go and show him what I want say 'just that little one there will do me I've have it in its jacket'... 'and show me what veg you want' and then he prepares it all but then I usually go in about quart to 5 and cook it which is nothing cos all I do is put the gas rings on... but as I say he'll say 'shout me if you want anything' and I sometimes shout 'can you just lift me this out of the oven or open me a tin' cos I find that hard opening tins hurts me er thing when you turn it, little jobs like that he'll come and do and then we have dinner and then he goes and washes up and think he makes another drink and that's when he brings me me (laughing) nightie and me bottle then at 8 o'clock

Julie: Bedtime

Jackie: He'll say 'what do you want taking up now?' and I have a flask with some fruit juice in (laughs) cos I'm always drying out so he takes the flask up (Julie laughs) bag of medicines I've got a plastic bag with all these tablets in - what else does he take up? I usually go

Julie: Like you are going away for a fortnight!

Jackie: all me equipment and then he pulls me, he takes the bedspread off for me cos we have like quilted thing on it he takes that off he'll say 'I'll just put you the telly on' he switches telly on (laughs) he does everything for me

Julie: It's funny how he knows just how you like things

Jackie: I just get in bed like the queen and I lay there reading and then I usually I'm asleep when he comes up

Here Jackie paints a very detailed picture of predictable days and represents her role in daily life in passive ways - stating that Clive is 'in charge' and 'he does everything for me'; the cooking she does is 'nothing' and at the end of the day she 'just gets in bed'. Her description in the above does however

also point to her role as an 'over-seer' in the day-to-day management of their daily life. She still has an eye on what is happening, as is implied by the enquiry it seems Clive routinely makes as to '*what we having?*', when they are preparing for their evening meal. As with Kathleen's morning cup of tea mentioned previously, in this exchange the historical pattern of Jackie and Clive's relationship seems to find an opportunity to be reproduced through the mundane medium of food.

The fact that Jackie was able to so clearly recall minute details of the actions Clive undertakes to try and ensure that she is cared for, even assigning particular sets of words to him, also indicates the centrality of these routines to the family's engagement with the life-threatening illness of one of its members, as well as, a real appreciation on her behalf of the effort involved. Perhaps this is why she was not always honest with Clive about her true feelings and the weariness she experienced, in spite of his meticulous care.

Jackie: Yeah, yeah but some mornings I do feel and that's morphine it's that that does that, you are like he wants me up and I think oh (laughs)

Julie: Is it morning? Leave me alone!

Jackie: He does he comes with the tray, cup of tea on, toast or whatever I'm having and... I have a - you'll laugh (laughs) - in bed I've got one of those V-cushion things which is lovely and comfy sitting up but it needs another pillow I think as well, a pillow straight up here first that supports that part of your back so when I sit up to eat me breakfast and to watch the telly I have this pillow here plus that V-pillow you see so when he gets out to go down and it's still dark - I've no idea what time it is or anything - he gets up and I'm thinking I don't know whether it's getting up time or whether he is just going to the toilet but when I realise that it's getting up time like he's going to come down I'll be asleep nearly and then I hear this thing bang onto the bed and I think oh it's the

cushion and its banging and that cushion wakes me up a bit and he comes down and I'm like this when he comes back up (sleepy) and then he puts the light on and I think oh I had better get up and I go (laughs) and I feel shocking I can't tell you how shocking I feel at that actual time I just think oh let me go back and lay down (laughing)

Julie: *And is that every day then?*

Jackie: *Yeah*

Julie: *You feel like that?*

Jackie: *Anyway I sit up and then he gives me, he does the same thing every morning, he gives me the plate in me hand so I sit with the plate and then I've this, that cushion's down here and I've got this one behind me back and I have to put the plate down go like this with the cushion and all this is such an effort I'm thinking (laughing) oh blinking cushion I've got to put this bloody thing here then I get this and by this time I get like this (signs) oh that's lovely I just sit there then like the queen (laughs)*

Although Jackie is clearly trying to explain how this morning routine sets in motion feelings of forced wakefulness which she admits are more a matter of '*I had better get up*' rather than actually wanting to get up, there is a sense that her experience of this is 'unknowable' to others; she cannot tell me how shocking she feels and in the above extract she actually does not. It appears that she cannot tell Clive about this either, and here she seems mainly concerned with finishing the narrative so she can 'right' or 'validate' the experience, and show how in the end she realises she is treated, once again, like a queen. There is the sense that Clive's efforts to care for her are exceptionally attentive and Jackie recognises herself as perhaps 'lucky' in this regard, and yet there is also an underlying tension in the suggestion that

she hides the extent of her desire sometimes to *not* keep the routine going - in this case by going back to sleep⁷⁸.

Interestingly there did seem to be a sort of 'gentleman's agreement' between the couple which meant that certain aspects of daily life would be negotiated and accommodated with minimum fuss so the overall routine could persist, and family life would keep going. Clive's sensitivity and pragmatic approach to an embarrassing continence problem Jackie experienced as part of her disease progression was something that she was extremely grateful for. Talking about how Clive took up the practice of 'doing' Jackie's body work as a concern of his own and thereby making it into a process of negotiating relationality, Jackie told me about how they managed the disposal of soiled pads, an action that was anchored in everyday considerations.

Jackie: You see there again he's been ever so good really Clive I mean I know he's my husband he's a rights to be but he just says, at first I kept wrapping em in a carrier bag and tying em up in another carrier bag and if it was in the middle of the night I'd just leave it in the bathroom down at the side of the linen bin... and then in a morning he'd got up you see and he'd just say 'I've took that bag, I've put it in the bin' you know and like done it right you know as if it were a normal thing that you'd be doing...

Jackie went on to explain that Clive thought of alternative ways to dispose of the pads, and that he just took the matter in his stride, building it into his

⁷⁸ It is perhaps also worth noting that some argue there exists a pervasive cultural and moral imperative for cancer sufferers to 'be positive' and to 'think positively' about their condition (Wilkinson and Kitzinger, 2000). As I will explore more closely in Chapter 8, keeping daily life and its routine going seem to be a central part of Jackie's stoical, some might say 'positive' approach to accepting her illness and terminal prognosis.

day-to-day routine. As this example shows, with this couple there was an intimate closeness brought about by the shift in general 'doing' roles necessitated by Jackie's illness. This was not an intimacy of overt emotional expression and dialogue, but one which was constituted by, experienced as, and understood in relation to, the performance of mundane tasks in daily life (see Christensen *et al.*, 2001). Jamieson (1998) challenges the idea that 'disclosing intimacy' - an overt, spoken and shared concern with declaring inner feelings between significant others - is the only 'true' form of 'doing' intimacy. She argues:

It is possible to imagine a silent intimacy. For example, clearly affection for and feelings of closeness to another person are not necessarily accompanied by a dialogue of mutual disclosure. A loving couple who believe they 'mean the world to each other' but yet are typically people of few words, may be as deserving of being called intimate as those who incessantly check out each other's feelings (1998: 8).

And so, as Jackie carefully explained in response to my question about how the illness had affected their relationship, certain 'silences' were important:

Jackie: Er I don't know how to say it really its (sighs) its, its, Clive's wanting to do I don't know whether he's like wanting to compensate or he feels sorry and he, he can't show that he does, he doesn't show his emotions - very rarely - but he's wanting to do, do, doing all the time everything I do 'let me do it, let me do it' that's how it's affected us so he's just taken over actually running the house he just - well he does do everything. Occasionally I'll - and I don't let him know I've done it (laughs) cos he's a love - I just sometimes if he's gone out I get iron out and I just iron cos he might have just ironed a blouse or something that's you know and he's left a big crease right where it shows but I don't say anything. So I just wait and

Julie: Until he's gone

Highlighting the relational dimensions of emotionality which are clearly evident in Jackie's account, Lupton argues that emotion is 'as an intersubjective rather than an individual phenomenon, constituted in the relations between people' (1998: 16). Like Jamieson (1998), Lupton problematises taken-for-granted ideas about emotional expression and intimacy by suggesting that ideas about emotions are culturally specific and that they therefore may not be the internal and innate forces that popular discourses about, for instance, gendered emotional behaviour, may imply. Therefore the circumstances of people's everyday lives as they are lived are central in understanding how emotions related to facing the prospect of death within a family, are negotiated and emerge in specific histories of relational contexts and practices⁷⁹.

Thus family practices are a key site for understanding how emotionality operates between Jackie and Clive; although they appear to be 'hiding' or not openly disclosing their emotions the couple are in other important ways 'doing' intimacy via the negotiation of family practices. And so Jackie stresses, in the above extract, how Clive became completely fixated with 'doing' things for her and she felt that this was his way of expressing his emotions related to the difficult transitions they were facing. Reciprocating this Jackie also engaged in her own small 'silences' - a form of emotion work - and she talks here about performing 'corrective' tasks in secret to ensure that Clive's care efforts are not undermined. If, as Jackie suspected, Clive was investing his emotions in his performance of daily tasks, making

⁷⁹ I discuss this more fully in Chapter 8.

sure that he did not realise that his ironing was not always 'up to scratch' was important so as not to communicate through the act of re-ironing, an undoing of sorts, of the emotional investment Clive had made.

And so what might seem like 'small' details about this couple's daily life can actually give a rich insight into the ways in which they negotiated the constraints Jackie's disease placed on her ability to be involved in family life and how it affected their relationship. For the Kennys, family practices provide a nuanced understanding of how continuity is negotiated by the family. Jackie strives to look after Clive's emotional well-being by 'doing' emotion work, something which she has perhaps always done when she was more able to undertake practical 'doing' tasks such as dealing with household matters which Clive was less confident at managing.

Regarding this matter of continuity and the maintenance of family life, a particular conversation with Jackie demonstrates the importance of shared processes of negotiation.

Jackie: I used to walk everywhere you see I never used to, I used to walk from here to town... We used to come back on a bus if we'd got shopping to carry but we just used to walk - we were never in really - and gardening they are my two hobbies that have just gone you see altogether - well Clive's, he's started he's taken over the garden now er I think he's got quite interested he'll not admit it but I think he has (both laugh)

Julie: That was one of your passions then gardening?

Jackie: Yeah gardening and me walking and outdoor things

Julie: Is it cos you get physically tired quicker than Jackie?

Jackie: Yeah, yeah

Julie: *Is that why?*

Jackie: *Yeah you just get yeah tired and I do get a pain in this side if I walk a long way even though I take morphine... if I just sit I'm alright but if I do much walking it sets it off you see so I have to avoid and its same with gardening I mean I do pottering I mean in fact I was just saying to Clive 'oh them pansies look nice'. When it was me birthday [last month] me son said 'what do you want for your birthday?' and I says 'oh I don't want anything'... I've got everything I want you know there's nothing I'm longing for... Anyway I says 'I'll tell you what' I says 'if you want you can buy me some compost'. Well he said 'I'm not buying you compost for your birthday', I says 'now you have asked me Johnny what I want' and I says 'if you'd buy me some compost and take me to the garden centre or somewhere and let me pick some plants' and I says 'I shall really enjoy sitting looking at em all coming up you know in the Spring, bulbs and that' - so anyway he did (laughs) so I have got three tubs outside here that I can see you know they are just starting to come there's primulas and pansies in and then some more - well I can do that you see Clive brought he brought em inside for me cos its winter time int it?*

Julie: *Yeah*

Jackie: *we put a dust sheet down in the hall and he tipped all the compost in and then I you know fuffed about putting all my plants in and I can do little things like that and I still take cuttings I've got cuttings in the kitchen off me fuschias and I've got geranium cuttings in the bedroom and that I still muck about...*

Jackie describes the significance of having some plants that she will be able to see from the position she takes up most often - in her chair by the window. As she was less able to be outside in the garden at this time, the gift she wanted from her son was for him to help her to shape what her future garden space would look like; to create something she could enjoy and see from her usual position indoors. However, Jackie still strove to maintain the continuity of an active role in this process and to help her to achieve this, temporarily, the boundaries between inside and outside were

made fluid as Clive brought the outside inside the couple's home, and created a space for Jackie to plant the bulbs Johnny had bought, in the hallway.

On another occasion a similar negotiation of continuity took place which involved facilitating Jackie's access to the 'outside' world. She explained how Johnny took her in his car to some blackberry bushes near their home so that she was able to continue a family practice established over the years, which was to make blackberry pies and crumbles. When talking about this Jackie begins by saying '*but er we have still gone about and you know done things*' and therefore she acknowledges their efforts to sustain practices to gain a sense of continuity. Yet she also ends by reflecting that without the car she was '*struggling getting back so it's a shame really but it does alter you*'. Although Jackie did acknowledge here, and on other occasions, that having cancer alters the person by restricting what they are able to do, she tended to talk about her family life in terms of negotiation as I have shown, and she pointed out the things she was still able to do. In the following extract she was talking about her son Johnny and how the illness had changed the things they did together.

Jackie: *Well I see him twice a week he will come mid-week and just stop an hour on his way home from work cos he finishes before his... partner... on a Wednesday he comes and sees us for an hour then he goes and picks her up from work and Luke (grandson) from nursery and then they either come Saturday or Sunday er but they don't, they used to come for their dinner, Sunday dinner - always came for Sunday dinner - but that's gone by the by cos I got to the stage where I couldn't lift the meat tin out of the oven - you'd be amaz[ed] what little things you know like if I open and shut my own door and things like that it hurts so in the end they said oh you know it's 'dad cooks dinner he has got enough on' just cooking for us two sort of*

thing so they don't come for their dinner but they come and bring Luke and we have been out day trips with em

Here Jackie was keen to point out to me that it was the smallest, 'little' or mundane things that when experienced in the course of doing day-to-day activities communicated to her a sense of keeping going, but also that her disease was worsening, and becoming more painful. In other words for Jackie these were central components of her family's illness story of negotiation, continuity and change and they were also fundamental to how she came to experience herself in relation to significant others, as the disease progressed.

The Everyday as Lived Experience

In these case studies, matters of mundane, everyday life feature heavily and are important for gaining a multi-faceted picture of family experiences. However, as Chapter 2 argued, theoretical focus to date has centred largely upon how life-threatening illness challenges the idea of an everyday, because facing death is associated with the production of rupture, crisis and disruption. This association, then, suggests that everything about the everyday becomes unpredictable and is transformed. Yet it is important to consider how the everyday is being defined and whether the theoretical association of death with rupture provides an over-determined and somewhat reductionist view of the everyday. Felski emphasises how everyday life is both fluid and processual; it shifts and is subjectively *lived* (produced) as a meaningful experience for individuals. She writes:

Everyday life simply is the process of becoming acclimatised to assumptions, behaviours and practices which come to seem self-evident and taken for granted... it is a lived process of routinisation that all individuals experience. Certain tasks which at first appear awkward or strange... gradually become second nature to us over time. Conversely, the everyday lives of others can seem deeply alien to us, precisely because the quotidian is not an objectively given quality but a *lived relationship* (1999: 31 my emphasis added).

Importantly, due to the inherently emergent quality of everyday life, Felski suggests that 'it makes more sense to think of the everyday as a way of *experiencing* the world rather than as a circumscribed set of activities within the world' (1999: 31 my emphasis added). And so when considering the families involved in my research, and for whom the life worlds of severe ill-health and/or dying shaped their experiences of daily life, I argue it should also be recognised that due to the subjective, relational nature of the everyday this is not something external or separate from the experience of living with and facing death. Rather, as I have shown in the above case studies, it is through the experience of the everyday and its mundane practices that families come to make sense of and *know* their world of severe ill-health and dying. In other words the experience of one constitutes and makes sense of the experience of the other.

Conclusion

Thinking about the everyday lives of the Bakers and the Kennys as lived experience (Felski, 1999), this chapter has shown how mundane, daily life is integral to understanding the ways in which families are produced and continue, during circumstances of life-threatening illness and impending

death. In the following chapter I return to, and consider more closely, the experience of *change* in families experiencing severe illness. This includes an exploration of doing family life in less familiar spaces and locations - in particular the hospice inpatient ward - and considers the processes of transition and negotiation between different spaces.

Chapter 6

Spatial Change and Family Life: negotiating dislocation and separation

Introduction

The previous chapter explored continuities in family life and how routine, everyday life is maintained during life-threatening illness. In this chapter I acknowledge that for many families continuity in daily life was also happening within a broader context of *change*. Here I focus specifically on how physical changes in a sick/dying person's body, precipitate *spatial* changes for that individual, their relatives and the conduct of everyday family life. The spatial changes I examine involve family experiences of dislocation, displacement and separation, and I consider family practices and processes of (re)negotiation in relation to these.

Maintaining a focus on what it is families are 'doing' to be families during this time, the chapter begins by exploring how families are produced in embodied and spatial terms as they experience 'doing' family in a more public and less familiar site of daily life - the hospice inpatient ward.

Furthermore, when observing families on the inpatient ward it appeared that sometimes they were negotiating how their taken-for-granted practices and usual ways of 'doing' family became displaced or felt dislocated in this less familiar site of daily life. Therefore, in the second section, I draw on data relating to the transference of family practices between home and the hospice. Here I show how practices associated with home life are

experienced and (re)negotiated in the ward setting, noting in particular that a sense of continuity can be produced by some families at a time of more marked change in their day-to-day lives.

Finally, although the last section begins by looking at experiences of separation when someone is staying on the hospice ward, I also draw on home-based interview material to examine how families experienced spatial separation more generally. Specifically I consider the 'comings and goings' of family members in the course of doing everyday life, and explore how these were experienced when changes in the ill-person's body meant they were sometimes less able to move about from place-to-place.

Bodies on the Ward: spatial experiences of relationality

As the case studies in Chapter 5 have started to explore, the negotiation of space within the home, and movement between home and other spaces, is significant for family experiences of doing daily life in the context of life-threatening illness. Writing about the interwoven concepts of time and space 'being at the heart of family life and its analysis', Morgan argues that these 'give a materiality to family life' (1996: 153). And yet despite this, Chapman (2004) believes sociologists have placed much greater emphasis on understanding relationships than they have on the domestic, home spaces within which these relationships and family practices are actually enacted and produced.

However, the observation that is perhaps most pertinent to this chapter is that there has been an even greater neglect of how personal relationships are produced and experienced in public places (Morrill *et al.*, 2005). The families I encountered on the hospice ward were negotiating family life in what was essentially a semi-public space that was directly related to the experience of severe ill-health and dying. As Hockey (1990) has shown in relation to older residents in a residential home, space can become a materialisation of what is happening to the 'failing' body. In the home where Hockey conducted her fieldwork she identified how the 'frail corridor' became a spatial domain for particularly ill and more perceivably dying bodies. Similarly, an awareness of their ill relative's deterioration may also have been realised 'spatially' by families visiting Spring House, as the spatial relocation of aspects of family life that was necessitated by a stay on the inpatient ward, were interlaced with the experience of identifying material changes in an ill relative's body. Although the inpatient ward was generally experienced as more satisfactory than acute hospital wards due to what many patients and relatives felt were more appropriate standards of care - for instance it has greater privacy, higher staff to patient ratios, generally comfier surroundings as well as tastier food - I gained the impression from most patients and their families generally, that going home was still the ultimate goal to aim for⁸⁰. And so despite processes of domestication within the hospice space which can make the place feel more

⁸⁰ I am not suggesting that home was necessarily the place where people wanted to return to die. For ethical reasons I did not ask this question explicitly and people tended not to talk about this if the ill person was not 'actively' dying but in the hospice for symptom control reasons, for example. I am referring in a general sense to wanting to continue with their usual lives - or as one patient explained, although she considered the care provided in the hospice as excellent, she wanted to return home to have her own things around her.

'homely' (Hollows, 2008), it was different to actually being at home for many patients and their relatives.

Perhaps one of the main factors which contributes to the experience of hospice as 'homely' but essentially 'non-home' space, is the quasi-public and quasi-private (Morrill *et al.*, 2005) nature of the ward environment.

Whilst there were four private bedrooms where the door could be closed to give some privacy, on the whole, it was more usual for the doors to remain open; except for those times when someone was gravely ill or actively dying⁸¹. In the 4-bedded communal area, privacy was far less possible and on busy visiting days families often sat in close proximity to each other and unless curtains were drawn around a patient's bed - and this was especially unusual in the communal area - all their interactions and a great deal of their conversation were essentially public acts.

And so, to all intents and purposes the ward was a quasi-public space, where it was possible to create quasi-private space by closing doors, drawing curtains or personalising space around a bed with personal items such as photographs, soft toys, 'treat' foods, pot-plants and religious symbols brought from home or as gifts (see Rigby *et al.*, 2010 and Kellehear *et al.*, 2009 for evidence of similar personalisation practices). It was, in Hollows' (2008) terms, a *hybrid* public/private space. Aware of the fact that families may try to create such 'quasi private' spaces on the ward I was reluctant at

⁸¹ Each bedroom door was also fitted with a spy-hole which staff could peer through without those inside the room realising they were being 'checked on'. Although in practice I did not notice this happening very often, the possibility was nonetheless ever-present.

times to risk 'invading' any privacy which had been created, and as a result I often found myself observing families from a distance. As I could not always hear what was being discussed or necessarily understand the complexity of exchanges between family members, I drew cues from the spatial dynamics which unfolded between them and observed their movements in and around the hospice space to understand how family was produced in spatially mediated ways. Thus I was often exploring how bodies appeared in the hospice space and therefore became aware that the experiences of relationality and family practices were deeply embodied (Morgan, 1996). For instance, on one occasion I regretted interrupting a moment of intimacy between a patient, Betty, and her husband - as I entered the room it appeared that he was just about to kiss his wife on the cheek. On his arrival Betty's husband had taken a plastic visitor's chair but he did not always sit on it, instead at one point he placed himself on Betty's bed to get closer to his wife who was sat in an armchair by the bed. Interestingly this was an act which appeared to reduce the symbolic boundaries between home and non-home space that may have been imposed by the rigidity of the plastic 'waiting-room' style chair.

It is accepted that physical intimacy as an expression of relationality can be inhibited when hospice environments offer little privacy to facilitate this unless specific requests are made (Ball, 2009). Ball (2009) underscores the importance of practitioners recognising the co-dependence of intimacy and space and he refers to lying down beside a dying loved one as something that may be desired by a relative and which could be made spatially possible

if requested. However as Betty's example shows, there are also more 'mundane' fleeting moments of what might once have been taken-for-granted intimacy, that may be interrupted, displaced or require negotiation in the hospice environment.

The quasi-public nature of the ward environment was also challenging in the sense that it brought different families and family practices into shared spaces, where on a few occasions I became aware that tensions were developing. This issue cropped up during a conversation with Rachel, the wife of a patient in his 60s.

'She talks briefly about when Patrick (her husband) was staying in the 4 bedded unit - she said - *'not mentioning names'* - and then explained that it stressed both her and Patrick out when other families had the TV on, and then talked over it'.

Whilst the source of irritation for this couple was an auditory intrusion into their 'personal space' by another family's indiscriminate use of the TV as 'background' noise to their interaction on the ward, on another occasion a different relative was more forthright in her complaints about the daughter of a patient who was in the next bed to her husband. Mabel was the wife of a patient called Rob. They were both in their 60s and had two sons who I met as they visited the ward. In the following I reflect on Mabel's frustrations relating to Tammy, a relative who stayed for long periods during the time her father was a patient on the ward.

'Mabel seemed quite anxious and worried tonight - this was confirmed further when she approached me at one point to complain about Tammy. It put me in an awkward position and as I didn't want to say anything to the staff and become involved. Mabel was really quite annoyed with Tammy and her nosy behaviour. Now Rob is in the 4 bedded unit his bed is next to [Tammy's dad's] and the families are in close proximity when they come and visit. Mabel described feeling as though she was being spied on by Tammy and told me that she thought she was very intrusive at times. Mabel tells me about how this is affecting Rob... [he] has been feeling uncomfortable when he hasn't been well and... he doesn't want to be throwing up in front of people. She has asked him if they should draw the curtains around for some privacy but he doesn't want her to - however when he was sick earlier she did it anyway and whipped them around him. She is angry and goes out for a cig'.

From my own observations of the developing situation I then noted further tensions.

'[Tammy] sets off back into the 4 bedded unit and I can hear her talking loudly on the phone. I watch Mabel who is sat by Rob's bed; her face appears very tense and annoyed as Tammy paces around [her dad's] bed conducting her phone conversation'.

Mabel clearly experienced Tammy's spatial dominance as an insensitive intrusion and a flouting of unspoken, but generally tactfully accepted privacy 'rules', which operate in shared spaces such as hospital wards. In this latter example she also seems to be angered by the way Tammy's voice carried across the bed spaces and the sense of intrusion she experienced into her family 'territory' was physical due to Tammy's pacing around, but it

was also auditory. In the first example Mabel refers to the feeling of being watched in the ward environment where this other family appear to not be abiding by the unspoken rules of maintaining imaginary quasi-private boundaries between the bed spaces and instead she suggests Tammy is actively 'spying'. The result of trying to manage this is that Rob and Mabel disagree on whether to shield themselves from Tammy's 'nosiness' by drawing the curtains around Rob's bed so the imaginary boundary between public and private becomes more material and fixed. Given the particularity of this setting as a place for gravely ill people, bodies and the breaching of bodily boundaries (see Lawton, 2000) also complicate issues of privacy and throws into disarray certain ideas about the appropriate front-stage and back-stage management (Goffman, 1969) of bodily integrity. As Mabel explains, Rob experiences Tammy's intrusion of his privacy most acutely when he is being sick and it is during a particular bout of vomiting that she decides to over-ride Rob's choice to abide by the 'usual' unspoken code of leaving the curtains open (I noted that it tended to be staff that closed them), and she whipped them closed in anger⁸².

Essentially, visiting a relative on the ward required negotiation as daily family life acquired a different routine which was experienced in spatial ways. Also for some, this embodied experience of 'doing' family differently impacted upon feelings they had about their family and how they

⁸² It is difficult to know the full extent to which families felt their privacy was invaded by other families - though clearly not all felt this way and some seemed to like having other families to chat with. Aside from the direct information I received from participants in the examples I cite here, I did notice rolling eyes and sighing on another occasion when the family of a particularly poorly patient were sharing communal space with another family who had a small noisy child.

related to one another. This was the case for Dave (30s) who, along with his older sister Mo, had been spending extended periods of time at the hospice with their mum Glenda who was staying in one of the single rooms. Being together in the ward space and existing out of what was usual routine time, had, Dave explained to me, created possibilities for a more satisfactory experience of family in the future where existing tensions between the siblings might become less of a barrier in their relationship.

‘Dave was able to try and take something positive from the experience and he talked about the ‘new nucleus’ which had been formed as a result. He used the phrase ‘*silver lining*’ to convey his feelings - suggesting that the situation had forced him and his sister to be together and develop new dimensions to their relationship... Dave said that Mo hasn’t always been very accepting of his partner but that he had naturally wanted them to be with him... so they have all been forced into the same space and he wonders if this has pushed Mo to consider their relationship and to enable some progress to be made. He feels that the dynamics have been stirred about a bit and shifted between them’.

How family member’s bodies are positioned in space around the dying person can also be revealing in terms of how relations within the family usually are, or how they operate more generally. Having been alerted by the ward staff to what they felt was ‘controlling’ behaviour by another patient’s son I was able to trace the contour of this dominance in bodily terms as I spent time with the family whilst Laura, a patient in her 60s, was unconscious. About the spatial dynamics and practices between Laura’s husband Joe and her son Adam, I observed the following:

'I notice that Adam's chair seems closer to Laura than Joe's. Joe's is also lower and his body is further from the bed than Adam's. Adam is leaning up against the bedside and his position and chair are higher than Joe's - he seems to dominate the space around Laura's body as he leans in and strokes her chin as he speaks to me. Joe's eyes are more downcast than Adam's and his body seems awkward somehow. He seems more vulnerable and sad than Adam. Initially Adam dominates conversation and I find myself having to make a special effort to include Joe, who at one point I notice picks up a medicine packet from the table and peers at it - I wonder if this is because he doesn't know what else to do with himself or feels uncomfortable?'

As the above examples have shown, actually observing how 'doing' relationality was performed spatially and through the negotiation of physicality in the ward environment, involved an awareness of what might appear *mundane* bodily positions or movements - in other words 'taken-for-granted' data. In the following notes it is apparent I was struck by these 'ordinary' spatial dimensions of visiting.

'Andy's wife... is with him throughout the time when I am there. I first encounter her trying to get one of the comfy chairs between a wall and Andy's bed so she can sit comfortably by his bedside - the bed is quite close to the wall and a small wardrobe/ unit thing, and it restricts this access'.

Whilst on the ward I did encounter examples of how family members tried to be physically close to a patient but it seemed they were challenged at times by the spatial arrangements of ward furniture or fittings. In particular this was evident in how bodies interacted across the distance created by one

body being laid down and another in a sitting position. Katie was a patient who was visited most days by her partner Stuart. I noted the following about one visit.

‘I had not been on the ward long before Katie’s partner Stuart arrived to visit her. Again she was sleepy today and on the occasions I popped my head around the door (about 3) he was sat on a chair pulled right up by the side of her bed, watching the TV as she was sleeping. He always seemed to appear to be leaning slightly forward and into the bedside - this decreased the distance between their bodies and they were close together as he huddled at the side of the bed’.

On another occasion I saw Billy arrive to be with his wife Jill (60s) after a nurse had called him to say that they thought she was close to death. Before when I had spent time in Jill’s room with him, Billy had sat on the bulkier recliner chair or stood by her bed. This time he drew one of the less bulky plastic chairs up close to the side of Jill’s bed and held her hand through the bed-bars.

‘Sarah [nurse] tells me that [Billy] told her that he would be an hour - and so she is wondering if this implies that he actually doesn’t want to be here when Jill dies... It is nowhere near an hour before Billy returns to sit with Jill. One of the staff tells another to go and see if he is ok and to ask if he wants a comfy chair. Later he is sat in a plastic one which allows him to sit closer to the side of the bed, his hand is underneath the sheet and holding or stroking Jill’s’.

In contrast to the attempts made to achieve physical closeness in the previous examples, Rachel - the wife of a patient in his 60s - expressed her

fear about being with her husband Patrick as he died, in the way she sat uncharacteristically far from his bedside. Having sought privacy in the 4-bedded unit by taking the unusual step of closing the curtains around Patrick's bed, now that he was in a private room because he was deteriorating, Rachel's apprehension at the intimacy of the increased privacy she shared with her dying husband was palpable.

'I notice that now Patrick has moved into [a single] bedroom his wife Rachel and sister stand in the doorway, removed from the bedside - the room inside is in darkness. I wonder as I watch them why they do not go inside and sit down. The curtain is pulled a little around Patrick as it was when he was in a single bed [in the 4-bedded area]. Later after the sister left I went into the room to speak with Rachel about the project, as I have always felt like I would be intruding before when they were in the 4 bedded unit. She is sat in a chair which is removed from the bedside - is quite close to the wall and the door. She has a magazine on her lap and the TV is now on... As I get talking to Rachel she tells me that she isn't really watching it, but that it helps to have it on as background noise as it breaks up the strangeness of being in the room'.

Rachel did explain to me that she was anxious about being with Patrick at the moment of his death, and this seemed to be reflected in her spatial positioning within the room where he was dying. She had spoken to her son who was supportive of her decision not to be there at the end, and he reassured Rachel that he would stay with his dad if she could not.

I believe what I observed in her bodily positions within the space around Patrick's bed, reflected Rachel's preoccupation with this decision - about

whether she could, and should leave the room - and I will be returning to explore the tension between staying with or leaving a family member in the chapter's final section. So far, having mapped out spatial experiences of being a family in the ward environment, I now turn my attention to focus more closely on how undertaking specific practices or ways of 'doing' family were negotiated in this setting.

Displacement and Transference of Family Practices

Sometimes on the ward it appeared that families were negotiating how their taken-for-granted practices and usual ways of 'doing' family became displaced or felt dislocated in this less familiar site of family life. This was clearly the case for one family member I met on my first day observing on the ward. She was an older woman and had arrived to visit her sister Doreen, who was staying in one of the single bedrooms. We chatted for a while outside Doreen's room whilst the nursing staff finished assisting Doreen to the toilet. In this time I learnt a little about what visiting was like for the sisters.

'The lady said she visits every morning, but that she sometimes finds it difficult to know what to talk about... [she] volunteered to tell me that she leaves the room when her sister's daughter comes to visit. She explained that they didn't get on and that the daughter lived away. I got the impression that there were tensions, which I learnt more about when Sarah (nurse) discussed the family in my briefing. Sarah explained that there were '2 camps' which divided the family - with the daughter and sister on opposite sides. The sister resents the daughter because she feels that the daughter has not been interested in her mother's care for a long time...'

It seems that when usual family practices involve managing tensions as was the case with this family, family 'space' and how people arrange themselves within it gets 'out of order' or displaced when family life is temporarily relocated to the hospice ward. Here the boundaries used to manage problematic elements of relationality had to be reinvented; moving in and out of proximity within space around Doreen's bed, marked the re-assertion of practices of distance which were intended on this occasion, to display disapproval on the part of one family member towards another.

On another occasion one family member in particular explained the displacement process quite discerningly for me, and what he shared provides a useful context for thinking about other families' experiences.

Don was a patient in his 80s and after speaking with his son about his visiting practices I reflected on the following:

'He spoke a little about the artificiality of visiting - mentioned how he found himself talking about the park that surrounds the ward - and [he] implied that this was odd, not how they might 'normally' interact in other circumstances. He qualified this later and said that with him having the kids he found the park interesting as he and his partner are at a time in their life where they are looking for things like this for the kids - but he laughed and said that dad's not interested in that. He went on to talk about the ill family member being removed from the family as Don was - he said that '*they become an activity*' for other members to complete - the going to visit. They aren't taking part in family activities any more, they are the activities'.

Discussing the artificial or 'staged' sense of interaction which Don's son felt took place during visits to the ward to see his dad, he seems to imply that Don's place within the family had become both physically and relationally dislocated. The experience of 'doing' or 'being' family was different in certain ways to what it had been like previously as a result of the arbitrariness of their surroundings. His feeling that the practice of visiting - actually seeing and being with Don became a family activity - is an interesting one. It adds layers to what I have highlighted previously about the public, or more 'visible', nature of 'doing' family/ family practices in the microcosm of the ward environment. Indeed this sums up what I observed about Rob and his wife Mabel's smoking practices. Both appeared very aware that their movements around the ward, necessitated by wanting a cigarette, involved a rather public display of their practices. The following notes indicate stealth and attempts at strategic concealment which point to the couple's experience of themselves as one of being 'watched' and having this practice that they think others will disapprove of, monitored.

'All the time we are talking I sense that Rob is eager to go for a cig - he keeps gazing towards the patio doors and keeping an eye on the pace of the rainfall - hoping for a suitable break to reasonably pop out and have a puff. Mabel teases him about this and with a more serious tone she tells him that it might be best to wait for the doctor to go because he wouldn't approve of him going out - *'he might tell you off'*. Mabel's comment about it not being the same as being at home pops into my mind as I watch them trying to negotiate what is usually a very normal, mundane part of their everyday life into the physical and moral regimes of the hospice as a particular institutional space. This exchange between them as they try and work out when Rob ought to go for his cig relates to a similar

discussion the other day when Mabel giggled... and told me that Rob had been '*told off*' by one of the nurses for smoking in the bathroom in the day time - even though Rob said that one of the other nurses had said it was ok... Later I spot the 2 of them organising Rob's trip out onto the balcony. True to what Mabel had said about him wearing her coat, she was helping him get into her winter coat which had a ring of fur around the hood... Earlier Mabel had said to me that she would be careful to pick up all the tab ends and the 2 of them talked about needing to search Mabel's handbag for a carrier to put them in. She tells me that she'll then have an excuse to go and have a cig in front of reception because she can place the carrier in the bin at the front. I watch her head off towards the main doors a short while after Rob returns from the balcony with her own coat on and carrier bag in hand'.

Rob and Mabel's performance of 'preparation' work involved in making a move towards the balcony or outside the main reception to have a permitted smoke, indicates how certain mundane family practices are displaced and more self-consciously experienced in the ward environment. Whereas arguably smoking can (usually) occur spontaneously within one's own home space and with far less orchestration, doing so on the ward would seriously displace the everyday order of how things worked there.

There were odd occasions however, where moments of such displacement did seem to occur. A memorable example happened on the build up to a night shift, where a family decided to stay with a patient, Archie.

'They [staff] started to talk about the daughter specifically and said that they found it strange that she gets changed into her pyjamas and

walks around the place in them. They tell me that she did this even before she knew they were stopping last night - and then they added, even if you knew you were stopping, they didn't think it usual to bother to change into night wear. Later... she emerges from the room in her pyjamas and asks us if we want a drink - she is going to make herself and her mum one. We all decline and she wanders up to the tea-bar by reception - again she is bare foot'.

Thus, whilst the leaflet used to advertise the inpatient service described the ward as offering 'a *homely* environment to all', some practices - such as wearing pyjamas - were perhaps 'too' homely for the setting and created the aforementioned feeling of being, 'out of place'. During this same encounter, the staff also mentioned how on one occasion, Archie's wife had been sat with her feet up on his bed. Although this could have created a moment of more 'homely' co-presence between the couple, it was not discussed in this *relational* sense - rather there were concerns expressed about Archie's ability to get proper rest and his need for *personal* space.

Indeed, staff members were actively involved in trying to understand how different family practices and families responded to, and used the ward space. In other words, they too formed part of an 'audience' that observed the performance of family life being enacted by families in the quasi-public ward environment. Thus, in this instance, Archie's daughter 'conducted' herself in ways more frequently associated with being in one's private, home environment. Not only was she dressed in clothing which is usually

reserved for being in the company of close intimates;⁸³ she was also prepared to go and make herself a drink and offered - much like one would a guest in their own home - to get the staff one. Here the relationship between host and guest in the environment seemed blurred and displaced, and the most 'appropriate' way to 'do' being a family in the hospice space became exposed as somewhat ambiguous. So, although it was clearly intended to be a space for families to be with their ill relatives, attention to certain embodied, material and mundane practices enacted and negotiated in the environment revealed the complexities of understanding the ward as a site for actually *doing* aspects of daily family life.

Like the previous example where Archie's family appeared to be making themselves comfortable (or 'at home'), I witnessed other family members taking up what might be considered 'homely' positions around the space and particularly within the area directly next to their relative's bed. Some of the difficulties regarding fixtures and fittings and bodies getting intimately and comfortably positioned in ward space were discussed previously, however family members would often assume certain positions, place furniture in a particular way or adjust their clothing to create a more 'at home' and comfortable visit. For example I noted on one occasion:

'Andy had a few visitors tonight - including his wife who seemed more relaxed. She was sat at the foot of Andy's bed with the other visitors... and had her feet up on another chair and was bare foot having taken her shoes and socks off'.

⁸³ Not all family members are equally likely to see another member in the clothes they wear to sleep in.

Furthermore, there were often also instances where staff actively tried to ensure that the hospice ward was a 'homely' environment for patients and families. In the following notes I give details of how John's family and one of the nurse's are all aware of the importance of transferring certain family practices from home into a patient's experience of staying on the ward. John was in his 80s, and I spoke to his family on the day that he was admitted.

'They tell me that John has placed an order for his tot of whiskey for 9pm, but the woman (daughter or daughter-in-law perhaps) says that he is worried he might be asleep by then; she asks if I can speak with the nurse to see if he can have it a little earlier. They joke that he'll enjoy it here because his wife has been strict with his whiskey at home - on doctor's instructions. Later that night one of the nurses says out loud that she must remember John's whiskey at 8.30pm otherwise *'he'll not feel at home'*.'

Having his measure of whiskey was obviously something associated with John's family experience, which is conveyed by the insight I am given about how John and his wife have been 'doing' things at home. The family joke that the nightly 'tot' is something which they perhaps have not always been in agreement about at home - John's wife identified as the strict one curtailing this practice John clearly enjoys, albeit *'on doctor's instructions'*. So in this way the practice had been somewhat displaced at home, and it was actually on entering a different site of family life - the ward space - where this practice associated with 'homeliness' could be re-experienced.

A similar point was made by another relative (a patient's daughter) when she explained that being at the hospice had created pockets of time for a family practice which actually might have felt far more rushed at home within the more 'usual' flow of family life. Linda's family in particular spent a prolonged period of time at the hospice. When I met them their mum Molly was in the end stages of her life and was sedated to make the experience for both herself and her family, more comfortable. She existed like this for about a week before her death, and during this period I spent quite a bit of time with her 3 children, Linda, Shelly and Nathan, who all had their own young children and families at home. On one occasion I sat in the communal ward area across from the nurses' station with Linda whilst she made her daughter a dancing costume. About this I wrote:

'Linda has a needlework project on the go and it is spread out across the floor. She, I and Rachel [another patient's relative] are sat on the floor around it and Shelly is in one of the comfy chairs beside us. The outfit is a dancing costume which Linda's daughter is going to wear to a competition which is coming up. Linda reflects that she'd probably have felt too busy to do this at home... Natalie [Linda's daughter] will be coming tomorrow for a 'dress-fitting' so Linda can pin it to fit her and stitch the outfit together'.

It seemed for some families, like Linda's, that had decided to stay at the hospice 'around the clock', the sense of displacement from daily family life was especially marked and she did on other occasions clearly explain her feelings about what she and her sister Shelley described as being '*in a bubble*'. However, as this example shows, this was not always experienced in a negative way and some practices were transferred into the hospice

space with an almost 'reaffirmed' sense of value, where there is time to actually experience more consciously perhaps, the 'doing' of family things⁸⁴. What Linda's dancing costume example also implies, is the way that the transference of family practices can sustain relations between relatives 'based' more at the hospice and those family members who are less closely involved with the 'vigil'. Therefore it suggests that the transference of family practices can create a sense of continuity within the spatial and more general changes families experience during life-threatening illness.

The examples discussed so far show how everyday practices become more visible when they are re-located to the ward environment. As family practices are displaced and/ or transferred due to spatial changes brought about by life-threatening illness, they develop into a focus for what are often rather public (re)negotiations of 'doing' family. Thus analysing everyday practices provides insight into the experiences of continuity and change as these are lived day-to-day during life-threatening illness. However, my analysis so far has focused entirely upon how hospice space was negotiated by families. In the final section I develop my analysis of space and family life beyond the ward and consider how being separated spatially was a salient consideration for participants more generally, as well as when the ill person required admission onto the hospice ward.

⁸⁴ I will be returning to explore this relationship between thinking and doing in family practice in Chapter 7.

Separations: coming and going, staying and leaving

'Comings and goings' are a necessary part of daily living and many families spoke about experiences which related to some aspect of movement by various family members between different spaces of everyday life. Due to changes brought about by the illness process - whether it meant an increased bodily or emotional vulnerability for the ill person at home, or necessary periods of admission into hospital or hospice wards - matters of coming and going, staying or leaving and essentially being with or without each other, became a key consideration for families in the course of 'doing' their day-to-day lives. Moreover, it seemed once again that perhaps against the 'bigger' context of death as a 'forever' separation, little, everyday separations could be a more immediate preoccupation in the doing of day-to-day family life.

Having identified some examples of how physical proximities of closeness and distance were experienced by families within the ward environment, I begin here by showing how decisions about staying and leaving made by family members were bound up with a sense of 'handing over' the ill-person to the hospice staff. After one observation session I encountered the wife of a patient who had just been admitted onto the ward, in the hospice car park. Here my notes indicate the need I felt to comfort and reassure her that her husband would be okay in her absence.

'... I learnt that [a new patient's wife] was distressed from [the staffs'] comments... I did encounter her later in the car park as I left and she was clearly shaken. She explained that she was feeling lost

and apprehensive and I immediately tried to provide comfort by underlining how well looked after her husband would be’.

As we were stood outside in the car park talking about her husband she had just left inside, the sense of her bodily separation from him felt quite stark and her admission that she felt ‘lost’ represents this quite clearly - like she had ‘lost’ or was without something.

As I spent more time on the ward I observed and learnt about practices family members used to negotiate this experience of separation imposed by admission onto the hospice ward. Again this sense of having ‘handed over’ a relative seemed powerful for another wife - Mabel - who knew that her husband would be attentively cared for on the ward, but her need to ensure this happened was still pressing. Mabel manages her leaving on this occasion by sending a text message to instruct her son to mediate her need for ‘watchfulness’. This could then still be practiced from a distance and through her son as a proxy.

‘Mabel says that it’s great here and Rob is well looked after - but it’s not the same as having him at home. She has been really worried about him; particularly not wanting to leave him at night... She tells me that she left to go home last night, leaving one of her son’s here. When she got home she sent her son a really long text message instructing him what to do before he went home - in it she told him he must ask Rob if he has any pain or feels sick and then if he does he needs to tell the nurses to make sure Rob is going to get medication to help him’.

Other relatives managed the distance by phoning the ward. In the case of one patient in his 50s, his wife did this to settle herself as much as she did to hear news about how well he had settled after she had left. Similarly an interviewee, who experienced the admission of her sister Vera onto the ward, explained her strategy of waiting until Vera's dinner had arrived before she left.

Helen: The worse thing about it was leaving her... I mean at the beginning I was going up morning and afternoon and I found that too much... so I just left it to the afternoons and I went up as soon as you could get in which was I think was half 1 or something and I stayed till after tea time... So I just came home after tea erm and when I was leaving I always felt - it's one of the reasons I waited till she had her dinner because I then felt she was doing something. I hated coming away and just leaving her, she looked so (slight pause) dejected somehow that you were going.

Whilst matters of staying and leaving an ill relative were clearly ever-present in the minds and practices of families, it appeared that some hospice staff also had ideas about this; about why it was appropriate and necessary to leave for a while. For instance, they actively encouraged Dave who was introduced above, to leave his mum sometimes and especially through the night. His mum Glenda had been diagnosed very recently with cancer and became sick incredibly quickly which precipitated the decision to admit her into the hospice. One afternoon I interviewed Dave in another room away from the ward and he explained how this had been an especially difficult decision which was made even more painful when after a few days on the ward, Glenda lost the ability to communicate verbally and the last word he heard her say was 'home'. Dave spoke at length about his day-to-day life at the time Glenda was an inpatient on the ward, and I recorded the following

about how he and his family were negotiating leaving practices after being prompted by staff that they ought to think about doing so.

‘... since Glenda has been in the hospice Dave has been doing all day and then Mo [his sister] has stayed with Glenda through the night. After a while this was noticed by the staff. Joanne (nurse) pulled them aside and talked to them about the sustainability of their visiting pattern... In response to this Dave tells me that they [the family] sat down together and carefully planned what would happen when they leave Glenda for the night. They wanted to introduce a staggered effect whereby people would gradually leave the room. So it was decided that his partner would leave first, then Mo and then lastly Dave. Initially Mo had said that she would stay until the end, but Dave felt that if Glenda cried or became distressed, Mo would be too likely to pull up a chair and stay all night because she can't cope with her becoming upset... He tells me a story about what happened the other night. Mo had been ready to leave for the night and had said to her mum 'right mum I'm going now, is that alright?' and Dave explained that she had dragged this questioning and seeking a response out for about 30 seconds, trying to get something from Glenda so she knew she was happy for her to leave. Dave said that in the end he just had to say to her, 'look! She hasn't spoken for 3 days so she's not going to say anything now; just go. You are making it worse'. By the time that she had made it to the end of the corridor Glenda was ok and Dave said that she was interested in what was happening in the jungle with the celebrities! [referring to a TV programme]. He tells me that he rang Mo about half an hour later to assure her that she was ok and settled. He said that he could tell that Mo was upset and that she had asked Dave to make sure that the nurses don't close the door after he has left'.

Despite expressing his frustration towards Mo regarding this issue of

leaving Glenda on the ward, Dave did carefully explain how he *also* experienced this tension between wanting to stay but knowing he needed to leave at some time.

'Dave talks about guilt a lot. He tells me that he feels guilty about leaving his mum at times during the day - just for a couple of hours - while he goes to work... Dave continues to talk about today in particular and tells me about his feelings and what he noticed when he arrived at the hospice. The easy chair that was in Glenda's room yesterday has been moved to another place in her room. He tells me that he has to fight the feeling of wanting to ask the nurses why - why has the chair been moved? He explains that he interprets this as indicating a range of possible things which might have happened in his absence. Does it mean his mum has had an accident? (Fallen or wet herself - not sure which he thought). Also he wondered why there was a fan in her room today - does this mean she was hot in the night? Is her temperature up? Why then is her temperature up? Dave expresses that he had all these questions bouncing around about what might have been happening while he wasn't here, but that he tries to rationalise them; he wants to ask but doesn't. He thinks he is over-reacting and so they stay in his own head. As an illustration of his anxiety over needing to be around and monitoring everything, and perhaps to justify why he thinks he needs to have such questions bubbling away, Dave tells me about Glenda's steroids being missed by the nurses yesterday. He explained that he wasn't mad - but that it just reinforces to him that he needs to be here all the time to oversee things.'

Echoing the need to be around and 'oversee' which was introduced with Mabel's text message example above, Dave's behaviour highlights the uncertainty and lack of control experienced by relatives as well as the ill person. Although the illness experience seemed to heighten this need to

'oversee' for him, in certain ways this dynamic was perhaps also a more extreme continuation of the pre-existing relationship between Dave and Glenda, because as Dave had explained, he tended to be the one who would sort things out if his mum needed help. However, what seems particularly significant about the way Dave encourages me to 'see' the experience through his eyes, is the central role he attributes to mundane objects in the ward environment. In his mind he plays out a number of scenarios which are embodied in the various objects and their positions in the room. Explaining the importance of 'little' details in the appearance of his mum's room, Dave conveys how he experiences the feeling of having been separated from her when he returns. He describes how he attentively 'reads' the spatial arrangement of objects around the room, to try and ascertain how his mum has been doing in his absence. In many ways the 'stories' he feels these objects might tell - such as the changed position of the chair in her room, or the arrival of a fan - means they act as a form of 'proxy' knowledge he can use to negotiate his need for control and any time spent away from the ward.

Whilst admission onto the hospice ward clearly creates the need for practices of staying and leaving to be negotiated by families as members move between the different sites of daily life, it was also evident that similar matters were on-going and shaping the everyday lives of interview families as well. In the earlier days when Malcolm was first diagnosed with his cancer, his wife Tracey was still working away from their home in the day, on a full-time basis. When describing what this period was like for them in

terms of managing spatial distance, Malcolm also points out the importance of the arrangement of mundane objects that punctuate day-to-day life, in space around their home.

Malcolm: Yeah, well when the complaint was diagnosed first I was having to go in for blood top ups probably every 4 weeks something like that... and it got really quite bad (pause)... And I was basically if I wanted to go to the fridge sometimes I was on my hands and knees to get there because I just couldn't walk and I'd have to sort of kneel down to see into the fridge cos you can't stand and things. And Tracey would have to set up the tea trolley

Tracey: This is when I was still working (full time) at that point

Malcolm: In the lounge every morning... And she'd have a little fridge there with the milk, kettle full of water, 2 or 3 mugs, cappuccinos and coffees and teas or whatever, biscuits. And that's how we existed isn't it?

Here Malcolm seems to point to the tea trolley as a sort of 'mediator' between his being inside, and Tracey being outside, their home. Tracey makes important, spatially aware preparations and imagines Malcolm's limited range of movement throughout the day in her absence, to organise objects he might need accordingly. Malcolm's final comment that 'this is how we existed' implies some of the difficulties separation in this way can entail - it appeared the couple were not 'living' at this point, they '*existed*'.

In other families the necessity of going out to work was not an issue, but nonetheless matters of staying and leaving were still a daily consideration. As I mentioned previously, Helen found it difficult to leave Vera when she was an inpatient on the hospice ward, but this was also something that the

sisters had 'disagreed' about before this time, and when Vera was still living at home. Here we are discussing the matter of Helen going out:

Julie: How do you feel about going and like Vera being here? Do you ever go out and

Helen: Yes well I sometimes go with a friend of mine we go out for a meal or we go to the pictures or we go shopping or that kind of thing

Vera: Not often enough

Helen: But I don't do it very often... but if I was going overnight anyway then Becky would come over just to make - cos we are not comfortable about leaving her on her own and I worry

Vera: You'd think I was a half-wit

Helen: (Little laughter in voice) I worry so much if she goes in and has a shower and there's nobody in the house

Julie: Yeah

Helen: I don't like that at all

Julie: How's that feel for you? Cos you said didn't you she should go out more?

Vera: I think she should go out more yeah of course she should; I mean I'm the one with cancer not her (laughs)

Helen: But then you worry what's happening (laughing)

Julie: Yeah

Vera: It's not going to leap out and

Helen: We don't know what the heck it's going to do cos it's done nothing it's been told so far

Vera: Well when it's time to worry I'll tell you

Helen: No you won't that's the problem

Vera: Yes I will

Helen: Sometimes you can see in her face she is feeling really bad and she'll say I'm fine, I'm absolutely fine

Vera: Don't give in to it (slight pause)

Vera's characteristic style of making a joke about her condition is evident here when she mocks Helen's anxiety that the cancer might pounce and do something dreadful at any given moment. Like it was with Dave, for Helen this unpredictability was the very thing that made going out feel like a gamble and something she would rather not do if it meant Vera was left in the house alone. Helen justifies her practices of staying at home or getting her daughter Becky to come over, by pointing to the fact that Vera was not always honest with her about how ill she actually felt. There is a sense here that the two women are performing the kind of understated 'emotional-labour' which was identified between Clive and Jackie in the Kenny family case study. Each sister in her own way is trying to protect the other - Vera by encouraging Helen to go out and continue her life, and Helen by seemingly being quite happy to forfeit this, to spend most of her time at home with Vera. Interestingly and rather movingly, Helen's strong sense of not wanting to leave Vera in their home alone later extended to the time when she no longer had a perceptible bodily presence to be separated from. After Vera's death and talking about her ashes, Helen explained the persistence of her practices of avoidance around the issue of leaving 'Vera'.

Helen: ...Well actually I've not [got her] cos my friend has taken her because it was upsetting me

Julie: Was it?

Helen: Yes it was really upsetting I couldn't get it out of my mind so my friend said 'well I'll keep them till you are ready to do something with them' so she has... And I feel better about it I do feel - I mean it just seems so ridiculous

Julie: No not at all

Helen: but I hated going out and leaving her; I hated going out, when I was going I just hated her here

As was the case with Vera and Helen, tensions around matters of staying and leaving were also addressed in a humour-tinged way, by Eve and her husband Charlie. As one interview in particular was drawing to a close, Charlie started to tell me about his planned movements for the rest of the day and I found myself situated within a conversation which had a certain familiarity about it - I felt these two had disagreed on this many times before.

Charlie: I've just got to nip up and order her prescription

Eve: You can nip up when you go up (to run an errand for their son)

Charlie: That's alright if I can get through there before it shuts

*Eve: Well if you can't get there, you can't get there can you?
(Pause)...*

Charlie: She can't be without her tablets, I can't get that through, you have got to have your tablets Eve love

Eve: Yes I know but I don't those particular ones, I can buy em, so I don't want you rushing up to thing, we can buy them

Julie: Does Eve worry that you are always dashing about then?

Eve: That's right

Charlie: It's what I was telling you earlier, she doesn't want me out of the house

Julie: Right - what are you worried about Eve?

Eve: I don't know, it's just like I like him where I can see him (Julie laughs a little)

Julie: You know what he's up too

Eve: I've told you it's all them women that he's after and chasing around... (Julie laughs and Eve leaves room for the loo again)

Charlie: *She'll be shouting, last thing I can hear when I'm going through the door is, as I go through the gate is, (shouting) 'don't forget your stick' (Laughs)*

Julie: ... *(Laughs) I mean cos we are joking aren't we but is that a, is that a bit of a difficult thing for you? Cos are you worrying that Eve is worrying when you are out? Do you know what I mean?*

Charlie: *Yeah, yeah you are not out long, you don't stop out long, you know if I get in a conversation with anybody I've got to sort of keep edging away you know... I don't stop talking to if I meet somebody I've not seen for a long time on the street it's more or less 'hello, goodbye' you know*

Here Eve makes a joke, but as Charlie explains (Eve was in the toilet at this point), when he is out of the house, getting home quickly is at the forefront of his mind. His account suggests some of the difficulties families experience with negotiating their comings and goings when one member is less able to get about as freely as they once did.

Another ill interviewee, Mavis, lived alone and although at times she could get about independently, since her cancer diagnosis and subsequent treatments she believed that she was more 'clingy'. Her account reveals some of the emotional factors which may also have played a part (unspoken, perhaps) in Charlie and Eve's experience.

Julie: *Do you think it's changed how erm how you are... [with] you[r] family? Or how they are with you has it changed the*

Mavis: *Oh I wouldn't know that*

Julie: *the time you spent together?*

Mavis: *With me, with me it's what can I say? - Its left me quite emotional I would say a lot more I've always been a very erm like I say me sister were outgoing and I was always on the nervous*

type... its left me - if Richie (son) came now I wouldn't want him to go

Julie: Hmmm

Mavis: You know what I mean?

Julie: Yeah

Mavis: I cling, I'm clingy

Julie: Yeah

Mavis: Same with Marcus (older son)... I don't cry and things like, I used to. I used too when especially in hospital, when I was in hospital I mean I never wanted em to go...

However, whilst Eve wanted Charlie to be out of her sight for the least amount of time possible, and Mavis struggled at times when her family left her, with other ill people I interviewed they particularly wanted their family to keep contacts up outside the home, and to get away sometimes. Indeed, this was the case with Helen and Vera and it was more a lack of willingness to leave, which caused their 'disagreement'. This was also the same for Hugh and his wife Dot. During the time I was interviewing them Hugh was not well enough to fly to Guernsey to visit Dot's daughter as the couple had planned and so Dot's son Adam had agreed to take Hugh's place. However it became apparent that the prospect of leaving Hugh and travelling without him was causing Dot some distress. Despite Dot's concerns, Hugh was adamant that she should go without him and he grew frustrated by her preoccupation that something might happen to him whilst she was away. Although some of her anxiety was buried beneath humour and playful banter, it was obvious nonetheless as I describe here.

'Hugh is firm about saying that he isn't going to Guernsey and that he'll be ok; Dot is obviously worried about this. I think the fact that there is little to be done about it but this doesn't prevent Dot from worrying is irritating Hugh. He tends to joke about being ok - and Dot reveals a real fear that she won't be around when he dies - as was the case with her first husband many years ago. There is a really poignant pause in the room when this gets played out and I watch Hugh glance downwards and try to joke that he will be ok - a lump comes to my throat and tears to my eyes...'

Making decisions and managing practices around the matter of leaving the ill person was then, a feature of day-to-day life. Thus it is important to acknowledge that families were often negotiating and responding to this issue, and to changes in the ill person's physical or mental health, which impacted upon everyone's ability to move between sites of daily life with a sense of freedom. One relative, who found it especially difficult to negotiate her mother's fluctuating responses to her going away to spend time with her boyfriend, was Ellen. When I interviewed her on her own she explained this to me.

Ellen: ... it's like sometimes I'll would say I'm going, I'm going to my boyfriend's I mean he lives down in (town about 25 miles away) erm and sometimes me mum will she'll like she'll say 'oh alright then' and then but you can, I can look at her and it be like well I don't want you to go. And it's like well do I go or don't I go? You know it's like pulling me in between erm and that upsets me as well...

Julie: And do you think because your mum is ill that's made that more... but because your mum's poorly... does it feel more intense for you to make the right choice?

Ellen: Yeah it is it's very difficult to decide what to do. I mean sometimes I'll say 'oh I'm just going to, we are going to Danny's

this afternoon' like on a weekend if I'm off and I'll say 'oh we are just going to Danny's' erm 'to go and see a couple of friends or go and see his mum and dad and what have you' and sometimes, the majority of the time she's fine then other times you can tell that she's like 'well I don't want you to go'. 'Why have you got to go down there for?' and it's like well we are only going and I'm coming back it's not like I'm staying forever and it's like trying to I don't know it's... she doesn't want to be on her own. She is scared of being on her own in case anything happens so...

Clearly, moving between different sites in her day-to-day life caused Ellen to reflect or question herself, which she described as an experience of 'pulling' and feeling 'in between'. In other words she is caught in the middle of the dichotomy between staying with or leaving her mother Mary, who in other interviews clearly expressed her own feelings of dependency and frustration at being limited in her ability to get out sometimes. Mary defined her sense of family life as being able to 'do things together' and spoke about her family as the type that 'did' things and were always going off to different places. Mary is evidently aware that her periods of enforced 'stasis' impeded the sense of freedom other family members felt they had to be out and enjoying day-to-day life. The women gave a poignant example of how their family practice of going to the football is displaced by Mary's illness and its treatment.

Mary: I don't think, I don't think anybody's life is normal when I'm on treatment because their lives revolve around me and if I'm not well then it makes life difficult for them because I think they don't want to be going out and enjoying themselves and I'm laid here throwing up so it affects them in so much as you know - put it this way when I'm good, when I'm quite well we go to football together as me and El (Ellen) go and El's boyfriend and Stephanie (younger daughter) and her boyfriend go so we go as a little unit now when I'm on treatment maybe I won't go and there's has been a couple of

occasions when I have actually been in (hospital) when they have gone to the game

Ellen: And we have already had a ticket for her

Mary: and they sent me a photo

Ellen: of an empty chair

Mary: you should be sat here you know

Ellen: It's not the same when she's not sat next to us cos that's what we always do, we go as a group

Mary: we all sit together

Ellen: and when there's one missing it's like, it's like a jigsaw puzzle if you have got a jigsaw puzzle piece missing it's not complete you can't enjoy that finished product

Ellen's analogy of the family as a jigsaw that experiences incompleteness in circumstances of separation is powerful. So too is the idea of 'doing' family practices via mobile phones and sending an image across space to show Mary how physical surroundings appeared without her in them. In doing this there was perhaps a 'unified' sense of absence created, that mitigated the experience of separation by making it at least one of 'togetherness'; in other words something which, the visual representation of the empty chair carried across time and space reinforced they were all experiencing. In other words, in circumstances of absence, a presence or connection was facilitated by this object (see Callon and Law, 2004 and Hetherington, 2004) - the mobile phone - and a sense of relatedness (Smart, 2007) was reinforced as Mary's children expressed how important her presence was to make this feel like a family activity.

In this example and the others I have discussed, the centrality of mundane objects as material anchor-points onto which experiences of 'doing' family in the course of daily life can be 'mapped', cannot be underestimated. It is the emptiness of Mary's seat at the football match which signals her dislocation from family life, and the idea that somehow family life is 'out of sorts' or displaced. Indeed, linking back to the examples I discussed in the previous section, Ellen and Mary's conversation also points to a displacement of family practices and signifies how these are spatially and materially - via the symbolism of mundane objects - experienced.

Conclusion

This chapter has explored aspects of change in relation to sites and spaces of daily family life, and it has continued the focus established in Chapters 4 and 5 on identifying what families are *doing* day-to-day as they experience themselves as families dealing with life-threatening illness. Thus, the present chapter began by considering how privacy was experienced and negotiated on the hospice ward, and discussed how relational dynamics were expressed and mediated spatially in how families managed, used, and placed themselves within this quasi-public space. The chapter also considered how in the ward environment, some family practices became more visible and a focus for what were often rather public (re)negotiations of 'doing' family. Examining how family practices associated with home life are transferred into (continued) and at times appeared displaced or

dislocated (changed) within ward space, pointed to the lived complexities of understanding the space as a site for the *doing* of daily family life.

Thus analysing family practices and interactions in the hospice space, provided insight into how continuity and change were experienced and negotiated in the ward environment. This was also evident in the final section which examined how families felt about the experience of separation, with my data showing that there was a tension between continuing with usual day-to-day 'comings and goings', and leaving the ill person alone. These experiences highlighted some of the emotional implications and challenges which periods of physical separation between relatives created.

Moreover, reasserting once again the importance of the mundane in family experiences of living with life-threatening illness, my data revealed the way that everyday, material objects took on significance for some individuals and families in their accounts of experiencing separation. In the following chapter I revisit the experience of separation, and consider specifically the *imaginative* potentialities that objects possess to enable families to maintain themselves as families, despite their experiences of spatial separation enforced by the illness. This analysis forms part of the following chapter's broader aim to consider the multi-faceted nature of family practices (Smart, 2007) where I focus upon how family members thought about, and *imagined* themselves as family during life-threatening illness.

Chapter 7

Making Connections, Re-making Families: imagination and family practices

Introduction

This chapter explores the imagined, felt and discursive aspects of family and will show how these relate to everyday family life during life-threatening illness. Appearing more implicitly in the previous three chapters where the focus has been primarily upon the 'doing' of family, here the multi-faceted nature of family practices (as assemblages of doing, thinking and feeling) is examined more closely. In 2007, Smart used a range of concepts to explore the 'interiority' of family relationships and the diverse, nuanced experiences of personal life. For the particular purposes of this chapter I will be drawing on these core concepts which are - memory, biography, relationality, embeddedness and the imaginary. I use them collectively, as they overlap and are 'mutually invested in each other', as a theoretical framework for exploring the imagined and felt aspects of family and how these relate to the 'doing' of family life (Smart, 2007: 37). Undoubtedly Smart intended to build on Morgan's (1996) important work on family practices and acknowledged that 'these conceptual fields may include what are commonly regarded as practices ('doing')' (2007: 37-38). However, what she actually wanted to show was 'the importance of thinking and imagining family relationships', and how intertwined thinking and doing are, in practice (2007: 38). In her work Smart uses these overlapping concepts to indicate

how 'thought and action permeate one another' and to show how 'family practices do not occur without thought, however ritualized some of them may become' (2007: 49). And so, placing my analysis in this broader conceptual context of family practices, I draw on family data to explore how thinking about, and imagining, 'family' is part of the experience of 'doing' and being a family affected by severe illness, dying and death. This also involves a more fluid and shifting temporal perspective on family lives. In the previous three chapters I provided insight into the mundane, *present-day* experiences of living as a family experiencing life-threatening illness. In this chapter I explore how families used imagination and thought to reflect on daily life as it was experienced in the present, but also how they imagined family futures and remembered family pasts in the course of their everyday lives.

More specifically then, the first section explores how families are engaged in thinking about and imagining family, as part of the process of 'doing' family in their present, day-to-day lives. Here I consider how living with illness creates moments where matters of mundane, daily life are more consciously experienced or reflected on by both the ill-person and their relatives. In other words, how life-threatening illness can stimulate individuals to 'give pause for thought' or to 'see' things differently. However, I do not suggest that these instances necessarily imply 'transformation' of the mundane and/ or everyday into something more existential in families' experiences, as a crisis model premised on the notion of death as the ultimate threat to meaning might suggest. Instead I argue

that it is the ways in which the mundane makes the more 'extraordinary' (severe illness) 'knowable', rather than how this transforms the mundane, which is important in my interpretation of family experiences.

As it can be argued that thought and knowledge often emanate from materially-grounded or embodied experiences, and especially when dealing with something unknowable like the end of life or the experience of another's illness (Pillsbury, 2001), I develop a more explicitly materially-grounded analysis in the following section. Here I consider how objects are imbued with relational importance and used as tools for displaying family life (Finch, 2007) and making absent relations present (Gibson, 2008). In other words, through the imaginative potentialities that objects possess, they enable families to maintain themselves in the *present*, as families, despite the experiences of spatial separation enforced by the illness that were discussed in the previous chapter. I will draw on some examples from interview families, including a case study of one family in particular, but the main part of my analysis will be dedicated to family experiences on the hospice ward.

Finally, in the last section, attention turns to family futures and how family members are involved in 'doing' planning in the present, whilst imagining a future where the ill person will no longer be around. The focus here is explicitly on how imagining the future impacted upon the 'doing' of daily family life in the present.

Reflections: 'thinking' and 'doing' in family life

In presenting data from families' everyday lives it is my intention here, as in the previous three chapters, to show how experiences of illness and dying are embedded and become meaningful as experiences of immersion within the familiarity of material objects, spaces and routines that make up the repertoires of 'doing' family life. In Chapter 5 I introduced the Baker and the Kenny couples and presented case studies to show how they were 'doing' continuing to be a family in their day-to-day lives. During my interviews with both families it also became apparent that they imagined, reflected on and in certain ways seemed to more consciously experience the mundane aspects of daily life, as a result of living with terminal illness. In a conversation with Tracey and Malcolm they reflected on their practices to imagine how family life could have been different without the illness. Particularly towards the end of the following extract they ground their thoughts in taken-for-granted or '*little things*' which get done a certain way in the course of their everyday life but which in an 'ideal' world, they would have liked to have happened differently.

Tracey: I think there's always that underlying sadness in the family despite the fact that you've got, you know everything's under control but you sort of feel because you know it's not normal, it's not as it should be... and to see somebody poorly... that you love is not an easy thing so consequently you know there is to some extent erm something inside you that fights it if you like (laughs) because you know it's not as it should be but erm its yeah it does it has quite a big effect on the family really... it limits your what you can do so much erm... like occasionally I do look at other couples or families and I think and they are all busy doing things and going here there and everywhere and couples doing things together and just enjoying life altogether and I have to admit that sometimes I think oh I wish

erm but it hasn't turned out like that for us so erm we are grateful for what we have.

Malcolm: (Malcolm's deafness means he overlaps with Tracey) It's also the little things

Tracey: When I think about it I could have lost him long time ago

Julie: Yeah, yeah

Tracey: couldn't I? Yeah so

Malcolm: Its - sorry

Tracey: Go on its you

Malcolm: I say its little things or what perhaps we don't perceive er going round Asda's with her, helping her with the bags, erm reaching up to the top shelf - it's all those things there's just such little things sometimes and yet if I was there it would make a huge difference to both of us wouldn't it?

Tracey: Yeah

Malcolm: To go round Asda's together, to take the dog out for a walk and that sort of thing. When I'm feeling a bit better I often potter in the kitchen with Tracey she does something and I do something if I you know when I'm better but there's so many times when I'm not... Erm but we've got our little routine but it's still a big thing er you know I come down and er the other day and there was Tracey ironing away - well (sighs) she could do with something else I mean not, well do the ironing but have something else - me here chatting to her or something. It's bad enough ironing (laughing) let alone ironing on your own.

Tracey: (Laughs) I lot of people have to iron on their own don't they?

Malcolm: I guess it's little things like that, big things, but there's also the little things that we just take for granted erm but when they are not there you miss em

Again, as was discussed in Chapter 5, the experience of having separate 'life clocks' and not being able to 'do' everyday things together was at the forefront of this couple's reflections about their family life. In this dialogue

they provided further insight into the lived experience of this as Malcolm imagined Tracey straining to reach items in the supermarket and Tracey imagined a life where they could be 'busy' doing more together. Here they expanded on this experience of separateness and stated quite explicitly that this was something that caused sadness and felt like a loss. Tracey admitted that sometimes she thought about a different family life and that she was aware that the one they currently had was '*not as it should be*'. Once again, the couple were thinking about what 'family' is by comparing themselves with an external model of how family should be done, or they imagined it was done by others (Gillis, 1996).

Jackie Kenny also reflected on the routine of her day-to-day life with husband Clive and she too imagined the possibility of a quite different life. Like the Bakers, in her dialogue below she reveals how she imagined what other families were like in terms of their practices and what they did. Talking about Clive's constant need to be '*doing*' things for her, Jackie explained:

Jackie: And he does things you know that I can do but he's there in front of me doing em you know

Julie: Yeah

Jackie: But aye you have just got to accept it haven't you? I thought oh at least he's, it's not as if he were ignoring me and not helping me, I mean I honestly don't know how I'd cope without him, I don't... but its little things you know at night if I'm not feeling well - I'm always worse first thing in a morning and then at night when you get tired - and in an evening I get to the stage where I just, it's too much bother to do anything and I sit here and he fills my hot-water bottle and he brings that and 'do you want some milk to take your tablets?' and he takes the hot-water bottle upstairs and he puts

it in bed and he turns the television on ready for me and I think if he weren't I wouldn't even want to do that you know when it gets to that time if he weren't here I think I'd probably just sometimes sit in this chair and fall asleep, not bother going to bed I feel, I think it must be awful when you are on your own it really must be yeah. When everything like that's such an effort you know and there's nobody there to do it for em, it must be - not big things its little things like that

Whilst Jackie began her reflections by expressing frustration at having to accept that Clive was now the 'doer' in their relationship, she soon balanced this with the gratitude identified in Chapter 5 - noting that he cared for her so attentively and her situation was indeed a lot better than she imagined a single person's would be. It seems that the source of her gratefulness sprang from her imagining what would have been a rather different illness experience, had Clive not been around to do things for her. Interestingly, as with Tracey and Malcolm, Jackie made it explicit that it was the '*little things*' that shaped the quality of her life and that it was these that were most vivid in her imagination; they were the things she experienced quite consciously it would seem, by the way she reflects on them here.

Once again drawing on this idea of experiencing aspects of daily life more consciously, Brian, the eldest child of Eddie and Kathleen Cox, explained how he thought more carefully about his telephone practices since his dad had been diagnosed with terminal cancer.

Julie: ... since you know your dad has had this diagnosis and you know it's going to come too eventually, has that made you think a great deal about your relationship and stuff with him then? Or has it sort of

Brian: *Well I have (sighs) I think Donna (Brian's wife) has made me think about it more than actually the illness cos she's actually picked me up on things like and this was before he was ill like when I'd say 'oh we'll go down to me mum's' - [she'd say] 'why do you say to your mum's?' ... in the past and if I phoned up and me dad answered the phone straight-away I'd say 'is me mam there?' if you know what I mean*

Julie: *I do yeah*

Brian: *and I'd speak to me mother. Now consciously while my dad's ill I'll ask me mother and talk to me dad if you know what I mean but I struggle - I can pick the phone up to me mother and me and me mother can have the rest of today on the phone*

Julie: *Just rattle about anything*

Brian: *and I don't do that - whereas with me dad I'm thinking what do I ask him next?*

Here Brian reflected on his telephone conversations with Eddie, and explained that when he was speaking on the phone he was thinking about what he was doing quite deliberately - wondering what he would ask his dad next. Brian was negotiating the spatial, but also the emotional distance he felt from Eddie as he explained how he *consciously* asked his mum to put him on the phone when he called home. Clearly Eddie's prognosis made Brian reflect more on his relationship with his dad, and he altered his telephone practices - to try and feel more connected to Eddie - as a result. This indicates how thought and action interacted in this particular situation of daily life and it also points to a paradox in the sense that whilst everyday family life is continuing, at times it is the very ordinary bits that are being especially reflected upon as the illness adds layers of negotiation to the 'doing' of particular relational contexts.

Continuing with the theme of spatial separation, Malcolm's wife Tracey, unlike Brian, did not need to facilitate a closer emotional connection with her husband during times when they were apart; she actually struggled to 'switch off' emotionally from his experience. Again, the significance of 'imagining' or thinking about aspects of 'doing' daily life was clearly expressed by Malcolm and Tracey as they discussed how the illness could play on a well relative's mind and occupy their thoughts in particular circumstances. Interestingly this was not something which Malcolm was unaware of, and it was he who actually described carefully the kind of situation where this might happen. They were both involved in a process of thinking about 'doing' that connected the couple in their negotiation of Malcolm's illness in day-to-day life. In the following example they suggested that whilst one was thinking about what the other was doing, the other was thinking about how what they were doing was affecting the other.

Tracey: ... in many ways obviously an illness does limit you anyway but you know it's more than that its, its er, a thought processes limitation because you constantly going back to - are they ok. And whereas normally, under normal circumstances you'd be quite carefree wouldn't you

Julie: Yeah

Tracey: You'd be not thinking about them at all, you'd just get on with what you were doing and erm you know not worry about it at all but erm, you are brought back constantly to this you know one thing really.

Malcolm: It is like it may seem a small thing but I suppose it is an added stress to your day-to-day situation erm, certainly not helpful is it?

Tracey: No not really. But there again I suppose you (meaning herself) feel responsible don't you so?

Malcolm: *But you do even for example if er Tracey knew I was perfectly alright in the sense that I had gone to the hospital for a check up and its one of these long things where they take your blood and they have to analyse it before they can see you so you are at least another 2 hours after you've taken your blood and everything erm, Tracey would be worrying is he alright on those seats you know because she knows how uncomfortable they can be and everything and so, that side of it would be going through her mind although she knew I was in a hospital (laughs a little) you know there were plenty of nurses around but it would be added stress for Tracey because she'll be thinking - oh I know he's not very, he's not going to be, has he managed to get himself a drink you know, has he managed to get himself something from the cafe to eat? Has he sort of - and so that's going through her head at the same time I suppose...*

Malcolm explained that he knew what would be 'going through' Tracey's mind as she thought about how he was getting on at the 'same time' that he was doing his hospital visit. In other words they were both involved in a process of 'imagining' the other which involved relating to one another's experience at the same time, but across space. Interestingly, Malcolm suggested this might only be a 'small thing' and by this I wonder if he meant an accepted part of daily life that although stressful (more 'extraordinary' experience), was actually also mundane ('ordinary' experience) and made necessarily so by its regularity, predictability and inevitability as a part of living with the illness.

Indeed it was striking that many families, despite the difficult times they were facing, kept rather mundane concerns in mind and interlaced these with their stories about daily life and life-threatening illness. I also noted the way that some relatives seemed to more consciously experience mundane aspects of daily life during a relative's dying. For example, one afternoon,

after a lengthy conversation with Dave, Glenda's son who was introduced in Chapter 6, I was struck by the way he reflected on his practices of that particular morning.

'He told me about this morning and explained how this particular one had been wonderful - he hadn't done anything special, it was just a very ordinary morning and that is why it was so great because of how different his life had been since Glenda's diagnosis 6-7 weeks ago. This morning was the first time in a long while that he had got up after 6am. He woke and was able to do normal things such as wiping down his kitchen surfaces and he described to me how he got pleasure from this, from seeing them clean... Despite having what he considered a lie-in, Dave was still at the hospice by 8am. He told me that he had deliberately asked his sister Mo if she could be at the hospice early, to give him a chance to have a break; although now he feels guilty about this'.

In this example, Dave appeared to feel 'bad' about thinking of, or 'indulging' in almost, the mundane, ordinary aspects of daily life at home whilst his mother was dying in the hospice. Nonetheless, the ways in which family experiences of illness and dying are made meaningful as lived experience through an immersion within everyday life and mundane practices, is once again underscored by his comments and quite conscious reflection on aspects of his daily life.

This example, and the others I have included in this chapter so far, suggest that living with severe ill-health and dying might create a particular awareness or consciousness of the mundane as it is experienced - a reflexive relationship between thinking and doing as family practice. Yet this does

not necessarily imply 'transformation' of the mundane and/ or everyday into something more existential in families' experiences. This would simply reaffirm the notion of dying as an extraordinary experience, and one which is unconnected with the everyday. Nonetheless the idea that 'small things' take on a particular resonance in the context of impending death is something which can be interpreted in some of the accounts I have presented above and which I will consider below. Whether this means that mundane aspects of daily life are somehow 'transformed' via this reflexive appreciation and are therefore no longer experienced as 'mundane' or 'everyday', is debatable. Rather, it seems more likely that elements of the mundane and everyday become important precisely *because* they are associated with regularity, familiarity and the understated flow and structures of daily life.

For instance, Clive filling Jackie's hot-water bottle is considered a '*little thing*' but one of particular importance, whilst also being a part of a very familiar bedtime routine and situated within her on-going relationship with Clive. Thus the 'properties' that make these practices 'small' or 'mundane' remain essentially the same, irrespective of this recognition, and they continue to be negotiated and understood in the context of emerging and on-going lived relationships. As I have shown here, these mundane elements are something which families can meaningfully 'peg' their understanding of dying, or the experience of illness, upon. It is then, most helpful to *not* view them as somehow abstracted out of the everyday as 'higher' experiences transcended by a family's awareness of death, even if sometimes being able

to do 'little things' or to have 'little things' done for you, is more appreciated or feels 'special'. Rather, I suggest, it is the ways in which the mundane makes the more extraordinary experience 'knowable', not necessarily that the experience of life-threatening illness transforms the mundane, or even that the illness is always experienced in extraordinary ways. Felski is critical of contemporary theorists who 'celebrate the everyday while pretending that its [routine, mundane] qualities do not exist' (1999: 31). Therefore to understand family experiences of terminal illness holistically, it is important not to lose sight of 'the ordinariness of daily life' (Felski, 1999:31) and the ways in which lived experiences are embedded in mundane routines; that is even if an awareness of impending death might bring particular reflexive qualities to bear on the 'doing' of aspects of the everyday.

Making Absent Present: imagining, remembering and 'displaying' family

Clearly, in the previous examples, individuals were experiencing themselves as 'connected' and linked into the lives of others they considered as 'family'. Thinking about the ways people *feel connected* and embedded in lives and concerns beyond their own, Smart (2007) recognises:

... the materiality of these feelings and associations and hence the importance of always putting the individual in the context of their past, their webs of relationships, their possessions and their sense of location (2007: 45 my emphasis added).

Utilising Smart's notion of the 'materiality' of familial connections, in this section I explore how objects are imbued with relational importance. Specifically I consider how they are used as tools for 'displaying' family life (Finch, 2007) (conveying to others how 'family' is 'family') and making absent relations and relationships feel present (Gibson, 2008) in circumstances of illness, dying and death. Discussing the matter of absence and presence, Callon and Law explore self-evident 'spatial truisms' and outline a conceptual re-working of ideas about objects and people in space. One of the 'truisms' they challenge is the idea that something or someone can either be absent or present in a particular space. Instead, they consider how the absent can be present and that presence cannot be reduced to the experience of (physical) co presence. Referring to Hetherington (2004), Callon and Law (2004) summarise his argument that the act of disposal (or absence) - even in death - is never final and that therefore the absent can have agency. As Hetherington himself argues:

The absent can have just as much of an effect upon relations as recognisable forms of presence can have. Social relations are performed not only around what is there but sometimes also around the *presence* of what is not (2004: 159 emphasis in original).

Indeed, empirical work suggests that an absence created by death is not necessarily absolute, as the dead can be made present and have agency in, and via, different forms (see Hallam *et al.*, 1999; Bennett, 1999). For example, as Gibson (2008) has argued, this can happen with objects which previously belonged to, or were associated with, the deceased (see also Hallam and Hockey, 2001 and Meyer and Woodthorpe, 2008). However, as I have mentioned previously, although there has been some focus on how

objects and routine practices facilitate relationships between the living and the dead (see Hockey *et al.*, 2001 as a further example), their relational significance in the pre-death period - especially in an everyday sense - is less well explored.

Thus, this section will refer to three specific instances of 'absence' or separation, focusing mostly on relationships in the pre-death period.

Drawing on Finch's (2007) notion of 'displaying family' I show how objects can be a way for families to maintain *themselves* in the present as families - considering examples of when an ill relative was absent from a family holiday, before moving on to explore experiences of staying on the hospice ward. Finally, I discuss an instance of more permanent separation, drawing on the post-death experiences of one family member in particular. In each of these circumstances, families experience *their* connections with each other in ways that require imagination and the negotiation of family memories and biographies which are often invested and embodied, as Smart points out, in inanimate objects.

Holidays: negotiating absence using imagination and 'display'

I start with examples from interview families who *shared* the experience of being physically separated when well relatives *went away* on holiday, leaving the ill person at home because they were *too poorly* to join them. The following extract is from an interview with Hugh and Dot where I ask about a bottle of whiskey which Hugh had opened *on a previous visit* to

Dot's daughter's home in Guernsey. We were discussing the recent trip Dot made to Guernsey without Hugh.

Julie: I was just going to ask what about your bottle of whiskey that was on, is that still there?

Dot: That's still there on top of the er unit yeah

Hugh: That'll be there on top of the cabinet in the kitchen

Dot: Yeah

Julie: Did you have a check Dot to see if it was still there?

Dot: Yeah it were still there. Maddy said 'mam his whiskey's still up there'

Hugh: They'll not touch that

Dot: She says 'it's not been moved since you were last here, since Hugh last had a drink'

Hugh: They'll not shift that; they'll not touch it (pause)

Julie: Waiting for you

Dot: Yeah she says it's still there

Here the bottle of whiskey acts as a symbolic representation of, or a 'surrogate for', both Hugh's presence *and* his absence from this family occasion. By defining the whiskey as explicitly 'Hugh's' and reiterating that it remains untouched without him there to drink it, it embodies a sense of agency on Hugh's part and represents his ever-present importance in their family - as this is expressed by the bottle being displayed in the kitchen but remaining exclusively for Hugh's consumption only. Yet the fact that it remains on the unit, but ultimately untouched, does also act as a material reminder of his absence from what had become a regular family occasion at Maddy's home in Guernsey. Towards the end of my time with the family,

Hugh's health deteriorated further and he suggested he would probably never travel to Guernsey again, telling me that *'I can't get over there, I can't see it Julie it's too far love, it's too much for me'*. Therefore the whiskey became a material representation of Hugh's fate - its permanent fullness; it's never going down - reflecting his deterioration towards death.

In another example, I was shown a painting which was purchased by Tracey and Karen on a recent trip to Krakow. Malcolm had explained to me in my third interview with the couple that it was important to him that Tracey had the opportunity to go away on holiday and to have a break from her caring role at home. He took great satisfaction in using the internet to search for city breaks and to book a short holiday for Tracey and their daughter Karen; he told me that knowing they would enjoy themselves was just as pleasurable for him as being there himself. When I saw them again after Tracey and Karen had returned, Tracey brought the painting down from upstairs and un-wrapped it for me to look at. The painting was an original canvas featuring a landmark bridge and it showed two silhouette-type figures that blended into the misty, atmospheric soft-focus of what was a 'rainy' scene.

Julie: *(On seeing the painting) Oh wow. (Pause) That is beautiful*

Malcolm: *Its superb int it?*

Julie: *Its gorgeous - really, really nice.*

Tracey: *So that's a good you know memory lane thing*

Julie: *Yeah it's beautiful.*

Malcolm: *(Pointing to figures in the painting) That's Karen and that's Tracey (Tracey laughs)*

Julie: *Is it? (Laughter in voice) Yeah I can see the resemblance yeah, definitely. It's so effective with the mist*

Tracey: *It is*

Julie: *and the rainy feel it's really*

Tracey: *Yeah, it's a beautiful, beautiful city*

Tracey's suggestion that the painting can act as a '*memory lane thing*' is interesting because the painting was given to Malcolm as a gift, and he had no direct, experiential memories of the trip as he did not travel. However Malcolm - who was completely deaf at the time of this interview and was therefore unaware of Tracey's suggestion that the painting was a memory-aid - also 'joined in' with this by placing his family in the painting and imagining the scene of them in Krakow. He playfully claimed that the silhouette-style figures in the painting were actually Tracey and Karen.

In both these examples, the objects that embody relational significance become a point of fixed materiality to facilitate the imagination of connections between people across time - the picture of Krakow as a '*memory lane thing*' for the Bakers - and across space - Hugh's whiskey symbolising his presence despite his physical absence in Maddy's home. In both instances Finch's (2007) notion of 'displaying family' is relevant as the objects are used to inform me - the researcher and someone external to the families - about how the families are a 'family' in spite of the difficulties illness can create. So in both these cases cancer had disrupted what many might assume to be a typical family activity - going away on holiday. The Mullins' narrative about Hugh's bottle of whiskey and the Bakers showing

me their painting of Krakow became ways of displaying to an outsider that they were still connected and embedded - to use Smart's (2007) terms - within important webs of relationality. Indeed, Finch (2007) does suggest that in particular circumstances (such as re-partnering or occasions in family life which are less 'routine') where practices might deviate from those which are most readily acknowledged as 'family-like', the need to display and assert a sense of 'family-ness' might be greater. Perhaps the challenges posed by life-threatening illness are another such circumstance where this idea of displaying family becomes especially important.

'Displaying' Family on the Ward: photos and their stories

Sontag has suggested that photographs are 'a portable kit of images that bears witness to [a family's] connectedness' - in her words 'cameras go with family life' (1977: 8). This association of photographs with the construction of 'family' is explored by Finch (2007) when she refers to photos as a 'tool' for the 'display' of family life. She points towards the role that these material objects can play in making absent relations and relationships present, when they are displayed in particular contexts. Disagreeing with the idea that displaying family is a purely performative process which therefore always requires co presence in the form of face-to-face interaction, she writes:

There are many means available for display that do not rely on immediate, direct interaction, but where meanings are conveyed and reinforced through indirect means. For example, grandparents who keep pictures of their grandchildren in a prominent place in their homes are 'displaying' these relationships irrespective of whether their grandchildren are physically present (2007: 77).

Thus the concept of 'display' and the idea that relations or relationality can be present whilst being physically absent, are tacitly entangled with one another in the family practice of displaying photographs. As Gibson argues:

Despite the Western perception of itself as rational and non-magical, photographs are treated as if something of the person in the picture is there, not just as an image but as part of the material object (2008: 87).

Gibson also suggests that photographs can be part of a 'visual narrative' which, amongst other material objects on 'display' in people's homes, can construct 'trajectories of individual and family lives through significant events' (2008: 83). They can tell *stories* about families - who they are, how they live, what is important to them - and these photos can evoke memories from the past for those who are within the family and know its history and the biographies of its members. But it is also the case that for those who encounter the photos without this knowledge, they can imagine from the images that families choose to display of themselves, particular things about a family and the relationships embedded within it (see also Miller, 2008: 57-66). And so aspects of family life which might be experienced in terms of absence whilst people are staying on the hospice ward⁸⁵ can be made present via the display of particular photos in the ward environment.

I encountered a number of patients and families who displayed photos on bedside tables and notice boards around patients' beds. Whilst placing meaningful objects in personal space within larger shared environments

⁸⁵ For instance being separated from certain individuals who cannot visit or missing out on certain family events which are on-going.

such as the work place can be a way to mark-out 'territory' (O'Toole and Were, 2008), or as identified by Kellehear *et al.*, (2009) in their study of hospice bedside objects⁸⁶, items such as photos help to 'personalize' inpatient space, I suggest something was also happening in terms of the representation of relationality and family life. Indeed, Kellehear *et al.* recognised the significance of photographs as objects 'devoted to social connection' and how more generally personal items helped to 'bridge' the gap between home and its familiar social networks and being at the hospice (2009: 150). Thus, I noted the following about the display of photos next to a patient's bed and realised that this was a way of keeping Andy involved with the continuation of family life, despite his absence from certain events and occasions.

'I notice that some photos had been pinned on the notice board by Andy's bed. I am told that their daughter has brought them in and put them up so Andy can see what went on at a birthday party attended by family members'.

Interestingly in another case, photographs were not displayed in a permanent sense in ward space as in the previous example; instead John's wife used pictures she kept in her handbag to facilitate her conversation with me about what life was like for them at home.

'While we chat, John's wife pulls photos from her bag and a few are of their garden at home which is bursting with beautiful flowers and colours. It is tended to now by a gardener - because John can't

⁸⁶ Importantly, this was the first empirical study devoted to analysing the nature and significance of hospice bedside objects, which underlines somewhat the lack of attention paid to the material and mundane in studies relating to palliative care and death and dying.

manage it. He used to do it all and I feel sadness for him and awkward when I'm told this'.

For John's wife the images helped her to display a connection to a site which was significant to the couple and to the life they have lived together. Carrying the photos in her handbag she was able to use the pictures to express to me how John's illness had changed aspects of their daily life. And yet at the same time she was able to proudly display, through the evident beauty of the garden depicted in the images, the hard-work and horticultural talents that her husband used to shape the landscape around their home. Whilst the photos might have acted as a visual 'counter-point' to the physical immobility that John was now experiencing, because the images were portable they also helped his wife to mobilise or 'make present', in particular conversational contexts, important aspects of John's biography and how he was known - for instance as a competent gardener - to his family. It can be argued that his social identity was materialised in the images as something which was different to the identity his physical, deteriorating body permitted. In other words the photos helped to display a more complete 'John' in the context of the life he had lived.

Thus in John's case the photos were able to convey to me aspects of his identity which were being eclipsed somewhat by his illness. This also seemed to be the case for another patient, Laura. For her family, arranging photos in a more permanent way around the private room she occupied, displayed important connections to a particular family member who was

unable to be physically present on the ward. Describing time I spent in

Laura's room I wrote:

'After Adam [Laura's son] has left I stay with Joe [Laura's husband] and ask if he minds if I take a seat where Adam had been sat. He doesn't and I feel glad for the seat, but I am aware of how close I am to Laura's frail body and that we are talking across her as she lies between us. I ask Joe about Adam's daughter Sophie (Laura's granddaughter) and whether she has been to visit Laura at the hospice. Joe explains that it would be such a shock for the child (approx 3-4 years) to see Laura as she is now and therefore the decision had been taken that she wouldn't come to see her grandma. However I notice a child's painting stuck up on the toilet door and I am told that this was done by Sophie. There are also photos of her on a small table by the door... One is in a frame and there is also a mini photo album with loads of different pictures of Sophie inside. It strikes me that Sophie is present in many ways in the small bedroom, despite never having been there in person...'

Clearly I was struck by the 'presence' Sophie had in Laura's room, despite the fact that she had never been allowed to visit her grandma there. As Miller says about the owner of one of the homes he visited for a study about people's relationships with 'things':

Marjorie also understands that what matters is the presence of the person, not their particular form. Nor is any particular genre especially worthy. A person may be here [in her living room] as a photo of their face, a drawing they did as a child... (2008: 63).

Sophie's physical form might have been absent from the hospice ward, but her presence as a significant person in the family could be imagined via the display of her 'personality' as it appeared in carefully selected photographs

and was expressed in her painting on the toilet door. In Miller's study Marjorie is the orchestrator of her living room environment. However, in the time that I spent with Laura and her family she was never fully awake, and so I did not actually see her looking at the photos on the little table and I gained the impression that it was not Laura herself who had placed the objects around in the space. It did seem significant however that Sophie's painting was stuck on the toilet door which would have been in Laura's line of vision, had she at some point been able to lift her head slightly and glance across the room. And so the images perhaps had an additional purpose beyond that of being available for Laura to view herself. They were also displayed 'for' her in the sense that they acted as a window into an important relationship she had, and one which she had not been able to 'actively' display in the ward environment. A presence for Sophie was created in the room via the display of her physical form in images, but what was also 'on display' was the relationship Laura shared with her as her grandparent. And so Sophie's symbolic presence helped to maintain this aspect of Laura's identity within her family as it was displayed around the room for whoever might enter - fellow family members, housekeepers, nursing staff - to 'see' and imagine.

For a different family the position of an image in space was especially important. In Eleanor's room I noticed that a photograph had been placed inside a frame with 'grandma' printed on it, and it appeared strategically positioned so she could see the image of herself and her granddaughter who was a small child at the time the photo was taken some years ago. Eleanor

was in her 80s and slept for much of the time that I saw her on the ward and she was therefore lying down in her bed. I had noticed that this framed photo was placed on a bed-table⁸⁷ and these were usually positioned by the side of or over a patient's bed, but in this instance it ran along the foot of Eleanor's. The photo was facing directly forward towards her and it demanded attention since the table on which it stood was generally free from clutter and other items. I spoke with Eleanor's relatives about why the picture had moved onto the table at end of the bed and noted the following:

'The 2 women are sat at the side of the bed and Eleanor's son at the foot of the bed... [The] son introduces me to Eleanor's granddaughter as the little girl in the photo. The young woman is in her early 20s... I say that I noticed the photo had moved onto the table at the end of the bed; the woman [Eleanor's daughter in-law] explains that her husband (Eleanor's other son) had placed it in view of the bed so that Eleanor would be able to see the photo. The rest of the family then agreed that they would make sure it was put back there, in view, when they left... I notice that when the 2 women leave a short while later her son moved the photo back into position and went and sat closer to Eleanor's bed'.

This family had decided between themselves that it was important that Eleanor would be able to see the image when she was left alone at the hospice. Managing the position of the photo in space was carefully negotiated by the family. In doing so they 'displayed' to Eleanor her continued presence within their lives and reminded her of the relational bonds she shared with them and remained embedded within. Describing the

⁸⁷ Table used in medical institutions - hospitals, hospices etc. - which is designed to fit across a patient's bed to facilitate eating, reading etc.

concept of 'embeddedness' in relation to personal life, Smart (2007) seeks to underline the multi-faceted ways in which modern families continue to experience themselves as connected, despite individualism and the social and familial changes of late modern life. She explains that:

These relationships are very 'sticky'; it is hard to shake free from them at an emotional level and their existence can continue to influence our practices and not just our thoughts... [embeddedness is] a concept [that] seeks to reflect the tenacity of these bonds and links... (2007: 45).

Here Smart once again points to the inter-relationship between emotional feelings and thoughts about relationality, and the 'doing' of family practices. This resonates with the actions of Eleanor's relatives who negotiated *how* to display a particular photograph in her room, and therefore 'made present' Eleanor's connection to the family in a space essentially unfamiliar to their family life. Thus there are similarities in these examples with empirical studies that document the continuation of relational bonds after death - such as memorialisation practices where material objects are displayed around grave sites by surviving relatives (Francis *et al.*, 2001).

O'Toole and Were have suggested that for some people, photographs 'are a window to a world peopled by friends and family who value them' (2008: 630). With Eleanor's family, how they displayed the photo so she would be able to see it clearly, expressed the value they placed on Eleanor's connection to the family but also the importance of her knowing this, in their absence. However it is also possible to consider how photographs can be a tool to enable families to provide a more layered, complex picture to

others about the person their ill relative 'is' and the 'people' they have been. For instance, on a previous occasion when I had commented on the photograph taken of Eleanor and her granddaughter, mentioned above, I was directed by her son to the striking blonde hair that his mum had in the image but which was somewhat different to the grey hair she had at the time she came to the ward. Though the son did not point out directly this obvious change, it was apparent that he was identifying for me qualities that had made his mum distinctive to him and which represented the different 'phases' of the woman he had known as his mother over the years. Thus there are similarities here with the photos of John's garden mentioned above - the garden he can no longer cultivate - representing a change to his physical and social self. About photographs Gibson writes; 'at some point in time, they may remind us of something, someone or somewhere that, at present, is forgotten and irretrievable' (2008: 81). Not surprisingly, as was the case with Eleanor above, the photos that were displayed around patients' beds were of times before the illness where the ill person looked well and presumably was more able to do things. As Gibson suggests the 'wellness' embedded in the photographs was now 'irretrievable'; it was a poignant absence against the frail bodies that lay next to the photos. With some female patients, seeing photos of them with long, glossy and coloured hair was often something I found difficult due to the absence of these qualities in the cropped, brittle, greying styles they tended to have when I met them on the ward. Nonetheless it seemed that 'wellness' was an important part of the images that were displayed by families, and as O'Toole and Were (2008) have identified, photographs in particular can act as a connection to

spaces, times and relationships beyond the specific locality in which they are displayed, which is something that is of importance for an individual's identity. Despite the juxtaposition that is created by the presence of the ill relative's 'well self' through the display of particular photos, this practice allows important connections to be made to a time of family life prior to the illness and it facilitates the narration of a more 'complete' biographical picture of the family's story. This felt most apparently the case with one couple in particular.

Jill was in her early 60s and due to the progression of her disease she was unable to communicate verbally. It was up to her husband Billy to display to me - in words and through the images he displayed in the space around Jill's bed - who the couple 'were' and the things they did together that demonstrated the bonds and relationship between them. About Jill's room I noted the following:

'On the notice board on the wall, Billy has transferred the photo of the 2 of them which I had seen on the board next to her bed in the communal area when Jill occupied that. Billy explains that it was taken of them when they were in Scotland - Jill looks radiant and really happy. They are sat close together in what looks like a pub. There is also a psalm that has been printed onto paper and which incorporated a photo of the 2 of them on the moors. They are keen campers and have taken many holidays in the UK... Billy talks to me for a little while about some of the places they have been. He tells me that they have taken the psalm sheet everywhere with Jill during her recent hospitalisations...'

Billy took the task of displaying the couple's life beyond the re-presentation of photographic images in the context and form in which they were originally shot and actually imposed a particular image of the couple walking onto a psalm sheet that reproduced a verse of religious significance for the couple. The couple were members of a local church community and Billy underlined the importance of the eclectic image he created, where aspects of their life together were presented alongside one another in a quite strategic way, by telling me that he had taken the psalm sheet from place to place so it could be displayed by Jill's bed in the various medical institutions she had stayed. However, as I noted above, for Billy these and various other objects and images were a tool to aid him in his narration (or 'display') of the couple's life and their experiences. On different occasions Billy shared things about the couple's life together - for instance, how they met and holidays they had taken. On another he gave me a copy of their church's newsletter which contained a 'prayer-call' for ill members in the congregation. I think he wanted me to see Jill's name printed in there and to be able to imagine how she was being prayed for and what was going on for them and what they were connected with, beyond the confines of the hospice room. Because Billy was aware of my researcher role, he also explained that he had a letter at home which he could bring that would help me to understand the couple's life as it had been lived. It was a 'Christmas message' they had drafted the previous year to send out to family and friends to update them on Jill's condition. About the day I received it I recorded the following.

'Not long after I had arrived, Billy emerged from Jill's room with a letter in his hand. It was the Christmas message which he had promised he would bring for me... he had remembered what he said last night, gone home and run copies off and brought them to my attention within minutes of my arrival... My name was written in neat, calligraphy style writing on the front of the envelope. We slowly headed back into [Jill's] room and we both stood by Jill's bed and talked... I decide to open the letter and inside there is the Christmas message and a memo he included which he thought might also be useful. He explains that he wrote the memo detailing what Jill was like at the time for the medical staff at a particular clinic she attended - to give them a detailed picture of how she was day-to-day. I started to read the message and Billy walked away from me and looked out of the window - jangling the loose change he had in his pocket. I wonder if he is a little uncomfortable and it occurs to me that perhaps this is Billy's way of telling me their story - as he hasn't really spoken very much about the illness and what's happened to Jill - apart from to say '*and that's when we knew things weren't right*'.

Thus, reflecting on my time with Billy, I wondered about his use and display of material objects that represented things that were significant to Jill and himself, and I felt that maybe he intended to give a presence to the life the couple had lived together as a way to introduce me to the story of Jill's illness.

Remembering Eddie: missing the mundane

In the previous section I explored how objects - especially photographs - can be imbued with relational importance and used as tools for displaying

family life and making absent relations and/ or aspects of relationships feel present in circumstances of illness and dying. However, when someone actually dies and the experience of physical 'absence' is more markedly permanent, the power of objects to connect bereaved people to their deceased relatives is more fully documented in the literature. For instance Gibson writes:

Death reconstructs our experience of personal and household objects in particular ways; there is the strangeness of realising that *things* have outlived *persons*, and, in this regard, the materiality of things is shown to be more permanent than the materiality of the body (2008: 1 emphasis in the original).

Although I am primarily concerned with experiences of dying and the anticipation of death, I did maintain contact with two families after their ill relative had died, and I interviewed an individual from each family to hear about their experiences of family life after this death. Here I consider Claudia's experience of 'mundane remembering' in relation to her present everyday life after the death of her father Eddie. I expand on Gibson's (2008) focus on 'objects of the dead' to think more about how mundane, *household* objects are experienced as a material focus for remembering, imagining and experiencing the absence of a deceased relative. In particular I focus on how these can be experienced in a *discordant* way by the living undertaking the routine aspects of their day-to-day life. For Claudia, because certain objects no longer felt embedded in a repertoire of *familiar* family routines which involved 'doings' undertaken by her father in particular sites and temporal ways, the part they played in anchoring memories about the 'kind' of relationship she had with her father, appeared

significant. As she explained to me, it was '*stupid little things*' she noticed that created a feeling of missing Eddie and his absence from her life.

Claudia: In a morning me dad used to bloody knock me up to pick Mitsy (dog) [up]... and I right miss him banging on me door. And I miss him traipsing in here [and I'd say] 'now then is your bloody feet clean?' Do you know what I mean? Or he'd come in just I don't know just little things that I miss - going in me dad being sat at me mum's at the table you know reading the paper but not reading the paper

Julie: Hmmm

Claudia: Sat in the chair, the chair, that chair do you know what I mean? And I don't know how I'd ever feel about that chair being got rid of cos that I symbolise that [with] me dad, yeah and like if I sit at the table I can actually see the telly now and I miss that I can see the telly cos his head was always in the way

Julie: Hmmm

Claudia: and I'd be like 'dad will you put your head to the other side?' and then he'd sit like that... and then I couldn't see the telly and then like he'd go to that side then and I miss that - it's stupid little things. Or like I say if I feel that road out... it's silly little things... Like in a morning walking into me mum's he used to be sat at the table having his breakfast when I dropped the dog off cos obviously by then he'd not, he weren't coming down here to pick Mitsy up, when I walk in its like oh hasn't he got up yet - oh no he's not here me dad is he? Just I don't know

Julie: Everyday things

Claudia: Everyday and because like I went every day like I went in a morning, when I'd finished work, I'd go back up before they went to bed - do you know what I mean? So there's different parts of the day like and I'll think oh he's not here is he, no.

Claudia's account is important because it explores something different to what Gibson found about bereaved people's feelings towards objects and 'things that carry with them the identity, character and memory-association

of a person' (2008: 5). About her participants' experiences of what they valued after a loved one had died, Gibson writes:

The interviews revealed that some objects *do not* trigger feelings of attachment, or specific memories or stories, for example, most household effects that are mass-produced and occupy collective household spaces and forms of use (televisions, fridges and so on) (2008: 4 emphasis in original).

As Gibson argues here, the value placed on a particular object stems from its ability to facilitate an attachment - a sense of making the absent person feel present. For her participants less personal objects - objects that contribute to the functioning of a household (e.g. TV) - did not have the same imaginative potency as those with a more specific association with the deceased (e.g. their clothes). For Claudia, however, it was precisely because the '*telly*' Eddie used to habitually watch was embedded in a familiar routine which involved her dad taking up particular bodily poses in *collective* household space, that observing the TV set after his death triggered memories and connections to her father. Although other family members, including Claudia herself, 'used' the television, the particular ways in which Eddie viewed it - sitting in '*that chair*', placing his head to one side incessantly - and how this shaped the way others experienced the space - Claudia not being able to see the telly from where she sat - meant that the absence of this habitual practice, and the predictable interaction it triggered between Claudia and Eddie, was something she missed when going about her daily life after Eddie's death. As Claudia glanced at the television she still expected to have an obstructed view of the screen, and so the TV as an object around which interactions of daily family life were

orchestrated, became integral to Claudia's experience of her father's absence. Again, as I have noted with other participants in previous examples, Claudia explained to me that she was aware that these were '*little things*' and implied - though these are not her own words - that she experienced a sort of 'mundane remembering' that connected her to her father and enabled her to 'expect' to see him again in certain sites and at certain times in on-going daily life. The intricacies of these memories as they are grounded firmly in the mundane, taken for granted aspects of family life are evident in the way Claudia describes what was 'done' in day-to-day life that made Eddie, 'Eddie'; for instance, him '*reading the paper but not reading the paper*' and entering her home but never taking off his dirty shoes.

Gibson has suggested that there is 'a notable absence of sociological research into grief and material culture' and 'the more intimate history of grief objects through interview research' (2008: 8). In this section I have tried to provide some insight into the arguably even more neglected area of material culture and *dying* experiences. Whilst I have drawn on Smart's conceptual fields to explore the interlacing of thinking and imagining family with 'doing' and 'displaying' family life, I have continued to underscore the importance of the mundane and seemingly 'ordinary' for understanding how families do being families at this time by focusing on material objects and their significance for families in everyday life.

‘Doing’ Planning: imagining death and family in the future

In this final section, I explore how, for some families I interviewed, imagining family futures impacted upon the ‘doing’ of everyday life in the present. To do this I will draw on data which examines how families are involved in ‘doing’ planning which is shaped explicitly by an awareness of imminent death and imagining family life beyond it. As in the previous sections, here the significance of thinking and imagining family relationships and lives (Smart, 2007) is evident in participant’s frequent use of the terms ‘*see*’, ‘*imagine*’ and ‘*think*’ (and their equivalents), when they were talking about plans and preparations they were making for family life after the ill person had died.

Malcolm and Tracey were very open about the fact that they were preparing for Malcolm’s death in certain ways. Field notes which refer to my second interview with the couple clearly show this and some of the rather mundane matters which were involved in the plans and preparations they were making.

‘The likelihood of Malcolm dying relatively soon was something which was accepted fairly openly during the interview - for instance Malcolm spoke about wanting to get around to showing Tracey how to work the TV and DVD players - in preparation for when she is on her own’.

The couple wanted to explain to me how their knowledge of Malcolm’s impending death meant that mundane, household things, that would effect

on-going family life after the death, needed to be considered in advance and active steps - doing and showing - taken to ensure very practical matters would be taken care of when Tracey was on her own.

Tracey: Right, you both have different roles and unless you actually explain to each other what you are doing or what how it goes then you are going to be lost. I mean if I went he'd be lost financially, he'd be you know

Malcolm: I'd be in a right mess

Tracey: he wouldn't know what was what or anything and... course when you know you have to think of those things a bit in advance really to make life a bit easier for each other. There was only just something yesterday wasn't there when we said it was this but something you said 'oh you'll have to tell me' (pause)

Malcolm: Heating

Tracey: Heating, how to do the heating?

Malcolm: Yeah

Tracey: Yeah, hmmm.

Clearly practices ('doing') and imagination were interlaced in the couple's experience of daily life as they encountered practical, everyday tasks which were reflected on and performed with one eye on the future. Very everyday matters and practices were an important part of imagining a future where Malcolm was not going to be present and were seemingly as relevant as those existential concerns more readily associated with thinking about death. In the following extract Malcolm clearly explained that, whilst having a terminal illness meant that he did have more time to think and reflect on his situation, it was often mundane matters that occupied his thoughts about how Tracey and his family would get along without him.

Julie: ...*I mean when you started talking (previously) about sorting out all the practical stuff and I just thought - yeah you know it's the small things as well - like you called them stupid things but I don't think they're stupid at all when you say what they meant and how the peace of mind that they have given you*

Malcolm: *Well it is it's like I saw Tracey trying to get into the loft (pause) and I thought there is no way I can be having that - putting some steps up and then having to get onto - because Tracey isn't very tall - the top step with nothing to hold onto and just trying to push this thing up and so that's it we are going to get a guy to put in a loft ladder, even now it's not very*

Tracey: *it's ok I can manage*

Malcolm: *You can manage yes*

Tracey: *I'm not very adventurous (laughs)*

Malcolm: *You just think I can't be having this you know what happens if? Tracey can't live with this you know. And you begin to sort of see things and in that sense really it's a good thing to be aware that you are not going to possibly be here. I don't think Tracey will ever be, find a difficulty with (pause) with pensions and benefits and sort of all that sort of side but you just want to guard against as you say as I would say a little thing - but it isn't a little thing, it's a big thing when there's no man to call on and there's nobody else to do it for you and you are on your own.*

As he observed Tracey going about their home, busy doing mundane chores, Malcolm appeared to 'see' his own absence in the materialities of the present. He also saw his home space, and how material objects were positioned and maintained within it, differently. He *imagined* how Tracey would be able to negotiate her way around the home when she was on her own and made plans about what needed to be changed, based on Tracey's day-to-day life as he 'saw' her moving about in home spaces and imagined her doing so after his death. Talking about how facing his own death precipitated a sense of wanting to make plans that would enable household,

everyday matters to be put in order, Malcolm explained to me the importance of feeling assured in the present about how family life would continue in the future.

Malcolm: It's made you sort of want to do the things that you would always otherwise put off. We haven't got great (pause) massive plans that we want to see fulfilled you know... there are things to the house that I wanted to be done (pause) so that Tracey could sell the house if necessary ever. Insurances, I wanted Tracey to have. Like when my father died I said 'right mother you want an insurance for water, you want an insurance for electric that you just pick up a phone and say look I've got this come out and they come out the same day'. And you sort of feel (slight pause) you know you want to do that, things like that they are quite simple things to do but they mean a lot to me. (Pause, stuttering - struggling with what he wants to say) like I, I bought her jewellery erm, that normally is beyond my price but... the reasons behind it was that if I... I could foresee a situation where maybe she would be taken ill, years down the line taken ill if she needed convalescent care which is going to cost you know things like that and she's not budgeted for it you know - where am I going to get this money from? I thought a couple of rings - flog em, it'll pay for somebody to come and or you to go in a home to be looked after for 2 or 3 weeks or whatever. Things like that, that's what my mind focused on - what if this happened? What if that happened? Can I make sure that Karen and Stephen (son) are ok and their partners? Can I, can I cover for that eventuality? Its (pause) I even bought a mole-hair wrap around didn't I?

Tracey: (Starts to laugh quietly) Yeah

Malcolm: Because I remember me mum sat in the chair being so cold with her blanket round her I just thought I don't want Tracey getting to that stage I'll buy her a wrap around (starts to laugh and Tracey laughs) she can put that over her it's supposed to be very warm. Stupid things but, this is, you know (pause) when you (slight pause) when you can't do much other than sometimes just lie in bed and at that time I was a lot worse than what I am now erm, you sort of (pause) I don't know whether you just think of these or whatever but that', that's how you think.

Malcolm explained how he could 'foresee' situations that Tracey may encounter in her life after he had died. The examples he gave of Tracey requiring nursing care and being cold in old age suggest how Malcolm imagined Tracey's life course would continue to unfold and she would enter 'old' age without him to be around to support her. Malcolm explained how the memory he had of his own mother in later life being cold in her armchair interlaced with him imagining Tracey in her old age, and the two seemed to contribute, to a renegotiation of expected life course plans and the idea that couples 'grow old together'. Such thoughts did interact with practices in present day family life, and encouraged Malcolm to strive for some sense of agency in relation to these future, imaged events. For instance, he spoke about purchasing a mole-hair⁸⁸ wrap in preparation for the days he saw ahead for Tracey. Once again the relational power invested in material objects is evident in how Malcolm can make himself 'present' in those future days when Tracey uses the wrap and thinks of, or feels closer to, her dead husband. The idea of planning for a presence beyond death is explored poignantly in Exley's (1999) study of the experiences of dying mothers. Here the women renegotiated their life course expectations of motherhood by preparing memory boxes containing significant objects, as a way to 'be there' for their children after they had died.

Finally, at the very end of this extract, Malcolm points to the 'kind' of thoughts facing your own death can bring about - telling me '*that's how you think*'. As has been identified previously, he is aware of the 'mundanity' of

⁸⁸ I think Malcolm was referring to mole skin.

the so-called '*little things*' that he refers to and he belies something of the 'inappropriateness' of seemingly mundane things in the context of 'almighty' death by referring to these as '*stupid things*'. Clearly, as I have argued throughout the thesis, the mundane and the everyday interlace with the emotional processes of negotiating and planning for a death in the family. And yet, there is at times a latent awareness in participants' own reflections which points to the 'uneasiness' of how the two sit together in the context of dominant discourses about death and dying as 'extraordinary' experience consisting predominantly of crisis and intensity.

Returning to my concern with making preparations, other participants focused in particular on the immediate aftermath of the actual death, and what they discussed suggests there are mundane, 'official' things that are also experienced as part of doing everyday life. Jackie, another interview participant said '*I can just imagine*' when she talked about how her husband would struggle to organise everything that would need doing if she were to die. Acting on these thoughts, and how she could 'see' Clive in the early days of his bereavement, Jackie told me about '*the tin*' and how preparing and organising its contents was her way of acting in the present to affect some order on events which she would not physically be here to oversee. Notably she refers to the possibility that death can happen unpredictably and that Clive could die before her⁸⁹. I got the impression that explaining her actions to him in these terms perhaps helped to 'soften' her actions in

⁸⁹ Interestingly this was also something Tracey mentioned in an extract above when she explained that Malcolm would be lost financially - organisation-wise - if she was to die first.

organising the tin, which might have appeared suggestive of the imminence of her death.

Jackie: And something else I did as well because I run round after Clive I actually made a list out of - I know it's awful - but it's still in the drawer and I thought no leave it and I've told, he knows it's there, I don't know whether he's ever looked at it because you know when you are like I mean he could die before me I know, he can drop dead tomorrow can't he but there's so much to sort out in there? ... so I thought I'm just going to make a list of everything that would need to be done and then it'll make it a lot easier for whoever it is who has to sort it out. And we have got a tin in there like most people have with their insurance policies in haven't they and what not and we had made a will - nothing to do with this (cancer) that was just we decided we would make a will anyway... So we had done that but then I did actually sit down one day and I went through all these forms like informing the bank, informing ISA's, informing er pensions place and somewhere else and I wrote it all down all my works pension place things like that there's quite a long list actually and that's in there and he knows it's there I just said to him you know I've made this list out because if not I can just imagine he wouldn't know where to start I don't think really cos there's an awful lot to do...

Julie: Did you worry about telling him that it was there? Do you know?

Jackie: In a way yeah I don't know how I came about it I think I reckoned 'oh I'll clear that drawer out or I'll clear that tin out' or something I did and then I said like 'you know I've put this is here Clive it just tells you know you know if whoever' how I say it is like 'whoever dies first we know what we've got to do for each other'. Cos as you get older I think you so start to think that way anyway like when you make a will it shows that you are starting to think on those lines in it?

Julie: Yeah sure

About this feeling of wanting to prepare and create order for those left behind, Alice told me how her close friend Mavis (who thought of Alice as

a daughter) tidied through and cleared out her possessions to 'put her life in order'.

Alice: ...cos they told her they thought it might be bone cancer

Julie: *Hmmm*

Alice: and er she says to me 'I have told Richie (son) but he doesn't always listen you know' I went 'what?' 'Everything you need is in that bottom drawer me policies, me thing for me death and all me jewellery and me will and it's all in there' and then I went round to pick her up for the Morrison's and there's all these bags filled up. I went 'what's all that?' she went 'well I don't wear that, and I don't use that' she says 'and I thought if I start clearing stuff out now it will be less for you and our Richie to do'. (Pause) So she has put her life in order

Julie: And is this recently - when was the bone cancer scare then?

Alice: Er 18 months but then she said about a fortnight ago 'oh I'll have to clear my wardrobes out I have got some rubbish in there' but I think that is, she knows she is going in the hospital again, she doesn't think she is coming out of the anaesthetic so I'll put me life back in order

Julie: *Hmmm*

Alice: Cos she says 'you do know I've changed me phone know don't you? I'm not with BT I'm with somebody else but it's all in the bottom drawer'. So I do I think you know like pregnant women nest?

Julie: Yeah

Alice: I think when Mavis's going in the hospital she sorts her life out and clears; she clears the clutter to give me and Richie an easy ride just in case she doesn't come out of it. But she is always saying 'everything's in the bottom drawer you know that don't you?'

Julie: That's almost a bit like code you think?

Alice: *Hmmm*

Like Jackie, Mavis collected all her financial and official papers in a particular place - her bottom drawer - and informed her family that she had

made preparations for them to ease the sorting process. Alice uses the analogy of a nest to suggest that Mavis' actions reflected the opposite of preparing for life (pregnancy); as she was actually dismantling the nest in preparation for her possible death. As Hendry and Watson have argued regarding indirect communication, 'actions and performances... apparently different modes of behaviour can in fact be ways of conveying specific ideas and sentiments to a recipient' (2001: 2). In the same way that Jackie explained her 'indirect' way of letting Clive know what preparations she had made, and 'softened' her actions by couching them in terms of necessity should *either* of them die, Mavis also seemed to use her drawer as an indirect code for implying she felt her death might be close at hand.

However, for Mary and her family it appeared that quite frank discussions about what might happen after her death, had taken place. Talking about how she had made plans with her family for where she would 'be' after death, Mary explained her desire to remain 'materially' present and close to the family and their on-going lives through having a place - even if it was in a cupboard, of all 'mundane' places - within their home.

Mary: ...Er, I have told em as a family what I want you know when the time comes what I want and I have told em I mean that even we tried to, we tried to make fun of by originally I said 'I don't want burning, you've got to bury me', [they] goes 'alright' - and then I changed me mind, I says 'no I've changed me mind, I want cremating'. And Jimmy (husband) says 'what are we going to do with the ashes?' and at that time I had a cream suite, very soft and I just laid on there for 12 months I didn't budge. He says 'I know what we are going to do with em; we are going to scatter em on the sofa' he says 'cos that's where you know you'd be like'. So I says 'no seriously I want you to keep me in a little urn' I says 'I don't care

where you put me but I don't want you to bury me until Jimmy passes on and then we can go together'. So of course then Ellen says 'and what if me dad gets married again?' I went 'oh I never thought about that' so Jimmy says 'oh I shan't get married again don't worry about that'. So I have told em straightforward I don't want no fuss, nice flowers, I'll pick me own music but you have got to keep my urn here

Julie: In the family home?

Mary: Yes. I said 'I don't mind if you shove me in a cupboard, (Julie laughs a little) under the stairs whatever but I want keeping here' so they have said 'right if that's what you want that's what you'll get' so I'm quite happy with that. As I said I don't want to be in a hole somewhere on me own you know so but erm she's (youngest daughter) alright about that she'll talk about that but she won't talk about as I say she won't ask 'well what can we expect?' You know 'what will happen?'

Julie: You mean if you get more poorly?

Mary: Yeah so er I mean she might as I get (slight pause) worse which is inevitable erm she might you know be a bit more forward about things but er she is the one who always say 'nah you'll be years yet, don't worry about it' so I hope she's right I hope I will be

Perhaps by suggesting she might be 'shoved' in a cupboard, rather than 'displayed' in the family home, Mary implies that she is aware that she will no longer be an 'active' member in the family and that it is in the hands of her surviving family to maintain her 'presence' through the 'status' she is afforded by the position of her ashes in their home. Equally the cupboard may represent her way of suggesting that she does not expect to be in the foreground of ongoing family life; it is simply being present within the home space which feels important. Indeed household spaces were deemed significant in making plans for Mary's resting place after death. As Mary explains, joking about the sofa - a material object which clearly embodied memories and spatial associations with Mary - helped the family to talk

about a fitting place for her *within* spaces of *ongoing* family life. It seemed important to Mary that she would still be involved in the family as an evolving web of relationships and that there was some comfort in imagining herself within the family home, as it was poignantly clear that she had also imagined herself alone, 'unconnected' to the family's unfolding future - in the ground⁹⁰. Negotiating a form of material presence for herself by requesting that her ashes stay within the family home until her husband dies, points to a renegotiation of generally expected life course plans. Thus Mary strove to have an agency which would persist beyond her material body (Hallam *et al.*, 1999) by referring to the romantic notion that at the end of their life course couples are reunited together in death. Whilst she asked her children to ensure that this would happen, when Ellen mentioned the possibility of Jimmy remarrying, Mary was reminded that her agency would be dependent upon the actions and remembering of others, and that family life would indeed go on in some respects without her.

More generally it seemed apparent that Mary had thought deeply about how the family that she had known and shaped would 'be' and manage in her material absence, and this was something which at first had caused her concerns. In the following conversation her eldest daughter Ellen is present and therefore Mary is both 'doing' the management of her future material absence - making Ellen party to her hopes about how things will be - as she is involved in describing these to me.

⁹⁰ For a similar idea see Hockey *et al.* (2007a). This study explored what people did with ashes once they had been collected from UK crematoria, and one participant cited explains that she did not want to place her husband's ashes in a cemetery where he did not know anyone.

Mary: Yes erm my first thought was how am I going to tell the girls? I couldn't tell them Jimmy had to do it and then you think how are they going to manage? You know I do everything or I do it with em erm that was my main, my main fears is that they won't manage. I know now they will, I know they will and Jimmy will in his own way but at that point I used to think oh dear they'll never manage, they'll never manage without me. That's being a bit big-headed I reckon now (Julie laughs) cos you know but as each you know each day comes I try now to make them do things especially Stephanie I have to push her she's got her own little business... this came up and er I thought well you know lets go for it erm so with the money I got from being finished at work she (Ellen) had a car out of me other one got money for a business so you know you give em both the same don't you? So we set her up and got her going but she needs me pushing her all the time so now I say 'right come on let's get this done let's get that done. Have you done so and so?' you know - 'no' I say 'well don't you think you ought too?' So I'm working on her, it's difficult but er I'm hoping when I'm not here anymore Ellen will take over the role of the pushing you know and getting there I hope she will anyway

Ellen: Aye leave it to me

Julie: You have been primed (Julie laughs)

Mary: Yeah erm but erm yeah I'm sort of moulding em a bit more now, I'm making em do things themselves you know so and Jimmy's not bad now its er (slight pause). I'm not worried so much as erm I don't feed em you know I don't do owt in the house Ellen and Stephanie although they are sisters they are different. Ellen will take me anywhere I want to go erm she'll fetch me owt, she'll do the shopping bla, bla, bla she doesn't do housework - she does not like housework, Stephanie loves it, she's obsessed

Although after her initial diagnosis Mary only saw a future where her family could not manage without her, with time and her own active practices of coaching, showing and encouraging her family members in day-to-day life, she reached a point where she was able to imagine who would do what, and how they would get along, after her death. Again the focus here is on the rather mundane and everyday aspects of getting by - eating, shopping,

housework and being generally organised. By actively '*moulding*' her husband and daughters to acquire and take over skills and roles she felt were typically 'hers' within the family - in other words 'preparing' them whilst she was still able - it is possible to see how Mary shaped a way to continue to be present in her family's life after her death (see Exley, 1999).

Conclusion

In this chapter I have explored the imagined, felt and discursive aspects of family and shown how these relate to the 'doing' of family life. More specifically I used examples to demonstrate how thinking about, and imagining 'family', is part of the experience of 'doing' and being a family affected by severe illness, dying and death. Although I identified that this could involve ordinary aspects of daily life being experienced more consciously, it was the way in which the mundane can make the more 'extraordinary' (severe illness) 'knowable' rather than how this turns the mundane into something more existential or transformative in families' experiences, which seemed significant for understanding family life at this time.

As central to these processes of imagination and practice, I identified the negotiation of absence via the establishment of presence. This was often achieved as families engaged in practices of 'displaying' family when changes brought about by the illness meant that certain members experienced separations. Discussing a variety of 'ordinary' objects - including photos, paintings and TVs - my analysis has revealed how,

through the imaginative potentialities inanimate objects can possess, they enable families to maintain themselves in the present as families, despite separations and absences created by the illness - including the 'ultimate' (in its permanence) separation of death itself. Furthermore, I have shown how this imaginative potential of objects relates individuals to their family pasts and family futures in their negotiations of aspects of relationality. In particular, this chapter has considered how dying individuals were able to use objects and/ or active practices of doing (getting the builders in or 'coaching' a child) to renegotiate certain life course expectations thwarted by terminal illness. Herein, individuals with life-threatening illnesses shaped opportunities for agency, control, and continued presence within future family life, after death.

In the next chapter the multi-faceted nature of family practices (as assemblages of doing, thinking and feeling) will continue to be a guiding framework for understanding family experiences, where the feelings and emotional worlds of families and their members are explored more explicitly.

Chapter 8

Families Facing Death: stoicism, humour and the 'everydayness' of feelings

Introduction

As I demonstrated in the previous chapter, Smart (2007) provides a conceptual framework for exploring how interior processes - thinking and feeling - are *entwined* with family practices and the 'doing' of family life. Thus to gain a more nuanced picture of family life and practices during life-threatening illness, this chapter considers how families felt about, and approached the emotional aspects, of 'doing' facing death. In other words, it considers participants' explanations of how they felt about the illness but it also suggests that these feelings were incorporated into an approach, or belief system about how to 'do' emotionality and to deal with feelings pragmatically, as part of getting on with day-to-day life. Accounts in the interview data in particular question the dominant assumption that when facing death and dying, individuals and their families are inevitably in the throes of crisis and experience heightened emotional vulnerability⁹¹. Rather, a sense of keeping grounded in the everyday continued to re-occur as families spoke about their experiences. Often their comments were communicated with a stoical pragmatism, humour and matter-of-factness

⁹¹ There did seem to be some differences between the ward and interview data in this respect. Families visiting the ward were often encountering the 'active' dying stages of their relative's life and displays of emotional distress - crying, fear and feeling overwhelmed - were more evident in this environment. Moreover, I was often less able to ask directly about people's feelings which made it difficult to acquire the same level of detail or contextual information from families I observed on the ward, compared with those I interviewed. Consequently the most of the analysis in this chapter refers to interview data.

that implied that many - especially the ill individuals themselves - accepted that dying was inevitable and that there was little to be done about it. In other words, responses and emotions came across as often rather 'ordinary' and understated. Notwithstanding the more overtly emotional moments during my field work, where distress was displayed by certain participants in particular⁹², a sense of pragmatism was evident in the interview data especially, and this demanded to be analytically explored. In taking up this analysis here I am not making any assumptions about how people felt; the purpose of this chapter is to analyse how people *appeared to be* and what *they* explained about their emotional approach to life-threatening illness in their day-to-day lives.

Therefore, I want to achieve two things. The first is to explore how family members felt about living with life-threatening illness. Although not explicitly focusing on Smart's (2007) concern with how people come to *feel* they are 'a family' (relatedness), the chapter does examine the emotional interconnections between how people feel about living in a family experiencing life-threatening illness, and how these feelings are negotiated and expressed in practice - directly and indirectly - between members.

Secondly, I consider my over-arching thesis argument about the importance

⁹² For instance, Mary was the youngest ill person in the interview sample and she was experiencing severe problems with pain and appeared 'low' during my last interview with her in particular. Her sister had also recently died from cancer. Mary was emotional and frustrated at times during the interview - she described feeling stuck as she was waiting for diagnoses and tests to determine if her cancer was spreading and causing the pain. She explained how she was losing limited time she could be spending with her daughters whilst incapacitated through the pain and feeling uncertain about her condition. Another interviewee, Mavis, was also experiencing painful and distressing symptoms as a result of different surgeries. Although her cancer had been removed and she was free from active disease at the time of the interviews, she spoke about being fearful of having further operations and grew upset at times.

of the mundane and everyday for understanding family experiences of life-threatening illness, and aim to present a critical exploration of this. As my thesis has so far challenged the idea that everyday life is suspended and transcended by the 'extreme' experience of severe illness and dying, I ask whether psychological *denial* might explain the 'lack' of apparent emotionality in some accounts. And indeed pose the question of whether processes of emotional avoidance *also* explain why mundane matters appear central for families. In other words, are they (more in accordance with the crisis and rupture model), a way for families to be distracted, to 'block out' and deal with, the 'extraordinary' threat posed by life-threatening illness? Essentially, in this chapter, I return to my data to suggest the inadequacy of this as a counter-interpretation. Therefore, in what follows, I point to the everyday contexts in which families situate their feelings and beliefs about how to 'do' facing death as 'getting on', and reaffirm my over-arching thesis argument about how illness and dying are made meaningful, as lived experience, through an immersion within everyday life and mundane practices.

Death, Denial and the Everyday

Psychological theory focusing on internal processes and experiences (Craib, 2003; Salander and Windahl, 1999; Becker, 1973), and studies about the psychological, emotional and communicative aspects of facing death (Salander and Spetz, 2002; De Montigny, 1993), do raise questions about the extent to which dying people and their relatives practice 'avoidance', 'pretend' or experience 'denial'. As Salander and Windahl (1999) point out,

denial, as it is understood in psychological and psychoanalytic literature and is applied in coping-related research, is traditionally associated with matters of trauma and strain and is therefore viewed as a defensive process very relevant to circumstances considered to induce severe strain, such as living with terminal illness. So when my participants told jokes, talked about mundane matters of daily life, or said that they accepted death would happen but that they did not see the point in focusing on it all the time, I am challenged by pervasive psychological and medical discourses to ask whether their 'real' feelings were being hidden, side-stepped or avoided somehow. Perhaps, it could be argued, that these feelings were too emotionally painful to face, or to show publically to me in any case.

Furthermore, as I have shown in Chapter 2, sociological theories about the denial of death and death's sequestration from daily life were informed by the psychological idea that humans have an innate fear of death that is universal (Howarth, 2007a). However 'denial' as a psychological concept has been operationalised in a variety of (problematic) ways across different theoretical and clinical frameworks (Salander and Windahl, 1999), and while it cannot be the purpose of this chapter to do any justice to the complexity of the concept and how it is variously considered to map onto cognitive, emotional and behavioural experiences, it is nonetheless important to acknowledge this point so I can more clearly outline how it is relevant to the story my data have to tell.

Salander and Windahl (1999) differentiate between the concepts of denial, disavowal and avoidance. They argue that the term 'denial' in its 'first-order', pathological sense should be retained for instances of unconscious, actual perception distortion, leaving the notion of 'disavowal' (originating with Freud) to operate as a term for the 'lesser' extreme state of knowing and not-knowing; a preconscious awareness that a reality exists but being able to reconstruct aspects of it creatively, to facilitate hope. Lastly 'avoidance' is the deliberate and therefore quite conscious avoidance of information - it is a common way of coping with strain, but not an act of denial. Given the pervasiveness of the notion of denial to describe a diverse variety of experiences and responses, the authors argue it is problematic that the term has been over-used and applied it to situations where patients *appear* to deny the reality of their condition because they fail to display the more accepted signs of expressive emotional turmoil but choose instead to avoid certain information and to focus more on positive things⁹³.

Salander and Windahl (1999) argue that these instances are a distortion or dilution of the term's original meaning. However, what this willingness to over-apply the more extreme notion of denial *also* suggests is the pervasiveness of associating death and dying with crisis, heightened emotional vulnerability and experiences of rupture. It is precisely because denial as a concept links into the discourse of death as an extraordinary

⁹³ Indicating that particular models of how to 'do dying' are pervasive, in a paper presented in 2009, Borgstrom *et al.* argued that, following the discursive analysis of over 200 final year Cambridge medical student essays about meeting dying patients, students tended to operationalise a concept of denial that was implicitly learnt and they often considered it as an obstacle to helpful communication, a 'good death' and providing ideal care.

event that I draw on it here to explore the 'ordinariness' of my data. As mentioned previously, I cannot, and do not, intend to make the focus of this discussion an assessment of the extent to which my participants were 'in denial' or employing various avoidance-based coping strategies. Rather, the psychological concept of 'denial' (in its various forms) and its pervasiveness as a part of the wider discourse of death as crisis means that it is useful for thinking about the key concern of the thesis which has been to explore how the everyday and mundane aspects of daily family life serve to make illness and dying meaningful as lived experience.

And so, what I mean to emphasise is that the idea that humans *need* to deny death has a firmly established history in popular and clinical thought within modern western societies. Thus, it can be argued that, there is an expectation that people facing death will be fearful and emotional and if they appear not to be, there is a tendency to assume that they are somehow 'denying' the reality of the situation. Writing about the experience of grief, Worden (1982) outlines 'four tasks of mourning' which include the need to 'accept the reality of the loss' (1982: 11-12). However he also suggests there are various forms of denial which can prevent this from occurring - for instance, some people, 'protect themselves' by denying the '*meaning* of the loss' (1982: 11-12 my emphasis added). In other words, they deny the emotional impact of the experience rather than the death *per se*. In a further example, writing about the psychologist's role in working with dying patients and their families, De Montigny, a psychologist herself, explains that:

Fatigue is extreme and the subject of death, as impossible to ignore as it is to face, holds a predominant place for the dying person. Denial and a conspiracy of silence prevails in the patient's room, burying the fear of the unknown... Silence and denial are the only possible tools of survival left and denial, described as the first temporary reaction to terminal illness, we believe persists, with most patients, until the end... Along the path to death are numerous upheavals and losses... This resulting sadness inhibits verbal expression and imprisons the internal world of the patient (1993: 6).

The powerful association between failing to display emotion and being in denial is evident in what De Montigny writes here. Furthermore, the notion of a 'necessary' human need to deny death also seems to stem from the general idea that death operates at the margins of life (see Seremetakis, 1991 for a critique of this) and therefore outside, or at a distance from the everyday, that it so profoundly threatens. Again to quote De Montigny by way of example, she suggests:

"Ordinary" life is suspended, in abeyance, since only the wish to be with the sick person to the very end matters for the healthy relative/ friend... While the sick person saves his/her moral and physical energy, the relative/ friend exhibits unexpected strength and overflows with energy and vitality drawn from a seemingly inexhaustible inner source. This inner world, the real self tends to emerge when faced with the ordeal of a loss (1993: 10).

The idea of death as a transformative (for the relative), spectacular experience which is presumed to exist at the margins of 'ordinary', everyday life is clearly suggested here. Although De Montigny appears to be referring to patients who are in the more end-stages of their dying, it is possible, nonetheless, to apply this pervasive idea to the more protracted experience of living with the knowledge of terminal illness - as was the situation for my interview participants and some families I met on the ward. In other words, there is a general expectation that somehow, when death is

'on the cards', everyday or mundane matters cease to be of importance or focal points for the attention and practices of ill people and their families.

For example, as Foster (2007) demonstrates in her ethnography of a hospice befriending service in the US, it was her expectation, and generally that of her fellow volunteers, that dying people and their families would be in a state of high emotionality. She explores how often those supporting dying people have their minds (and so expect it to be the case with ill people and their families) focused on the dying process and the moment of death, rather than the mundane practices of day-to-day life involved in living with dying. Evidencing this point, one volunteer Foster interviewed said the following about their expectations of the 'spiritual' time they would spend with terminally ill patients:

"Before I started, I was expecting to be dealing more with people dying. And it's so totally not that. I was expecting it to be more spiritual than it is. But I'm not disappointed; I don't want to sway our conversations that way" (2007: 107).

At different points throughout her book, Foster shows how once the volunteers met with patients very little of their interaction was based around, or concerned with, the matter of dying but involved many ordinary or mundane activities. About time spent with the patient she befriended

Foster writes:

Dorothy and I did not talk about her illness and approaching death; perhaps it was "denial", as Jackie [a hospice nurse] suggested to me, or perhaps it was simply that she did not wish to spend our time together talking about death (2007: 137).

On a couple of occasions, Foster refers to a nurse's belief that Dorothy (a seemingly stoical woman) was 'in denial' about her terminal illness. Clearly Foster is not sure about this. Implicitly, she appears to suggest that immersing oneself in activities of daily life and not talking about death does not necessarily equate to being in some sort of psychological denial. Similarly, Salander and Spetz (2002) argue from their empirical work with couples facing the 'serious facts' that one of the pair has a brain tumour (malignant glioma), a majority practiced 'mutual acknowledgement' of the seriousness of the diagnosis but they did not frequently - some hardly ever - talk openly about this using the terms 'death' or 'dying'. They felt that for their participants:

...it was not a matter of *intentionally pretending*, but merely a way of making life as meaningful as possible, as long as there is life... the pretence of mutual acknowledgement, even if implicit, forms another basis for understanding how couples can deal positively with strain (2002: 312 emphasis in original).

Tacitly, it appears that the authors believe the couples were not 'in denial', or in any case intentionally pretending their situation was less serious than it was, rather they 'could *disavow* the meaning of the situation and *avoid* further distressing facts in order to try and look forward positively' (2002: 311 emphasis in original). Not talking about dying so much and focusing on getting on with life was an important part of this.

Humour, Life-threatening Illness and Death

Whilst stoicism and a lack of talking or being 'appropriately' emotional about death, are sometimes considered to indicate denial, the use of humour

- 'black humour' as it is often considered⁹⁴ - is frequently identified as a way of coping day-to-day with life-threatening illness and death (Chapple and Ziebland, 2004; Klein, 1998). For instance, Chapple and Ziebland (2004) suggest that some of the men they interviewed about their experiences of testicular cancer used jokes or humour in the interview situation to divert attention away from discussing issues they felt were sensitive. Some also said they used humour to cope in hospital and health care settings, and 'to hide their feelings' (2004: 1128). Moreover, humour is also considered as an aid for those employed in professions where deathwork is habitually experienced. As Scott argues, making jokes can help to 'normalize' death and enhance solidarity between workers, so that 'emotionally exhausting situations' can be dealt with in everyday practice (2007: 351).

Finally, from a personal perspective, Martin (2009), a mother, writes about humour at the time of her child's death - perhaps an even more 'taboo' topic for humorous treatment because of the 'un-timeliness' of the death and its association with tragedy. Candidly she explains:

In an attempt to search for the positive in any situation, however, Sharon [a friend] proclaimed that only having three children now would, in fact, make it much easier for me in the mornings with less children to get ready. Yes, Sharon, every cloud...! Was I upset at what she'd said? No. Did I laugh? Yes, a lot, and it did me good, I'm sure (2009: 139)

⁹⁴ Conveying the idea that death is not a normatively 'legitimate' laughing matter.

Whilst Martin describes the loss of her son as a ‘most awful’ experience in the midst of which she felt ‘wildly ranging emotions’, she is able to reflect on how humour provided a ‘welcome and necessary respite’ (2009: 138). Furthermore, she *also* experienced grieving for her son as located in the ongoing flow of mundane daily life. As Martin explains:

The surreal nature of the events surrounding a bereavement can be quite funny: drawing up a list of things to do included ‘collecting the ashes’ on one occasion, ‘phone Interpol’ on another, alongside the usual ‘clean floor, buy cat food’ (2009: 139).

Here, I suggest, Martin reflexively notes an ironic interlacing of the emotional and the mundane in her experience of bereavement. Although she does not explicitly state this, her sentiments and suggestion that she found this ‘quite funny’, points to an awareness that matters of death are not generally associated with an immersion in the mundane and the everyday. I found Martin’s account particularly significant because the families involved in my research were, like Martin, able to draw on humour, whilst, I *also* noticed an ‘everydayness’ about their feelings which were often expressed and explored, in relation to the mundane realities of daily life.

‘Everydayness’ and Family Feelings: acceptance, stoicism and humour

So what then am I talking about when I refer to the ‘everydayness’ of people’s feelings and the ordinariness in their accounts? The following example from my ward data where I reflect on a conversation with Rob’s wife, Mabel, is a powerful case in point.

'When we are by his bedside later she tells me there had been talk of Rob going home, but that she doubts this will happen now - she feels he is going backwards. She still isn't sleeping very well and was up early today. She jokes with me and tries to be positive saying that at least she got the windows and curtains washed'.

Here Mabel discussed her day-to-day life and the most mundane of chores, whilst interlacing her thoughts about these with her feelings regarding Rob's declining health. In other words, her feelings about his deterioration and what this might mean had a distinctive 'everyday' quality. In the following extract from an interview with Hugh and his wife, Dot, the 'everydayness' of their feelings about Hugh's impending death is also evident. The couple's neighbour, Debbie, called in while I was at their home and we were discussing Hugh not being able to get insurance to fly to Guernsey to stay with Dot's daughter Maddy.

Julie: Could you choose to go without insurance if you wanted to Hugh?

Dot: yeah but if owt happened to him... I'd have it all to pay

Julie: I see yeah

Hugh: There's £2 in me pocket love you'd be alright

Dot: Lesley (daughter-in-law) said 'Hugh you can't go without insurance because' she said 'if you do it's going to take Dot's money and some of ours'

Debbie: Yeah, yeah it would cost a lot if owt was to happen but

Dot: I'd put you in Maddy's back garden

Debbie: He can go in with the guinea pig (Debbie and Dot laugh)

Hugh: No she'll be able to afford to fetch me back over here - put me in the shed at the top of the yard at Maddy's

Dot: No there's no beer in that now

Hugh: There will be if I'm in it (Dot laughs)

Drawing on humour to talk about Hugh's illness and his dying was something I encountered frequently during my interviews with the couple. The pragmatic topic of money and quoting their daughter-in-law's concerns about cost if they had to fly Hugh's body home, might seem rather insensitive and indeed unemotional. While it is arguable that any of this is suggestive of denial, it does point to an unequivocal concern with the mundane matter of money⁹⁵, and the pragmatic, rather than the emotional consequences likely to be experienced by Hugh's death. Moreover, their feelings towards Hugh's impending death are contextualised very much in terms of familiar, mundane things that have formed the backdrop to this family's experiences. For instance, Hugh's death is associated with him being placed in Maddy's garden, her shed or in with the guinea pig and his obvious fondness for beer is mentioned. Despite the fact that these were not serious suggestions, and the use of humour clearly played a role in facilitating 'banter' between the discussants, it is significant that the couple showed me how they were facing up to the reality that Hugh was terminally ill, by contextualising his death in terms of what was preoccupying them most at that point in their day-to-day life - the fact that he was not able to visit Maddy in Guernsey.

⁹⁵ In the example from the Cox family provided on page 172 (Chapter 4), the same pragmatic focus on money - despite the family's circumstances (facing death) - is apparent.

In an interview with Jackie I was struck by the similarly mundane way in which she shared her realisation that she was dying. Her account is particularly powerful; not because it is highly emotive in the way one might anticipate, but because the pragmatic attitude she expresses is grounded in, and given meaning by, the very mundane practices within her everyday life. For her, the possibility that she might die in the next few months was understood in terms of whether or not she should bother buying a new winter coat.

Julie: ...how has it [the illness] made you feel? You know in your sense of yourself and how you feel towards your body and is it, has that been something difficult to, to get your head round?

Jackie: Not really no (pause) no I can't say it has really no, no. Just accept it everything's just sort of come on and I've just accepted it all from day one... I just don't think about, I don't honestly I can honestly say I don't think about tomorrow or oh if I'm here then or if I'm here then - I just carry on you know, not normal because it's not normally how I was but... I'm quite happy to just carry on like this and yeah. I mean when they first, when they first tell you that you have got cancer and that you know for a fact that they can't get rid of it all then I did at very first like when it came to the winter and I'm thinking oh I don't know whether to bother (little laugh) buying a new winter's coat or not you know, I mean I did I must admit I felt like that at first but then this year I have been out and bought one cos I thought oh its time I had a new coat, even though I don't go out very often I want something when I go out...

Although Jackie's stoic admission that '*I just don't think about it*' might sound like a practice of avoidance, it does not necessarily mean that she was in denial about facing her death. Indeed she indicates her recognition - albeit indirectly - by explaining that '*they can't get rid of it all*' when referring to her disease, and her pragmatic understanding of her situation is

made quite evident when we discuss the prospect of her having further treatment.

Julie: So you think if you have the opportunity you'll take it up - the chemo?

Jackie: Oh I will

Julie: Yeah

Jackie: Oh yeah because I mean as I say if it's only going keep plodding you on for 9 months, 12 months it's there int it?

Here it is clear that Jackie realises that her time is limited and interestingly she describes continuing to live as '*plodding*', which suggests that living in a rather mundane way - just plodding - is valuable and to be appreciated; as she says, '*it's there int it?*' Jackie did not seem to have grandiose plans or unrealistic ideas about the type, or amount of 'living' which more chemotherapy could offer her.

Thus, as Jackie talked more about herself and how she felt day-to-day, she was consistent in her view that emotional turmoil was not something she could identify her experience with. Whilst Worden's (1982) argument about *emotional* denial implies Jackie may have denied the meaning or emotional impact of her terminal condition in spite of her accepting attitude, in general this interpretation felt inconsistent with my data. Jackie appeared to acknowledge in a realistic way that the diagnosis had changed her life significantly, but her emotional and ontological experience of this change did not resonate with a sense of rupture. For her it was perhaps not so '*horrendous*' that it needed to be denied:

Jackie: As I say it's very different it alters your life drastically but it's not, to me it's not horrendous you know it's not such a big thing you know

Once again, emphasising the irrelevance of rupture as a part of her experience, Jackie indicated she was aware nonetheless that others might perceive her as in a 'sorry' situation, but she did not feel her experience mapped onto this common perception of facing death.

Jackie: Oh yeah that's what I say it hasn't been such a massive upheaval and no not at all and I don't know how people outside see you and think about you and whether they think oh poor Jackie I don't know but no as I say

Julie: Cos... I don't know how you feel about [it], often when I'm like reading stuff about this or whatever or talking to professionals a lot of people are like concerned with how people are going to cope and how are families going to cope

Jackie: Yeah, yeah

Julie: but it seems that sort of like

Jackie: It's just a natural thing that takes over; it is yeah

Julie: It's not necessarily all doom and gloom and crisis then?

Jackie: No its sort of no it isn't and because you know you've no alternative then you just - well I have - I have just accepted it yeah oh no we are not miserable no, no not at all. Oh no we are never fed up or miserable neither of us you know

The pragmatic beliefs Jackie expressed as central to her feelings about the illness were conveyed when she explained that nothing could be done about the situation, it had to be accepted. She was also quite insistent that I should not misconstrue how she, and her husband, Clive, felt in their daily lives - they were not miserable. Here Jackie seems keen to distance herself from

the narrative of terminal illness as 'tragic', 'depressing' and 'hopeless' (Bury, 2001). Adopting this emotional persona might draw pity from others and would undermine Jackie's sense of herself as clearly accepting, and therefore *living with*, her terminal illness.

Similarly, for Eve, it seemed from her stoical, pragmatic approach that she was not in denial about the inevitable fact that she would die soon. Both she and her husband Charlie were keen to tell me how surprised the medical team were with the way she just accepted the news of her diagnosis. She was also, like Jackie, realistic about the changes illness had brought to daily life; but once again this was something to be 'got on' with.

Julie: Do you think you would be able to sort of just sum up for me then possibly how the illness has affected your family life?

Eve: Well it affects your life it has to affect your life because you can't do the same things as you'd normally do. We have tried not to erm; we have tried to erm get through it best you can... and erm well that's it - you've, we've tried to get on with it and get on with things. Same as I said as long as each day comes and I can wake up in a morning

Julie: Yeah - so it's very much on a day to day

Eve: basis, yeah it is a day to day basis yeah

Here Eve contextualises her acknowledgement of the possibility of dying very much in the routine of her daily life. Speaking about being able to wake up and managing things in a very day-to-day sense, she too adopts a stoic, seemingly unemotional attitude of getting on, accepting things,

making the best of it. Earlier in this interview, the matter of being able to get up out of bed had already been mentioned.

Julie: How do you feel about, about your life and things at the minute then Eve - what are the things that you really sort of look forward too? Do you know what I mean?

Eve: Well I look forward to waking in a morning (laughs)

Julie: Well yeah (all laughing) that's a good one!

Charlie: That's important that one love

Eve: although I had a bad night last night; that's what might be up with me as bad as I am today with the tiredness yeah

Julie: Anything in particular that made?

Eve: I don't know really, just that it was a bad night

Julie: Could you not get off to sleep or did you?

Eve: No I got off to sleep and it was at er and then I laid awake and then for ages... (explains kept sleeping and re-waking) and then when it's time to get up - which I haven't got to get up I know I haven't - I don't want to get up. Some mornings I could lay in bed now

Julie: You could stay

Eve: Yeah, yeah

Julie: And, but would you not lay in bed then?

Eve: No

Julie: What stops you from laying in bed then?

Eve: No you die in bed, you (laughs)

Julie: You have got to keep going then?

Eve: Yes, don't give in

Julie: Yeah, so even if you felt really sleepy you would still get up and come down?

Eve: Well yeah as far as I can as now yeah

The idea of getting up and not staying in bed - so not like an 'ill' person in the archetypal 'deathbed' - seemed significant and was also something which Jackie drew upon to present herself in a similarly stoical sense.

Jackie: ...I could I think oh I'll just lay back down but I do get up I think no get up and get dressed and you know don't start that laying in bed business but some people do don't they you know

Julie: What is it do you think that makes you want to

Jackie: I don't know

Julie: that sounds like a bit of a funny question

Jackie: I don't know

Julie: that makes you want to push yourself to do that, is it?

Jackie: Just because I'm like er (pause) because like I told you before I can't I don't really believe that what's wrong with me, I don't think about it, I don't ever sit down and think oh God I've got cancer, I just think no I can't stop in bed I've got to keep going you know

Again, the way that Jackie explained she did not think about, or believe what was wrong with her, does imply that some sort of 'denial' might have been taking place. Although, by contextualising how she felt in the 'doing' of her continuing daily life - getting up each day - and underlining how this action interlaced with her determination to 'keep going', it is also possible to focus on what she is communicating about her immersion within the everyday as something which makes the reality of death actually *more* meaningful. Thus in recognising that she could still get up she understood that she was not dying *yet* - rather than denying the fact that death would inevitably happen. Identifying that '*some people*' lay in bed, Jackie showed once again, her determination to distance herself from the 'tragic' narrative

and archetypal image of the ill, dying person. Again I would argue that this attempt at distancing was not about denying that she was terminally ill, but more about the experience of agency that is attainable through maintaining a stoical approach (see Hockey, 2002b). Therefore her pragmatism ought to be viewed as an important emotional state in itself because it suggests how Jackie constructed and experienced herself *emotionally* in her day-to-day life - as strong, pragmatic, accepting and determined.

And so when talking to interview participants about the illness and daily life, comments similar to the following made by Eddie were not uncommon.

*Julie: Do erm, what was it like when you first found out and you first got diagnosed then Eddie? Did you have to, did you tell everybody?
Or*

Eddie: No I more or less guessed it actually

Julie: Did you?

Eddie: I didn't accept it badly but er when they put it to me there's no use being any other is it? I can't alter it

Moreover, as Dot's joke about Hugh's body being laid to rest in her daughter's back garden showed, humour was used at times to talk directly about matters of dying and death. On a particularly memorable occasion whilst observing on the ward, I was taken aback by Laura's son Adam, when he was bluntly and with an ironic humour able to talk about Laura's evident proximity to death. He was very pragmatic about me not waiting around if I wanted the family to contribute to the research.

'When I encounter Adam he speaks very confidently and loudly. He is friendly and happy to help in any way with the research - but I best get a move on I'm told, as he nods in Laura's direction and I learn that he is quite aware of his mum's fragile state. I find this remark uncomfortable as Joe [Laura's husband] yesterday and Adam today make a point of telling me that [unconscious] Laura can still hear things'.

Moreover, whilst on the ward, I was often observing behaviour to try and interpret feelings rather than asking participant's more directly about how they felt, and there were times when I was struck by the laughter which travelled from patients' rooms. The following example is interesting as it indicates once again how the hospice attempted to create a 'homely' environment by allowing pets onto the ward to 'visit'. Regarding humour, it also highlights the perceived 'inappropriateness' of laughing too audibly in this particular environment and context. Here I describe what happened when extended members of Molly's family visited her - her late husband's cousin, his wife and their dog - and they spent time with Molly's three children who had been staying for long periods of time on the ward. I saw them on this single occasion and the scene implied it had been their only visit to the ward and it was their 'final' goodbye to Molly who was unconscious.

'The dog is let off the lead and toddles about the place. She is a little terrier and allows me to stroke her. I sit on the floor in the communal area and she rolls onto her side to let me fuss her. I notice that Linda, Shelley and Nathan [Molly's children] leave their 'aunt' and 'uncle' [Linda referred to them as such] to say goodbye to Molly. As they all leave the room they are laughing about the dog

and what she has been doing; Nathan says 'sssh' - which implied something about needing to construct appropriateness for the situation. Having watched the family in Molly's room today I get the impression that it has been a 'family' day - Nathan and 'uncle' are chatting about jobs etc. and doing usual catch up things. Once the 'aunt' and 'uncle' had said their goodbyes the 5 stand outside of the room milling around for a while and chatting. Linda starts to cry as the aunt and uncle leave'.

Displays of emotion - particularly tears - were not unusual on the ward. However, as this example shows, some emotional experiences were also interlaced with more 'everyday' matters such as Nathan and his 'uncle' discussing jobs and the general unfolding of what appeared to be a family 'catch up'. In previous chapters I have referred to how the everyday and the more intense interlace in the same experiential frames and, following Robinson's (2008) notion of 'mundane extremities' outlined in Chapter 2, this data shows once again how the mundane and the emotional can intersect in families' experiences of illness and dying.

Whereas in the above examples both Molly and Laura were 'actively' dying and very close to death, data from a post-death interview with Claudia and her daughter Joanna powerfully demonstrates how the Cox family experienced humour in the after-math of Eddie's death. As I discussed in the previous chapter, although my thesis is concerned with the period prior to death, Claudia's 'mundane remembering' of her father Eddie is particularly significant because the intricacies of these memories were grounded firmly in the mundane, taken for granted routines of family life.

In the following examples Claudia and Joanna interlace the everyday and ordinary practices of family life with what would generally be considered the 'sacred' activity of collecting and finding a place for, Eddie's ashes.

Claudia: ...but going back to getting me dad back

Julie: Aye you were going to the Co-op (funeral directors) and Joanna was in the (car) seat

Claudia: Joanna was in the seat and we come back and me dad always had an opinion on something - he hated Coronation street, he said he hated it, he always watched it

Joanna: Oh Deal or no Deal - 'oh there's I'm telling you there's that little man changing them boxes'

Claudia: Yeah he used to think there was something under the boxes switching the boxes⁹⁶...Emmerdale Farm - oh there was always something to say about Emmerdale Farm, always something to say about Coronation Street

Joanna and Claudia: EastEnders

Julie: I can see him now sat in that chair actually with the telly

Claudia: Oh yeah and me mum and him have had some right spurs do you know what I mean - 'shut up! I'm trying to bloody watch telly'

Joanna: War films, bombing all the time

Claudia: Yeah but aye he never said owt then did he?

Joanna: No (laughter in voice)

Claudia: And er so me brother phoned me up and he says to me, he says 'have you brought me dad back?' I says 'I have' he says 'oh right where have you put him?' and as soon as I'd put, as soon as I brought him in I put him in his chair and er I switched the telly on. Me mother says 'what you doing?' I says 'I'm putting the telly on' I

⁹⁶ They are referring here to the Channel Four game show, Deal or No Deal, where participants have to open as many boxes as possible without revealing the larger sums of prize money. The longer they can keep the large sums in play, the more inclined the show's 'banker' will be to make a deal with them to walk away with 'x' amount of money guaranteed.

says 'if me dad had come in what were the first thing he would have done?'

Joanna: Come in took his shoes off, go and sit

Claudia: Put the telly on, put the telly on like so she says 'oh right'. So of course our Brian phone's half an hour later and he says 'have you picked me dad up' and I says 'I have' I says 'do you know something Brian' I says 'its the first time' I says 'in years' I says 'that me and me mother's been able to sit through Emmerdale Farm and Coronation Street' and I says 'and he's not said that' (clicks fingers). And he just like went quiet and he started laughing and he went 'well there's only you could say that Claudia'.

It seemed important to Claudia and Joanna that they were able to tell me about the 'funny story' of bringing Eddie's ashes home. It was indeed the ordinariness of this which, although not explicitly stated by them, added to the humour because it jarred with what one expects about the solemnity and 'sacredness' of the occasion. Claudia discussed with the same joviality the current state of affairs regarding where Eddie's ashes were residing in the family home.

Claudia: He's in me mother's bedroom - he weren't allowed in for 8 years I'll tell you (Julie laughs), never slept together for 8 years cos he erm... like he used to have cold legs and his feet and he used to rub em on me mum's legs and she used, she couldn't stand it cos me mum's got veins on her legs and she couldn't stand it so she ordered him in the other bedroom and I says to her the other day I says 'chuffing marvellous' I says 'for 8 year he weren't allowed in' I says 'and now' I says 'now he's chuffing dead' I says 'he's sleeping with you!'

Julie: Pride of place!

Claudia: Yeah

Julie: Is he on like a bedside table then or?

Claudia: Er I think she has him at side - he's in a bloody Co-op bag I'll tell you - he looks like he's going to a party as the present! (Both laugh) Yeah that's what he looks like

Importantly, these accounts suggest that the dominant association of death with painful feelings does not take into account the ordinary ways in which some people draw on aspects of everyday experience to find humour and light-heartedness in relation to their experiences. Thus, when I asked Vera about the course of her cancer, she replied by saying that *'I've went past my sell by date'* to let me know that she had outlived the original timescale the medical team had indicated at initial diagnosis. Likewise, as was especially typical of Hugh, he joked about finding his wife Dot another husband so she would not be alone after his death. A neighbour, who they often poked fun at, was once again the 'butt' of their joke.

Hugh: What's important to me is as our Dot's alright that's my most important thing is making sure she's alright that's all I'm bothered about... its leaving her on her own that's bothering me

Julie: Yeah

Hugh: I shall have to (slight pause)

Dot: No you are not finding me another husband

Hugh: him next door

Dot: Oh! (Julie laughs)

Julie: Is that him with the jumpers (they laugh about his clothing)?

Hugh: Aye

Dot: Oh I'd do my sen in (kill herself) before I - oh my God no! Oh

Despite the obvious humour here, Hugh's use of the continuous present does suggest that leaving Dot was an on-going worry, in the same way that leaving Tracey in a house she could not comfortably manage was a concern for Malcolm in Chapter 7. Thus, I reiterate, although some families used or experienced humour, this is not to suggest that they were never upset, they did not have concerns or that they were unprepared to discuss these. For instance, as I explained in footnote 92, Mary was experiencing a variety of upsetting emotions at times during my two interviews with her. And yet threads of stoicism and humour were also part of her family's approach. This is demonstrated in the following exchange where, in thinking about family life after Mary's death, her daughters joked about what they thought they might do with the doll's house that was an on-going project Mary had been undertaking for some time, and which she was keen to complete.

Steph: (From the adjoining dining room) And where's it going to live afterwards mum? (Laughs)

Mary: I don't know, the only problem is finding somewhere to put em

Julie: Yeah I was thinking is it just going to stay on display

Mary: Well at the moment it's on the table because I can't get down but when I've just done that bottom flooring erm I've got a table, I bought a table for it and it's going to sit in there but erm when I'm no longer here I don't know what they'll do with it

Ellen: Sit and play with it

Steph: We'll move in (Julie and Mary laugh a little)

Although Mary's daughter Steph was not part of the project sample, she was on this occasion present in an adjoining room whilst our interview was

taking place⁹⁷. She had obviously been listening to our conversation and the spontaneous way she chipped in with her humorous comment about living in the doll's house after Mary's death, demonstrated how dying could be communicated about in an 'off the cuff' way. Talking about death in this instance did not involve the seriousness of eye contact, hand-holding or even all being in the same room, but nonetheless the daughters used humour to speak in 'code' about the embedded way Mary would continue to be present in the family's lives. Whilst interestingly, echoing the importance of the mundane, this exchange stemmed from a rather practical, but also 'loaded' question, about where the completed dolls house - a material symbol of Mary's craft and care - would permanently reside.

And so, some participants' comments were conveyed with humour. They were also stoical in the sense that they tended to focus on not letting the situation get them 'down' - recognising and realistically acknowledging there was nothing that could be done about things and so it was best, they believed, to make the most of how things were *day-to-day*. Getting on with things, keeping going and so orientating selves towards everyday life, was clearly important and hence explains in part my notion of the *everydayness* of family feelings. More generally I use this phrase to refer to the 'non-spectacular' or 'non-dramatic' 'ordinariness' which took shape in family accounts about their feelings. Furthermore I have suggested that the understated and seemingly 'unemotional' ways in which some participants

⁹⁷ When she came down from upstairs and was introduced to me by Mary, she did not place herself conspicuously on the sofa with us, but sat at the computer in the next room.

expressed feelings in relation to the situation, did not mean they were in 'denial' about what was going to happen in the near-future.

The Best Way to 'Be'

A particular conversation with Hugh and Dot contains, and therefore seems to typify, many elements of the pragmatic approach I have been discussing so far, and it highlights in particular, how this approach was considered the 'best' way to 'be' when dealing with life-threatening illness. The following conversation took place during my third and final interview with the couple and I was trying to find out how they were feeling about Hugh's recent period of hospitalisation. At the time I was working from my own assumptions that this must have registered as deterioration and, for the couple, have seemed like a move closer to Hugh's death.

Julie: And did you and Dot have a talk when you came back out of the hospital or? You know about how things?

Hugh: Oh aye we had a natter about it but it's same as we know, we know in us own mind it's a matter of time and we have got to try and live best as we can er she says 'get in the hospital and stop there while ever' but she doesn't mean it

Julie: No

Hugh: it's er thing that we have got to try and make the best of what we can lass - she keeps hitting me but er she's still me friend (joking)

Julie: She's still your friend. When you say make the best of it then, what can you do day-to-day to make the best and what have you?

Hugh: Well have a laugh and a joke, keep eating, drinking

And so it is evident that the couple were aware that time was limited for Hugh, and although they did have a '*natter*' about this, focus was shifted towards the matter of getting on and making the best of things. Hugh let me know that they continued to joke and banter between themselves in spite of the situation; he made reference to Dot saying he could pack himself off to the hospital and not really meaning it, and he joked that they were still friends even though Dot '*hit*' him. Throughout my interviews with the couple, Hugh often suggested that Dot was mean to him - would not make him food and she '*hit*' him. Although this was clearly not true, it did tend to provoke a response from Dot and the two of them would banter and laugh about this in a way that suggested how things had always been between them. On one occasion I saw Dot bash Hugh over the head with a cushion during an exchange of teasing. Clearly humour and '*sparring*' in this playful way was integral to how the couple related and this sense of relational continuity echoes what I discussed in Chapter 5, about Kathleen's cold morning cup of tea representing continuation in her relationship with husband Eddie.

Furthermore, Hugh told me that part of orientating towards the everyday and '*making the best*' was about having a laugh - he also mentioned the daily matters of eating and drinking. Although he did not use the word '*plodding*' as he spoke about keeping going in the everyday, Hugh echoed Jackie's unexceptional sense of '*plodding*' - of not aiming for anything extravagant - just mundane, day-to-day life. However, achieving this was something which you had to '*fight*' for, as the couple explained to me with

Hugh somewhat didactically telling me *'it's all in the mind dear'* and trying to teach me that there was a quite particular approach to how best to 'do' emotion at this time.

Julie: *...like you say you try to stay positive and that you use your humour*

Dot: *Well we have to live don't we? I mean we have to*

Julie: *Yeah*

Dot: *try and keep*

Hugh: *If we went any other road, if we moaned about it and grumbled about it and being upset about it all the time*

Dot: *He wouldn't be here now*

Hugh: *I'd have been gone now, there's no doubt about it it's er, you have got to fight it and you have got to laugh about it a bit; you've got to live*

Julie: *Hmmm*

Hugh: *It's no good being depressed... It's all in the mind dear; you've not got to be depressed, keep going*

In the similar way that Jackie and Eve continued to get out of bed in a morning, Hugh suggested that 'living' was about fighting and this underpinned his stoical approach.

However, associating being pragmatic and accepting as something one achieves through 'fighting' was not a view shared by all participants. Vera was irritated by the 'heroic' idea of the stoical cancer 'fighter', which she clearly felt was a stereotype that existed. In conversation with her sister Helen she explained:

Julie: Hmm so how often when you are spending time together or you are just, it's an average day... do you talk very much about the illness or is it just sort of something that's there?

Helen: No we [don't] talk about the illness very much only if Vera has got pain or anything

Julie: Right

Helen: like that we'll talk about what's happening or whether she should take a paracetamol or something just that you would do with somebody in the house with a cold you know?

Julie: Yeah sure

Helen: But we don't discuss it all

Vera: No

Helen: we just tend to ignore it and get on with what we have got to do

Vera: Cos I think you could make too big a thing about it, it would take over your life you know if you allowed it too

Julie: Yeah

Vera: No

Helen: I think once you accept the restrictions that it's imposed on you and are content with what you have got then it doesn't become such a big deal

Julie: Hmm

Helen: I think if you were felt deprived, deprived of your outings, deprived of

Julie: Yeah

Vera: That's why I say I don't understand this fight against it - what's the point you know? You are not going to beat it, it'll beat you if you - for instance walking up that drive I'm shattered I have to take Helen's arm to get up the drive... er just imagine you trying to get up there every 2 seconds battering your head against a brick wall, no point. So I just sit in my chair

The way the two women claimed to accept the illness as not '*such a big deal*', resonates with what was conveyed by Jackie previously about rupture or great disruption not reflecting so much the experience of living with the terminal illness day-to-day. Furthermore on the matter of '*fighting*', earlier in the interview Vera had explained that:

Vera: Yeah and you know people will say 'oh she's a real fighter, she's fighting it' I don't believe in that at all; I'm not fighting anything, let it go its way and get on with it. What's the point of fighting it? How do you fight it? I don't understand that expression anyway

When her sister, Helen, pointed out that she did have a positive attitude though, and she did not let the illness '*get her down*', Vera replied:

Vera: Oh no well what's the point of that?... destroy my body aye it will do, but it's not going to destroy me... what I think for me is extremely good, I'm not frightened of it not in the least bit frightened of it and you know when the man said to me 'you have got 4 to 6 months to live' I was not the least bit frightened...

So clearly Vera considered herself as having accepted her prognosis - she had no fear about dying and when she claimed that the cancer would destroy her body but not '*herself*', this did sound rather like '*fighting talk*'. Yet on the other hand she also explained that you have to '*let it go its way and get on with it*'. '*Getting on with it*' is typically stoical, but Vera also pointed to her acceptance of not being able to win - so facing up to the futility of the bodily fight. Therefore Vera's stoicism related to her pragmatic and realistic view that there was no point in wasting her energy fighting a battle she could not win. Vera's comment that '*so I just sit in my chair*' is very

powerful as a contrast to Eve and Jackie's insistence on 'getting up', and it conveys poignantly her 'alternative stoicism' in the sense that she was fighting in her own way, via a sort of resigned and accepting apathy. Whereas Eve and Jackie insisted on 'getting up' as a mode of 'fighting on', Vera felt herself to be stoical in her 'sitting down' and letting the illness come. It was more a matter of splitting mind and body for Vera; of giving in to the futile bodily fight, but keeping going for her 'self' which she considered as something separate. Thus, ultimately, her belief in a 'best way' to go about emotionally facing the circumstances was still aligned with the stoical, pragmatic approach which certain participants were keen to 'educate' me about when I tried to 'unpack' their feelings with my questions.

Although I had not set out to understand so much about how families 'coped', they appeared to want to share with me their beliefs about a particular way of approaching the illness in their everyday lives - about how they 'did' managing their feelings as much as what those feelings were. I shall return to this point in the following section where, having presented the stoical accounts and approaches of particular ill individuals and their relatives, I now consider more specifically the relational context of emotionality as it was negotiated between family members.

Not Talking about It

Vera and Helen, the sisters I discuss above, explained that they did not talk about Vera's cancer. Helen made the point that they '*ignore it*' and Vera suggested that talking about it might turn it into a '*bigger*' thing with the potential to '*take over*' their life. This was consistent with having a pragmatic approach - talking about what was likely to happen would only make things worse, there was nothing to be gained by it. It seems that Eve and Charlie came to a similar conclusion.

Charlie: You know we don't go on about illness too much do we?

Eve: No

Charlie: Don't rattle (talk) on about it do we?

Eve: No because it is depressing in't it? It can be, you know you have got it and that's it

Julie: Yeah

Eve: And you know it's going to take you - they have told me that, that's it end of that so you know, er but as we keep on going as we are we are not so bad

Julie: Yeah from day to day

Eve: you know what I mean? Yeah, yeah - living from day to day, take each day as it comes and er I think that's all you can do

In both accounts, reference to being able to adjust and keep going in a daily sense was cited as important. In telling me about the circumstances of Vera's actual death, Helen remembered how they did not talk about what was going to happen, either earlier on in the illness process as they both confirm above, or even more latterly as Vera was admitted onto the hospice ward where she did eventually die. Apart from making wills the previous

year to safeguard one another because the ownership of their home was shared between them, Helen explained that the experience of Vera dying or the prospect of her death just never came up in conversation. About this silence, she said:

Helen: I don't know that we did it deliberately or we just I don't think we wanted to believe it was going to happen. We talked about absolutely everything under the sun and we never discussed that you know when they say people have their, what they want at their funeral - the hymns they want or prayers or the format of the funeral. We never discussed anything like that - ever.

Here Helen refers to not wanting to believe that Vera was going to die, and so I asked her directly if she felt that by not talking about this it meant that they had been denying in some way that it would happen.

Julie: ...You know so you said you and Vera didn't talk but did that necessarily mean you were denying what would happen?

Helen: No well I find that difficult to (pause) you are not consciously aware you doing that but you could be in denial but I'm not consciously aware that I - it wasn't a case of oh I'm not going to think about it

Julie: Yeah

Helen: It was just you got into the routine of how you lived your life going up every day to see her (in hospice); I mean altogether she was out of the house 8 weeks, she had been 2 weeks in hospital and then 6 weeks in the hospice and that became a routine which you just lived that day by day. I wasn't consciously aware that I am not going to think about her dying - I just didn't. And I think she was the same I don't think it was anything that you were aware of it just didn't come up at all, we just erm we living as the day came sort of thing you know. I mean my daughter and I right from the beginning when she was diagnosed did talk about what we would do without her you know erm but again we used to say this on numerous occasions 'what will happen after Vera dies, I don't know how we are going to manage you know' you can't believe there would be a world still

going on and she wasn't here but even having said that we weren't ready for it at the end it just came so quickly.

Whilst Helen did reflect carefully in response to my question about denial, ultimately this was not something she could easily accept as a satisfactory explanation of what took place. Moreover it was an acknowledgment of the 'everydayness' of doing family life that was cited by Helen as having had an important bearing upon 'organising' the emotional worlds and feelings of the sisters.

On the other hand, the fact that Helen and her daughter Becky spoke together about Vera's impending death, does point to relational complexities in how thoughts and feelings are at times communicated between different family members with varying degrees of 'directness' (Hendry and Watson, 2001). Indeed, this appeared to be the case for the Cox family. In separate interviews, two of Eddie's children gave a different view of their dad's feelings about his terminal cancer. Both Brian and Claudia presented their father as typically stoical and refusing to complain or openly talk about his illness. For instance, Brian explained:

Brian: To be quite honest I don't think me dad has changed at all I think me dad's just, I mean me dad is the only one that seems totally unaware that he's ill. Now I don't mean that in a way that he doesn't know he's ill but he doesn't mention it... he doesn't moan he's not a complainer he doesn't want sympathy or owt like that er but it's certainly not altered his attitude

However, despite also agreeing with Brian about this, Claudia did offer a different insight into what she understood to be a part of her father's

emotional world that he would only show to her. Explaining how her dad was angry that he would not live to see eighty years, Claudia told me:

Claudia: Yeah ... (Talks about deaths in Eddie's family)... So I don't know where he got this 80 into his head, why

Julie: Hmmm cos you said he was quite angry you felt, that he showed that to you

Claudia: Yeah

Julie: sometimes that perhaps other people in the family didn't see it but he showed to you that he was quite

Claudia: I think as well with him cos me and me dad were alike that's why he could be like he were with me and I'm glad he were but he were very angry about getting cancer, very angry

Significantly, Eddie had not let on to me that he was angry. Thus emotions and the expression of these are negotiated in complex ways between different family members, as well as with those outside of the family⁹⁸.

Therefore, at times, particular ways of responding to the illness were not always known about, shared by or helpful to all family members. As I have identified over the course of this chapter, Hugh was someone who used humour frequently and made a lot of jokes. Although, often his wife Dot was an equal, and willing party in this, there were times when his humorous approach 'denied' full expression to Dot's feelings. About her concerns that Hugh might die whilst she was away in Guernsey, Dot explained:

⁹⁸ Thus, to reiterate the point I made at the very beginning of this chapter, throughout this analysis I am mindful that researchers need to be aware of the problematic nature of accepting statements about feelings as a straightforward basis for speaking definitively about the emotional, inner worlds of others (Wilkinson and Kitzinger, 2000).

Dot: *Well only thing I [am] waiting for now to hear is er if it's going to get worse or*

Hugh: *Well it's obvious you know I shan't get no better don't you? Eh*

Dot: *I know you won't but erm*

Hugh: *It's a thing that'll not go over night dear*

Dot: *I don't like folks to suffer*

Julie: *Hmmm*

Dot: *I know me first husband did and I keep thinking of him when he were bad*

Hugh: *Well kick me*

Dot: *and I were thinking, I am thinking of things he went through*

Julie: *Hmmm*

Dot: *and I don't want him to be the same*

Julie: *Hmmm*

Dot: *Know what I mean?*

Julie: *I understand that yeah, I do (pause)*

Dot: *And I wouldn't like him to go same way as he went. I mean my first husband he went in a coma on the Friday night and he was in the coma while Monday teatime and the nurse were there and the doctor had just walked in and me dad were there... but I weren't in the room I were in the kitchen with the babbies (small children) - and I heard me dad shout 'Dot he's woke up'. And I just got to the room door and he says 'aye do Tom' - that were me dad - and he died. So I didn't get to see him that weekend at all; well I don't want the same to happen to him*

Hugh: *Oh no I'll tell you I'll write you a letter love (Julie laughs a little)*

Dot: *No don't be funny that's not funny Hugh (slight pause)*

Hugh: *Keep getting onto me and tha'll go before me*

Dot: *I don't want owt to happen to you while I'm in Guernsey*

Hugh: *There's nowt will happen while you're in Guernsey don't worry I've got 2 bob in my pocket says' tha won't - plus that 2 bob I've got to send you with*

Dot: *That's only thing what's, what's*

Julie: *That's playing on your mind?*

Dot: *Yeah*

Hugh: *Nowt will happen while you're in Guernsey; I've got 2 bob here says it won't*

Dot: *Cos it's not as though I can get away, home straightaway*

Hugh: *No*

Whilst Dot - not sparing Hugh this account of his potential suffering - clearly tried to explain her feelings and fears about history repeating itself and not having the chance to be with Hugh when he dies, Hugh constantly interjected with humorous remarks which seemed to 'play down' the seriousness of the situation and acted as attempts to 'close down' Dot's bid to voice her concerns. At one point she actually told him not to be funny and he replied by once again joking and being flippant about his death - suggesting that if she did not stop '*getting onto*' him (nagging), he (or perhaps he meant the stress), would finish her off first. In a later interview when I asked Hugh directly whether he made jokes to make things easier, the following was explained to me:

Julie: *Does he joke all the time Dot? Is he making jokes all the time?*

Dot: *(Sad almost) Yeah, yeah*

Julie: *Do you sometimes have to tell him not to make a joke?*

Dot: *I have, I have*

Julie: *Is that easier for you to make jokes?*

Hugh: *No I shall be daft when I grow up (Dot laughs)*

Dot: *Eh dear*

Julie: *Do you think using humour and jokes helps you?*

Hugh: *You've got to do, it's no good being miserable about it Julie*

Julie: *But were you like that before?*

Hugh: *Oh aye I know er*

Dot: *He were but he's getting worse now (laughter in voice)*

Hugh: *I know what'll win like, I know in the end I shall be going feet first through the door*

His pragmatism was absolute in the evident belief that his 'jokey' way was simply how you had to be; being miserable would not help anything. However, what is especially important is that Hugh implied that he understood the 'hidden' intention behind my question, when he categorically let me know that he was under no illusion about the fact that he would lose the 'fight'; the cancer would win and he would leave the house '*feet first*' - or in other words dead. He wanted to leave me in no doubt that his joking around was not evidence that he was denying the fact that he would die soon. And so, whilst his apparent lack of emotionality and attempts to 'close down' conversations, may seem like ploys of emotional avoidance and denial, assuming this, rather than paying attention to how he more generally endorsed a pragmatic orientation towards on-going everyday life, is not an adequate interpretation. Instead, I have shown how participants wanted to share their beliefs about a particular way of approaching illness as the 'best' way to be. Blaxter defines *beliefs* 'as those

things which people know or think to be true' (1990: 148) and the assertiveness in Hugh's didactic tone, in particular, does indicate that he knew that his approach was the best way to be - he was not in denial - and he wanted to be sure that I had understood this.

Consequently, for individuals in my study such as Hugh, I have considered how their belief in a particular way to 'be' emotionally when dealing with life-threatening illness, might have intermeshed with wider everyday social, cultural and biographical milieu. For instance, in a rather different cultural context, Wikan (1988) explores the *situated* and *contextual* nature of emotions and death-related experience, and discusses a commitment to keeping cheerful after death, which is pervasive in Balinese society. In this cultural context not displaying painful emotions is understood to be for the good of society and it enables people to 'get on'. Moreover, generally, there is a diverse body of literature surrounding lay-health beliefs which underlines the cultural specificities and the biographical and historical influences that shape understandings and approaches to health and illness (Keeley *et al*, 2009; Fenton and Sadiq-Sangster, 1996; Blaxter, 1990; Williams, 1983; 1990; Curren, 1986; Curren and Stacey, 1986; Seabrook, 1986; Cornwell, 1984; Ablon, 1973). Many of these have been concerned, though, with the link between beliefs and health-related behaviours (lifestyle) and the causation/ prevalence of particular illnesses. Fewer have focused specifically on lay beliefs about *mental* health and especially in terms of emotional well-being when facing adversity. There is research,

however, about older Aberdonians⁹⁹ and their beliefs regarding illness and death (Williams, 1990) which does consider the influence of religious and economic legacies and how these intertwine in the lives of older people to shape attitudes towards managing or coping with illness, death and bereavement. Hockey (2002b), focusing more on the specific deterioration and dying experiences of older people in a residential home draws on Williams' work to suggest that she also 'found a similar continuity of values across time' which became resources drawn upon by the older people to inform their generally stoical attitudes towards death (2002b: 56). Her empirical work highlights the inherent diversity of dying experiences as she argues that, through exploring dying people's values and beliefs, it is apparent to see how often we 'die the way we live'. Therefore, similar to the critique of biographical disruption's applicability to all illness experiences I presented in Chapter 2, both Williams (1990) and Hockey (2002b) point towards the importance of relating beliefs about how to 'do' emotional coping with illness and dying to the context of people's personal, social and historical biographies. The analysis I have offered here adds to this argument by taking a sustained look at how beliefs intersect with *everyday lives* and shape what I have called the 'everydayness' of family feelings.

⁹⁹ People living in Aberdeen in Scotland.

Conclusion

In this chapter it has not been my intention to suggest that individuals and their families are unaffected or 'unemotional' about life-threatening illness and facing death, nor are they only concerned with mundane, daily matters. Rather, given the prevalence of stoicism within the data, it felt important to explore these approaches to highlight further the ways in which death interlaces with everyday life in terms of particular pragmatic beliefs about how to 'do' or show emotion within familial contexts. Thus, I have argued that families do not just 'do' being stoical and pragmatic; this becomes part of a belief system based around the idea of how best to approach 'doing' emotion during life-threatening illness by essentially getting on in day-to-day life. Drawing on data about the lived, everyday feelings of families negotiating life-threatening illness, it becomes apparent that deterministic, universal theories - like those, which speak of the innate fear of death and dying and therefore presume there is a need to deny it - are not nuanced enough to appreciate the everydayness of people's emotions as they are contextualised in particular circumstances and kinds of dying experience. Kellehear has convincingly argued that dying is as diverse and complex an experience as living, and that therefore the current state of theoretical and empirical knowledge about dying experiences is in need of re-examination and critical reflection to go beyond seeing dying 'as simply sad and bad' (2009a: xiii). My data and subsequent analysis of it contributes to meeting this challenge. As accounts and observations of family life have shown throughout the thesis, life-threatening illness, dying and death might not always be about intensity, crisis and the extraordinary. Rather it is

important to acknowledge, seriously, the place of the mundane and ordinary in relation to everyday practices *and*, as argued in this chapter, to *also* recognise this 'everydayness' in the emotional lives of families facing illness and death.

Chapter 9

On Mundanity and Life-threatening Illness in Everyday Life

Introduction

I began this thesis by describing how the study developed from my observation of families during voluntary work on a hospice ward. Although I identified the emotionality that accompanied some of these experiences, I also pointed to how I had begun to reflect upon the everyday aspects of being a family experiencing life-threatening illness. Essentially, the culmination of these early thoughts and experiences was that I wanted to understand more about what living with dying might mean for having an *everyday* family life, and for negotiating relationships and identities within families.

As my ideas developed with time spent looking at different literature, Morgan's (1996) notion of family practices encouraged me to find out what families were actually *doing* over the dying process. Curious, as a result of my earlier experiences, I wanted to know about how families managed to 'be' families and do family-like things at what is generally understood to be a most difficult and disruptive time. Indeed, in the early planning stages of the research my own acceptance of popular and academic constructions of death- as-crisis interlaced with different ways of approaching and thinking about dying experiences that my time as a volunteer had prompted me to consider.

Thus it was a mixture of personal experience and engagement with academic theory that formed the impetus to plan and carry-out this research. The ethnographic approach that I employed reflected my objective to consider family experiences in an in-depth, non-retrospective way. I wanted to gain insight into how people were experiencing themselves as part of a family in the 'here-and-now' of their everyday lives and over a more sustained period of time. Although this was not always possible, due mostly to the unpredictability of the disease process, I have been able to achieve a protracted view of family experiences, rather than simply snapshots. As the fieldwork unfolded, and I became more immersed in the worlds of the various families I spent time with, my ethnographic approach enabled me to note the 'mundane' things happening on the ward, or in accounts families shared with me, and to develop an analytical view of what is considered a most remarkable or extraordinary experience (Silverman, 2007).

In this final chapter, I retrace the contours of the thesis argument that emerged from this empirical exploration. How my 'findings' fill a gap in the wider picture of theorising about dying experiences will be discussed in terms of the contribution the research makes by using empirical data to understand the previously neglected relationship between everyday life, and experiences of severe illness and dying. In trying to establish the broader implications of the study, I move on to consider how the analysis provided might be usefully extended to other areas of death and illness-related research in the future. After this, some brief reflections on how the research is relevant for practice in hospice and palliative care settings will be offered.

Finally, I end on a personal note and present one last extract from my field notes which sums up the emotional journey involved in undertaking the research.

Speaking of Models...

The Laughing Buddha

Beside the pond in our garden is a statuette of a laughing Buddha. He stands with arms stretched upwards in joyous celebration. Except that one arm is broken... when the accident happened, I asked my husband to stick the piece back on. Noticing that the repair went undone for some considerable period of time, I enquired as to whether there was a problem. 'I quite like it like that', was the response. Over time I have come to agree... The wounded laughing Buddha speaks of joy reaching through pain, of severed connections nevertheless sustained. It has more to say than the perfect model.

(Holloway, 2007: iii)

This personal story, cited at the beginning of Holloway's (2007) book about negotiating death in contemporary health and social care, helps to draw together, through the power of analogy, some of the key threads that have weaved throughout my thesis. We learn, in the above quote, about Holloway's instinctive orientation towards fixing and reinstating the 'perfect' model, as something she is familiar with and expects to 'see' - her Buddha with *two* arms stretched upwards towards the sky. However, what she describes next is the realisation that there are other 'models' or ways of 'seeing' that can actually reveal much more, which is also what I have found to be the case regarding experiences of living with illness and dying. And so, over the preceding pages, I have asked questions of the dominant models we tend to 'think with' when considering matters of severe ill-health

and death. Aptly, Holloway's Buddha 'has more to say' about the experience of losing his arm than a sense of severance, and similarly my families seemed to 'speak of' more than rupture, as the death as crisis and disruption model did not reflect the totality of their experiences. Rather, despite living with impending death, a sense of continuity and 'keeping going' were - as Holloway recognises with her Buddha - for many families 'nevertheless sustained' (2007: iii). I have chosen to present this analogy here as it helps to convey what has been my experience in realising that my data required me to tell a somewhat 'different' story, about living with dying.

Thesis Story: life-threatening illness, dying and everyday life

This thesis has utilised the concept of family practices (Morgan, 1996) and explores its inextricable links with the mundane and everyday to suggest that practices - as broader assemblages of doing, thinking and feeling (Smart, 2007) - can be a lens through which to see something more mundane than crisis and rupture in family experiences of living with life-threatening illness. Whilst it has not been my intention to 'do away' with the rupture/ crisis-based model and to replace it with another, or to suggest that encountering life-threatening illness cannot be an extraordinary, emotional and difficult experience for individuals and their families, my thesis does explore the aspects of dying experience which have remained largely on the peripheries and margins of existing work. Throughout the data, a sense of continuity, a belief in pragmatism and an immersion within mundane matters of the everyday were clearly important to many families and these

demanded to be analytically explored as an integral part of representing participants' experiences as they were explained in their own, situated terms. And so, guided by my data, I have been challenged to question the *theoretical generalisation* of death-related experiences in predominantly crisis or rupture-related terms; though I am not suggesting that dying is not at times a difficult or crisis-provoking experience.

After a year spending time with families to learn about their daily lives, I was able to use my data to interpret how mundane routines, habits, objects, spaces and temporalities of family life, became significant experiential sites for negotiating how families continued to be and understand themselves as a family, in the context of life-threatening illness. Thus my central and overarching argument has been that, for these families, experiences of illness and dying were made meaningful as lived experience through family members' immersion within everyday life and mundane practices. As I demonstrated in Chapters 4-7, everyday practices, spaces and routines were experienced as significant for family experiences. These data underline how more existential or 'intense' processes often associated with dying do not provide a comprehensive picture of daily life during contemporary dying. As this is often a protracted experience, exploring the question of what families were actually *doing* at this time was important to understand illness and dying as a process which essentially happens *day-to-day* and not only in more intense moments of crisis or drama. In other words, my data suggested that, for these participants, encountering ill-health and dying were not discrete ontological experiences existing outside and separate from

everyday family life. Therefore I have argued that finding out about the 'doing' of family life brought more squarely into view the everyday as a lived experience (Felski, 1999) *within* which families came to 'know' their experiences of illness and dying

In Chapter 8 I developed this argument further by focusing less explicitly on the 'doing' of family life and more on the felt, 'inner worlds' of family members, to explore how their feelings and beliefs about illness and the prospect of death *intersected* with processes of relationality. Essentially I considered how individuals understood that they needed to 'do' and approach the emotional aspects of living with dying, in their day-to-day lives. Indeed, as was argued in Chapter 2 and revisited in Chapter 8, emotion is high on the agenda in theoretical and practice-based work in this area. However, my data offered a distinctive way of understanding how emotion was 'managed' and approached as part of a more complex lay-mental health belief system grounded in the specificity of the everydayness of participants' lives. My analysis of the families' perspectives moved away from the more familiar model of emotional crisis and rupture in relation to severe ill-health and dying, to ask new questions about the 'everydayness' of people's feelings during these times. I argued that these data about the lived, everyday feelings of families facing death, suggested that deterministic, universal theories about the innate fear of death and dying which presume there is a need to deny it - are not nuanced enough to appreciate the everydayness of people's emotions in particular circumstances as they experience certain kinds of dying.

Indeed, as I outlined in a review of the literature in Chapter 2, my approach has contrasted with work in this area which has either neglected to focus on everyday life and therefore kept it at the theoretical margins (as Seremetakis, 1991 critiques), or considers it in a way that essentially transcends and eclipses its focus on the mundane by referring predominantly to the transformation or intensification of aspects of everyday experience in relation to illness and dying. Therefore, throughout my analysis chapters, but more explicitly in Chapter 7, I addressed the challenge of how to pay serious analytical attention to the everyday and mundane without interpreting aspects of it as the basis for more 'transformative', 'special' or 'meaningful' experiences (Highmore, 2002; Felski, 1999). Although, at times, individuals did say 'small things' had become more significant or that the knowledge that they, or a family member was going to die soon had made them think differently or appreciate certain things more clearly, my main focus has been to argue that mundanity is something which families can meaningfully 'peg' their understanding of dying, or the experience of illness, upon. To suggest that the everyday was relevant only in the sense that it became a 'higher' experience, transcended by a family's awareness of death, does not provide an accurate representation of how it appeared meaningful for the families I spent time with. Instead, I have argued that it is the ways in which the mundane makes the more seemingly 'extraordinary' - severe illness and dying - 'knowable', rather than how the extraordinary transforms the mundane, that was important in interpreting family experiences. In other words, my analysis has explored 'ordinariness' (Felski, 1999) and lifted to the fore (Highmore, 2002) what might otherwise

have been taken-for-granted data about mundane life, to show how everyday practices are integral to understanding the ways in which families are produced during circumstances of severe illness and impending death.

Future Research: bringing the mundane to the centre

As I have already pointed out, my argument about the mundane, everyday and ordinary as experientially significant in dying experiences, provides something different to the established theoretical ideas in the death studies literature. In Chapter 2, I argued that an all-pervasive association of death with rupture and intense emotionality obscures and neglects its ordinary and mundane aspects, and that it is these which are less well understood and integrated into theoretical perspectives. Considering this, there is opportunity to build on the practice-based approach taken in my research and to 'look' for the ordinary and mundane in different dying experiences and situations. I therefore suggest that future death-related research can aim to bring the 'marginal' to the centre of its analysis. For instance, in sudden or unexpected deaths, where perhaps the model of 'crisis' and rupture may be more generally applicable to people's experiences¹⁰⁰, there is opportunity to analyse the inverse of what I have considered here; that is, to see how the everyday and mundane might manifest itself in such circumstances. Thus, whereas my data has suggested that experiences of disruption, intense emotionality or a sense of crisis are to be acknowledged as interlacing with

¹⁰⁰ For instance, see Guy and Holloway (2007) regarding 'special deaths' which refer to a specific manner of dying - usually sudden death - where a sense of crisis and rupture can more generally be assumed to be relevant or applicable. For example murder or a short period of time in intensive care before death due to an accident or acute illness (see Seymour, 2001).

a more sustained immersion *within* ongoing everyday life and mundane matters, further research can consider the inverse relationship, where an intense period of crisis or sense of rupture perhaps precipitated by a sudden dying trajectory, might be interlaced with experiences of the mundane and everyday practices. Bringing the mundane more squarely into future analyses can aid in understanding more comprehensively, the lived, *day-to-day* experiences of those affected by severe illness, dying and bereavement in a variety of diverse circumstances.

My suggestion that future work should look to bring the neglected margins to the centre of death-related research, is especially timely as a recent multidisciplinary collection of papers has underlined the need to ‘pause and think again, and to re-examine our common fate more carefully, more thoughtfully, even more hopefully’ (Kellehear, 2009a: xiii). The collection editor (Kellehear, 2009a) underlines that there is a great deal which our current knowledge-base cannot tell us about dying experiences and points out that the diversity of dying has been obscured by a ‘problems-based’ research tradition, often rooted in medical, health and care concerns. He writes:

Specific research on dying as a particular form of social life and experience that goes beyond, yet providing context to illness and its associations, receives far less attention even today (Kellehear, 2009a: 1).

Thus, exploring dying as a form of *everyday* experience, as I have undertaken in this thesis, is a step in the direction of expanding knowledge and understanding about dying as a social, relational process.

Informing Practice

During the Birmingham International Workshop on Supportive, Palliative, and End-Of-Life Care Research, which was held in 2005, leading researchers in the field identified ten areas they believed were in urgent need of research and further exploration; one of these areas was family and informal care-giving (Addington-Hall, 2007). As gaining a greater understanding of how families are affected by life-threatening illness is currently one of the key challenges facing palliative care, my research makes a contribution to meeting this challenge.

I would argue that it is important to have a deep and situated understanding of what being in a family and having a family life means to those *actually negotiating* life-threatening illness, before palliative care practitioners can set about the task of improving the quality of life of the families they work alongside.¹⁰¹ My in-depth, ethnographic data has enabled me to develop a perspective on illness and dying experiences grounded in the daily lives of the families I worked with, and it can therefore provide some of this insight and deeper understanding about ‘doing’ family during this time.

Furthermore, my analytical ‘findings’ have a focus which is different to the concerns that appear to dominate in the palliative and nursing-based literatures. For instance, as was outlined in Chapter 2, concentrating on family functionality and identifying families as ‘systems’ leads to a concern with determining family resilience, ‘coping strategies’ and ‘needs’. This is

¹⁰¹ This is stipulated as a key goal in the World Health Organisation’s definition of palliative care.

undoubtedly important in aspects of care-planning. However, as my data have shown, averting 'crisis' is not the whole story that families want to tell about their lives at this time and there is perhaps more to be engaged with and learnt.

Furthermore, as I considered in Chapter 3, the concept of 'family' is important in hospice culture and the ethos of the movement places the patient within a familial or wider social context, with support needs which extend beyond medical provision and symptom control (du Boulay, 1984). My research can help achieve this holistic goal of patient care by making apparent the different voices and implicit actions involved in processes of (re)negotiating familial relationships and of living as part of a family *day-to-day* at this time. It steps outside the care-centric perspective and can therefore inform the provision of services to families, providing a more evidence-based account of what is meaningful to those families in terms of the everyday, more mundane, and therefore perhaps overlooked aspects, of their day-to-day lives. In this sense it may be of particular use to those practitioners delivering hospice services to people in their own homes, where considering the implications of life-threatening illness for everyday family life are especially pertinent.

Leaving Vera

Finally, the following extract reflects the personal side (Smart, 2009) of conducting sensitive research which has been a constant backdrop to my

own experience of producing the thesis. Furthermore, it also serves to underscore what I have argued over the course of this thesis about the analytical power of the mundane.

(Visiting Vera at the hospice...)

‘On a couple of occasions Vera complements me on my rings and we chat about jewellery. As I am about to leave she asks if she can try my amber one on and I slip it off my finger and hand it to Vera. She says there’s no way it will fit her fingers properly, but she manages to slip it onto her little finger and holds her hand out to admire how it looks. How beautiful she thinks it is and I talk about where I got it from. I feel a bit embarrassed; like the ring represented frivolousness or something - or was it simply that I am living and Vera is dying? The ring symbolising hope, happiness, getting dressed up and readying myself for life? Not being able to choose to wear nice things, or not being bothered - I associate this with sickness, with being in an institution, with losing identity? The moment just felt quite complex for me somehow. It was also terribly moving and as I slipped the ring back onto my own finger I felt as though part of Vera was with me...’

Interestingly, when I wrote the above, I referred to my ring, which so interested Vera at the time, as something ‘frivolous’. I say the exchange caused me embarrassment and imply somehow that it was inappropriate, insensitive perhaps, because Vera was dying. Looking back it appears that it was the seemingly ‘small’, everyday ordinariness of two women talking about jewellery which contributed to the feeling. With analytical reflection I see how I was uncomfortable with mundanity where there was also dying.

However, I did not want to end with this extract purely as a way to revisit my central thesis argument. This reflection on my time with Vera also enables me to finish by acknowledging the challenging nature of what I have undertaken. Although I have focused upon mundanity in dying experiences, this does not mean that I took any of what I encountered 'lightly'. Rather my participants helped me to recognise in practice what Silverman (2007) suggests - that the real value of ethnography is in the opportunities it creates to see the mundane in order to understand more about what we consider to be the most remarkable events and contexts. For my participants' guidance with this, I am very grateful.

Appendices

Appendix 1: Participant profiles

The Participants

Below I briefly introduce the 9 families involved in the interviews. All forenames and family names assigned here are pseudonyms.

The Baker Family: Malcolm Baker (57 yrs) had been living with leukaemia for approximately 2 years when I met him. He is married to Tracey (59 yrs) and has a long and complex history of poor-health, having been critically ill on a number of occasions throughout their married life. The couple's daughter Karen (27 yrs) was involved in the interviews and Malcolm and Tracey also have a son who was not interviewed. I conducted 8 interviews with the family in total. At present Malcolm's condition remains stable.

The Kenny Family: Jackie Kenny (68 yrs) had been living with cancer of the uterus for approximately 2 years when I met her. She had been married to Clive (74 yrs) for 46 years; they have 2 children. When approached Jackie wanted to be involved in the study but was unable to encourage her husband or son to take part and therefore she was the only representative for this family's experience. Although this was not ideal in terms of the objectives of my research, ethically it seemed important to allow Jackie the opportunity to share her story. Jackie died in the hospice inpatient unit after being admitted there for a short time. I interviewed her twice in her home and visited her briefly on the ward a week or so before she died.

The Moore Family: Eve Moore (72 yrs) had been living with lung cancer for approximately 2 years when I met her, though her primary cancer was in her uterus which she developed about 15 years before. Eve had been married to Charlie Moore (75 yrs) for 49 years and they have a son. I interviewed the couple together 4 times at their home. Eve died in the hospice.

The George Family: Vera George (76 yrs) had been living with lung cancer for approximately 10 months when I met her. She was single and had never been married. In recent years Vera had moved in with her younger sister Helen Duke (69 yrs) who is a widow and has one daughter. I interviewed the sisters once together at their home and conducted a further interview with Helen after Vera's death. I visited Vera in the hospice a few days before she died there.

The Cox Family: Eddie Cox (78 yrs) had been living with stomach cancer for approximately 6 months when I met him. He had been married to Kathleen Cox (75 yrs) for 57 years and they have 3 children - Brian (52 yrs), Laura (49 yrs) and Claudia (37 yrs). I interviewed the couple and all their children, including one grandchild - Claudia's 13 year old daughter Joanna. Eddie died in the hospice. I also 'bumped into' the family on a couple of occasions there, and I visited Eddie shortly before his death.

The Davy Family: Mavis Davy (69 yrs) had been living with bowel cancer for approximately 3 years when I first interviewed her. She had been divorced for 15 years and lived alone. She has 2 sons neither of whom took

part in the research. She also has a *very close* friendship relationship with Alice (51 yrs) who Mavis describes as 'like a *daughter*'. Although technically the women are not 'related', the way Alice is considered as a daughter by Mavis seemed an interesting dynamic to explore. I interviewed both women separately on 3 occasions. Of all the participants Mavis was the only person to have stated that her prognosis was not terminal. However she continues to experience symptom problems related to her treatment.

The Fielding Family: Anna Fielding (68 yrs) had been living with breast cancer for approximately 5 years, though it had started to spread further about 12 months prior to me meeting her. She was single but had been divorced. Anna had also suffered with a chronic, degenerative condition since her 30s. She has 4 children - her 2 daughters Sue (45 yrs) and Cindy (36 yrs) participated in the interviews, though her 2 sons did not. All women were interviewed separately. I visited Anna and Sue in the hospice a few days before Anna died there.

The Mullins Family: Hugh Mullins (69 yrs) had been living with lung cancer which was diagnosed approximately a year before I met him. He had been married to Dot Mullins (76 yrs) for 24 years. He had no biological children but was considered a 'father' Dot's children from a previous marriage. I interviewed the couple 3 times at their home and I took Dot to the hospital to visit Hugh once. Although Hugh did return home on this occasion, he eventually died in hospital.

The Blake Family: Mary Blake (51 yrs) had been living with breast cancer for about 3 and a half years when I met her and the cancer had started to spread further. She had been married to Jimmy for 28 years and they have 2 daughters - Ellen (25 yrs) and a younger daughter (22 yrs). Mary also had an older sister who died from cancer between my second and third interview with the family. I interviewed Mary and her older daughter, Ellen, at their home - both separately and together. Mary died on the hospice ward.

Appendix 2: Table of interview contact

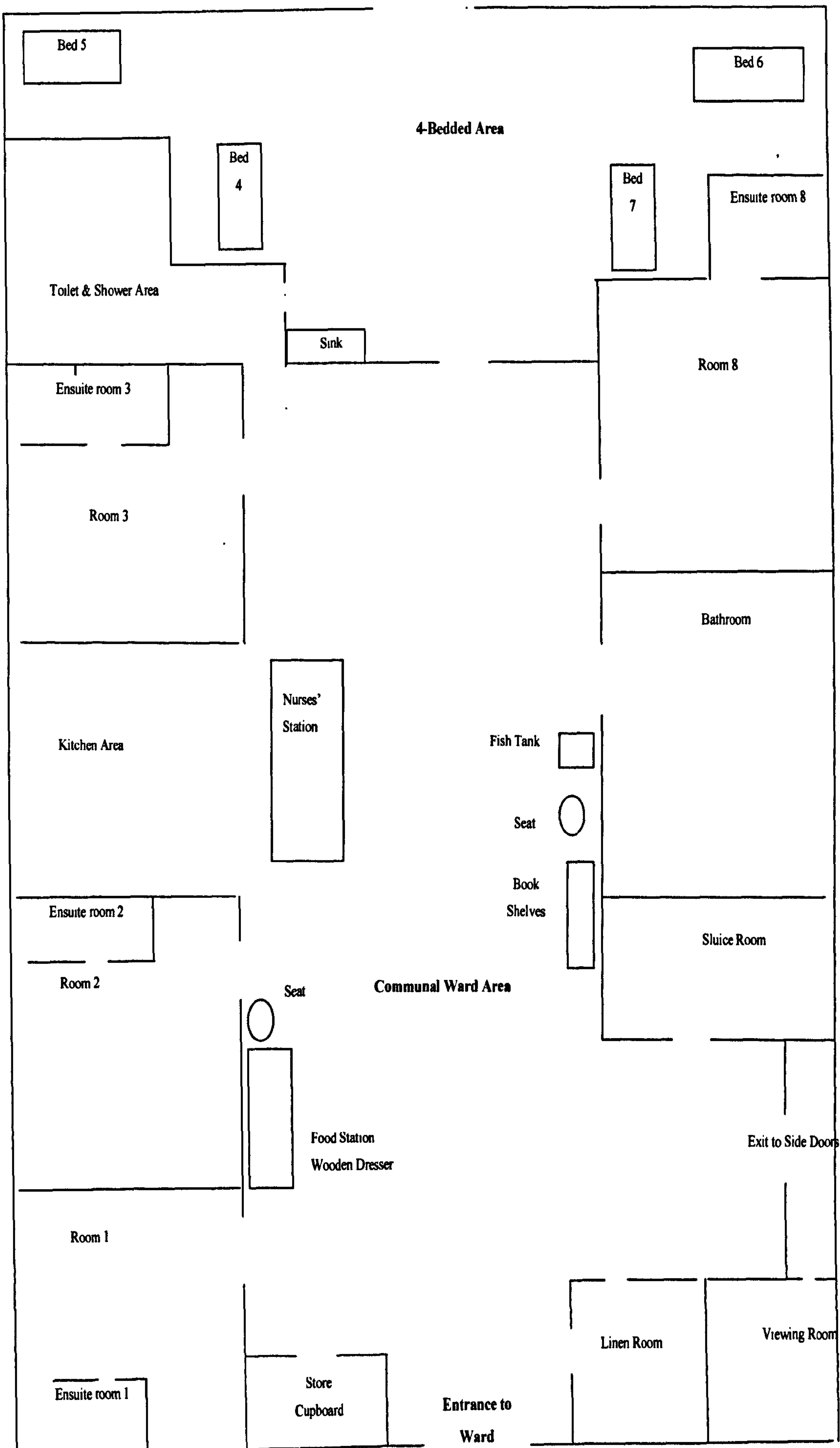
The following table gives an overview of the extent and nature of the contact I had with the 9 families and different family members. It includes all interview occasions and other time I spent time with families.

Family	Participant details	Nature/ amount of contact with family/ family members
Baker Family	Malcolm (patient, 57 yrs) Tracey (wife, 59 yrs) Karen (daughter, 27 yrs)	Malcolm & Tracey jointly = 4 times in their home Tracey alone = once at home Karen alone = 3 times at work <i>Total contact = 8 Interviews</i>
Kenny Family	Jackie (patient, 68 yrs)	Jackie alone = 2 times at home <i>Total contact = 2 Interviews Plus 1 hospice ward visit.</i>
Moore Family	Eve (patient, 72 yrs) Charlie (husband, 75 yrs)	Eve & Charlie jointly = 4 times at home <i>Total contact = 4 Interviews.</i>
George Family	Vera (patient, 76 yrs) Helen (sister, 69 yrs)	Vera & Helen jointly = once at their home Helen alone = once at home after Vera's death <i>Total contact = 2 Interviews Plus 2 hospice ward visits.</i>
Cox Family	Eddie (patient, 78 yrs) Kathleen (wife, 75 yrs) Claudia (daughter, 37 yrs) Brian (son, 52 yrs) Laura (daughter, 49 yrs) Joanna (granddaughter, 13	Eddie and Kathleen jointly = once at their home Claudia and Joanna jointly (with Joanna popping in and out of some interviews) = 4 times at their home Brian alone = once at his home Laura alone = once at her home

	yrs)	<i>Total contact = 7 Interviews Plus 1 hospice ward visit and 2 chance meetings at the hospice. Also 1 visit to Eddie and Kathleen's home to discuss the research process before first interview</i>
Davy Family	Mavis (patient, 69 yrs) Alice (friend, 51 yrs)	Mavis alone = 3 times at her home Alice alone = 3 times at her home <i>Total contact = 6 Interviews</i>
Fielding Family	Anna (patient, 68 yrs) Sue (daughter, 45 yrs) Cindy (daughter, 36 yrs)	Anna alone = once at her home Sue alone = 2 times at her home Cindy alone = once at her home <i>Total contact = 4 Interviews Plus 1 hospice ward visit.</i>
Mullins Family	Hugh (patient, 69 yrs) Dot (wife, 76 yrs)	Hugh & Dot jointly = 3 times at their home <i>Total contact = 3 Interviews Plus 1 hospital visit. Also one visit to Hugh & Dot's home to discuss the research process prior to first interview</i>
Blake Family	Mary (patient, 51 yrs) Ellen (daughter, 25 yrs)	Mary & Ellen jointly (with Ellen leaving mid-way through one interview) = 2 times at their home Ellen alone = once at home <i>Total contact = 3 Interviews</i>
TOTAL = 9 families	TOTAL = 23 participants	TOTAL = 39 interviews

Appendix 3: Ward Plan

Patio Area

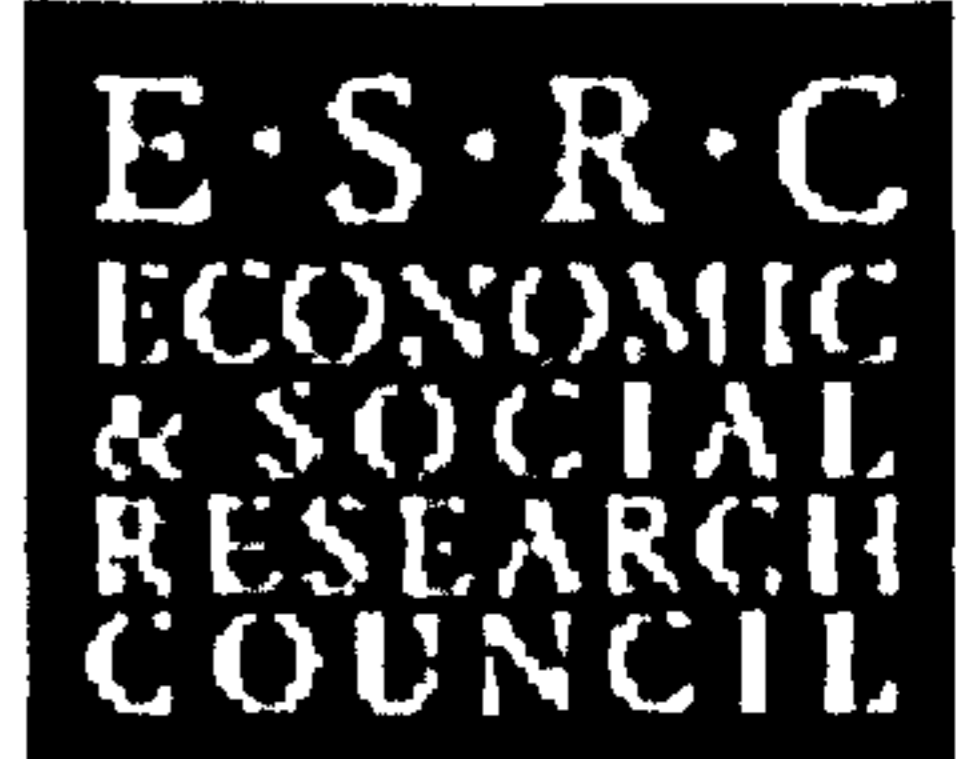




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Appendix 4a: Cover letter
for patients (interviews)

Department
Of Sociological
Studies.



Julie Ellis
Postgraduate Research Student
University of Sheffield
Department of Sociological Studies
Elmfield, Northumberland Road
Sheffield S10 2TU
Tel: **** *
Email: j.c.ellis@sheffield.ac.uk

A Research Project: Everyday Family Life during Life-threatening Illness

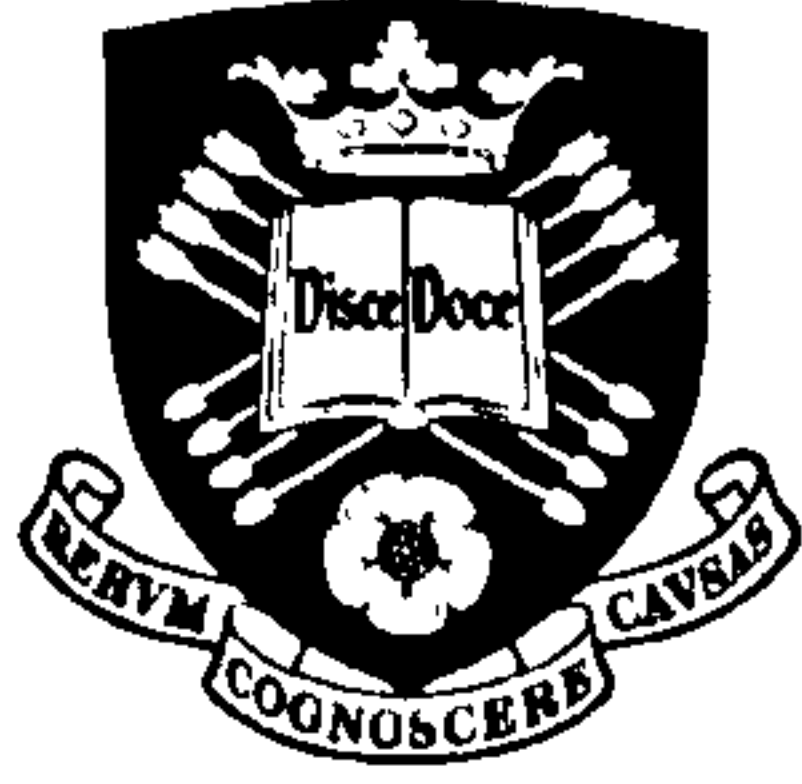
Hello,

You have been given this information sheet today as a way of inviting you and your family to consider taking part in a research project. If you could spare the time to read it, I would be most grateful.

You will notice that I have included a few information sheets in this pack. The other sheets are for people in your close family. I would be very interested to speak with you and other members of your family about what life is like for you all at the moment. Please give these information sheets to relatives who you think might want to take part. It doesn't matter if you don't all live in the same house, or if there is just one other person - like your partner for example - who wants to be involved. As long as you are in regular contact with the other person, or people, and you all belong to the same family, I would very much like to talk to you. Please also note that I would really like to speak to children and young people as well.

I realise that you might have a lot going on in your life right now, so I would like to say thank you for taking the time to read this information. If you think you can help, it would be great to meet you. Thank you and best wishes,

Julie



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**Appendix 4b: Cover letter for
family members (interviews)**

Department
Of Sociological
Studies.



Julie Ellis
Postgraduate Research Student
The University of Sheffield
Department of Sociological Studies
Elmfield, Northumberland Road
Sheffield, S10 2TU

Telephone: *****
Fax: *****
Email: j.c.ellis@sheffield.ac.uk

A Research Project: Everyday Family Life during Life-threatening Illness

Hello,

You have been given this information sheet today as a way of inviting you to consider taking part in a research project. If you could spare the time to read it, I would be most grateful.

You have most probably received this letter and information sheet from a close relative who attends day care at the Hospice. A member of staff at the day unit has approached your family member to see if they and members of your family would like to take part in this research. The project is about how families get on with their everyday lives when someone has a life-threatening illness. I would be very interested to speak with you and other members of your family about what life is like for you all at the moment. Please also note that I would really like to speak to children and young people as well.

I realise that you might have a lot going on in your life right now, so I would like to say thank you for taking the time to read this information. If you think you can help, it would be great to meet you. Thank you and best wishes,

Julie



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Everyday Family Life during Life-threatening Illness

Participant Information Sheet

Hello, this is me →

Image of
me

Thank you for reading this information sheet. It is really important that before you make any decisions about taking part in my project you understand why the research is being done and what you will be asked to do. Reading this information sheet will help you but you can also ask others, including myself for further information before you make a final decision.

This sheet is divided into 2 sections; part 1 contains general information about my project and will give you an idea about what you will have to do if you agree to take part. If you are still interested in learning more about the project after reading part 1 you can read part 2, which goes into more detail about what's involved.

Part 1

What is the research and who is doing it?

I am inviting you and members of your close family to take part in a research project I am carrying out as part of my postgraduate research at the University of Sheffield. I have been involved in hospice work for the last 5 years as a volunteer, although I have now resigned from my voluntary position whilst I complete this research. During my time at the hospice I have become interested in learning more about how families carry on with their lives when someone has a life-threatening illness. I have decided to try and find out about people's experiences and am now doing this research as part of my PhD.

What is the project about?

The project you are being invited to take part in will ask people to describe how their family gets on with their daily family life, over a period of time when someone in the family has a life-threatening or terminal illness.

Why is it being done?

When someone finds out they have a life-threatening condition, life might become very different for the person who is ill and their close family. I am interested to find out how the more routine, everyday aspects of daily family life might change at this time. I think it is important to hear people's stories,

so services like the hospice can develop a broader understanding of how illness affects families.

Why have you been invited to take part in this project?

If you are a patient at the hospice: I have asked members of the day unit team to approach patients like yourself who are currently attending the day unit, to see if anyone would like to take part in my research. The day unit team may have selected you because you have close family members supporting you at this time, which is ideal for my research because I need to talk to people from the same family about their experiences, rather than just individuals. They may also feel that your family circumstances are particularly suitable for the research.

If you are a close relative of a patient at the hospice: You have been approached to take part because you have a close family member who is attending day unit and they have shown an interest in taking part in this research. They may have passed this information on to you, after receiving it from day unit staff.

Your family is not the only family who has been approached. I am hoping to talk to people from, approximately 5 different families and I will also be observing other families on the hospice inpatient ward. At this moment in time I do not know which patients and families the day unit staff have asked to take part in my research. I will only find out that you have been approached if you decide you would like to be involved.

Do I have to take part?

No! It is completely your decision and no one will mind if you decide not to take part - you do not even have to give a reason. As I have said, the day unit staff will not tell me that they have given you this information unless you decide to take part.

Although the hospice is helping me with the research, it is my own project which the University of Sheffield is responsible for; it is **NOT** a hospice project. Therefore no one at the hospice is relying on you to take part, and whether you say yes or no, the care you, or your relative receives from the hospice will not change in any way.

What will I have to do if I say yes?

I would like to get to know you and your close family quite well so I can try and understand how you have been affected as individuals, but also as a family. To do this I will ask you and the other members of your family who are taking part, to meet with me on 3 occasions over a period of 5 months¹⁰². When we meet we can chat informally and you can tell me about your experiences and your daily life. If it is okay with you I would like to visit you at your home to do the sessions, so I can see for myself a place which is often very important for family life. However, if you would prefer to meet at the hospice or the university, this is absolutely fine and I will reimburse you for your travel costs.

Although I will generally be interviewing people individually, if for example you would prefer me to interview you and your partner together, then this can be arranged. Also if you are the patient and you do not want to be

¹⁰² As I discuss in Chapter 3, when I actually conducted the interviews, the number of interviews and length of time over which I was involved with families varied for different reasons which I discuss in this chapter.

involved with the research but you have someone in your family who does, then if it's okay with you, I'd be happy to speak with them even though you are not taking part in the interviews.

Our sessions can be as long or as short as you want. I am quite prepared to go with the flow on the day, but as a general rule I would expect them to last about 1 and a half hours. Before we begin the session I will spend some time giving you more details about the research and what will happen to the information you give me. Then, before we begin the first interview, I'll ask you to sign a consent form to say you are still happy to take part and give you a copy of this to keep. **Please be aware that at this stage or at any time, you can still withdraw from the project without giving a reason.**

If it is okay with you, I may also call you on the phone in between our meetings to chat for a few minutes so I can keep up to date with your day-to-day life. If you do not want me to make phone contact it is fine, we can just do the informal interviews.

All interviews will remain confidential, and no personal details will be given to anyone. I will not tell the day unit staff or other members of your family what you have talked to me about. All names will be changed before any findings are released, unless you wish to keep your real name; but this is something we can talk about in more detail if you decide to take part.

Is there anything for me to be worried about if I take part?

Because this may be a stressful time for you right now, I would like you to think carefully before agreeing to take part in this project. When I chat with you I am not going to be looking for 'right' or 'wrong' answers and I hope that our sessions will feel relaxed. However there is a chance we might get talking about things which are difficult for you, and could make you feel upset. I would not expect you to carry on with the session if this happened and I would ask you whether you would like to end the interview or to talk about something else. It is not a problem, however, if you do get upset while we are together, and it will not embarrass me or make me feel uncomfortable.

What are the possible benefits of taking part?

Some research participants have said that taking part in interviews can be a positive experience and that talking about things sometimes made them feel better. However I can't promise that this will be the case for you, or that you will benefit directly from taking part. However it is hoped that your help with this research will provide information which will benefit other families in the future.

What do I do next?

If you are happy to take part in the research, please complete the forms enclosed in this pack. I have included a few forms but if you need more, see ***** at the day unit who can give you some. **Remember** you don't all have to live together, but you do need to be members of the same family and keep regular contact. When everyone has completed their reply forms you can return them all together using the envelope provided, or you can send them back separately; there are enough envelopes for each reply form and **you do not need a stamp**. If it's easier you can also bring them to the day unit and give them to *****, who will pass them on to me. I will then contact you to arrange a time and date when we can meet for our first session.

If you do not want to be involved in the research, you don't have to do anything with the reply slips.

Thanks for reading so far. If you are still interested, please now read part 2 which gives you more detail.

Part 2

What will happen when the research project comes to an end?

When the study has finished I will look at all the information I have gained from talking to people like you. I will then write a report in everyday language about the findings and I can send you a copy. I will submit a piece of academic work based on what I find out for my PhD, and I will also use some of the information to write articles to be published in academic journals and to give presentations to hospice staff and other researchers.

What happens if there is a problem or something goes wrong?

This is very unlikely. But if you do feel unhappy about anything to do with the research, I will be happy to talk to you about your concerns at any time. You can also stop taking part at any time.

What can I do if I am unhappy about something to do with the study?

In the unlikely event that you are harmed by taking part in this research, there are no special compensation arrangements. If however you are harmed as a result of someone's negligence, then you do have grounds for legal action, but you may have to pay for it. If you would like to complain or have any concerns about the way you have been approached or treated during the course of this study, you can contact the local NHS advice service. There is a leaflet enclosed in this information pack.

Also, if you have any complaints or concerns, please contact Julie Ellis on a number at the end of this information sheet. If you are not happy with the response you receive, then you can contact my supervisor Professor Jenny Hockey by telephone on **** * or email her at *****

Who will know that I have taken part?

Obviously some members of your family will know that you have been involved with the research. Also, especially if you are a patient, members of the day unit team will be aware that you have participated; although what you choose to tell me during the research will remain private and between us. The only time I will take action and speak to another appropriate person about you, is if I am really concerned for your safety or the safety of another person. An example would be if you were very distressed when we spoke and talked about feeling suicidal. I would tell you about my concerns before I spoke to anyone else, and my only reasons for doing this would be to help you or another person.

Any notes or tapes will have your name and address removed so you cannot be recognised from them. All material relating to the project that is kept on a computer will be password protected; only I will know the password. All personal information which relates to participants such as addresses and signed consent forms, will be kept locked away securely at

the University and only I will have access to the information. The information collected during the project will be destroyed after 3 years¹⁰³.

Often when researchers write up their work, they like to include quotes to show what people have told them. If I want to write about something you had said to me in any future publications no one will know it is you because I will refer to you using a false name. I will refer to the hospice by a false name as well.

Who is organising and funding the research?

I am the only person working on this research project, but I do have two experienced supervisors, Professor Jenny Hockey and Professor Allison James at the University of Sheffield, who are available to advise and support me. I will work closely with them and we will talk about the project, but even they will not know who you are or have access to any of your personal details, such as your address.

The organisation funding the research is the Economic and Social Research Council (ESRC).

Who has reviewed the project and said it is okay?

Before any research goes ahead it is checked by an Ethics Committee. They make sure that the research is okay to do and that participants will be treated with care and respect. The project has been checked and approved by the ***** Ethics Committee. Throughout the years that I will be working on the research both the University and the NHS governance departments can ask to see my work and will monitor my progress.

Who can I contact for further information about taking part?

If you would like to contact me to discuss anything to do with this research then please do not hesitate to do so - my contact details are as follows:

Julie Ellis
Postgraduate Research Student
University of Sheffield
Department of Sociological Studies
Elmfield, Northumberland Road
Sheffield, S10 2TU
Tel: (leave a message on) ***** or call *****
Email: j.c.ellis@sheffield.ac.uk

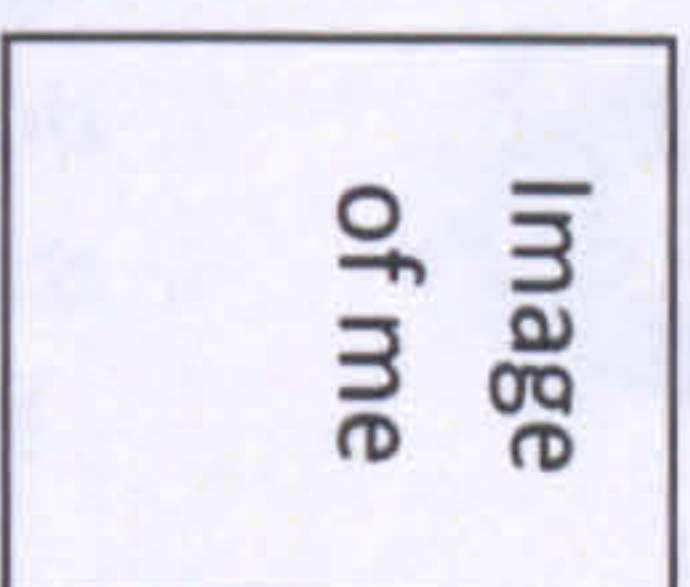
Or you can also contact the local NHS advice service for independent advice about taking part. A contact number is on the leaflet enclosed.

Many thanks for reading this - if you have any questions please ask.

¹⁰³ Since the issue of this information sheet, consent has been gained to keep the anonymised interview transcripts for future research-related work and beyond the 3 years stated here (see appendix 6c). It was clarified however that personal details will be destroyed 3 years after the submission of this thesis.

Who am I?

My name is Julie Ellis and I am doing some research at the University of Sheffield. This is me:

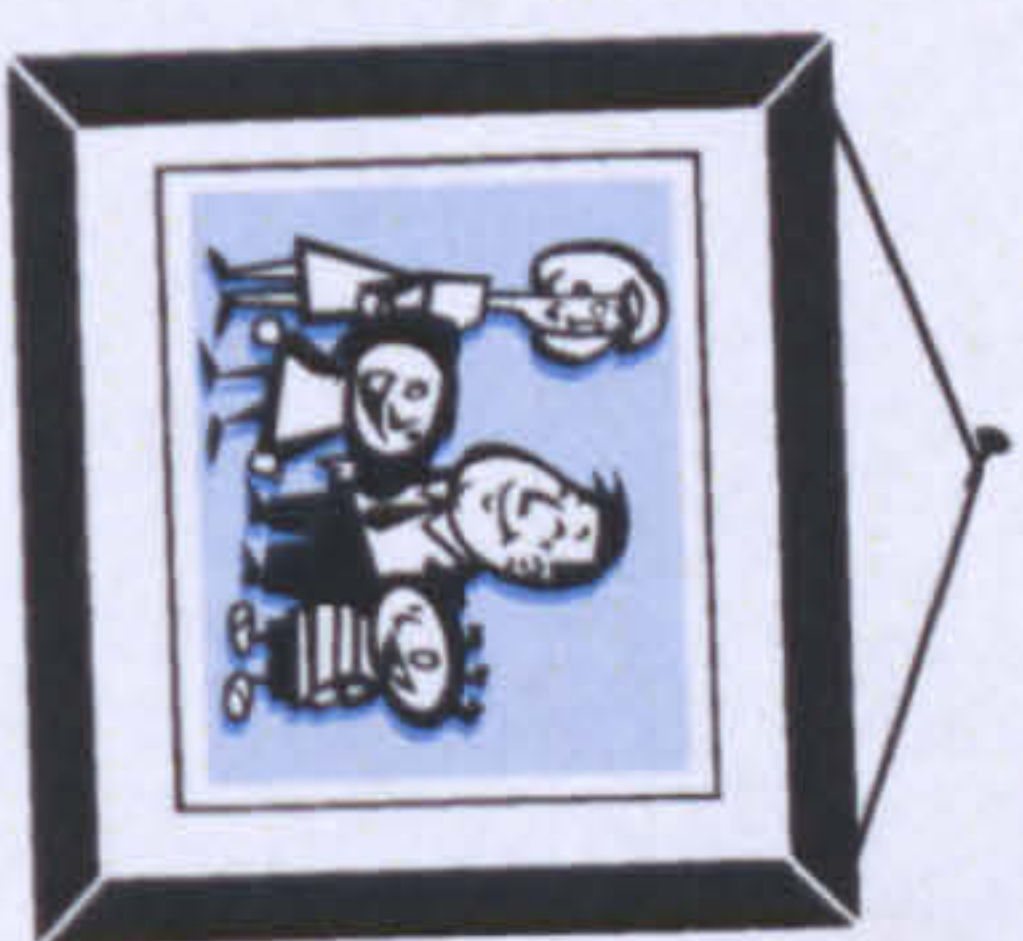


What's research?

Research is something that we do to find out answers to important questions. Researchers talk to people to find things out and then they write about this in books and reports for other researchers and people to read. Research helps us to learn about things.

What's Julie's research about?

I am doing some research with families because I want to learn about what it's like having someone in the family who has an illness. You have been chosen because someone in your family is poorly and they go to the hospice sometimes. I am going to be



speaking to different people from different families and then I am going to write a report about what I find out. I am doing this because I want to help places like the hospice to understand how to help families like yours when someone is poorly.

Can you help me?

I would like to talk to you about what your life is like and what kind of things you do in your family. I'd be really interested to hear about what you have to say. There are no right and wrong answers. As well as talking I have some drawing and craft activities for us to do. It's up to you if you want to meet with me - it doesn't matter if you don't want to, no one will be upset. If you

do take part I would like to visit you twice either at your house, the hospice or the University.

Will taking part help me?

You might enjoy being able to tell me about your family, and this may make you feel good. But you will not get anything for taking part, although you will be able to keep the crafts you make. You might also help other children and families like yours by taking part in my project because I can learn from what you tell me.



What happens after we have finished?

I will put what you have said in a report for other people to read, but you can choose me a pretend name so no one will know who you are or what you have said.

What if something goes wrong?

I don't think anything will go wrong. But if you do feel upset or worried about the research you can tell someone in your family and we can all talk about it to try and make it better. Also it is really, really, really important that you remember that you can stop doing the research at any time and no one will be cross with you. You don't have to talk to me about anything you don't want to.

What if you don't want to join in any more?

If you want to stop joining in at any time just tell someone and you can stop doing the research straight away. You could tell me or you could also tell someone in your family and they could ring me up and tell me. You don't have to say why you don't want to do it anymore - and remember no one will be cross or upset.



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Will anyone else know I've joined in?

Only your parents, some people in your family and a couple of people who work at the hospice will know. Everything that you tell me will be private. I won't tell your mum and dad what you say unless you tell me something that makes me feel worried about you then I would want to talk to someone so we could try and help you.

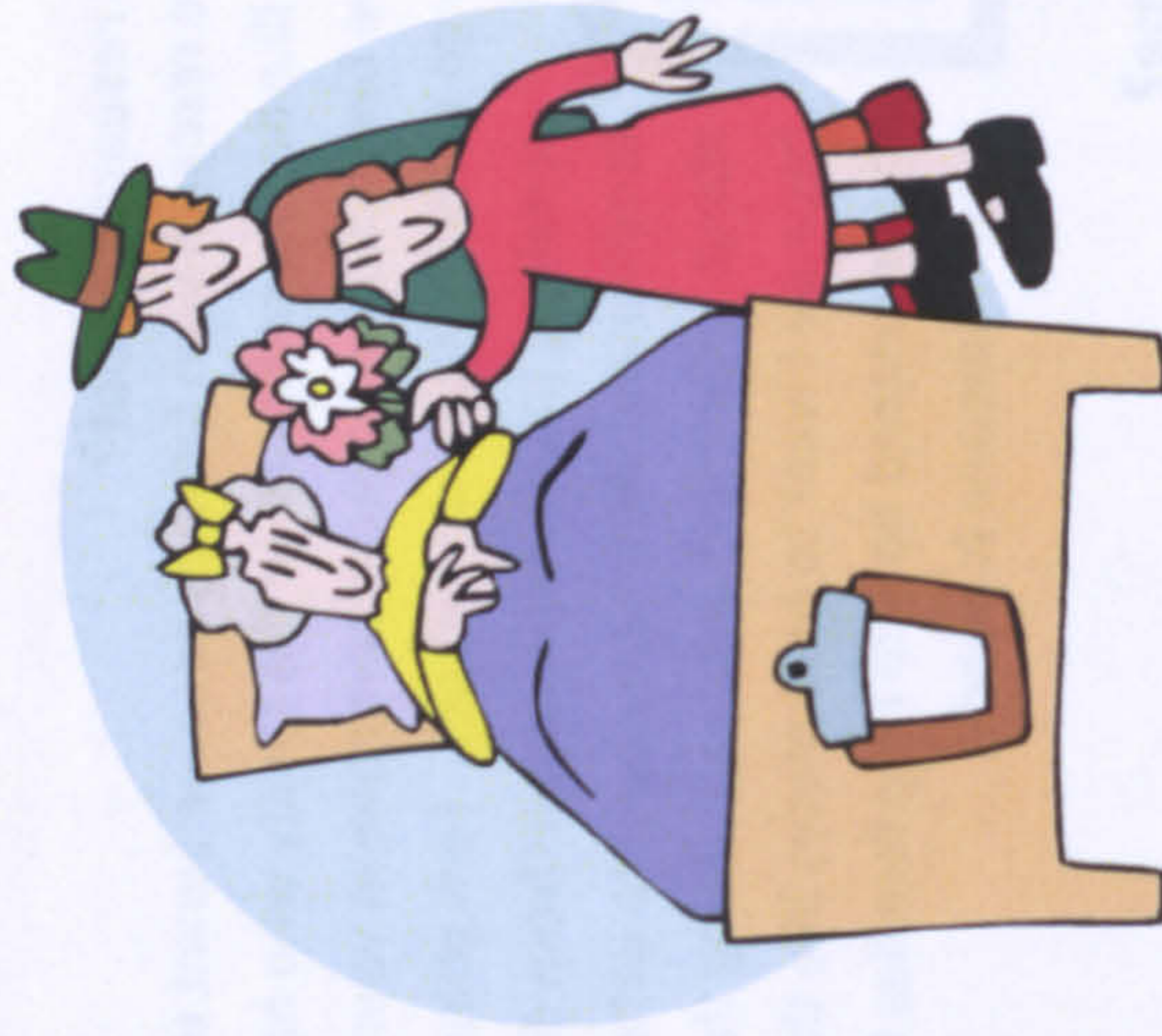
What do I need to do now?

In your information pack there is a reply slip for you and one of your parents to fill in. If you would like to join in write your name, age and telephone number on the form and then give it to your parents to fill in. Ask them to send it to the hospice. I will then phone you and your parents to make a time for us to meet. If you have changed your mind and you don't want to join in, it doesn't matter.

You might want to ask me some more questions before you say yes. If you do you can ask me on the phone, send me a text or an email. Call Julie Ellis on ***** or my mobile number is *****. If you are calling on your mobile and don't have much credit I can phone you back. My email is: j.c.ellis@sheffield.ac.uk

Or if you would rather talk to someone else before you decide, you can ask an adult to help you ring a special NHS advice service which can help you think about whether you want to join in. There is a leaflet which tells you all about them in this information pack.

Thanks for reading this. I hope to see you soon.



Information Booklet

Introduction

Thank you for meeting me today. *Check*: are you still happy to be involved with the research?

(Give participant my details card). Suggest they put it in a safe and/or prominent place e.g. notice board, so it can act as a quick point of reference if they need to contact me at anytime).

Points to discuss with participant prior to signing Consent Form¹⁰⁴:

- I will be recording the interview, is this okay? *(Show participant device)*. It is just so I have something to help me remember more accurately what we talk about today. It also means I don't have to make loads of notes whilst we are chatting. Don't worry - I won't be playing the recordings back to anyone else, only I will hear them.
- What we talk about today will remain confidential - I won't be sharing any details with other members of your family, or the hospice staff. However if you do mention, or I witness something that makes me feel really worried about your safety, or the safety of someone else, I will have to share this with an appropriate person so they can try and support you. In the unlikely event that I need to take this action I will tell you first. The kind of thing I am talking about is if you said that you were feeling suicidal or you told me the name of a child who you believed was being abused.
- Also please bear in mind that I am going to be speaking to other members of your family. Although I will anonymise all the material and therefore it is unlikely to happen, it is possible that someone in your family might still be able to recognise something you have said. Please take this into account.
- If there is anything you don't want to talk about just say so. This interview is about me having the opportunity to understand what life is like for you and your family at this time - you are the expert, and to a large extent I hope to be following your lead in terms of what we talk about today. If however we do stray onto a subject that you don't want to discuss now or at any other time during the research, then please don't be afraid to tell me and we can talk about something else.
- We can stop whenever you like. If you want to take a break, feel upset or unwell; please just let me know and we can finish the session.
- You will not be named in anything I write about this research. So that I can protect your identity I would like you to choose a false name for me

¹⁰⁴ The guidance in this document was prepared prior to entering the field and represents an 'ideal type' interview situation. Thus as I noted in Chapter 3, the practicalities of being in the field meant that I had to be flexible in how I went about securing informed consent - though I strived to keep as close to the protocol documented here as possible.

Appendix 5a: Interview guide - first session

by which you would like to be known¹⁰⁵. (*Show participant an example of a qualitative research report where author uses participant quotations, and explain how their words might be represented in a similar way*).

Signing Consent Form

(Explain to participant why using a written agreement. Read through consent form with participant, asking them to initial each box after checking they; a) understand the statement, b) they agree with it, and, c) they have had opportunity to ask questions).

Does this all sound okay? Would you like to ask me to explain anything, or do you have any questions?

Ask participant to sign 2 identical forms - 1 which I take away, the other is a copy for the participant to keep.

Explain - I will not ask you to sign one another one of these. What you have agreed to today will apply to the entire research process. However I will remind you of key points each time we meet, because it is very important that you are happy with the research and feel informed. If as the project proceeds, you have any questions or want something clarifying, you have my contact details on the information card I gave you today and on the top of the consent letter - please call me or ask me when I next see you.

Begin interview

'My Family Story' and 'People in family' exercises¹⁰⁶.

So I can get an idea of who is who in your family and some of the important things that have happened in your family life, I will begin by asking you to tell me the story of your family so far, what its like at the moment and how you see it in the future. We can use timelines to help us note down what you feel has been/ is/ will be important, and there is a family diagram which you could use to tell me about who is in your family and how they are related to you.

(Probes to be used)

1) The past

¹⁰⁵ Only one participant did this. The others were happy for me to choose a name and did not seem to consider this important, or I chose the names automatically. I did this because sometimes due to how an interview unfolded I did not get a suitable chance to ask. Sometimes I also felt that it was not appropriate - 'trivial' perhaps given the issues we were discussing and I was mindful of not making the process feel like a 'game' somehow.

¹⁰⁶ Please note that after my first couple of interviews it became clear that participants were happy to talk about their family and the illness openly. Therefore I did not use the participatory exercises in any of the interviews with adult participants - as it did not feel appropriate. I did use some exercises with Joanna (family 5) in a joint interview with her mother Claudia. However, these were never fully completed and therefore did not form part of the project data set. They were more a way of making the interview feel less formal and more inclusive for Joanna.

Appendix 5a: Interview guide - first session

- What stands out for you as important things /milestones that have helped to make your family how it is today?
- What has the idea of being a family meant to you over the years?
- Who have been important people in your family over these years?

2) The present

- What is important about your family life today? E.g. what events are happening?
- What does being a family mean to you at the moment? Has this changed at all from how you used to think about being a family or having a family life?
- Can you tell me about the part that your family/ being in a family plays in your everyday life?
- Who would you say is 'in' your family? (*Complete 'People in My Family' sheet*).

3) The future

- Is there anything you would like to tell me about your thoughts about your family/ family life for the future?

N.B. The order in which the timelines are completed will be left up to the participant - they can begin wherever they like in their story.

If a participant does not want to complete the tasks, they will be invited to talk about their family story in terms of its past, present and future.

Post Interview - debrief

- Are you feeling okay about what we have talked about?
- If you are still happy to continue taking part, can we arrange a date and time for our next session?
- *Outline what happens next:* 1) Now I am going to go away and type up what I have recorded today. The purpose of the research is to understand what everyday family life is like for families who are experiencing life-threatening illness. 2) Is it okay for me to contact you on the telephone between now and our next interview? I would be ringing to ask how things are so I can get a fully idea of what your life is like day-to-day.
- You can contact me at any time to discuss what we have shared today or if you have any questions about the research.

N.B. If the participant becomes upset or becomes physically unwell I will use the following approaches depending on participant's wishes and circumstances:

- 1) *If participant has another person to provide care and would rather I leave, I will end the session and leave. Later that day I*

Appendix 5a: Interview guide - first session

will make a follow up phone call to check how participant is. Say will ring back in a few days to discuss whether participant wishes to continue involvement with project and check out if participant would like contact details of appropriate support agencies using information I have gathered for a resources pack.

- 2) If the participant is happy for me to do so, I will stay with the participant until they are feeling better and either leave or restart session depending on participant's wishes.*
- 3) If I feel there is reason to be concerned for the physical or mental health of a participant, I will inform the participant of my intention to take appropriate action - e.g. call GP - or contact the hospice to inform them of situation and to get advice.*

N.B. Interviews 2 and 3 will follow the same format.

Introduction

Check: are you still happy to take part? How have you been feeling about being involved in the research since I was last here?

Recap: Can I just check that I understood the things you told me last time? (*I summarise key points took away from the last session and ascertain that my impressions are accurate*).

Consent Reminders (see points on guide for interview 1- appendix 5a)

The Interview

The following areas will all be very relevant to explore with participants during interviews 2 and 3. However the order in which topics are discussed will be flexible and participant led. I will use the key questions (informed by the project's main research questions) to guide the session, and encourage the participants to talk about their lives in response to these broad questions and in relation to the various topic areas listed. Additional areas brought up by participants will also be explored.

Key questions: (*Probe with regard to the topic areas which follow*).

Could you describe a typical, ordinary day in your/ your family's life?

What's changed about family life since you realised you/ your relative had a life threatening-illness?

What are your current, immediate concerns/ considerations about what's going on in your everyday life at this moment? Do you think these are the same as what's going on for other people in your family?

Have you/ your family changed anything in particular to keep family life going in some way since you/ your relative developed a life-threatening illness?

What do you think about your life at the minute?

Appendix 5b: Interview guide - sessions 2 and 3

Topics:

Contact/ relationships

- When you are around other members of your family, what is it that you tend to do together?
- Who do you see, when, and what for?
- Are certain times/ occasions for family things? What are these?
- How would you describe relationships in your family at the moment?
- If you had to say who has what role in your family, or describe the kind of person people are, what would you say? Have these people always seemed like this, or have things changed since you/ your relative became ill?

Routines (*encourage participant to provide details about...*)

- Cooking
- Driving/ getting about
- Shopping
- Housework
- Personal care, inc. medicines, treatments.
- Appointments
- Finances
- Bedtimes
- Paid work or voluntary commitments
- Who does what? When? Why?

Flow of Information

- Who talks to whom?
- What kind of talk?
- What about?
- Nostalgia - stories, 'in' jokes - what are these and when does such collective reminiscing happen?

Appendix 5b: Interview guide - sessions 2 and 3

- Does your family talk about the illness? If so, who talks to whom? What do they say? When does it tend to get talked about?

Home

- Have you changed anything in your home since you/ your relative developed a life-threatening illness - changed any rooms around? Moved items? Had features installed?
- Emotional landscape - how do you feel about your home?
- What is important about your home to you and members of your family? Is it central to your idea of being a family and doing everyday family things? (*If yes*) Could you talk to me about why you think this, and about what some of these family things are that happen in the home?

The hospice

- Does the hospice have anything to do with your family life? If so how?

Leisure/ social time

- Holidays
- Clubs
- Going out to places
- Socialising

Post Interview - debrief

- Are you feeling okay about what we have talked about?
- *If interview 2:* If you are still happy to continue taking part in the project can we arrange a date and time for our final session?
If interview 3: Thank you for your time. What you have shared with me during this research has been valuable and very much appreciated.
- *Outline what happens next:* Now I am going to go away...

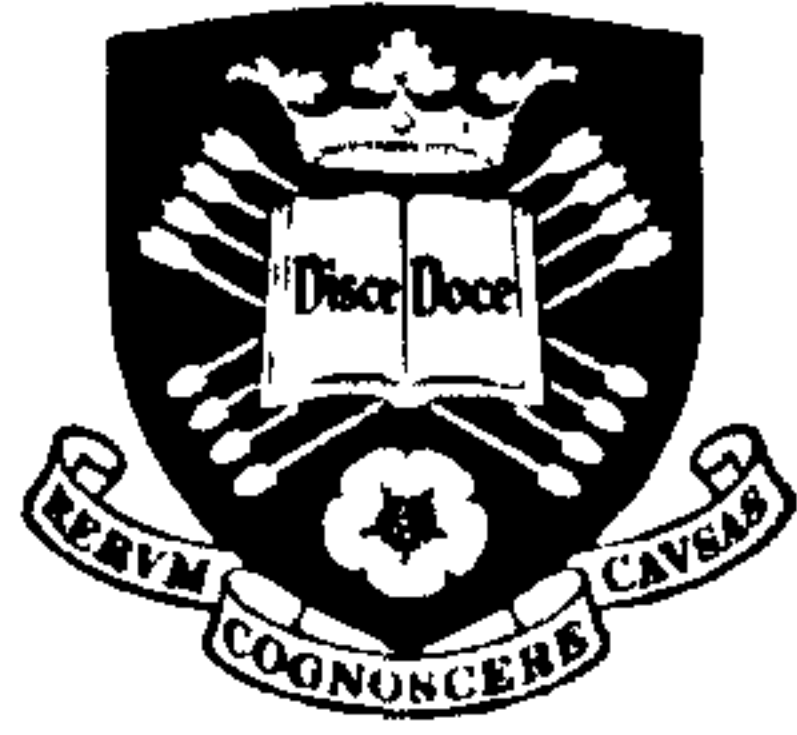
Appendix 5b: Interview guide - sessions 2 and 3

If interview 2: and type out what I've recorded today. The purpose of the research is to understand what everyday family life is like for families who are experiencing life-threatening illness. Is it okay for me to contact you on the telephone between now and our next interview? I would be ringing to ask how things are so I can get a fully idea of what your life is like day-to-day.

If interview 3: and type out what I've recorded today. I will add it to all the other material I have gathered during the research and write a report for my PhD. I will also be writing a report in everyday language - would you like to receive one? The purpose of the research is to understand what everyday family life is like for families who are experiencing life-threatening illness.

- You can contact me at any time to discuss what we have shared today or if you have any questions about the research.

N.B. If the participant becomes upset or becomes physically unwell during the interview I will same approaches mentioned in guide for interview 1 (appendix 5a).



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E·S·R·C
ECONOMIC
& SOCIAL
RESEARCH
COUNCIL

**Appendix 6a: Consent letter
for interviews**

Department Of
Sociological
Studies.

Everyday Family Life during Life-threatening Illness

Participant consent form

Dear _____

Julie Ellis
Postgraduate Research Student
The University of Sheffield
Department of Sociological Studies
Elmfield, Northumberland Road
Sheffield, S10 2TU
Telephone: *****
Fax: *****
Email: j.c.ellis@sheffield.ac.uk

You have been invited to take part in a research project which will find out how everyday family life carries on when someone in the family has a life-threatening illness. This will involve you being interviewed on 3 occasions over the next 5 months. It is expected that each interview will last for an hour and a half and will be like an informal chat. After each interview I will also ask you if I can make a phone call to you between interviews, so we can chat for a short while and you can keep me more up to date with what is happening for you from day-to-day. With your permission the interviews will be tape-recorded so that I can be accurate when I come to write up the research. The purpose of making this agreement is to ensure sure that I use the research material you provide in a way that you are happy with and that you feel fully informed about the research. Please note that I will be using and storing research material such as notes and tapes which relate to you for research and publication purposes only. No names or addresses of anyone taking part in the research will be shared with others, apart from members of the day unit team. I will not however be telling them about what you say to me, they will only be aware that you have taken part.

Taking part in this project is completely voluntary. If you decide at any point that you no longer want to be involved then you can stop taking part. If you do this it will not affect the care which either you, or your relative receive from the hospice. All the information I gather will remain confidential and nothing that could identify you will be kept on a computer. With your permission I will use a false name to refer to you in research publications. All personal information such as addresses, which relates to participants, will be kept locked away at the University. Both my computers at home and at the University are protected with a password so only I can access them.

I also ask your permission at this stage, to keep your contact details for a period of 3 years, just in case I need to contact you or your family in the future to clarify information or to request participation in further research in this area.

If you have any problems or feel you would like to know more, please do get in touch.

Many thanks, Julie

Participant Consent Form¹⁰⁷

Name of participant: _____

Participant Identification Number for this project: _____

Please initial the boxes

1. I confirm that I have read and understand the information sheet for this project and have been able to ask questions.
2. I understand that taking part is voluntary and that I am free to withdraw at any time. I DO NOT have to give a reason and my legal rights and the support I/my relative receive from the hospice will NOT be affected. If I want to stop taking part in the research I can contact Julie directly or speak to a member of staff at the hospice.
3. I understand that if at any point during the interview I feel upset or unwell, I can take a break or stop the interview.
4. I agree that sound recordings can be made of the interviews, and that the purpose for which the material will be used has been explained to me in a way which I have understood.
5. I understand that any information I give will be used for research purposes only, including research publications and reports. I give my permission for my contributions to be used for research-related work and presentations.
6. I understand and am happy with how the researcher will protect my right to confidentiality and anonymity.
7. I understand that everything that is stated here applies to my entire involvement with this research project and on each occasion I am interviewed.
8. I give my permission to be contacted again within a three-year period.
9. I agree to take part in the above research project.

Name of Participant

Date

Signature

Researcher

Date

Signature

¹⁰⁷ Separate - and for some participants this was done retrospectively - consent was gained (using another form - see appendix 6c) to retain the anonymised interview transcripts and to archive them in a qualitative data storage bank. In cases where participants had died, proxy consent was gained from family members.

Use of Data: Participant Consent Form

Name of participant: _____

Participant Identification Number for this project: _____

**Please initial the boxes you
ARE HAPPY to agree to for
your own interviews.**

1. Julie has explained to me that an interview transcript is the typed out version of what me and Julie said during our interviews.
I confirm that I am happy for Julie to keep copies of my interview transcripts once the current research project I have taken part in has ended.
I understand that the transcripts which Julie will keep will be anonymised so that either now or in the future, I will not be able to be identified as the person talking in them.
I understand that Julie may use the information in the transcripts for future research projects and publications.
I am aware that the transcripts will NOT be destroyed 3 years after the project has ended, but all personal information about me, such as Julie's records of my name and address will be.

2. Julie has explained to me that she has been asked by the organisation which has funded her research if they can have copies of the interview transcripts produced during the research project to put in a computer-based archive run by the Economic and Social Data Service (ESDS).
I understand that this will mean that other researchers and teachers can look at interview transcripts which involve me and they can use the information to help them think about their own research and future projects.
I consent to an anonymised version of my interview transcripts to be deposited with this online data storage service and I am happy for them to be put in the archive. However I understand that this might not happen if the transcripts are not suitable.

Name of Participant

Date

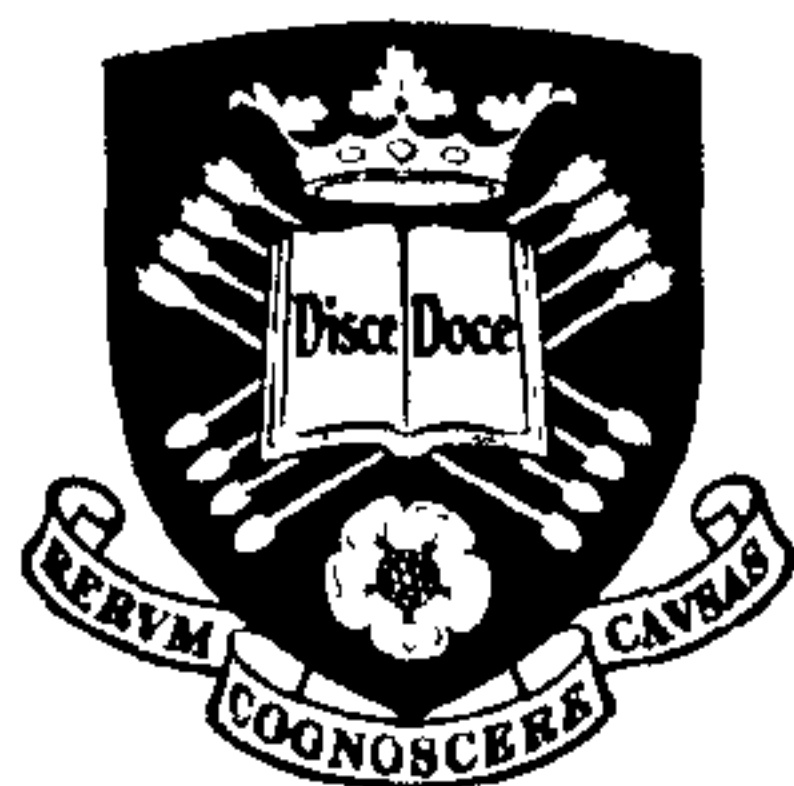
Signature

I also give permission on behalf of [deceased relative/ participant]
For point 1 and point 2.
For just point 1.
For just point 2.
For none of the points.

Researcher

Date

Signature



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Appendix 7a: Cover letter for
families (observation)

Department
Of Sociological
Studies.



Julie Ellis
Postgraduate Research Student
The University of Sheffield
Department of Sociological Studies
Elmfield, Northumberland Road
Sheffield, S10 2TU
Telephone: *****
Fax: *****
Email: j.c.ellis@sheffield.ac.uk

Research Project: Everyday Family Life during Life-threatening Illness

Hello my name is Julie Ellis and I am working on my PhD at the University Of Sheffield. You have been given this information letter about my project because I am on the hospice ward today doing my research. I would really appreciate it if you could take the time to read the information sheet attached to this letter, and contact either me or a member of staff on the ward if you have any questions about this research or would like more information.

If you have children or a young person with you today, could you please make sure they read the special information sheet I have provided for them. There is one for children aged 8-12, and one for young people aged 13-16. If they haven't already got one - please ask the person on reception, or me when you get onto the ward.

Many thanks for your time,
Julie



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Everyday Family Life during Life-threatening Illness

Image of
me

Hello, this is me



Please take a couple of minutes to read through this information sheet, which will let you know why I am present on the hospice ward today. Thank you for your time.

Part 1: To give you first thoughts about the project

What is the research about and who is doing it?

I am carrying out postgraduate research at the University of Sheffield, doing a project about family life when someone has a life-threatening illness. I want to learn about what everyday life is like at this time and what happens when families are visiting someone at the hospice. This research is part of my PhD study.

Why is it being done?

When someone finds out they have a life-threatening condition, life might become different for the person who is ill and their close family. I am interested to understand how the more routine, everyday aspects of daily family life might change at this time. I think it is important to hear people's stories, so services like the hospice can develop a broader understanding of how illness affects families.

Why is Julie on the hospice ward today?

I am getting involved in life on the ward to find out what it is like for patients and their families when a family member has a life-threatening illness. I will be making observations and learning things which will help me understand what family life is like at this time, and the information I gather will be used for my research.

How often will Julie be spending time on the ward?

I started my observations in September 2007 and I will be continuing to visit the ward until March 2008. I will be there at all different times of the day and night and on an average week I will spend 2-3 days, or approximately 10-15 hours doing my research on the ward¹⁰⁸.

Whenever I am on the ward visitors will be given the information you are reading, so everyone knows that I will be around. If you visit again and you

¹⁰⁸ Please note this did not always work out in reality when I was actually conducting the fieldwork and my time was often arranged more fluidly and on a week-to-week basis.

are offered this information, you can just say that you have already seen it - but I do apologise if you are asked on a number of occasions.

What will Julie be doing when she is on the ward?

I will be observing what goes on and making notes about how families spend their time on the ward. I will also be chatting to patients and members of their family if they are happy for me to do so, so I can learn more about what family life is like for you at the moment. You won't see me making loads of notes whilst I am on the ward. I will be writing up what my day has been like when I return to my study. This is so I can spend more time talking to people and getting involved.

Whilst I am on the ward I will be doing the same sort of duties as a volunteer. I am **NOT** however a volunteer and it is important that everyone realises that I am a researcher doing my project. This does not mean that you can't ask me to help with something; just like you might ask any of the other volunteers - I can make a reasonable cup of tea!

Will it matter if I say I don't want to be involved?

No! It is completely your decision and no one will mind if you decide that you do not want me to observe you today or at any time in the future; you don't even have to give a reason. If you say it is okay today, it doesn't mean that you can't say no on another occasion, or equally if you say no today, that you can't ask to be involved in the future.

Although the hospice is helping me with the research, it is my own project which the University of Sheffield is responsible for; it is **NOT** a hospice project. Therefore no one at the hospice is relying on you to take part, and if you say no, the care that your relative receives from the hospice will not change in any way.

Also please be aware that I will also be asking patients if it is okay for me to include them in my observations; if someone says no, then I will not be observing them or any of their family members.

What will I have to do if I say yes?

Nothing! Just do what you would normally. But if you do want to chat with me and I can spend some time with you and your family, then that would be great.

Is there anything for me to be worried about if I take part?

There are no risks to either you or other members of your family being involved in this research. You do not have to talk about anything you don't want to, and **you can ask to stop taking part at any point**. It is not my intention to make anyone feel uncomfortable. If you do, please tell me and if you would rather not take part then, should we happen to pass on the ward, I won't record anything at all about you.

What are the possible benefits of taking part?

Some research participants have said sharing stories about what is going on in their lives can be a positive experience and that talking about things sometimes made them feel better. However I can't promise that this will be the case for you, or that you will benefit directly from taking part. However research like this is an important way of helping other families in the future.

Part 2- More detail. Things you need to know if you take part

What will happen when the research project comes to an end?

When the study has finished I will look at all the information I have gained from observing and talking to families like yours. I will then write a report in everyday language about the findings which will be available in the hospice seminar room around October 2009, and you can ask to have a look at it. I will also submit a piece of academic work based on what I find out for my PhD. Some of the information will be published in academic journals and made available in presentations to hospice staff and other researchers.

What happens if there is a problem or something goes wrong?

This is unlikely to happen. But if you do feel unhappy about anything to do with the research, I will be happy to talk to you about your concerns at anytime. You are also free to stop taking part in the project at anytime.

What can I do if I am unhappy about something to do with the study?

In the unlikely event that you are harmed by taking part in this research, there are no special compensation arrangements. If however you are harmed as a result of someone's negligence, then you do have grounds for legal action, but you may have to pay for it. If you would like to complain or have any concerns about the way you have been approached or treated during the course of this study, you can contact the local NHS advice service. Please ask a member of ward staff for a leaflet which will contain a contact number.

Also, if you do have any complaints or concerns, please contact Julie Ellis on the number at the end of this information sheet. If you are not happy with the response you receive, then you can contact my supervisor at the University, Professor Jenny Hockey by telephone on ***** or email her at *****.

Who will know that I have taken part?

Members of the nursing team on the ward may be aware that you have participated, although what you choose to tell me over the course of the research will remain private and between us.

Any notes I write will have your name removed so you cannot be recognised from them. All the information from the research will be kept securely and anything with personal information on it will be locked away at the University. Material relating to the research will be destroyed after 3 years. Any information which is kept on computers will be password protected. In any publications or research reports I will not refer to the Hospice using its real name - I'll make a false one up, so no one can be identified.

Who is organising and funding the research?

I am the only person working on this research project, but I do have 2 experienced supervisors, Professor Jenny Hockey and Professor Allison James at the University of Sheffield, who are available to advise and support me.

The organisation funding the research is the Economic and Social Research Council (ESRC).

Who has reviewed the project and said it is okay?

Before any research goes ahead it is checked by an Ethics Committee. They make sure that the research is okay to do and that participants will be treated with care and respect. The project has been checked and approved by the ***** Ethics Committee.

Who can I contact for further information about the research?

I am going to be on the ward today; you have seen my picture so if you want to speak with me or to tell me that you don't want to be involved in the project then let me know. If however you would rather not speak to me directly, mention that you don't want to take part to one of the nurses. They will pass this on and I will act in accordance with your wishes.

If you would like to ask or discuss something at a later date about the project, then please do not hesitate to contact me. My details are as follows:

Julie Ellis
Postgraduate Research Student
University of Sheffield
Department of Sociological Studies
Elmfield, Northumberland Road
Sheffield, S10 2TU
Tel: (leave a message on) ***** or ring *****
email: j.c.ellis@sheffield.ac.uk

You can also contact the local NHS advice service for independent advice about taking part. Please ask me or a member of ward staff for a leaflet.

Many thanks for reading this - if you have any questions please ask



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**Appendix 7c: Cover letter
for children and young people
(observation)**

Department
Of Sociological
Studies.



Julie Ellis
Postgraduate Research Student

The University of Sheffield
Department of Sociological Studies
Elmfield, Northumberland Road
Sheffield, S10 2TU

Telephone: *****

Fax: *****

Email: j.c.ellis@sheffield.ac.uk

Research Project: Family Life and Illness

Hello my name is Julie Ellis and I am doing some research at the University of Sheffield. You have been given this information booklet today to tell you about my project because I am on the hospice ward today doing my research. I would be really grateful if you could read the booklet now to see if you want to take part. I'll be on the ward when you get there, so ask me anything you like.

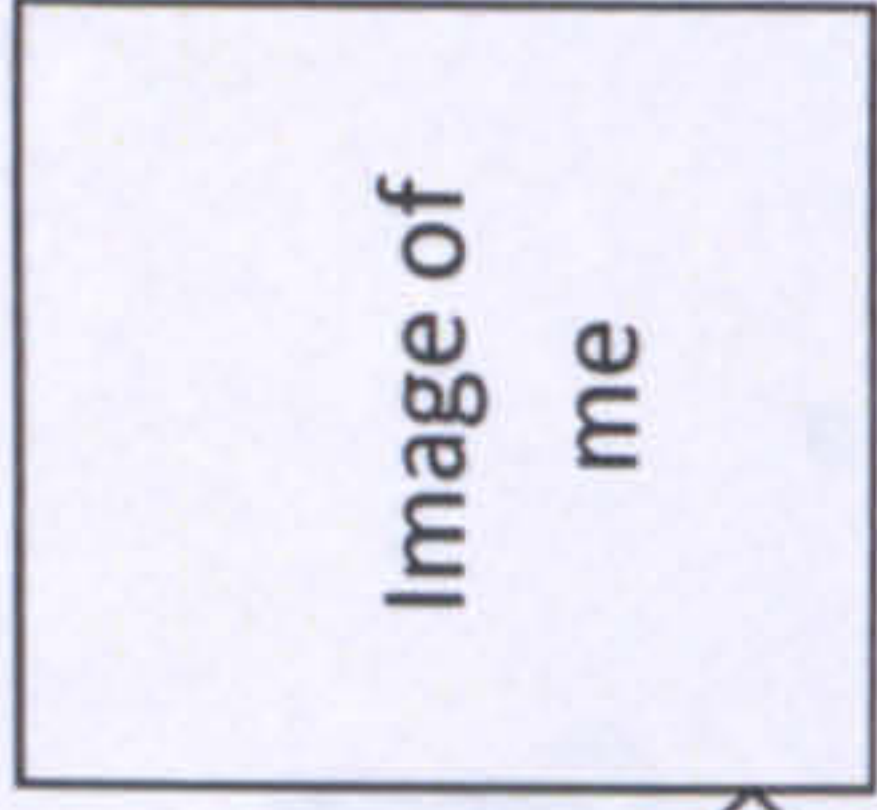
Thanks,

Julie

Appendix 7d: Information booklet for Children (8-12 yrs) (observation)

Who am I?

My name is Julie Ellis and I am doing some research at the University of Sheffield. This is me:



What's research?

Research is something that we do to find out answers to important questions. Researchers talk to people to find things out and then they write about this in books and reports for other researchers and people to read. Research helps us to learn about things.

What's Julie's research about?

I am doing some research about families because I want to learn about what it's like having someone in the family who has an illness.

Why is Julie at the hospice today?

I am going to be speaking too and watching people from different families who come to visit someone in the hospice. I am doing this because I want to help places like the hospice to understand how to help families like yours.

What will Julie be doing at the hospice today?

I will be doing jobs like making drinks and making beds, but I do not work at the hospice. The reason I am at the hospice today is to do my research. This means I will be watching families who come to the hospice to visit people. I will be talking to them and finding out things for my research. When I get home I will write down

what I have learnt and what people have told me and then I will put this in my research report.

Do I have to join in?

No! If you do not want me to watch you or talk to you then tell someone in your family or one of the nurses, and I promise I won't write anything about you in my report. No one will be upset or cross if you don't want to join in with the research.

Will joining in help me?

You won't get anything for taking part in the research. But you might be helping other children and families like yours because this research will tell us important things about what families need to help them.



What happens after?

Everything that I learn about you and your family will be private. I won't tell anyone that I have seen you at the hospice and I won't tell anyone what you have said. When I write about you and your family in my report I won't use your real name - so no one will be able to know that it is you.

What if I feel worried about something or if something goes wrong?

I don't think anything will go wrong. But if you do feel upset or worried about the research you can tell someone in your family and you can stop joining in. It is

Appendix 7d: Information booklet for Children (8-12 yrs) (observation)

really, really, important that you remember that you can stop taking part at any time and no one will be cross with you.

What if I don't want to join in anymore?

If you want to stop joining in at any time just tell someone and you can stop doing the research straight away. You could tell me or you could also tell someone in your family, or a nurse at the hospice. You don't have to say why you don't want to do it anymore - and remember no one will be cross or upset.

What do I do now?

Just keep doing what you do when you come to the hospice to visit. I might come and talk to you, but if you don't want me too then just tell me and that will be fine.

What if I want to talk to Julie in the future?

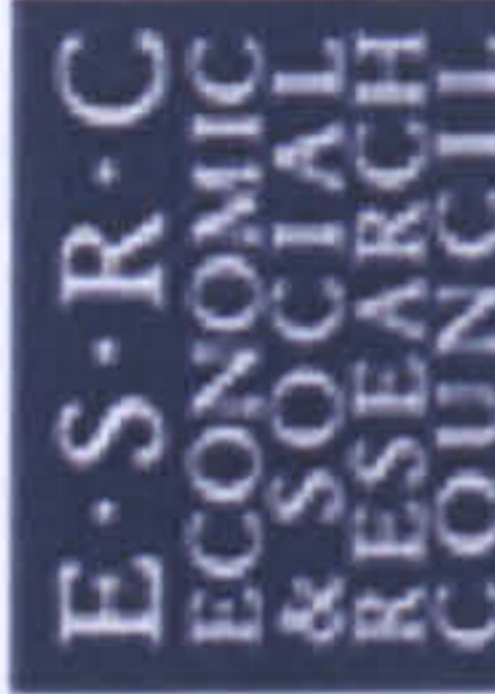
If you ever want to talk to me about the research or to ask me some questions then please get in touch with me. You can call me on the phone or you can send me a text or an email.

Call Julie Ellis on ***** or my mobile number is *****. If you are calling on your mobile and don't have much credit I can phone you back if you like.
My email is: j.c.ellis@sheffield.ac.uk

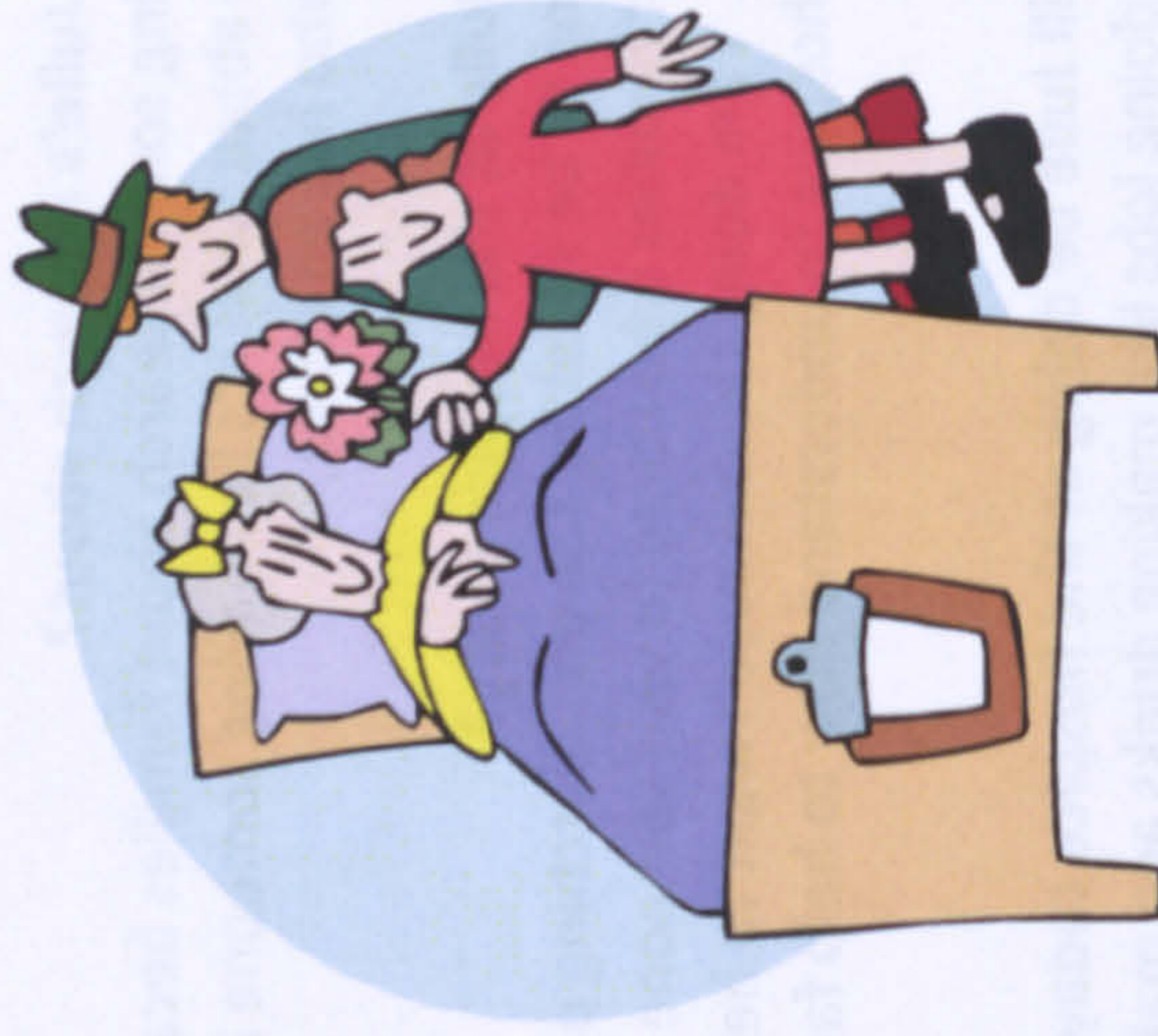
Thanks for reading this. Ask me any questions you have.



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A Research Project about Families and Illness



Information Booklet

Appendix 8: Patient information sheet (observation)



The
University
Of
Sheffield.



About Julie's Project: Everyday Family Life during Life-threatening Illness

Information for Patients

Image of
me

Just a reminder, this is me!

About the project

The research is being carried out as part of my postgraduate studies at the University of Sheffield, and it will help me to achieve my PhD.

It asks how families carry on with their everyday lives when someone has a life-threatening illness. Including how families spend their time when visiting someone at the hospice.

It is NOT a hospice project; it is a University project.

It is being done so services like the hospice can have a broader understanding of how illness affects family life.

What Julie will be doing on the inpatients' ward?

I will be coming to spend time on the ward for 2 or 3 days a week, for a total of 7 months. I will be observing patients and members of their family and noting how they spend their time on the ward. I will also be talking to patients and their families and asking them a few questions. What I learn during this time will be used for my research.

I will do the same duties as a volunteer; but I am NOT a volunteer.

What will Julie do with the information?

Each time I go home after spending time on the ward I will write up notes about my day and what I have learnt. None of the notes will have your name on them; so people will not be able to identify you. All information

to do with the research will be kept securely and anything with personal information on it (such as names) will be locked away at the University.

I will be writing a report in everyday language which will be made available for people visiting the hospice to read. This will be finished around October 2009. I will also submit a large piece of work for my PhD, write journal articles and do presentations. Your name or the name of the hospice will not be used in any of this work.

What you will need to do

Nothing really! Just be yourself and act as you usually would. If you are willing and feel well enough to do so, I would be interested to chat with you about your experiences. You could also invite me to spend some time with you and your family when they come to visit; but this would be up to you.

What will happen if you don't want to be involved?

You can tell me you don't want to be involved at any time. Just because you say yes on one day, this does not mean that you have to take part on another day. Either let me know directly, or speak to one of the nurses if you don't want to be observed.

If you would rather not take part, I understand. Please be assured that I will not observe you or your family for the research. I will however be around to help you, like the volunteers do.

Your care will not be affected in any way and none of the staff will mind if you say no.

Possible benefits of taking part

There are no direct benefits as such, although you might find it a positive experience to talk about your experiences and to know that your voice will be heard. Also the research will provide knowledge to help families in the future.

Possible problems with taking part

This is unlikely. However you can talk to me or a member of nursing staff about any concerns or complaints you have. My contact details and the contact details of my supervisor at the University are below, we would be happy to try and help. You can also contact the local NHS advice service for independent advice about taking part. Please ask me or a member of staff for a leaflet.

Key things to remember

- 1) You are free to tell me to stop observing/ speaking to you at any time.
- 2) Not being involved won't affect your care in any way.
- 3) I am a researcher and NOT a volunteer.
- 4) Your help is appreciated greatly - thank you.

How can I get more information?

- 1) You can ask me now, or whenever I am on the ward.
- 2) Or you can contact me any time, my details are here:

Julie Ellis

Postgraduate Research Student

University of Sheffield

Department of Sociological Studies

Elmfield, Northumberland Road

Sheffield, S10 2TU

Tel: (leave a message on) ***** or ring *****

Email: j.c.ellis@sheffield.ac.uk

- 3) Or you can call the local NHS advice service to get independent advice about taking part. Please ask me or a member of staff for a leaflet.

Thank you for taking the time to read this – please ask any questions you have

WHAT FAMILIES DO

Changing sites of family practices

- Bodies in space, between spaces
- Home & hospice/ medical - practices from each into other & displacement of practices
- Getting out/ being in - staying/ leaving - being with/ not with
- Visiting experience *later some data collapsed into other relevant codes*
- Making absent present and/ or displaying family

Negotiating and maintaining family practices

- Doing day-to-day living *later collapsed into doing routine*
- Importance of doing routine (inc. being out of routine)
- Something special (inc. planning for)
- Death and/or after death (inc. planning for)
- (Re) negotiating life course plans & expectations

Food and eating practices

- Identity
- Tension/ conflict/ power & powerlessness
- Routine & joining in *later collapsed into togetherness*
- Togetherness
- Wellness/ sickness
- As Treat

WHAT FAMILIES THINK ABOUT/ ARE CONCERNED WITH

Time

- Lost & imagined lost times
- No time
- Quality time & spending time
- Waiting/ stuckness

Uncertainty

- The condition - (bodily - disease progression/symptoms/pain/ medications)
- Death & dying
- How life will carry on or be

Thinking about the everyday

- Family ways - knowledge & stories (inc. post-death interviews & mundane remembering)
- Routines, mundane and daily life
- Mundane reflected on (recognised as important - everyday more consciously experienced)
- Illness cues (noting day-to-day)

WHAT FAMILIES FEEL/ HOW RESPONDING

Feelings between people

- Indirectness, silence and gaps
- Negotiating who/ what to tell & talk about (can inc. openness)
- Frustration and/ or tension in relations - e.g. managing expectations
- Closeness

Pragmatism/ acceptance

- Stoicism
- Humour
- Spiritual/ religious belief

Continuity/ change

- Relationships
- Routines/ daily life
- Outlook/ self
- Bodies (how affect what can do as well as material changes)

WARD SPECIFIC - (interaction between emotional & mundane elements)

Life of the ward

Dying on the ward - (inc. emotional & mundane landscape & moments)

Professional's perceptions of families and appropriateness

INTERVIEWEES IN CONTEXT - (interaction between emotional & mundane elements)

- Embodied interaction between family
- Emotional & mundane landscapes & moments

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