Reading and Writing Chronic Illness, 1990-2012:
Ethics and Aesthetics at Work

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Abstract

This thesis is about autobiographical and fictional accounts of chronic illness professionally published between 1990 and 2012. It begins with a survey of popular and critical thinking about illness accounts, in which I show how both the medical humanities and literary studies have placed restrictions on what these accounts can mean, and thus on the kinds of cultural work they can do: restrictions that frequently belie the complexity of the aesthetics and ethics at work in many of the texts considered in this thesis. I build on this claim through close reading of a cross-section of contemporary illness accounts in which I flag up the presence of aesthetic elements distinct to the literary—including aspects of imagery, form, symbolic structure, address, and so on—, and show how these elements work not just to underscore the informative content of these illness accounts, but also to create new patterns of meaning, new networks of relation, and new modes of engagement.

Though this project focuses on the contemporary, Virginia Woolf’s essay *On Being Ill* (1926) acts as its theoretical nucleus. In chapter 2, I show how *On Being Ill* provides a productive framework within which to explore the relationship between illness, literary aesthetics, and ethics. I also tease out the themes that are to define the chapters that follow, for, as Woolf demonstrates, at stake in the representation of the embodied self and the sensations it experiences are issues such as the referentiality of language and of fiction; the workings of metaphor and allegory; and the possibilities and limitations of the discursive sediment that accrues around words, images, and narrative tropes. In chapter 3, I explore this latter issue in a study of the construction of the narrative self and of the body in four autoethnographies by women academics. In chapter 4, I look at the representational experiments that Hilary Mantel and Paul West undertake in their memoirs as they seek to describe the physical and psychological effects of illness. Finally, in chapter 5 I consider how two South African fictions of illness—J. M. Coetzee’s *Age of Iron* (1990) and Marlene van Niekerk’s *Agaat* (2006)—provide a valuable case study for thinking about the relationship between illness and allegory in fiction. My conclusion draws these strands together, arguing that illness accounts can contribute not just to our understanding of the illness experience, but to our thinking about the nature of the literary and its participation in the ethical also.
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Author’s Declaration

The work presented in this thesis is my own, and is the product of original research undertaken at the University of York between September 2009 and January 2014. This work has not previously been presented for an award at this, or any other, University. All sources are acknowledged as references.
Introduction

*Every era casts illness in its own image. Society, like the ultimate psychosomatic patient, matches its medical afflictions to its psychological crises; when a disease touches such a visceral chord, it is often because that chord is already resonating.*

Siddhartha Mukherjee (182)

In the late twentieth century, there emerged a public culture of illness quite unlike any seen before: a culture in which personal experience was thrust to the fore, and first-person accounts of living with, through, and beyond illness flourished in a range of media, including life writing, fiction, film, theatre, television drama, and blogs. By the turn of the twenty-first century, the illness account had become well established as a genre—particularly in the field of life writing—and has since shown no sign of disappearing. Instead, it has continued to flourish, buoyed up by growing popular and scholarly interest in the subjective experience of illness, as well as the intersection between medicine and the arts and humanities. As Nancy Mairs—herself an author of several works on her experience of multiple sclerosis—observes, “we’re not talking about a handful of books here. Dozens have poured forth from publishers large and small in the United Kingdom as well as the States. My shelves groan under their weight” (xi).¹

Of course, this culture was not spontaneously generated: accounts of illness and treatment have for a long time circulated within social networks, in the form of personal correspondence and diaries, some of which have been published posthumously or brought to a wider audience through the work of social historians of medicine. Well-known examples from the late eighteenth and early nineteenth centuries include Samuel Johnson’s reports of temporary aphasia (and other ailments) in his letters and journals,² and Frances Burney’s account of the

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¹ The deluge of accounts that Mairs describes here is given quantitative impact in the second edition of Anne Hunsaker Hawkins’s *Reconstructing Illness: Studies in Pathography* (1999), which records that between 1993 and 1997 the number of published autobiographical illness accounts almost doubled (159). This figure has continued to increase into the present day, as a 2012 replication of Hawkins’s 1997 OCLC World Catalogue search and analysis demonstrates.

² See, for example, Critchley (1962).
mastectomy she underwent—without anaesthetic—in a letter to her sister Esther. A more recent illustration of this kind of account can be found in Alice James’s diary, which documents her experiences of mental illness and breast cancer in the late nineteenth century. Sheila Rothman’s 1995 study of tuberculosis narratives in the late nineteenth and early twentieth centuries charts the beginnings of the transition from diaries and personal correspondence to more public accounts, such as those published in sanatorium newsletters, while in Illness and Narrative (2011) Ann Jurecic identifies the precursors of these accounts in professional medical journals and the popular press (Jurecic 5-6). However, though the first half of the twentieth century saw the appearance of personal narratives about illness, medicine, and healthcare in professional medical journals and the popular press, it was not until the second half of the century that first-person illness accounts began to move from the private sphere into the public in large numbers: a movement tightly bound up with cultural and technological shifts such as the democratization of autobiography, the growing influence of so-called “therapy culture,” the mass production of paperbacks, and, more recently, the digital revolution.

What remains surprising is that, while in recent decades a substantial body of scholarly work has grown up around the burgeoning genre of published illness accounts, the principles and practices of literary studies do not occupy a central role in this scholarship. While valuable literary readings of life writing and fiction about illness do exist, in general these readings, and the approaches they represent, remain on the periphery of the medical—or “health”—humanities. For, though ostensibly cross-disciplinary in ethos and methods, the field is currently dominated by “a very limited set of influential critics (and works of critical insight) whose own specialisms are not those of the humanities but instead come from the sociological and health

3 As high-profile figures, and themselves biographers—Johnson of “the most eminent English poets” and Burney of her father—is it likely that they anticipated the publication of their letters and journals, including their accounts of illness and treatment. This certainly seems to have crossed Burney’s mind. In her study of Burney’s account, Julia Epstein argues that it was “a more studied text than the usual casually informative, familiar letter,” though she appears to have had no intention of publishing it during her lifetime (137).
4 Covering the period from 1889 to 1892, James’s diary wasn’t published until 1934, with a complete, comprehensively edited version not appearing until 1964.
5 For more on this, see chapter 1 in Jurecic (2012).
6 In this sense, the medical humanities approach to life writing and fiction about illness forms a stark contrast to that found in literary and cultural studies of disability, a field that emerged from the disability rights movement, but which is now well established in its own right.
7 See, for example, Herndl (1993), DeShazer (2005), Diedrich (2007), and Jurecic (2012).
disciplines,” with the result that illness accounts are seen to represent “either ‘data’ to be mined for information-giving patterns or ‘life stories’ which require some form of generic categorisation or typologies,” as Keir Waddington and Martin Willis observe (iv). To this list, we can also add the use of storytelling in therapeutic contexts, and the integration of narrative studies and creative writing into medical education and professional development, which frame illness accounts in relation to ideas of psychological and pedagogical utility.

These interpretive limitations are further compounded by two factors. The first of these is the profoundly presentist worldview that currently holds sway in the medical humanities – a worldview in which the ascendancy of the biomedical model over the course of the twentieth century is seen, through its systematic occlusion of the subjective experience of illness in favour of the medical record, to be the major causal factor in the emergence of the illness account genre. Attempts to categorize illness accounts thus tend to focus on their relation to the representational norms of modern biomedicine, and specifically on whether they resist or reproduce these norms. In doing so, they often overlook the wider contemporary context in which illness accounts exist, as well as the influence that longitudinal patterns of writing and reading illness exert on these accounts.

The second limiting factor lies in the assumption that narrative representations mirror clinical, social, or psychological reality, either mimetically or, in the case of unconscious perceptions and responses, symbolically. This assumption precludes the possibility that, in adapting experience into narrative, those who account for illness might consciously undertake any kind of reflective, interpretive, or representational work, and that this work might have meaning and value. As a result, both the burden and the power of interpreting and evaluating accounts of illness are placed squarely

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8 The biomedical model has its origins in the growth of laboratory sciences—such as bacteriology and pathological anatomy—during the eighteenth and nineteenth centuries, and represents an approach to illness that is “causally specific” and “pathologically based,” in contrast to the “symptom-oriented” approach that had previously held sway (Bury 2-4). This model came to dominate medical thought and practice in the twentieth century, bolstered by a rapid acceleration in medical research and technology, and reached a kind of apotheosis in the century’s middle decades. However, in the late twentieth and early twenty-first centuries this model has been subject to increasing criticism for its failure to account for social, psychological, and environmental factors. This logic drives studies such as Brody (1987), Kleinman (1988), Frank (1995), and the vast majority of Eric Cassell’s body of work, of which *The Nature of Suffering and the Goals of Medicine* (1991) is perhaps best known.
in the hands of scholars and practitioners, rather than those of the person with illness: an arrangement that is more like than unlike that of modern biomedicine.

In its attention to persistent discursive patterns and commitment to thinking about representation as a form of work, the field of literary studies appears to offer a powerful antidote to the limitations of the medical humanities in its current configuration. And yet, literary scholars have for the most part approached illness accounts with a narrow-mindedness similar to that of the medical humanities. This narrow-mindedness is bounded on the one side by an unwillingness to explore alternatives to the tradition of using and interpreting fictional portrayals of illness allegorically—a tradition Susan Sontag calls “metaphoric thinking”—and on the other by a reluctance to take life writing about illness seriously as literature: a reluctance that underpins a group of critical practices based on a “general distrust of affect” and of testimonial writing, and which Ann Jurecic thus describes as “suspicious” (13). The coincidence of these suspicious critical practices and the growth of the medical humanities has resulted in the inadvertent annexation of non-fiction illness accounts by the medical humanities, while the unwillingness of scholars in literary studies to think outside the parameters of metaphoric thinking about illness in fiction not only places unnecessary restrictions on the scope of meaning attributed to fictional accounts of illness, but also overlooks those fictions that do not fit this interpretive mould. Like the medical humanities, then, literary studies also offers a somewhat limited view of the significance of illness accounts and the kinds of cultural work they undertake.

Neither of these approaches is wrong, per se. Illness accounts are often valuable qualitative sources of information about medical practice and patient experience, which can be put to use in pedagogy, professional development, and policy-making. Furthermore, the long tradition of employing illness as a metaphoric device in fiction, as well as a means of developing plot and character, constitutes an important

9 A recent example of this can be found in the work of Kate Granger, a doctor and cancer patient who has documented her illness experience in two self-published books and on a blog. Granger’s observations have instigated some significant, practitioner-led changes in healthcare practice. For example, following a blog post based on Granger’s observation that many staff failed to introduce themselves to her during her time as an in-patient, a voluntary pledge to do so began trending on twitter (under #hellomynnameis) and on Granger’s blog, and several hospital wards have invested in public noticeboards based on the project. For more on this, see <www.drkategranger.wordpress.com>.
part of illness’s discursive history in Anglophone Western cultures – a history that continues to bear on writing and reading illness in the present day. However, the picture of illness accounts that emerges from these approaches is necessarily incomplete, with some areas only crudely sketched out, and others left entirely blank. Crucially, these lacunae not only point to a lack of meaningful interdisciplinary research at the interface of the medical humanities and literary studies, but also—and perhaps more importantly—to the intellectual and methodological limitations of these fields in their current forms.

What this problematic suggests, I argue, is a pressing need for more thorough engagement with the challenges that illness accounts pose to the critical models on which these fields depend. This need is at the crux of my thesis, which seeks to further understanding of how the principles and practices of literary studies can make visible previously overlooked dimensions of the contemporary illness account, and how these accounts can in turn yield valuable insights into the nature of the literary and its participation in the ethical: an aim driven not just by a commitment to the possibilities and limitations of my own field (that of literary studies), but by a desire to articulate these possibilities and limitations for a wider cross-disciplinary audience, as an important step towards the emergence of the kind of meaningful interdisciplinary work that critics such as Waddington and Willis call for. Though the scope of such a project is potentially endless, my particular interest lies in a cluster of illness accounts published between 1990 and 2012 in which the literary in its various forms is not only particularly pronounced, but is staged in ways that strike up powerful resonances with notions of identity, accountability, responsiveness, and recognition: notions that lie, in the wake of Lévinas and his interpreters, lie at the heart of contemporary ethical philosophy.

Consequently, this project takes as its frame of reference a group of book-length, published accounts by British, American, and South African authors written in prose and from a first-person perspective, in which illness not only forms both the motive for writing and the central theme, but is entwined with the act of accounting

10 Though J. M. Coetzee has lived in Australia since 2003, and became a citizen in 2006, Age of Iron—the novel on which I focus in chapter 5—is set in South Africa, and was written when Coetzee still lived in the country.
for the self before others both real and imagined. Illness accounts of this description not only cut across the crude distinction between life writing and fiction, but also range over the entire spectrum of published material, from the lowbrow to the experimental. The texts on which this thesis focuses constitutes a cross-section of these accounts, ranging from autoethnography to experimental fiction. By accident, rather than design, they also fall under the rubric of chronic illness, primarily, I suspect, due to the time frame with which this thesis is concerned—a period in which chronic illness emerged as a major global disease burden—but perhaps also because of the nature of chronic illness itself.

### Defining and Describing the Chronic Illness Experience

Though few histories of chronic illness exist, it is not, of course, an entirely modern phenomenon; nor is it the only kind of illness experienced in the present day. Nevertheless, chronic illness is an increasingly prominent facet of contemporary life, and one that is unlikely to diminish as the population ages and as therapies and interventions are developed that allow people with previously untreatable, aggressive conditions—such as HIV/AIDS and many cancers—to survive for decades. Plenty of evidence exists to suggest that chronic disease is increasing, both in incidence and

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11 In his contribution to the edited collection *Illness in the Academy: A Collection of Pathographies by Academics* (2007), Christopher R. Smit defines autoethnography as a work in which one “uses the same principles of ethnographic writing (i.e., observation, analysis, storytelling, deduction, and theoretical exegesis, etc.), but the lens is turned back on the author rather than on another group or culture” (272). As such, this mode of writing is marked by “shifts between personal anecdotes and reflection, storytelling and analysis,” with the result that “much of the interpretive work is done for the reader” (Smit 272; Myers 7).  
12 Echoing influential medical historians such as Roy Porter and Adrian Wilson, Ian Miller writes that historians of medicine “have often been too cautious” in their engagement with chronic diseases, preferring to focus on more sensational, life-threatening diseases such as smallpox, plague, tuberculosis, and HIV/AIDS (5). Carsten Timmermann makes a similar argument in his contribution to *The Oxford Handbook of the History of Medicine* (2011), where he critiques the emphasis of social and cultural history on epidemic disease before going on to examine the continuities between the contemporary chronic illness experience and nineteenth century accounts of consumption. Literary studies of illness tend to replicate this restricted gaze, producing monographs on cancer, HIV/AIDS, tuberculosis, and so on. However, as G. Thomas Couser points out, this is as much to do with the material available as it is the limitations of the scholarly gaze, since, he argues, “those illnesses that are especially threatening—either because they are common or because they are particularly fraught with cultural significance—tend to provoke relatively large numbers of narratives” (8). In more recent years, this has been counterbalanced to an extent by the focus of literary and cultural disability studies on more chronic conditions and impairments.
However, the array of statistical information on offer does not provide much insight into the lived experience of being chronically ill. What defines chronic illness as an ontological state that exceeds a set of physical signs and symptoms, and what drives people to write and read about it? In answering these questions, much hinges on the distinction between disease, sickness, and illness: the triad of terms used in English to describe human ailment in the late twentieth and early twenty-first centuries. Though in colloquial use these terms are largely interchangeable, in disciplines such as medical sociology, medical anthropology, and philosophy of medicine, they represent three distinct ways of thinking about human ailment (Hofmann 651). Within this framework, disease refers to “a physiological malfunction that results in an actual or potential reduction in physical capacities and/or a reduced life expectancy,” while sickness signifies “a social identity” in which an individual’s “levels of performance with reference to expected social activities…fail to meet social standards” (Twaddle 8, 11). By way of contrast, illness is defined as “a subjectively interpreted undesirable state” in which an individual perceives their bodily functioning and general competence to be inadequate (Twaddle 10).

What happens, though, when we add chronic to these descriptors? As its etymology—from Χρόνος, the personification of time in Ancient Greek literature and culture—suggests, the term is first and foremost a temporal qualifier: it refers to something persistent or recurrent. According to the World Health Organization

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13 Published in The Lancet in 2012, the Global Burden of Disease, Injuries and Risk Factors Study 2010 revealed that, for the first time in recorded history, chronic, non-communicable conditions such as obesity, cardiovascular disease, chronic pain, disabling injury, and mental illness outweighed acute, communicable diseases as the primary cause of morbidity and mortality worldwide, with the result that, though “men and women worldwide have gained slightly more than ten years of life expectancy overall” since 1970, they now “spend more years living with injury and illness” (Lozano et al. 2095; “Global”). In the UK chronic conditions currently account for anywhere between forty and seventy percent of mortality, depending on age. This disease burden is likely to persist, and potentially increase, due to the region’s growing ageing population (Alder et al. passim). Likewise, according to the Center for Disease Control (CDC), in the US approximately seventy percent of deaths are from chronic disease, with approximately 133 million Americans (or almost one in two adults) living with at least one such condition, a quarter of whom experience major limitations in their daily life as a result (“Chronic Diseases”). The outlook in many other nations is similar: according to the World Health Organization (WHO), chronic disease is “by far the leading cause of mortality in the world, representing 63% of all deaths” (“Health Topics”). Neither is the disease burden of chronic conditions restricted to the developed world: again, according to the WHO, ninety percent of premature deaths from chronic disease in 2008 occurred in low- and middle-income countries (“Health Topics”).

14 While the distinction between “disease” and “illness” has been in use since the 1950s, this triad was first introduced in the late 1960s, and has since been subject to both further definition and to critique (Hofmann 651).
WHO, then, chronic diseases are medical conditions characterized by their “long duration and generally slow progression”, and include heart disease, stroke, cancer, chronic respiratory diseases and diabetes (“Chronic Diseases”), whereas chronic sickness reflects an ongoing failure to meet social and cultural norms of well-being, and manifests in phenomena such as long-term absenteeism. What, however, is chronic illness? In spite of the importance of this issue to both medical discussions and everyday life in the present day, thinking about chronic illness remains “extraordinarily vague” (Ishiwata 56). “Does chronic illness refer only to the temporal dimension of illness,” asks philosopher Ryuji Ishiwata, “or is it some species of illness, or type of illness or simply the incurability of illness?” (56). Is it—like chronic disease and most aspects of chronic sickness—an experience that, apart from its long duration and slow progression, is in all other aspects identical to that of its acute form? Or is it something fundamentally different?

In its acute form, illness is typically described in terms of disruption. According to Gay Becker, one of the major sources of this disruption proceeds from the tendency of its physical symptoms to throw into disorder the familiar “flow of bodily experiences” that characterize our daily lives (81). When these symptoms are “transitory and of no great consequence”—a muscle twinge, for example, or a minor headache—“one may within minutes return to one’s habitual world” of bodily absence, as Drew Leder points out in The Absent Body (1990) (79). However, when symptoms endure, a more significant disruption takes place (Leder 79). This disruption is characterised by what Leder calls “a heightened thematization of the body,” in which its aches and pains, its weaknesses and its internal workings come to occupy the forefront of everyday experience — often to the occlusion of all else (81). With acute illnesses lasting for a few days or weeks, this thematization soon recedes into the familiar, automatic flow of everyday experience, in which the body is, for the most part, an “absent presence” (Leder 13). But, when illness turns out to be chronic, persisting for years or even decades, this heightened thematization of the body comes to define everyday experience.

In the case of illnesses that are life-threatening, disabling, or otherwise chronic, this heightened thematization of the body is joined by a sense of ontological disruption and of instability. Arthur Kleinman describes chronic illnesses as subjective states of
experience that “tend to oscillate between periods of exacerbation, when symptoms worsen, to periods of quiescence, when disability is less disruptive” (7). Crucially, Kleinman’s description accommodates states of remission from serious illness, including autoimmune conditions and cancer – states that medical sociologist Arthur W. Frank, who has himself lived with cardiovascular disease and in remission from cancer for over a decade, defines in terms of being “effectively well” without ever considering oneself “cured,” an idea that Eve Kosofsky Sedgwick echoes in her description of remission as “decades and decades of free-fall interpretive panic” (Frank 8; Sedgwick “Queer” 13). As in Kleinman’s definition of chronic illness, then, in Frank’s experience of remission “the foreground and background of sickness and health constantly shade into each other” to create an ongoing sense of instability (9). Genetic and other forms of predictive and diagnostic testing add a further dimension to the illness experience, as Sontag observes when she notes that “with the most up-to-date biomedical testing, it is possible to create a new class of lifetime pariahs, the future ill” (AIDS 33-34). Consequently, though only some of the accounts considered in this thesis attest to the experience of living with conditions that fit the biomedical definition of chronic disease, all describe the experience of being chronically ill: of living in a state of perpetual uncertainty and disruption, both ontological and corporeal.

The experiences of those who spend months, years, even decades in the penumbral state of chronic illness are not only disruptive for the individual and their immediate network of family and friends, but also trouble the two-outcome paradigm that underpins both medical and popular thinking about illness and health in the industrialized West: a paradigm in which illness results either in death, or in full recovery, and which thus has a narrative trajectory of sorts (Smart and Smart 65). More specifically, these experiences also come into conflict—often repeatedly—with the more detailed storylines that, in the late twentieth and early twenty-first centuries, have become entrenched in institutional and popular thinking about illness. These storylines have been documented at length by scholars from a range of disciplinary backgrounds—including Frank (sociology), Couser and Hawkins (literary studies/life writing), and Jackie Stacey (cultural studies)—, whose findings

15 See also Frank’s memoir, At the Will of the Body: Reflections on Illness (1991).
give a sense of the discursive context of accounting for illness at the turn of the twenty-first century. Generally speaking, retrospective illness accounts—ones told from a point of substantial recovery—display a drive to absorb and integrate the illness experience into a “coherent story of success, progress, and movement” (Stacey 8-9). This thrust is most evident in the restitution narrative beloved of modern biomedicine, with its “basic storyline” of “yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again” (Frank 77). An alternative to the restitution trope can be found in the “quest” narrative, a storyline that has proved increasingly popular in the late twentieth and early twenty-first centuries. Frank uses this term to describe a cluster of narrative strands organized around the idea of illness as a journey, including the “automythology” narrative, which revolves around the adage that ‘what doesn’t kill you makes you stronger’;¹⁶ the memoir, or “interrupted autobiography,” which combines the illness story with an account of other events in the author’s life; and the manifesto, a storyline that tends to drive contemporary illness activism (Frank 120). At the other end of the spectrum—and of the two-outcome paradigm—lies what Hawkins describes as a “new ars moriendi,” or “guidebook to the art of dying” (Reconstructing 92-93). David Servan-Schreiber’s Not the Last Goodbye (2011) and Philip Gould’s When I Die: Lessons from the Death Zone (2012) are classic examples of this genre, while Ruth Picardie’s Before I Say Goodbye (1998) and Christopher Hitchen’s Mortality (2012) offer satirical, but no less poignant plays on its conventions.

The lived experience of chronic illness defies these narratives at every turn. With its unpredictable cycles of illness and remission, increased susceptibility to secondary conditions, and changing treatment protocols, the chronic illness experience clashes with ideas of progression and recovery. Conversely, though many people with chronic illness are given a long-term prognosis that ultimately leads to death¹⁷ most—if not all—lack any concrete sense of how and when its various stages might

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¹⁶ The quest narrative is for the most part synonymous with the “hero” narrative that Stacey discusses at length in her illness account-cum-cultural study Teratologies: A Cultural Study of Cancer (1997), while the automythology variant in particular can be aligned with the conversion narrative genre that Hawkins uses as her point of departure in Reconstructing Illness: Studies in Pathography (1999).

¹⁷ Of the accounts considered in this thesis, some illnesses—like Stacey’s cancer—are accompanied by a prognosis that includes the possibility of remission, but also of death. Others—like Mary Felstiner’s rheumatoid arthritis—are not in themselves fatal, but predispose one towards a range of other medical conditions, including osteoporosis and cardiac disease.
unfold, and what the lived experience of this unfolding will feel like, making it
difficult to reconcile the chronic illness experience with the *ars moriendi* trope. And
yet, as the texts considered in this thesis attest, accounting for chronic illness is not
impossible, by any means: such accounts do exist, and are growing both in quantity
and diversity.

Though only a fraction of those who experience illness publish their accounts in
book or digital form, this practice has grown almost exponentially in the late
twentieth and early twenty-first centuries, with the result that the illness memoir is
now an established life writing form in its own right. And, while they often utilize
elements of established illness narratives, contemporary accounts of chronic illness
tend to differ from more conventional illness accounts in a number of ways, leading
Thomas G. Couser to posit that “prolonged, serious, or chronic illnesses and
disabilities may ultimately yield more complex and multidimensional narratives than
acute illnesses” (12). One of the major differences is that while those who survive
acute illnesses with no lasting effects and no threat of recurrence might be able to
“partly absorb” the experience to create a recognizable “before and after” effect—a
common feature of the hero and memoir forms, for example—those with chronic
illness tend to find themselves engaged in an ongoing struggle both with the specific
narrative types that have come to dominate the illness experience in the late
twentieth and early twenty-first centuries, and with narrative as an organizing
concept for lived experience and subjectivity more generally (Stacey 9). In
particular, the conventions of narrative—its demands for coherence, consistency,
causality, closure and so on—prove a major stumbling block in attempts to account
for the chronic illness experience, and it is in part for this reason that I have chosen
to refer to the texts considered in this thesis as illness accounts, rather than illness
narratives.

**Literary Aesthetics and the Ethical: Methodological and Theoretical
Considerations**

In my reading of chronic illness accounts, I cover ground that has already been tilled
by scholars in a range of disciplines, from sociology to philosophy to literary studies.
Though my own approach draws on this rich seam of work where appropriate, one
study in particular provides the foundation on which it stands: Virginia Woolf’s short essay *On Being Ill* (1926). This piece might at first seem out of place, given the period on which this thesis focuses, and the contemporary nature of the theoretical framework described thus far. However, in spite of the changes in the landscape of illness that have taken place since its publication in 1926, Woolf’s essay remains remarkably relevant to the present day, both in its call to attend to the relationship between illness and literature, and in the practices of representation and interpretation it demonstrates and describes. Alongside the survey of the key critical metanarratives that underpin thinking about writing and reading illness at the turn of the twenty-first century, my exploration of Woolf’s thinking about illness and literature in chapter 2 of this thesis forms the springboard for my close readings of contemporary illness accounts in chapters 3 to 5. Before moving onto these chapters, however, I want first to conclude this introduction with a brief description of how I use the terms ‘aesthetics’ and ‘ethics’ in this thesis, followed by an overview of the project as a whole, including its methods, structure, and key themes.

Both historically and in the present day, the meanings of the terms ‘aesthetics’ and ‘ethics’ in relation to the literary are highly contested, and though my use of these terms is developed in greater detail in the chapters that follow, I want at this point briefly to lay my cards and allegiances on the table. In thumbnail, my use of the term “aesthetics” in the context of illness accounts is not allied to the notions of beauty and truth with which the aesthetic is traditionally associated, but instead signifies a dimension of writing and of the printed text that interacts with, but is distinct from, the information it contains. This dimension consists in elements of representation such as imagery, temporality, address, metaphor, form, symbolic structure, style, and so on. Though not necessarily specific to verbal expression nor to the text as artefact, these elements take on particular kinds of meaning and power within the context of the written work: forms of meaning and power that come to life in the encounters that readers have with written works, in ways unique not just to the work, nor to the reader, but to each and every act of reading.

In this argument, I am particularly influenced by Attridge’s reappraisal of the concepts that underpin our thinking about literature in *Singularity*. Central to this
reappraisal is the suggestion that acts of writing and reading involve an encounter with and response to alterity, or otherness. This way of looking at literature and our engagement with it is indebted to the ethical philosophy of Emmanuel Lévinas, as filtered through the work of Attridge, Butler, and Ricoeur, who in turn approach this philosophy both through direct reading of Lévinas, and through of the work of his interlocutors, including Maurice Blanchot and Jacques Derrida.

For Lévinas, the basic unit of the ethical is a kind of phenomenological, pre-cognitive—or “face-to-face”—encounter between the self and the other, in which the self is compelled to respond to the other by offering up an account of itself. The self is thus, in the very act of affirming the other, brought into an awareness not just of the particularity of its being as a self—or what Butler describes as “a relational being” (Giving 20)—but also of the fact that this particularity necessarily exceeds what can be rationally accounted for, let alone evaluated, within traditional epistemological and moral frameworks. The face-to-face encounter thus unfolds as a scene of recognition based on difference—a scene in which intimacy proceeds from a shared condition of unfathomability, and familiar epistemological and moral frameworks are rendered strange.

Similarity and difference, familiarity and alterity, intimacy and strangeness, unfathomability and recognition: Attridge draws on these aspects of the Levinasian tradition in his discussions of the way in which we experience literature. In Singularity, this discussion begins by looking at how the handling of the aesthetic dimensions of writing and of the published text opens up new possibilities of meaning, and at how these possibilities are most fully realized in the act of reading—features that are central, Attridge argues, to our understanding of how the literary differs from other art forms and from other written media, and, crucially, of its participation in the realm of the ethical. In this vein, Attridge’s thinking challenges

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18 For further discussion of this issue, see Lévinas (1961, 1974). In brief, for Lévinas, as for many of his interlocutors, ethics involves a phenomenological encounter between the self and the other, whereas morality signifies a set of rules that govern social conduct and determine what is ‘good’ or ‘bad.’ This tension between ethics and morality in relation to accounting for the self and responding to the other is of central importance to the work of both Butler and Ricoeur, and forms one of the major points of intersection between their ethical philosophies and that of Lévinas.
the traditional dualism that divides form from content, arguing instead that one of the distinguishing features of the literary is the way in which its deployment of the aesthetic dimensions of language and of the printed text not only intensifies and extends the themes that authors explicitly set out, but also inaugurates patterns of referentiality, symbolicity, metaphoricity, and so on that come together to create another kind of content: a content that is distinct—but not necessarily disconnected—from the work’s stated themes. This content is realized in the act of reading, and thus takes on different emphases and meanings depending on a range of factors, including: the reader’s knowledge of the discursive contexts on which a work’s aesthetics draws; the attitudes, values, experiences, beliefs, and judgments that individual readers bring to the work—attitudes, values, experiences, beliefs, and judgments that are not fixed, but which change over time in ways that render each subsequent reading of a work unique—and the ways in which a work brings these attitudes, values, experiences, beliefs, and judgments forth. Crucially, then, by opening up seemingly endless possibilities of meaning, this content complicates, challenges, and disrupts the idea that a work can ever be exhaustively and objectively known.

At root, then, for Attridge literature’s participation in the realm of the ethical lies in the complex engagement between self and other that, in the act of reading, brings this content into being. This engagement unfolds as a kind of phenomenological face-to-text encounter that closely resembles the face-to-face encounter at the heart of Levinasian ethics, and consists in the reader’s apprehension of a work’s simultaneous familiarity and alterity: an apprehension that is always already a response in which the reader is interpellated—or brought into being—as a self. The realization that each reading, whether of the same work or of a different work, will therefore present a different combination of familiarity and strangeness—and thus interpellate a different self—further extends the connection of the literary to the ethical, by fostering a form of recognition based not on comprehension nor assimilation nor evaluation, but on an awareness of the instability and inscrutability
not just of the other, but also of the self\textsuperscript{19} – the ethical importance of which is explored in greater detail by both Butler, as we will see in chapter 2, and Ricoeur, as we will see below.

In focusing my attention on the aesthetic dimensions of contemporary illness accounts and their ethical implications, my intention is not to romanticize illness, nor to downplay the difficulties faced by those for whom the prospect of accounting for illness in any form is inconceivable. Rather, in taking this approach, I seek to show what is lost when these dimensions are not taken into consideration. Given the emphasis here on subjectivity in the experience of the literary and its participation in the realm of the ethical, it could be objected that any attempt to describe the patterns of meaning, allusion, symbolism, and so on that come into being through reading will tell us more about the reader than about the work itself, and thus be of limited value as a foundation on which to begin constructing a new approach to writing and reading illness accounts – especially one that aspires to cross disciplinary borders. These concerns are valid: though mitigated somewhat by in-depth contextual research, multiple re-readings of the accounts concerned, and a sustained engagement with other readings of these accounts where possible, what I offer here will of course be shaped by the attitudes, values, experiences, beliefs, and judgments that I bring to this selection of illness accounts.

Earlier, I suggested that illness accounts possess the potential to reshape our ideas about the literary, about its participation in the realm of the ethical, and about the ethical itself. Consequently, while the basic framework described above is at the crux of this potential, in this thesis I am not fundamentally concerned with whether, as a genre, illness accounts display the kinds of aesthetic activity in which Attridge sees the essence of the literary and its ethical potential to lie, but with the ways in which certain illness accounts explore and extend our thinking about the literary and its ethical potential. More specifically, I’m interested in a cluster of illness accounts

\textsuperscript{19} This awareness highlights the inherent slipperiness of the self-other dyad in the Levinasian tradition, not only by revealing the fundamental incomprehensibility of the self and the grounds for recognition that this—somewhat paradoxically—establishes, but also by blurring the boundaries between the multiple significations of “the other,” including, but not limited to, the other as a real or imagined individual; the other as a real or imagined collective; and the other not as a human presence \textit{per se}, but a concept, artefact, or mode of articulation.
that have emerged over the past two decades in which the aesthetics deployed take shape as a self-reflexive staging of the process through which literature participates in the ethical, and thus give rise to readings that, though specific to individual accounts and to each reading they undergo, ultimately work towards the same ends.

The illness accounts considered here are therefore bound together by their capacity to create and sustain literary performances that are not only ethical in their effects, but ethical in their content, by which I mean that these accounts not only facilitate encounters in which the reader is compelled to respond to the other—and thus to interpellate the self—but themselves dramatize these encounters and the complex experience of responsibility and interpellation they entail. They do so by foregrounding the creative labour involved in responding to others and accounting for the self: creative labour necessitated by the tension between the phenomenological experience of being and encountering—the basic unit of Levinasian ethics—and the discursive norms, or morals, that govern the experience of accounting for the self and responding to others.

All accounts of the self, Ricoeur argues, involve creative labour. Though it is “often repeated that life has something to do with narrative,” the assimilation of lived experience into a life story is far from straightforward, he contends, for the lived experience is not, in itself, amenable to the norms of storytelling (“Life” 20). Rather, the transmutation of lived experience into a life story involves a significant degree of what Ricoeur calls “emplotment,” a concept he borrows from Aristotle (“Life” 21). Emplotment, in Ricoeur’s sense of the term, signifies “an operation,” or “integrating process” through which the “heterogeneous elements” of lived experience are synthesized into a story which is “unified and complete”: a story organized around a logic of concordance, coherence, causality, culmination, and closure (“Life” 21-22). For Ricoeur, furthermore, the labour of emplotment is central

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20 For Ricoeur, the “elusive character of real life” is the product of both the ontological and the biological limits of self-knowledge (Oneself 162). Of the latter, he writes: “there is nothing in real life that serves as a narrative beginning; memory is lost in the hazes of early childhood; my birth and…the act through which I was conceived belong more to the history of others—in this case, to my parents, that to me. As for my death, it will finally be recounted only in the stories of those who survive me” (Oneself 160).
to the ways in which we embellish the “biological phenomenon” of life with existential meaning and value, and thus to an ontology that is distinctively human ("Life" 28).

Emplotment is an iterative process, involving an active and ongoing deployment of fiction to shape the discordant, heterogeneous, unstable nature of lived experience. While Ricoeur’s emphasis on the importance of emplotment within an ethical context differs from the argument I develop as this thesis progresses, several of the claims he makes here are salient to my project ("Life" 20; Oneself 178). Foremost amongst these are his insistence that emplotment is only ethical insofar as we remember that the stories it yields consist in “an unstable mixture of fabulation and actual experience” – a claim that places intentionality and an awareness of one’s audience at the heart of the first-person account (Oneself 162). When we lose sight of this mixture and its instability, Ricoeur warns, emplotment ceases to operate as an ethical process—a pathway to self-understanding—and becomes instead a kind of moral prosthesis. By fully assimilating lives to stories, and vice versa, good life stories—those that are coherent, consistent, and so on—become synonymous with good lives (in the moral, rather than ethical, sense of the term), while those which fail to conform to these standards of narration are seen to be morally suspect.

In their staging of the creative labour through which the subjective experience of

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21 In this, Ricoeur aligns himself with a wider philosophical movement, in which selfhood is seen to be fundamentally narrative in nature – a movement that has in recent years been subject to a small but significant body of criticism. Prominent amongst its critics are Galen Strawson, who vigorously deconstructs this thesis in “Against Narrativity” (2004), and Butler, who in Giving is concerned with the anti-ethical implications of normalizing narrativity – an approach I discuss in greater detail in chapter 1.

22 Though both are centrally concerned with the intersubjective encounter, and distinguish between ethics and morality, Ricoeur’s thinking about these issues differs in significant ways from that of Levinas. Whereas Levinas is interested in the phenomenology of this encounter, Ricoeur is more teleological in his approach, and values the intersubjective encounter primarily in its relation to the Aristotelian concept of eudaemonia, or the “good life”. Ricoeur’s understanding of the “good life” is complex, and for the most part tangential to my argument here. For present purposes, it is sufficient to recognise the importance he places on the Socratic maxim that “an unexamined life is not worth living,” which places narrative self-understanding at the heart of the good life (“Life” 20; Oneself 178). For more on this, see the Seventh Study of Oneself (169-202).

23 I use this not in David Mitchell and Sharon Snyder’s sense of prosthesis as a narrative process in which deviance is resolved—a concept they develop from the work of David Wills—but rather to signify the use of the artificial to give a semblance not just of wholeness, but of normativity (Mitchell and Snyder 2000; Wills 1995).
illness is rendered into an illness account, the works considered in this thesis are ethically active in both the Levinasian and the Ricoeurian senses. Rather than simply rejecting the prostheses offered by illness’s discursive past and present, and by the conventions of autobiography, they instead handle these prostheses—examining and describing them, even trying them on—in ways that draw attention to the gap between lived experience and life stories, and to role that fiction plays in bridging this gap. In doing so, they foster what Ricoeur sees to be an ethical perspective on emplotment, and resist its slippage into the realm of normative morality. Further, by unharnessing the impulse to engage with and respond to the other from conventional modes of writing and reading the self—both in illness and in health—they open up a space in which to explore alternative ways of representing the self and interpreting otherness.

These properties are by no means limited to accounts of illness: as I have already intimated, the aesthetics and ethics at work in the accounts considered here are representative of a wider movement to extend and revitalize a set of approaches to representing lived experience and the encounter with others that are broadly modernist in origin, though of course, as Attridge reminds us, modernism in turn has “antecedents and foreshadowings in earlier periods” (Coetzee 4). Neither are they are common feature of the contemporary illness account: the works addressed in the pages that follow are for the most part outliers in a genre that tends instead to conform to the narrative typologies sketched out by Frank, Hawkins, Stacey, and others. This is not to say that illness does not play an important role in issues at stake in these accounts, however. Illness, and particularly chronic illness, is particularly conducive to the problems of self-representation described thus far, for several reasons. First amongst these is the fact that illness is typically accompanied by demands to account for oneself: demands that are both abstract and concrete in origin, and which come from multiple directions, as I discuss in greater detail in chapter 2. At the turn of the twenty-first century, furthermore, any attempt to respond to these demands is necessarily overdetermined by multiple discourses, including those of illness and of autobiography more generally, each of which offers the possibility of prosthesis – a possibility that, in its continual disruption and inherent instability, the chronic illness experience renders impossible.
“Stories about illness,” Stacey claims, “are an intensification of the way in which we generally understand our lives through narrative” (8). In their telling, she argues, they make “explicit the importance of narratives in the construction of the self in contemporary culture” (8). And yet, she argues, illness accounts—and particularly chronic illness accounts24—also “put pressure on the structures of conventional genres of storytelling,” in ways that open up alternatives to these structures (Stacey 8-9). In the accounts considered here, this combination of intensification and pressurization gives rise to a series of compelling performances that not only dramatize the tension between experiencing and accounting for illness, but also enact the literary and its participation in the ethical in ways that make the arguments put forward by Attridge, Butler, and Ricoeur come alive. This latter quality makes the accounts I consider here a particularly productive frame of reference not only for the attempt to introduce the principles and practices of contemporary literary studies into the medical humanities, in both research-focused and pedagogical environments, but also for the encouraging scholars and students in literary studies itself to take illness accounts seriously as sophisticated, aesthetically- and ethically-active works.

**Thesis Overview**

Because of its focus on literary aesthetics, this thesis is organized according to genre, rather than chronology or geography. Beginning with a group of illness accounts written by academic women and ending with experimental fictions from South Africa, it seeks to demonstrate how illness accounts of different genres put aesthetics to work in surprisingly similar ways to those that Woolf describes and deploys in *On Being Ill*. Further, it shows how illness accounts test assumptions about the aesthetic sophistication and ethical complexity that different modes of writing make possible, and, in doing so, prompts us to revisit our ideas about what constitutes “the literary.” My intention here is not so much to challenge the existing hierarchy of literary value, but rather to suggest that, in focusing our attention on these texts, we risk both underestimating the potential of what have been crudely labeled “middle-” and “lowbrow” modes of writing, and unnecessarily restricting the relevance of our

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24 Stacey’s example here draws on Derek Duncan’s work on autobiographical accounts of HIV/AIDS, a condition that has since the late 1980s become increasingly manageable in the long-term for those with access to treatment and to the personal or state resources necessary to fund it.
scholarship. This risk is particularly high when the objects of our scrutiny are illness accounts, because so many are produced and consumed within these “popular” paradigms of writing and reading.

By the same token, my gaze spans several geographical regions. In covering this wide territory, I seek to show how accounts of chronic illness are aesthetically and ethically active in ways that not only cross genres, but also borders. Whereas Diedrich proposes the existence of “different national arts of being ill” in her comparison of American and British cancer narratives (xx), I instead focus on how first person illness accounts published between 1990 and 2008 contribute to a transnational aesthetic and ethical project. As such, the texts considered here all draw on distinct social, political, and cultural histories and identities in important ways, but without collapsing entirely into the local. Finally, I have included texts by both male and female authors, though the latter significantly outnumber the former – a dominance that reflects both the higher burden of chronic disease that women confront and the late twentieth-century feminist politics of writing about embodied experience. Thus, the extent to which gender forms a central part of my reading varies depending on whether—and in what ways—an account or group of accounts themselves engage with gender.

To set the scene for my readings of contemporary illness accounts, my first chapter takes shape as a survey of the key critical metanarratives that underpin current thinking about writing and reading illness. This survey is organized according to the two major areas of scholarship, practice, and pedagogy on which I draw in this thesis: the medical humanities, and literary studies. Using Waddington and Willis’s call for the development of “an increasingly sophisticated and inclusive humanities approach to narratives of illness” as my point of departure, in this survey I focus particularly on the opportunities and challenges that literary studies approaches to illness accounts present, and ultimately question whether the present critical crisis in the medical humanities can really be resolved through a methodological reorientation towards these approaches in their present form (v).

See, for example, Malmusi et al. (2012).
My second chapter shows how in *On Being Ill* Woolf’s consideration of the relationship between illness, literature, and ethics takes shape as a powerful creative and critical manifesto that not only identifies the major challenges that illness poses to representation, but which also explores possible ways of engaging with, and potentially overcoming, these challenges. The principles and practices set out in this manifesto, I argue, offer a valuable paradigm for thinking about writing and reading illness in the present day: a paradigm that has not only been taken up, but revitalized and extended by contemporary writers of illness accounts, and which offers an alternative to those currently employed in both literary studies and the medical humanities. Not only does this paradigm resist the tendencies of mainstream literary criticism towards suspicion and instrumentalism, it also offers a convincing counter-argument to approaches that frame these accounts as being outside the established purview of literary studies. As such, *On Being Ill* provides a rewarding, though perhaps unexpected, way into the analyses of contemporary illness accounts enacted in chapters 3 to 5 of this thesis.

In chapter 3 I show how, in accounting for illness the feminist academics Jackie Stacey, Eve Kosofsky Sedgwick, Mary Felstiner, and Ann Oakley have had to find—and occasionally fight—their way through the complex maze of discursive politics in which, as people with illness, as academics, and as women autobiographers, they find themselves automatically enmeshed. Within this framework, these women not only make increasingly bold decisions about the terms on which they engage with these genres, but also explore—and, where necessary, create—alternatives. Like Woolf in *On Being Ill*, they do so by combining in their writing an explicitly interrogative approach with more subtle and open-ended aesthetic strategies that expose the operations of language and representation in accounting for the self, thus foregrounding the creative labour involved in this process and continuing Woolf’s work at the interface of illness, literature, and ethics into the twenty-first century.

My fourth chapter considers the illness accounts of two established writers of literary fiction, Hilary Mantel and Paul West. My reading of these accounts focuses on the
hypersensual, synaesthetic qualities of Mantel’s and West’s prose, and the hallucinatory passages that form a common leitmotif in their writing. Herein, I suggest that these elements can be fruitfully read as an exploration of the ways in which illness derails, suspends, and disrupts the referentiality of language, as well as a series of experiments in the redirection of this referentiality. In doing, I show how Mantel’s and West’s accounts of illness attest not just to ontological disruption or to a heightened thematization of the body, but also to the ways in which language can be stretched to accommodate new ideas, new experiences, and new patterns of referentiality, and the implications of this capacity for its participation in the ethical.

In the fifth and final chapter of this thesis, my focus shifts from the referentiality of language to the referentiality of fiction. In contrast to chapter 4, in this chapter I look not at how illness resists referentiality, but at the ease with which it is assimilated into interpretive frameworks based on notions of national allegory, and thus uses as its frame of reference two fictional illness accounts set in South Africa during the late twentieth century: J. M. Coetzee’s Age of Iron (1990) and Marlene Van Niekerk’s Agaat (2006). My readings of these novels explore the ways in which they simultaneously solicit and problematize the allegorical readings to which both illness accounts and South African fiction are regularly subjected, and consider the implications of this stance towards allegory for the reader’s sense of responsibility towards the work in their hands.

This selection is by no means comprehensive, and it is important, I think, to note that the accounts considered here are predominantly those of relatively privileged, heterosexual, white people – primarily for reasons of availability and of methodology. Consequently, though I approach these accounts as representatives of a distinct genre, with implications for our understanding both of illness accounts

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26 Though first person, English language illness accounts are just beginning to emerge from developing and newly industrialized countries, to my knowledge these tend to be dominated by issues specific to the region from which they emerged, and/or to participate in the discursive traditions that have grown up around particular conditions, such as HIV/AIDS: considerations that fall outside the scope of this project. The emergence of the HIV/AIDS epidemic in post-apartheid South Africa is a case in point, around which has arisen a growing body of fiction, life writing, and scholarly work. Examples include Phaswane Mpe’s Welcome to Our Hillbrow (2001), Liz McGregor’s Khabzela: The Life and Times of a South African (2005), and Ellen Grünkemeier’s Breaking the Silence: South African Representations of HIV/AIDS (2013).
in general, and of everyday life, I acknowledge the limitations that accompany this demographic choice. To reiterate, then, what links the accounts considered here is double-edged reading experience they sustain: the way in which they incite, in the reader, a sense not only of aesthetic activity, but of an active probing at and beyond the epistemological and ontological horizons both of illness and of subjectivity more broadly.

The objectives of this thesis, then, are threefold. First, in bringing together a comprehensive range of materials related to the practice and theory of writing and reading about illness, it not only consolidates an important, yet under-examined, strand in the medical humanities, but also showcases the specific contributions that literary studies can make to the field, thus providing a crucial stepping stone for further research and pedagogy. Second, like many of the texts it considers, this thesis seeks to provide a resource for those at the coalface. In its engagement with the experience of accounting for chronic illness, it draws attention to the ontological issues at stake in illness, and encourages a more open-minded, and potentially even counter-discursive, approach to thinking about writing and reading illness accounts. In this, it seeks to appeal not only to people living with illness and its aftereffects and those who care for and work with them, but also to those who encounter them on different terms: those, for example, who have yet to experience their own serious illness or that of others, except through reading. Finally, it seeks to demonstrate how accounts of chronic illness offer insights that further our understanding of the literary and its participation in the ethical.
Chapter One

Contested Fields: Writing and Reading Illness in the Medical Humanities and Literary Studies

In *On Being Ill*, Woolf describes illness as an archipelago of “undiscovered countries,” while a revised version of the essay likens it to “an unexploited mine”\(^{27}\) – analogies that, at the time of writing, would have been intensely evocative (*Being* 3). The phrase “undiscovered countries,” for example, brings to mind the daring expeditions undertaken in the late nineteenth and early twentieth centuries into harsh regions such as the Antarctic, the Himalaya, South America, and the Sahara,\(^ {28}\) while as Jurecic notes that of “unexploited mines” would have recalled the unexploded land mines left over from the recent war (5). It would not be long, however, before Woolf’s analogies proved not merely evocative, but prophetic. In the decades that followed the essay’s publication, the writing and reading of illness accounts underwent a dramatic explosion, firing missives back from the kingdom of the sick with increasing regularity.

The illness account genre was further consolidated as the century progressed, when from the 1960s on the medical humanities and its related subdisciplines began to establish themselves as “academically respectable” fields of study, and, in turn, to validate the objects of their study (Greaves and Evans 1). During this time, scholars across the arts, humanities, and particularly social sciences have helped to bring substantial tracts of the landscape of illness to light, unearthing previously overlooked accounts and monitoring the emergence of new ones. And yet, in spite of this foundational work, much of its terrain remains critically under-explored, if not almost entirely uncharted, for reasons that are both material and methodological, while the canonization of cultural artefacts and scholarly approaches within the field

\(^{27}\) This version, entitled “Illness: An Unexploited Mine,” was published in the New York magazine *The Forum* in April 1926.

\(^{28}\) This allusion is reinforced in Woolf’s subsequent comments on how literature shows the mind “ignoring the body in the philosopher’s turret; or kicking [it], like an old leather football, across leagues of snow and desert in the pursuit of conquest or discovery” (*Being* 5)
has become an increasingly heated topic of debate.

Though not a primary concern of this thesis, one prominent subject of dispute centres on the almost exclusively Western worldview of the medical humanities, as reflected in both the materials on which it focuses and the cultural values it upholds.²⁹ This tension arises not only in non-Western countries, where higher education institutions are taking up the discipline at a rapid rate, but in the West itself, whose health care workforce and patient populations are increasingly diverse. Another major source of controversy is the elisions that accompany what Waddington and Willis describes as the current emphasis on “presentist contexts” in the medical humanities (as opposed to the history of medicine) (v). By concentrating on illness accounts produced after 1950, they argue, we risk overestimating the shifts in thinking about writing and reading illness that have taken place over the twentieth century, as well as overlooking the many continuities that link contemporary first-person illness accounts to more long-running debates about representing illness and accounting for the embodied self. However, the focus of my critique in this chapter is not on cultural bias, nor on the lack of historical perspective, but on the assumptions that underpin current thinking about writing illness accounts in both the medical humanities and literary studies, and the limitations of the readings that result.

According to Waddington and Willis, in its current configuration the “mainstream” medical humanities needlessly restricts “what illness narratives might be allowed to mean, and even what they might look like” by focusing on only a certain type of illness account—“the linear, progressive, story framed with the context of biomedicine and the doctor-patient encounter”—and by viewing it only through certain interpretive lenses (iv). In his analysis of university-level courses on literature and medicine, Arnold Weinstein extends this line of argument. Weinstein sees in these courses a tendency to focus exclusively on certain kinds of literary materials—primarily realist fictions that take as their subject matter explicitly medical contexts and events, and which he thus describes as “docile”—and to avoid those that are more “unruly,” such as “experimental, avant-garde, or postmodernist

²⁹ Hooker and Noonan provide an interesting discussion of this issue in their article “Medical Humanities as Expressive of Western Culture” (2011).
texts” (“Unruly” 1). Further, he finds fault not just in this selection of materials, but in the methods used to interpret them, arguing that the pedagogical distinction drawn in the medical humanities between docile and unruly texts is entirely spurious, for literature, he insists, “cannot be cleansed of its ambiguities, its excesses, its meta-consciousness as a verbal artifact, its incessant trafficking in fantasy, desire, fear, folklore, myth, and the like,” no matter how transparent it at first appears (“Unruly” 2). Weinstein’s critique suggests that the principles and practices of literary studies might yield more sophisticated analyses of literature’s engagement with the medical, including accounts of illness. And yet, as we have already seen, only a handful of scholars in the field of literary studies have produced studies that engage in any significant and sustained way with the “unruliness” of literature about illness, while the potential of these studies to extend the interdisciplinarity of the medical humanities, and particularly the depth and scope of its literary branch, is often limited by the historical specificity of their materials, the theoretical complexity of their arguments, and the jargon of the discipline.30

Though the development of the “increasingly sophisticated and inclusive humanities approach to narratives of illness” that Waddington and Willis call for in their assessment of the field is riddled with difficulties, it is not impossible (v). At the most basic level, it requires scholars at the intersection of the medical humanities and literary studies to work towards the development of new paradigms for thinking about writing and reading illness. These paradigms need to be of sufficient complexity to do justice to the principles and practices of literary studies, but also to be accessible to scholars from other disciplinary backgrounds, and to students in both the medical humanities and the literary studies classrooms. In order to do so, however, a thorough understanding of the obstacles that have thus far prevented the development of such paradigms is necessary. In this chapter, I thus seek to take stock of the ways in which illness accounts are typically interpreted in both the medical humanities and literary studies, in the form of a schematic survey that builds on many of the themes mentioned earlier, including the therapeutic and pedagogic uses

30 For example, in a review of Lisa Diedrich’s Treatments: Language, Politics, and the Culture of Illness (2007) Kimberly Myers—a professor who teaches humanities at a medical school—writes that, in spite of Diedrich’s claims to appeal to a wide audience, the accessibility of her work is limited by a “highly intricate” theoretical framework as well as a tendency to be “condescending” toward some of the readers it hopes to reach (Rev. 430, 434).
of illness accounts in healthcare practice, and the modes of metaphoric thinking, suspicious reading, and docile analysis found in literary analyses.

Policy, Pedagogy, Therapy: The Uses of Illness Accounts in the Medical Humanities and Healthcare Practice

Though the approaches at work within the medical humanities range widely, one thing most contemporary critics tend to agree on is that illness is, in the words of Frank, a “call for stories” (53). In the main, this storytelling impulse is not seen to be purely utilitarian, in the sense of the signs and symptoms described to health care professionals and the explanations offered to and/or solicited by family members, friends, colleagues, and fellow patients, but also to possess a therapeutic dimension, in which storytelling offers a way of making sense of illness’s effects on the past, present, and future, and of integrating change into an existing life narrative. This kind of thinking is reflected in popular attitudes to illness accounts: in a 2011 article for The Independent, for example, journalist Arifa Akbar attributes the emergence of the published first-person illness account to two factors: “the in-built narrative arc of critical illness,” which, she suggests, “predisposes it to storytelling”; and the “need to describe and unburden” that people with illness experience (Akbar).

The perceived affinity of illness for storytelling both proceeds from, and seems to be corroborated by, the dramatic expansion in the writing and publication of illness accounts that took place in the second half of the twentieth century, and which has persisted into the opening decades of the twenty-first – an expansion that is increasingly reflected in a range of other genres and media, including fiction, journalism, essays, art, dance, and film (Jurecic 10). And yet, in spite of this critical consensus, thinking about the writing and reading of these accounts has in recent decades become increasingly contested territory. Influenced by the health and social

31 As Brian Lobel notes in his description of the “questioning stares” he experienced as a person with “the visible outward symptoms” of cancer, the demand to account for illness that others inadvertently impose can take both verbal and non-verbal forms (31).
32 This is one of the major distinctions between the medical humanities and the history of medicine. While medical humanists tend to assume that illness is a call for stories, in general, historians of medicine don’t. Rather, they see the stories that do arise from illness as historically valuable and contingent on a range of social, cultural, political, technological, and economic factors. For historians of medicine, then, narrative is not necessarily the “self’s mode of being,” but a useful by-product of literate culture.
sciences, much early work on illness accounts looks not at published accounts but at
oral narratives, focusing on those brought into being as part of the research process
itself, either in the form of interviews, or through the observation of patient
encounters with health care professionals. This kind of approach continues into the
present day, and—as Waddington and Willis point out—has come to exert a
powerful influence over the field.

In the main, studies of this kind tend to focus on the ascendancy of the biomedical
model and its effects on the experience of illness and the attempt to account for it.
Medical practitioners such as Howard Brody, Eric Cassell, and Arthur Kleinman,
along with social scientists such as Arthur Frank and Byron J. Good, frame these
effects in terms of colonization and disenfranchisement, arguing that as “modernist
medicine claimed the body of the patient as its territory,” so the record set down in
specialist medical language by a qualified physician increasingly took precedence
over the patient’s account (Frank 10). Within this disciplinary framework, illness
accounts tend to be analyzed according to their tendency to reproduce or resist the
narrative of restitution associated with the biomedical model, primarily with a view
towards applying the findings of this analysis in healthcare policy and pedagogy,
though the therapeutic outcomes of storytelling for people with illness are also taken
into consideration, primarily by researchers and practitioners in psychology and
related fields.33 This latter phenomenon takes its cue from the work of Freud, who,
under the rubric of “abreaction theory” or “the talking cure,” formalized the notion
that talking about traumatic experiences is therapeutic, and in doing so can be seen to
have inaugurated the therapy and self-help cultures evident both in contemporary
Western society and elsewhere.34 Present day practices such as “expressive
writing”—also described as “the writing cure”—are heavily influenced by this
dimension of Freud’s work and the various ways in which it has been extended,
while collections such as Rita Charon and Peter L. Rudnytsky’s *Psychoanalysis and

33 James W. Pennebaker is one of the leading figures in this field. The influence of his work on
“expressive writing” can be found in edited collections such as Lepore and Smyth (2002), and also in
the work of individuals such as Myers (2008), and Nicholls (2009). Another form of expressive
therapy used in illness is “bibliotherapy,” which Ella Berthoud and Susan Elderkin describe in *The
Novel Cure* (2013) as “the prescribing of fiction for life’s ailments” (1). Bibliotherapy has been used
in a healthcare context for hundreds, if not thousands, of years. For more on the history of this
practice, see Jack and Ronan (2008).
34 For more on this, see Furedi (2004) and Illouz (2008).
Narrative Medicine (2008) have explored the theoretical and practical intersections of the two fields in further detail. The resemblance is not purely conceptual, moreover: the instructive aims and stylistic features of Freud’s publications, which often incorporate patient case studies and autobiographical elements alongside guides to their interpretation, can also be seen to prefigure the presentation of more recent pedagogical works such as Charon’s Narrative Medicine and the Illness in the Academy anthology.35

Crucially, in the last twenty or so years, medical humanities scholars have begun to look beyond the biomedical context and to consider how other social, cultural, and political factors might shape the illness experience and the accounts that emerge from it, to create a kind of medical history of the present.36 Some such enquiries, like Frank’s analysis of quest narratives in The Wounded Storyteller: Body, Illness, and Ethics (1995), are general in scope, while others are specific to certain diseases. One of the most relevant findings of such studies to my project here is that realisation that even those stories which emerge in resistance to the biomedical model have a tendency to become themselves dominant, often in a relatively short space of time, and to trigger in turn further narratives of resistance — a process that can be accelerated by scholarly attention, and by the entrance of these stories into mainstream culture.37 Thus, as more narrative templates have emerged, medical humanists have responded by looking beyond the influence of the biomedical model to engage with the range of stories about illness and health that circulate in popular culture, and position illness accounts in relation to them.38 However, though there is much to commend this expanded view of illness accounts, the resulting studies tend

35 The link between contemporary illness accounts and Freud is further consolidated by Hawkins’s adoption of the term “pathography” from Freud via Joyce Carol Oates. In a 1988 review, Oates used it to describe “a new subspecies of the genre [of magisterial biography].” “In the traditional biography,” she argues, “the subject is usually substantial enough to support high claims for his or her cultural significance.” Pathography, however, “typically focuses upon a far smaller canvas, sets its standards much lower” and takes as its distinguishing motifs “dysfunction and disaster, illnesses and pratfalls, failed marriages and failed careers, alcoholism and breakdowns and outrageous conduct.”

36 In this way, this area of medical humanities research has come to overlap with a range of other fields of enquiry, including the sociology of the body, narrative and autobiography studies, and trauma studies. Indeed, trauma studies and “witnessing literature” form part of Charon’s “Foundations in Narrative Medicine” module at Columbia, as the course website attests: <http://ce.columbia.edu/narrative-medicine/courses>.

37 This can take place in a variety of ways, from films and television dramas that feature illness to media coverage of and life writing by high profile celebrities with illness.

38 Barron Lerner’s studies of celebrity illness (2006) and on breast cancer activism (2001) are good examples of this kind of approach.
to offer typological overviews such as those found in Frank’s *The Wounded Storyteller* and Hawkins’s *Reconstructing Illness: Studies in Pathography* (1999), rather than in-depth close readings, which perpetuates the restricted view of illness accounts described by Waddington and Willis.

This emphasis on the uses of illness accounts in policy development, pedagogical, and therapeutic contexts is reflected in a more recently established area of practice and enquiry, known as narrative, or narrative-based, medicine — the rubric under which many of the literature and medicine courses Weinstein refers to operate. Narrative medicine has its origins in the work of doctors like Brody, Kleinman, and Cassell, which emphasizes the need for health care professionals to develop a more nuanced understanding of the ways in which patients account for illness. In the late 1990s, this scattered movement crystallized into a distinct field—narrative medicine—in which emphasis is placed on pedagogical approaches that encourage health care professionals to develop “narrative competence”: a quality Rita Charon—a practicing physician, professor of clinical medicine, and proponent of the narrative medicine approach—describes in terms of the ability “to recognise, absorb, interpret, and be moved by [...] stories of illness” (* Narrative* vii). Prominent amongst the pedagogical techniques of narrative medicine are close reading of illness accounts, and creative writing,39 both of which are intended to equip students with the “skills of observation, analysis, empathy, and self-reflection” necessary for the kind of narrative competence Charon describes (NYU School of Medicine).40

In recent years, narrative medicine courses have become integrated into medical education programmes at many institutions in the United States, and increasingly in the United Kingdom and beyond.41 A key consequence of this integration has been the establishment of a distinct literary branch of the medical humanities (Jurecic 2).

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39 Creative writing in particular has gained in popularity following the success of recent forays into fiction by medical practitioners, including Abraham Verghese’s novel *Cutting for Stone* (2009) and Louise Aronson’s short story collection *A History of the Present Illness* (2013).

40 Narrative medicine has increasingly become integrated with the growing movement in clinical practice towards evidence-based medicine. Pioneered by Charon and her colleagues at Columbia under the rubric of narrative evidence-based medicine (or NEBM), this approach seeks to “recognise[s] the narrative features of all data and the evidentiary status of all clinical text” (Charon and Wyer 297). Further discussion of this approach may be found in Charon and Wyer (2008) and Meza and Passerman (2011).

41 For more on this phenomenon, see Early and DeCosta (2009), Hooker and Noonan (2011).
However, as Weinstein points out in his critique of literature and medicine courses, the contribution this branch makes to the interdisciplinarity of the medical humanities is compromised by its preference for “docile” reading, as well as its tendency to repackage, rather than resist, the privileged role of the health care professional as the final arbiter of an account’s meaning and value. This preference manifests in the kind of questions students are encouraged to ask about illness narratives. For example, in Kimberly R. Myer’s anthology *Illness in the Academy* (2007)—a text created with the pedagogical uses of illness accounts in mind—a each account is followed by a series of questions intended to support these readers to develop “narrative competence.” Though a small proportion of these questions point to the aesthetic dimensions of the account concerned—symbolism, narrative structure, and so on—in the main they focus on issues of content, in the traditional sense of the attitudes, behaviours, opinions, judgments, and values explicitly depicted in a work. “How can medical personnel deal with patients who are unable or unready to hear bad news about their health?”, they ask; “Why do sufferers write personal narratives about depression?”; “What complements to traditional medicine does the author offer as valuable?”; and so on (Myers *Illness* 54, 130, 72).

This overview of the medical humanities gives a sense of the field’s scope: the range of methods and applications that researchers and practitioners in the field employ, and the ways in which the medical humanities has drawn attention to—and in many cases promoted—writing about illness, while also formalizing existing conventions for reading illness and establishing new ones. In addition to their shared emphasis on the relationship between storytelling and illness, one of the common themes that emerges in this overview is the assumption that both the historical conditions that allowed for the emergence of the modern illness account, and contemporary thinking about the writing and reading of it, are unique to the late twentieth and early twenty-first centuries, and that illness accounts are thus useful indices of a particular cultural moment. Moreover, where exceptions to this presentist mode of thinking are made, they tend to be portrayed as part of an essentialist conception of human nature—a case in point being the influence of Joseph Campbell’s concept of monomyth, as set

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42 The anthology evolved in response to a conversation between Hawkins and Myers about the difficulty of teaching book-length accounts in a medical pedagogy context, and the consequent need for “a collection of shorter, chapter-length narratives” (Hawkins “Foreword” xi).
out in *The Hero with a Thousand Faces* (1949), on Frank’s thinking about the hero narrative (Frank 117-119). In doing so, they frame illness accounts as reflective not of a particular cultural moment, but of an ahistorical cultural consciousness.

**Instrumental Attitudes, Suspicious Criticism, and Metaphoric Thinking: Literary Approaches to Illness**

Alongside the growth in the medical humanities and narrative medicine, in the late twentieth and early twenty-first centuries accounts of illness in both autobiographical and fictional forms have increasingly attracted the attention of scholars in literary studies. Generally speaking, the engagement of literary scholars with autobiographical writing about illness tends to combine a set of interpretive habits and routines similar to those at work in the medical humanities, and particularly its social science components. Studies such as Couser's *Recovering Bodies: Illness, Disability, and Life Writing* (1997), Hawkins's *Reconstructing Illness*, and to a lesser extent Mary K. DeShazer’s *Fractured Borders: Reading Women’s Cancer Literature* (2005), take shape as generic surveys, focusing on the comparison of groups of accounts rather than in-depth close reading of individual texts, and pairing contextual information—such as motivations for writing and the patterns of composition and publication—with synopses of their master plots and recurrent thematic concerns. These surveys are geared towards documenting the formulas and conventions of the genre, marking its boundaries by defining individual texts in terms of their relative conformity or resistance to the archetype. As in the social sciences, moreover, they tend to take one of two forms: a generalist survey—such as Hawkins’ *Reconstructing Illness*—or a study focusing on a specific illness, like DeShazer’s, or Monica B. Pearl’s *AIDS Literature and Gay Identity: The Literature of Loss* (2012). However, some works combine this approach by juxtaposing chapters on specific illnesses to create a broader overview, of which Couser's *Recovering Bodies* is a good example.

One thing these studies tend to focus on is the role of more general factors—that is, factors that are not *directly* connected to illness—in the growth of writing about illness. Chief amongst these are the democratization of literature—including both autobiography and fiction—and the destigmatization of writing about the embodied
self, both of which they see as distinctive to the twentieth-century. Thus at the turn of the twenty-first century, Gilmore asserts, memoir is no longer the province of “elder statesmen reporting on the way their public lives parallel historic events,” as it had been in the nineteenth century, but has been taken up by a far wider range of people, including those who are until the publication of their memoirs unknown to the public but whose experiences are sufficiently “emblematic of a cultural moment” or social or political issue to attract readers – a category into which people with illness often fall (Limits 1). According to Catherine Belling, moreover, though in the early twentieth century “the story of the self was seldom told in public — or at all, especially if it involved private bodily suffering,” contemporary cultural discourse is saturated with “memoirs and pathographies, [...] confession and testimony, truth and reconciliation” — a view that echoes Frank’s assertion that, at the turn of the twenty-first century, stories are “the self’s medium of being” (Belling 57; Frank 53). Elizabeth Grosz’s work adds a further dimension to this viewpoint, counterbalancing Frank’s thinking about narrative ontology with the statement that in the postmodern era, the body is “the very ‘stuff’ of subjectivity” (Grosz ix). As a general rule, arguments of this type thus seek to explain the growth of life writing about illness in the twentieth and twenty-first centuries as the product of shifting discursive and other cultural factors, in much the same way that medical humanists pin this growth on the emergence of modern biomedicine and its colonization of the illness experience.

In Illness as Narrative, Jurecic charts another trend in contemporary responses to life writing about illness, which she terms “suspicious criticism.” In this mode of engagement, the critic’s interpretive energy is channeled into an exposé of the workings of affect and ideology in a cultural artefact or collection of artefacts, and is particularly evident in readings of works that deal with suffering of some kind. Lauren Slater, herself a memoirist of mental illness, captures this suspicious critical

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43 Peter Brooks’s observation that the body has acted as a “key organising element” in Western narrative since at least the late eighteenth century provides a compelling counterpoint to the claims put forward by Belling and Grosz, among others (47). For Brooks interest in “private life” and embodied experience is not a new phenomenon: rather, he argues, art forms such as the novel reveal these to have been prime subjects of cultural concern for many centuries, and to have attained particular prominence in the nineteenth (29-30, 26).

44 Jurecic’s study joins more general responses to suspicious criticism by figures such as Bruno Latour, Eve Kosofsky Sedgwick, and Rita Felski. For more on this, see Jurecic (3-4, 10-17, see also chapter 5 passim).
attitude well when she suggests that “illness as an artistic or narrative device is cheap, easy to sensationalize, obvious in its plot” (166). She writes:

the illness memoirist need not grapple with the problems of how to render those fleeting poignant moments of being, those Woolfian wisps that disappear in mid-formation, the quarks of emotion or perception [...] . The illness memoirist need not struggle with all the possibilities of point of view—first person, close third person, alternate voices—because her tale is relentlessly singular. And how much easier to dramatize the syringe or the psychosis than it is to conjure up the haunting emptiness of the Don DeLillo suburbia or the poverty of Jean Toomer’s inner city. (166)

Slater’s tongue-in-cheek analysis here implies that underpinning suspicious criticism is a widespread belief that illness accounts are not seen to be authentically literary, and therefore do not undertake any significant form of cultural work. The effects of this approach can be profoundly inhibitory for both established and aspiring life writers: a phenomenon the poet and novelist Sarah Manguso gestures to when she confesses that she “avoided writing about her disease” for years because “the subject seemed garish, obvious, banal, embarrassingly personal” (Couser 7; Manguso, cited in Akbar).

Critical attitudes to fictional accounts of illness display somewhat different constraints, and tend to position illness as a symbolic device, or as means of plot or character development. The most obvious example of these attitudes can be found in the inclination to think about illness as a trope that can only ever be metaphorical. This kind of “metaphoric thinking” about illness is described most fully in Sontag's study *Illness as Metaphor* (1978), which not only documents the long literary and cultural history of this practice, but attests also to its persistence in the twentieth century. In this, her gaze sweeps from Shakespeare’s obsession with infections and impairments of the body politic to the political rhetoric of the late twentieth century, which abounds with metaphors that link corruption, totalitarianism, and the like to
Like many of the foundational works in the medical humanities—a field that was in its infancy when she wrote *Illness as Metaphor*—Sontag emphasizes the transformative role of the biomedical model, arguing that it not only brought about a renaissance in metaphoric thinking about illness in popular and particularly political discourse, but also facilitated the development of new stereotypes and symbolic associations by taking up new metaphors—such as those based on military culture—into its own discourse.46

For Sontag, then, metaphoric thinking represents both the use and the interpretation of certain illnesses as metaphors in literary, political, and popular discourse, as well as the use of metaphors to discuss these illnesses and their treatment. “In an era in which medicine’s central premise is that all diseases can be cured,” she argues, those which seem “intractable and capricious”—such as cancer, for which she had recently completed treatment, and AIDS, which she discusses with great foresight in her subsequent study *AIDS and Its Metaphors* (1988)—have become so “encumbered by the trappings of metaphor” that it is virtually impossible to experience them without feeling overwhelmed by their associations (*Illness* 5). In the late twentieth century, such illnesses—illnesses that we would now think of as chronic—are shaped by particularly powerful fantasies of “inescapable fatality” and “military metaphors of aggressive warfare” that leave little room for the deeply personal experience of living through the “calamity of disease” (*Illness* 87, 42) — an experience that, though it featured extensively in her journals, Sontag talked remarkably little about

45 Metaphoric thinking about illness has its origins in theories of illness that arose prior to the advent of the biomedical model. In *Illness as Metaphor*, Sontag traces metaphoric thinking about tuberculosis and cancer back to at least the fourteenth century, but focuses particularly on the way in which nineteenth-century “fantasies” about tuberculosis set the stage for the “lurid metaphors” that have come to dominate the experience of cancer in the twentieth-century (*Illness* 9, 14, 5, 4). Studies that share Sontag’s focus on public discourse and metaphor but look at earlier periods include Byron Lee Grigsby’s *Pestilence in Medieval and Early Modern English Literature* (2003) and Jennifer C. Vaught’s *Rhetorics of Bodily Disease and Health in Medieval and Early Modern England* (2010), although an earlier precursor of both can be both in Saul Nathaniel Brody’s monograph *The Disease of the Soul: Leprosy in Medieval Literature* (1974). Similar texts include Sander Gilman’s *Disease and Representation: Images of Illness from Madness to AIDS* (1988) and David Shuttleton’s *Smallpox and the Literary Imagination 1660-1820* (2007).

46 Interestingly, in *AIDS and Its Metaphors*, Sontag notes the longevity of this particular metaphor, citing John Donne’s description of “illness as an enemy that invades, that lays siege to the body-fortress” in *Devoitions upon Emergent Occasions* (1627) (*AIDS* 8). In the present day, this phenomenon is evident in the use of rhetoric such as “rogue cells,” metastatic “invasion,” and “the war on cancer” in popular and medical discourse (*Illness* 65-66). For more on this see Martin (1994) and Cohen (2009), particularly chapter 4 on “the defensive poetics of modern medicine"
during her lifetime.\textsuperscript{47} In this sense, Sontag’s critique of metaphoric thinking thus resembles the drive of early medical humanists to carve out a space for the subjective experience of illness that they saw modern biomedicine to have occluded.\textsuperscript{48}

In its groundbreaking critique of metaphoric thinking about illness, as well as its relatively accessible style, \textit{Illness as Metaphor} participates in the heterogeneous culture of activism and resistance that emerged during the second half of the twentieth century – a culture in which critical and social justice movements focusing on gender, disability, sexuality, race, and other forms of marginalization cohere around the attempt to challenge both the construction of normalcy as white, male, heterosexual, able-bodied, undiseased, cognitively unimpaired, middle class, and so on, and the privilege experienced by those who fit one or more of these criteria. In these movements, life writing, fiction, and literary and cultural criticism have provided productive supplements to social activism and political lobbying, while also reflecting the cultural achievements of these latter activities.\textsuperscript{49} And yet, the changes wrought by these publications and the social movements they represent on both popular and scholarly thinking about writing and reading illness are not always as profound as both their wide readership and their afterlife in pedagogy and research might indicate: a phenomenon that is particularly evident in current approaches to writing and reading about illness. In spite of the fact that \textit{Illness as Metaphor} has, since its publication, become an iconic text much cited in life writing about, and literary and cultural studies of, illness, and has driven substantial changes in medical and media practices, metaphoric thinking continues to exert a powerful influence over both popular and scholarly readers of fictions of illness.

In the late twentieth century, a substantial body of work in this vein emerged,

\textsuperscript{47} In his account of her final illness, Sontag’s son David Rieff comments on this, noting that both \textit{Illness as Metaphor} and \textit{AIDS and Its Metaphors} are not just “anti-autobiographical,” but “intentionally so” (28).

\textsuperscript{48} In a study based on popular and professional responses to neoplastic, or potentially cancerous, disease in North America in the first half of the twentieth century, Barbara Clow challenges Sontag’s claims about the social pervasiveness of metaphoric thinking about illness and its negative effects on patients (Clow 2001). Nevertheless, its presence in fiction is marked.

\textsuperscript{49} Again, like Grosz’s notion of embodied subjectivity, this too evolved out of nineteenth-century literary culture, in which the novel often acted as a vehicle for social reform. For more on this, see, for example, Lovesey (2011).
focusing on the ways in which the association between illness, the aberrant, and the undesirable is inscribed in European and American fiction prior to the twentieth century. Lawrence Rothfield’s reading of Mme. de Merteuil's bout with smallpox in Laclos’ *Les Liaisons Dangereuses* (1782) illustrates this practice well. “In disfiguring her,” he argues, “the smallpox offers…readers a legible figure of moral, social, and narrative closure, a ‘very true’ representation of Merteuil's evil character” (3). This reading forms part of Rothfield’s examination of the relationship between clinical discourse and realism in the novels of Gustave Flaubert, Honoré de Balzac, George Eliot, Emile Zola, and Arthur Conan Doyle in *Vital Signs: Medical Realism and Nineteenth-Century Fiction* (1992). Other examples of this mode of writing and reading illness are discussed in Jeffrey Meyers’s study of European and American fiction of the late nineteenth- and twentieth-centuries *Disease and the Novel, 1880-1960* (1985), which ranges from the use of epilepsy as a metaphor for “spiritual insight” in Dostoevsky’s fiction to that of tuberculosis to represent “the pathological state” of Europe in the 1930s and 1940s in A. E. Ellis’s *The Rack* and Thomas Mann’s *The Magic Mountain*, whose fiction Sontag describes as “a storehouse of early-twentieth-century disease myths” (Meyers 8, 105; Sontag *AIDS* 23). In the materials they deal with and the approaches they take, these studies both attest and contribute to the long tradition of “metaphoric thinking” in writing and reading fictions of illness: a tradition in which illness is seen to serve "a quite restricted literary purpose" (Rothfield 3). More recently, the Jamesonian notion that postcolonial fiction must always on some level take shape as national allegory has led to the extension of this way of thinking, as typified in readings of illness and disability as metaphor in novels such as Salman Rushdie’s *Midnight’s Children* (1980), Bapsi Sidhwa’s *Cracking India* (1992), and Tsitsi Dangarembga’s *Nervous Conditions* (1988) – though such interpretations are often anticipated, and problematized, in the texts themselves, as Clare Barker’s study *Postcolonial Fiction and Disability: Exceptional Children, Metaphor and Materiality* (2011) demonstrates.50

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50 A similar phenomenon can be traced in works such as Dostoevsky’s *The Brothers Karamazov* (1880), which both uses illness as a means of character development—mainly that of Alyosha as a kind hero, through his engagement to Lise Khokhlakov, whose illness confines her to a wheelchair, and his desire to help the family of Ilyusha Snegiriov—and holds this strategy up to scrutiny through the epileptic Pavel Smerdyakov’s exploitation of the association between his illness and prophecy to instill anxieties and suspicions amongst the members of the Karamazov family.
A similar problematization of the relationship between illness and metaphor can be found in contemporary life writing about illness. An example of this problematization can be found in Melanie Thernstrom’s *The Pain Chronicles* (2010), a work that blends medical history, cultural criticism, and memoir. An important narrative strand in this work revolves around Thernstrom’s attempt to keep a pain diary, as advised by her rheumatologist – an activity in which she repeatedly finds herself grappling with metaphorical thinking (10). In her reflection on this activity in the introduction to *The Pain Chronicles*, Thernstrom notes how the diary “became a place for embroidering my pain with pernicious meaning” and “metaphors that obscured my medical situation,” and recalls being “struck” at seeing this same tendency in the other pain diaries she read (10). And yet, at the same time, balanced against this critique of metaphoric thinking is the suggestion that the kind of demythicization of illness that Sontag demands might pose its own set of problems. We can see this in Thernstrom’s interview with Dr. Clifford Woolf, a specialist in pain medicine:

“But pain feels meaningful,” I suggested timidly, like a riddle or a dream.”

“That’s crazy,” he said forcefully. “That’s like the myths about TB we were talking about. Chronic pain is not some”—he searched for the right word—“code. It is a terrible, abnormal sensory experience, pathological activity in the nervous system.”

Could these science terms, still so foreign in my mouth, become mine? Could the demon that clothed itself in my body turn into excitotoxicity and overuse atrophy? Cervical spondylosis and spinal stenosis and impingement syndrome—if I truly believed that’s what it was and that’s all it was—would be far less alarming than a curse, a punishment, a private sorrow, a symptom of aloneness, an inexplicable blight, or any of the myriad unhappy ways I understood and experienced and expressed my condition.

Would it also be less painful? (189)

Here, the technical language of modern medicine appears to offer a neutral alternative to the morally-weighted language of metaphor: a way of undoing the destructive psychological effects of the analogies commonly deployed in accounts of illness. But, for all its perniciousness, the language of metaphor is familiar to Thernstrom, while that of science remains “foreign.” With her final question, moreover, she evinces both excitement and uncertainty about language’s ability to
modulate physical sensation.

Ultimately, The Pain Chronicles attests to the need not to dispense with metaphoric thinking, but to be attendant to its workings and, in doing so, to rework it. This attestation manifests in multiple ways, ranging from reported conversations such as that above to extracts from Thernstrom’s pain diary. Some sections appear to continue the tradition of metaphoric thinking on which Sontag focuses—Thernstrom’s likening of pain clinics to Dante’s Inferno is an example of this, as is her blurring of the boundary between romantic and physical pain—, while others seek to highlight, it seems, the contradictions inherent in Sontag’s deployment of metaphor in her prose (Thernstrom 10; Romm). Thernstrom achieves this latter effect by incorporating frequent echoes of the image with which Illness as Metaphor opens, in which Sontag describes illness as “the night-side of life, a more onerous citizenship” (3). “Everyone who is born,” she writes, “holds dual citizenship, in the kingdom of the well and in the kingdom of the sick,” and, “although we all prefer to use only the good passport,” she continues, “sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place” (3). We see this image invoked by Thernstrom in her introduction to The Pain Chronicles, when she asserts that “To be in physical pain is to find yourself in a different realm – a state of being unlike any other, a magic mountain as far removed from the familiar world as a dreamscape” – a reworking that contains within it both an homage to Sontag’s critique, and, through reference to one of its targets (Mann’s The Magic Mountain), an ironic commentary on the proximity of her writing to that which she sought to challenge (Thernstrom 5). In this way, and as Gilmore notes, Thernstrom’s staging of her struggle with metaphoric thinking is representative of a growing emphasis in contemporary accounts of pain—a genre that overlaps closely with that of the illness account—not on the limitations of the “ready-made languages of pain”51 per se, but on the many ways in which pain can be characterized: an emphasis that foregrounds both the complex relationship that obtains between the experience of pain and its expression, and the overdetermination of this relationship by competing discourses (Gilmore “Agency” 86).

51 As will become apparent in chapter 2, Gilmore borrows this phrase from Woolf’s On Being Ill.
The final interpretive approach I wish to discuss here can be allied to what Attridge calls “literary instrumentalism,” in which both life writing and fiction are treated “as a means to a predetermined end” (Singularity 7). At its simplest, this involves “coming to the object with the hope or the assumption that it can be instrumental in furthering an existing project”—a project that may be “political, moral, historical, biographical, psychological, cognitive, or linguistic”—“and responding to it in such a way as to test, or even produce, that usefulness” (Singularity 7). Though as a critical approach this clearly has its limitations, in relation to illness it has the potential at least to resist existing interpretive modes and pursue alternatives, as the work of critics such as Lisa Diedrich and DeShazer show. However, the most common examples of instrumental attitudes to illness accounts have their origins in trauma theory. As a result, while they are not necessarily invested in the idea that only certain life stories have meaning and value, these approaches also impose restrictions on the ways in which illness accounts signify and the kinds of cultural work they might undertake. Crucially, they also risk distorting the field by placing emphasis on those works that corroborate existing theories or further existing projects, while neglecting those that do not.

One of the central tenets of trauma theory is the notion that trauma is an experience to which “language is inadequate” (Gilmore “Agency” 85). Sociological and psychological approaches to illness accounts are often underwritten by this view of illness: the reparative role of storytelling that Frank describes in The Wounded Storyteller, for example, takes as its point of departure the idea that illness instigates an experience of “narrative wreckage,” a state of ontological chaos in which an individual is loses her “sense of where she is in life and where she may be going”.52 However, whereas scholars such as Frank focus on the therapeutic role of storytelling, in literary studies emphasis tends to be placed on the narrattractability of illness as a form of trauma. In such readings, the silences and fractures in a narrative

52 Frank adapts this term from Ronald Dworkin’s Life’s Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom (1993). Here, Dworkin discusses the role of the individual’s ‘sense of self’ in determining the relative benefits and drawbacks of prolonging life. Whereas Dworkin stresses that, because individuals have “radically different senses of self” that relate to “what has been critically important to their own lives”—the different meanings and values they attribute to activities such as reading or exercising, for example—the experience of narrative wreckage is always highly personal, Frank uses the phrase in a more general sense, based on a more universal understanding of selfhood as fundamentally narrative in nature – for “stories,” he maintains, “are the self’s medium of being” (Dworkin 211; Frank 53).
are interpreted as evidence of the writer’s struggle to meld the compulsion to witness trauma with its fundamental unnarratability. A case in point can be found in Belling’s argument that the 1918-1919 influenza pandemic not only “overwhelmed language” at the time of its occurrence, but has continued to resist “being recalled and recounted” in more recent historical fiction,\textsuperscript{53} while Jason Tougaw’s reading of AIDS memoirs focuses on the ways in which the “fragmentation” evident in their narratives reflects “the authors’ own ravaged communities and traumatized psyches” (Belling 57, 59; Tougaw 167).

These approaches are not, of course, mutually exclusive. When taken to the extreme, the instrumental attitude to illness accounts taken by scholars influenced by trauma theory risks straying into the territory of suspicious criticism, for, in their validation of fragmentation and silence as the markers of authentic trauma, they risk implying that accounts in which illness is ‘made sense of’ are somehow inauthentic. A common variant on this is the belief that “trauma cannot be spoken of or written about in any mode other than the literal” and that any attempt to aestheticize, or metaphorize, thus “risks negating it” (Gilmore \textit{Limits} 6). Conversely, in the work of Shoshana Felman, metaphoric thinking, instrumentalism, and trauma theory come together in her readings of Albert Camus’ \textit{The Plague}, which she sees as “a transparent allegory for the massive death inflicted by the Second World War and for the trauma of a Europe ‘quarantined’ by German occupation and desperately struggling against the overwhelming deadliness of Nazism” (8). Underlying this approach is the suggestion that any attempt to read the novel against allegory—and thus to consider its aesthetic dimensions in other terms—constitutes a denial of its central purpose as an “an act of bearing witness to the trauma of survival” – a suggestion that stands in stark contrast to the criticisms of Camus’ novel put forward by several of his contemporaries, including Jean-Paul Sartre and Roland Barthes, who argue that “in representing its subject allegorically, [\textit{The Plague}] fails to represent real material history” (Felman 8; Krapp 655).\textsuperscript{54}

\textsuperscript{53} Interestingly, Belling’s conclusion here is in opposition to the project she initially embarked upon, which centred on the “expectation…that historical fiction about the pandemic could somehow work…as an antidote to our collective amnesia” about the event (59).

\textsuperscript{54} For more on this, see chapter 4 in Felman and Laub (1992) and Krapp (1999).
Conclusions
In their recent call for scholars in the medical humanities to undertake a major “rethinking” of their approach to accounts of illness, Waddington and Willis emphasize the need to expand the disciplinary horizons of the field in the direction of the humanities (iv). For Waddington and Willis, literary studies should be at the forefront of this expansion: in addition to a keener sense of historical perspective, “traditional literary methods […] of close reading and textual analysis,” they insist, will need to occupy an increasingly central position in future illness account research if the limitations of existing methodologies are to be overcome (iv). My discussion in the first half of this chapter looks at current thinking about writing and reading illness accounts in the medical humanities, and in this way builds on Waddington and Willis’s critique by exploring in greater depth the assumptions that underpin this thinking: assumptions in which the writing of illness accounts is primarily seen as a therapeutic process, and the reading of these accounts an important component of training healthcare professionals in skills of empathy and cultural sensitivity. In my analysis of current thinking about writing and reading illness accounts in literary studies, however, I depart from the general thrust of Waddington and Willis’s argument to question whether the present critical crisis in the medical humanities can really be resolved through a methodological reorientation towards this thinking in its present form.

The assumption that literary studies might offer an antidote to the shortcomings of the medical humanities is, I argue, as problematic as it is promising, for literary studies has its own preconceptions and blind spots when it comes to thinking about writing and reading representations of illness. In my survey of literary approaches to these representations in the second half of this chapter, I demonstrate how in the limits they place upon what illness accounts might mean, and the kinds of cultural work they might undertake, these approaches inflict interpretive crimes similar to those perpetrated by the medical humanities. Though the studies cited by Waddington and Willis as examples of the kind of “sophisticated and inclusive humanities approach” that research into illness accounts requires are not of this ilk, the faith they place in the ability of literary studies to extricate the medical humanities from its current state of crisis should not be left unchecked. Rather, any attempt to integrate the principles and practices of literary studies into the medical
humanities needs to take cognizance of the convoluted relationship that literary studies has had, and continues to have, to representations of illness, and to subject its methods to sustained analysis.

Few critical attempts to challenge the limitations of thinking about writing and reading illness in literary studies currently exist, and those that do have not had quite as profound an effect on scholarship as one might imagine, as my reading of Sontag’s *Illness as Metaphor* suggests. And yet, beyond this narrow strand of critical resistance, the limitations of the critical metanarratives that underpin this thinking have not gone entirely unnoticed. As I indicate in my reading of Thernstrom’s *The Pain Chronicles*, illness accounts can themselves offer an important check on the tendencies of these critical metanarratives to limit what illness accounts can look like, and the ways in which they might signify. In the chapters that follow, I look in greater detail at how established patterns of writing and reading illness are problematized in a range of contemporary illness accounts, using this problematization as a point of departure from which to consider both the ways in which these accounts make use of the aesthetic elements that define the literary, and the implications of this aesthetic activity for our thinking about the nature of the literary and its participation in the ethical.

Though not an illness account in the conventional sense of the term, Virginia Woolf’s 1926 essay *On Being Ill* can in many ways be seen to inaugurate this tradition of problematization. Herein, Woolf puts forward a compelling account of the relationship between illness, literature, and ethics in which the conventions of the literary are subject to extensive critique, and the challenges that illness poses to writers and readers explored. As such, the essay provides a rewarding, though perhaps unexpected, way into the analyses of contemporary illness accounts enacted in this thesis, and thus forms the subject of my next chapter.
Chapter Two

Undiscovered Countries and Unexploited Mines: Woolf on Illness, Literature, and Ethics

*Each of the books Woolf wrote around the time [of The Waves (1931)] strained across genre, attempted to break through—or disturb—the limits of the essay, the novel, the biography, to touch realities denied by accepted forms. In all her work there was an astute awareness that apparently literary questions – of genre, language, plot – are questions that touch the pith of how society constitutes and contains itself”*

Gillian Beer (1996, 77)

Written from Woolf’s sickbed in 1925, *On Being Ill* is the first published work devoted to the relationship between illness and literature. Though its initial reception—by T. S. Eliot, in his capacity as commissioning editor for *New Criterion*—was “unenthusiastic,” and though, as Jurecic notes, no evidence exists to suggest that Woolf’s argument had any substantial influence on the writers of her era,55 recent interest in writing and reading about illness has led to a resurgence in the essay’s popularity (Lee “Introduction” xxv; Jurecic 5; Lee “Introduction” xx). Reissued twice by the Paris Press in recent years—one in 2002, and again in 2012—Woolf’s commentary has increasingly featured in both scholarly studies and personal accounts of illness (and related conditions, such as pain), ranging from Elaine Scarry’s *The Body in Pain: The Making and Unmaking of the World* (1985) to Hilary Mantel’s hospital diary, *Ink in the Blood* (2010). However, whereas at the turn of the twenty-first century critical reappraisals of Woolf’s essays by scholars in

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55 A reflection of the presentist emphasis of the medical humanities, the relationship between illness and literature in the early twentieth century remains under-researched, though this is slowly beginning to change. In this vein, Miriam Marty Clark’s work on illness and injury in Hemingway’s early fiction (2004) and Jane Fisher’s monograph *Envisioning Disease, Gender, and War: Women’s Narratives of the 1918 Influenza Pandemic* (2012) have been pivotal in opening up the field, while Alice Hall’s reading of disability in Faulkner’s fiction has also made a valuable contribution (2011). In the opening to *Illness as Narrative*, Jurecic also notes the presence of illness—and particularly the 1918 influenza pandemic—in several American novels and novellas published between 1920 and 1945: Willa Cather’s *One of Ours* (1922), Thomas Wolfe’s *Look Homeward, Angel* (1929), Katherine Anne Porter’s *Pale Rider, Pale Horse* (1939), and Wallace Stegner’s *The Big Rock Candy Mountain* (1943) (Jurecic 1). Moreover, as Clark suggests, William Carlos Williams’s medical narratives, which are scattered through his poetry and prose work and which were later published as the edited collection *Doctor Stories* in 1984, can also be seen as a precursor of the surge in autobiographical and creative writing by medical practitioners at the turn of the twenty-first century (M. Clark 168).
literary and women’s studies seek to reclaim the relevance of these essays to Woolf’s artistic project, and to modernism and women’s writing more widely, On Being Ill has for the most part continued to be viewed as a text peripheral to these issues—a work that reflects, but does not extend, ongoing themes in her non-fiction writing.66

Moreover, from a medical humanities perspective, the essay is regarded as an early but anomalous blip on the radar—a work with no obvious ancestors and no notable descendants—and valued primarily as a source of pithy axioms about the ineffability of pain, as well as a pseudo-historical proof of the absence of illness from literature prior to the emergence of the illness account genre in the mid-twentieth century.67 As such, engagements with On Being Ill in both critical and creative works tend to favour a literal interpretation of the essay, dissecting out pithy maxims and scraping them clean of the “deviations and devagations” that give the work its character, before using these more quotable portions as convenient, but largely inadequate, proxies for Woolf’s argument as a whole (Lee “Introduction” xxv, xxvii). In this chapter, I counter these views by examining how in On Being Ill Woolf interweaves illness, literature, and the everyday, and, in doing so, leaves hanging threads that are picked up by later generations of ethical philosophers, literary critics, and authors in the fields of life writing and experimental fiction. In doing so, I set out my approach to contemporary illness accounts, and give a clearer sense of the foundational role that On Being Ill—a text that antedates the earliest of these accounts by over six decades—plays in it.

On Being Ill as Critical and Creative Intervention

In recent decades, a handful of exceptions to the approaches described above have emerged, in which fragments of the critical and creative project that Woolf undertakes in On Being Ill are uncovered. Hermione Lee’s discussion of the “satire on conformity” that takes shape in the essay’s second half is one such exception, as

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66 A case in point can be found in Bowlby’s insightful reading of On Being Ill in relation to the wider theme of “multiple selves” in Woolf’s writing (259-260).

67 For an example of this approach, see Jack Coulehan’s annotation of the essay for the Literature, Arts, and Medicine Database. Hosted by the New York University School of Medicine, this online database provides a dynamic, open-access annotated bibliography of works of interest to medical practitioners, students, and scholars in the medical humanities and related disciplines, and can be accessed at <http://litmed.med.nyu.edu>.
is Rachel Bowlby’s reading of the work as key moment in Woolf’s thinking about
the multiplicity of selfhood (Lee “Introduction” xxx; Bowlby 259). To this we can
also add Kimberly Engdahl Coates’s analysis of the essay as an exploration in the
“organic aesthetic” she sees as central to Anglo-European modernism, and Stella
Bolaki’s reading of its depiction of “aesthetics as work” (Coates 247; Bolaki 120). In
this chapter, I bring these fragments together with others uncovered in my own
readings of On Being Ill, to provide the first sustained exploration of the essay as a
critical and creative work in its own right. Drawing on Woolf’s non-fiction more
widely—including other essays from the same period and biographical material such
as diaries and letters—I show how On Being Ill not only speaks to key debates in
Woolf’s oeuvre, but ultimately extends these debates in ways that have significant
implications for writing and reading illness in the present day.

Central to my reading of the essay is an understanding of the relationship between
the essay’s critical project and Woolf’s own lived experience of illness. As Lee
points out, illness is “one of the main stories” of Woolf’s life – a story characterized
by debilitating physical symptoms, including headaches, palpitations, insomnia, and
faints, “entwined” with periods of mental distress, ranging from severe agitation to
profound depression (“Introduction” xiv). Though the cause of Woolf’s ongoing ill
health is unknown and, in spite of much retrospective speculation, ultimately
unknowable, what we can be certain of is that it would, by today’s standards, be
classed as chronic illness – a category of conditions that not only challenges medical
epistemology, but which also defies the conventions of narrative at virtually every
turn. When, in “Professions for Women” (1931) she writes about how her career has
been driven by the attempt to tell “the truth about my own experiences as a body,”
then, illness must have been a significant part of this truth, and On Being Ill therefore
part of her attempt to tell it – an assertion Lee corroborates in her suggestion that
Woolf saw in the conventions of the essay an opportunity to draw on “personal
material” without lapsing into “confession” (Woolf “Professions” 241; Lee “Essays”

38 According to Thomas Caramagno, Woolf’s account of these symptoms in her diaries and letters has
led to a posthumous diagnosis of bipolar disorder by multiple psychiatric specialists (Flight 6). However, Lee
speculates that she might have had some form of long-term “febrile or tubercular illness,” while considering the
possibility that the treatments she received—which included chloral hydrate, veronal, and the highly
toxic digitalis—might have been more detrimental than therapeutic (“Introduction” xv).
104-105). In this combination of critical and creative intervention, *On Being Ill* forms both important precursor to the late twentieth- and early twenty-first century illness accounts on which this thesis focuses, and a valuable point of departure for the argument I develop in my readings of these accounts.

*On Being Ill* is a characteristically Woolfian text. Like many other of her essays from the period, it strains across genre to create what Hermione Lee calls “a curious, original mixture” of “manifesto, literary criticism, feminist argument, meditation on life, fiction, biography, history, and autobiography” in which the intellectual, the affective, and the aesthetic are inextricably entangled (“Introduction” xxiii). As such, any attempt to engage critically with this essay, and to articulate this engagement in ways accessible to others, will necessarily involve acts of compartmentalization and alignment that go against the grain of Woolf’s writing. With this problematic in mind, I have chosen to structure this chapter as a series of readings of the essay, each of which builds on the findings of its precursor. I begin by looking at the philosophical dimension of Woolf’s essay: how her descriptions of illness gesture to its coextensiveness in her thinking with everyday lived experience. I then build on this reading through a consideration of the limitations that Woolf sees in existing attempts to represent these experiences, with emphasis on her suggestion that illness brings these limitations into sharp relief. Finally, I conclude with an examination of the alternatives approaches to writing and reading illness that she gestures to in the latter half of the essay.

**“Astonishing Disorder”: Woolf on Illness and the Everyday**

According to Bowlby, Woolf’s notion of selfhood as an experience marked by multiplicity can be seen to reach its apotheosis in *On Being Ill* (259). Though Bowlby’s reading of *On Being Ill* is restricted to a short passage in which Woolf describes how fiction allows one to “live over and over again,” and which is not specifically linked to illness, (18-19), in including this essay in her thematic reading, Bowlby not only draws attention to an important dimension of *On Being Ill*, but also suggests a degree of overlap between Woolf’s thinking about illness and her take on everyday lived experience more widely. In this section, I want to pursue Bowlby’s
suggestion by investigating how far this overlap extends, and what implications it might have for our understanding of the critical and creative intervention Woolf makes in *On Being Ill*.

Written shortly before *On Being Ill*, the essays *Mr Bennett and Mrs Brown* (1924) and “Modern Fiction” (1925) provide particular insight into this overlap. Herein, Woolf depicts everyday lived experience as a dynamic constellation of affective and intellectual impressions. In *Mr Bennett*, for example, she suggests to her reader that

> In the course of your daily life this past week [...] You have overheard scraps of talk that filled you with amazement. You have gone to bed at night bewildered by the complexity of your feelings. In one day thousands of ideas have coursed through your brains; thousands of emotions have met, collided, and disappeared in astonishing disorder. (*Bennett* 23)

In “Modern Fiction,” on the other hand, she uses the third person to describe the “incessant shower” of “myriad impressions” received by “an ordinary mind on an ordinary day,” but with similarly evocative results (“Modern” 189). Though superficially repetitive, the “myriad impressions” encountered on “an ordinary day” fall into new patterns, with new accents, “as they shape themselves into the life of Monday or Tuesday,” leaving one with the sense that “Life is not a series of gig lamps symmetrically arranged; [but] a luminous halo, a semi-transparent envelope” (“Modern” 212). For Woolf, then, the phenomenon of daily life unfolds as a series of open-ended encounters and experiences, each “stranger” than the last, that leave one “bewildered” and “filled…with amazement” and can only be made sense of in retrospect, if at all (*Bennett* 23).

From the very beginning of *On Being Ill*, Woolf frames illness as an everyday experience, rather than an extraordinary event, as the essay’s opening line
“Considering how common illness is” indicates (Being 4). The striking similarity between Woolf’s descriptions of everyday lived experience in these essays and her descriptions of illness in On Being Ill are integral to this framing. Woolf’s description of sky-gazing while ill is a case in point. “Able, perhaps for the first time in years, to look round, to look up,” she writes of how the ill person finds themselves witness to an “extraordinary spectacle” (12). Instead of a backdrop for “chimneys and churches” or a symbol of the weather, the sky reveals itself to be a site of “endless activity,” featuring an “incessant making up of shapes and casting them down,” a “buffeting of clouds together, and drawing vast trains of ships and wagons [sic] from North to South,” an “incessant ringing up and down of curtains of light and shade,” an “interminable experiment with gold shafts and blue shadows, with veiling the sun and unveiling it, with making rock ramparts and wafting them away” (13). With its shifts in perspective and synaesthetic sense impressions, illness is depicted by Woolf as a case of everyday experience in extremis: the dynamic constellation of affective and intellectual experiences with which she describes daily life in Mr Bennett and “Modern Fiction” magnified in the swirling cloudscapes and moving shadows of On Being Ill. In doing so, moreover, Woolf indicates that On Being Ill is as much an essay on being as it is an essay on being ill.

As Bowlby and others have pointed out, both in her essays and her fiction Woolf displays an ongoing concern with the nature of selfhood, and particularly the discrepancy between the vagaries of lived experience and the monolithism of what Sidonie Smith calls “the autobiographical ‘I’” (1). For feminist critics such as Smith and Gilmore, this “I” reflects a fundamentally masculinist and “occluding vision” of “universal selfhood” which has its origins in “Enlightenment notions of the human subject,” and as such acts as a textual manifestation of the ability to “master[] the chaos of experience” through “self-narration” (Smith 1-2; Gilmore 83-84). Woolf’s descriptions of lived experience in both her essays and fiction provide a striking

59 In this, Woolf preempts the work of prominent scholars in literary and cultural disability studies such as Davis and Thomson, both of whom argue that, though social and economic inequalities significantly shape the lived experience of disability, as a form of social, cultural, and biological difference it is “more fluid” than categories such as race, gender, sexuality, and so on (Thomson 14). “No whites will become black; few straights will become gay,” Davis writes, “but every normal person can become disabled. All it takes is the swerve of a car, the impact of a football tackle, or the tick of the clock to make this transformation” (Bending 4). Likewise, every normal person can become ill: all it takes is the bite of a mosquito, the ingestion of a pathogen, or the mutation of a gene to make this transformation.
counterpoint to this “I,” to which *On Being Ill* is no exception.

And yet, *On Being Ill* doesn’t simply reiterate the model of subjectivity set out in *Mr Bennett* and “Modern Fiction”: a model that frames the self as multiple, inconsistent, and ultimately incomprehensible. Rather, in this essay, Woolf extends this model in compelling and significant ways. The satire on conformity that Lee identifies in the second half of the essay is central to this extension. This reading takes its cue from Woolf’s descriptions of the ill as “outlaws,” and “deserters from the army of the upright” (22, 12). These descriptions that are not critical, but celebratory, for as the essay progresses, it becomes increasingly clear that Woolf sees in this outlawry both a liberation, and a kind of existential awakening. In illness, she suggests, one is freed from the “genial pretense,” “the make-believe” of normative social behaviour (12). Released from the need “to communicate, to civilise, to share, to cultivate the desert, educate the native, to work together by day and by night to sport”—to participate in the processes and transactions of normative social, political, and economic life—the person with illness is at leisure to examine and reflect on all that “the cautious respectability of health conceals” (12, 10). On first reading, this is reminiscent of the Romantic notion of the “mad poet,” in which illness engenders “a revolutionary and liberating madness” that releases the imagination from the mundane constraints of everyday life and inspires creative vision — a pigeonhole into which Woolf herself has been posthumously placed by many critics (Burwick 2-3; Caramagno *Flight* 8). 60

But in *On Being Ill*, I argue, Woolf is getting at something very different — something that coalesces, both in this essay and in Woolf’s critical oeuvre more widely, into an exploration of what Michèle Barrett terms the “power of difference” (x).

According to Barrett, Woolf’s thinking about the power of difference hinges on the alternative perspectives on and insights into the workings of normative society that the experiences of those who circulate outside, or on the margins, of this society might yield. In much of Woolf’s work, Barrett argues, this power is located in the experiences of women, and particularly in their written accounts of these experiences, both fictionalized and autobiographical (x). However, at certain

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60 For more on poetic madness, or *furor poeticus*, see Burwick (1992) and Whitehead (2010).
moments in Woolf’s oeuvre we see this thinking extended to other forms of social, historical, and biological difference, including animals—as *Flush* (1933), her biography of Elizabeth Barrett Browning’s cocker spaniel, suggests—and people with illness.61 In the first instance, the power of difference that illness engenders takes shape as a stripping back of illusions of self-knowledge to acknowledge the basic condition of being as one of the unknown and unknowable, of incoherence and opacity. In fact, Woolf contends, in illness we go beyond basic acknowledgement, to embrace this condition: we not only come to realize that the self is “a snowfield where even the print of bird’s feet is unknown,” but to accept that we “like it better so” (12). This recognition of preference is in many ways the crux of Woolf’s argument, for in its aftermath we realize that “always to have sympathy, always to be accompanied, always to be understood”—always to be subject to the illusions around which the “genial pretense” of normative social behaviour is constructed—“would be intolerable” (12).

Indeed, for Woolf these illusions are positively dangerous. She writes:

…weighted as they already are with sorrow, [if people] were to take on them that burden too, adding in imagination other pains to their own, buildings would cease to rise; roads would peter out into grassy tracks; there would be an end of music and of painting; one great sigh alone would rise to Heaven, and the only attitudes for men and women would be those of horror and despair. (9)

In illness, Woolf thus suggests, we not only come face to face with the epistemic limits of self-knowledge, but find in the recognition of these limits something that feels good, in the ethical sense of ontological well-being, rather than moral achievement, and which thus in turn offers the possibility of new and exciting forms of intersubjective engagement that take these limits as take as their point of departure. In this regard, Woolf’s treatise on illness does not advocate a retreat from the social, but rather a renegotiation of the terms of recognition and engagement on which the social is based.

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61 We see this in *Flush*, for example, when Woolf writes of how, as Flush and Elizabeth Barrett Browning (then Elizabeth Barrett) “gazed at each other” for the first time, they experienced a mix of familiarity and strangeness (26). She writes: “Each felt: Here am I – and then each felt: But how different!” (26). Flush’s amazement at, and lack of self-recognition in, his own reflection earlier in the work offers an interesting counterpoint to this (24).
The discussion of selfhood and intersubjectivity that unfolds in *On Being Ill* both
to anticipates, and can be further elucidated by, the ethical philosophy Judith Butler
sets out in *Giving an Account of Oneself* (2005). Here, Butler offers a powerful
response to Levinasian ethics and its legacies in literary and philosophical
 scholarship. Like Ricoeur, she sees the lived experience of subjectivity as “unstable”
and “elusive,” characterized by contingency and incoherence, while also stressing
the importance of distinguishing between lived experience and narrative conventions
(Ricoeur *Oneself* 162). Nevertheless, her response differs from Ricoeur’s in
significant ways. Though Ricoeur is wary of the risks inherent in assimilating well-
told life stories to morally good lives, he places emphasis on the role of
emplotment—or, of narrative synthesis and integration—in understanding the self
and giving value and meaning to lived experience, and thus sees self-narration to be
an integral part of the aspiration towards the ethical. In *Giving*, however, Butler
takes a harder line, arguing that assimilation and moral evaluation are inseparable
from the practices involved emplotment. Whereas Ricoeur sees in emplotment a
tendency to slip from ethics into morality that is entirely avoidable, then, Butler sees
the antithesis of the ethical.

In opposition to Ricoeur’s emphasis on emplotment, Butler claims that any viable
attempt at thinking through the relation between the self and the other—at
recognizing and being recognized, at responding and being responded to—must be
predicated on this sense of incoherence, of opacity, of necessary failure. For Butler,
then, as for Woolf, one’s capacity to understand oneself and to recognize others is
not achieved through thinking in terms of coherence and consistency—the kinds of
qualities associated with the autobiographical “I”—but through thinking outside
these terms. In her development of this argument, Butler puts forward two concepts
that give shape to Woolf’s critique of the “genial pretense” of everyday life and to
the power of difference that illness engenders, and thus to the alternative practices of
writing and reading accounts of lived experience—in both fiction and non-fiction
forms—that emerge in *On Being Ill*. The first of these is “ethical violence,” which

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62 In this vein, it is interesting to note that though in *Giving* Butler covers much of the same terrain as
Ricoeur does in *Oneself*, his work is only mentioned once by Butler and even then only as an aside, in
a footnote focusing on Adriana Cavarero’s more recent study *Relating Narratives: Storytelling and
Butler describes as the demand “that we manifest and maintain self-identity at all times and require that others do the same” – a demand implicit in the equation of good life stories to good lives (42). The second emerges in resistance to this, in the form of Butler’s envisioning of an alternative sense of ethics based on an apprehension of the limits of self-knowledge (42-43).

Crucially, while in Giving Butler offers a useful vocabulary for the ideas which Woolf grasps towards in On Being Ill, in On Being Ill Woolf explores how ethical violence is both perpetrated and perpetuated by the modes and conventions through which the literary is defined in early twentieth-century England, while simultaneously putting to the test the potential of alternative critical and creative practices not merely to resist, but altogether to circumvent this violence, and thus to cultivate the kind of alternative ethical sensibility that Butler describes in Giving. We see an early version of this argument played out in Mr Bennett and “Modern Fiction,” both of which take as their central target the discrepancy between lived experience and its representation in literature. In both these essays and others from the period Woolf repeatedly depict writers and readers as the gatekeepers of literature, in the institutional sense of a particular mode of writing and canon of works. In their capacity to safeguard certain habits of production and interpretation, she suggests, writers and readers conspire—some intentionally, others unwittingly—in the preservation of literature with a capital ‘L.’

As part of this argument, Woolf takes the previous generation of authors to task for allowing their obsessive attention to material detail to take precedence over their engagement with everyday lived experience: an argument that positions aesthetics as a major force in literature’s participation in the ethical. In the period since 1910, Woolf claims, these modes of representation have come to feel increasingly disconnected from everyday lived experience, with the result that readers, troubled by the “momentary doubt[s]” and “spasm[s] of rebellion” elicited by their encounters with these representations, begin not only to question whether “life [is] like this?”

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63 Some variants on this exist, such as the conversion, or automythology, narrative, in which self-identity is marked by a discrete moment or period of radical change, to create what Stacey describes as a recognizable “before and after” effect (9).

64 As Lee notes, in many of her essays Woolf articulates a profound “antipathy…to the censorship, corruption and hierarchies of the professional literary world,” while also accommodating for the subconscious effects of these mores on the common reader (“Essays” 91).
but also to ask “Must novels be like this?” (“Modern” 188-189). At times like these, she insists, the aesthetic conventions of the literary thus “cease to be a means of communication between writer and reader, and become[] instead an obstacle and an impediment” (Bennett 21).

“Must Novels Be Like This?”: Woolf on Literature, Ethics, and Aesthetics

The relationship between literary aesthetics and ethics is therefore one of Woolf’s principal concerns at the time of writing On Being Ill. Herein, Woolf uses the absence of illness from literature to highlight the roles of writers and readers in safeguarding a particular idea of the literary—of what it should look and feel like—and the ways in which the aesthetic habits and interpretive conventions that underwrite this idea of the literary make possible forms of ethical violence. In the essay’s opening sentence, Woolf bemoans the absence of illness from literature—a term that, for both the author and her contemporaries, encompassed fiction, poetry, life writing, and the essay—complaining that, “considering how common illness is,” it is “strange indeed that [it] has not taken its place with love and battle and jealousy amongst the prime themes of literature” (3-4). This sentence is often taken as a pseudo-historical proof of the absence of illness from literature prior to 1926, and thus used to reify a scholarly narrative in which the emergence of the illness account genre is attributed primarily to the ascendancy of the biomedical model in the mid-to late twentieth century, spurred on by changes in thinking about the body and the self that occurred during this period. In his annotation of On Being Ill for The Literature, Arts, and Medicine Database, Coulehan takes this line of argument, concluding that, as a result of this rapid expansion, Woolf’s central premise is “no longer true.” What Coulehan fails to attend to, however, is the specificity of Woolf’s phrasing: she writes about the absence of illness not from literature, but from its “prime themes.”

Though Woolf doesn’t explain exactly what she means by “prime themes,” contextual research into the established modes and conventions of writing illness at the time in which she wrote On Being Ill gives us a good idea of what these prime themes are defined against. While book-length published illness accounts of both fiction and non-fiction varieties were rare before the mid-twentieth century, illness
certainly wasn’t absent from literature at the time Woolf wrote *On Being Ill*. Rather, illness was a popular trope in the fiction of the late nineteenth and early twentieth centuries, where it was put to a range of different symbolic and metaphoric ends. As a central figure in the London literary scene, and a voracious reader, Woolf would doubtless have been familiar with many of these works, and indeed a significant number of them can be found in the Woolfs’ library. She also seems to have been aware of the ways in which illness fuelled a range of non-fiction accounts in the late nineteenth and early twentieth centuries, and particularly the ways in which these accounts were constrained by competing popular and medical discourses, not least from her own experience of chronic mental and physical illness, which she documented at length in her diaries and letters.

When embedded in this historical context, the statement with which Woolf opens *On Being Ill* reveals itself to be not a factual observation, as Coulehan and others would have us believe. Instead, it indicates that, for Woolf, the core problem lies not in literature’s failure to depict illness, but in the aesthetic strategies and interpretive habits traditionally associated with these depictions of illness – strategies and habits that revolve around metaphoric thinking and the symbolic inscription of difference and which are, therefore, not so different from those at work in the present day. At the time in which *On Being Ill* was written, then, illness was present in literature, but not as a prime theme. In the opening pages of the essay, Woolf offers a brief survey

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65 For further discussions of illness in this body of fiction, see Meyers (1985), Rothfield (1992), and Herndl (1993).

66 The Woolfs’ library contained many of the texts identified by Meyers, Rothfield, and Herndl as examples of the presence of illness in literature (King and Miletic-Vejzovic).

67 For more on Woolf’s documentation of her experience of chronic illness, see chapter 10 in Lee’s biography *Virginia Woolf* (1996). Examples of the kind of non-fiction writing about illness that Woolf would have encountered include the letters Woolf’s maternal grandmother Maria Jackson, whom she baptised “the invalid of 22 Hyde Park Gate,” sent to Julia Stephen—her daughter and Woolf’s mother—in which she recorded every detail of her symptoms and treatments in page upon page of “hypochondriac complaints” – letters which Woolf read and attempted to catalogue (Reid 457-460). Popular guides to illness, health, and care—the precursors of the “self-health” genre Stacey identifies in 1990s Britain—also circulated extensively during this time both in the UK and the US, including Florence Nightingale’s bestseller *Notes on Nursing* (1859) and Catharine Beecher’s *Letters to the People on Health and Happiness* (1855). Indeed, Woolf’s mother herself contributed to this movement with the slim guide *Notes from Sick Rooms* (1883) published shortly after Virginia’s birth, and which appears alongside *On Being Ill* in the most recent Paris Press edition (2012). Another work of interest is the *Mausoleum Book*, written by Woolf’s father Leslie Stephen around 1895. This text came into being as a response to the illness and death of Woolf’s mother Julia Stephen and, to a lesser extent, that of Leslie’s first wife Minny Thackeray, but leaves out the details of both women’s illnesses. Of Minny’s death, Stephen writes “I rememb er only too clearly the details of what followed; but I will not set them down,” while of Julia’s final illness he simply says “I cannot venture to speak of the last terrible time” (22, 96).
of the three key reasons she sees to keep illness from these prime themes. The first of these can broadly be described as the conventions of the form, and particularly the ways in which these conventions dictate the subjects that writers choose to focus on: conventions that deem the “daily drama of the body” a matter unworthy of literature’s attention (5). The second builds on the first by pointing the finger at reader expectations regarding thematic content and narrative structure: “the public,” Woolf writes, “would say that a novel devoted to influenza lacked plot,” and “would complain that there was no love in it” (6). The third and final barrier that keeps illness from literature's prime themes can be found in one of the essay's best known lines, which describes the “poverty” of the English language and bemoans its lack of “words for the shiver or the headache” (6). Though Woolf qualifies this last statement by suggesting that illness, and particularly physical pain, is a creative catalyst powerful enough to compel the “sufferer…to coin words himself,” she stresses that this kind of linguistic innovation will fall on deaf ears. The “brand new word[s]” that illness yields will “probably […] be something laughable,” she writes, “for who of English birth can take liberties with the language?” (7). Inherent in her use of the phrase “take liberties” is a doubleness that apportions blame to both writers and readers in equal measure: while writers are reticent to explore the full scope of their linguistic creativity, she suggests, readers are unwilling to tolerate the results of this exploration. Though illness holds within it the possibility of a “new language,” this new language will inevitably be “more primitive, more sensual, more obscene” than the English are capable of either creating or receiving. The conventions and habits of writing and reading are thus, she suggests, instrumental in the short-circuiting of literature’s potential to resist ethical violence through aesthetic innovation.

In this critique, the unsuitability of illness as a literary theme rubs up against both the dearth of strategies through which it can be represented, and the reticence of readers to take seriously attempts to develop such strategies. Illness, Woolf suggests, poses challenges to established thinking about narrative structure and the referentiality of language of sufficient scope to render it if not unrepresentable, at least unrecognizable to her contemporaries as literature proper. In this sense, her argument replicates that set out in Mr Bennett and “Modern Fiction” in such a way as to suggest that, for Woolf, the topic of illness and literature might simply provide an
opportunity to rehash an old hobbyhorse and thus a way of quickly spinning out a publication—and generating income—after a relatively fallow period. And yet, certain elements of *On Being Ill* suggest otherwise, indicating instead that *On Being Ill* represents an important extension of the arguments about literature and everyday lived experience set out in these earlier essays. Specifically, this extension takes shape, I argue, as a development of the suggestion made in *Mr Bennett* and “Modern Fiction” that though everyday lived experience is at root “disconnected and incoherent,” unknowable and uncircumscribable, there exists a kind of intellectual and affective integrity to lived experience that allows readers to recognize—on a subconscious and even visceral level, in the form of “momentary doubt[s]” and “spasms of rebellion”—when literature’s attempts to convey it fall short: to recognize, therefore, when ethical violence is being perpetrated (“Modern” 212, 188-189).

And yet, Woolf suggests, these attempts do not always fall short. Rather, literature’s ability to capture and convey these common dimensions of human experience makes possible forms of identification and engagement in the teeth of radical difference. We see Woolf’s commitment to this idea most clearly in her contention that reading allows one

to live over and over again, now as man, now as woman, as sea-captain, or court lady, as Emperor or farmer’s wife, in splendid cities and on remote moors, at the time of Pericles or Arthur, Charlemagne, or George the Fourth.  

*(Being 18)*

By allowing its readers to “live[] out those embryo lives which attend about us,” therefore, literature thus offers a powerful antidote to the tyranny of the autobiographical “I” and, in doing so, can begin to facilitate forms of intersubjective engagement independent of this “I” (19). Neither in *On Being Ill* nor in other of Woolf’s essays is the difference between literature that facilitates this engagement and literature that prevents it explicitly delineated, though her critique of illness’s absence from literature in the former give an indication that this difference might be

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68 As Lee notes, for significant portions of her career Woolf made money almost entirely from her journalistic work, rather than her fiction (“Essays” 90). However, between the publication of *Mrs Dalloway* and the first series of *The Common Reader* in early 1925 and that of *On Being Ill* in April 1926, Woolf spent months in bed, and was during this time forbidden by her doctor to write (Lee “Introduction” xvi-xvii).
at least in part to do with representational strategies. Woolf’s explicit self-presentation in these essays as reader, rather than writer, is instrumental in this ambiguity. The specificity of her critique of the literary marketplace means that individual authors and works stand in for more detailed descriptions of literary style and technique, while the abstract, highly affective language that characterizes her personal accounts of reading gives us insight into Woolf’s responses to works, but not into the nature of the works themselves.

*On Being Ill* is replete with literary allusions, and invokes an eclectic range of texts, from the highbrow—Shakespeare, Keats, “the Miltons and the Popes,” Shelley, Mallarmé, Lamb, and Donne—to the middlebrow and beyond, including newspapers such as *The Times* and *The Morning Post*, and Augustus Hare’s three-volume work of biography, *The Story of Two Noble Lives, Being Memorials of Charlotte, Countess Canning, and Louisa, Marchioness of Waterford* (1893) (7, 16, 21, 23, 14, 17). In this sense, Lee proposes, the essay is “as much about reading and writing”—as much about literature, and the ways in which people engage with it—“as it is about illness” (“Introduction” xxxi). And yet, on closer scrutiny, Woolf’s emphasis on reading, and her reluctance to discuss the act of writing, reveals that the former, rather than the latter, dominates her discussions of the literary in this essay.

**Rash Reading: Realizing and Responding to the Literary**

In contrast to the analysis of the literary marketplace with which *On Being Ill* opens, the essay draws to a close with an intimate description of reading while ill. This description follows in the wake of Woolf’s account of sky-gazing and—by way of a brief detour through a garden bedecked with “gladioli; dahlias; lilies” and other assorted flowers—also of the satire on conformity described by Lee. A thematic continuity of sorts can be traced between this satire and Woolf’s descriptions of reading while ill. In illness, she writes, “responsibility [is] shelved and reason [held] in the abeyance – for who is going to exact criticism from an invalid or sound sense from the bed-ridden?” (20). Released from the obligation to read critically—from what Lee describes as “the cultural power structures which get in the way of the reader's conversation with the book”—in illness one is free to let “other tastes assert themselves”: tastes that are “sudden, fitful, intense” (Lee “Essays” 94; Woolf 20). These tastes, Woolf proposes, draw us to poetry, to the work of writers who share
with ill people both an awareness of the “mystic quality” of words, their “scent” and “flavour,” and the freedom to make use of this quality in their writing – writers who bring to life the kind of “primitive…sensual…obscene” dimensions of language that Woolf suggests the attempt to account for illness requires (19, 21, 7).

The attraction that poetry holds for the ill is reinforced as the section continues, in which she describes how, in illness

We grasp what is beyond [the] surface meaning [of words], gather instinctively this, that, and the other—a sound, a colour, here a stress, there a pause—which the poet, knowing words to be meagre in comparison with ideas, has strewn about his page to evoke, when collected, a state of mind which neither words can express nor the reason explain. (21)

It is at this point that the central motif of Woolf’s account of reading while ill begins to come into focus. This motif is “rashness,” “a propert[y] of illness” that has much in common with her descriptions of illness’s liberatory effects earlier in the essay: the feeling of being “irresponsible and disinterested,” free from “the stirrings of civic ardour” and able to look beyond “dignity and self-possession,” for example (22, 12, 14, 15). In illness, rashness spreads from one’s engagement with the world to our engagement with literature, instilling in one not only an affinity for poetry and a disinclination for prose, but, crucially, an ability to look beyond the “buzz of criticism” and the suspicion that, no matter what “conjectures” one makes while reading, “someone has said it before, or said it better” (22-23). As such, in Woolf’s thinking rashness can thus be seen to signify an openness to and investment in the potentially limitless possibilities of meaning inherent in a work. However, in relation to reading, it also signifies a willingness to participate in bringing these meanings to life, and thus to create the kind of collaborative content that, in Singularity, Attridge sees to emerge in the interactions of readers and works. Like Attridge, then, Woolf sees certain kinds of writing—and particularly poetry—to facilitate this kind of unmediated engagement with the text – an engagement driven not by “intelligence” but by “our senses” (22, 21).

69 In this regard, Woolf's word choice is particularly apt, with “rashness” denoting an impetuous attitude or behaviour while also bearing the homonymic traces of disease – traces that in turn evoke the contagious nature of this impetuousness as it spreads from one's view of normative society to one's engagement with literature.
This viewpoint is reinforced by the contrast Woolf sets up between “rash reading” and what could, by way of contrast, be called ‘cautious’ reading of Shakespeare. When “fully conscious and aware” of the canonical status of Shakespeare’s work, and the critical legacy that surrounds it, she suggests, the reader is “intimidate[d] and bore[d]” (22). By way of contrast,

Illness, in its kingly sublimity, sweeps all that aside and leaves nothing but Shakespeare and oneself. What with his overweening power and our overweening arrogance, the barriers go down, the knots run smooth, the brain rings and resounds with Lear or Macbeth, and even Coleridge himself squeaks like a distant mouse. (23)

However, though Woolf presents illness as the catalyst for this transition from cautious to rash reading, it is clear that she does not see this property to be unique to illness. Rather, she not only believes in the possibility of sustaining this propensity both for rashness and for rash reading in the transition back to health, but also in the possibility of attaining rashness, and of reading rashly, in the absence of illness. In fact, she goes even further, insisting not on the possibility of doing so, but of its necessity. In this vein, she writes: “It is rashness”—rather than illness—“that we need in reading Shakespeare” (22). With its monolithic implications, the task of “reading Shakespeare” contrasts dramatically with the fragments of poetry enjoyed in illness, and in sheer volume alone represents a readerly undertaking of sufficient scale to challenge the memory and stamina of the fittest. This contrast, furthermore, is in direct proportion to the effort Woolf sees rash reading to require. Whereas in illness, rashness comes naturally, then, in health it requires the reader to undertake a form of liberatory labour that, I propose, anticipates Attridge’s description of “creative reading” as a form of engagement based on “a suspension of habits” and “a willingness to rethink old positions” (Singularity 80).

At this point, Woolf performs one of her characteristic half-turns of the head. “But enough of Shakespeare – let us turn to Augustus Hare,” she writes, before launching into an account of Two Noble Lives (23). As Lee notes, on first reading this section seems “a peculiar coda” to an essay on illness and literature, prompting Woolf’s readers to ask “why are we being treated to a potted version of a minor nineteenth-
century historian’s life of two unknown aristocratic ladies [...]” (“Introduction” xxxiii). Indeed, the “rush of scenes and stories” that Woolf recounts here is markedly different from the critique with which the essay opens, though to those familiar with her wider oeuvre her depiction of Lady Louisa Waterford as oppressed artist conforms closely to Woolf’s “quest for female forebears” and for “female inspiration within a patriarchal tradition,” as evidenced in later works such as A Room of One’s Own, Three Guineas (1938), and her essays on Renaissance literature (Lee “Introduction” xxix; Lee “Essays” 93). Further, the image with which it closes—of Lady Waterford crushing the fabric of a “heavy, mid-Victorian” curtain in her hands in silent expression of her “agony” as she watches her husband’s hearse depart—makes “a startling echo” of the ill person who, earlier in the essay, is depicted in the act of crushing pain and sound together to forge a language for illness (Woolf 28; Lee “Introduction” xxxiv).

And yet, in relation to the creative and critical intervention Woolf sets out in On Being Ill, this account of Hare’s Two Noble Lives is not simply a momentary diversion into literary feminism, nor the rhetorical equivalent of a closed cadence. Rather, in these final pages Woolf gives a vivacious performance of rash reading in action, and, in doing so, adds a further dimension to this practice: a dimension that can best be described, I propose, in terms of the Attridge’s notion of creative reading as inventive response. According to Attridge, creative reading not only brings new content into being, but, in doing so, frequently pushes the reader “to an articulation in words” of their engagement with and response to the work in hand (92). It is “as if,” he writes, “the work being read demanded a new work in response” (92). With this in mind, I argue that, in this final section of On Being Ill, Woolf presents her reader with much more than a “potted version” of Hare’s history. Though the descriptions and ideas about women and their lives that circulate in Hare’s narrative—and in the letters and journal entries that this narrative links together—are for the most part reflective of the broader cultural trends that Woolf targets in essays such as “Professions for Women” and A Room of One’s Own, her reading also surpasses the limitations of critical commentary. Rather, in this final section of On

71 For more on Woolf’s essays on Renaissance literature, see Dusinberre (1997).
72 Relevant examples include the Angel in the House trope, and the fraught relationship that women historically have had to creativity and artistic production, as typified by Countess Canning’s description of her sister’s “painted-glass mania” (Hare I.270).
*Being Ill* Woolf differentiates herself from the figure of the cautious reader sketched earlier on—the reader who, intimidated and bored by “all the views of all the critics,” is hesitant to voice her opinions out loud, and instead “hazard[s her] conjectures privately” and “make[s her] notes in the margin”—by offering up a powerfully creative response to *Two Noble Lives*: a response in which her reading of Hare’s work flows over into a writing of the ideas, images, and emotions this text imprints upon her, and the wide-ranging associations it calls to mind (*Being* 22).

Furthermore, as a published work in its own right, Woolf’s account of *Two Noble Lives* invites her readers to engage and respond in various ways both to her creative response and to the original text, should they be familiar with it. By posing this invitation in the final section of the essay—conventionally, the section in which the author’s argument would come to a conclusion—moreover, it is implicitly extended, inviting a response not merely to Woolf’s account of *Two Noble Lives*, but to the essay as a whole. In doing so, she couples the notion of reading as subjective response to that of reading as recursive, transhistorical conversation\(^7^3\): a notion that is enhanced, rather than diminished, by Hare’s original text. Though *Two Noble Lives* is for the most part a curation of the wealth of writing Countess Canning and Lady Waterford left behind in the form of letters, journals, and sketch-books, rather than a narrative in its own right, this curation reveals as much about Hare’s attitudes, values, experiences, beliefs, and judgments as it does about his subjects’, and, as such, can be seen as both a creative response to, and an extended conversation with, his source material (*Hare* I.v). In this way, the final passage of *On Being Ill* thus extends Woolf’s thinking about rash reading beyond the idea of an unmediated, phenomenological engagement with a work, to include the suggestion that the literary both comes to life through, and invites the reader to participate in, creative response.

Woolf’s emphasis here on the changeable and highly subjective nature of the literary

\(^7^3\)This approach to reading both stems from, and feeds into, an ongoing theme in Woolf’s non-fiction writing, which Lee summarizes in the following sequence of statements:

Books change their readers; they teach you how to read them. But readers also change books. […] Writers must adapt to changing conditions. Books alter as they are re-read [and] are read differently by different generations. […] Readers, therefore, need always to be aware of themselves not as isolated individuals, but as part of ‘a long succession of readers’ […]

(“Essays” 89)
as it comes to life in the reader’s encounter with the text builds on the distinction she makes earlier in *On Being Ill* between the feelings of enjoyment and identification that certain approaches to the representation of lived experience elicit in the individual, and more universal judgments of moral value or literary merit. In light of this, both Woolf’s choice of Hare’s *Two Noble Lives* and the nature of her response to this text are central, rather than peripheral, to the argument set out in *On Being Ill*. Hare’s marginal status as a writer—the fact that his work has never been recognized by critics to have any real significance or merit, leading Lee to describe it as “trash” (“Introduction” xxix)—coupled with Woolf’s avoidance of any evaluative comments on the text in her response concord with her distaste for the institutionalization of literature, and her criticism of the complicity of writers and readers in the conservation of this institution, primarily through a habitual equation of certain modes and conventions of writing with the literary.

In this way, Woolf’s response to *Two Noble Lives*, I argue, leads us back full circle to the vision of the literary set out earlier in the essay, as well as in *Mr Bennett* and “Modern Fiction.” Herein, Woolf constructs the literary not as a mode of writing that makes use of specific tools and conforms to a set of recognizable conventions, but as one that instigates in its readers feelings of recognition and, ultimately, response, even in the face of radical difference. Crucially, in Woolf’s view, as in Attridge’s, this kind of literariness is not always palpable to every reader of a given text, and depends as much—if not more—on the attitude with which the reader approaches a text than on the text itself. Further, when present, the feelings of recognition and the kinds of response that come to life in the encounter with the literary are not only unique to each reader—a feature that, in its reflection of her personal and political concerns, Woolf’s account of *Two Noble Lives* demonstrates—but to each reading.

And yet, as we have seen in *Mr Bennett* and “Modern Fiction” as well as in *On Being Ill*, investing all responsibility for the realization of the literary and its ethical implications in the reader is for Woolf a temporary solution to the crisis she saw facing literature in the early twentieth century: a means of buying time and tolerance for writers battling to adjust, and appropriately respond, to the widespread existential and cultural changes she sees to have taken place in and around 1910. As such, she stresses the importance for writers to avoid complacency at all costs, and to commit
fully to the innovation and experimentation necessitated by these changes. Indeed, just as in “How Should One Read a Book,” *A Room of One’s Own*, and *On Being Ill* she warns against the inhibitory effects of the social context of reception on literary innovation, her exhortations in *Mr Bennett* and “Modern Fiction” that readers remember their “duties and responsibilities…as partners in this business of writing books” carry with them a simultaneous, though unvoiced, appeal to writers to resist these pressures. In *On Being Ill*, Woolf negotiates this difficult situation in interesting ways, exposing both the opportunities and the limitations inherent in her vision of a literature capable of accommodating illness amongst its prime themes. She does so by interlacing her critique of the relationship between illness and literature with what can perhaps be best described as an indirect attempt to enact the experience of accounting for—or rather, attempting to account for—illness: an experience that, she suggests, involves extensive creative labour. In the final section of this chapter, then, I explore the representative strategies that Woolf grasps towards in this attempt, and from this add to her theory of rash reading a paradigm for writing illness based on the principle of aesthetics as work.

**Woolf’s Robust Philosophy of Representation: Illness, Autobiography, and Aesthetics as Work**

As we have seen, illness is, according to Woolf, one of the most common features of lived experience in the early twentieth century, in both the habitual and universal senses of the term. Furthermore, in Woolf’s worldview the phenomenon of illness is not discrete from that of health, but is instead a kind of everyday experience *in extremis*. For Woolf, then, the kingdom of the sick is ultimately not an “undiscovered country” so much as a well-travelled, but woefully under-described, hinterland of daily life. As such, she suggests, the representation of illness offers challenging, yet fertile terrain in which to undertake the type of innovation and experimentation that her vision of the literary necessitates. Though Woolf never realized this in her own work by producing a novel “devoted” to illness, over the course of her writing career she explored its representation in several fictional works, including *The Voyage Out* (1915), *Mrs Dalloway* (1927), and *The Waves* (1931). The “overlap” that Lee sees between these various depictions is suggestive of a sustained attempt to explore ways of representing illness in prose fiction, though one
subsumed under Woolf’s commitment as a writer of fiction to other issues, including everyday lived experience more generally, and that of women (albeit of a certain demographic) in particular (Lee “Introduction” xiv).

Significantly, while in these novels illness is not a prime theme, in the sense Woolf gestures towards in *On Being Ill*, in her depictions of the illness experience she moves away from tradition by combining elements of metaphoric and symbolic thinking with a kind of existential realism. Rather, in these texts, Woolf makes use of aesthetics—including metaphor and symbolism—to convey the experience of illness in much the same way as in her depictions of lived experience more generally, both in her essays and her fiction, to create a series of small-scale experiments in treating illness as a “prime theme” of literature. In both *The Voyage Out* (1915) and *Melymbrosia*—an earlier version of the novel reconstructed from Woolf’s manuscripts—, for example, we find Woolf describing of her protagonist Rachel Vinrace’s daily life in ways evocative of her depictions of everyday lived experience in *Mr Bennett* and “Modern Fiction.” Replete with synaesthetic sense impressions, abstract land- and sky-scapes, and perpetual movement, this mode of description is intensified, rather than dispensed with, during Rachel’s fatal illness as her subjective perceptions of the world segue into feverish delirium. In killing off her female protagonist Woolf can be seen to participate in a wider tradition in women’s writing and visual art – a tradition exemplified in the late nineteenth and early twentieth centuries in images of dead women, such as Sarah Bernhardt’s self-portrait “Sarah in Her Coffin,” and literary deaths, such as that with which Edith Wharton’s *House of Mirth* concludes, and which takes shape in Woolf’s own oeuvre as the act of “killing the Angel in the House,” which she describes as “part of the occupation of a woman writer” and one of the two “adventures of my professional life” (“Professions” 238, 241).74 By describing not just Rachel’s death but her experience of illness in detail and at length, however, in *The Voyage Out* Woolf intertwines this with the second of

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74 Though closely related to depictions of female illness and death in the work of their male contemporaries, these artistic and literary stagings of death were radically subversive. As Herndl notes, this phenomenon represents not a conformation to a “male-defined genre” by women writers and artists so much as a turning of “that genre to their own psychic needs” (137). “If these women produced artistic objects to satisfy the demands of patriarchal disciplinary power,” she writes, “then those productions could take their places in that power structure,” and enable the fictional invalid/dead woman to “shield [her creator] from having to embody cultural norms” (137). For more on this, see Herndl (135-140) and Showalter (1985).
these adventures: the struggle to “tell[ing] the truth about [her] own experiences as a body” (“Professions” 241).  

As has already been discussed, illness is “one of the main stories” of Woolf’s life, and her desire to find a language for this story can be traced not just in her fiction, but in her diaries and letters. Lee describes the depictions of illness in her diaries as “some of the most powerful and accurate pieces of prose she ever wrote,” before going on to argue that “to arrive at this language for illness she had to work past a whole swathe of prescriptive terms, some of which she never quite shed” (Woolf 187). Like the “new language” forged from pain and sound in On Being Ill, then, in both her fiction and autobiographical writing Woolf attempted to “create an original language of her own” distinct from “the competing narratives” of illness that circulated in the early twentieth century – a language “which could explain her illness to her and give it value” (Lee Woolf 191). However, in spite of the clear autobiographical connections between On Being Ill and Woolf’s lifelong struggle to articulate her experience of illness, the relevance of this essay, and particularly of its aesthetic dimensions, to this struggle has thus far been overlooked.

Though in On Being Ill, as in most of her essays, Woolf's narrative is never explicitly autobiographical—as both Bolaki and Lee note, she does not at any point say “I” (Bolaki “Lights” 119; Lee “Introduction” xxxiv)—she frequently makes use of the first person plural in her descriptions of illness and of reading, thus implicating herself in the activities, affective experiences, and opinions she describes. However, the most obvious clue to the autobiographical subtext of On Being Ill can be found in Woolf’s rash reading of Two Noble Lives. For Lee, this clue, which resides in the tableau of Lady Waterford with which the essay ends, is the only dimension of this section that makes sense (“Introduction” xxxiv). It does so by presenting “an image of fierce courage” that not only links back to the figure of the ill person who, earlier in the essay, is described in a similar act of crushing, but is ultimately autobiographical in nature, reflecting Woolf’s “heroic powers of endurance and courage, her lack of self-pity, and the use she made of her physical and mental

35 In this endeavour, Woolf can be seen as an early pioneers of what Bolaki terms the “body Bildung” – a narrative in which the female body acts as “a site of experience, knowledge, development, and resistance” and “a key player” in “a continuously renewed project of learning and teaching,” and which is exemplified, she argues, in the work of Audre Lorde (Bolaki Unsettling 185).
suffering [...] how she put [these qualities to work], and transformed them into a new kind of writing” (“Introduction” xxxiv). To this I would add the many parallels between the lives of Lady Waterford and, to a lesser extent, Countess Canning to Woolf’s own, as well as the implicit connection between Lady Waterford’s crushing of the “heavy, mid-Victorian” curtain and Woolf’s call for writers to dispense with the tools and strategies of the Victorian realist tradition and its preservers in the Edwardian era—such as Bennett, Galsworthy, and Wells—in order better to describe the lived experience of the everyday in essays such as Mr Bennett and “Modern Fiction.”

This autobiographical dimension to On Being Ill is not, in itself, unusual: as Lee notes, Woolf’s essays come together to create “the autobiography of a reader” (“Essays” 104). However, in her non-fiction work one can also sense moments in which Woolf seeks to articulate her experience as a writer. In On Being Ill, this comes to the fore in her description of how, from the recumbent perspective of illness, the sky is perceived as if for the first time—revealing itself to be an “extraordinary spectacle” of “light and shade,” rather than “a background for man” or a symbol of the weather (Being 13). Earlier in this chapter, I pointed to the close correspondence between this passage and those in which Woolf seeks to describe the everyday lived experience in Mr Bennett and “Modern Fiction.” I now want to take this further by suggesting that her description of sky-gazing might also be legible as a veiled attempt to describe the experience of illness, just as in these earlier essays Woolf’s critique of the Edwardian literary tradition partially conceals her attempts to find a new language for everyday subjectivity: an idea corroborated by the reference to “veiling [...] and unveiling” in this section of On Being Ill (13).

These include the sisters’ childlessness, their experiences of chronic illness and long periods spent in isolation, and their significant, but largely unrecognized, creative outputs. To this one might also add the posthumous curation of their lives and work by Augustus Hare, a phenomenon that could plausibly have intersected in Woolf’s mind with her husband Leonard’s role as editor and advocate of her work, which he continued after her death. Further, the emphasis Woolf places on the sisters’ separation—in which she elides the many trips to Europe that Charlotte made in her role as Lady of the Bedchamber to Queen Victoria and focuses solely on her move to India in 1855, which she anachronistically synchronizes with Louisa’s move to Ireland in 1842—in her account of Two Noble Lives, one might posit, could be seen to reflect Woolf’s preoccupation with the impending departure of her close friend and lover Vita Sackville-West to Persia at the time of writing On Being Ill: her description of the letters that “begin to cross vast spaces in slow sailing ships” a premonition, perhaps, of the years to come (Lee “Introduction” xvii-xviii; Woolf Being 26).
This indication that, in *On Being Ill*, Woolf seeks to explore new ways of accounting for illness is almost overshadowed by a quick preview of the satire on conformity that Woolf develops in the second half of the essay: a structural arrangement that somewhat disrupts the creative momentum achieved in her description of sky-gazing (13). However, instead of using this contrast to mark the conclusion of one point and the introduction of another, however, in this section of *On Being Ill* Woolf jumps the rhetorical gun, to finish on the more sober enjoinder that “one should not let this gigantic cinema play perpetually to an empty house” (14). The shift in tone here re-establishes the narrative voice with which the essay opens—a voice associated with Woolf’s “more theoretical pieces on fiction” (Lee “Essays” 95)—and is further intensified by the invocation of another of Woolf’s essays of the same period and genre, entitled “The Cinema” (also 1926), which shares with *On Being Ill* a concern with the representational possibilities offered by a given medium. This reference consolidates the link between Woolf’s impressionistic descriptions of lived experience—which in this context can be seen to create a montage-like effect—and her call for “new forms for our new sensations.” It can also be seen as a hint to the reader that, in *On Being Ill*, Woolf’s agenda goes beyond a critique of the relationship between illness and literature to include an attempt—however diffident—to bring the gigantic cinema of the illness experience to a wider audience, and, by capitalizing on her growing reputation and readership as an essayist during the 1920s, to bring an audience to this gigantic cinema.

At the time this must have seemed like an effective strategy, for as Lee points out, in the interwar period Woolf was better known as an essayist than a novelist (“Essays” 91). However, in the aftermath of her death, Woolf’s work as an essayist fell into “relative neglect” (Lee “Essays” 89), with the result that in the late 1990s Bowlby would write

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77 Momentarily impersonating the comical outrage of the “middlebrows”—a social group Woolf describes as “the busybodies who run from one to the other with their tittle tattle and make all the mischief”—she expresses indignation at the fact that the sky “has been left to work its will year in and year out,” with “the waste of Heaven knows how many million horse power of energy” (“Middlebrow” 179; *Being* 14). This seems, she continues, “to call for comment and indeed for censure” – “Ought not some one write to The Times?”, for “use should be made of it” (Being 14). Woolf’s detour here into pastiche contrasts with the overall style and tone of *On Being Ill*, introducing into the essay elements from a different category of her non-fiction writing: one comprised primarily of her reviews of contemporary literature and letters to newspapers, and which tends to be sharper and more satirical in tone.

78 For more on this, see Bowlby (253-254).
Virginia Woolf the novelist and Virginia Woolf the essayist are two writers who might seem to have very little in common. One is famous, the other is not. One is a key figure in the history of modernism, the other was principally a journalist, working to commissions for weeklies and other periodicals. One wrote for art, the other (much of the time) for money. …One has been widely studied, and is the subject of numerous critical works; the other is little known, and often considered merely as an adjunct to the first, enhancing readers’ understanding of the novels. (220)

Indeed, Woolf’s essays did not receive widespread critical recognition until the 1980s, though this too was not without its limitations: as Bowlby goes on to note, those essays which are widely read tend to reflect the chief division in Woolf scholarship and pedagogy between modernist studies and feminist studies, a division that leaves On Being Ill out in the cold.

Consequently, On Being Ill has suffered a double neglect: first, at the hands of this historical disregard for Woolf’s essays, and particularly their aesthetic strategies; and second, during the more recent reconsideration of Woolf as essayist, as a result of the apparent disconnect between the essay’s subject matter and Woolf’s oeuvre more widely – a disconnect that, as I have shown, does not hold up to scrutiny. In the first half of this chapter, I show how On Being Ill not only reflects, but ultimately extends on-going themes in her non-fiction writing. Likewise, in this final section, I show how the essay builds on Woolf’s attempts at “telling the truth about [her] own experiences as a body” in her writing more widely: attempts that Caramagno, among others, has characterized in terms of the ‘translation’ and ‘transformation’ of the symptoms of bipolar disorder. I do so by exploring how the aesthetic strategies deployed in On Being Ill go beyond an attempt to translate the experience of illness, and of embodied subjectivity more generally, and instead work towards an enactment of the experience of accounting for illness—and thus for the embodied self—in ways that draw on, but are not limited by, the multiple discourses that overdetermine these experiences.

79 In this respect, the publication in 1986 of the first in a six-volume collection bringing together all of her essays, articles, and reviews—a project that was not completed until 2011—was a real watershed.

80 For more on this, see Caramagno (1988).
As Bolaki points out in her reading of the essay, in *On Being Ill* Woolf resists “settling on the idea of the ineffability of pain” articulated early on in the essay, and instead pursues the notion that, in response to the inadequacies of existing discourses of illness, the sufferer is “forced to coin words himself,” and thus to undertake a form of strenuous creative labour (Bolaki “Lights” 120; Woolf *Being* 7). The image of linguistic invention that follows epitomizes Woolf’s aesthetic approach in the essay: an approach in which, Bolaki argues, the notion of work is central. “Taking his pain in one hand,” Woolf writes, “and a lump of pure sound in the other (as perhaps the people of Babel did in the beginning),” he “crush[es] them together” with such intensity “that a brand new word in the end drops out” (7). This image is repeated at the essay’s close, though in this latter case they are the hands not of an ill person, but of Lady Waterford as she crushes the fabric of a “heavy, mid-Victorian” curtain in her “agony” at the burial of her husband (28).

These images act as a lodestar for Bolaki’s reading of “aesthetics as work” in *On Being Ill*, a concept she adapts from Alan Radley’s *Works of Illness: Narrative, Picturing and the Social Response to Serious Disease* (2009). Though Bolaki doesn't give much of a sense of what “aesthetics as work” might entail, with this phrase she picks up on something fundamental to the essay, and to its relationship to Woolf's oeuvre more widely. From the very beginning, Woolf’s prose quivers with exertion, both physical and intellectual. Like many of her essays, the impression of effortless rumination it gives belies a razor-sharp analysis, its compact format disguising the sheer scope of allusion and reflection it displays. Beneath what Lee describes as “its sleight-of-hand and playfulness, and its appearance of having all the ‘space and leisure’ in the world for allusion and deviation,” then, we find in *On Being Ill* a busy factory, noisy with the din of intellectual and aesthetic work, crowded with the tools and materials of writing (“Introduction” xiv). The image of coining words illustrates this well. With words like “forced” and “crush,” the lexical field of this passage combines with the central figure of the human body, and particularly the hands on which Woolf focuses, to create a sense of intense manual labour. Her parenthetical reference to Babel calls to mind not only the making of language, but also the brick making and building work involved in the construction of the titular tower, while the phrase “a lump of pure sound” evokes the raw materials of industrial processes such as smelting, combustion, coking, and mining, the last of which brings to mind the
essay’s alternative title “Illness — An Unexploited Mine.”

For Bolaki, the “lasting legacy” of On Being Ill lies in Woolf’s emphasis on “the importance of taking seriously the aesthetic dimension and imaginative work underlying illness narratives” — a legacy that chimes with Woolf’s revisioning of the literary, particularly her call in essays such as Mr Bennett and “Modern Fiction” for writers to experiment with new modes of representing lived experience, and also her descriptions of rash reading and creative response in the second half of On Being Ill (“Lights” 120). In this short piece, Bolaki can only gesture towards what, for her, are the ethical implications of Woolf’s essay. However, both these gestures and the rooting of her reading in Radley’s Works allow for the extrapolation of an argument that draws on many of the themes discussed above. For both Radley and Bolaki, the aesthetic constitutes an important way of making sense of the illness experience and rendering it meaningful, to the person accounting for illness, to others with illness, and even to those who have previously had “no access” to this experience (Bolaki “Lights” 120). The production of aesthetically-active works, Radley posits, offers people with illness the opportunity to “render[ing] life’s conundrums somehow graspable” and to “re-creat[e]” their experience for others (36, 41). In this respect, their approach is evocative of the relationship Ricoeur sees to obtain between lived experience, emplotment, and the ethical, both in the sense of self-understanding and of recognizing and responding to others.

In her reading of On Being Ill, Bolaki thus makes an important and long overdue case for re-examining the relevance of Woolf’s essay to the present day. However, in looking to Radley’s Works, rather than Woolf’s wider oeuvre, as a guiding framework in this re-examination, I argue, she ends up missing, by some margin, the full significance of the creative intervention staged in this essay in relation to contemporary illness accounts. Nevertheless, the contrast between Radley’s analysis and Woolf’s deployment of aesthetics in On Being Ill is illuminating, for it draws into sharp relief the key difference between this deployment and the kinds of translational activity Radley describes. As we have seen, for Woolf the representation in literature of the everyday and of illness should, in their ideal forms, share a common prime theme, or idea to which the aesthetics they deploy are directed. This prime theme consists in the gap between lived experience and
representation, and the work involved in bridging it: a gap that illness brings to the fore. The aesthetic activity that this prime theme requires is thus not translational, but meta-translational: a kind of self-referential foregrounding of this work. Crucially, then, though in *Works* Radley stresses that the question of whether or not “stories or paintings made by ill people are ‘art with a capital A’” is, for him, “a secondary concern,” the meta-translational ethos that underpins Woolf’s thinking about aesthetics as work in *On Being Ill* resonates with both the idea of the literary and its relationship to the ethical put forward in her essays more widely, and attempts to describe this relationship in contemporary theory and criticism, as exemplified in Attridge’s formulation of this relationship in terms of literature’s “staging of the fundamental processes whereby language works upon us and upon the world” (Radley 38; Attridge *Singularity* 130).

We can see this meta-translational quality of aesthetics as work in Woolf’s use of the word “coin” in the image of the ill person described above (*Being* 7). Here, Woolf layers a sense of linguistic invention and creative labour with the physical work of minting, a process that involves work both blunt (hammering) and fine (milling, inscribing), and which has ancient, artisanal origins as well as associations with the modern technology of mass production. The use of the infinitive in this sentence keeps “coin” free from inflection, and thus enables it to retain a sense of its significance as a noun, or object – a characteristic that is reinforced by the sentence’s closing image of the “brand new word” that falls, like a newly minted shilling, from the sufferer’s hands. This tactic enables the word to take on multiple symbolic roles, ranging from an artefact with intrinsic, historic, and/or aesthetic value—such as bullion coins made of precious metal, or the tetradracmas of Alexander the Great—to a token of socially and politically constructed value and medium of exchange: a multiplicity that plays on the double-sided nature of the coin as artefact. In this way, Woolf not only foregrounds the polysemic potential of language and image, but does so in ways that feed into and extend her argument about the institutionalization of the literary. By embedding this manoeuvre within an image of linguistic innovation driven by illness, moreover, she engineers one of many instances in which the aesthetics of *On Being Ill* work to consolidate the connection between illness, literature, and the everyday, and thus to complement—and even extend—one of the essay’s prime themes.
Conclusions
In her essays, and particularly in *On Being Ill*, Woolf harnesses the sense of self-reflexiveness that explicit aesthetic activity creates to the act of accounting for the self, using it as a means of performing and problematizing the gap that separates the subjective experience of daily life from the narrative conventions—such as coherence, consistency, causality, closure and so on—according to which this experience is both conveyed to and evaluated by others: a gap that, as we have seen, Woolf believes illness to foreground. This gap is explicitly addressed only once in *On Being Ill*, in Woolf’s description of the “embryo lives which attend about us in early youth” are “suppressed” by the autobiographical ‘I’ (19). And yet, at the same time, her handling of aesthetics in the essay repeatedly reinforce and extend this idea, not just in her omission of the ‘I,’ but also in the work’s oscillation between omniscient narration and the first person plural, and in the moments of blended consciousness and embodiment between author and reader that this latter mode creates. The range of roles that Woolf plays in this essay—ordinary reader, novelist, critic-scholar, person with illness—and the heterogeneous cast of characters with which her prose is populated, including dentists, philosophers, lion tamers, schoolgirls, organ grinders, and explorers, also contribute to this effect.  

As a prelude to the chapters that follow, however, I want to bring this reading of *On Being Ill* to a close by looking briefly at the directions in which Woolf develops the principle of aesthetics as work. Like Woolf’s fiction and non-fiction oeuvre more widely, *On Being Ill* is replete with vast, abstract land- and sky-scapes such as those found in the essay’s middle section: vistas that are distinctly post-impressionistic in their deployment of colour and shape. Comparative reading of these passages in *On Being Ill* alongside Woolf’s descriptions of lived experience in essays like *Mr Bennett* and “Modern Fiction,” as well as similar moments in her fiction, might thus lead one to the conclusion that, when Woolf talks about the need for writers to create for their readers a “common meeting-place,” she has in mind something along the

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81 This element in turn sheds further light on Woolf’s interest in Hare’s *Two Noble Lives*, which, as a predominantly epistolary text enveloped by an overarching omniscient historical narrative that spans over a century, can be seen to foreground the process of emplotment through which life stories are given coherence, causality, and so on. Moreover, Hare’s inclusion of letters written by himself in the third volume exaggerate this aspect of the work further.
lines of these panoramic vistas, and the rejection of mimesis that they represent. In this regard, *On Being Ill* not only constitutes an important extension of Woolf’s critique of mimesis as set out in essays like *Mr Bennett* and “Modern Fiction,” but can also be seen to epitomize her individual take on the principles and practices of modernism, and thus to illuminate further the ways in which these practices are extended and revitalized in the late twentieth- and early twenty-first centuries by the writers considered in this thesis.

To this, Woolf’s essay “The Cinema” (1926)—a work directly contemporaneous to *On Being Ill*—is a particularly valuable resource, as her reference to illness as “this gigantic cinema” indicates (*Being* 14). Woolf’s exploration here of the potential of the cinematic medium “for evoking the pathos of time having past, or the complexity of modern experience” not only takes her discussions of artistic innovation in *Mr Bennett* and “Modern Fiction” in new directions, but, in doing so, encapsulates that which makes the literary inimical to aesthetic formalism as theorized and practiced by her contemporaries: the dependence of its aesthetic strategies on words (Bowlby 253). In contrast to those images that are “cast in bronze or traced by pencil,” she writes, “the images of a poet […] are compact of a thousand suggestions of which the visual is only the most obvious or uppermost” (“Cinema” 170). For Woolf, this is both an opportunity and an obstacle: words are polysemous, capable of signifying in multiple directions, and acting on multiple sensory levels, at the same time. And yet, she reminds us, there are also areas of lived experience that are inaccessible to words: areas that cinema, she posits, might be able to tap into (“Cinema” 170). Both in her descriptions of illness and of everyday lived experience, and in her rash reading of Hare’s *Two Noble Lives*, Woolf can be seen to explore different approaches to the matching of words to lived experience, or to what we might call the referentiality of language—and particularly to the forging of a “new language” for illness—with specific emphasis on those associated with post-impressionism and formalism: associations significant in their relationship to ideas of mimesis and of the separation of the aesthetic from other realms of experience.

In the chapters that follow, I show how the critical and creative manifesto that Woolf sets out in *On Being Ill* is taken up in a group of illness accounts written at the turn of the twenty-first century. I doing so, I do not mean to suggest that any causal
connection exists between Woolf’s essay and these contemporary accounts: though some of the texts considered in this thesis explicitly engage with *On Being Ill*, they tend to do so in ways that perpetuate the essay’s distorted afterlife by borrowing a sentence or two on the ineffability of pain and the absence of illness from literature to support or contradict their own observations. And yet, in their engagements with the critical issues and creative practices set out in *On Being Ill*, these accounts testify to the substantial, but as yet unrecognized, afterlife of Woolf’s thinking about illness, literature, and the everyday in contemporary literature – an afterlife very different from that which can be constructed from the essay’s various citations in critical and autobiographical writing about illness from the late twentieth- and early twenty-first centuries. Further, these accounts demonstrate how the principles and practices set out in *On Being Ill* can be seen to offer a valuable paradigm for thinking about writing and reading illness in the present day: a paradigm that not only offers an alternative to those currently employed in both literary studies and the medical humanities, but which, in doing so, might constitute a valuable point of departure from which to begin working towards the kind of “sophisticated and inclusive humanities approach” to illness accounts that Waddington and Willis advocate for.
Chapter Three

On Being Ill, Academic, and Female

Contemporary Autoethnographies of Illness

“Neither the woman experiencing an illness nor the author writing a story about a woman’s illness is free of the ways that illness has been represented before, but neither one is entirely constrained either.”

Diane Price Herndl (12)

During an abortive foray into alternative medicine, Jackie Stacey discovers that, as an “academic lesbian,” her experience of illness is from the outset overdetermined by multiple discourses of gender, sexuality, and illness (Teratologies 39). In a remarkable display of insensitivity, the Reiki practitioner she consults shortly after emergency surgery for a ruptured endodermal sinus tumour—a rare, and highly malignant, cancer originating in the germ (sperm or egg) cell—and in the hope of avoiding chemotherapy, comments on how her profession as an academic and her homosexuality might have disrupted the balance of masculinity and femininity in her life, and directs her to the work of Louise Hay, a self-health guru who “believes that illnesses are a result of emotional distress” (4, 30, 38-39). She recalls how, “fresh from the alienating experience of conventional medicine,” she had expected “something better from its alternative counterparts,” but was left feeling “equally patronis[ed] and insult[ed]” (38). “Not only had this Reiki healer introduced new orthodoxies,” Stacey writes: “she had also reinforced certain very traditional ideas about essences, about woman and nature, and about sexuality and reproduction,” and deployed these ideas in ways that seemed both illogical and opportunistic, “an over-blatant clutching at straws” (38).

In Teratologies (1997), the work that emerged out of Stacey’s cancer experience, the discursive overdetermination of illness and particularly cancer forms a prominent theme. Beginning at a strictly somatic level with the contested aetiology of her illness, the sensation of being repeatedly “rewritten” rapidly comes to pervade Stacey’s lived experience, as the “new narratives” imposed on her body “rescript the
story of [her] life with ruthless editorial authority” (4). This overdetermination is facilitated, Stacey suggests, by the disruptive effects of illness on her sense of self, which quickly come to resemble the state Frank calls “narrative wreckage” (Frank 53-56).

For Frank, narrative wreckage demands repair. Illness happens, he writes, “in a life that already has a story, and this story goes on, changed by illness, but also affecting how the illness story is formed” (54). However, for Stacey, the relationship between illness, narrative, and life is not so straightforward. The disruption caused by Stacey’s unexpected cancer diagnosis forces her into an awareness of “the extent to which all kinds of narratives had quietly structured [her] imagination previously, almost without [her] knowledge”: narratives that were not only prospective, but retrospective (6). On the one hand, she writes of how, before the diagnosis, she “had harboured the hackneyed (though barely articulated) fantasy that [she] would live until [her] early eighties and would die suddenly, but peacefully, in [her] armchair,” and of cancer’s sudden compression of this distant future “into the most frightening of time scales” (5). On the other, she notes that, “in the light of diagnosis, the recent past” demanded reexamination “for clues of this newly revealed deception” (5). As such, for Stacey the disruptive effects of illness throw into sharp relief the gap between lived experience and narrative, by fostering a sudden and overwhelming awareness of the life narrative that one has subconsciously set in place – or, rather, the life narrative to which one has subconsciously subscribed, for as Stacey points out life narratives, like illness narratives, tend to conform to certain cultural templates.

In addition to foregrounding the gap between lived experience and narrative, in *Teratologies* Stacey describes how illness creates an ontological vacuum to which other narratives crowd to fill. Indeed, though from the outset she is resistant to the narratives with which the contemporary cancer experience is colonized, and conveys this resistance in *Teratologies*, her account also attests to their power and their allure. Stacey’s acknowledgement that her turn to analysis and scholarly discourse is in part a coping mechanism—a way of making the illness experience “more familiar and more manageable”—is one such example: an example that accords with Frank’s thinking about the kind of repair work that narrative undertakes in the aftermath of
illness (3). Her integration of this analytic mode with autobiography is another. This integration is not only representative of her “educational histor[y] and race and class backgrounds,” her identity as a member of a generation of highly politicized, “participatory patients,” and her academic profession (3). It also reflects the influence of feminist scholarship on women’s life writing about illness, and vice versa, in the late twentieth and early twenty-first centuries in response to the exclusions and assumptions inherent in the body politics of second wave feminism.

Stacey is sympathetic to those who turn to narrative for palliation, and acknowledges that her account of cancer “follows one of the typical trajectories” of illness narratives in its dramatization of “crisis, rescue, and recovery” and strong push towards closure. Her project in Teratologies, however, is not to valorize narrative, but to expose its artifice. Though narrative offers “the promise of delivering the truth about the illness,” she argues, in reality it tends instead to “cover up the absences, the amnesia and the gaps in the story” and “iron out the competing accounts, the multiple meanings, the lack of meaning” that characterize the illness experience (14). In this respect, it is reflective of a deep-seated cultural preference for thinking about “lives as coherent stories of success, progress and movement,” stories in which “loss and failure have their place but only as part of a broader picture of ascendance” (9).

In Teratologies, then, Stacey’s analysis is underwritten by a distinctly Woolfian hypothesis on the coextensiveness of illness with everyday lived experience. We see this overlap most clearly in her assertion that:

Stories about illness are an intensification of the way in which we generally understand our lives through narrative. The experience of cancer may bring these narrative processes into particularly sharp focus, but in many ways it only makes explicit the importance of narratives in the construction of the self in contemporary culture. (8-9)

Additionally, the suggestion here that narrative is one of the key terms that illness and everyday lived experience share brings to mind Butler’s critique of narrative

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82 For more on the politicization of patienthood, see chapters 1 and 2 in Diedrich (2007).
83 “It is impossible,” she writes, “to have cancer and not be seduced by the power of [the] cultural narratives” that surround it (13).
identity. And indeed, though *Teratologies* unfolds as an anatomization of the specific narratives, myths, and metaphors of cancer and of illness more generally that circulate in Western culture in the late twentieth century, these narratives, myths, and metaphors also act as a stalking horse from behind which Stacey takes on the postmodern assumption that narrative is, to borrow Frank’s phrase, the self’s medium of being: a project that closely aligns *Teratologies* with the ethical philosophy sketched out in *Giving*.

From the synopsis I have given thus far, Stacey’s interrogation of this assumption, and of the specific ways in which it impinges on the illness experience, appears to take place in what would traditionally be described as the content of her writing—the events, behaviours, and experiences it describes, and the opinions, attitudes and judgments it explicitly voices—and in this way to conform to a mode of writing that combines academic analysis with testimonial evidence. As such, *Teratologies* ostensibly takes shape as a work of autoethnography—a genre in which the principles of ethnography are applied to the author and the culture within which they live, and which is thus self-reflexive in essence. Like the illness account, the autoethnography is an almost exclusively modern phenomenon whose origins can be traced back to the 1920s, and indeed a significant history of overlap obtains between the two genres.84 In its autoethnographic approach to illness, *Teratologies* is thus representative of a wider trend: a trend that has its origins in works such as Audre Lorde’s *The Cancer Journals* (1980) and Robert Murphy’s *The Body Silent* (1987), but which gains particular prominence at the turn of the twenty-first century, when autoethnography increasingly becomes the genre of choice for women academics, as exemplified in works such as Zillah Eisenstein’s *Manmade Breast Cancers* (2001), Susan Greenhalgh’s *Under the Medical Gaze: Facts and Fictions of Chronic Pain* (2001), Kathlyn Conway’s *Illness and the Limits of Expression* (2007), Havi Carel’s *Illness: The Cry of the Flesh* (2008), Barbara Ehrenreich’s *Smile or Die: How Positive Thinking Fooled America and the World* (2009), and Susan Gubar’s *Memoir of a Debulked Woman: Enduring Ovarian Cancer* (2012).

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84 A comprehensive discussion of the history of the autoethnography can be found in L. Anderson (2006). For more on the manifesto narrative, see chapter 6 in Frank.
In these accounts, as in *Teratologies*, the overdetermination of the illness experience by discourses of gender, sexuality, and illness is described and analyzed, in keeping with the conventions of the autoethnography genre. Typically, moreover, in these accounts this blend of description and analysis is spliced to a politics of resistance and a call for social action: a trajectory that broadly conforms to Frank’s “manifesto” narrative, but which, in the context of late twentieth-century women’s writing, is also evocative of “the feminist Bildungsroman,” a narrative that charts “the changing self-consciousness of women accompanying their gradual entry into the public domain” (Felski *Beyond* 133). This resistance is typically directed against the discourse or set of discourses that the author has found particularly overbearing during their experience of illness. Works such as Lorde’s *The Cancer Journals* and Eisenstein’s *Manmade Breast Cancers*, for example, challenge the cultural preference for reconstruction or prosthesis in the aftermath of mastectomy, though Eisenstein takes a more flexible stance on the issue than Lorde, while in *Smile or Die* Ehrenreich targets the hyperfeminization and sentimentalization of breast cancer. In doing so, these accounts undertake important cultural, social, and political work, as DeShazer shows in *Fractured Borders*, and act as valuable resources not just for health care professionals and educators, scholars in the medical humanities, and the friends, colleagues, and families of women with illness, but for society at large.

*Teratologies* differs from this genre of feminist illness autoethnography in two key ways. The first proceeds from Stacey’s positioning of her critique of the discourses that define British cancer cultures of the 1990s in relation to a more widespread tendency to assimilate lives to stories, and vice versa: a positioning that gives *Teratologies* a more general ethical scope than many other such autoethnographies. The second lies in the work’s striking literariness, and of the ways in which this literariness is repeatedly foregrounded. *Teratologies* is from the outset not only a richly aesthetic work, but one in which the relationship between the aesthetic dimensions of Stacey’s writing and its conceptual content is of central importance.

85 This process is often recursive: in her 2002 essay “Reconstructing the Posthuman Feminist Body Twenty Years After Audre Lorde’s *Cancer Journals*,” Diane Price Herndl recounts her departure from an antireconstructionist stance influenced by Lorde, and develops a counter-argument in favour of prosthesis that draws on posthumanism.
Surprisingly, the literariness of *Teratologies* has received little critical attention. Instead, responses to the work exemplify the tendency amongst both medical humanists and literary scholars to read autobiographical illness autoethnographies for content, and to consider their formal features as symptoms of cultural preference rather than authorial intention. DeShazer’s reading of *Teratologies* is a case in point. For DeShazer, Stacey is considered first and foremost a “postmodern feminist theorist,” and her illness account interpreted accordingly as a work of cultural analysis, rather than an autobiographical account – a framing that is most evident in her citation of it alongside other more conventionally academic works to support readings of more conventionally ‘literary’ texts, such as prose fiction (Gini Aldaheff’s *Diary of a Djinn*), life writing (Justine Picardie’s *Before I Say Goodbye*), and the poetry of Adrienne Rich (24, 231, 29). Further, when DeShazer acknowledges the autobiographical element of Stacey’s text, she does so primarily in citations that frame this element as a source of sociological insight into the experience of illness, and a form of historical testimony representative of the treatment of “thousands of other women in the United States and Great Britain from the 1940s to the 1980s” (41, 79, 27). A similar tunnel vision is evident in Radley’s reading of *Teratologies*, and particularly the comparisons he draws between Stacey’s account and the photography of Jo Spence.\(^6\) Though both make extensive use of *Teratologies* in their studies of illness accounts, therefore, at no point do Radley or DeShazer consider the text as a literary work in its own right: a work in which style and form function not merely as rhetorical strategies, but as meaningful aesthetic deployments in which not only are the affective and perceptive dimensions of the illness experience enacted, but the observations and arguments they engender reinscribed and often extended.

In this chapter, I offer an alternative to these readings by showing how Stacey’s deployment of aesthetics extends the observations, experiences, and critical interventions set out in *Teratologies* in compelling and meaningful ways. In doing so, moreover, I use *Teratologies* as my point of entry into a small but significant—and thus far overlooked—cluster of illness accounts by feminist academics in which

\(^{86}\) See, for example, Radley (106-107). Franziska Gygax replicates this approach as well in her reading of *Teratologies* alongside illness accounts by Eve Kosofsky Sedgwick and Jill Bolte Taylor: for more on this, see Gygax (2009).
the conventions of the autoethnography—and those of the genres with which it frequently overlaps, such as the manifesto and feminist Bildungsroman—provide a framework within which a politics of resistance is spliced to more wide-ranging ethical enquiry and a sophisticated and meaningful deployment of language and of the aesthetic possibilities of the published text, to create accounts that are at once robustly analytic and distinctly literary. Alongside Teratologies, my readings in this chapter will look at three other feminist autoethnographies of illness from the late twentieth and early twenty-first centuries: Mary Felstiner’s Out of Joint: A Private and Public Story of Arthritis (2005) and Ann Oakley’s Fracture: Adventures of a Broken Body (2007), both of which are book-length, and one shorter essay from Eve Kosofsky Sedgwick’s collection Tendencies (1994), entitled “White Glasses” (1991), though I will also draw on Sedgwick’s discussion of breast cancer in her later essay “Queer and Now” (1993), from the same collection.

Ontological Cracks and Uncanny Effects: Illness Autoethnographies and the Literary

“White Glasses” is both the earliest and—at 15 pages—the shortest of these accounts. Though later published—first in the Yale Journal of Criticism (1992) and later in the essay collection Tendencies (1993)—“White Glasses” was first delivered as a conference presentation, and was originally conceived as an obituary for Sedgwick’s close friend, the poet Michael Lynch, whose death from HIV/AIDS appeared imminent. By the time of the conference, however, Lynch’s health had improved—though he was in fact to die exactly two months after Sedgwick’s presentation, and thus before the work’s publication—while Sedgwick had been diagnosed with the breast cancer that would eventually kill her. An open-ended, highly performative text that draws on feminism, queer theory, and HIV/AIDS activism, in both its urgency and its compactness “White Glasses” represents the sharp end of the texts considered in this chapter.

In contrast, at the soft end we find Felstiner’s Out of Joint, a work published over twenty years after “White Glasses.” Out of Joint takes shape as a retrospective account of almost four decades spent living with rheumatoid arthritis (RA), which

87 For the purposes of this thesis, I will henceforth refer to “White Glasses” as an essay, rather than a presentation.
Felstiner developed in her late twenties, after the birth of her first child and towards the completion of her doctorate in history. Though not “a standard autobiography,” in its largely chronological structure and consistent narrative voice, Felstiner’s illness account bears the closest resemblance to conventional memoir of the accounts considered here—a feature that reflects her work as a historian and biographer, best known for her work on the German Jewish artist Charlotte Salomon—while also incorporating elements of key illness tropes such as the automythology and the manifesto, as I will discuss in more detail below (ix). Oakley’s Fracture recounts an orthopaedic injury that occurred in her late fifties and its disabling aftermath, including a diagnosis of osteoarthritis and a drawn-out lawsuit. In contrast to Out of Joint, Fracture alternates between autobiography and analysis in ways similar to Teratologies: a feature that represents both a break from, and a continuation of Oakley’s existing archive of writing about illness and about health care. This archive covers her personal experiences of illness—“including a misdiagnosed and nearly fatal ectopic pregnancy, cancer, and a herniated lumbar disc”—as well as those of others, in the form of interviewees, and ranges across multiple decades and multiple formats, to include the “part autobiography, part sociology, part true romance, ‘memoir, polemic and fictional/fictionalized account of a clandestine love affair’” Taking It Like a Woman (1984); the collaborative study-cum-guide Miscarriage (also 1984); Telling the Truth About Jerusalem (1986), a collection of essays and poems; and Essays on Women, Medicine and Health (1993) (Oakley “Re: Fracture”; Taking xvi).

Like Stacey in Teratologies, in their accounts Felstiner, Sedgwick, and Oakley attest to the experience of narrative wreckage. Though Oakley begins with the optimistic intention of treating her accident as “only a minor interruption in the ordinary flow of [her] life,” one that “will run its own course and then move on, leaving [her] intact,” she soon comes to realize “that [her] spirit as well as [her] arm is broken” (3, 13, 14). In a similar vein, Felstiner describes how RA “took hold of [her],” and, virtually overnight, her life “got thrown out of joint” (xi). This sense of wreckage is both particularly prominent and particularly poignant in Sedgwick’s “White Glasses,” when she recalls how four months prior to its presentation, she thought that Lynch was dying and that she was healthy. She writes:
Unreflecting, I formed my identity as the prospective writer of this piece around the obituary presumption that my own frame for speaking, the margin of my survival [of Lynch] and exemption [from illness], was the clearest thing in the world. In fact, it was totally opaque: Michael didn’t die; I wasn’t healthy […] I got everything wrong. (255)

Further, like Stacey, these authors use their personal experience as a point of departure from which to describe and interrogate the discursive overdetermination of illness, gender, and sexuality in the mid- to late twentieth and early twenty-first centuries. In doing so, they pick up on many common themes, including the alienating rhetoric of conventional medicine and metaphorical thinking. In *Fracture*, for example, Oakley comments on “the sanitising and obscurantist medical language,” and of how “the conundrum of illness and the self produces metaphors” (4, 132). Likewise, in her readings of “sixties research on pain” and the “health books” of the 1990s, Felstiner encounters—and feels similarly angered by—versions of the psychosomatic model of illness that Stacey encounters in her Reiki session: a model in which Felstiner’s gender and Jewish ethnicity mark her out as particularly prone not just to illness, but to an “exaggerated expression of pain” also (Felstiner 130-132). In “White Glasses,” moreover, Sedgwick critiques the gender-essentialism and heteronormativity of breast cancer culture in her account of being told by a social worker at a “hospital-organized breast cancer support group” that “with proper toning exercise, makeup, wigs, and a well-fitting prosthesis, we could feel just as feminine as we ever had and no one (i.e., no man) need ever know that anything had happened” (262). “Gender,” she writes, “is so strongly, so multiply valenced in the experience of breast cancer today […] that […] even while [breast cancer] is supposed to pose unique challenges to one’s sense of ‘femininity,’ [it] nonetheless plunges one into an experience of almost archetypal Femaleness”: a phenomenon that is comically dramatized in “White Glasses” when she recalls that her first reaction to diagnosis was “Shit, now I guess I really must be a woman” (“Queer” 13; “White Glasses” 262).

For all of these women, the combination of narrative wreckage and discursive overdetermination is a driving force in their illness accounts, and positions their writing at the junction of illness and the everyday, insofar as these conditions are
experienced by academic women who identify as feminist, queer, or both. This impetus is explicitly signalled in their writing, in statements such as Stacey’s on stories about illness being “an intensification” of the more general ways in which we “understand our lives through narrative” (Stacey 8). In each, however, we find a distinct variation, or angle, on this common impetus. In “White Glasses,” for example, Sedgwick focuses on the “ontological cracks” of which illness has made her hyperaware, and also on the entrenched stereotypes of gender and sexuality it brings into stark focus—themes she shares with Stacey—, whereas in Fracture Oakley is concerned the with “the universal, intensely perilous status of […] bodies” more broadly (Sedgwick 257; Oakley vi). Though written retrospectively, Out of Joint charts the shifts in Felstiner’s view on and response to her illness chronologically, resulting in a work whose emphasis on the limitations of the women’s health movement and the role of disability activism, though signalled in the work’s preface, only fully develops in part four of this five-part account. Within this framework, or set of frameworks, each author takes on smaller, more specific case studies. In Teratologies and Fracture, for example, these case studies are organized around specific discourses and concepts, while in “White Glasses” and Out of Joint these include political issues, such as illness activism and access to healthcare.

And yet, in spite of this variance, what really binds these works together as a distinct group of illness accounts, I argue, are the ways in which their deployment of aesthetics feeds back into issues of identification as bodies and as selves that are particularly prominent in the late twentieth- and early twenty-first centuries. This dimension has been almost entirely overlooked in critical responses to these works: I say almost, because, in her recent article on chronic pain accounts and posthumanism Leigh Gilmore touches on issues of relevance here in relation to Fracture and Out of Joint, though she does not put forward any close readings of these particular works. This is an unfortunate blind spot in critical responses to these works, both in literary studies and in other disciplines, because, like Stacey, Felstiner, Sedgwick, and Oakley all foreground the aesthetic dimensions of their

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88 In her reading of Out of Joint, for example, Rosalía Baena traces an “affirmative model of disability” in Felstiner’s account of “the process that took [her] from tragedy and catastrophe to a positive identity as a disabled woman” (128). Baena’s approach to Out of Joint is instrumental in the extreme, and argues that Felstiner’s background as an academic justifies a reading in which her narrative is seen to “self-consciously embody […] theoretical and critical studies concerning disability and illness” (128).
writing. We see this, for example, in Felstiner’s account, the ‘literariness’ of which is signalled from the very beginning in her choice of title, which in the work’s epigraph is attributed to both the Bible and to Hamlet, and also in the poetic line arrangement of the work’s contents page: an arrangement that consists of blocks of chapter titles alternately aligned to either side of the page centre, and which recalls the articulation of the skeleton, and particularly of the spine, on which her narrative is focused. We see this too in Fracture, in Oakley’s repeated references to semiotics. She describes her sling as an “emblem of disability,” and her scars as “the stigmata of loss,” while at the same time reading symbolic meaning into both her injury and her post-injury behaviour: of how the right hand—the hand left with permanent nerve damage after her accident—stands in certain traditions “for the self” and for “self-identity,” and how her destruction of a set of bathroom scales in a fit of frustration might be driven by its symbolic connection to the body (14, 25, 51). “Is there a symbolism in this,” she asks, “destroying an instrument that measures the body most exactly, because it’s exactly the body that has failed?” (14). Perhaps the best example of this foregrounding of the aesthetic, however, can be found in “White Glasses,” the title of which acts as a synecdoche for the author (Sedgwick) and her subject (Lynch), both of whom wear white glasses. This material correspondence in turn gestures towards both another bodily commonality, and to a difference: their terminal illnesses, and their genders. Though this difference in gender is largely meaningless to Sedgwick and Lynch, it inflects the symbolic orientation of their white glasses in radically different ways. Sedgwick writes:

One thing I learned from this is that the white of the glasses means differently for a woman, for a man. The white of the glasses is two things, after all. White is a color—it is a pastel. White the pastel sinks banally and invisibly into the camouflage of femininity, on a woman, a white woman. In a place where it doesn’t belong, on Michael, that same pastel remains a flaming signifier. (255)

She goes on to note that, though “in many cultures white is the color of mourning,”

On women of all colors white refers, again banally, to virginity […] and the flirtations of the veil—to the ways in which our gender tries to construct us heterosexually as absence and as the dissimulating denial of it, and tries also to inscribe in us, as a standard of our own and other people’s value, the zero-degree no-color of (not the skin of Europeans themselves but) the abstractive
ideology of European domination. (255)

Though “the ruly ordinariness” of “a white woman wearing white” makes this “corrosive aggression” invisible, she argues, “the series of uncanny effects” that take shape around these white glasses bring to the fore questions of signification and identification in which gender, race, and sexuality are both instrumental and at stake (255).

In this chapter, I examine how the arguments, experiences, and analyses that Felstiner, Oakley, Sedgwick, and Stacey directly describe in their illness accounts are not only reflected in their handling of language and of published text, but extended in ways that are politically and ethically significant. My readings of these works focus on two aesthetic strategies in particular: strategies that are not only evocative of the kind of self-reflexiveness and interference that characterize Woolf’s deployment of aesthetics in On Being Ill, but which also draw in productive ways on feminist philosophy and performance art of the late twentieth and early twenty-first centuries. For both of these strategies, the notion of discursive play acts as a centre of gravity: of a simultaneous evocation and deconstruction of recognizable discourses, particularly of illness but also of gender and sexuality. The first strategy I look at uses a process of bricolage to push against the parameters of the autoethnography genre, and in this way to effect a form of transgenericism. This transgenericism, I argue, enables the authors considered in this chapter to explore both the ontological cracks that, though not unique to illness, become increasingly prominent to those experiencing it and the multiple discourses that seek to plug these cracks. The second strategy I examine plays on the kinds of “uncanny effects” that Sedgwick observes in her description of the white glasses, and consists in these authors’ construction of both the textual and the photographic body as a volatile, floating signifier.

Bricolage, Transgenericism, and the Subject in Motion

In all of these accounts, the illness experience is described in terms of narrative wreckage. According to Frank’s schema of illness, the overwhelming sense of chaos that accompanies this wreckage is impossible to tell except in retrospect (97). “Lived chaos,” he writes, “makes reflection, and consequently storytelling, impossible” (98). As such, he proposes, though chaos stories can be retrospectively reflected on
and integrated into a more coherent illness narrative, they cannot exist in isolation: like radioactive waste, they are destined to decay unless contained within a stabilizing matrix. On the one hand, in their pairing of autobiography with critical analysis, their integration of illness into ongoing research projects, and their development of a clear narrative trajectory—a trajectory Stacey summarizes well when she describes Teratologies in terms of a movement “from the personal to the political, from the individual account to the social and cultural implications” (25)—Felstiner, Oakley, Sedgwick, and Stacey can arguably be seen to create for their illness accounts a stabilizing superstructure of this sort, and thus to contain the chaos of narrative wreckage. On the other, these authors clearly state that, rather than attempting to repair this wreckage through subscribing to any one of the potential storylines they encounter, they instead seek to approach it as a vantage point from which to survey the vast range of discourses with which illness, and particularly female illness, is overdetermined. This contradiction is captured in Sedgwick’s observation that, though disorienting, the experience of illness—first Lynch’s, and then her own—raises issues consistent with her life project and her life story, such that her response to cancer involves a “turning […] back toward a confrontation with the theoretical models that have helped [her] make sense of the world so far,” and a “hurling [of her] energies outward to inhabit the very farthest of the loose ends where representation, identity, gender, sexuality, and the body can’t be made to line up neatly together” (“Queer” 13).89

At a textual level, this discursive survey manifests in these writers’ invocation and combination of characteristic elements of these discourses in dynamic and often chaotic ways, to create an effect that not only draws on the concept of bricolage, but puts its indeterminacy and ambiguity to work in ways that foreground the constructedness of these discourses while also interfering with the stability of the autoethnographic accounts they offer. With its origins in the work of Claude Lévi-Strauss, for contemporary social scientists the term “bricolage” signifies an interdisciplinary methodology capable of accommodating multiple perspectives: an

89 However, while this provides a continuity of sorts, it is not without risk. As Oakley notes, “academia traditionally regards personal narratives with deep distrust”: a distrust that “is very bound up with the whole issue of gender politics, and the continued location of academia in the politics of patriarchy”, and which is exemplified by the refusal of her institution “to recognise Fracture as a work of scholarship” (“Re: Fracture”).
approach that at root seeks to conduct research and to produce knowledge that not only accounts for “the complexity and heterogeneity of human experience” but to do so without asserting claims of objectivity (Kincheloe 680-681). As such, bricolage has found a welcome home in feminist enquiry, with figures such as the philosopher Margrit Shildrick not only identifying their methods as “that of the bricoleur,” but proposing that “a properly based enterprise in women’s studies demands no less” (Leaky 5). In their illness accounts, Felstiner, Sedgwick, Stacey, and Oakley can be seen to put this principle of bricolage into practice through their deployment of aesthetics. They do so through a series of referential gestures in which multiple and competing discourses of illness, gender, and sexuality are put into circulation: gestures that add to the overall sense of illness’s overdetermination.

In many ways, Sedgwick can be seen as a forerunner of the kind of epistemological and methodological bricolage on which I base my readings of these illness accounts. A poet, performer, and queer studies pioneer, she describes her life as “fiercely transitive, shaped by a thirst for knowledges and identifications that might cross the barriers of what seemed my identity” (253). The multiplicity of knowledges and identifications that Sedgwick signals here pervade the essay’s content. We see this multiplicity, for example, in the way Sedgwick frames her life’s work in terms of a desire “to make decisive interventions on two scenes of identity that were supposed not to have to do with each other: the scene of feminism […] and the scene of gay men’s bonding, community, thought, and politics,” and in her references to the work of fellow queer theorists—such as Judith Butler and Michael Moon—on identification and masks, a feature that links closely to my discussion of bodies in performance in the next section of this chapter (253-254, 257-258). We see this multiplicity also in the range of materials and modes on which she draws, which encompasses reported speech; textual citation, both from academic works and from other materials, such as letters and poems; and sections of anecdote, auto/biography, and autoanalysis; and in the varying impulses and roles the work narrates and performs.

A conference paper that breaks with the conventions of its form, “White Glasses” is, like the Names Project AIDS memorial quilt panels it briefly describes, a work fundamentally driven by “the obituary imperative” (265). At the time of delivery,
however, it also constituted both a public and a private “act of homage to a living friend,” the latter dimension of which is apparent both in the intimacy with which Sedgwick describes moments from her friendship with Lynch, and in the paper’s closing section, which reprises an earlier conversation between them about the recording of her presentation before concluding with a few sentences directly addressed to Lynch (254, 266). Moreover, as the transcript of a recorded performance that survives not only the object of its homage but the person who pays it, the print version of “White Glasses” also acts to memorialize Sedgwick and her idiosyncratic style of analysis, in which heavyweight theory is given affective texture and sensory depth through interspersion with anecdote, confession, poetry, and other wide-ranging fragments. Finally, in its incorporation of accounts of Sedgwick’s illness experience, her relationship with Lynch, and their role in a defining period of queer studies and of queer experience, it also constitutes an important contribution to the historical archive.

These different facets of “White Glasses” create a strong sense of transitivity, of multivalency, and of border-crossing: a sense that is reflected in the make-up of the essay and in its position as the final essay in a collection that ranges widely across genre, combining “poetry, wit, polemic, and dazzling scholarship with memorial and autobiography,”90 as well as in the opening pages of each piece in the collection, which in their typographical arrangement—a column that slants from right to left as it descends the page—gesture to the techniques of concrete poetry and to ideas of deviation as well as, perhaps, the politics of the left, which Sedgwick invokes in her critique of the lack of healthcare subsidy. The essay itself begins with an extract from the poem “Tobacco”: a poem not by Sedgwick but by Lynch, from his collection These Waves of Dying Friends (1989). Like “White Glasses,” These Waves of Dying Friends is driven by “the obituary imperative” that not only encompasses the author’s friends, but is self-reflexive: Lynch tested HIV-positive in November 1985, in the midst of a period in which huge numbers of his friends were dead or dying from AIDS (Silversides 109-110). By the time that Sedgwick presented “White Glasses,” however, she too was one of Lynch’s “dying friends,” while Lynch himself was dying. This inclusion, and their mutual identification as

90 This quotation is taken from the back cover of the 1994 paperback edition of Tendencies.
people with terminal illness, is reinforced by the self-portrait that lies at the centre of the extract, in which Lynch imagines himself through the eyes of a passing stranger as “a close-cropped man/ with briefcase, white rolled/ shorts, white glasses”: a vision that acts as a prelude to the opening lines of Sedgwick’s essay, in which she recalls meeting Lynch for the first time in early 1986 and the impression his white glasses made on her, but also to her later description of the “uncanny effects” that differentiate her wearing of white glasses from his (252). Further, as she moves into the essay proper, Sedgwick combines anecdote and analysis, reported speech and academic citation, and shifts between internal monologue, private conversation, and public presentation in a seemingly organic manner: a strategy that, in its transgeneric tendencies, puts pressure on the autoethnography form and the hybrid self it constructs.

Though thus far I have used the term ‘autoethnography’ to describe the interweaving of autobiography and analysis in these texts, on closer scrutiny it becomes apparent that these texts are only hybrid in this very basic sense, and that within this two-part mixture they display a more complex and wide-ranging transgenericism. Stacey draws her readers’ attention to this transgenericism early on in Teratologies, when she describes the autobiographical component of her account in terms of a series of fragments that are “difficult to label” (24). Do these “modes of personal writing […] draw on autobiography, memoir, confession, or testimony?” she asks (24). However, though at moments such as this the transgenericism of Teratologies is explicitly foregrounded, it also forms an important part of the work’s aesthetic dimension, primarily through the staging of what Stacey calls “a series of ‘textual rhetorics of the self’” (24). These textual rhetorics take multiple forms, ranging from the use of “different modes or ‘registers’ of writing,” including the “personal, political and theoretical,” to substantial typographic shifts and other dramatic effects, such as the reconstruction of the Reiki consultation as a one-sided “commentary,” rather than a dialogue, in which the practitioner’s words are italicized, and Stacey’s responses represented by blank space: a technique that prompts the reader to quite literally read between the lines (24, 37-38). Further, though occasionally discrete in presentation—the textbook format at the beginning of chapter 2 of Teratologies, for example—these forms are more often interwoven in complex and inventive ways, to
create a sense not of code-switching, but of discursive play and of the subject in motion.

We see similar forms of discursive play in *Fracture* and *Out of Joint*. Though in *Fracture* Oakley emphasizes the dual nature of her account, describing herself a “moonlighter” with “a second career as a medical patient,” both her methodological approach to the analytic portion of the work and her autobiographical narrative draw on elements of bricolage in ways similar to *Teratologies* and “White Glasses” (26). *Fracture*, she writes, “combines my personal story with those of others, and with history, anthropology, neurology, and the sociology of the body, health, and illness” (v). Within this interdisciplinary framework, Oakley embeds a small selection of photographs, all of which serve to illustrate her injury and its physical aftereffects, as well as a range of different textual materials, including a fictionalized version of the online blurb for the hotel at which her accident occurs and extracts from her medical notes.

In contrast to the conspicuous transgenericism of Sedgwick, Stacey, and Oakley’s accounts, Felstiner’s *Out of Joint* appears relatively conventional, both in its narrative style and in its deployment of aesthetics. When considered as a whole, this account takes shape as a kind of manifesto, as well as a source of solidarity and a guide for those with RA. With *Out of Joint*, Felstiner seeks to create the book that, in the early days of her RA, she “wanted to find in the worst way” (92). She hopes her account might help other people to “view illness in fresh ways” and perhaps even to learn from the coping strategies she has developed over the decades (xv). But most of all, she is driven by the need in “public space” for a “full personal disclosure about the disease”: a disclosure she approaches by “tracing a private timeline and splicing it into a public one” (xii, xiii). And yet, within the framework of the manifesto, Felstiner brings a wide range of discourses of illness into play, in ways that reflect her changing attitude to and feelings about her illness. One of the ways in which Felstiner achieves this involves an extension of the splicing work on which her manifesto is based, in which she articulates elements of recognizable illness discourses to her autobiographical narrative as she finds “new way[s] to identify [her]self with [her] malady” (169). In the work’s preface, for example, we find fragments of the therapeutic narrative that underpins the practice of expressive
writing in Felstiner’s description of her account as an attempt “to heal by delving into history” and of how “expanding the scope of [her] disease is how history healing works,” whereas in the account itself the notion that illness, like trauma, is ineffable surfaces often (xiii, 189). Her “second discovery about illness,” she writes, is that “language isn’t up to it,” an articulation she later links to Woolf and to Scarry but also to her work with Holocaust survivors (24, 53, 108). We also find in Out of Joint a fraught relationship with the automythology, which oscillates between acceptance and rejection. Moreover, though as a chronic, degenerative condition RA is fundamentally incompatible with narratives of physical restitution, in Out of Joint Felstiner inverts this narrative through a range of metaphoric figures, some inventive, some more predictable. She describes “backstrok[ing] painfully up and down the pool, with no inkling how [she’ll] get to go forward again,” and writes of how “[her] joints match [her] neighbourhood, gilded but gone fragile”: a reference both to the treatment of RA with gold compounds, and to the osteoporosis that is both a direct result of the disease and a corollary of its treatment protocol (32, 31).

Indeed, the concept of metaphoric thinking arises often in Felstiner’s account, and though it is clear that her feelings towards it are ambiguous, her stance is not Sontagian: she acknowledges that “some people try for relief by wedging a metaphor into illness” (133).

The overall effect of this narrative splicing in Out of Joint is not of a careful orchestration of various discourses of illness, but of an organic experience in which she attempts to recreate in retrospect a historical sense of the different discourses of illness she has encountered, and at times subscribed to or resisted, during her experience of RA, as she “fold[s] the whole story [of her illness] into its times” (198). In this, the sense of discursive play at work in Out of Joint mirrors her juxtaposition of different textual materials, most of which are autobiographical, and are positioned in her account in roughly chronological order. Like the works already described, in Out of Joint these include diary entries and medical records, and, in keeping with Felstiner’s experiments in narrative splicing, reflect her changing attitude to and feelings about her illness. However, by acting as discrete snapshots of Felstiner, taken from specific angles and at specific times, they effectively capture the ways in which illness defines her at key moments in her life, and thus convey its effects on her sense of self.
Bodies in Performance: Literature and the Politics of Embodiment

Rebecca Schneider’s study of feminist performance art begins with a description of the feminist art collective The Guerrilla Girls, who “appear in public wearing gorilla masks […] [to] keep their identities secret” (1). These masks, Schneider observes, not only “render anonymity,” but “make explicit a social contract which has historically marked women and people of color as less evolved, more ‘primitive,’ than the implicitly higher primate, white Man” (1). “Alluding to primitivity,” she writes,

the gorilla masks appear to quote the racist primitivism at the heart of colonialism as well as the mimesis of all things ‘primitive’ at the base of modern art. The conflation of the ‘primitive’ mask with the masked identities of the female artists suggests a complex interrelatedness between codings of race and gender, especially vis-à-vis the politics of representation and artistic authority. (1-2)

In such performances, Schneider argues, these women seek “to expose not an originary, true, or redemptive body,” but rather to draw attention to “the sedimented layers of signification” that “surround their bodies,” and thus to the body’s function as “a site of social markings, physical parts, and gestural signatures of gender, race, class, age, sexuality” (2).

Schneider’s concept of bodies in performance provides a useful lens through which to examine the representation of bodies in these illness accounts, particularly when considered alongside Shildrick’s notion of the leaky body, which corresponds closely to the politics of signification that underpin the performances Schneider describes. This concept builds on Shildrick’s theorization of the body as at root “an always insecure and inconsistent artefact” overwritten by “a plethora of competing discourses,” whose semblance of “material fixity” proceeds from the relative dominance certain discourses achieve over others through processes of “normalisation and reiteration”: processes in which, as Davis and Thomson point out in their work on the cultural construction of disability, literature is both complicit and a powerful site of resistance (Shildrick *Leaky* 13). In this section, I look at how Felstiner, Sedgwick, Stacey, and Oakley deploy aesthetics in ways consistent with Schneider’s description of the body in performance, and in this way recast the leaky
body as a tool of resistance both to the discourses that seek to determine it, and to the notion of any originary, true, or redemptive body.

In all of these accounts, the body acts as a call for stories: its failings initiate and shape autoethnographic acts. Indeed, bodies are not just at the very centre of these texts—as they are to all accounts of illness that include physical symptoms and interventions—but, in the case of Fracture and Out of Joint, on their covers too. The editions cited in this thesis both bear images of their author’s affected body parts, though it is worth mentioning that, in Out of Joint, this is counterbalanced by a photograph of Felstiner on the back. The cover of Out of Joint bears a photograph of hands distorted by RA, whereas Fracture reproduces an X-ray image of Oakley’s shattered humerus and elbow: a monochrome study that is at once shockingly material in its depiction of the solid framework that gives the body its structure, and strangely abstract, a series of coarse grey brushstrokes on black canvas. This abstraction is taken further by Stacey in the paperback edition of Teratologies, which takes as its cover an abstract image entitled Beework by Canadian artist Aganetha Dyck. The accompanying blurb links this image to the workings of cancer, while also evoking feminine stereotypes in ways evocative of the instability and overdetermination that for Shildrick characterize the body:

The beework is about cells. Fragile cells filled with sensuous, mysterious substances. Programmed cells, determined cells. Cells which are shaped, reshaped, filled, drained, cleansed, painted, prodded, invaded and monitored. Powerful and sexual they are filled with nurture, need and desire.

Between the covers, this body-centricity is signalled in both the visual and verbal dimensions. In the preface to Fracture, for example, Oakley describes the text as “the story of an accident that happened to my body”: an accident that developed into “a kind of research project” centred on “the universal, intensely perilous status of our bodies” as entities that are both biologically and culturally determined (iv-v). Likewise, Out of Joint begins with Felstiner “casing [her] joints,” “spot-check[ing] [her] ankles” and “flex[ing] her fingers”: an image that soon becomes a recurrent motif in the text, and which Felstiner often splices to the act of writing in phrases such as “cracking a life history joint by joint” (xi, 110). The myth of origins that Stacey constructs for Teratologies takes this even further, depicting the story of her
cancer in terms reminiscent of an accidental pregnancy, to create a macabre play on the nature of her tumour and its silent gestation, “the repeated biomedical insistence [sic] that [she] might be pregnant despite [her] certainty to the contrary,” and the metaphoric links between cancer and pregnancy, which she unpicks in chapter 3 (39, 89-96). On one level, as first person accounts that take women’s bodies as their frame of concern, these works can be seen to participate in more widespread acts of resistance undertaken by their generation(s) of feminists. For instance, they could be aligned with what Felski describes as “the narrative of female self-discovery,” in which the female body is claimed as a legitimate source and subject of autobiographical writing in resistance to the institutionalized preference of this “Western, male-dominated tradition” for “unique, unitary” self “unencumbered” by embodiment – a project that reaches back to Woolf’s desire to tell the truth about her experiences as a body (Felski Beyond 122; DeShazer 217; Smith 4). Moreover, in foregrounding the vulnerability of the body, its illnesses and—in the case of Felstiner and Oakley—its ageing, these works challenge the normative impulse of which second wave feminism is often accused: its occlusion of those bodies and selves that are not white, heterosexual, healthy, and upper-middle-class. Indeed, this agenda is clearly signalled by Felstiner in Out of Joint. Recounting her involvement in a women’s group and her first encounter with Our Bodies, Ourselves in the late 1970s, she recalls her private dismay at realising that, according to this “brave new source,” women “have hot flashes and sexually transmitted diseases and cervical cancer—but never joints” (29). Where RA is concerned, she concludes, “feminism leaves an attention deficit as deep as the public one” (104).

However, in doing so, these women encounter a double-bind: since the bodies they seek to claim as a legitimate source and subject of autobiography are ill, in writing about them they risk reinscribing the very stereotypes they seek to resist, including the sexual politics of embodiment—in which women are “associated, indeed virtually identified, with the body” while men are “associated and virtually identified with the mind”—, and what Ehrenreich and English describe as the sexual politics of sickness, in which women are seen not only as sick, but as “potentially sickening to men” (Spelman 126-127; Ehrenreich and English 9). Oakley neatly sums this dilemma up in a chapter entitled “Our Bodies, Ourselves”—a reference to the same handbook that so disappointed and alienated Felstiner—when she writes that women
“historically have been seen as more about bodies than minds and personal identities,” resulting in an academic feminism “wary of the body, especially the sexual body, wanting to avoid the oppressive patriarchal mistake of identifying women too narrowly with their bodies” (23-24).

For Sedgwick, this double-bind offers an opportunity for an “adventure in applied deconstruction”: an adventure from which “White Glasses” and parts of “Queer and Now” emerge, and which can be traced in her performance of the body in the former essay (“Queer” 12). Towards the end of “White Glasses,” Sedgwick describes to her audience how in the aftermath of her cancer diagnosis “the initiations of surgery, of chemotherapy, of hormone therapy” render her body the perfect mise-en-scène for a performance that crosses boundaries of gender, sexuality, religion, class, ethnicity, and, ultimately, of the human (263). With a generous dose of humour, she observes that just getting dressed in the morning means deciding how many breasts I will be able to recognize myself if I am wearing (a voice in me keeps whispering, three); the apparition of my own slightly fuzzy head, facing me in the mirror after my shower like my own handsome and bald father, demands that I decide if I would feel last alienated or most adventurous or comforted today as Gloria Swanson or Jambi,91 as a head-covered Hasidic housewife, as an Afro wannabe in a probably unraveling head rag, as a drag queen who never quite figured out how to do wigs, as a large bald baby or Buddha or wise extraterrestrial, or as—my current choice—the befezzed disciple of my new gay fashion gurus, Akbar and Jeff. (263)

In this passage Sedgwick stages a masquerade in which her bald head acts as a blank canvas, though as Shildrick reminds us, “the neutral, biological body is in itself an effect of language” (Leaky 14): a performance that brings to mind Butler’s comment in Gender Trouble that “laughter in the face of serious categories is indispensable for feminism” (xxviii). This masquerade, I argue, sets out in miniature the ways in which bodies perform in these texts: the ways in which they come to act as floating signifiers, and to represent entities that are not undisciplined so much as undisciplinable.

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91 Jambi the Genie is a character from the children’s TV show Pee-wee’s Playhouse, who wears a red turban, blue or green face make-up, and red lipstick, and lives in a jewelled box.
While at the time “White Glasses” was first delivered, Sedgwick’s physical presence in the room would have, one imagines, mirrored the latter image of “the befezzed disciple,” in the hardback edition of *Tendencies* the textual body that she creates here is implicitly compared and/or contrasted not with Sedgwick’s ill, befezzed, part-organic, part-prosthetic body, but with the intact and apparently healthy body that appears as part of a triptych of photos of Sedgwick and Lynch—both wearing their white glasses—alongside the work’s dedication (viii). Though the overall effect is one of stark contrast, the multiplicity of Sedgwick’s textual bodies in performance roughly replicates the three almost-identical but subtly different photographic versions of Sedgwick, while the photographs’ composition—in which Sedgwick and Lynch stand side by side behind Emily Dickinson’s tombstone, their arms around one another and heads touching—is also suggestive of a conjoined physical identity, a grotesque two-headed, stone-bodied hermaphrodite that captures perfectly Sedgwick’s “fiercely transitive” identity (viii, 253).

Sedgwick’s juxtaposition of text and image anticipates the photographic paranarratives in Felstiner’s, Oakley’s, and Stacey’s accounts: paranarratives that both reflect and complicate their juxtaposition of analysis and autobiography, and in which their bodies perform. This effect is particularly pronounced in *Teratologies*, where Stacey’s use of photographic paranarrative extends the textual rhetorics of the self staged in her transgeneric narrative. Crucially, in Stacey’s hand, this paranarrative gestures towards several distinct discourses of the body, without giving any one precedence over the other. It begins with a sequence of medical photographs and histological sections from a 1989 *Atlas of Germ Cell Tumours*—the latter of which, as a magnified image of cells, recalls the Aganetha Dyck image on the book’s cover—before moving on to consider the materials with which Stacey’s home discipline (media and cultural studies) typically works, such as pedagogical materials, promotional pamphlets, and visual art (35, 90, 92, 109, 145, 167, 168, 170-171, 205, 206, 208). Amongst this, she includes two personal photographs, a device one might expect to find in a more conventional autobiography or memoir (138, 139). The first of this pair of “holiday snaps” shows Stacey looking “healthy [and] tanned” two months before her diagnosis, while in the second, taken shortly after completing chemotherapy, she looks “strange” and “puffy” (137, 139). When
considered as part of the work’s visual paranarrative, the inclusion of these personal photographs serves to foreground the transgeneric nature of Stacey’s account. This is not, however, the limit of their significance. Instead, as Stacey acknowledges, in their evocation of various, competing cultural forms and interpretations, they signify in ways that go beyond self-conscious commentary on the work itself. This pairing is reminiscent, she notes, of “the ‘before-and-after’ genre” associated with representations of the female face and body, in which a “dowdy, plain face (and sometimes figure)” is transformed into a “strikingly glamorous one that would not be passed by without notice” (139) — making this a device that, given Stacey’s sexuality and intentionally queer appearance is not only ironic, but parodic. This, in turn, complicates the second image even further. As Stacey notes in her commentary on the photographs, while in relation to cancer her hair loss is simultaneously a “striking announcement” of disease and a meaningless symbol that “tells us nothing” about its stage or likely outcome—“sometimes the baldness signifies recovery, sometimes imminent death,” she notes—her sexuality and political identity project additional potential meanings onto the smooth white surface of her scalp (139). Regarding herself through the eyes of another, she asks: “Have I been ill or is this a radical fashion gesture or even a political statement?” (137).

This pair of photographs also gestures to another version of the “before-and-after” narrative, cited earlier in Teratologies as “life before and after illness” (9). In particular, this pairing complicates the “before-and-after” narrative, challenging our thinking about health and illness, and particularly about what these states should look like. In this sense, they create a “disorientating effect,” which Stacey summarizes as follows: “in the first, I look healthy, but have cancer; in the second, I look ill, but do not have cancer” (139). Further, as Stacey notes, in the first she felt well—“casual, relaxed, contented”—whereas in the second she felt ill, her body “devastated” from the “onslaught” of chemotherapy (137, 189). When embedded in this context, therefore, this pair of photographs comes to signify “a radical disjuncture,” “a gaping discrepancy,” an “uncanny mismatch” between representation and reality that throws familiar ontological and epistemological frameworks—including narrativity—into disarray (140). When seen from this angle, she writes, these photographs and the memories that accompany them “resist[s] the story that ensued”: the story of life before and after illness (141). For Stacey, then, there is “no sequence and no
continuity” in the juxtaposition of these two photographs: the story they should represent “makes no sense” (141). As such, it challenges “the notion that the outside, observable body reliably represents an inner being”: a notion that, Gilmore notes, is central to the tenets of humanism, and which thus comes into alignment with the textual rhetorics of the self that Stacey stages in Teratologies (“Agency” 90).

Both Felstiner and Oakley make use of photographic paranarratives in ways similar to Sedgwick and Stacey in their accounts, though these paranarratives are not central to the ways in which bodies perform in these texts. As discussed above, both accounts feature images of body parts on their covers: body parts that bear little obvious relation to gender or sexuality, but which are not entirely neutral either. With their slender fingers and manicured nails, the hands on Out of Joint are recognizably feminine, while also evocative of traditional female roles such as caring and nurturing. Likewise, the slight, translucent bones in Oakley’s x-ray evoke the fragile frame stereotypically equated with the female body, and, to the trained eye, demonstrate the low density associated with osteopenia and osteoporosis — conditions that, as Oakley argues in chapter 7 of Fracture, are synonymous with the ageing female body, despite shaky medical evidence to support this association.

However, in these works the phenomenon of bodies in performance is most pronounced in their use of figurative language, which they employ in ways that highlight modes of metaphoric thinking about illness and about gender in a range of different discourses, from the medical to that of academic feminism. In Fracture and in Out of Joint especially, the kind of recursive, volatile, multidirectional relationship between signifier and signified that we see in Sedgwick’s white glasses comes to the fore: a relationship in which the body, rather than the glasses, becomes a floating signifier, continually bent and stretched to suit different discursive conventions, and from which no dominant themes emerge.

The images of disjointed limbs that dominate the covers of both these accounts are symbolic of the dissociation that Felstiner and Oakley feel towards their bodies: a dissociation caused by illness, in Felstiner’s case, and in Oakley’s by an accident, though it continues well into the aftermath. In both accounts, this dissociation is articulated and subjected to analysis. In Out of Joint, Felstiner describes her first
flare of RA as a discovery made not by her, but by “the person under [her] skin,” while in Fracture Oakley regards her injured arm with “detached interest,” and perceives her hand as “a turtle, a claw-shaped aquatic animal that has nothing to do with me” (Felstiner 4; Oakley 20, 27). Though this latter phrase presages a well-informed account of misoplegia—the technical term for feelings of antipathy towards and alienation from a paralyzed limb—and neural damage, it is in itself indicative of the bodily performance that takes place in Fracture: a performance in which Oakley transmogrifies her arm into a startling array of objects, ranging from the domestic to the mechanical. It is “a bag full of loose old bones, like chicken drumsticks or a medical student’s toys,” and appears in x-ray as “a shining metallic motorway” from which “screws jut out […] in a series of dead end streets” (3,11). Unbandaged, she regards her wound like “an oddly dressed stranger on a bus,” and likens it to “a thickly encrusted modern oil painting of a bent zip fastener”: an image in which the realm of art meets the world of domestic technology (12-13). In Out of Joint, this performance is even more dynamic and wide-ranging, with Felstiner depicting her body as an ever-changing conglomerate of matter both organic and inert. Her toes resemble “a piano with the keys sprung,” pointing “five to starboard, five to port” (140, 30). Beneath her “pumpkin head” and “moonface,” her wrists are “starched” and her feet “hold the ground like pickets,” while her limbs are “cemented” by the “dinosaur disease” (88, 3, 139, 57, 114). She is “a woman of parts who stores her scraps inside a pantry of skin” (133).

Conclusions:
In “Queer and Now,” Sedgwick writes of how illness, though “draining and scary,” has ultimately proven “just sheerly interesting with respect to exactly the issues of gender, sexuality, and identity formation that were already on my docket” (12). For Sedgwick, this interestingness reflects, rather than introduces, a life in which personal experience and cultural critique are deeply intertwined. Both “Queer and Now” and particularly “White Glasses” attest to this intertwining, and thus to the ways in which Sedgwick not only lives with and through illness, but begins to think with and through it too. For Sedgwick, illness prompts both a “turning […] back toward a confrontation with the theoretical models that have helped [her] make sense of the world so far,” and an “adventure in applied deconstruction” (“Queer” 12). It also gives rise to moments of creative exploration at the interface of experience and
representation, particularly in relation to embodiment, as my reading of “White Glasses” shows. In its integration of autobiography and analysis and its testing of the limits of signification, Sedgwick’s essay is representative of the illness autoethnographies considered in this chapter, while in its theoretical gestures it offers a framework within which the significance of these aesthetic interventions can be apprehended as acts both critical and creative.

These illness accounts play on the potential of the literary to sustain forms of self-reflexiveness and to interference in the structures of discourse. In this chapter, I have considered two of the strategies through which they do so. Through combining disparate forms and styles to create a kind of transgeneric bricolage, these texts engage in a dynamic process of discursive play that challenges the preeminence of any one mode of self-narration. In this way, they disrupt the continuity between the autobiographical “I” and the self in ways that challenge the consistent and coherent conceptualization of narrative identity Butler decries in Giving, but without making recourse to its postmodern equivalent, a hybrid identity that can be comprehensively deconstructed into its constituent parts. Likewise, through a recursive emptying out and refilling of a key symbolic substrate in the representation of illness, gender, and sexuality—the body—they further compound this sense of disruption. In doing so, I argue, they both tell and untell stories about illness, in ways that convey a sense of the discursive overdetermination of this experience while remaining defiantly outside of its sway. This testing of the relationship between signifier and signified, and of the capacity of various aesthetic approaches to disrupt the rigidity of meaning that cultural discourses impose upon this relationship is not only crucial to our understanding of aesthetics as a mode of resistance in these autoethnographies, but provides an important point of departure for my next chapter, which looks at the illness memoirs of Hilary Mantel and Paul West. Better known as authors of literary fiction, in their memoirs Mantel and West build on the acts of resistance to discursive overdetermination outlined in this chapter, by how language itself can be stretched to accommodate new ideas, new experiences, and new patterns of referentiality, and the implications of this capacity for its participation in the ethical.
Chapter Four

The Devil’s Dictionary: 
Illness and Language in the Literary Memoir

“How can I write this, I wonder? I am a woman with a delicate mouth; I say nothing gross. I can write it, it seems: perhaps because I can pretend it is somebody else, bleeding on the table.”

Hilary Mantel (Giving up the Ghost 189-190)

Shortly after undergoing major surgery to repair some of the damage wrought by decades of severe endometriosis, and while still in hospital recovering, the novelist Hilary Mantel reads On Being Ill, it seems for the first time. In her hospital diary, Ink in the Blood (2010)—a work largely written, like Woolf’s essay, from her sickbed—she records her response. Describing it as “schoolgirl piffle […] like one of those compositions by young ladies mocked in Tom Sawyer,” she proceeds to dismiss Woolf’s essay on grounds both personal and intellectual. Mantel’s criticism of On Being Ill centres on Woolf’s comments on the poverty of language in the face of illness, the lack of anything “ready-made” with which to render it intelligible: a claim that Mantel “can’t understand.” To counter Woolf’s claim, in the passage that follows she invokes “the whole vocabulary of singing aches, of spasms, of strictures and cramps; the gouging pain, the drilling pain, the pricking and pinching, the throbbing, burning, stinging, smarting, flaying.” These are “all good words,” she argues, “all old words.” “There is even,” she adds, “a scale you can use to refine it.” “No one’s pain is so special that the devil’s dictionary of anguish has not anticipated it,” she concludes, though she consents that Woolf, with her “genteel” suffering and “decorous illnesses,” her “melancholia” and her “ladylike” tears might not have been speaking from direct experience.

Mantel’s claims about the expressibility of illness and pain take their authority not only from her lived experience of chronic illness, but also from her authorship of two autobiographical accounts on the subject—Giving up the Ghost (2003) and Ink in the Blood—, and by the sheer size and continued growth of the genre in which these accounts participate. However, though in her dismissal of On Being Ill she claims to
draw on “old words,” her list of examples is decidedly modern, as exemplified in her reference to the numerical rating scale that has, since the 1990s, been promoted as a recommended pain measure in Western clinical settings:

[The atmosphere Mantel recreates in this passage with a cameo appearance from “the doctor,” who asks “on a scale of 1 to 10, how much this hurts” before disappearing offstage. On a subtler level, this allusion to modern medical culture is underscored by the list of “good words” she cites. Though these words are indeed “old,” all but two have been appropriated by modern biomedical culture as part of the McGill Pain Questionnaire, a scale that organizes sensory and affective descriptors for pain according to intensity, and which entered Western medical practice in the mid-1970s: around the time that Mantel first began to consult doctors about her symptoms (Noble et al. 15, 17). Even her references to “the devil’s dictionary” and to “the torture chamber,” though redolent of the Middle Ages, confound instead the notion of an old language for pain and of the stability of language: the former invoking the satirical reference book of the same name compiled by Ambrose Bierce and published in the early twentieth century, and the latter Elaine Scarry’s influential work, *The Body in Pain: The Making and Unmaking of the World* (1985), which takes the torture room as its first scene of enquiry.

Implicit in Mantel’s grouping of these words as a “whole vocabulary” for pain, then, is not a call for people with illness to return to an old, enduring language, but an embrace of what Gilmore calls “the clinical rhetoric of pain”: “a product of the institution of [modern] medicine, which includes the language in which professionals are trained to diagnose and treat symptoms and in which they communicate to hospital personnel and people in their care alike” (Gilmore “Agency” 85). As such, Mantel’s response to *On Being Ill* echoes Coulehan’s claim that, because of the “great deal” of writing about illness now in publication, Woolf’s central premise “is no longer true” the argument that, because of biomedical advances in the understanding of pain, Woolf’s claims about the lack of a “ready made” language for this experience are no longer relevant (Coulehan). In doing so, moreover, Mantel appears not only to reinforce the presentist critical metanarrative that underpins both scholarship and popular thinking about the expression of illness, but also, as Gilmore

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92 For more on this, see Noble et al. (2005).
points out, to “write[…] against the notion in trauma theory that language is inadequate to pain” (“Agency” 89). The rhetoric of pain Mantel defends here is at root a dialect of “the sanitising and obscurantist medical language” that the authors considered in chapter 3 experience as alienating and patronizing: a language that, Gilmore asserts, “often exerts a disorienting effect on people who find themselves translated into it” (Oakley Fracture 4; Gilmore “Agency” 85). In her response to Woolf, Mantel thus appears to go against the grain not only of trauma theory, but of contemporary writing about illness and pain as well.

And yet, as Bolaki observes, Mantel’s defense of medical language in this section of *Ink in the Blood* is “striking,” given that earlier in her diary, and also in *Giving Up the Ghost*, she proves herself “a strong critic of the ‘short exclamatory hospital talk’ with its ‘swift acronyms’ and of the belief that everything can be measured scientificaly” (Bolaki “Lights” 117; Mantel *Ink* cited in Bolaki). Equally striking, Bolaki proposes, is the contradiction between Mantel’s endorsement of the clinical rhetoric of pain in response to Woolf and the atmosphere of powerless and alienation that pervades her illness memoirs. Crucially, rather than distancing Mantel’s writing about illness from *On Being Ill*, for Bolaki the contradiction between her response to this essay and her deployment of aesthetics in *Giving Up the Ghost* and *Ink in the Blood* instead highlights the ways in which these texts continue the aesthetic project that Woolf sets out: a project Bolaki defines in terms of invention and experimentation at the interface of language and experience (“Lights” 115).

In this chapter, I take this argument further by examining how in the memoirs of two contemporary authors the experience of illness galvanizes a series of explorations in the matching of words to lived experience, with particular emphasis on the scope and limits of language’s ability to evoke a range of non-, or pre-, verbal phenomena, from sensations of discomfort and pain to the appearance of a wound or the noises of medical machinery. Alongside *Giving Up the Ghost* and *Ink in the Blood*, I consider how these explorations play out in the illness memoirs of Paul West, who like Mantel is better known as an author of fiction. With these memoirs Mantel and West join a burgeoning group of established authors for whom illness—experienced either on a first-hand basis or as an intimate witness to its effects on a friend, partner, or family member—presents “an occasion for an experiment in life writing” (Couser
To Couser’s original list of William Styron, John Updike, Joseph Heller, Audre Lorde, Reynolds Price, Richard Selzer, Paul West, Paul Monette, we can now add many others, including Joan Didion, Siri Hustvedt, John Bayley, Sarah Manguso, Jo Shapcott, Alan Shapiro, Susan Schultz, and Adrienne Rich. However, in relation to the project undertaken in this thesis, two features in particular cause Mantel’s and West’s accounts to stand out from this crowd. The first of these is the nature of their explorations, which oscillate between attempts at mimetic representation and a form of abstract, expressionistic evocation reminiscent of Woolf’s descriptions of illness and of everyday lived experience more widely both in On Being Ill and in essays such as Mr Bennett and “Modern Fiction.” The second is the common trajectory of Mantel’s and West’s illnesses—a trajectory defined by long periods of chronic ill-health punctuated by periods of crisis—and the serial nature of their memoirs. As accounts of illness experiences that have unfolded over decades, and in tandem with their authors’ careers as writers of fiction, these works reveal an ongoing, evolutionary approach to the portrayal of illness that has much to tell us about literary aesthetics and their engagement with ethics.

The Limits of Language: Illness and Referentiality

Born in Derbyshire in 1930, Paul West emigrated to the United States as a young adult, where he went on to build a successful career as an author of literary fiction and memoir and a professor of creative writing. From the very beginning, West’s life has been punctuated by illness, ranging from childhood hives to the debilitating migraines of his adolescence and adulthood, on which he has published short accounts in a range of periodicals. However, it was not until experiencing a transient ischaemic attack (TIA), or mild stroke, in his early fifties that West began to contemplate writing about illness. Admitted to hospital for the first time in his life, West recounts how, “lying there with nothing to do except to dream of survival,” he “dreamed of, and listed, the books [he] would write if [he] got the chance” (Stroke 37, 40). Prolific to a fault, he does indeed survive to write again: publishing well over twenty works of long fiction, non-fiction, short stories, and poetry in the years following the TIA, including an illness account entitled A Stroke of Genius: Illness and Self-Discovery in 1995, over ten years after the incident. A Stroke of Genius is broadly structured around the TIA and its aftermath, including the permanent paralysis of West’s left arm and hand, the fitting of a pacemaker, and a subsequent
diagnosis of diabetes. Part memoir and part polemic against the institution of modern medicine, this text is, as West acknowledges, a testament to his work as “a passionate hobbyist of my own illness” (137). However, almost a decade later, in 2003, illness was to take over West’s life once more, when on the day before his discharge from hospital following treatment for a kidney infection, he suffered a massive stroke. The stroke resulted in a short period of global aphasia—a disturbance in the comprehension and formulation of language—during which his speech consisted only of a single syllable, followed by more permanent state of moderate receptive and extensive expressive aphasia. West’s experience of aphasia forms the subject of his second illness memoir, *The Shadow Factory* (2008).

Like West, Mantel was born in Derbyshire, though somewhat later in 1952, and like West, her life was from a young age shaped by illness, including “growing pains,” mysterious fevers, and “raging headaches,” to the point that the family doctor takes to calling her “Little Miss Neverwell” (*Ghost* 82, 87). Her first account of illness, *Giving up the Ghost*, begins as a memoir in which illness features, before shifting just over halfway through into a full-blown illness account as chronic pain and debilitating medical interventions increasingly encroach upon her everyday life, forcing her to give up work and the hope of having children. In contrast, *Ink in the Blood*, her second account of illness, is a compact diary that records the weeks Mantel spent in hospital following major surgery in the summer of 2010, and was first published in the *London Review of Books* in November of that year.

In many ways, West’s and Mantel’s illness accounts conform to the characteristic features of the illness account genre. Both protest against the prejudices and impositions of modern medical culture, and describe feelings of narrative disruption and of a heightened thematization of the body. Mantel observes that “everything about me—my physiology, my psychology—feels constantly under assault,” and recounts how illness has “torn up” the “roots of [her] personality” while long-term steroid use has caused her body to become “grotesque” and “perpetually strange” (*Ghost* 222, 54). In a similar vein, West recounts feeling “dispossessed” of his body by “wires, oscilloscopes, tubing, and big drafts of chemicals,” an unwelcome “guest in the throne room of juices and sludges” (*Stroke* 35, 36). As migraineurs, moreover, they also experience a heightened thematization of perception: of its vagaries and its
deceptions. As Mantel notes in *Ink in the Blood*, “given my record with the vaporous, I am not as surprised as some would be, when in the hospital I blink and life flits sideways,” while West describes his “sense of being out of control, while being also undistortedly aware of the fact from moment to moment” (*Stroke* 5).

Furthermore, like many of the illness accounts described in this thesis, these authors also confess to a desire for narrative coherence and integration, though they ultimately fail to achieve this. Mantel writes of her repeated attempts “to rearrange [her] life so that illness was only a feature of it, and not the whole, but illness insists on its pre-eminence”: a theme that recurs in these texts not only in relation to illness, but in relation to the autobiographical act more generally. In *Giving up the Ghost*, for example, she claims that she writes “in order to take charge of the story of [her] childhood and [her] childlessness; and in order to locate [her]self,” an act that is not finite but recursive (222). She confesses:

I have been so mauled by medical procedures, so sabotaged and made over, so thin and so fat, that sometimes I feel that each morning it is necessary to write myself into being – even if the writing is aimless doodling that no one will ever read, or a diary that no one can see till I’m dead. (222)

“When you have committed enough words to paper,” she continues, “you feel you have a spine stiff enough to stand up in the wind. But when you stop writing you find that’s all you are, a spine, a row of rattling vertebrae, dried out like an old quill pen” (222-223).

In *A Stroke of Genius*, the desire to give narrative shape to illness forms an even more prominent theme. When contemplating living in close proximity to death, he marvels at how he keeps managing “to come to the end of another chapter,” while in his more optimistic moments, he ties his illness to the master-narratives of Western epistemology, which he describes as “a very American faith […] in progress and remedy, tacked on to a medieval sense…that a symmetry oversees us and provides a corrective for every ill” (92, 58). And yet, like Mantel, West’s engagement with the techniques of conventional storytelling in *A Stroke of Genius* is conspicuously uneasy. Indeed, this uneasiness is such a definitive feature of the memoir that it forms the focus of its opening paragraph, which is worth quoting in full:
The rueful jubilation in what follows honors a trajectory, perhaps a crash dive, certainly a chronic illness whose phases have always puzzled me and some of my doctors. The weird constellation of my symptoms has something to it of infernal wizardry, and I still lack the synoptic holist of a doctor who can put it all together, dominating by naming it. Surely, I ruminate, so many things gone wrong over a long time do not necessarily belong together; they just overlap, far from being siblings. I wonder, though, if there are not invisible linkages, like those Vietnam bridges built under water. My artist’s sense of symmetry craves relatedness and clear lines of causation, from hives and flesh tags to migraine and stroke, and thence to diabetes. (1)

This tension between symmetry and chaos is to characterize West’s memoir. The disagreement between his affinity for “relatedness and clear lines of causation,” and his experience of chronic illness as a mode of being that defies these structures, centres on narrative – its strengths and its frailties. Long after leaving hospital, he continues to circle around the TIA, without ever getting close enough to hone in on it. Like his doctors, he puzzles fruitlessly over its aetiology; like the archetypal chronic patient, he speculates obsessively over its possible semantic and syntactic relationship to the rest of his life narrative:

While I was still in hospital, and long after I left, a seminar met weekly to figure out what was wrong with me: neurology or cardiology? [...] The debate went on, unresolved now as then, but at least abandoned. Yet the worry lingered in my head. Why did that anemic, hive-afflicted boy who blinked nonstop become the patient he became? Again and again, I the medical voyeur, like the person with a toothache jabbing tongue into the agonizing cavity, thought back to the night before my stroke and scoured its every cleft, fondled its fiber, wondering not only what had caused it, but what it had really been like. (58-59)

West’s resolution anxiety peppers his memoir. Chapter 2 begins with a section entitled “The shapelessness of things to come”, and closes with the reflection that “My nonanalyzing mind was not yet ready to link up the things that seemed wrong with me and attempt a hypothesis” (11, 24). In spite of the promise this last phrase holds of narrative synthesis, West never gets further than tentatively identifying “the last cause in the indecipherable chain” (34).
Consequently, in these illness accounts, narrative does not deliver the kinds of reparative effects that Frank describes, but is instead a source of anxiety and unease. Instead, it seems, in the face of illness’s disruptive effects, these authors look to literature as their principal means of recourse, in ways reminiscent of the “eclectic web of […] literary allusions” that Woolf spins in On Being Ill (Bolaki “Lights” 116). This appeal to the literary is particularly prominent in A Stroke of Genius, as West observes in a brief third person reflection on the migraines that plagued his adolescence, describing himself as “a youth [who…] began to dote on works of art because his body kept failing him” (115). According to Danielle Ofri, this recourse to the arts, and particularly literature, as a mode of expressing illness is a vivid illustration of “how writers…use their poetic coping skills in the face of bodily revolt” – a statement made in direct reference to A Stroke of Genius (304). To elaborate on Ofri’s observation, in A Stroke of Genius West uses literature in two key ways. The first of these is as a sort of shorthand – a way of lending emotional depth and texture to his narrative. The second is as a mode of translation, in which the alignment of West’s private experience with iconic figures and events in the literary canon achieves a sort of empathetic generalization (albeit one limited to a certain generation of canonically-minded “Western intellectuals”) (Stroke 63). When faced with the prospect of a pacemaker, for example, he describes how he

became, in a flash, as obsessed as John Milton became with Pelops, dismembered and offered as a mince to the gods, but restored by Hermes except for the piece of shoulder already devoured by Demeter, which had to be replaced by a chunk of ivory. (65)

Though less prominent, these techniques are present too in Giving Up the Ghost, which draws not just on canonical literature but on a heady mix of Proust, St Augustine, Shakespeare, Emily Prager, Margaret Atwood, George Orwell, and Ivy Compton-Burnett, as well as folk songs, nursery rhymes, hymns, popular music, and contemporary poetry.

However, in these illness accounts, the appeal to the literary overlies, and to an extent obscures, Mantel’s and West’s struggles not to narrativize their experience of illness, but rather to articulate it at all: a struggle that reflects a more fundamental concern in their writing with the referentiality of language, and particularly the
difference between its mimetic, documentary capacities and its evocative, affective, atmospheric potential. For Mantel and West, this concern is of course central to their work as writers of fiction, and is intricately enmeshed with notions of perception. Nevertheless, for both the referentiality of language is brought into particular prominence by illness, in a variety of ways, and reaches a critical point in their experiences of various forms of speech disturbance and aphasia, in which language is severed from both the interior world of thought and the exterior, material world. For Mantel, this is a corollary of hypothyroidism, which causes her to feel “that some rustling, suspicious activity” that she “couldn’t put a name to” was taking place “at the left side of [her] head” and “muddle[s]” her speech, resulting in her calling “a clock’s hands its fingers, and a chair’s arms its sleeves” (Ghost 184). While aphasia forms the focus on West’s second illness account, The Shadow Factory, he experiences this for the first time as a temporary consequence of the TIA he describes in A Stroke of Genius, in which he recalls feeling “amazed” that he “could still think while being unable to speak,” and subsequently of “talk[ing] for the sheer joy of speech regained” (Stroke 31, 33).

Though these experiences of aphasia derail the normal referentiality of language entirely, it is clear from Mantel’s and West’s accounts that illness has troubled this referentiality from the very beginning. Their accounts are replete with the notion of that which is nameless and unwritable, but which exists nonetheless: of the inability of language to describe things deeply felt and newly seen. Both seek out solutions to this crisis, with little success. While, as we have seen, the literary offers some ready analogues, if little more, the language of medicine proves not only inadequate, but prohibited: when West attempts to join in the “arcana” of his doctors, he is met with disbelief and disapproval (Stroke 42-43). This problematic drives both authors to embark on the kind of creative labour that Woolf describes in On Being Ill when she imagines the “sufferer […] taking his pain in one hand, and a lump of pure sound in the other” so as “to coin” the right words himself (Being 7). As such, Mantel’s and West’s memoirs can be seen as an evolving series of attempts to seek out, and then, devise a representational mode fit for illness: attempts fraught with dissatisfaction and dead ends, but important nonetheless.
Sotuqnangu and the Circus Strongman: Literature and the Invention of a Language for Illness

In these attempts, Mantel’s and West’s shared identity as migraineurs plays a key role. We see this in the passage that leads into Mantel’s description of her first migraine, which she experienced at the age of seven:

Sometimes you come to a thing you can’t write. You’ve written everything you can think of, to stop the story getting here. You know that, technically, your prose isn’t up to it. You say then, very well: at least I know my limitations. (*Ghost* 106)

But Mantel doesn’t stop there, leaving silence to speak for trauma. Instead, she goes on, pushing herself beyond her limitations in an attempt to forge a language in which migraine can be described. She writes:

I can’t see anything, not exactly see: except the faintest movement, a ripple, a disturbance of the air. I can sense a spiral, a lazy buzzing swirl, like flies; but it is not flies. There is nothing to see. There is nothing to smell. There is nothing to hear. But its motion, its insolent shift, makes my stomach heave. I can sense – at the periphery, the limit of all my senses – the dimensions of the creature. […] I am looking at a space occupied by nothing. It has no edges, no mass, no dimension, no shape except the formless. (*Ghost* 106)

Marked by a rhetoric of absence and amorphousness, her description here evokes a kind of representational black hole that strains not just at the limits of Mantel’s senses, but at the limits of her ability as a writer.

Somewhat ironically, this early encounter with formlessness is a formative moment both in her personal life—which is from this point on to be defined not just by migraine but by illness and debilitation more widely—and in her professional, or writerly, life. It “sets up a sick resonance within [her] bones and in all the cavities of [her] body” (*Ghost* 107): a resonance that, like pain, occludes all else. This resonance drives Mantel to seek out a language through which it can be discharged. As her migraines had become increasingly enmeshed within a wider lattice of symptoms that her doctors describe as “idiopathic”—a term she wryly defines as “disease about which we doctors have no bloody idea”—this search for a language through which to articulate migraine becomes a more general search for a language to describe illness, and, contra her critique of Woolf, meets its first dead end in the
rhetoric of modern biomedicine (177, 189). However, the influence of these early migraine experiences on the languages that Mantel experiments with in her memoirs remains key. For, in revealing one’s experience of reality to be not only subjective, but wholly volatile, migraine rules out entirely the possibility of mimetic representation.

We see a similar phenomenon unfold in West’s writing about illness, which begins not with *A Stroke of Genius* but with an earlier essay in which he “enacts the phenomena of migraine,” and which forms an appendix to this later, book-length work (4). Though a “prelude to other illnesses,” West explains this “relegat[ion]” of the essay as a decision based on its prose style which, “costive and dense,” would “slow the reader to a crawl” (5). As such, when West notes in the “overture” to *A Stroke of Genius*, that migraine is “the backdrop to all that happens” in this work, then, he speaks not merely of the events it relates, but of the aesthetics it deploys in his attempt to create a language capable of conveying “how the migraines felt, what they were” (4).

What these experiences of migraine do suggest is the possible existence of common objects that might make possible forms of analogic, rather than mimetic, representation. The search for such objects, I argue, is central to the languages that Mantel and West develop in their recursive attempts to describe illness. As I take this argument forward, I want to pass briefly through a work mentioned above: Elaine Scarry’s *The Body in Pain*. Herein, Scarry takes Woolf’s comments in *On Being Ill* on the lack of a “ready-made language” for illness as the point of departure for an extended exploration of pain’s resistance to objectification, and to the processes through which this resistance can be overcome. Early on in this study, Scarry provides a brief survey of the various groups of people engaged in “the attempt to invent linguistic structures that will reach and accommodate” pain, within which she includes writers and artists (6, 10). “Alarmed and dismayed by his or her own failure of language,” she writes, “the person in pain might find it reassuring to learn that even the artist—whose lifework and everyday habit are to refine and extend the reflexes of speech—ordinarily falls silent before pain” (10). The “isolated instances” in which they do not, however, provide “reassurance” in the form of “fictional analogues […] that can be borrowed when the real-life crisis of silence comes” (10).
Scarry’s comments here are reminiscent of Ofri’s discussion of “how writers…use their poetic coping skills in the face of bodily revolt”: a mechanism I have traced in Mantel’s and West’s use of literary allusion in their illness accounts, and which reveals more about the work of others than it does about their own. What am I interested in instead is how Mantel and West take up the idea of the analogue in their own attempts to objectify not just pain, but the multidimensional experience of illness more widely, and, in doing so, offer insights into the ways in which literature works.

The influence of migraine on Mantel’s and West’s writing is most profound in their initial accounts of illness, which take as a central analogue for illness ideas of hallucination, synaesthesia, and of mythological or supernatural beings. For West, Hopi mythology, and the figure of Sotuqnuangu—“the god of the heavens”—form a central trope in *A Stroke of Genius*, and, though in his descriptions of migraine he repeatedly references the visual, the images he creates call on multiple senses, not just one (19). We see this in the aural and kinesthetic dimension of phrases such as the “blinding saw wheels and coruscating fortification spectra” and “the flying flies of Tucson, the pulsing red-bull’s eyes that not even Sotuqnuangu could intimidate or quell” (28, 31). In *Giving up the Ghost*, Mantel uses a similarly synaesthetic technique, describing “hallucinations of taste” and odours “so thick you felt you could graze [them] with your knuckles” (129). Most prominent in this account, however, is the recurrent motif of ghosts: a motif that acts as an analogue for the ontological disruptions and physical changes caused by her illness. She writes of “glimps[ing] the ghosts of other lives you might have led” and of “houses haunted by the person you might have been,” as well as of the “ghost baby” and “ghost children” of which endometriosis has robbed her (20, 158, 224). Crucially, moreover, she speaks of how, in the act of writing, “the ghosts of [her] own sense impressions […] re-emerge […] and shiver between the lines” (23).

In the opening scene of *Ink in the Blood*, the motif of the ghost is replaced by that of the surrealist hallucination, as Mantel “come[s] out of the bathroom and spot[s] a circus strongman squatting on [her] bed.” This hallucination inaugurates the analogic mode adopted in Mantel’s hospital diary, which is marked by surreal metaphors that draw on the botanical, the bestial, and the bibliographic. She admires the “spiral
binding” of her abdominal wound, likening it to a “manuscript,” and then later comments on how she looks “like a watermelon with a great slice hacked out,” while the machine used to drain it “snorts like an elderly pug.” As Bolaki points out, the circus strongman, whose image is also emblazoned on the cover of Ink, recalls “the dentist-visit hallucination” in the first sentence of On Being Ill (Bolaki “Lights” 116). Even more than this, it brings to mind the “lion tamer” described later in the essay,” and indeed not just the lion tamer, but the motley crew of stock characters that litter its pages. From this comparative perspective, the synaesthetic hallucinations and ghostly figures that haunt A Stroke of Genius and Giving up the Ghost come into alignment with Woolf’s descriptions of sky-gazing in On Being Ill, and also with the impressionistic portraits of everyday life she paints in Mr Bennett and “Modern Fiction.” I say this not to force a direct connection between the two works, but rather to suggest that, in their experiments in accounting for illness, Mantel and West explore similar avenues of representation to Woolf: a coincidence, perhaps, but one that suggests that illness poses specific, rather than general, challenges to the normal referentiality of language.

These challenges come to the fore in The Shadow Factory, West’s second illness account and a work he describes as “the first aphasic memoir” (1). Here, the referentiality of language is almost completely suspended by aphasia, a condition that West continues to experience today, and yet the text that emerges from this experience is profoundly literary. The following passage illustrates this well:

The bright wind of morning returned Dr. Sanjeev Vohra from below in a flash. For a patient who waited impatiently, for as much as an hour or two while the circuitry of Earth made a burrowing sound, I wanted not at all for time. “There is no pain so there is no poison.” I felt privileged to assist in his mystery, although the experience seemed much as before. He who was monarch of all he surveyed was the archduke and master of us all. First, he showed me a sonogram with a brown, centrally located ball that in some ways might have been a fragment of Mars but plainly was not, as an excited brain raced on to prove. I was myself caught between affection for Mars and his balanced presentation. (15)

With some effort, West’s account of a bedside visit paid by his doctor can be extracted from this passage. However, the bizarre idioms with which this account of
events is ornamented create an effect in which familiar structures of language, and particularly of referentiality, repeatedly collapse into “fragments”—not just of words, but of images, sounds, and other sensations—whose significance is insistent yet impenetrable.

Towards the end of *The Shadow Factory*, West describes aphasia as an experience in which one

savor[s] this small consort of [correctly remembered] words in full view of the vast sea of language out there among the charcoal seas, knowing you will be defeated in all probability by any schoolboy’s notion of completeness. Still, it bears thinking about: the gigantic caravan of all the words in the world versus the few one has of one’s own – and some of them mispronounced as well. (130)

He then goes on to propose that “there is room […] for all sorts of language. Not only for the thousands of versions of English, but also for the literate formations of people who have been persuaded they are not speaking English at all – and are therefore silenced” (130). This proposal harks back to a moment in *A Stroke of Genius*, in which West complains about what “some of these recently graduated sawboneses said about my incapacity to describe my symptoms,” insisting instead that “[his] version of [his] symptoms was not simple enough for them to understand, [not] couched in words well within their spectrum of anticipation” (43). What West points to here, I suggest, is the difference between a mimetic understanding of language’s referentiality, and a wider, more abstract sense of its expressive potential.

**Conclusions**

In her reading of *Ink in the Blood*, Gilmore suggests that we see Mantel’s illness account in terms of a critique of humanism, at the heart of which lies a disturbance of the notion “that the outside, observable body reliably represents an inner being” (“Agency” 90). In this chapter, my comparative reading of *Ink in the Blood* alongside Mantel’s earlier illness memoir, *Giving Up the Ghost*, extends this notion of disturbance beyond the body to address conventional thinking about the referentiality of language and the viability of mimetic representation. Both in *Giving Up the Ghost* and *Ink in the Blood*, Mantel explores the limits this way of thinking imposes on the attempt to account for illness, and conducts a series of experiments in
which she attempts to redirect this referentiality, and thus open up new modes of expression.

The nature of these experiments can be best understood, I suggest, through Scarry’s notions of objectification, as set out in *The Body in Pain*. This model in turn reveals the close relationship that obtains between the aesthetic analogues Mantel creates in her memoirs and modes of expressionism and surrealism at work in both literary and visual art. West’s memoirs not only add further substance to this argument, but extend it in ways that foreground illness’s capacity to derail, suspend, and disrupt the referentiality of language. As he writes in the overture to *A Stroke of Genius*, illness, and particularly his experience of aphasia, “inspired” him as a writer, by “animat[ing] [him] beyond the usual” (3). “A mind stretched to a new idea never returns to its original dimension,” he writes, and posits this as an explanation for the “sustained period of creativity” that followed in the aftermath of his TIA (40).

The ethical implications of these experiments are significant. According to Alan Radley, creative acts of textual and visual representation are an important way of making sense of the illness experience and of rendering it meaningful, not just for the person with illness but to others. As such, these acts offer people with illness the opportunity to “render[] life’s conundrums somehow graspable” and to “re-creat[e]” their experience for others: a line of argument that echoes Woolf’s ideas about intersubjective engagement and the literary (Radley 36, 41). In contrast to what he sees as the limitations of “medical, scientific, or documentary” modes, these creative representations not only offer a means of articulating the more subjective facets of the illness experience in ways accessible to others, but also enable people with illness to achieve a sense of agency in the face of illness through “the deployment of an ethic of freedom” that manifests in aesthetic experimentation (Radley 38, 41, 36).

With its emphasis on the mediatory role of aesthetics, Radley’s thesis brings to mind Woolf’s description in *Mr Bennett* of the literary as a “common meeting-place”: indeed, his suggestion that creative portrayals of illness should “ usher” their viewers in closely echoes Woolf’s assertion that writers should ensure readers are able to reach this common meeting-place with ease (Radley 185; Woolf *Bennett* 17).

This notion of the literary—and of art more generally—as a privileged mode of
ethical engagement is problematized by the illness accounts of Mantel and West. In attesting to the challenges that illness poses to the referentiality of language, their memoirs draw into question the possibility of articulating illness with authenticity, and thus trouble the paradigm on which Radley’s argument depends. Rather, in the emphasis they place on the attempt to objectify the experience of illness, rather than the objects themselves, Mantel and West offer an alternative view of literature’s ability to facilitate intersubjective engagement, and thus to participate in the ethical. In this view, the literary offers as a basic term of recognition not a common aesthetic language for experience so much as an awareness of the labour involved in the attempt to achieve this language: an approach that has much in common with the ethical philosophies of Butler and Ricoeur.

Acts of writing and reading subjective experience are central to J. M. Coetzee’s *Age of Iron* and Marlene van Niekerk’s *Agaat*, the novels on which my next chapter focuses. In these experimental fictions, Coetzee and Van Niekerk focus not on the challenges that illness poses to our thinking about the referentiality of language, but on the widespread tendency to read fictional representations of illness metaphorically – a tendency that is particularly pronounced in fictions that, like *Age of Iron* and *Agaat*, take as their settings moments of political, social, and cultural crisis. Like the other texts in this thesis, these novels deploy aesthetic strategies that problematize our assumptions about the ways in which illness signifies and the referentiality of fiction, and in this way draw into question the responsibilities that writers and readers have not only to texts but to each other.
Chapter Five

The Via Dolorosa in the Southern Hemisphere:
Illness, Fiction, and the Question of Place
in Two South African Novels

The blow catches him from the right, sharp and surprising and painful, like a bolt of electricity, lifting him up off the bicycle. Relax! he tells himself as he flies through the air (flies through the air with the greatest of ease!), and indeed he can feel his limbs go obediently slack. Like a cat he tells himself: roll, then spring to your feet, ready for what comes next. The unusual word limber or limbre is on the horizon too.

That is not quite as it turns out, however. Whether because his legs disobey or because he is for a moment stunned (he hears rather than feels the impact of his skull on the bitumen, distant, wooden, like a mallet-blown), he does not spring to his feet at all, but on the contrary slides metre after metre, on and on, until he is quite lulled by the sliding.

J. M. Coetzee (Slow Man 1)

Thus opens Slow Man (2005), Coetzee’s eleventh novel and the first written after his relocation to Australia from South Africa in 2002. As a result of this catastrophic cycling accident, Paul Rayment—a childhood immigrant to Australia from France now in the twilight of middle age—loses his right leg, and is transformed from a healthy, physically intact and fully able human being into a hospital patient temporarily bedridden and permanently disabled by the amputation of his right leg. Slow Man charts Rayment’s progress—or, rather, his lack of progress—in the aftermath of the accident: his refusal of physiotherapy and rejection of prosthesis, and his awareness that throughout “he has not behaved well, has not risen to the occasion” (10, 15). Lying in bed, refusing to work up the momentum to take “just a few steps,” Rayment also resists the pressure to move on in narrative terms from crisis towards acceptance and restitution: a movement repeatedly emphasized in the advice of his doctor and nurses, as well as his friends (10). Instead, he circles back to the “the incident on Magill Road” in a compulsive rewriting of the novel’s opening paragraph, before returning home, where he is cared for on a part-time basis by a recent Croatian immigrant (14-15). After witnessing Rayment’s post-accident depression, the theft of a prize specimen in his collection of early Australian photographs, his erotic and romantic misadventures, and the invasion of his flat and
private life by one Elizabeth Costello—the titular character of Coetzee’s previous novel and a writer herself—, the novel’s final scenes are surprisingly sentimental, and offer the prospect, if not the guarantee, that Rayment might begin to move on with his life – a prospect symbolized by the customized recumbent tricycle he receives from his carer’s family as a gift of thanks for his advice and financial support.

In her review of *Slow Man* for the British daily *The Times*, Sarah Emily Miano describes the novel as “another exemplary tale of suffering from one of the best writers of our time,” and commends Coetzee for “dar[ing] to articulate our incomprehensible existence”; a feat whose success depends, she suggests, at least in part on the novelist’s identification and exploration of the “differences [that] lie between narrative prospects and real ones” (Miano 2005). Here, Miano reproduces a metanarrative that in the early twenty-first century has come to hold increasing sway in both scholarly and popular readings of Coetzee’s oeuvre: a metanarrative in which this oeuvre is seen to have as its central concern the incomprehensibility of human existence, and the suffering that forms a central part of this existence. In this, Miano is joined by a host of reviewers and scholars, including Stephen Abell, who in a 2011 article for the *Times Literary Supplement* describes Coetzee as “our best authority on suffering,” and Alice Hall, who in *Disability and Modern Fiction* (2012) places *Slow Man* within the author’s ongoing engagement with “questions of universal significance […] about care, bodily, linguistic and technological dependencies and the formation of narrative and identity” (Abell 3; Hall 93).

Strongly orientated towards an essentializing humanistic philosophical tradition that is Western in origin, this critical metanarrative is by no means new. As Attridge points out, its roots can be traced in early responses to Coetzee’s fiction (*Coetzee* 33), and indeed may have proved instrumental in the exemption of his work from the apartheid government’s draconian censorship laws. Its ascendancy can also be seen to mirror the evolution of Coetzee’s fiction, which, with the exclusion of the semi-autobiographical novel *Summertime* (2009), has in the early twenty-first century been marked by a turn away from the South African context to that of North

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93 Peter D. McDonald discusses the encounters of Coetzee’s fiction with government censors in *The Literature Police: Apartheid Censorship and Its Cultural Consequences* (2009).
America, Europe, and Australia in the novels *Elizabeth Costello* (2003), *Slow Man*, and *Diary of a Bad Year* (2007), and, more recently, the unnamed utopian setting of *The Childhood of Jesus* (2013).

Crucially, this critical metanarrative has to a large extent displaced that which dominated the response to Coetzee’s late twentieth-century fictions, beginning with *Dusklands* (1974), a work of two parts set in the United States of the 1960s and in eighteenth-century South Africa, and culminating in the dystopian post-apartheid novel *Disgrace* (1999). Taking its cue from Jameson’s proposition that “third-world texts […] necessarily project a political dimension in the form of national allegory: the story of the private individual destiny is always an allegory of the embattled situation of the public third-world culture and society,” this earlier metanarrative consists in “allegorical readings” of a highly localized, historicist kind (Jameson 69; Attridge Coetzee 33). Based on “the widespread assumption that any responsible and principled South African writer, especially during the apartheid years, will have had as a primary concern the historical situation of the country and the suffering of the majority of its people,” Coetzee criticism in this vein thus tends to “translate apparently distant locales and periods into the South Africa of the time of writing, and to treat fictional characters as representatives of South African types or even particular individuals” (Attridge Coetzee 33). To this mode of historicist allegorization, even those of Coetzee’s novels that are explicitly located in the contemporary South African content have not been immune: as Attridge notes, *Age of Iron* has often been read “as an exemplification of the condition of South Africa during the township wars and States of Emergency of the mid-1980s” and *Disgrace* as “a schematic portrait of the country in the early years of democracy after the official end of apartheid” (Coetzee 33).

However, for all the tension that exists between these two metanarratives, the difference between them is perhaps less profound than might at first appear. As Attridge points out both approach Coetzee’s fiction as fundamentally allegorical in nature (Coetzee 32-33). Whereas allegorical interpretations in the historicist mode read Coetzee’s fiction in relation to a specifically South African symbolic economy, then, those at work in the readings of Miano, Abell, and Hall—among many others—take as their frame of reference a supposedly universal notion of the human
condition, and consequently read individual characters as manifestations of this condition (Coetzee 32-33). Though in the context of apartheid South Africa these interpretive approaches might have appeared incompatible, then, at root they both speak to more essential debates about literature, and particularly about the writing and reading of fiction.

In relation to these debates, tropes of illness, disability, and the suffering body occupy a particularly interesting position. As Sontag points out in her critique of metaphoric thinking, illness is invariably read as in allegoric and/or metaphoric terms, and subsequent studies—including Mitchell and Snyder’s Narrative Prosthesis (2000)—have only served to bolster this argument. This way of thinking is particularly pervasive in contexts such as South Africa, as Attridge has pointed out. And yet, for Coetzee, the suffering body is that which is beyond allegorization. Speaking in relation to Foe (1986), his reworking of Robinson Crusoe, he describes the suffering body as the “simple […] standard” that stands over his fiction, and “a counter to the endless trials of doubt” (“Interview” 248). The “power” of the “body in pain,” he urges, is undeniable and authoritative, and thus, he appears to suggest, cannot simply be collapsed into allegory (“Interview” 248). Taking this problematic as my point of departure, in this chapter, I consider the contribution that two fictional accounts of illness that are broadly realist in style, and which take as their setting decisive moments and significant spaces in South Africa’s historical and cultural life, can make to thinking about literature’s relationship to the local context in which it comes into being, and the kinds of responsibilities this relationship demands of writers and readers.

Structures of Ambiguity: Illness and Allegory in Age of Iron and Agaat

Age of Iron takes as its setting suburban Cape Town in the mid to late eighties, or what David Attwell describes as “the worst years” of the States of Emergency imposed by the National Party government in the decade prior to the collapse of apartheid (Attwell Coetzee 120). A slim novel presented as an extended letter from one Mrs (Elizabeth) Curren—an ageing white woman and former classics teacher who lives alone in a deteriorating inner-city suburb—to her daughter, who lives in self-imposed exile in the United States, this text falls under the rubric of the epistolary novel, though, as Attridge reminds us, Mrs Curren’s narrative provides
“little in the way of realistic reinforcement that might enable us to imagine the words issuing from a pen onto a sheet of paper” (Attridge Coetzee 91). Early on, Mrs Curren relates the news that the cancer for which she has previously been treated has recurred, and is terminal, though in a moment of temporal confusion typical of her circuitous narrative style, the letter opens not with this terrible news, but with a description of an encounter with a vagrant who has set up camp next to her garage. Known only as Vercueil, this man becomes a central figure in the novel, eventually moving into Mrs Curren’s house and becoming a carer of sorts. The letter covers the development of their unusual relationship over the last weeks of Mrs Curren’s life, in a city racked by political violence and social unrest.

In contrast to Age of Iron, Agaat is, at well over 600 pages, a fat breezeblock of a book. Van Niekerk’s monumental novel spans the second half of the twentieth century, but is primarily set in 1996, on a family farm in the Overberg region of the Western cape – one of only two provinces that failed to elect an African National Congress provincial government in the nation’s first democratic elections, and the only one to re-elect the National Party at this time. These events form the backdrop against which Van Niekerk narrates the final months of Milla de Wet’s life, during which she is bedridden and increasingly paralyzed by motor neurone disease. No longer able to speak or write, Milla is subjected to hours of what her nurse Agaat—a woman whose relationship to Milla is complicated by the informal adoption through which, as a child “cast-off” by her parents, she first entered the de Wet household—calls “reading-aloud time” (9, 662). This “reading-aloud time” involves Agaat reciting from a small library of South African and European literary classics, out of date women’s magazines and farmer’s weeklies, academic texts, and, most crucially, Milla’s old diaries. Alongside this, Van Niekerk sets Milla’s attempt to account, both as a final testament and in the teeth of the self story with which Agaat confronts her, for her “life and times […], her place of origin, her purlieu on Grootmoedersdrift, her hereditary home” (21). The narrative that results is disordered, and weaves together the present, which Milla narrates in the first person; the past as retrospectively reconstructed by Milla, which is narrated in the second person; and the past as documented in her diaries, and as embellished by Agaat: a strand also narrated in the first person. This amorphous whole is bookended by two short
sections that detail the brief visit made by Milla’s son Jakkie to Grootmoedersdrift, in which he buries his mother and bequeathes the farm to Agaat.

Like *Age of Iron*, *Agaat*’s political backdrop has shaped critical responses to the text, both within and without South Africa, in ways reminiscent of the kinds of historicist allegory Attridge traces in readings of Coetzee’s fiction. This is exemplified in Liesl Schillinger’s review of the novel for the *New York Times*. Here, Schillinger explicitly reads *Agaat* as national allegory, deciphering the relationship between Milla and Agaat as a symbolic embodiment of the country’s past. She writes: “it is apartheid itself that Agaat and Milla embody, two women, black and white, ink and paper, who together, over 50 years, inscribed upon each other a scroll of wrongs, betrayals and sacrifices that cannot be redressed, only reread.” Scholarly readings of the work display a similar tendency, using the novel as a testing ground for the transposition of theoretical concepts from exogenous contexts into a South African milieu.\(^\text{94}\) Perhaps even more so than *Age of Iron*, *Agaat* invites such readings – it is, after all, a novel that engages in detail and at length with South Africa’s literary tradition—particularly with the genre of the *plaasroman*, or farm novel—and with its peculiar socio-historical conditions. And yet, as Van Niekerk wryly notes in an interview with Hans Pienaar, readings of the novel that take this “frame of referentiality” as their starting point are often “plotting for more” than her writing can—or, she suggests, *should*—provide (Van Niekerk “So”).

In one of the more interesting moments in this awkward interview, Pienaar likens *Agaat* to Coetzee’s *Disgrace*, asking Van Niekerk if “the former can be read as a response to the latter.” Though Van Niekerk acknowledges being “pierced to the quick” by Coetzee’s novel, she dismisses Pienaar’s suggestion, stating that though both novels are “about power” and “about land,” in *Agaat* she is “specifically interested in the intimate relationship between two people, the dynamics between them” (Van Niekerk “So”). With this statement, Van Niekerk stymies Pienaar’s attempt to discuss the intertextuality of her work. And yet, rather than distancing her work from Coetzee’s oeuvre entirely, her response instead suggests that, in linking

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\(^{94}\) Studies in this vein include the work of Loraine Prinsloo and Andries Visagie (2009); Rosemarie Buikema (2009); and Caren van Houwelingen (2012).
Agaat to Disgrace rather than to Foe, say, or to Age of Iron, Pienaar might simply have missed the wood for the trees.

In its depiction of the final months of an ailing, ageing white woman on an isolated farm during a period of radical social and political tension, Van Niekerk’s Agaat can quite clearly be seen to resurrect the ghost of Mrs Curren, rather than restage the carnage of Disgrace. Indeed, the parallels between these two texts are profound, and build on the themes that link Age of Iron to Coetzee’s oeuvre more widely. Though Milla de Wet is dying not from cancer but from motor neurone disease, the debilitating effects of her illness combined with the absence of family—both women have only one child, and like Mrs Curren’s daughter Milla’s son Jakkie also lives in self-imposed exile in North America—leave her in a similar situation to Coetzee’s protagonist. Housebound and entirely dependent on others, Milla is cared for primarily by Agaat. While the resemblance between Milla and Mrs Curren is striking, that between Agaat and Vercueil is uncanny, and takes place on both a somatic and a semiotic level. Both bear names that are unstable and ambiguous. Agaat’s original moniker Asgat, or “ash-arse,” is modified by Milla into the Afrikaans endearment “aspatat,” or “baked-potato,” and then condensed into the initial “A.” before the local minister suggests “Agaat” – a name that carries with it the notion of intrinsic good from its root in the Greek agathos, but which also signifies the semi-precious stone known in English as agate (666, 470, 479, 487). In a similar vein, in Age of Iron Mrs Curren is mystified by Vercueil’s name, remarking “Vercueil, Verkuil, Verskuil […] I have never come across such a name before” (34). Though unrecognizable in any language, these permutations of Vercueil hint at meaning in their morphemic resemblance to various French and Afrikaans words—“ver,” for example, means “worm” in the former and “far” in the latter, while in Afrikaans “skuil” and “ferskuil” mean both “to hide” and “to shelter”—and thus also gesture to a putative ancestry. Further, though the question of whether Vercueil is, like Agaat, coloured in origin is debatable, the two share an unusually specific physical marker in their disabled right hands. Vercueil’s is immobile, its “three fingers curled into the palm,” while Agaat’s “deformed arm” ends in a “hand bent down from the wrist, the fingers half squashed together, the thumb folded in so it looks like a shell” (10; 656).
The close resemblance between Vercueil and Agaat is not, however, an indulgent intertextual gesture on Van Niekerk’s part. It is instead, I argue, an important clue to the specific nature of the intervention that these novels stage in relation to the critical metanarratives that have come to dominate thinking about the ways in which fictional depictions of illness signify. In his discussion of the ways in which Coetzee both solicits and problematizes allegory in his fiction, Attridge uses Vercueil as his case in point. “Interpretations of Vercueil in Age of Iron that allegorize him as the angel of death,” he insists, must take account not only “of Mrs. Curren’s own tendency to do just that throughout the novel” but also of her “rejection in many places of this allegory” (34, 35, emphasis in orig.). Examples of these tendencies are plentiful, and Attridge cites them at length; what matters most however is their cumulative suggestion that “an allegorical reading of Vercueil’s part in the novel cannot be straightforward” (35). In light of this suggestion, I argue, Agaat’s close resemblance to Vercueil can be seen as a statement of affinity with the stance towards allegory that Coetzee takes in Age of Iron.

The ambiguity of this stance is most pronounced in the interactions staged between bodies and landscapes in these novels, I argue, and ultimately unfolds in ways that pit the authority of history—an authority that, Coetzee insists, “lies simply in the consensus it commands”—against that of the suffering body, the “standard” that he erects over his fiction and which, he argues, acts as “a counter to the endless trials of doubt” (“Novel” 4; Doubling 248). In my readings of these interactions, I take as my lodestar Attwell’s discussion of the experience of place, and of South Africa in particular, in Coetzee’s oeuvre, as set out in articles such as “Coetzee’s Estrangements” (2008) and “J. M. Coetzee and the Idea of Africa” (2009). For Coetzee, Attwell writes, South Africa is “the unchosen but intimately known milieu” of writing (“Estrangements” 237, emphasis in orig.) — a connection that arguably holds true for many South African writers, including Van Niekerk. This tension, he argues, manifests itself in acts of “fictive displacement” and “imaginary relocation”, and also in the “tripartite architecture” that, for Attwell, “surfaces again and again in the novels” (“Estrangements” 233). This architecture consists of

the subject (frequently a subject living unhappily in a body, often a body in pain, marked by contending social forces); history (as a field of contestations, "tortions of power" in Coetzee's phrase from the Jerusalem Prize acceptance
speech) [...] and language (as a field of representations, cultural codes that precede the subject, themselves historical and forever slipping into obsolescence). (233)

Mrs Curren and Milla de Wet are both subjects living unhappily in a body in pain and marked by contending social forces, engaged in a struggle to the death with history and with language. Crucially, however, it is illness—and not South Africa per se—that forms the unchosen but intimately known milieu of narration for these women. As part of the novel’s alleged epistolary structure, in Age of Iron Mrs Curren’s impulse to write is presented as a response to the news that her cancer is terminal, by leaving some form of last testament for her daughter in exile: her letter is a gift, an embrace, a mother’s attempt “to pass [herself] on beyond death” (5). Before all else, then, this is a narrative brought into being by illness, and not—at least not directly—by apartheid. Similarly, Milla’s desire to paint a convincing “self-portrait” is provoked not by the political transition unfolding around her, but by Agaat’s reading aloud from her diaries and her inability to respond – a situation fundamentally dependent on Milla’s illness (21).

In his reading of estrangement in Coetzee’s œuvre, Attwell attends to the way in which he uses aesthetic defamiliarization to “serve a much more wide-ranging practice” that is at once “existential, political, ethical, as well as aesthetic” (“Estrangements” 238, 236). Attwell finds an example of this in Mrs Curren’s palimpsestic description of the “alley down the side of the garage” with which the novel opens (Age 3). This space is first a place where Mrs Curren’s daughter and her friends would “sometimes play”, then a “dead place, waste, without use”, before being occupied by a “a house of carton boxes and plastic sheeting and a man curled up inside” – the man being Vercueil, who she later invites into her home (Age 3). For Attwell, this scene constitutes “a renewal of perception of sorts, in which meaningfulness returns in an unexpected if unwelcome way” (“Estrangements” 242). Crucially, he attributes “the interruption causing the estrangement” to “the presence of death and separation - the news of the illness, the appearance of Vercueil, and the absence of the daughter” (242). It is against this “dark background of morbidity”—and I would probably rephrase this as its “dark foreground of morbidity”—, he argues, that “Cape Town in the mid-1980s will be reassessed” (242). Crucially, for Attwell this reassessment enables
a defamiliarization of place so complete that a reexamination of social relationships […] can be explored de novo. It is not only the perception of objects that is renewed, in Shklovskian terms; it is also the country itself, in all the complex, incommensurate interconnections that are implied by native land and nation-state, pays and patrie, the intimacies of home and the detachments brought about by the exercise of power. (242)

In his later article on the idea of Africa in Coetzee’s fiction, Attwell turns his attention to a process he calls “occultation”: a representative technique in which an object is “rendered potent and mysterious” (“Idea” 71). This forms part of a wider scheme of estrangement, which writers achieve through “appropriating places and their names to their own narratives and structures of meaning” (74). Crucially, however, occultation as a distinct representational mode involves “emptying signs that are not free of social content and filling them with something else” (74). According to Attwell, in Coetzee’s fiction “the occulted sign of Africa ensures that the eclipsed object continues to hold sway over the subject’s imagination, releasing an aesthetic charge and leaving an ethical disturbance” (71). In summary, then, in Attwell’s use of the two terms, estrangement signifies a multivalent process of aesthetic, existential, political, and ethical defamiliarization, while occultation refers specifically to a form of defamiliarization in which pre-existing signs, signs loaded with culturally-specific meaning, are recast within an alternative framework of reference. In the close readings of Age of Iron and Agaat that follow, I examine how illness acts as a driving force behind estrangement and occultation, to enact a kind of conceptual slippage and traffic that both solicits and resists allegory.

Early on in Age of Iron, the novel’s terminally ill narrator Mrs Curren takes a trip up Cape Town’s Boyes Drive, an elevated road that hugs the slopes of Muizenberg Mountain above “the sweep of False Bay” (16). At the top, she stops to contemplate the view, taking in “A breaker, perfectly straight, hundreds of yards long, rolled inshore, a single crouched future on a surfboard gliding ahead of it” and “the mountains of Hottentots Holland” that stand out “clear and blue” across the bay. As she does so, she is overcome by what she describes as “a hunger of the eyes…such hunger that I am loth even to blink”. “These seas, these mountains”, she writes, “I want to burn them upon my sight so deeply that, no matter where I go, they will
always be before me. I am hungry with love of this world” (16). Here, the significance of the word “world” is threefold. Poised above the shoreline, not far from the continent’s southernmost tip, Mrs Curren stands on the threshold both of the natural landscape and of the nation-state — tropes central to the novel’s political and philosophical content. And yet, the circumstances that have brought her narrative into being lend this scene an additional symbolism that combines the specificity of her location with the fundamentals of human experience. “This world” is not only the scrubby fynbos and strandveld of the Cape peninsula, with its quaint Victorian houses, Art Deco apartment blocks, and labyrinthian townships, but material world in general: a world in which bodies and landscapes interact in the production of knowledge and the creation of meaning.

Our knowledge of Mrs Curren’s impending death is sufficient to sustain such a reading, and yet it is clear that neither Coetzee nor his author-protagonist are content to leave this as just one among many competing thematic strands. The centrality of illness to Mrs Curren’s experience of the False Bay vista is heavily underscored by the scene’s resemblance to an earlier paragraph:

We sicken before we die so that we will be weaned from our body. The milk that nourished us grows thing and sour; turning away from the breast, we begin to be restless for a separate life. Yet this first life, this life on earth, on the body of earth — will there, can there ever be a better? Despite all the glooms and despairs and rages, I have not let go of my love of it. (11-12)

Shared metaphors of hunger and desire link the two sections, as does a reoccurring imagery of the body – an imagery that is most pronounced in the analogy set up between Mrs Curren’s cancerous body and the body of earth on which she stands. The nipple to Africa’s drooping teat, in centuries past the Cape nourished the Dutch East India Company, channeling the riches of the region’s mines and the sticky wine of its vineyards to nurture Europe’s expanding empire. And yet at the time in which Age of Iron is set apartheid has ravaged the Mother City, leaving her more of a toxic, neglectful hag than a nurturing, milky-breasted matriarch. Moreover, the “glooms and despairs and rages” that Mrs Curren describes not only link her debilitating episodes of physical pain and chaotic psychological state to the riots and crackdowns of South Africa’s state of emergency, but also recall the volatile weather and deceptive landscape to which the epithets “Cape of Storms” and “False Bay” refer.
This complex chiastic structure brings the novel’s representation of the natural landscape and the nation-state into conversation with the experience of inhabiting an ageing, malignant white female body — a body that has been largely overlooked in feminist and other modes of literary and cultural criticism. This neglect is particularly pronounced in South Africa, where attention has tended to focus on other bodies. The mutilated bodies of young black men litter apartheid-era texts, from Elias Tekwane in Alex La Guma’s *In the Fog of the Seasons’ End* (1972) to Wally Mongane Serote’s *To Every Birth Its Blood* (1981), while post-apartheid fiction is particularly memorable for its depiction of the violated female body, of which Lucy in *Disgrace*, Lydia Ali in Achmat Dangor’s *Bitter Fruit* (2001), and Dulcie Olifant in Zoë Wicomb’s *David’s Story* (2000) are all salient examples. Likewise, though illness is an increasingly prominent trope in South African fiction, its representation is typically limited to HIV/AIDS - a condition associated, particularly in South Africa, with youth and desire, rather than ageing and isolation.

*Age of Iron* engages at length with these emblematic bodies. The corpse of Mrs Curren’s domestic worker’s son, murdered during a Gugulethu riot, is a “massive, solid presence” in the text: a presence reinscribed in the body of his friend, John, who survives the riot only to be discovered in hiding on Mrs Curren’s property and executed there by the police (96, 142). However, instead of obscuring the symbolic power of the ageing white female body, this engagement, I argue, serves primarily to intensify it. The contrast that Coetzee sets up between the resistance to meaning represented by Mrs Curren’s body and the susceptibility of Bheki’s and John’s bodies to socio-political interpretation is crucial to this intensification. This contrast is evident, for example, in the scene of John’s execution. Although the act takes place off-stage, John’s body is the nucleus around which the scene revolves. During this episode, Mrs Curren is repeatedly ignored, her body and voice occluded by the black-and-white pattern of political violence. The police pay no attention to her protests against the invasion of her home:

‘Wait!’ I called, and ran, truly ran — I did not know I had it in me — to the kitchen door. ‘Wait!’ I called, slapping at the pane, fumbling with the bolts and chains — ‘Don’t do anything!’

There was someone in a blue overcoat standing on the veranda with his
back to me. Thought he must have heard me, he did not turn. (138)

She is soon removed from the scene, first into the kitchen and then from the house altogether. This displacement is coupled with an insistent covering of her ageing body. She emerges from the house with bare feet, wearing only a “white nightdress”—a garment that makes her appear like “a body risen from the dead” (138-9). This is first covered by a “policemen’s overcoat” and then by a quilt, a covering that simultaneously reflects and refracts the image of John’s blanket-covered body as it is wheeled down the driveway and into an ambulance (139, 141, 143). On the one hand this sequence of displacement and disguise reinforces what Kathleen Woodward describes as the “invisibility of older women”, in which the ageing female body is both metaphorically and literally kept “out of sight” and thus “out of mind” (xiv, xii-xiii). On the other, however, the repetitive tug-of-war that takes place between Mrs Curren’s disruptive presence and the attempts of the police to contain it constructs the ageing female body as something that cannot be contained nor controlled. While Bheki and John can be shot on grounds of national security and the singularity of their living, breathing bodies compacted into political allegory, Mrs Curren presents a more complex challenge to the symbolic economy of South Africa in the apartheid era.

Though the symbolic substance of Mrs Curren’s ageing, malignant body is continually eclipsed by the more readily readable bodies around her, I argue that, in doing so, its power to complicate the categories of being and systems of meaning associated with its context is intensified. The occulting of Mrs Curren’s body is evident from the novel’s opening scene, in which she presents herself as little more than an inanimate clotheshorse, upon which “the winter stockings, the blue coat, the skirt with whose hang there has always been something wrong, the grey hair cut by a strip of scalp” are draped in a two-dimensional semblance of a body (4). This description anticipates the series of ethereal self-portraits found in the latter half of the novel. She describes herself as “hollow […] a shell” (103), “[a] white moth, a ghost emerging from the mouth of the figure on the deathbed” (119), a ghostly “body risen from the dead” (138). “Were I to be opened up”, she writes, “they would find me hollows as a doll, a doll with a crab sitting inside licking its lips, dazed by the flood of light” (103). Reduced to a crab, the symbol of her cancer, Mrs Curren is continuously engaged in a process of emptying out, of occulting herself.
And yet, in spite of this, the liminality and transience with which her ailing, ageing body is associated dominates the symbolic logic of the novel. The first, scene-setting paragraph, for example, is redolent of death and decay: the claustrophobic, tomb-like space of the alley a “dead place” full of rotting leaves. It is also, however, a record of a personal past very different from the letter’s present. This vacant, unused space acts as a reminder of her daughter’s growth into adulthood and her subsequent departure from South Africa, which in turn signals Mrs Curren’s loss of utility and social value as a mother and the denial of her symbolic value as a grandmother. This is reinforced a few paragraphs later, when Mrs Curren observes Dr Syfret “withdrawing”, a sign of “his allegiance to the living, not the dying”, and also later in the novel, when we learn that she made her living as a classicist, by “giving voice to the dead” (4, 176).

These idioms percolate through the paragraph that follows. A “derelict” living off donations, drink, and discarded food, Vercueil lacks social function and value (3). He smells of “urine” and “mouldy clothing”—waste and decay—and, lying in his “box” with “his legs stretched out like a marionette’s [and] his jaw agape”, he resembles nothing so much as a corpse awaiting burial (3). Though apparently occulted in this scene by Vercueil’s unusual appearance and olfactory overload that accompanies it, Mrs Curren’s body casts a long shadow of morbidity. This complex performance of occultation recurs throughout the novel. When Bheki is knocked off his bicycle by a police van, Mrs Curren’s description of her attempt to stem the flow of blood from his injuries is at first entirely focused on Bheki’s body. Her narrative is saturated in his blood, her hands obscured by it:

Blood ran down the boy’s face in a steady, even sheet…. As long as I pinched tight I could hold in most of the flow. But when I relaxed blood poured again steadily. It was blood, nothing more, blood like yours and mine.

Mrs Curren’s role as a grandmother is never directly mentioned in the novel, but is hinted at when she shows Vercueil a photograph of her daughter’s two sons. Significantly, she calls them “their children” rather than ‘my grandchildren’, and describes them without affection as “two little boys in caps and coats and boots and gloves standing to attention beside a snowman”, an image far removed from her own childhood photo, with its sunshine, “hollyhocks” and “bed of melons” (27-28, 101). The contrast between the two photos is made all the more profound by the fact that the latter was taken in Mrs Curren’s grandfather’s garden, a detail of family intimacy that emphasizes the distance separating her from her own grandchildren.
Yet never before had I seen anything so scarlet and so black. Perhaps it was an effect of the skin, youthful, supple, velvet dark, over which it ran; but even on my hands it seemed both darker and more glaring than blood ought to be. I stared at it, fascinated, afraid, drawn into a veritable stupor of staring. (58)

However, the narrative soon returns to its narrator, and back to tropes of history, land, and maternity familiar to the reader from the scene on Boyes Drive. Bheki’s blood sets in motion a sequence of “unsuspected linkages, at once decentered and systemic” that leads us from a Cape Town street to “a Baikal Sea scarlet-black under a wintry blue Siberian sky” and then on to “a place apart, in a mud-walled dam in the Karoo with barbed wire around it and the sun blazing down, the blood of the Afrikaners and their tribute-bearers” (58-59). She then goes on to describe how

For twenty years I have not bled. The sickness that now eats at me is dry, bloodless, slow and cold [...]. To have fallen pregnant with these growths, these cold obscene swellings; to have carried and carried this brood beyond any natural term, unable to bear them, unable to sate their hunger: children inside me eating more every day [...] Like insect-eggs laid in the body of a host, now grown to grubs and implacably eating their host away. (59)

In this way, Coetzee’s novel fashions a semiotic logic in which conceptual boundaries exists primarily as sites for continuous slippage and traffic, in ways redolent of the bodies in performance discussed in chapter 3.

_Agaat_’s various narrative strands are disordered and digressive, with little concern for conventional narrative principles such as causality, coherence, or consistency. Among the novel’s many unruly features can be found a potent defamiliarization of place similar to that Attwell identifies in _Age of Iron_. Like Milla’s diaries, which Jakkie describes as being extensively annotated “in [his mother’s] handwriting with dates, days and even months, years later than the original entry” (680), the Grootmoedersdrift homestead is a site of ongoing transformation — a transformation that becomes increasingly driven by Milla’s illness. Beginning with the transfer of Grootmoedersdrift from Milla’s parents to her husband Jak and culminating in the legalisation of _Agaat_’s “benevolent dictatorship,” land ownership is a key issue in the novel — an issue that lies close to the heart of South Africa’s apartheid and post-apartheid history (Van Niekerk “So”). And yet land ownership is only one of many
interrogations of space and belonging at work in Agaat. In a technique that recalls Woolf’s The Waves, the abstract, italicized prose poems that punctuate Milla’s narrative, for example, brings together agricultural rhythms and biogeochemical processes in a stream-of-consciousness narrative that forms an abstract counterpoint both to Milla’s diaries and to her final attempt to account for herself:

\[
\text{they have not heard from me for so long they may well think I am dead it leaves me cold really I cannot deny I have let the world slip by my hand sometimes I still have the urge to call to scream to get up the need walks in waves but congeals an ocean of glassy gel noiseless salty white coast a dream but I am not sleeping am not dead am awake between me and me all hollows are silted shut a mountain without caves storeys without stairwell...images no longer offer solace my filling seed soil wind I am who I am impermeable no turn up or down or round possible the sight of a dead wall could relieve me but I am myself the wall am name am flour am history have occurred my damage is dense is black my tongue silts my mouth full of water oh my soul in me there is no room for you to mortify yourself (622)}
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In addition to their role in Van Niekerk’s depiction of Milla as unreliable narrator, these sections work towards a defamiliarization of place similar to that found in Age of Iron. Raising complicated questions about the relationship between culture and nature, and particularly about what Michiel Heyns calls “human dealings with the soil” (132), they play with the “complex, incommensurate interconnections” that link “native land and nation-state, pays and patrie, the intimacies of home and the detachments brought about by the exercise of power. Central to this sense of an estrangement that is at once existential, political, ethical, and aesthetic is Van Niekerk’s use of a densely patterned figurative vocabulary that draws on cartography, needlework, scarification, and textuality – a vocabulary whose organic evolution simultaneously evokes the chaotic congestion of Milla’s motor neurons, the cadences of the landscape, and the unsuspected linkages and “retarded logic” that govern human emotion and interaction (Agaat 11).

This element comes to the fore in a scene in which Agaat hangs an “embroidery experiment” on the wall next to Milla’s bed, in order to give her something to look at: Milla’s restlessness is, she feels, an attempt to communicate that “she wants to
see something” (217, 208-209). The embroidery is of a “great rainbow”, and, in its impenetrable evocation of the “rainbow nation” of post-apartheid South Africa, the embroidery is thus easily read as a gesture towards the wider context in which the novel takes place. Too easily, perhaps: though Agaat is “anaesthetised” by the creative labour involved in producing it, her intention is to estrange the familiar. Milla recalls her saying “Everybody thinks they know what a rainbow looks like…but when it’s from close by like this, they’ll wonder what they’re seeing” (217). Seen through Milla’s eyes, the embroidery achieves the intended effect:

A straight inside section of the body of the rainbow. All over the cloth. The yellow of the spectrum runs off into creamy white, then pure white. The veld gradated so subtly that my eye reels, that I seek for a stay inside of me, for the blue-green of the Waenhuiskrans horizon, for yellow-green shoots of self-sown oats, water-green pineapple drink, lime peel, sunflowers, orange cannas, a dust-dimmed sun over stubble field, a harvest moon blood-red, a watermelon’s flesh. And Geissorhiza radians, Babiana purpurea, amongst dark bracken the seven other purples of September. Swift effulgences, pleats of light.

But here is neither place nor time. It’s an embroidery of nothing and nowhere. What Agaat must have imagined to lie behind the tender despair of defenceless creatures, behind the firefly, the evening star, the poppy, the blond lad in his corduroy pants. Everything that slipped out of her grasp, Jakkie’s whole childhood, replaced with this embroidered emptiness. [...] What am I supposed to do with it all? (218-219)

At once abstract and layered with meaning, the embroidery prompts interpretation only to undermine it, evoking everything and nothing at the same time. Furthermore, Milla’s restlessness, her desire to “see something” is, as the reader knows, a desire to contemplate once more the map of Grootmoedersdrift - a desire that becomes a driving force in the novel. Agaat’s attempt to sate this desire with the rainbow embroidery thus establishes a connection between the homestead and the nation-state, but one that stymies attempts to interpret the farm and its community as the rainbow nation in miniature.

Van Niekerk’s intricate entangling of the natural landscape, the family farm, and the nation-state is further complicated by the figure of the ailing, ageing female body.
Like Mrs Curren, Milla’s descriptions of her body invite a reading of occultation. Her somatic self-portraits are similarly two-dimensional, ethereal: she is “a little bundle of bones and feathers” (215). In the mirror, she sees “a shadow of myself, my sloping shoulders, my face on which my features appear vague, as if an artist had rubbed his sleeve over a preparatory study, or flattened the modelling clay with his palm” (21). Unlike *Age of Iron*, however, in *Agaat* there are few bodies with which to occult Milla. Aside from Agaat, most inhabitants of the homestead are reduced to sounds—the bakkie coming back from town, “the laughter of the farm boys down by the drift”, the banging of screen doors (61, 65). Those that do visit are fleeting: the doctor Leroux’s fumbling consultations, for example. Consequently, there are few opportunities for Milla’s body to be occulted by the bodies of others. She is instead occulted by Grootmoedersdrift, represented both through the landscape and through the symbolic repetition of this landscape in a series of maps: “the old map of conveyance,” “the old transfer-duty map,” “the surveyor’s map,” “the topographical map,” “the big soil composition map,” “the whole of South Africa, and a world map, Jakkie’s school maps” (156-157).

Through Agaat’s ministrations Milla is quite literally emptied out, of phlegm and piss and shit; through her own descriptions she is refilled with organic matter of a different kind. She is like a “rag doll,” “filled with sawdust. Or lupine seeds. Or clean white river sand” (15). Embarking on her final “self-portrait”, she tries “to find handholds inside [her]self”, landing on “Rye grass, klaaslouw bush, wattle branches to anchor myself against the precipice. Diehard species. I feel around inside me. There’s still vegetation, there’s water, there’s soil” (16). As in *Age of Iron*, here the relationship between the ailing, ageing white female body and the natural landscape—a relationship implicit in Milla’s slouch towards death and thus toward burial—is paramount. The trope of the handhold, moreover, anticipates Milla’s response to the rainbow embroidery—in which she seeks “for a stay inside of me”—a connection that brings ideas of belonging and nationhood into conversation with this symbolic nexus of flesh and farmland.

This conversation reaches its apogee in chapter 5, when Milla imagines herself becoming one with the map of Grootmoedersdrift:

They must unroll it in the dust and place stones on its corners so that it
doesn’t roll shut […]. They must remove the brace so that my neck can bend. They must take my head in their hands so that it doesn’t become too heavy, and lift it up and lower it as the rod points on the map and the hand points over my world, so that I can see the map of Grootmoedersdrift and its boundlessness […].

Between the land and the map I must look, up and down, far and near until I’ve had enough, until I’m satiated with what I have occupied here.

And then they must roll it up in a tube and put on my neckbrace again like the mouth of a quiver. And I will close my eyes and prepare myself so that they can unscrew my head and allow the map to slip into my lacunae. (104-105)

The extended soliloquy leading up to this fantasy draws on tropes of burial and the becoming-earth that follows. The passage is full of containers—“bottle”, “crate”, “basket”, “cage”, “basin”, “jars and tubes”, “sacks”, “the caverns of the shed”, a “coop”—while Milla describes herself as “a clod in a field, a shallow contour” (101-104). Again, as in the embroidery scene, the impossibility of interpretation is key. Milla asks: “What must I make of it? What is the message?” (101).

Like Mrs Curren, Milla is engaged in an ongoing process of emptying out and refilling, replacing her vital organs with a selection of natural and manmade objects that link her to the land and to the nation-state — tropes that, in the context of post-apartheid South Africa, are particularly burdensome. And yet, rather than allowing these symbols to dominate the symbolic logic of the novel and thus reinforce Milla’s allegorical role as a beneficiary of apartheid, this process serves instead to intensify the singularity of her situation and to extend her influence within the novel. Just as Van Niekerk resists Pienaar’s attempts to read Agaat as a novel about farming methods and the politics of land ownership, then, Milla resists attempts to be read as trope, preferring instead to remain a site of structured ambiguity.

Conclusions
In “The Novel Today,” a lecture given in Cape Town in 1987—and thus shortly after he had begun work on Age of Iron—Coetzee takes to task the kinds of historicist thinking that underpins allegorical readings of South African realist fiction. Herein, he focuses on “the powerful tendency […] to subsume the novel under history, to
read novels as [...] imaginative investigations of real historical forces and real historical circumstances” (2). “Storytelling,” he insists, “is not a way of making messages more [...] ‘effective’,” but represents rather “an other way of thinking” about “the underlying patterns of force at work in our public and private life” (4, 2). Novels, he therefore argues, have the right not only to operate, but to be recognized as operating, “in terms of [their] own procedures,” and thus to “issue in [their] own conclusions” (3).

To my mind, the argument that Coetzee puts forward in “The Novel Today” is driven by many of the same concerns that animate Woolf’s thinking about literature at the time of writing On Being Ill. Like Woolf, Coetzee acknowledges the power of the literary to obviate the traps that are set for it, arguing that “in laying down rules that stories may not transgress, and enforcing these rules, [censors] fail to recognise that the offensiveness of stories lies not in their transgressing particular rules but in their faculty of making and changing their own rules” (3). Nevertheless, like Woolf, Coetzee admits to being deeply troubled by the prevalence of modes of reading that take as their primary motivation a deciphering of the relationship that obtains between a work of fiction and the “time and place” in which it is written, particularly when the work of fiction concerned explicitly engages with “the historical present” (2). For Coetzee, then, these modes of reading enact a form of interpretive violence through the restrictions they place on what such fictions might mean.

In light of the argument Coetzee sets out in “The Novel Today,” his simultaneous solicitation and problematization of allegory in Age of Iron can be seen as a means not only of resisting interpretive violence, but of drawing his reader’s attention to limitations of the interpretive habits they bring to certain kinds of fictional representations: an agenda that resonates in powerful ways both with Woolf’s critique of illness’s absence from literature’s “prime themes” and with her notion of rash reading as an interpretive approach cognisant of, but not limited to, the tropes and trends of traditional literary criticism. In this sense, the construction of a novel that not only engages with the historical present, but which unfolds as an account of illness, can be seen as a means of rendering this issues particularly acute. In a similar vein, Van Niekerk describes how in her writing she seeks “to complicate matters [...] in such a densely patterned way that the text will not stop eliciting questions and
that it will refuse to provide any definite answers to questions such as [those its readers] might ask” – a statement of intent that aligns her thinking with that set out by Coetzee several decades earlier (Van Niekerk “So”). The manifestation of this thinking in Coetzee’s and Van Niekerk’s fictional accounts of illness, I argue, cultivates in their readers what Sarah Nuttall has called a “spliced reading”: a reading in which “apartheid as signifier and symptom hovers, is drawn in, re-fused, modified, as potent after-effect, now in combination with new formations of self and meaning” (86, 106-107). “Together,” Nuttall writes, these readings “make for an entanglement, as point of difficulty and release” (107). In Age of Iron and Agaat allegory acts as this point of difficulty and release, and in this way encourages readers to explore not only the ways in which fiction engages with the historical present, but also the nature of their responsibility to these fictions.
Conclusion

I began this thesis with the aim of undercutting a stance of resistance in both the medical humanities and literary studies to recognizing illness accounts as works of literature, in Attridge’s sense of the term as texts whose aesthetic dimensions—their deployment of narrative form, imagery, metaphor, generic convention, and so on—generate structures of meaning distinct from those set out in its more literal content: the events it narrates, the characters it contains, and so on. As I demonstrate in chapter 1, this stance is predicated on a set of deep-seated assumptions about writing and reading illness. First amongst these is a failure to countenance the possibility that an individual might, in attempting to account for illness, undertake any kind of reflective, interpretive, or representational work, and that this work might have meaning and value. From this perspective, the stylistic idiosyncrasies of illness accounts can offer its interpreters insight into the cultural context in which the illness experience and its narration take place, as well as the subconscious desires and fears of its narrator, but no more. In opposition to this, the second assumption takes shape as an insistence that fictional representations of illness are always underwritten by forms of authorial intention that take as their object either metaphor or the development of the work’s plot and/or characters. Perhaps most problematic, however, is the third of these assumptions, which uses this all-or-nothing view of authorial intentional to dictate the terms on which illness accounts can be read, and thus betrays the profoundly conservative bent of much research in the field.

To someone trained in a post-deconstructive tradition of literary scholarship—a tradition oriented towards the currents of contradiction, ambiguity, and interplay that percolate below the surface of the text—the complicity of literary studies in this conservatism is not only surprising, but seems to go almost entirely against the grain of the discipline. Animated by the need to address this conflict, my readings of late twentieth- and early twenty-first-century autoethnography, literary memoir, and experimental fiction in this thesis have therefore sought to uncover the aesthetic complexity of the contemporary illness account. Crucially, these readings not only attest to the ways in which the aesthetic dimensions of a text intensify the bare facts it narrates, but also demonstrate the ways in which these aesthetic dimensions create
a content of their own that adds both to the scope of the account and to the experience of reading it.

In my analyses of illness accounts by Eve Kosofsky Sedgwick, Jackie Stacey, Mary Felstiner, Ann Oakley, Hilary Mantel, Paul West, J. M. Coetzee, and Marlene van Niekerk I show how these authors encounter a series of fault lines at the interface of experience and expression, including the overdetermination of the textual body and of narrative voice by competing cultural discourses of gender and illness; the referentiality of figurative language; and the relationship between story and setting; fault lines that are largely unaccounted for in the critical metanarratives that underpin current thinking about illness accounts in both the medical humanities and literary studies. In tracing their explorations of these fault lines, my analyses also illuminate how, for these authors, the attempt to account for illness raises wider questions about the textual representation of the embodied self; and about the responsibilities that writers and readers assume in relation to these representations. In this way, I demonstrate how both the accounts themselves and the interpretive practices I have brought to bear on them can act as an important and necessary check on the critical metanarratives that continue to underwrite illness account research, as well as a point of departure from which to consider thinking about literature and its participation in the ethical.

My emphasis in this thesis on the critical vistas that such analyses open up is not, however, tied to a call to dispense with its predecessors altogether. Nor is meant to suggest that the kinds of analyses I undertake should always be performed. Indeed, it would not be right to put forward a critique of this sort without reflecting on the limitations of the alternatives I propose. Chief amongst these limitations is the risk of being seen to champion the literary over other forms, by framing the aesthetically sophisticated accounts of illness considered in this thesis as both more meaningful and more valuable than those that take a more straightforward approach to representation. Illness accounts of all types are, and will continue to be, valuable sources in a range of different research and pedagogical projects, and in many instances it is most appropriate to read these accounts in non-literary ways. In both of these instances the methodologies of the medical humanities are indispensable tools.
Rather, my objective with these readings is to show both the magnitude and the relevance of what is missed when the habits and conventions with which scholars approach illness accounts fail to look for and engage with the characteristics of the literary. Consequently, though the explicit aesthetic sophistication of the accounts I consider here offers the best illustration of the argument I wanted to set out in this thesis, in drawing this argument to a close I am centrally concerned with the need to show how the kinds of interpretive approaches I practice in its pages can be applied to illness accounts that are not self-evidently “literary,” and how these readings might further contribute to our understanding of the relationship between illness, literature, and ethics. Given that the vast majority of illness accounts published in the late twentieth and early twenty-first centuries do not display the complex, self-reflexive aesthetic strategies that characterize the texts on which this thesis focuses, the credibility of any claims I might make to have contributed to the development of scholarly practice in the field of illness account research depend on a convincing demonstration of the ways in which my findings might be extended beyond these parameters. And yet, this project demands that I provide such a demonstration for other reasons too, for it was with the epitome of the non-literary—the celebrity illness memoir—that it in fact began.

In its earliest incarnation, the research on which this thesis is based focused on the representation of suffering in Coetzee’s fiction, and it was in my search for an archetypal illness narrative against which to compare Coetzee’s explorations of illness and disability in Age of Iron and Slow Man that I first came to read Lance Armstrong’s 2001 cancer memoir It’s Not About the Bike: My Journey Back to Life, a work co-written with the award-winning sports journalist Sally Jenkins.96 Published shortly after the first of Armstrong’s seven consecutive Tour de France victories, the memoir embodied the popular not just in style, but in the sheer extent of its readership, reaching number one on the New York Times Bestseller List in 2001 and winning the William Hill Sports Book of the Year Award in 2000. As a cycling fan, I was familiar with the general outline of Armstrong’s story: of his diagnosis, at the age of just twenty-five, with stage three testicular cancer, including

96 For the purposes of this conclusion, I will refer only to Armstrong as the author, though I will discuss the implications of this co-authorship in greater detail where relevant.
metastatic growths in his brain, lungs, and abdomen; his return from radical
treatment to dominate professional cycling; and his establishment of the Lance
Armstrong Foundation, a nonprofit organization that offered support to people with
cancer. I thus hoped to find in this account a textbook example of either a restitution
narrative or, ideally, an automythology: an expectation that reviews of the memoir
on websites such as Amazon and Goodreads appeared to corroborate. I didn’t find
quite what I was looking for, but what I did find was fascinating, for a range of
reasons. In the pages that follow, I offer a brief articulation of Armstrong’s account
and its pivotal role in my research, as a means both of drawing together the major
conceptual and analytical interventions that I have sought to make with this thesis,
and of sketching out the implications of these interventions for scholarship in the
field of illness accounts more widely.

*It’s Not About the Bike* is first and foremost an illness account: its narrative centres
on Armstrong’s diagnosis, treatment, and recovery. In keeping with the various
“media accounts, autobiographies, biographies, and Lance Armstrong Foundation
materials” that circulated in the aftermath of his recovery, the memoir frames cancer
as a major catalyst in Armstrong’s development as an athlete, activist, and public
figure: a framing so pervasive that, Monica J. Casper and Lisa Jean Moore note, “the
story of Lance Armstrong, über-cyclist, cannot be told outside of the story of Lance
Armstrong, testicular cancer survivor” (159). The now-defunct Lance Armstrong
Foundation website added a moral dimension to this superheroic narrative, through
statements such as the following:

> Cancer left him scarred physically and emotionally, but he now maintains it
> was “…the best thing that ever happened to me,” [sic] This new focus allowed
> him to think beyond cycling and focus on his debt to the cancer community.
> He formed the Lance Armstrong Foundation within months of his diagnosis to
> help others with their cancer struggles.\(^97\)

The resulting reinvention of Armstrong as champion, philanthropist, and icon of
survival—his elevation from Armstrong to LiveStrong™, from survivor to
superhero—effectively transformed what might have been a straightforward story of

\(^97\) The Lance Armstrong Foundation website was taken down at some point in 2013: these quotations
were taken from the website in May of that year.
recovery into the stuff of myth, and rendered its protagonist a living, breathing testament to the parable that “what doesn’t kill you makes you stronger.” As such, it took shape not as a restitution narrative but as what Frank calls an “automythology.” In this narrative type, the author “tells self-consciously of being transformed” by illness, and usually implies “that [they have] been given something by the experience...some insight that must be passed on to others” (118). That the automythology is, Frank argues, the story that most people who experience illness, as well as their friends and family, want not only to hear, but to assimilate and reproduce, might explain at least in part the overwhelming popularity of It’s Not About the Bike among readers (77).

In relation to narrative decodings of the sort that Frank’s typology of illness storylines represents, content is everything, and the specificities of form are rarely taken into account. A ready example of this type of decoding can be found in Casper and Moore’s study of the Lance Armstrong “legend” in Missing Bodies (2009), their sociological analysis of bodies both actual and symbolic in contemporary American culture (159). For Casper and Moore, the Lance Armstrong legend was both made possible by, and is emblematic of, a moment of profound crisis in American culture, and as such offers a valuable framework within which to investigate the intersections of “masculinity, illness, sports, philanthropy, and the redemption of American national identity in wartime” (159). In this approach, It’s Not About the Bike constitutes just one of many venues in which these intersections can be traced: a work that testifies to the complexity of the Lance Armstrong legend, but only in its capacity to document the ways in which this legend is embedded in wider cultural discourses. In relation to this legend, Casper and Moore’s reading of It’s Not About the Bike—a reading that also draws on the memoir’s sequel, Every Second Counts (2003)—focuses on the text’s archival qualities, and particularly its cataloguing of a series of events that, they argue, are symptomatic of Armstrong’s “quest” to reassert “his lost masculinity”: events such as his “successful efforts [...] to produce children through in-vitro fertilization” and his devotion “to hard bodily work, pain, and suffering through sport, the annihilation of his opponents in the Tour, and a series of risky practices including diving headfirst off a 50-foot bluff into Dead Man’s Hole [...] just to remind himself that he’s still alive” (165).
Though both compelling and informative, in Casper and Moore’s analysis of the Lance Armstrong Legend *It’s Not About the Bike* is thus construed as just one source amongst a set of data that, though heterogeneous in form, are largely homogeneous in content, and which can thus be mined for information in similar ways. In this regard, their work falls into step with the kinds of approaches that Waddington and Willis target in their critique of illness account research. In relation to my own analysis of this research, moreover, their reading exemplifies the tendency amongst both medical humanities scholars and those in literary studies to restrict their thinking about the stylistic idiosyncrasies in ways that limit their significance to an unmediated reflection of the cultural context in which the illness experience and its narration take place, the subconscious desires and fears of its narrator, or both.

At first glance, Ted M. Butryn and Matthew A. Masucci’s article “It’s Not About the Book: A Cyborg Counternarrative of Lance Armstrong” appears to offer a radical counterexample to the work of Casper and Moore. Herein, Butryn and Masucci not only restrict their gaze to the text, but also draw on a theoretical paradigm—cyborg theory—that is well-established in, if not central to, the humanities. Moreover, though they share a background in sports studies, from a methodological perspective both their acknowledgement of the “agency and authority” implicit in Armstrong’s acts of self-representation, and their particular focus on the role that metaphor plays in these accounts, set up for an analysis informed by a relatively sophisticated engagement with the principles and practices of the humanities (127). Butryn and Masucci’s reading traces in *It’s Not About the Bike* a “cyborgian” counternarrative (125). Particularly compelling is their account of the “simultaneous juxtaposition and convergence of identity and technology” at work in Armstrong’s telling of his illness experience: a simultaneous juxtaposition and convergence that yields moments of slippage palpable at the level of metaphor (125). And yet, this account never quite delivers on its promise of close reading, but instead unfolds as an over-theorized and under-read analysis of the ways in which “Armstrong’s articulation of multiple, competing identifications is consistent with a postmodern notion of fractured, incomplete identity” (124).

The process through which *It’s Not About the Bike* was written means that questions of authorial intentionality are particularly fraught, though the public release of the
US Anti-Doping Agency investigation findings in 2012 reveal that Armstrong’s contribution to this process certainly involved deliberate acts of elision and fictionalization. Moreover, the collaborative nature of its production also places severe restrictions on the kinds of claims that can be made about the aesthetic strategies the memoir contains. Nevertheless, with these caveats in mind, it is possible, I believe, to approach this account as one would a more self-evidently literary text, and to take seriously therefore the ethical implications of the aesthetic strategies that such an approach uncovers.

As demonstrated in the work of Casper and Moore, the automythological narrative of Armstrong’s spectacular recovery and reinvention was, for over a decade, the glue that held the vast range of visual and verbal representations of the Lance Armstrong legend together. *It’s Not About the Bike* is no exception to this rule: references to this narrative trajectory not only recur again and again in its pages, but are present from the very outset of the account. On page 4, for example, we are informed that:

> The truth is that cancer was the best thing that ever happened to me. I don’t know why I got the illness, but it did wonders for me, and I wouldn’t want to walk away from it. Why would I want to change, even for a day, the most important and shaping event in my life? (4)

As “the most important and shaping event” in Armstrong’s life, illness acts as a kind of pivot point on which the narrative turns, a notion reiterated in statements such as “‘There are two Lance Armstrongs, pre-cancer, and post,” and his descriptions of cancer as “a route to a second life, an inner life, a better life” (4, 157).

And yet, at the same time, two elements of *It’s Not About the Bike* appear to trouble the preeminence of the automythology in Armstrong’s illness account. The first of these is by far the more prominent, and centres on Armstrong’s summary and outright rejection both of the Lance Armstrong legend and of the automythology form upon which this legend is based, complete with ironic capitals and italics:

> I’m sure you’d like to hear about how Lance Armstrong became a Great American and an Inspiration To Us All, how he won the Tour de France, the 2,290-mile road race that’s considered the single most grueling sporting event on the face of the earth. You want to hear about faith and mystery, and my miraculous comeback, and how I joined towering figures like Greg
LeMond and Miguel Indurain in the record book. You want to hear about my lyrical climb through the Alps and my heroic conquering of the Pyrenees, and how it felt. …

…I’m asking you now, at the outset, to put aside your ideas about heroes and miracles, because I’m not storybook material. This is not Disneyland, or Hollywood. (3)

The contradiction between this statement and the traces of automythology in It’s Not About the Bike is emphatic, but short-lived, and primarily functions as a stamp of authenticity that ultimately reinscribes, rather than undermines, this narrative trope.

The second version of the relationship between Armstrong’s account and the automythology narrative is less prominently signalled, but more pervasive and more problematic. It focuses not on rejection but on integration, and achieves this through an extension of the automythology form beyond his cancer story, to encompass his life story as a whole. From this angle, it is adversity in general, rather than cancer in particular, that shapes this life story, creating an undulating narrative in which the arc of his diagnosis, treatment, and recovery lies alongside the series of obstacles that Armstrong encounters and overcomes on his journey to success: obstacles that range from being the child of a single, teenage mother to the death of his friend and teammate Fabio Casartelli in the 1995 Tour de France to chemotherapy-induced infertility. This extension is initiated in chapter 2, in which Armstrong begins his account of his childhood and teenage years with the statement that “Your past forms you” (17). It reaches its apotheosis, however, during a pivotal moment in his comeback—his first post-cancer attempt at Beoch Mountain, “a crucial stage in [his] two Tour du Pont victories” in 1995 and 1996—when he recalls that

As I rode upward, I reflected on my life, back to all points, my childhood, my early races, my illness, and how it changed me. …As I continued upward, I saw my life as a whole. I saw the pattern and the privilege of it, and the purpose of it, too. It was simply this: I was meant for a long, hard climb.

(201-202).

Even the account’s title—which I initially took to signal a privileging of cancer’s significance to Armstrong over that of cycling—speaks to this subtext, as we see in the following extract:
I had learned what it means to ride the Tour de France. *It's not about the bike. It’s a metaphor for life,* not only the longest race in the world but also the most exalting and heartbreaking and potentially tragic. It poses every conceivable element to the rider, and more: cold, heat, mountains, plains, ruts, flat tires, high winds, unspeakably bad luck, unthinkable beauty, yawning senselessness, and above all a great, deep self-questioning. During our lives we’re faced with so many different elements as well, we experience so many setbacks, and fight such a hand-to-hand battle with failure, head down in the rain, just trying to stay upright and to have a little hope. The Tour is not just a bike race, not at all. It is a test. It tests you physically, it tests you mentally, and it even tests you morally. (71, my emphasis)

Armstrong’s mother acts as a focal point for his extension of the automythology in *It’s Not About the Bike.* In the opening to chapter 2, he writes

My mother was 17 when she had me, and from day one everyone told her we wouldn’t amount to anything, but she believed differently, and she raised me with an unbending rule: “Make every obstacle an opportunity.” (17)

Along with similar phrases like “you can’t quit,” this phrase is repeated in various iterations at several points in the text, and always in quotation marks or italics, with the result that his mother ultimately becomes one of the text’s most prominent voices (38, 29, 52). This is further consolidated when, towards the end of the book, Armstrong tells of his mother’s response to his 1999 Tour de France victory:

The press swarmed around her…and someone asked her if she thought my victory was against the odds.

“Lance’s whole life has been against all odds,” my mother told him. (261-262)

She is also present at the climax of the account’s first section, a suspense-filled passage in which the reader knows that Armstrong’s cancer diagnosis is just around the corner though his narrative persona remains blissfully unaware, and which, in another version of events, might have formed the end of a childhood memoir. Having just won the 1993 World Championship in Oslo, he writes: “It seemed like the end of something for my mother and me, the finish line. […] Maybe it was the end of the long, hard climb of childhood” (65). In this way, the point of origin for the Lance Armstrong legend is identified not in his illness experience, but far earlier, in
his childhood, with the result that the automythology form comes to envelop his life story as a whole, rather than his cancer story in isolation. The triumph against adversity narrative for which his mother stands thus becomes a prophetic structuring device into which one might expect Armstrong’s cancer experience to neatly fit.

This retrospective deployment of the automythology as a prophetic structure device is not, in itself, particularly surprising, but rather takes shape as a simple inversion of what Frank identifies as one of the key functions of the memoir form: namely, “the incorporation […] of illness into the writer’s life” (120). What is surprising, however, is the conflict that arises between Armstrong’s incorporation of the illness experience into his life story and his privileging of the illness experience elsewhere in It’s Not About the Bike. This tension is indicated at key moments in the text: for example, when Armstrong’s coach calls his agent after the Beech Mountain breakthrough to say “Get ready. He’s coming back a different guy. The guy we used to know” (203). It is also reflected in the organisation of the text, and particularly the inclusion of a photographic paranarrative roughly midway through.

Though chapter 1 recounts Armstrong’s first symptoms and initial diagnosis, and in this way places the experience at the forefront of the reader’s mind, the rest of the text is then organised chronologically, bookending his illness with dramatic accounts of events that defined his childhood and return to cycling. The photographic paranarrative departs from this front-loaded structure and instead reinforces the sense of chronology that characterizes the bulk of the memoir, sandwiching images of Armstrong during his treatment between childhood photos and racing shots familiar from the pages of international newspapers and websites. The emphatic foregrounding of cancer performed by chapter 1 is thus absent in this visual storyline. As a narrative that is almost, but not quite, identical to that within which it is embedded, this photographic section thus appears to the reader as both a challenge to and a performance of narrativity.

The continual contortion of the automythology narrative in It’s Not About the Bike is just one of the ways in which Armstrong’s memoir draws attention to its aesthetic dimension, and distinguishes itself from the realm of documentary. However, though this contortion gnaws away at the foundations of the automythology, it is not, in
itself, sufficient to destabilise it entirely. This destabilisation is instead achieved by the text’s volatile approach to figurative language, an approach that is experienced as a curious, and at times uncomfortable, oscillation between continuity and change, sameness and difference. Through an alternate rejection and reinscription of metaphor, simile, analogy, and so on, the text gives rise to a series of performances similar to those described in earlier chapters.

As one might expect, Armstrong’s use of figurative language centres around cycling - even his account’s title, as I pointed out earlier, proceeds from an extended metaphor in which cycling is portrayed as an analogy for life. Predictably, cycling—and sport more generally—also provides Armstrong with a battery of imagery with which to describe his illness experience. He describes his state of mind before the first operation as being “as if I was getting ready for a big competition”, and later writes that “The more I thought about it, the more cancer began to seem like a race to me” (78, 89). The tumours in his lungs are “like white golf balls”, and encouraging blood results “a slam-dunk” (77, 146). Armstrong finds “an odd commonality in the language of cancer and the language of cycling”: his dropping tumour markers are “my motivator, my yellow jersey”, and he begins “to think of my recovery like a time trial in the Tour” (92, 146). He recounts “wanting to tear the legs off cancer, the way I tore the legs off other riders on a hill” (146). Even the titanium staples holding his head together after neurosurgery are familiar: titanium, “an alloy used in some lighter-weight bikes” (126). Even his friends and doctors use cycling metaphors. Rick Parker refers to cancer as “a speed bump”, and in response to Armstrong’s questioning of his credentials, neurosurgeon Scott Shapiro responds “as good as you are at cycling…I’m a lot better at brain surgery” (74, 111).

Against this, however, can be found a peculiar disavowal of figurative language. In a similar way to Armstrong’s treatment of the automythology form, this disavowal doesn’t take place in isolation, but as part of a rapid oscillation between two modes: the figurative, and the literal. This is particularly pronounced in the opening section of the text. Early on in chapter 1, for example, he describes how, as a cyclist, he’s been hit by “so many vehicles…so many times…in so many countries, I’ve lost count,” while also signalling his toughness by talking about how he would “wave a fist at the disappearing taillights”, and “take out [his] own stitches” (2). He then goes
on to draw an analogy between this experience and his illness. “Cancer was like that,” he writes: “It was like being run off the road by a truck, and I’ve got the scars to prove it” (2). Shortly after this passage comes the statement we encountered above, in which he both summarises and rejects the Lance Armstrong legend, emphatically stating that “I’m not storybook material” (3). To illustrate this, he provides an example:

I’ve read that I flew up the hills and mountains of France. But you don’t fly up a hill. You struggle slowly and painfully up a hill, and maybe, if you work very hard, you get to the top ahead of everybody else.

Cancer is like that, too. (3)

As you can see, here Armstrong does a very strange thing, in literary terms. He shifts, almost without skipping a beat, from an outright rejection of figurative language to a reinscription of it, with the simile “Cancer is like that, too”.

This paradoxical shifting back and forth between the literal and the figurative is a recurrent feature of Armstrong’s account – a feature that not only reflects his conflicted relationship with the illness automythology and the Lance Armstrong legend more broadly, but also, and perhaps inadvertently, taps into the ambiguities Sontag and others have identified in the relationship between illness—and particularly cancer—and metaphor. Part of this stems, no doubt, from the temporal conflict inherent in an account that seeks to balance a retrospective awareness of the narrative arc of his illness—an awareness that most, if not all, of Armstrong’s readers bring to the text—with an attempt to authentically recreate this experience as it played out in real time. Likewise, the tensions that characterize Armstrong’s use of the automythology narrative as structuring device can easily be interpreted as evidence of illness’s disruptive effects. And yet, at the same time, I argue, these elements of Armstrong’s account—elements that only come into focus through the practice of close reading and textual analysis—instill in the reader a sense of multiplicity and contradiction that far exceeds the moments of uncertainty described in what would conventionally be thought of as the account’s content. This sense of multiplicity and contradiction, moreover, prohibits the reader from a simple decoding of Armstrong’s account, and instead encourages an engagement with the text characterized by ambiguity and open-endedness.
In this brief analysis of Armstrong’s memoir, therefore, I combine my own readings with those of other critics so as to give a sense of the complex and conflicting interpretations that *It’s Not About the Bike* invites. In doing so, I show how Armstrong’s memoir sustains multiple decodings, and in this way can be aligned with several of the key critical metanarratives that underpin current thinking about illness accounts in both literary studies and the medical humanities. Alongside this anatomization, however, I also identify elements in this account that are not only literary in the sense of aesthetic complexity, but which, by means of this literariness, thoroughly problematize the decodings alluded to above in ways not dissimilar to those identified in my readings of more self-evidently “literary” illness accounts. As such, in this compact reading of *It’s Not About the Bike* and its responses, I have sought both to draw together the main conceptual and analytical interventions of my research, and to demonstrate how these interventions might productively be extended well beyond the scope of this thesis.

Though admittedly an unlikely example with which to illustrate the potential of reading illness accounts for the literary, Armstrong’s memoir is a testament not only the ease with which illness accounts—and particularly popular and/or non-fiction illness accounts—are seen to be outside the purview of the literary, but also to the way in which a more creative—or “rash”—approach to reading illness accounts in general can open up new interpretive possibilities and, in doing so, contribute to our thinking about the literary and its participation in the ethical. Given that the vast majority of the illness accounts that have poured forth in recent decades are not explicitly “literary,” the development of the increasingly sophisticated and inclusive humanities approach to illness account research that Waddington and Willis call for, and the integration of this perspective into the mainstream medical humanities, is particularly pressing. And yet, my readings in this thesis not only expose the limitations of existing literary studies approaches to illness accounts, but also demonstrate the capacity of illness accounts themselves to act as both an important and necessary check on the critical metanarratives that are brought to bear on them, and a forum within which new interpretive modes can be explored. As a final coda, then, I want to emphasize the importance of what Woolf calls rashness to the future of illness account research: to ways of reading that look beyond the need to make sense of illness accounts so as to let “other tastes assert themselves.”


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