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Creativity and Illness: An anecdotal exploration of a writing practice; Coming Undone: A collection of poems & a thesis as an anecdotal exploration of a writing practice

Matthew Patrick Roberts
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The version of the thesis consists of the Exegesis only.

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**Creativity and Illness: an Anecdotal Exploration
of a Writing Practice**

Coming Undone: A Collection of Poems

&

**A Thesis as an Anecdotal Exploration of a Writing
Practice**

This thesis is presented for the degree of
Doctor of Philosophy

Matthew Patrick Roberts, B.A. (Hons.)

School of Arts and Humanities

Edith Cowan University

25th February, 2016

I certify that this thesis does not, to the best of my knowledge and belief:

i. incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education;

ii. contain any material previously published or written by another person except where due reference is made in the text of this thesis; or

iii. contain any defamatory material

Matthew Roberts

25th February, 2016

Abstract

This thesis combines both creative and critical writing in an exploration of creativity and illness. When I began my candidature, I started writing a novel but found with the diagnosis of chronic illness I could no longer write narrative and was irresistibly drawn to poetry.

The collection of poems was written during the period immediately following the diagnosis of, and during my subsequently living with, a chronic autoimmune illness, and is an expression of the lived experience of both being ill and being a writer. The poems have been separated into three chronological parts, each reflective of the emotional changes throughout the disease. That the poems do not focus solely on illness is in part to do with my inability to confront my condition, and in part a reflection that my illness, while influencing my creative practice, is not the same as my creative practice.

In the critical portion of the thesis the intersection of creativity and illness is further examined. It explains the themes of my abandoned novel and the subject of grief as seen through Freud's early work 'Mourning and Melancholia', and how that came to be an aspect of my new lived experience as a writer with a chronic illness. It then engages with Jacques Derrida's theory of *différance* and discusses how this theory speaks to my switch from prose to poetry. The exegesis explores the nature of writing while ill, and of writing being separate from, as much as informed by, illness. Through an exploration of the work of a number of writers who have recorded their own illness (such as Donald Hall, Siri Hustvedt), or recorded the illness of those close to them (David Rieff, Simone de Beauvoir), the exegetical essay attempts to draw writing into a meaningful interaction with illness. Arthur Frank, Louise DeSalvo, Gregory Orr and others cast writing as a tool for healing; while this may have wider merit, I look at the implications in regards to my own circumstances. Underlying most of the topics explored are some key aspects of the personal versus the universal evident in Terry Eagleton's *How to Read a Poem*. The coda looks at how, in a final twist, my illness seems to have been misdiagnosed and so, in many ways, I experienced it metaphorically. This is explored in response to Susan Sontag's ideas, initially expressed in *Illness as Metaphor* (2002), regarding illness as a literal experience that becomes complicated by metaphorical language. The coda discusses how my illness seems to have dissipated and what that revision may mean for a discussion of illness and creativity.

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This work has only been possible through the patience and knowledge of my supervisor, Dr Marcella Polain. Further to this, the understanding that Marcella gave to me while I was writing this thesis with an uncertain future due to my diagnosis was invaluable to me. For all of this, I thank you.

To my Fellow poets, Dr Shevaun Cooley and Dr Nandi Chinna, thank you for all the critiquing and discussions we had in regards to my poems. It has made a vast difference to the quality of my work.

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My associate supervisor Dr Ffion Murphy provided some key works that are discussed in this thesis and provided feedback on late drafts of the work. It is much stronger for her discerning eye.

The list could go on. This thesis has been a long time in writing. To all my family and friends who have supported me over the years I say a very heartfelt thank you, and hope you know that this very much includes you. The support and patience, laughter and distractions, have all contributed to this work. Whether you've been along for the whole journey, or just part of it, I could not have done it without you.

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At the request of the author,
pages 1-81 of this thesis are not available for public viewing.

**Exegesis: Creativity and Illness: an Anecdotal
Exploration of a Writing Practice**

Introduction

'...it becomes strange indeed that illness has not taken its place with love and battle and jealousy among the prime themes of literature.' Virginia Woolf from 'On Being Ill' (Woolf 2013, loc. 10-14)

Virginia Woolf's essay, 'On Being Ill' was published in 1930 (Woolf, 2013, loc. 6). In the above quote she is referring to the prevalence of illness in our everyday lives that she believes should count among the 'prime themes of literature' because, like these other themes, illness is an essential part of the experience of being human. Literature aside, there is a large body of writing when it comes to illness and being a writer (in both the sense of being a writer who is ill writing about their experience, and the benefits of writing for people who are ill). Susan Sontag wrote *Illness as Metaphor* in the 1970s after undergoing treatment for an aggressive form of breast cancer. In the last fourteen months of his life Anatole Broyard wrote *Intoxicated by My Illness: and Other Writings on Life and Death*. Donald Hall wrote *Life Work* when he found out he was ill with cancer and, in a sad twist of fate, he notes the irony of surviving his wife, as she became ill and passed away while he recovered (Hall, 2003). The list is extensive, but limited for the constraints of space allowed in this exegesis. Illness is approached by writers of prose and poetry, as well as in academic and medical discourses. This collection of poetry, and accompanying exegesis, examines my own illness within a critical framework that engages with how poetry functions. My purpose is to examine what it means to be a writer who is ill, thereby contributing to a growing body of knowledge.

In *Anecdotal Theory* Jane Gallop notes that "'Anecdote" and "theory" carry diametrically opposed connotations and that the aim of anecdotal theory is to 'cut through these oppositions in order to produce theory with a better sense of humor, theorizing which honors the uncanny detail of lived experience' (Gallop, 2002, p. 2). In one of the essays from the collection, 'A Tale of Two Jacques' (an essay on the intersection of deconstruction and psychoanalysis), there are the lines, 'a fantasy: an interpretation of dreams where dreams interpret theory rather than vice-versa. A fantasy? Or maybe we call it psychoanalytic theory?' (Gallop, 2002, p. 96). The essay focuses on the theories of Lacan, Derrida and Freud

as they manifested in a dream that Gallop had. She notes in her introduction that, 'Freud used his dreams to theorize; he did not just take his dreams as evidence of his theory but theorized in his sleep' (Gallop, 2002, p. 10). From this it can be seen that what we experience in our lives adds to our collective understanding of the world, even while it is a wholly personal experience. It is not *the* definitive experience, but it is *a* definitive experience. In the essay 'Dating Derrida in the Nineties', Gallop uses the relationship she has with a student to interpret her relationship with Derrida's *Spurs* and what she sees as the outdated aspects of that writing (Gallop, 2002). Gallop sets up the idea that it is through our lived experience that we can understand and interact with theory. The term 'anecdotal theory' does not set up a narrative per se, instead it seeks to look at how theory and narrative intertwine and to recognise that they are interdependent in a way that is explicit.

It is from this perspective that I wish to examine an important part of my life. This thesis is not an inquiry into the validity of anecdotal theory; rather, it is based in it by using my lived experience to explore theories relating to that experience. In 2009 I was diagnosed with an autoimmune condition called scleroderma. At the time I had written half a novel for my PhD, but found myself unable to continue it. The prognosis was worrying, and the information I could find on scleroderma was disruptive to the order and meaning of my daily life. For a few months I thought I had a fatal condition that would have a rapid negative impact on my physical health. Without really thinking through the implications of the decision, I switched from writing the novel to writing poetry. The first section of this exegesis, 'Freud and Past Grief', centres on this period. Initially I felt I could not focus on the long arc of the novel. Under stress of worrying about how long I might have to live, it felt better to leave some finished poems, rather than an unfinished novel. I did not consider switching to writing a series of short stories because poetry had more to offer than merely a shorter arc, but I was not consciously aware of the depth of difference between prose and poetry at the time.

I use the anecdotal experience of my illness to interrogate the works of theorists such as Freud, Derrida and Frank, among others. I also investigate the writing of literary figures that include Susan Sontag, Donald Hall and Simone de Beauvoir, as they relate to their own experiences with illness. By unpacking my story against the theoretical frameworks that are explored in this thesis, I have come to see the value and layers within my lived experience. Anecdotal theory allows me to look at that experience from an alternative perspective, and it also allows me to push against the evolving limits of the theory. Is this not the point of

academic enquiry – to critically examine accumulated knowledge, to uncover its potentials and shortcomings, to evolve new ways of thinking? Theory demands a text in order to have context.

Jacques Derrida's discussion on *différance* is useful in closely examining the change in direction of my work. Derrida discusses the differences between the written and the spoken word from thought (Rivkin & Ryan, 2004), and I employ this distinction in the second section of the exegesis, 'Living *différance*: Illness, Derrida and Poetry', in both the investigation of difference of expression through poetry versus expression through prose, and the lived experience of illness. Any illness temporarily defers wellness, but chronic illness is an ongoing (often permanent) deferment from a 'normal' life. In this way, Derrida's *différance* penetrates my creative work and enables a discussion of my way of being in the world that produced this work.

Havi Carel talks about the importance of the lived experience when examining what illness does to the individual or, perhaps more accurately, what it means to live as someone who is ill. In *Illness* she says:

My main discomfort with the orthodox concept of illness is that it originates in a *naturalistic** approach.... Naturalistic descriptions of illness exclude the first person experience and the changes to a person's life that illness causes. (Carel, 2013, pp. 9-10)

Carel argues that orthodox concepts of illness should be augmented with the lived experience to give a fuller view of what it means to be ill and that, 'on the phenomenological account, illness is no longer seen merely as a biological dysfunction to be corrected by medical experts' (Carel, 2013, p. 10). In my case, the condition I was diagnosed with has no cure or treatment for the illness itself. I was repeatedly told only the symptoms, not their cause, could be treated. For the ill subject living with the disease, this is confusing, for what is the experience of disease other than its symptoms? Even treating the symptoms is not easy or uniform because symptoms can vary (and therefore the medical treatment may vary). An

* Note that Carel defines naturalism as, 'a label for a broad spectrum of views saying, roughly, that natural or physical facts are sufficient to explain the human world. On a naturalistic view, illness can be exhaustively accounted for by physical facts alone.' (Carel, 2013, p. 9).

article on treatment for scleroderma from an American publication, *Arthritis Care and Research*, notes that:

The rarity of the disease, the clinical heterogeneity, and the lack of effective agents to date render therapy a major challenge. There are currently no widely disseminated therapeutic guidelines for the management of scleroderma. (Pope, Ouimet & Krizova, 2006, p. 138)

In many autoimmune cases, such as mine, the medication can treat the symptoms, but it cannot correct the biological dysfunctions that cause the disease because these biological dysfunctions are not fully understood. This distinguishes certain diseases (of which autoimmune conditions are part) from cancer, for example. I am aware that the term ‘cancer’ is more complicated than this comparison suggests, but I am using it to illustrate a point. Cancer treatments are often harsh and the approaches used (chemo- and radio-therapy) are often blunt and damage tissue and the immune system in the process of eliminating cancer cells; however, the mechanisms of many types of cancer are at least understood, so the cancer itself is treated and not just its symptoms. Susan Sontag herself survived two bouts with two different types of cancer. She notes that although ‘*the* remedy does not exist, more than half of all [cancer] cases can be cured by existing methods of treatment’ (Sontag, 2002, p. 100). Her emphasis indicates that there are several options for cancer treatment, not just one solution. This particular statement was made in 1989 as part of the publication *Aids and its Metaphors*, noted here because there have been many advances in the treatment of cancer since then. Cancer, what cancer actually is, can be targeted and treated, but scleroderma can only be managed.

So there are limitations to my experience through the medical system that are expressed above by Carel because it is a naturalistic system that is designed to treat my physical symptoms. I am aware that there are treatments available for psychological illnesses/problems that might arise from being chronically ill through psychologists and psychiatrists, but these options were not offered to me as part of my treatment for my illness and I did not seek them out. Instead, poetry allowed me to explore my lived experience beyond the limitation of a naturalistic treatment and, further to that, by examining my own illness experience through Derrida’s theory, I am able to further enquire into what it means to ‘be ill’ and what it means to be a writer.

The third section of the exegesis, 'Am I the Wounded Storyteller?', is a discussion of Arthur Frank's theories on writing as a means of healing in *The Wounded Storyteller* (1995). This is closely coupled with a look at Louise DeSalvo's *Writing as Healing* (1999), which extends some of Frank's work by looking at writing as a therapeutic device for recovering physically from illness. What was revealed in analysis of these texts is the difficulty in discerning the boundary between writing to heal oneself and writing to be a writer. As becomes evident in the research, tension exists between the two aims: the latter has to suppose an audience and the former has to dismiss one. This is not to say that there is no audience for someone writing or telling their story as part of the healing process, just that the audience is incidental and that the process is done for the benefit of the individual rather than the wider audience. This leads to a deeper contemplation of the idea of being ill and being a writer, and this is examined in light of other writers' experiences. Gregory Orr, an American poet, writes specifically on poetry in *Poetry as Survival* (2002) that helps to bridge the gap between my illness and use of poetry.

Being ill does not mean an individual ceases to fulfill other roles: partner, student, worker. While the collection of poetry in this thesis does not always reflect illness directly, it was written through the lived experience of someone with a chronic illness and a poor prognosis. In the fourth section of this exegesis, 'Poetry of an Illness', I discuss the poems and their exegetical aspects in some detail. The poetry does not have an easily identifiable theme, but is rather a creative account of my experience of being ill. They are the poems of a man who is ill, but they rarely deal directly with illness. Part of this, which is explained further in 'Poetry of an Illness', is my inability to face the reality of the potential consequences of being ill.

The first part of the exegesis to follow will be a short background on my original PhD project. In order to examine the significance of the change of direction, it is important to look at what I was initially trying to achieve. I was writing about death, illness (not my own) and grieving as part of what had occurred in my family. By the time I started working on my PhD there was some emotional and psychological distance between my recording the events and the experiences upon which they were based. When I was diagnosed with my illness there was no distance between me experiencing the events and me recording them. This forced a change in direction. The work, both creative and critical that I had been doing, still

informed significant aspects of this new direction.

Freud and Past Grief

My initial project was to write a fictionalised account of my father's childhood. I did not want to explore the accuracy of my family history; rather I wanted to look at what I had come to understand about inter-generational loss (my father lost his brother as a teenager and I lost my mother when I was eleven). To this end, the narrative also contained regular interruptions in the form of short, autobiographical pieces relating to the loss of my mother. The main story was about a family in the 1950s and 60s, living on an isolated trading post located in the Eastern Transkei of South Africa. The only white people for miles around, the family consisted of a father and a mother, their two boys and a daughter. The novel was written in third-person and from the perspective of the oldest son, Junior. The style was realism and the novel builds a picture of a close-knit family. The youngest son, Numpy, dies when he falls off a cliff. The novel then explores the effects of Numpy's death on the family and on Junior in particular. Junior is the fictionalised version of my father who lost his brother in this way; the family is also based on my grandparents, aunt and uncle. The autobiographical interruptions in the text reveal memories around the loss of my mother to cancer. The two plots intertwine in various ways, to suggest that losses that occurred in the past still resonate in the present. The inability of a family to grieve its past means that it never finds a way to resolve or even fully accommodate its grief. The other feature of the autobiographical element is that it foreshadows, by the chronology of the narrative, the death of Numpy.

The following extract from an early draft of the novel shows how the autobiographical interruptions worked:

*Wake up. Christmas will never be the same again. Or a wedding. Daze. Drink sweet tea.
Wake up. She's dead. You saw a sack of bones with skin stretched over it. It wasn't in a Nazi war camp. It was in a faintly distant past. It was how many days ago? It was so very obvious.
Wake up. It's time for mourning. You're doing so well. You're going to eat some brownies and wear shorts and be impatient in that church. Foot to foot. Stand. Sit. Look around. Good boy.
Wake up. She's dead. It's getting hot already. What date is it? WHAT DATE? I can't recall.*

Too late to know now. When's her birthday? What's her favourite film? What's her favourite smell? Did she have moments like these? Where the cigarette was smoked and it wasn't just an in out motion that its become. When that cigarette smoke is poured into the blood stream and it brings such a slight and blindingly overwhelming euphoria. And you think, not knowingly, "this is why I smoke and I will never stop".

Wake up. It's time to forget everything you thought you ever knew. It's time to peel away at layers of yourself and lie there again and again and again. Not knowing what happened or how it is you might exist.

Like this extract, these autobiographical pieces are short, disorienting and have little context. They were to build up to a fuller narrative over the length of the novel. The gradual revelation of the full story of my experience with my mother's illness reflects of the recovery of my memories of her. When she died there was a deliberate attempt to forget her on my part because of the overwhelming feelings I had to face when I thought of her. I was only able to grieve her passing and look back at my memories of her when I was in my early twenties, and even then it was only through a deliberate process of grieving and a conscious effort that I was able to recover those memories.

At the time I switched the project to poetry, the theoretical aspect of the doctorate was not fully formed. I was concentrating on the novel and expected the focus might be grief/grieving on a personal and inter-generational level. I vaguely aspired to tie it in to the broader post-colonial context of South Africa as a nation in mourning and to examine, for example, the Truth and Reconciliation Commission and its attempts to enable public grieving. I wished to engage with Freud's 'Mourning and Melancholia'. I am well aware that the theories have moved on from Freud and become far more sophisticated and developed; however, the primary text is seminal, bears a lot of relevance to my personal grief, and links strongly to the intergenerational and post-colonial grief. It also became important in developing ideas linking writing and healing.

Freud's works are in German and translation is a complex process. There are many papers and discussions on the difficulty of translating. I will not engage with that difficulty here, but it is worth noting. In *The Standard Edition of the Complete works of Sigmund Freud* (1914), the first footnote in 'Mourning and Melancholia', states that, 'The German "*Trauer*", like the English "mourning", can mean both the effect of grief and its outward manifestation.

Throughout the present paper, the word has been rendered "mourning" (Freud, 1914, p. 243). This is problematic because the effect of grief is not always its outward manifestation. It is all well and good that the translators have noted it, indicating that there is an awareness of the potential problems arising from it, but there is no solution given. The relationship between the two psychological states, melancholia and mourning, may be affected by the differences in grief and in outward manifestations of grief. Freud distinguishes between mourning and melancholia:

Mourning is regularly the reaction to the loss of a loved person, or to the loss of some abstraction which has taken the place of one, such as one's country, liberty, an ideal, and so on. In some people the same influences produce melancholia instead of mourning and we consequently suspect them of a pathological disposition. It is well worth notice that, although mourning involves grave departures from the normal attitude to life, it never occurs to us to regard it as a pathological condition and to refer it to medical treatment. (Freud, 1914, p. 243)

Here I would say that mourning and grieving need a distinction. Is Freud saying that it is normal for people to grieve? Further, is it normal for people to be in a strange state that is more complex than just crying? Surely we have different ways of grieving. But sometimes we fail to move past this stage. That results in melancholia. My interest in this lies ultimately in my personal history because although I had been in a state of mourning since the death of my mother, I had been unable to grieve her loss. I had outward manifestations of mourning as a result of grief, but they were not grieving. Some signs of my inward struggle were an inability to sleep and a refusal/inability on my part to discuss my mother or her death for many years. This inability was a result of my being unable to grieve her death because I knew if I had to talk about her I might be overcome by grief and end up crying. My relationship with grieving is anecdotal and the intention was for it to be explored through the literary work I was undertaking. That is why the distinction and unpacking of what Freud was engaging with was so important to me. I could see a lot of my history, and my family's history, in this paper written nearly a century earlier.

My personal experience with what Freud was writing here was also at stake. My mother's death had a significant impact on my life. I had been to see healthcare professionals who had

been willing to call me depressed (clinically) and prescribe medication for the psychological symptoms that I displayed outwardly and experienced inwardly. Freud states that the mourning and melancholia are almost indistinguishable. He cites some theoretical differences – notably the idea of melancholia culminating 'in a delusional expectation of punishment' (Freud, 1914, p. 244). I could certainly claim that delusion and it is explored in the novel's autobiographical intersections through the desire to live after years of not caring; I developed a phobia of dying. I also turned disappointment in others on to myself (Freud, 1914, p. 248). It is worth noting that Freud admits that there is not a large basis for parts of his theory of the differences between the two emotional states of mourning and melancholia, and defining terms that separate or 'treat' melancholia, as opposed to mourning, are entirely theoretical. As he writes, 'the conclusion which our theory would require... has unfortunately not yet been confirmed by observation. In the opening remarks of this paper, I admitted that the empirical material upon which this study is founded is insufficient for our needs' (Freud, 1914, p. 250). Likewise, I am not in possession of sufficient empirical data to draw generalised conclusions, but it piqued my interest enough that I could see the value in those studies versus my lived experience of being a young boy in a society that inadequately deals with death and grieving. The legacy of my loss of my mother is a repetition of the lifelong unresolved grief of my father as a result of his brother's death.

Through active grieving I was able to start to come to terms with the loss of my mother and move on with my life. I joined a community based peer-counseling group as a twenty-year-old and managed to grieve in a very traditional and deep way. I managed to use grief as a healing rather than a hurt. Indeed, in terms of the experience of pain (emotional or physical) we can only physically emote it once it has occurred, even if we are crying under the weight of a chronic and persistent pain. There is no 'now' in terms of pain and its expression. I found that this resonated with how Jacques Derrida discusses the idea that there is no present moment in expressing our lived experience through written or spoken language in his famous '*Différance*' lecture (Derrida, 1982). This relationship between Derrida's theorising and my own circumstances came to be important to me. After writing half a novel and having done the bulk of my primary research for my dissertation I found myself diagnosed with a chronic, and potentially fatal, illness.

The themes explored in my unfinished novel still recur in this exegetical essay and the poems that accompany it. My mother died when she was forty-one. There is this expectation

somewhere in me that I will also die young. My illness calls back her illness. She does not exit the narrative, but becomes part of how I explore my changing emotional state. The unfinished novel explores events that I worked through and has the perspective of time. When I fell ill there was no perspective because there was no distance. I was unable to continue with the novel because of the thought, 'I might die before I finish this'. In contrast I knew I could write a few complete poems before my death. But, on investigation, there was a deeper relationship than merely the brevity of the form; there was a difference in how to exist in a state of perpetual illness and the creativity that results from that state of existence. From this, I began to realise one difference between poetry and prose lay in the complexity of the term *différance* as coined by Derrida.

Living *différance*: Illness, Derrida and Poetry

Poetry is a kind of phenomenology of language – one in which the relation between word and meaning (or signifier and signified) is tighter than it is in everyday speech. (Eagleton, 2007, p. 21)

In January 1968, Derrida delivered an address to the Société française de philosophie (Derrida, 1982) in which he proposes a concept that became one of the hallmarks of Derridean theory because of its paradoxical nature. The concept of *différance* is seemingly simple, yet, upon interrogation, difficult to understand and interact with. Derrida coined the term *différance* in order to illustrate the difficulty of using language to de-construct language and to look at the idea of privileging the spoken word over the written word (Derrida, 1982). The word is spelled differently from, but pronounced in French exactly the same as, *différence*. It refers to Saussure's concept of signs (words that denote any thing) as being what they are not because they represent what something essentially is, but because the name explains what it is not (Rivkin & Ryan, 2004, p. 278). That is, the word 'chair' embodies the idea of a chair not through any essential idea of chair, but because it is not a table or a book etc. An analogy might be that a heart-shape cut into a piece of paper is defined by the paper around it rather than by what it is itself. We learn about such difference as we learn our language.

The second, and just as important aspect of language conveyed by Derrida in coining the term *différance*, was the idea of deferred meaning: that all expressions of thought (whether voiced or written) exist in the past. There are 'future present' moments that we move towards, and through, but no stable present state. The present is a moment that exists between the past and the future present. As it comes to be, it is almost immediately past. This leaves us in a state of deferred meaning, with words defined by difference and bearing traces of meaning to other words, and in a present that is not stable because it has traces of other 'presents' in it. These traces are a consequence of our trying to convey a precise meaning, but ultimately failing because the idea of language existing in differences means that there is no substance to meaning (Rivkin & Ryan, 2004, p. 278). Meaning is the hole in that paper.

The difficulty of conveying this idea lies in the way it uses the very tool (words) that it is examining in order to examine it. Barbara Johnson claims that 'an essay about writing, therefore, is an unclosed loop: it is an attempt to comprehend that which it is comprehended by' (cited in Rivkin & Ryan, 2004, p. 340). Derrida's lecture, while conveying a complex idea, is also very playful in its engagement with language. He uses a series of clever puns that succeed in showing another side to the discussion, such as creating the new word *différance* that he explains as, '...*différance* with an *a*' (Derrida, 1982, p. 4). He is not only examining the concept of *différance*, but also using this concept to look at differences between the written and spoken word. As Barbara Johnson says:

By closely analyzing those writings, Derrida attempts to uncover the ways in which the Great Books [the Western canon] rebel against their own stated intention to say that speech is better than writing... cannot completely eliminate the fact that speech, like writing, is based on a *différance*... Speakers do not beam meaning from one mind to another. (cited in Rivkin & Ryan, 2004, p. 343)

I come to Derrida's concept in a particular way: as a man who, at the age of thirty, was told he had scleroderma. My diagnosis changed everything about my life, including my PhD. Derrida's *différance* has played a role in the way I have expressed and understood my condition because it uncovers a complexity in language that resonates with the complexity of the lived experience.

I sometimes wonder how much time I have to live. There were some very bleak months after my diagnosis. From within that bleakness I made the decision to switch from writing a novel to writing poetry but was unaware at the time how great was the link between my illness and *différance*, and how Derrida's lecture, given half a century before, would come to resonate with this decision because I had not read Derrida at the time. Being a rare disease, scleroderma is not well understood and, in many ways, it is defined by what it is not – by its differences from other conditions. There are various conditions that display similar symptoms, hence the year-long process of arriving at an official diagnosis. I have even had it said to me over the years since the diagnosis, bearing in mind that I have an atypical version of the disease, that I might not even have scleroderma. At other times it has been harder to

deny, especially given that a dermatologist cut out four coin-sized pieces of my skin that came back from a laboratory with paperwork that said 'scleroderma'. So my future presence is deferred daily, and my awareness of the tenuousness of the present is made available through a potentially premature end to an imagined future. All people live with that uncertainty, but young people in good health have no cause to believe that they will die soon. I must have treatment, and see doctors. My life becomes deferred, no longer my life as I imagined it, but my life as a person with an illness. It bears all the traces of me as I am up to that point because my past is the same past, but it is now different relative to this new information. Any attempt to live outside this new identity is still relative to that identity. There is no escape. It is the same as using language to explain the function of language because I can no longer be outside of the diagnosis.

This interruption of my life had a profound effect on my creative work. I could no longer engage with writing a novel. While there were interruptions to the main narrative in that novel, the form was hardly experimental; because of this, in the discussion that follows I am not referring to experimental novels like JM Coetzee's *Diary of a Bad Year* (2007), which seeks to interrupt the temporal experience of engaging with one plot by having (at times) three narratives running parallel on the same page, or Anne Carson's *Autobiography of Red* (1998), which sits in-between a novel and a poem. I am talking about the novel as a form that has a fairly detailed and straightforward narrative over a long arc.

Novels are long, even when they have an economy of language. They have a plot. They require a sustained process in both reading and in writing. I had been writing a novel for about eighteen months when I was diagnosed and I was halfway through the first draft. The production of poetry is vastly different. I might work on a particular idea or poem for years but I can still produce a large body of other poems in that time. They can vary in theme and length. Even within the poem itself there is room to change direction and subject with relative ease. The novel spins out its ideas through building plot, seeks to follow through the traces that emerge as a result of its signs. It seems to trust the reader but not itself because it is using language (an unstable form) to convey meaning (a stable form), and so the novel builds a specific meaning and a narrower subtext as a consequence. This is not to say it has less meaning, just that it functions very differently from a poem. Perhaps a novel is closer to a pre-Raphaelite painting and a poem is closer to an abstract work, more actively engaged with the idea of the trace. Both are valid works of art within the same medium, but how they

convey their meaning is vastly different.

Poems deliberately play with the concept of the trace beyond the idea of connotation. Poetry relies on compression of language and the multiple layers of meaning produced within this compression. It is easy enough to give a summary of the plot of a novel and an explanation. But a poem cannot be summarised in the same manner because an attempt to summarise a poem is always an explanation of the poem and is, in effect, an expansion of the poem. Traditional narrative also implies a completion. Poems do not require completion and are often forever incomplete, open. On the other hand, novels, for the most part, offer endings even if not resolutions. Their narrative arc is in some way completed even if the ending allows readers to imagine that the story goes on beyond the concluding point. My novel is incomplete, but I was always had a specific ending in mind. With poetry the ideas are frayed and incomplete, and this incompleteness provided a contradiction to my mortality as it bore down on me. I thought I had a few years left and that they would be physically difficult. I was determined to fight my death until the end. That was the metaphor I sought in my writing – poems that could engage with highs and lows, provide ways to reflect on the physical and emotional aspects of what I was living through. Writing the novel seemed to me in the opposite stead. It offered a race towards a finishing line, an ending. What would win, my writing or my illness? In this regard the switch to poetry became more than just a practical consideration for me. In its multiplicity, it provided a variety of potential endings/conclusions and beginnings.

The differences that exist between these two practices existed within me as someone pre-diagnosis and someone post-diagnosis. I say diagnosis because it is the diagnosis that mattered. Sure, symptoms were affecting my work practice before it became official, but they were manageable. It was the diagnosis that caused a shift in the way I perceive(d) my future. This relates to the idea of *différance*, as it relates to the idea of the present moment: the present is an unliveable moment, but the only place we exist. This diagnosis displaced me further from my present life and poetry offered me a way to engage with that displacement. I became further divorced from my past while still being just as much a product of it.

This new way of living reminded me of the way that we embody the idea of *différance*. Our bodies are made up of cells, almost all of which regenerate. Our skin, heart, and lungs – most of our organs – are made up of cells different from those we started with, but they carry

through the information of being older (Wade, 2012). That is why we age. The cells themselves are young, but they take us further through decaying to death. They are new, yet we are not made anew. They are a collection of what we were and consequently what we have become. They literally carry the past into the present.

Simone de Beauvoir lost her mother to cancer and wrote a memoir about it called *A Very Easy Death* (1964). Her mother was terrified of ever getting cancer. This, coupled with the standard practice at the time of concealing the illness from the patient and informing only the family (Sontag, 1978, p. 7), meant that de Beauvoir's mother was never informed that she had cancer – her mother was aware that she was ill, just not aware of the specifics of that illness. de Beauvoir took on the burden of the diagnosis and, although she did not have the illness, de Beauvoir was tormented by the coming death (de Beauvoir, 1964). She was the one who needed comfort. While it was her mother who suffered the illness and her mother who died from it, de Beauvoir took on the emotional role of her mother's mortality. I am not advocating the practice of keeping a diagnosis from the patient, merely looking at the differences between illness and diagnosis so that the relationship can be better understood.

This relationship becomes more tenuous once we start to move away from acute terminal diagnoses. Autoimmune diseases vary in intensity from patient to patient and symptoms present to varying degrees. It is possible to live to a standard life expectancy and die of something unrelated. That said, it is also possible to have severe flare-ups and serious related medical problems along the way. For the purposes of examining this diagnosis/illness relationship, let's assume that a patient is physically unaffected by the disease in any significant way. If this is the case, she or he will still have to live as one diagnosed, as someone who is 'ill'.

It was the diagnosis that sent me in search of a sustainable future. It was the diagnosis that altered my consciousness. Scleroderma cannot be treated; it can be monitored and the symptoms managed. This is a very difficult concept for me to contemplate: that we can treat symptoms and not the disease itself. What is a disease if it is not its symptoms? I have to draw myself away from the disease in order to understand this. I have to draw on an analogy and the one that comes to mind is that of a child hurting itself. There is a tendency to hush the child, to stop their crying, to tell them that it will be okay. The crying is a symptom of the hurt. Stopping the crying does not stop the pain and it does not heal the wound.

Administering painkillers stops the pain but it does not heal the injury.

So I take a drug that suppresses my immune system. I feel better than when I am not on the drug. I have regular blood tests, as well as annual tests of my major organs, notably my heart and lungs. These tests monitor possible negative side effects from the treatment. The drug itself has the potential to cause the very harm that it is currently preventing in my body. This can occur at any time and after any period of time. (I might have no problems from the drug for five years and then, without much warning, my body will not be able to handle it.) If this occurs, then I must move on to an alternative drug. Sometimes, but not often, I forget that I have this diagnosis. Or, rather, I have moments when I live as someone without the diagnosis. It is not part of my reality for that moment. People around me know that I have it and, subconsciously, I must always know. But sometimes this 'forgetting' happens when I am writing poetry. The topic I write about is removed from here and now, but it is always filtered through here and now.

So, as Derrida's theory goes, we experience moments in the present and relate to them in the past, and poetry is, among other things, an expression of those 'past present' moments because it is expressed through language. But poetry seeks to engage with language to draw out the traces and disrupt our relationship with the signifier and the signified. In this way it is future-seeking. Poems not only serve as autobiographical details, they also function dynamically as moments that seek to connect with the reader. As Terry Eagleton says in *How to Read a Poem*, 'The very act of writing a poem, however desperately private its materials may be, is a "moral" one, since it implies a certain communality of response' (Eagleton, 2007, pp. 31-32). He also states that poems are 'moral statements... because they deal in human values, meanings and purposes' (Eagleton, 2007, p. 29). In this way, Eagleton points out that poems are works of fiction. They are designed to be moral statements and are not beholden to the idea of factual truth. They may be literally true, but we should read the first-person as a speaker in the poem who is not necessarily the poet. So, as well as being future-seeking, poems are also fictional. As a reader, it is my subjectivity, my understanding and my identification with the moral statement produced by the poem that enables my connection to it. I can only relate to what is written through my own lived experience and understanding. This is a summation of ideas proposed by Immanuel Kant in *Critique of Pure Reason* and has been expanded on by theorists that followed him, including Edmund Husserl (Rivkin & Ryan, 2004, p. 129-130). The relationship between the reader and the written word has been

the subject of a complicated discourse over the years, but it is a history that sits outside of the scope of this inquiry. Suffice to acknowledge the Kantian understanding that the mind constructs knowledge of the world as an active participant, not as a passive vessel. So, while biographical details of the author can produce certain insights, the poem needs to function outside of this if it is to survive in the world on its own and have meaning for an audience.

This brings us to David Rieff, Susan Sontag's son. In his memoir *Swimming in a Sea of Death: A Son's Memoir*, Rieff mentions a poem by Bertolt Brecht called 'When in my White Room at the Charité'. Rieff's memoir is about the period leading up to, and including, his mother's death. This is Brecht's poem in full:

When in my white room at the Charité
I woke towards morning
And heard the blackbird, I understood
Better. Already for some time
I had lost all fear of death. For nothing
Can be wrong with me if I myself
Am nothing. Now
I managed to enjoy
The song of every blackbird after me too. (Brecht, 1976, pp. 451-452)

Rieff writes that Brecht penned this as the last in a series of a series of poems while he lay dying in the hospital Charité in Berlin. He also goes on to give an explanation of the poem as being an actual experience of Brecht's, 'In the last of them, he looked out his window at a bird in a nearby tree whose call he found beautiful' (Rieff, 2008, pp. 167-168). He reads it biographically and literally. The biographical aspect is understandable because Brecht is, after all, actually in the hospital as he writes this poem. The literal reading is problematic though, and Rieff relies on the poem as a point of reference to draw the conclusion:

Brecht writes of thinking that after he is dead, the bird will be alive, in its tree, warbling its beautiful call. The wisdom of poem lies in the artist reconciling himself to that fact [that the bird will live on after the artist's death], reveling in the beauty of the world, resigning himself to his own transience, his own evanescence (Rieff, 2008, p. 168).

Rieff's interpretation of the poem is clearly influenced by the death of his mother because he is writing about the poem in the context of her illness and death. He laments that Sontag could not find peace in her imminent death, whereas he clearly feels that Brecht could, even referring to it as, 'Brecht's calm at his end' (Rieff, 2008, p. 169). Here, in this poem, is proof for Rieff that being at peace with one's inevitable end was possible. There is a flaw with this reading, however. The speaker in the poem is not necessarily Brecht. That being said, it seems quite likely that it is, but, even given that, it is not Brecht giving us an autobiographical account of his life. Brecht was in hospital when he wrote these poems, but, as Eagleton notes, 'Shakespeare did not need to experience sexual jealousy in order to create Othello. When he penned some of Hamlet's most magnificently distraught speeches, perhaps all he was feeling was whether the imagery sounded suitably diseased' (Eagleton, 2007, p. 113). So Brecht may have been inspired by his circumstances without necessarily experiencing them in the same terms as the narrator of the poem. I also mention this because it is a poem and, as previously stated, Eagleton notes that poems are fictional by their very nature (Eagleton, 2007). By Eagleton's reckoning, poems are above all moral statements that we connect with.

Even if Rieff's literal reading of Brecht is correct, it fails to acknowledge the fixed nature of Brecht recording such a moment in writing. If this moment was true for Brecht while he was waiting to die, it was not necessarily an attitude that carried through to his death. The nature of any experience, or moment, is that it can be subject to rapid re-assessment and/or change. In terms of Derrida's lecture on *différance*, this relates back to both speech and the written form always being in the 'past present' moment (Rivkin & Ryan, 2004). 'When in my White Room at the Charité' is a 'past present' moment that has been formally expressed in poetry. Therefore, because we cannot transfer our thoughts directly, they are subject to change even while we are expressing them because we are expressing them in the past. Brecht may well have reconciled himself for a period of time to the fact that he was going to die, but then lamented his impending death immediately after writing this poem. This speculation is included only to show how Rieff's failure to engage with the poem as an expression of a moment in time, and his choice to rather engage with it as Brecht's personal realisation and lived experience, has been applied to his own experience of his mother's death. In fact, it is impossible to know Brecht's feelings when he wrote this poem, and whatever Brecht felt is beside the point. The poem exists outside Brecht's experience. It is impossible for us to

assume that we can know. A poem is a fixed 'past present' moment and is not an ultimate resolution. That is, I would argue, why poems are never truly finished. They don't tell stories, they tell experiences, thoughts, feelings, beliefs. Rieff wants the peace he sees in the poem for his mother, but he sees that peace so strongly because of his mother's dying. This is his subjectivity and is a logical Kantian experience. Where it differs is that he sees an intention in the poem for which he offers no evidence. He confuses the poem with the poet's experience of illness and dying.

The structure of a poem is essential to the meaning of the poem itself. Eagleton asserts that, 'Poetry is language in which the signified or meaning is *the whole process of signification itself*' [original emphasis] (Eagleton, 2007, p. 21). This process of signification extends to the structure, including the verses and line length, because the syntax is bound by the form the poem takes. The form is part of what creates meaning. For the purposes of discussing the meaning of the Brecht's poem, and relating it to Derrida, I will talk about both the complete sentences in the poem, and also look at how the form – focusing on enjambment, on how the sentences break against lines – operates within the poem. It is worth noting that the poem is a translation from the German, but the German version is still has a broken sentence structure. The four sentences of the poem are broken up over the nine lines in a way that allows us to read a rhythm that reflects the tone of the poem. It gives a sense of someone actually thinking their way through a moment of realisation, rather than stating it in a neat and considered way. It allows us to experience the speaker having a realisation rather than merely having that realisation related back to us. Seemingly awkward phrasing and different uses of tense in the poem compound this effect.

The poem's tone is tranquil through the opening sentence, with a foreshadowing of the illness implied through the name of the hospital and the word play on morning/mourning^x. The morning/mourning play is made stronger by omitting a definite article from the sentence (as in, 'woke towards *the* morning'). The use of morning calls to mind Freud's work 'Mourning and Melancholia'. Here we have a speaker that has, in effect, mourned their own passing, and hence they have the ability to find a peace in their coming death. They have resolved their mortality and not fallen into a state of despair akin to melancholia. That said, there exists an

^x For the purposes of this thesis I will discuss the poem in its translated form. Although the play on words for morning/mourning does not exist in the German language version of the poem, Rieff only discusses the translated version and his observations are the reason for my close reading of the poem.

irony in this idea because Freud wrote 'The disturbance of self-regard is absent in mourning...' (Freud, 1914, p. 244). Rieff seems stuck in a state of melancholia over the death of his mother because he has not yet mourned her death. He observed Sontag stuck in the same state over her demise in his many accounts of her unhappiness at her coming death and her refusal to accept it (Rieff, 2008). However, I wonder if there is an exception for melancholia versus mourning in the face of one's own death. In Sontag's case there was a desire to live and she was prolonging it by any means necessary. She refused to acknowledge her potential to die. This might seem contrary to the idea of melancholia, but she had a strange disregard for her physical existence in that she was willing to have treatment at any cost, even when several doctors were sceptical of the benefits of treatment versus the negative side-effects (Rieff, 2008).

This first sentence of Brecht's poem ends with the words, 'I understood/ Better'. This is an odd phrasing. There is an implication here that the speaker is able to better understand, and therefore express, what was previously known. This aligns with Derrida's *différance* in that the speaker is saying they can get closer to expressing their actual thoughts, but that conveying them is imprecise (hence the use of the word 'better', because there isn't an absolute expression. Even the word 'best' means the best *at that particular moment*.) The speaker here has narrowed the difference between not being able to express, and being able to express, meaning.

This reminds me of a mathematical idea of halving a number. We can halve a number infinitely without ever reaching zero. We can refer to it as effectively zero, but it is not. The same can be said of Derrida's expression of language. The traces of other signs we see in language are the same as each number halved relating to all the halved numbers that come before it. The number can also be doubled infinitely and there is an implied relationship with all numbers in-between because they still 'exist' in the spaces between the numbers that are doubled, i.e. two doubled to four has a relationship to three in that four exists as coming after three. Like the number approaching zero, we can get exceedingly close in our expression with language, hence our ability to communicate with each other, but we never quite escape the fact that there is one more step in between our thoughts and our expression of these thoughts. As Derrida explains:

Whether we are concerned with the verbal or the written sign, with the

monetary sign, or with electoral delegation and political representation, the circulation of signs defers the moment in which we encounter the thing itself, make it ours, consume or expend it, touch it, see it, intuit its presence. (Derrida, 1982 p. 9)

There is a practical value in the speaker of Brecht's poem having a clearer idea of what they want to express, because it allows them to give voice to what follows. This is confirmed in the second sentence, 'Already for some time I had lost all fear of death' (Brecht, 1976, pp. 451-452). Here the speaker tells us that the feeling is not new, but there is a new way to express it. The third sentences give us a context to read the final sentence. It shows that the speaker has lost all fear of dying because what is death to someone who is dead: 'For nothing/Can be wrong with me if I myself/Am nothing'. The last sentence, broken over the last few lines, could easily slip into the present tense, but it does not. It is the past tense looking into the future – a future in which the speaker is nothing. The speaker can only be at peace with the future while alive, because the future only exists when we are something. The poem's relation to time is very much in line with Derrida's discussion on the present being deferred into the past and future.

In a general sense, poetry also has a strong relationship to the present. Because it is a compact form of expression, it can be written in a shorter period of time. I was using prose, in my attempt to write my novel, as a reflection on past events, not current occurrences. Early in her memoir *A Year of Magical Thinking* Joan Didion reflects on her writing practice and how the medium is inadequate to express the experience of losing her husband:

I have been a writer my entire life. As a writer, even as a child, long before what I wrote began to be published, I developed a sense that meaning itself was resident in the rhythms of words and sentences and paragraphs, a technique for withholding whatever it was I thought or believed behind an increasingly impenetrable polish. The way I write is who I am, or have become, yet this is a case in which I wish I had instead of words and their rhythms a cutting room, equipped with an Avid, a digital editing system on which I could touch a key and collapse the sequence of time, show you simultaneously all the frames of memory that come to me now, let you pick the takes, the marginally different expressions, the variant readings of the same lines. This is a case in which I

need more than words to find meaning. (Didion, 2006, pp. 7-8)

I mention Didion's memoir here for two reasons. Firstly, I see it as functioning in a similar way to the novel I had been writing. Mine was a fictionalised account, but it was ultimately to explore my personal relationship with the loss of my mother and my father's loss of his brother before that. Secondly, this particular moment in her memoir talks about how writing is a limited form of expression for this exploration, but it is, in essence, what she has. I think that the form that Didion was writing in had a greater role to play in this particular feeling than is explored in her memoir. The desire to collapse the sequence of time is actually about the desire itself, because even with the editing equipment she is only giving us a closer version of her experience. She is trying to get us closer to her thoughts/feelings, but *différance* prevents this.

If we cannot authentically have an experience, does it matter how close we get to it? By this I mean, if we are going to swing a golf club at a ball, does it matter how close we get if we are never going to hit it? Why even bother at the difference between missing by ten metres or missing by ten millimetres? The analogy is obviously flawed because conveying meaning and experience is far more complex than it explores, but it has a conclusion that underpins the idea of it being impossible to ever really convey meaning. Derrida investigates the impossibility of our expression being linked to the present time. In this respect we can only ever discuss how we felt rather than how we feel. In this sense, to pursue the analogy, we are talking about the 'past' present moment in which we have hit the ball rather than how we are trying to hit the ball or how we are hitting the ball. What we are trying to do is explain that moment and there lies a world of difference in how that is done. The medium is one choice and Didion discusses film, but what she seems to me to be trying to convey is the importance of the difficulty in expressing herself adequately.

We can think in extremely complex ways. Our brains hold a lifetime of learning and experience, and can access vast amounts of information; but we can only convey it in a limited way. Communication acts as a funnel. We can develop new ways of funnelling, like building a wider spout, but we have a limited capacity to take information in. We have to be able to receive the information and process it. The width of the spout is insufficient; what controls the amount of information entering the vessel is the diameter of the entry point. We need to be conscious of this relationship between giving and receiving information. What

Didion does is convey her frustration at not being able to communicate fully her experience and she does it well. With poetry I have an opportunity not to change the funnel but rather the information put through it. That is how it is different from prose.

To unpack this further, poetry seems to give language flexibility to interact with experience; the form permits a loosening of the rules of language. Writing a poem is also an ongoing process in that what constitutes a finished product for a poem is an ambiguous idea, much like grieving the loss of someone you have loved. It is not trying to describe the entire event, but rather to give us moments in that experience. A memoir is trying to encapsulate the experience and give it a narrative shape and context, but the act of losing someone is not such a well-behaved process. It is worth noting that in this statement about needing more than words to find meaning, Didion is expressing both loss and a particular moment of despair. Didion's memoir explores the subject of her loss thoroughly, but in the last part of this statement, specifically the clause, 'I need more than words to find meaning', the expression is flat. This gives us a sense of her disconnectedness from her practice as a writer of the memoir, but this particular moment is likely to be lost in the size of the narrative. It is the moment that shows just how adrift Didion is as a person and it is almost the very question 'Why go on?' while she, as a writer, does go on. It is not entirely overlooked as a moment in the memoir, however, as I am writing about it. That said, it is not given the regard I think it is due, as a moment of Didion the grieving wife who writes, and not Didion the grieving writer, and I find that to be a pity. I write about this difficulty of expression in my poem 'The last word':

Not another poem about a dead mother
or sibling or friend

Some piece that fails its way towards loss and the cost and the everyday

It will be imagery about graces that are animal like and the stopping
of time
of everything

It will be light brush strokes and fondness
and comically tragic and a call to laugh at an embarrassing

affectionate
memory

laughter is best
or inappropriate
or all I can manage right now.

because otherwise this poem would be screaming
and red eyes
no neat answers and fear of sleep.
It would be selfish and struggling
and wouldn't say 'how good' or 'too good'
because good got buried before her funeral ever took place

and wailing is hard to read out loud

and my mother is dead and nothing will comfort me

This poem is an expression of the inadequacy of language to accurately express emotion. Specifically, it is about poetry's inability to do so. Language is all we have to express that frustration. In extremis what is signified here, by signifiers, is the inadequacy of signifiers. There is a paradox – poetry disrupts language and is so precise that it pushes at the boundaries of language towards 'thought', to the inexpressible. It narrows the gap between language and thought. The poem alludes to other poems in their attempts to express loss and qualities of the lost person. It focuses on a particular instance. The central tragedy does not get lost in a greater narrative. Didion is exploring the loss of her husband and documenting it because it is what she does (Didion, 2006, p. 8). My poem is based on an autobiographical account, but its relationship with the reader calls into account the very idea of expressing loss and not just my personal inability to find a way to do so. Didion being failed by language is personal – mine is as well, but I use a particular moment to explore the very idea of that moment. And the poem, by not being read as purely personal, becomes an expression about loss; whereas this moment in Didion's memoir remains a personal failure of her craft's ability to express her feelings. People might relate to, but it remains a failure for her, rather than a failure for 'us'. My poem calls out to the readers' experience. Didion may inadvertently call

out to the readers' experience but it is not her intention. She is saying, 'I, the professional writer, am failed by my craft', and the poem says, 'No matter who you are, words are not enough'. There is an obvious tragedy in Didion being let down by the thing she is best at. It is the hero being powerless to stop the villain and in being failed by themselves there is a lot of room for sympathy. If they cannot do it, what hope do we have? But it is a memoir and the narrator is not a fictional character. It is not meant as a metaphor or a lesson. The nature of biographical accounts (being factual) gives them power because we know it actually happened to someone. By that same logic, though, the fictional aspect, even of the most personal poetry (as discussed above), gives it power because it seeks to go further than the individual.

The novel I was originally writing was closer to Didion's memoir than are the poems because it was a longer meditation on recalled events and it was after the fact, not during. It was the form that I felt best suited my personal reflection on what happened. There is no implication here that Didion's memoir is a failure as a body of work. I merely point out the difficulty in the expression of a moment within it, and the consequences of that moment in the wider context of the memoir. I had attempted to interrupt this difficulty in my novel by interjecting the main narrative I had been writing with personal memories that were disorienting and had little context. The idea was that they would build a context as the text went on and the slowness of this build-up would reflect the process of attempting to come to terms with a significant loss.

Like Didion I was displaced by my loss. It was still relatively soon after her husband's death when she started writing *The Year of Magical Thinking* ('It is now, as I begin to write this, the afternoon of October 4, 2004. Nine months and five days ago... [my husband had] a sudden and massive coronary event that caused his death (Didion, 2006, pp. 6-7)), but it was still looking at what she had lived through more than what she was living through. I was writing on my mother's death some eighteen years after the event, and the idea was essentially the same because it was in the past. The illness that I have, on the other hand, is a continuing present and 'future present' moment. I become the subject of my own potential loss in that I cannot reflect on my own death. I can contemplate it and I can reflect on the illness and diagnosis, but one's own death can only ever be a speculative idea. In that sense poetry allows me a greater scope to connect with my experiences as they are/were/might be. I can even do all this within the one poem. Poetry allows for deviation and distraction because that

can be the enacted in writing a poem.

I was writing a novel because I had space and time to reflect and had managed to get to a point in my life where I could write about the loss of my mother. Although her death continues to affect me, the event is a fixed point. My illness is not a fixed point. I needed some other way to interact with it, to reflect on it because it is constantly changing. Not just in the sense that reflections on it change as my perspective changes, because that is surely true of any experience, but the symptoms and consequences of the illness change through time.

This was particularly true through the first year of diagnosis that I went through. The GP sent me to a specialist when I saw him about a tingling sensation in my hand when I made a fist. This symptom then led to numbness in my fingers. Convinced that I had carpal tunnel, the symptoms shifted and the feeling returned to my fingers without any treatment but I started getting arthritic pain in my finger joints. My hands swelled up and I could not form a fist, which became so severe that I could not hold a pen. These are just part of the shifting symptoms I experienced. Even when the symptoms do not shift there is the potential for them to do so. The death of my mother is final and my diagnosis is ongoing. Therefore I need/ed a new form of writing, and poetry allowed for the complexity of engaging with ongoing and shifting reality. It also allowed for me to be actively engaged as a writer for an audience rather than as a writer of a personal diary. It was a way for me to write a thesis and examine the way I physically experienced the concept of *différance* by using poetry to interrogate the experience.

Am I the Wounded Storyteller?

In 1995 Arthur W Frank published *The Wounded Storyteller*. While it introduces some interesting thinking around illness and how writing can relate to the experience, and while it states clearly that it has limitations and that it in no way covers all aspects of illness and storytelling, Frank's conclusions are sometimes confused when it comes to the benefits of writing when ill. I will mostly engage these aspects of the book because they are the areas that resonate with me as a writer who has found himself to be ill. The most obvious and unacknowledged aspect is the failure of Frank to draw a distinction between being a writer who is ill and being an ill person who writes a personal narrative for a general audience. The distinction is not black and white, for there are narratives that lie in-between, but it is a distinction worth exploring because it is the very difference that I found myself having to explore when I discovered that I had scleroderma. Frank is also by no means the only person to write in this area and to fail to explicitly acknowledge this distinction. This section will use Frank's work as a starting point to explore this idea.

Suffjan Stevens sings 'Oh I want to be well, I want to be well, I want to be well, I want to be well. I'm not fucking around', over and over in increasing intensity. The Cold War Kids sing, 'Something is not right with me, something is not right with me, how was I supposed to know?' over and over. I play these songs on repeat. There is a sympathy and a longing in them. When I find out that I am ill I contemplate how I might beat this. Conventional medicine offers symptom management through drugs that can kill as easily as they heal (but you might never have any adverse effects). I see naturopaths and use homeopathy (and I am suspicious of this the most – but I want to be well.) My specialist has visible disdain when I mention alternative medicine (What did you think I'd do, N- ? Did you expect me to take no alternative to the bleak and meagre offering I got from you?) I use my peer-counselling network and get to show where it is hardest. Maybe that's why I don't need writing for therapy - I get to have human beings instead.

In 2012 John Ross published *Orwell's Cough: Diagnosing the Medical Maladies and Last Gasps of the Great Writers*. He examines evidence to suggest various maladies that afflicted

writers such as Emily Bronte, Shakespeare and George Orwell, among others. Ross searches out historical and empirical evidence to support his claims. He does not use the literature of the writers to ascertain his diagnosis because he is a man of science, though he makes mention of their works. This is an investigation by a medical expert (Ross, 2012, p. ix). Orwell himself, when speaking of *Nineteen Eighty-Four*, 'admitted to friends that its gloom had much to do with his illness' (Ross, 2012, p. 220). The ongoing struggle of Orwell with bouts of various illnesses is extensively covered by Ross. But it would be a poor experience to reduce the reading of Orwell's, or any of these authors' works to these apparent pathologies that were part of their lives and in some cases it could be misleading. Their illnesses would have an influence on their work, as would any major occurrences in their lives (births, deaths, political turmoil), but the works go beyond being about the authors. Otherwise we would read literature as a diary and that would be a mistake.

For me, this is where the confusion lies in the models put forward by Frank. Namely, Frank advocates the idea of reclaiming power for the ill person by telling their story without acknowledging that personal narratives versus stories written for an audience are different. In an interview for *The Paris Review*, the poet Donald Hall says to Peter A Stitt, 'I don't believe poets when they say *I*, and I wish people wouldn't believe me. Poetic material starts by being personal but the deeper we go inside the more we become everybody' (Stitt, 1991). This echoes the earlier argument by Eagleton that poetry is fictional by its very nature (Eagleton, 2007). Stories, or any creative works, that come out of our being ill are not easily reduced to being narratives about being ill and, where they are, they are no longer in the realm of being from a writer who is ill. Instead they become a person writing about their illness.

Frank talks about a woman, Judith, who gets in touch with him after reading his story about his own cancer and watching a lecture that he gave (Frank, 1995). There is clearly an audience for Frank's story about his cancer (as Judith attests), and Judith's chronic fatigue syndrome, but this idea of an audience is very limited. Frank notes that, 'even though we did not know each other, Judith needed to write to me... for me to witness her story and her personal change' (Frank, 1995, p. 1). The idea of Frank's audience here is someone to personally witness/hear another's story. This sets the tone for the way Frank explores being a storyteller, but it seems to me to be more about the value of sharing our lives with each other and not shrinking into isolation when we are ill. There is merit and value in this, but it is clearly a different way of expressing our stories than constructing a consumable narrative.

There is a further distinction between writing a memoir and writing a series of poems. Of course writers can write across genres, and it is possible to write a memoir in verse, but that is not the discussion that I am entering into in regards to my own work.

Despite some reservations, I find myself exploring the nature of writing as a form of healing and the implications of this for me as a writer. Louise DeSalvo published *Writing as a Way of Healing* in 1999. As with Frank's work, it advocates the necessity of writing as a clear benefit to the healing process. DeSalvo uses quotes from writers to support her theory:

H.D., in *Hermetic Definition*, phrased it most succinctly: "Write, write, or die." And Henry Miller..."The more I wrote," he said, "the more I became a human being. The writing may have seemed monstrous (to some), for it was a violation, but I became a more human individual because of it. I was getting the poison out of my system." (DeSalvo, 1999, p. 4)

These strong statements belie a problem in DeSalvo's work that is also evident in Frank's because they imply an emotional, rather than physical, form of healing. Writing is a wonderful tool, but it is not the only form of such healing. Their works are focused on the benefits of healing through writing and frame it as the definitive method, rather than acknowledging other avenues of recourse. The benefits these quotes ascribe to writing can be gained through a counselling process. In my own counselling process, I feel confident that my story is being heard and that I am getting rid of my emotional baggage. While I appreciate the ideals that Frank holds out by wanting our physicians to listen to us, I also know that the reasons they cannot are systemic and complex and so unlikely to change quickly. It is worth pursuing, but in the meantime I am ill.

DeSalvo writes about memoirs as a way of healing – very much in the spirit ascribed to studies that she quotes in the sub-section, 'What Kind of Writing Helps us Heal?'. She says:

Writing that describes traumatic or distressing events in detail *and* how we felt about these events then and feel about them now is the only kind of writing about trauma that clinically has been associated with improved health... In controlled clinical experiments, then, only writing that describes *traumatic events and our deepest thoughts and feelings about them, past and present, is*

linked with improved immune function, improved emotional and physical health, and behavioural changes indicating that we feel able to act on our own behalf. [DeSalvo's emphasis] (DeSalvo, 1999, p. 25)

This leads to several questions. Why do we need quotes from authors of fiction, poetry and memoir to support this central idea? Surely any person, as long as they follow this prescribed manner of writing, would benefit? In fact, I doubt that any of the well-known authors quoted in this book participated in this study. I draw this distinction because professional writers are quoted when it comes to any written word, but we have other ends for which we use our writing. Anyone literate can write their own life in their own words (which DeSalvo advocates as a way of healing), but writers are professional people, as are engineers or accountants. My poetry, including the pieces for this thesis, has no doubt been affected by my experience of illness, but they remain written for a purpose beyond the therapeutic, whatever catharsis they might give me. I write them first and foremost for an audience. One suspects an engineer, for example, can benefit as much from DeSalvo's writing therapy if they are ill, but we would not consider relevant to it their thoughts on their profession of engineering.

DeSalvo is writing about a specific use of writing as therapy and then taking that writing and converting it into a memoir; therefore, the focus is heavily on the individual's experience. It is a writing guide that discusses editing and making your story readable to an audience and giving that story shape and cohesion, albeit in a gentle manner. (Note the passive use of the word 'perhaps' in the following quote. It seems to suggest that 'we are dealing with an emotionally fragile topic'): 'Perhaps now, for the first time, we think of a reader, someone completely unfamiliar with our experience, to whom our work must be completely intelligible.' (DeSalvo, 1999, p. 143). Such advice is necessary for writers to write something readable, but is it part of this healing process that DeSalvo discusses? The answer is a resounding 'no' within the strict limits of the clinical experiments, as quoted above. This moves the book from a scientific study that might help people who are ill, to a mixture of self-help and basic literary theory. It is a guide that might be useful for new writers, but it is not written for a professional writer. Therefore the use of the quotes from famous writers about their experience of emotional healing through their writing practice are out of place because they apply to neither the physical healing that the book describes, nor the process of writing as a professional.

The clinical experiments mentioned above detail what to write, but DeSalvo shifts it here from the personal to the public. This seems unnecessary to me unless her book is re-titled: *Writing as a Way of Healing (and then converting that into a written resource for a readership)*. And it is a distinction worth noting because, as mentioned previously, I have found that I have much the same experience in getting the emotional healing I get from counselling and then writing my poetry separately from that experience, sometimes even using my illness as the subject of my work. I am not, in the sense described above, writing as a way of healing, but neither is DeSalvo advocating that as an overall argument in this book. Rather, she is writing advice on transforming the writing one does for healing into a narrative for a wider audience. This transition is not delineated clearly enough to make the distinction between writing as healing and writing for an audience obvious on any level because DeSalvo does not indicate that 'writing as a way of healing' is finished and she is now moving on to a different part of the writing process.

I am not naïve. I appreciate that DeSalvo is using a legitimate study to give credibility and weight to her argument. She is an academic and there are protocols to follow. But she never acknowledges the possibilities of healing outside of writing and draws slant conclusions from the study that she uses. Like *The Wounded Storyteller*, we see a book that sits uncomfortably between self-help and academic instruction (with both books having an author whose personal experience with illness that informs and drives their work, while they try to remain emotionally distant from it).

I want to leave – to get away. It will be better for everyone. I fantasise about catching a plane and losing myself. Sometimes it's a crowded city, other times a remote (tropical?) destination. No one I know will have to watch me suffer and die. It may sound like cowardice, but I watched my mother dying for over a year and it broke us all in ways we're still coming to terms with twenty years later. So I sit here and feel the weight of the credit card in my pocket that offers me escape.

Later, when I decide to stay, I realise I need some kind of plan. My body is in pain. A normal nine to five job seems difficult, especially when it comes to disclosure about my physical state. Writing is possible, physically, but my mind cannot hold onto the characters from the novel any more. How can I contemplate their fates? Whenever I try, my own demise comes blustering in and threatens them all into submission. I cannot leave, I cannot stay.

I have become invested in this inquiry. I am not on the short ride that is a definitive terminal illness. My disease can leave me relatively unaffected for years. I have not heard the term remission applied to me because remission means that there is dormancy to the illness outside of treatment. The best outcome is the odd spontaneous self-cure that I have read about but do not hold out hope for. Being ill leaves you in a position to receive a lot of advice. Sure there are many situations that lend themselves to advice being given, but there is a keener edge to that advice when your life, or even your death, depends on it. Frank writes about wanting to free sick people from the oppression of the medical system that seeks in many ways to silence them by telling them that they must tell their stories in order to have the best chance of recovery (he does not seem to care if you want to or not). DeSalvo tells you that she is backing a method that has only one proven way to give yourself a decent shot at recovery. I realise that there is a greater complexity to the works of Frank and DeSalvo, but as a man with an illness who was searching for alternatives to the medical discourse, these were the aspects of their work that struck me.

In *Intoxicated by my Illness* Anatole Broyard makes sweeping statements about the experience of being ill and how liberating it is (Broyard, 1992). He might appear to be/actually be writing for himself, but there is an underlying tone that says he speaks for 'we the afflicted' and he never explicitly denies this. Sontag writes, in *Illness as Metaphor & Aids and its Metaphors*, that she has the definitive method for going forward as a person who has an illness, and never acknowledges the extremely lucky circumstances under which she managed to survive her first bout of cancer. I have no doubt that her tenacity and perseverance contributed to her recovery, but she is very single-minded when it comes to her own story. What all of these writers unintentionally do by refusing to acknowledge the limits of their experiences is to criticise everyone who falls outside of their methods. It might be bad enough that this criticism falls on people who might have suffered a lot, but it further falls on those that have died through no fault of their own and undermines the very arguments that they put forward to help those people. Of course, the net can be cast much wider than these four writers, but I have limited space to engage with the material and they resonate closely with how I have come to experience my illness from my perspective. I find myself trying to find the 'right way' to be ill. Do I fight harder? Do I graciously admit defeat and quietly go about my days? Do I use some alternative method or trust solely in Western medical science? These texts are helpful in the wider discourse of illness and treatment, but

they have an impact on peoples lived experiences that is more immediate than the cerebral manner in which they are presented.

Et tu Sontag? I read you so that you can be the champion. You will give us the right perspective on the whole mess. You can defend the ill. But you are hurt and so have come out swinging. Backed into a corner you tell me, 'I hoped to persuade terrified people who were ill to consult doctors, or to change their incompetent ones for competent ones, who would give them proper care' (Sontag 1991 p. 100). Who are the competent ones? Surely they are the ones who save you, but how do you know you have one of them? Did my mother have an incompetent one? Should she have been more radical in her treatment? Would she be alive today if she had the fortitude of Susan Sontag? Is Susan Sontag better than my mother? Sontag, I know the value of modern medicine. It has quite literally saved my life on several occasions. But you must understand that it gives me nothing more and that is why I'm trying other ways. I plead with you to understand this – but your words are relentless and unmoving on the page. I do not judge you for writing this, but part of me hates you (and my ill-will, for all I know, is making me less well, although I find some comfort in knowing that this blame is what you sought to eliminate).

Am I a victim in this? My instinct is to say *no*, but the evidence seems undeniable. It is a complicated relationship between me and my illness and my writing. Victims are, by their very nature, passive in that they have an action done to them. This does not make them weak, it makes them victims. They can resist, even violently, and yet still fall victim to the action of an 'other' (whether a person or circumstance). Our lifestyles can (and often will) contribute to our illnesses and there can be direct correlations (lung cancer from smoking), but the ill person is still a victim of the disease. There are people who smoke who never get lung cancer. The Quit Resource Centre, based in Victoria, Australia, states that, 'research estimates that one-in-two lifetime smokers will die from a disease caused by their smoking' ('Deaths & disease from smoking' n.d.). It can be inferred from this that half of all lifetime smokers never get a disease from their smoking, certainly not lung cancer. I have thought many times about what factors may have led to my illness. Sometimes this has been under the guise of wanting to know so that I can heal, but underlying this enquiry I can feel the weight of the Question 'What did I do to deserve this?'

Being a victim also becomes complicated by the ongoing and changing nature of chronic

illness. In relation to Freud's concepts of mourning and melancholia, the trauma of the ongoing illness cannot be mourned because of those changes. Or rather, it needs to be perpetually mourned, because it is made different with each change. I cannot mourn (and therefore cannot move on from) being an ongoing victim. I am stuck in the role. It is different from the diagnosis of a terminal disease, although the journey may be similar in many ways, but the end date that you are trying to survive past is unclear. It seems to make no difference whether one is fighting back (and winning) or 'giving in' and getting some relief; one is still a victim. In, 'My Strange Head: Notes in Migraine', Siri Hustvedt talks about the state of American culture when it comes to illness that is, conventional wisdom suggests one has to fight, and if a person gives in to their lot then they are labelled a 'quitter, a passive, pessimistic, spineless loser who deserves only our contempt' (Hustvedt, 2012, p. 24). Hustvedt adds that as soon as she stopped thinking of her condition as the enemy, she had a much easier existence. She was not cured, but she was better (Hustvedt, 2012). This is a wonderful alternative to other people who are unwell. Giving yourself over is not the worst thing one might do. But both ideas are strategies of coping in order to facilitate some kind of recovery. At the root of it, the language we use is irrelevant because the inescapable outcome from these approaches is that the ill person is the victim of an illness. Metaphors matter – Sontag makes a clear case in *Illness as Metaphor* and Rheumatoid Arthritis sufferer MEA McNeil has this to say in the first chapter of *The First Year–Rheumatoid Arthritis*, entitled, 'The Immune Metaphor':

The archaic belief that illness is punishment for some wrongdoing, as foolish as we know it is, still casts a long shadow over the way we think. I could only conclude that I somehow brought this upon myself, this anarchy of the knees. (McNeil, 2005, p. 1)

McNeil does add that there are positive metaphors that can help a patient's understanding of their illness, which can be very clinical and scientific in nature (McNeil, 2005). Ultimately though, while they may have a significant effect on patients by changing the relationship to the illness, they do not alter the reality that the illness exists.

Frank, DeSalvo, Broyard and Sontag were all victims of illness. Victims with different outcomes and different approaches to handling their lots. They all describe their interactions with illness as being definitive in some way. Hustvedt establishes an approach to being ill

that works for her. Ultimately, these are sick people writing about their coping mechanisms in regards to their illnesses. What they commonly display is a desire to discuss a better way to deal with illness generally, but they end up showing that it is a deeply personal choice. I read them hoping to find the right way to be sick and interact with it. I cannot choose whose method to follow (although Frank, DeSalvo and Hustvedt lived and so did Sontag for a long time beyond expectation). I keep coming to the unfortunate conclusion that there is no right way, but I seem to be finding some relief in writing poetry.

Poetry, as a creative expression, offers advantages to me that were not immediately apparent when I made the decision to switch to it. Poetry is a precise form, but it pushes words and their meanings to their limits in order to evoke. Hence, there is potential to trace the other meanings of words, as Derrida discusses (Derrida, 1982). Eagleton says, 'Poetry is a kind of phenomenology of language – one in which the relationship between words and meaning (or signifier and signified) is tighter than everyday speech.' (Eagleton, 2007, p. 21). This unforeseen revelation is also true of the experience I have when writing poetry. Everyone has their own method when it comes to producing creative works. I tend to gather and edit a series of ideas in my head and then have words rush out in one sitting. Then I refine the work. Even through this revision and editing I am surprised by the links that people draw from my work when we gather for our monthly writers' group. There are some strengths and weaknesses in the connections people find, but it is the surprise itself that delights me. Eagleton says of poetry, 'rather than just allow us to consume the stuff, it forces us to wrestle with it: and this was especially true of modern poetry' (Eagleton, 2007, p. 21). This is true even when you are the author of that piece. To draw on an analogy, writing poetry, as opposed to prose, can be likened to scaling a mountain as opposed to hiking up it. They both achieve the same end and are both challenging. There are great rewards in scaling a mountain via a route that you do not know beforehand, but the mistakes one can make can have dire consequences in either circumstance, but they do differ. It was only later, on reflection that I could see what poetry might be able to do for me. Prose draws out these ideas and demands that the narrative provides stronger links that make the possibility of these discoveries later, as an author, much less likely. In fact, I would go so far as to say that if you miss them as an author it could even weaken your work.

My journey as a novelist-turned-ill-poet led me to Gregory Orr's *Poetry as Survival*, a compelling explanation of the powerful role of poetry in his coming to terms with the fact

that he accidentally shot his brother when they were young (Orr, 2002, pp. 6-7). It was a hunting accident and this context would, I believe, mean that the psychological consequences are different than if he had accidentally discharged a weapon that was not his, as Orr was experienced with guns, having owned a rifle since he was ten (Orr, 2002, p. 6). Orr could find no consolation in the people around him, or in the divine. He writes:

I lived for about four years after my brother's death without any hope at all. Nothing that I found in my culture sustained me. Even my relationship with the natural world, which had been so important to me earlier, was not enough to alter my grief, despair, and guilt. Then, thanks to Mrs Irving, the librarian in my small public school, I discovered poetry. I wrote a poem one day and it changed my life. I had a sudden sense that the language in poetry was “magical”, unlike language in fiction: that it could create or transform reality rather than simply describe it. (Orr, 2002, p. 8)

Orr does have a disclaimer further on that, 'Much of my book is speculative and meant to be suggestive rather than definitive' (Orr, 2002, p. 8). While this may be true, I contest that he is doing fiction a disservice in this comment. While it is clear that he is writing about his own experience, surely he has come across fiction that creates and transforms reality rather than describes it? It is difficult to believe it is not so, and acknowledgement of it would not harm, and may even strengthen, his case for, 'poetry as survival'.

Reading Orr unsurprisingly leads me to reflect on my own experience with my mother's death. I was not responsible for her death in any way, and I certainly did not feel guilt in the same way as Orr, but I did have a difficult time coming to terms with her death. So much so that I did not discuss it with anyone. I even had an attempt at using religion to try and resolve my problems, as did Orr. I also eventually found some relief from the agony of unexpressed grief and the gamut of complex emotions that come with the loss of a loved one. Mine came in the form of counselling. Through counselling I came to be able to explore the events surrounding my family's grief and the inter-generational consequences of my personal history in the novel I was writing. Unlike Orr, I was not trying to 'create or transform reality'; rather, I was trying to uncover the reality. And indeed, I was trying to describe it in order to recover it.

If I can write the right poem I'll live. If I can cry the right way, unburden myself of the right trauma, sadness, self-loathing. Fight it. Give in. Take this, do that. Write the right poem.

I'm too tired to think whether I'm too tired. Maybe it's not as bad as it feels. I'll give it a few days. Maybe I hurt my wrist doing something else, and it will feel better. Fish oil. Vitamin D. Magnesium. Turmeric. I read that pineapple can help. Be careful with your diet. Be physically active. Write the right poem.

I can feel myself coming undone some days. Sometimes I just lie really still, like I did when I was a young boy and scared at night – too scared to sleep, but unable to go find comfort because I was terrified of what might be in that darkness. I would lie still, hoping that my lack of movement would fool whatever was out there into moving on.

Move on.

In the novel I was writing, I was trying to recover an overall picture of the events that surrounded grieving in my family and take back the parts that I had deliberately disengaged with at the time. Later, when I myself became ill, I was able to understand the idea of poetry as survival. I have mentioned my reluctance to classify all the poetry I write as 'about the illness'. I have also discussed the complexity in that because, however else I might want it to be, my life is lived as a person with a chronic, life-long condition. And there certainly is a joy in being able to lose myself within work that is about something that is sometimes about other subjects entirely. It is true that the process of writing poems has a direct relationship to the illness. It is sometimes a relief from the existential weight of contemplating my own mortality (or just the discomfort that I might feel day-to-day within my own body); but that still does not mean the work must reflect this relief.

Gregory Orr will always write poetry as a man who accidentally shot and killed his brother when they were young. Everything he experiences has this fact attached to it because it is part of what makes him who he is. But not everything he writes is about this or should be read through this frame. Even when he is 'losing a sense of himself' in the act of creating a poem, writing is a conscious act, and the conscious act of writing a poem and then editing it is a professional process that goes beyond any guilt he might carry. As a poet, he is not just writing down what he feels, but also actually constructing a piece of art. This distinction is important, and also applies to other parts of our identity, not just loss and grief. For instance, Frank O'Hara wrote as a gay man, but, although his sexual identity is significant in, and informs, his work, it is not the sole subject of [all] his work. As Mark Ford notes in *New York*

Poets: An Anthology, 'O'Hara's poems are full of references to his artistic enthusiasms, to the lives of friends and lovers, to social events in Manhattan or the Hamptons, and to the latest productions of Hollywood' (Ford Ed., 2004, p. 4). O'Hara had many biographical aspects to his poetry that contributed to his work. His sexual identity was just one of those aspects. Drawing on this overall picture of O'Hara, I would say that I am not the wounded storyteller, but instead I am the storyteller who is wounded. The semantics of the latter way of phrasing the relationship between my illness and my writing places an emphasis on the 'storyteller', which is the primary part of my identity in this context.

Poetry of an Illness

Poetry is something which is done to us, not just said to us. The meaning of the words is closely bound up with the experience of them. (Eagleton, 2007, p. 21)

A large part of the poetry in this collection, 'Coming Undone', is autobiographical. The collection has been presented in three parts, in chronological order. The separation is reflective of where I was in terms of my illness. The initial diagnosis was difficult and the disease took a long time to settle into any pattern. In part one the poems are generally shorter and only a couple focus directly on my illness because I was avoiding looking at it, hence the subtitle to the first section is 'Denial'. In the second part I begin to explore my illness more and still look back at the loss of my mother. There is a stronger element of 'me' in the poetry because I could look at aspects of my illness. At this point I was coming to accept it as part of my life, but there were consequences to acknowledging my illness and so it has the subtitle of 'Anger'. The poetry in the third part represents another shift. It is similar to the second part, but the poems are longer and look outwards. This is not to say there are not personal, highly autobiographical pieces in the third part, more that, as my chronic illness goes on, the reality of having to live with it has given me a perspective of longevity that I feel is reflected in the lengths and subjects of the poems. Therefore it has the subtitle of 'Acceptance'. The three subtitles are three of the five stages of grieving found in the Kubler-Ross model of grieving, which are listed as denial, anger, bargaining, depression and acceptance (Smaldone & Uzzo, 2013). They are the three stages that best suit the undertone of my emotional state and, I believe, are reflected in the poetry.

While I have discussed (in 'Living *différance*: Illness, Derrida and Poetry') the poem 'The Last Word' and how it is about the loss of my mother, I also wanted to look at the wider grieving process in South Africa. Freud, in talking about mourning the loss of a loved one, gives us the following thoughts (bearing in mind that when he talks of opposition here, he is talking about the unwillingness of the living person to 'let go' of their thoughts and feelings for the person who is lost – referred to as 'the object'):

This opposition can be so intense that a turning away from reality takes place and a clinging to the object through the medium of a hallucinatory wishful psychosis. Normally respect for reality wins the day. Nevertheless its orders cannot be obeyed at once. (Freud, 1914, pp. 244-245)

Freud goes on to explain that mourning is a painful and slow process that takes a long time. The poem 'How to Remember' relates to this issue because the protagonists are stuck in the past and unable to engage with the present. The poem concerns an evening I spent with my father and an old friend of his in Durban, South Africa. We were there as part of a research trip for my novel. I had, just before this trip, been to my first medical appointment that would ultimately lead to the diagnosis of scleroderma one year later.

How to Remember

It's raining and foggy and it's Durban
it's Kloof – cliff – and
We are driving, the sun is fading and
I am remembering where prayers come from.
My father's asking the African man directions
in a petrol station.
He feels he's being treated badly
and Colin's house has no security
just a revolver that he straps on each night.
They are remembering the old days
and I am remembering where prayers come from.
They are stuck and awash with memory
angry that such former glory is destroyed.
The hope and redress feels as worn out
as the thirty-year-old furniture we sit on –
like the arms of the discoloured chairs.
So, while they are remembering fanciful things
I am remembering where prayers come from.

The place from which prayers emerge, in this context, is fear. This poem looks back to a pre-

diagnosis time, but does not have a yearning towards that period as idealistic. It is not directly about illness, but fear and how it manifests. It would not be too great a stretch to link my psychological state as an ill person to the sentiment of this poem, but they are also wholly separate. The fear in the poem is about a different threat altogether, it is about the everyday threat of violence that exists in modern-day South Africa. The poem also calls beyond the three people it describes to speak to that larger idea of fear. In being ill there is a resonance for me with the ideas expressed here, in that fear of death caused the narrator to seek comfort in an old, almost reflexive way by reaching out to prayer. The father and Colin in the poem are failing to engage with the shortcomings of the system they previously lived under. There is an implication here that they are delusional about the reality of the past. This is reflective of a wider attitude that I see being carried forward in South Africa, one that claimed to be against racism, yet is willing to live off the benefits of a regime that comes from racism.

Poetry has ability to take language to the edges of meaning, which creates moments that are paradoxical. Cleanth Brooks, part of the literary movement from the early twentieth century called the New Critics, writes about this in the paper 'The Language of Paradox' in which he states that, 'there is a sense in which paradox is the language appropriate and inevitable to poetry' (cited in Rivkin & Ryan, 2004, p. 28). He goes on to examine the work of various poets, such as Wordsworth, Coleridge, Pope and others, and looks at the paradoxes within their works to create meaning that links the concrete to the universal. In another of my poems, 'Bat poem', the repetition of a line referring to an echoed cry as being 'itself, itself, itself' is representative of the echo itself, but is also a call further into the idea of what is being referred to as 'itself'. It is an attempt to explore the essence of the pronoun. One could express it as the analogy: you are the youest you in existence. The statement reads nonsensically (youest is ungrammatical) but it holds a particular truth. It is much like the line from Dr Seuss' book *Happy Birthday to You!* which has the line: 'Today you are you! That is truer than true! There is no one alive who is Youer than You!' (Seuss, 1959, p. 42). This search for authenticity calls back the ideas posited in the concept of *différance* in that it is calling to the authentic nature of language. A chair is a chair not because it is, but because nothing else is. Earlier in this exegesis I used the analogy of a heart shape cut into a piece of paper being defined by the paper around it, rather than by what it is itself. This hollowness that is shaped by what-an-object-is-not does not have substance (it is an empty space), so the refrain of 'itself, itself, itself' can act in taking us further into that emptiness, or define the

border around the shape and hence give the shape a more defined border, but the shape itself is still emptiness. The refrain also shows the abstraction of ideas versus the solid reality that they represent. If ideas were solid, then they could not be penetrated by language in this way.

The poem 'Five parts for breathing' takes a different approach in showing the boundaries of language. The poem ends with the following concurrent stanzas:

the quickening of my heart	the slowing of my
heart	
drawing long slow words out	drawing long slow words out
I can only say romance and ever mean	I can only say regret and ever mean
what it is I want it to have meant	what it is I want it to have meant
the is	the is
and the and	and the and
is the and the is	is the and the is
the and	the and
and the	and the
is	is
and	and
and is	and is
the	the
the	the
the the	
isisisisis	
aaaaaaaaaannnnnnnnn(d)	
isisis	
aaaaaaaaaannnnnnnnn(d)	
isisis	
aaaaaaaaaannnnnnnnn(d)	
isisis	
aaaaaaaaaannnnnnnnn(d)	

The stanza that starts on the left is titled ‘the little death’, a French euphemism for orgasm. The stanza on the right refers to this with its title ‘when he stopped breathing’. The left heads towards the nonsense of the climax and the right heads towards the nonsense of a gradual loss of consciousness – an anti-climax. But they come to the same point of expression. While the language is used symbolically, rather than literally, the orgasm sees the language break down in a rush towards a crying out; the anti-climax see us slowly losing breath and consciousness and has the last drawn out words as a drone. They are representative of the machine (or the body as machine, beyond control) taking over the breathing for the speaker. That these moments can almost be expressed in the same language highlights the way that expressing ourselves in extremis leaves us detached from knowing something in the controlled present, however much that control may be illusory. Of course, tone and context have something to do with language and expression, but they act as a function of language because they are not separate from it.

‘Fukushima’ repeats the nonsense question: ‘Fukushima, isn’t that a mountain?’ or some variation on this. It functions by conflating a Japanese town that was hit by the 2011 tsunami (and specifically the nuclear power plant located there) with a fictional Japanese landmark. The poem is simultaneously metaphorical and literal and uses this to push the reader towards meaning. While it refers directly to the power plant (Fukushima Daiichi), it also keeps deferring from it and uses the disaster to explore other themes like the mother with cancer. It shows a refusal to accept the reality of a potential disaster occurring and how it rolls out of the international news cycle and therefore out of public consciousness (specifically a Western news cycle – I am unsure of the Japanese coverage).

The poem ‘Tonight’ explores the inadequacy of poetry: ‘an exact expression that can never be true’. It is about a specific moment in time. It is an expression of hopelessness that is inadequately (hopelessly) expressed. It opens with the line ‘poetry does no good’ and concludes:

tonight poetry does no good

tonight there is no good

no night

no there

The poem physically falls to its ending by finishing with four individual lines. The falling away of language represents the interior state of the protagonist in equal measure the language being used. The form expresses the meaning where language is failing. It is preceded by the line ‘meta metre meet her meater’, a play on the poetic function – the rhythmic and the sound play (homophonic) – of metre that trails off into a nonsense, another falling away. It does serve an aural/visual play, but it also reflects the state of the narrator and their inability to articulately express themselves. The inarticulate, however, contains its own articulation. This still sits at the heart of poetry as a form that demonstrates that, ‘the signified or meaning is *the whole process of signification itself*’ (Eagleton, 2007, p. 21).

Poetry also gave me the opportunity to explore what it meant to be ill, directly and indirectly. I was conscious of trying to make my writing accessible to a reader, including an audience beyond those who are unwell. As I have discussed previously, (when looking at the ideas in *The Wounded Storyteller* and *Writing As a Way of Healing*), I am writing as a poet foremost and a sick person subsequently. The relationship between my being ill and being a writer is complicated because I do embody my illness and so it is part of who I am, but illness is a subject I explore and not the reason I write. It has been the impetus for my switch to poetry, but it, in itself, is not the poetry. So I was not trying to just escape the illness in my writing practice – I was aware of making the work for a wider readership. One of my early drafts for a poem about my experience of being ill was called ‘Rats’:

Scratching and clawing

oil trails running down walls

asbestos lined playgrounds

and a diet of oranges

long teeth sink through dimpled flesh

they make holes and clean out the inside

please, my dear rodent friends,

come clean the disease from these arms of mine
they've hardened too much for me
to find them appetizing.

When they are husks then I will know
they cannot hurt me anymore.
They can curl up
white at the edges.
In the sunlight
they can
stop

Of course, it was re-worked at a later date, but it felt finished to me at the time. This was my first real attempt to write about my condition, using as metaphor the rats in the ceiling of the room in which I was living. The building was made of asbestos and they would leave oil trails on the external surfaces. They would also eat oranges and leave the skins to dry up in the sun. At the time, my forearms hurt and they were swollen and tight. In that context the poem works, but that narrow success is not what I wanted, even at that difficult point of my illness. I wanted to write poems for people to read, not just poems for me to excise emotion. The poem moves in the right direction, because illness invokes hopelessness and defeat (amongst many other things), and that is what I was feeling at the time. Cutting the first two stanzas would help significantly, but I was attached to them, not only because they are a description of where I was living, but also because the flesh on my arms resembled the skin of the oranges. I was trying to be literal which is much closer to the therapy aspect specified in DeSalvo's *Writing as a way of Healing* than it is to writing a poem for a public audience. Here is a subsequent re-working of the poem:

A plea to some rats

Come rodents,
eat this disease from these arms of mine
they've hardened too much for me
to want them.

Leave the husks
to curl up in the sun
white at the edges.
While my
life goes
on

This speaks to a broader context and is written like a poem from a poet who is sick rather than recording what actually happened. Illness still sits at the heart of the poem, but I shape it into the re-worked version, whereas illness seems to shape the original. The change was also a way for me to have more agency, and this is an important aspect of why I turned to poetry: to explore the illness and escape it. In the re-worked version of the poem I realise both these desires. In drafting I am able to write a heartfelt version that is literal and later develop it into a version that allows me distance. While the subjects of my poems vary, there is a consistent part of the collection that focuses clearly on illness, while still seeking to be accessible to a wider audience. To this end, Phillip Hodgins does an excellent job in his collection *Blood and Bone* (Hodgins, 1986). This work by Hodgins is a series of autobiographical poems about a man receiving treatment for cancer; hence the title. There are numerous examples of poems that speak of his illness and echo an understanding of an audience beyond the ill. Hodgins is not writing a diary. These are very measured words:

Room 1 Ward 10 West 23/11/83

Wordless afternoon
before my friends
for all their reasons
look in on me

They have time
to choose the words
they would
like me to hear

I am attached

to a dark
bag of blood
leaking near me

I have time
to choose the words
I am
likely to need

At twenty-four
there are many words
and this one
death

This poem is very direct, yet still careful. The short lines work in two ways: they suggest a taxing physical struggle, and to echo the poem's subject, that is the choosing of words, and the narrator's emotional struggle. The quietness of the 'leaking' blood and the gentleness of friends 'looking in' belie what it really means to be in Room 1 Ward 10 West on the twenty-third of November in 1983. Those parts of the poem are the lived experience, almost the drudgery (which has its own pain). But this leads to the one word sitting under them all – death. Furthermore, the poem shows an understanding of being on both sides of the illness. We can see that his friends are good people in their consideration of him, but that it will not really matter in the end. He seems to appreciate those friends, but still the larger issue dominates (of course).

'When I was six' is a poem that speaks directly about the experience of my illness. It starts from a memory of someone else dying and then moves to my mother's death. The poem takes a turn into the idea of what I 'wanted' it to be, 'this was supposed to be about wolves/and rope/and the lie of the lone wolf'. This wanting to escape the constant thinking about being ill is similar to Hodgins' idea, and suggests that my narrator is not in control of either the subject or how to present it on the page or, more accurately, his emotional state. The last stanza shows this, 'This was much stronger when I thought/it last night. Then/defeat felt a bit noble./Today it just feels sad/as it ekes the me out.' The poem refers to a specific defeat, by illness, but it suggests the wider experience of defeat and the personal and cultural

possibility of defeat as being courageous. This poem is about illness; it is about losing to it, but not only to this as defeat is part of the experience of living.

When looking at Frank's *The Wounded Storyteller* and DeSalvo's *Writing as a way of Healing*, I acknowledged their usefulness in encouraging personal narratives of illness, but, as I have argue, writing as a therapeutic form is separate from being a writer who is also ill. A writer can embody an illness and have that influence her or his writing (even so far as being the topic of the writing) but not have the writing be confined to illness, it is the latter that I aim for. DeSalvo cites a study by Pennebaker which is the basis for advocating a specific writing as a tool for healing, and Frank is advocates having our own stories told as part of treatment in the medical system. However direct and autobiographical my writing may be, and however far along DeSalvo's and Frank's aims my writing may travel, my intention is that it stands as poetry first (with all the demands that suggests) and everything else comes second.

The poem 'How the weekend began' is a good example of this. It is autobiographical, yet it still has a narrator outside of 'me', and the narrator is ill. The narrator embodies my life directly, but they are not me. The narrator in this poem does not have the same distance from the subject as the narrator of some of the other poems in the collection. This poem is about the look of the illness, what it does to the skin, and how a moment of noticing makes the disease 'real' again. The narrator is caught out in that moment, the way a glimpse of our body (in a mirror, for example) can catch us unawares because we live subjectively inside it. This poem asks for sympathy for the narrator without echoing a reciprocated feeling. It says 'this is my reality' and not 'this is our reality'. So it is personal in that the narrator is not reaching out to a specific wider experience, but, rather, showing a personal moment and inviting the reader in. It is still grounded in the universality of human experience, but it is an uncommon moment caused by a specific illness.

'Remind me' is written in the same way:

remind me to tell you sometime why I couldn't get up
without heaving myself and pushing
every joint through its motion

remind me to tell you sometime how I cried
in the dark by myself

remind me to tell you about the night when
autumn had finally arrived and the house lay open.
When I walked out from the shower, sat in my towel
on the veranda while the wind dried me,
and thought about the idea of never standing up

The construction of the poem reflects the subject. The three short stanzas give contained information that alludes to a more complex emotional landscape. The reader does not know why the narrator struggles to get up, or why she/he is crying in the dark, but there is a clear connection between those ideas and the concluding consideration of never standing up. The line breaks of the first two stanzas, breaking against sense, suggest the physical struggle being discussed, 'joint' calling attention to the particularity of that physical difficulty. In an earlier draft, it read as 'every single joint' but more restraint is achieved by omitting 'single'. While re-inclusion of 'single' would still work for the poem, the line is improved if the frustration and emphasis is implicit rather than explicit. Every joint, in this instance, is already every joint used in getting up. Having to push each joint 'through its motion' also puts the desire of the narrator at odds with her/his body – they are not working together with ease.

In order to avoid 'I cried in the dark by myself' undermining both the image and the poem by being cliché, the stanza begins with 'remind me to tell you sometime'. This creates a particular context for the direct emotional statement that follows, and it also defers/displaces that emotion, allowing it to have an impact without being cloying. The reader is then quickly taken to a new idea in the third stanza where the rhythm changes and the pace increases. The lines flow into each other and the reader is swept to the conclusion. The third stanza opens with the same words as the previous stanzas because repetition is a key device in this poem, but offers new detail about a specific incident. While the first two stanzas talk about 'why' and 'how' without detail, the third provides concrete information. The last line refers to the poem's opening (the difficulty of getting up). The word 'never' sits strongly in the last line, suggesting the inevitability of death and a sense of defeat.

A number of poems in this collection use a similar method of ending that relates to the experience of my illness. 'The Art of War' ends with 'Your body cannot help you./You must/go on/cry/let go.' 'When I was six' ends with: 'This was much stronger when I thought/it last night. Then/defeat felt a bit noble/today it just feels sad/as it ekes the me out.' 'Songs for the sick' ends on: 'Now leave us be, we are so very tired'. These poems do not end with a strength that resonates powerfully beyond the poem, yet they still seek to have an impact, a quieter reverberation. They do not point towards a triumphant moment, but, rather, towards a moment that shows a narrator who is weary and under siege and unable to reach any forceful conclusions. To let go might be brave, but it is not forceful in that it is an act of giving oneself over, losing one's autonomy. This speaks to the idea previously mentioned in this exegesis about acceptance, or even giving in, being a potential way of dealing with illness. Siri Hustvedt, previously cited on this subject, unpacks this further:

Our culture does not encourage anyone to *accept* adversity. On the contrary, we habitually declare war on the things that afflict us, whether it's drugs, terrorism or cancer. Our media fetishizes the heartwarming stories of those who, against all odds, never lose hope and fight their way to triumph over poverty, addiction, disease. (Hustvedt, 2012, p. 24)

The 'giving in' is a defeat in light of the tradition of fighting back against an illness, and these poems seek to engage with that idea beyond the brave face that people put on, and without the hyperbole that can surround the difficulty of handing oneself over to one's mortality. The way many of my poems conclude suggests the narrator's quiet desperation rather than suggesting there is a way out. The poems run out of steam along with the narrator. The use of 'eke' in the last line of 'When I was six' embodies what the defeat is doing to the narrator who is slowly being hollowed out.

While the title for 'Trying to get rid of a disease' directly signals the intent of the poem, the poem itself takes a more indirect approach to illness. Part of this is to do with the nature of poetry; the indirectness of poetry is helped by the strong association of the form with metaphor. Further to this, the title is unpacked through the body of the poem. To actually try to get rid of a disease consists of direct physical treatment, but illness spills over into all aspects of life because it is carried always and everywhere; there is no escape from it. This poem, like others of mine, refers to looking at stars, which is something I like to do. There is

also a reference to Japanese lore around a thousand folded origami cranes giving the maker a wish, something that also occurs in my poem 'Fukushima'. The cranes sit differently in this poem, with the narrator using them as a cynical device. 'In Japan a thousand folded cranes means a wish./I saw it in an advert'. At the same time, the narrator seeks hope from any source, whether it is the sky or a cross-cultural reference identified in an advertisement.

In 'Trying to get rid of a disease', I also deliberately interrupt the uniform font size to bring the reader closer to the narrator. There are two instances where a noticeably smaller text is printed: 'the light pollution of the city /obscures (Ifear) the fainter shooting stars' and 'because my cancerdeath mother was devout'. These two instances evoke the ever-present voice in the narrator's head and provide an insight into the narrator's emotional state. In the statement about fear, the small voice reaches out to confirm the narrator's interior state. It also serves not to overwhelm the indirectness of the narrative. If it were printed in the same font size as the rest of the poem, it would no longer be offered as a glimpse into the narrator, but constitute to a declaration. The words also run together – Ifear and cancerdeath. Doing this produces a quickness in the way they are read and is different to the instance a couple of lines later in 'smart people and theyI think no one's better/than anyone else'. The latter is an attempt for the speaker in the poem to acknowledge and express a close relationship between self and ancestry. It is not printed in a smaller text and attempts to collapse the distance between the individual and collective while making each visible, as the use of 'we' does not. I again try to work with this particular difficulty in the poem 'Apparently'. The main difference is that in 'Apparently' I am talking about the relationship of oneself to one's disease (how much it is 'embodied'). The third part to the poem is as follows:

To Lupus (An Aubade)

Every morning

by the smallest degrees

I ~~we~~ move more beyond your realm

physically

Emotionally I ~~we~~ are one.

And so I go (and go, and go)

Here again the pronoun is insufficient to show the relationship of being 'me' and having something (lupus) that is both part of that and separate. The sentences – and their sentiments

– demand a new way of expressing ‘self’.

Part two of ‘Apparently’ has a different visual wordplay:

Some dictionaries have given in and define literally as figuratively

now I lose out when I say

my body is literally coming apart

because instead of disbelief

it elicits a state of compassion

I literally want to kiss you

Is this the act or the desire?

y o u a r e c o m i n g a p a r t

god hates you

you hate you

The third last line expands to embody the idea of coming apart, but it acts in a more complex manner than this suggests. While it is a printed version of a word literally coming apart down the graphemes, it is also figurative because it is printed language on a piece of paper and a version of a literal act or, rather, a representation. This calls back to the 'literally' of the stanza preceding it. It is a signifier that acts in the same manner as its signification – pushing the relationship of the sign and signified closer together. It also serves to draw out the pace of the third last line. The reader is slowed into the act of the narrator coming apart (over time as the disease acts on the body). This part of the poem concludes with stark declarative statements (‘god hates you/you hate you’) their sharp concision highlighted by the slow line preceding them.

The poems in this collection, with two exceptions, do not follow any traditional structures or forms. This is intentional to a large degree because I write to the rhythm that I feel best embodies the poem. For that reason, line length line breaks end up being inconsistent. The aesthetic is part of that, but ultimately it is to instruct the reader on how to read the poems. 'Fukushima' is one long stanza, with the intention that it is read all at once as a series of thoughts spilling out from the narrator. 'When I was six' has four stanzas that vary in length without consistency. They are reflective of a narrator who is thinking in a meandering way and so at a slower pace.

Overall, I think the lack of formal poetry in my work is significantly related to the inconsistency in my life in both the symptoms I had that were constantly changing, and the uncertainty I had at times in regards to my future. The two notable exceptions in the collection are 'Tsunami' and 'Sonnet (for Charles)'. Tsunami is a haiku and I chose the form for its Japanese tradition. The Boxing Day tsunami of 2004 prompted me to write it and because we use a Japanese word to identify the act of nature I thought it best to use a Japanese form. 'Sonnet (for Charles)' is not a sonnet in the traditional sense, but plays on that fact to drive its meaning. It is still fourteen lines and has a rhyming couplet at the end, but the poem uses its failure to have a consistent line length or rhyme scheme to call itself into question.

There are other similarities in themes and tone throughout this collection, but, given the limitations of space in this thesis, I cannot cover all of these in this discussion. I came to write these poems as someone who was ill and, largely for financial reasons, needed to continue writing. There are other choices in diction and structure that could be discussed, but it is my intention they are addressed, indirectly, through the theorists and ideas presented throughout this exegesis.

Conclusion

This exegesis examines the change in my creative process as it relates to my illness. This is marked by the change from my unfinished novel to the collection of poetry presented here. I recognise that novel has maintained a significant presence in this thesis, and I believe that is because the shift from narrative to poetry can be viewed as a metaphorical representation of the wider changes in my life. I mentioned anecdotal theory in the introduction, specifically the diametrically opposed connotations that Jane Gallop lists. They are: 'humorous vs. serious, short vs. grand, trivial vs. overarching, specific vs. general' (Gallop, 2002, p. 2). While I have written this exegesis to reflect the idea of anecdotal theory that Gallop presents, I also see my poetry as functioning in a similar way. The poems examine the everyday and connect to the overarching; they are about specific moments, but they relate to the human condition. They also show the humorous aspects of serious themes. In this, I believe way the poetry also embodies anecdotal theory.

When I first started writing the poetry for this thesis I was unsure how long I had to live. The information I read indicated a five-year life expectancy would be a good outcome. It is fair to say that Wikipedia has been a thorn in the side of people having to mark undergraduate research papers, myself included, but one night in 2009, soon after being given an uncertain prognosis, it was also the place I learned some disturbing possibilities about scleroderma, possibilities that turned out (unsurprisingly) to be only partially true and without sufficient context. The doctor who gave me my initial diagnosis was careless with her words and not very informative. More broadly, this is a rare condition that can present and develop in a variety of ways. Nevertheless, and understandably, the diagnosis and prognosis affected me greatly. This thesis marks the journey I embarked on because of that diagnosis and the myriad ways it has affected my relationship to creative writing.

I switched from writing a novel about a past trauma to writing poetry about a current trauma. There was a pragmatic element to the change, but it became about more than that. The illness experience was immediate and, being lived in the present, I found a space in poetry to push language towards its expression. Derrida talks about the inadequacy of language to express our actual present because we are always deferred temporally from our thoughts through

having to use language, and he discusses the way signs function to defer us from meaning because their meanings lie in their difference to other signs. Poetry pushes hard at language and seeks to express meaning through a fresh series of significations.

The significance of this, not evident initially to me, was that I was able to better express my circumstances through the language that poetry made possible. Prose had worked well when I was reflecting on an event in my past, but it was not as effective for writing about my circumstances as they unfolded. It was more than just that the subjects I covered were different. The fundamental way the poetic form/s expressed my lived experience resonated strongly with me, and Derrida had provided an explanation through his inquiries into *différance*. Beyond the change of how I was using language in my creative practice, I also looked at the significance of my being ill as a writer. I turned my attention to others writing about illness, including work from poets and academics who wrote about their own or someone else's illness. The broad idea that seemed to underpin most of these pieces was an underlying message about the correct way to be someone who is ill. There are more varied and complex arguments that accompany this idea within the writing of the theorists that I have cited (Arthur Frank, in particular, explores some excellent ideas around the body and how we relate to it), but I chose the specific aspect of how writing creatively links to the idea of 'the correct way to be ill' because it had an immediate bearing on me. Louise DeSalvo and Gregory Orr relied on the scientific study conducted by James W. Pennebaker, and through this advocated for a correct way to engage with illness through writing. Susan Sontag wrote to champion the unwell in a sea of misinformation, but she still talked about the right way to engage with illness.

Some weeks I had almost no pain; other weeks I had to find the motivation to get out of bed, knowing I would be in pain most of the day. This ebb and flow powerfully affected the nature of my creative work in the way it deals with illness and defeat, and the way it examines other aspects of the lived experience beyond being ill. Of course, I am by no means the only writer to struggle with this. Leaving aside the problems I had with the conclusions drawn in the book *Orwell's Cough: Diagnosing the Medical Maladies and Last Gasp of the Great Writers*, there is still a list of famous writers in the book who suffered health problems, including: Shakespeare, John Milton, the Bronte sisters, Herman Melville and George Orwell, among others (Ross 2012). Through the range of their work, they significantly contribute to the assertion that an author is more than just their illness.

Yet their illness still feeds into their work, much the same way my illness fed into my work. Avoiding writing about my illness was still a direct result of having an illness to avoid and you can see the effects of this in part one of the poetry collection. The only direct writing about illness in that section is in my poem 'A plea to some rats'. In Part ii there are a number of poems that directly address illness. I could not avoid the reality of my illness any longer and was expressing my experience through my poems. A shift comes again in Part iii, most markedly in the poem 'Apparently' which is a longer poem that has attempts a more sophisticated relationship with illness. All parts attempt to straddle to difficulty of being authentic and being relatable, but they are driven by the desire to have a connection with an audience rather than an expression of my illness (for the sake of healing or any other end). In this way they are from a writer who is ill.

This can be seen in the approach taken by Philip Hodgins. His collection of poems, *Blood and Bone*, is entirely about his (ultimately unsuccessful) battle with cancer. He writes poems beyond the literal experience to connect with a wider audience, but there is no denying his subject. Hodgins is writing directly about his experience of being ill, but he is still more than just his illness. He writes with highly developed technique and devices to illicit meaning to those who do not share his experience.

This thesis is exploratory. It does not offer answers, rather it questions the way we have come to interact with illness through creativity. This is explored through the work of creative writers like Philip Hodgins, or through the academic distance that looks at the process of writing, which happens in Arthur Frank's *The Wounded Storyteller* and Louis DeSalvo's *Writing as a way of Healing*. Others have examined the process via seeing a loved one struggle with illness, as evidenced in Joan Didion's *The Year of Magical Thinking* and Simone de Beauvoir's *A Very Easy Death*. For me there are no definitive answers to how illness and creativity intersect, but to the existing body of work I add my own lived experience.

Coda

I'm angry. Or maybe more confused than angry. Am I meant to be angry when I'm not dying from a disease? Or, more accurately, angry that I'm not dying from a disease? Which, of course, makes little sense. In season two, episode nine of Scrubs (Allan, Donovan, Goldman, Winston & Trilling, 2002) a patient sues a doctor because he finds out he has been cured and so he isn't dying anymore. He had prepared himself for death and now it isn't coming in his immediate future. Even though he was a fictional character, I like to think I have a good capacity for understanding people, but I always wanted him to simply be grateful and get on with his renewed life. When I was told I don't have scleroderma – or, more cautiously, I am unlikely to have it – I didn't know what to think. What I definitely do not have anymore are the symptoms that I was being treated under the diagnosis of scleroderma. Over the years I've had carpal tunnel pain, arthritic pain, muscular pain, exhaustion, nausea, body hair loss, swelling, itching and other symptoms. I've taken topical and systemic anabolic steroids, as well as a weekly dose of a toxic drug called methotrexate (used in chemotherapy) to suppress the immune system. These medications act against the symptoms. The disease itself is untreatable. It can be managed, but it can also attack one or more of the major organs and kill. A specialist once told me it was the kidneys you had to watch out for – that's what kills you. I have keenly been aware of my lower back since that consultation.

The culmination of my symptoms versus my medication came to a head in August of 2013. Methotrexate is a powerful drug that can prevent particular damage from an out of control immune system, but it can also cause other damage. For this reason monthly blood tests to measure various potential problems are required. In that July of 2013 my blood test indicated a liver function problem. I have tried to be brave while facing this disease, and overall I have functioned quite well, but I cannot face knowing the medical details of what is occurring to me. This might seem counter intuitive when I also believe that knowledge is power. Still, medical details about what is happening to me result in depression and emotional withdrawal. I become angry. I place my trust in the knowledge of my health care professionals because I recognise they have expertise that I do not, but also because I need them to filter the details for me. I cannot bring myself to fully confront those details. Even now, six months after the worrying liver function result, I have not investigated exactly what this problem was. The reading was outside the acceptable range. I stopped the methotrexate

immediately, as directed, and waited a week for another test. The liver function result was slightly worse.

At this point methotrexate was not the only possible problem as scleroderma can attack organs. I had a liver ultrasound. I was not even aware that they were checking for fatty liver, an indicator that my liver is in a very unhealthy state, until after the ultrasound. I started to think back over the recent months and the problems I had started having with methotrexate. I would have the drug on Thursday nights before going to bed. Fridays were starting to become hell. There are any number of reactions to the drug (the list of possible side-effects is extensive[†]), but nausea is very common. I had managed to avoid it almost entirely through my years of treatment. Then started struggling to think positively about Fridays. I work in a bookshop, and Fridays would find me standing behind a counter feeling lethargic and slightly ill, unsure of how much was caused by the drug and how much by anxiety about the drug. It was suggested to me that my nausea may be an indicator of liver problems – but my tests had always been stable until that July.

The decline of my overall health and increasingly severe symptoms through that July to August period ended with a diagnosis of hypothyroidism. My thyroid no longer functions, so I take a daily hormone replacement. I no longer take any other drugs to treat symptoms and I no longer have the physical effects of scleroderma that I was being treated for. Finding myself in this new state of health, I cannot help but revisit Susan Sontag's assertion: 'Illness is illness' (Cott, 2013, p. 25). Jonathan Cott interviewed Sontag in 1978 for a *Rolling Stones* article and, in 2013, a full transcript of that interview was published. Sontag made the above statement when she was talking about her writing of *Illness as Metaphor* and the objective she was trying to achieve in it. Sontag had 'undergone surgery and treatment for breast cancer between 1974 and 1977' (Cott, 2013, p. xvi). Her experience from this was the impetus for writing *Illness as Metaphor*. I want to explore this idea because my illness (as diagnosed and lived out by me) was not the illness my healthcare professionals and myself believed it to be.

Illness is illness.

[†] See Appendix

This statement is irrefutable in a literal sense and it seems to me to be the core of what the essays (including *Aids and its Metaphors*) were trying to achieve, but in trying to achieve its ends this statement limits the experience of illness too much. In the first chapter of *Aids and its Metaphors*. Sontag says, reflecting on *Illness as Metaphor*:

The purpose of my book was to calm the imagination, not to incite it. Not to confer meaning, which is the traditional purpose of literary endeavour, but to deprive meaning... I hoped to persuade terrified people who were ill to consult doctors, or to change their incompetent doctors for competent ones, who would give them proper care. To regard cancer as if it were just a disease – a very serious one, but just a disease. Not a curse, not a punishment, not an embarrassment. Without “meaning” (Sontag, 1991, pp. 99-100).

I think that the intention is wonderful, but it is also an idea I have experienced as impossible for a number of reasons, the overriding one being that illness does not happen isolated from all other parts of the individual's life. I do not think it is possible to live the idea of being a person who *has* an illness; instead, you are a person who *is* ill. It is always being done to your person and so is part of your lived experience (done to your person even when it is ‘your person’ doing it to itself, which is what happens with autoimmune diseases). I recognise this is slippery territory where we can end up thinking that people *are* their illnesses. Sontag rightly acknowledges and writes to resist this, but I believe she takes her point too far. ‘Illness is illness’ is too reductive and so are the calls for proper and correct care that spring from this premise.

Sontag’s statement may be less strident when seen in context. When Cott asks Sontag about the notion that ‘one is somehow responsible for one’s disease’ (Cott, 2013, p. 19), he cites a group awareness-training program developed by Werner Erhard called Erhard Seminar Training or est [the group prints its abbreviation in lower case letters] (Cott, 2013, p. 19). Irvin D Yalom identifies the main tenet of the philosophy behind this personal development course as the ‘assumption of responsibility’ (Yalom, 1980, p. 255). Yalom examines est against a broader context, but he gathers some quotes from participants of the est course that speak to the nature of Cott’s question to Sontag. He records:

One participant describes her recollections of the workshop in this manner: “When you are responsible,” Stuart [the trainer] thundered, “you find out you didn’t happen to be lying there on the tracks when the train passed through. You are the asshole who put yourself there.”

The theme of responsibility pervades every aspect of the training. In fact, if I were to sum up in a few words what I got from the training data it would be that we are each the cause of our own experience and responsible for everything that happens in our experience. (Yalom, 1980, p. 256)

While this shows the overarching relationship of est to personal responsibility, the philosophy did target specific aspects of people’s lives, including illness:

Most est graduates, when discussing their gains, emphasize, above all, the assumption of responsibility. One est graduate stated that people realized they created their own backaches, migraines, asthma, ulcers and other ailments.... Illness doesn’t just *happen* to us. It was remarkable to watch person after person get up and admit that they and they alone were responsible for their physical ailments. Once these people faced the experiences of their life honestly, their ailments vanished. (Yalom, 1980, p. 257)

Yalom also quotes a man being told he is responsible for his wife’s cancer. A trainer also ‘argues effectively’ about an individual being responsible for being mugged (Yalom, 1980, p. 256). The argument is not made effectively in fact, but that does not alter the context in which Sontag was writing; the notion of personal responsibility appears to have been popular at the time Sontag wrote *Illness as Metaphor* and *Aids and its Metaphors*. Cott frames his question in terms of est, but Sontag responds to the wider discourse on the topic, say ‘I’m very impressed by the fact that all these ways of thinking are so anti-intellectual – most of the people who are most impressed by the psychological theories of illness don’t believe in science’ (Cott, 2013, pp. 19-20). While Sontag does not name any other movements, they are implied through the use of ‘theories’. ‘Illness is illness’ seeks to speak against these movements and remove blame from the victim, but the question of what a victim is goes beyond just this example, and is worth exploring a bit further because it is part of what it means to be ill. I am not ill any longer, but was I a victim of my misdiagnosis? What implications are there in my work?

Just to be clear, before I proceed: blaming a victim is when we note/say they should/could have taken some alternative action/s in order to prevent finding themselves in their circumstances – even when others take the exact same actions and have different outcomes. We can take smoking as an example. While there is a direct link between smoking and lung cancer, those who smoke and develop lung cancer still deserve compassion and treatment, and there are people who smoke yet never develop lung cancer. There is also the deeper issue of what led them to smoke in the first place. While it is easy (and sensible) to say they should have stopped smoking for the sake of their health, life is more complicated than such statements suggest. This leads back to a particular aspect found in the books of both Louise DeSalvo (in *Writing as a Way of Healing*), and Gregory Orr (in *Poetry as Survival*). They both refer to studies performed by psychologist James W Pennebaker relating to the written disclosure of personal trauma and the positive effects of this disclosure on the health of patients (Orr, 2002, pp. 89-90; DeSalvo, 1999, pp. 19-25). DeSalvo notes that:

Pennebaker and Beall reached their landmark conclusion (later replicated by other investigators and confirmed in more sophisticated follow-up studies) that simply writing about trivial topics or only venting one's feelings about trauma or only describing trauma isn't sufficient to improve health. *To improve health, we must write detailed accounts, linking feelings with events.* [Their emphasis] (DeSalvo, 1999, p. 22)

Further to these follow-up studies, Pennebaker has also written several books on/related to studies in this area including: *Opening Up: The Healing Power of Confiding in Others* (1990), *Opening Up: The Healing Power of Expressing Emotions* (1997), *Writing to Heal: A guided journal for recovering from trauma and emotional upheaval* (2004). As noted in section 'Am I the Wounded Storyteller?' of this exegetical essay, both DeSalvo and Orr look to writing as a way of healing from their personal traumatic experiences. Pennebaker's cited studies do not specifically mention what illnesses were studied, but its conclusions (whether it was intended or not) have me beg the question, 'If I had expressed/purged traumatic experience, would I have become ill?' DeSalvo and Orr directly echo this question, however implicitly. When I was ill I was never offered any professional counselling as part of my treatment for my illness. I was aware of support groups existing, but never actively encouraged to attend. Some mainstream medical practitioners viewed the alternative medical

practices I sought with disdain. These are just some aspects of victimhood that exist in being ill within the Australian medical system for me.

The other side to this argument is: 'Is it victim blaming when there is evidence to support the fact that (knowingly) someone's actions led to their circumstances?' No one is actually saying that the people are to blame for their trauma, but are they to blame for not dealing with it? If they could, then they would have a better chance of healing. At what point are we responsible for our own problems? To be frank, this is a fraught argument with varying degrees of passion on either side and it is something I contemplated many times over my years of being ill. I find that it is too vast to unpack further here, but it is worth acknowledging as a person who ~~has~~/had an illness. I appreciate Sontag for trying to undo this, especially because no matter how personal it was for her, she inadvertently had to do it for all chronically ill people. But I do not think that it is useful to engage with opinions that espouse the 'right way to heal', no matter how factually supported they might be, because they often define healing in a naturalistic way. The problem with victim blaming is that it has emotional consequences, even when it does not intend to. Pennebaker's study feels very personal, even when viewed from the perspective of scientific research. I feel like I have to follow the study in order to heal properly. One could argue that the onus should be on the medical staff to employ the technique of writing out our traumatic experiences in order to heal, but ultimately the responsibility of being properly expunged of one's trauma falls back on the ill person. How deep must I trawl my traumatic experiences in order to be healthy?

In the context of est and its encouragement of victim blaming, Sontag's concerns about such blaming were, and remain, valid, but she goes too far when she talks about the 'healthiest way of being ill' (Sontag, 1999, p. 3) and the implications that spring from this about the 'right' way to live/die. There is a cost in this way of thinking that ignores aspects of the lived experience. A friend's father who refused to be treated for a terminal form of cancer because it would mean that he was very unwell and might get only a few extra months of life, but low quality life (as he saw it). It would mean a lot of pain and nausea. He chose to be lucid and relatively pain free so that he could enjoy his time with his family, and he only lived for a few months. His decision was right for him, but it is not right in an absolute sense. Perhaps a long and painful treatment process would have saved him, much like it did Sontag, but in his case (as in Sontag's) he would have been an anomaly. 'Illness is illness' is Sontag's wish to speak of illness in pragmatic terms and to dispel any alternative ideas people might have

about their illness/treatment, without acknowledging that others might choose to believe those alternatives and they have the right to do so.

Perhaps there is more to Sontag's fervour than an (as she sees it) impartial desire to free people from the ignorance and superstition surrounding illness. Statistically, she was not meant to survive her fight with breast cancer. She had a very advanced, aggressive tumour. She opted for extreme surgery and treatment. Even within that treatment, her survival is anomalous. She never seems to acknowledge this in her scholarly writing, or even in her discussions of her life. Her son, David Rieff, talks to this in his memoir about his mother:

I look back at my mother's struggles with breast cancer in the seventies, with the uterine sarcoma in the nineties, and, of course, with the MDS that killed her. For as the years went by, my mother began more and more to think of her survival not as a species of miracle, since the miraculous had no place in the way she thought, nor as an accident of faith or genetics, let alone as a statistical anomaly, but rather as a result of medical progress and also her willingness to have the most radical, mutilating treatment, which was something many people who subsequently came to see her for advice or referrals for their own cancers refused to do, much to her consternation. (Rieff, 2008, p. 38)

There seems to be an emotional distance between Sontag and her near death experience, and it is this distance that speaks to the very heart of the statement 'illness is illness'. While I experienced scleroderma emotionally, it appears I never experienced it physically. More accurately, because I may have a version of the condition, the physical symptoms that my doctors and I attributed to scleroderma were, apparently, due to something else. It was the experiencing of those symptoms that made me fearful for my life, and it was precisely the advent of those symptoms coupled with poor delivery of my diagnosis that led to my questioning how long I had to live and, consequently, changing the focus of my doctorate.

While it would be unfair and inaccurate to suggest that Sontag never experienced her illness emotionally, it might be equally unfair to say I never experienced scleroderma physically. There is evidence of Sontag's emotional experience, such as a diary entry where she states, 'I feel like the Vietnam War. My body is invasive, colonizing. They're using chemical weapons on me. I have to cheer', or, 'People speak of illness as deepening... I don't feel deepened. I

feel flattened' (Rieff, 2008, p. 35). Despite this, she presents a clinical view of illness in *Illness as Metaphor* (illness is illness) and expands on this idea in the late eighties when she writes *Aids and its Metaphors*. While she does an excellent job of dealing with the physical aspects of illness, I think that it is an eagerness to separate herself from the likes of Werner Erhard and practices such as est that led to her rejecting the emotional experience of illness. I can see why she might do this, but surely there are options between the two positions of est on the one hand and 'illness is illness' on the other.

To go back to Simone de Beauvoir's account of her mother's death, *A Very Easy Death* (1964) with my new state of health, she recounts that when her mother was diagnosed with cancer, her family and doctors kept the information from her mother. Sontag nods to the history of this practice in *Aids and its Metaphors* where she notes:

Although European and Japanese doctors still regularly impart a cancer diagnosis first to the family, and often counsel concealing it from the patient, American doctors have virtually abandoned this policy (Sontag, 1991, pp. 100-101).

By this definition, and based on the likely premise that I do not have scleroderma, I experienced my illness completely as a metaphor. The name of an illness I was given belonged to something else. What, then, does this mean for my creative work? This is the crux of the inquiry of this coda. The previous sections of this thesis are based on my life as someone who has a specific chronic illness. To be chronically ill is one thing, to think your life might end prematurely is another. There are many degrees within a chronic illness – factors such as level of and frequency of pain – that have an effect on the individual. I am not/no longer dying in the sense that, for years, I thought I was. I struggle to sit down and write poetry. Mostly I go out. There is no urgency in my desire to express the complexities of existing as a human. I can get out of bed and be active for sixteen hours. I think I am avoiding some of the emotional toll of being in the 'not dying' category.

When my specialist told me it may have just been a thyroid problem all along, she also said she would see if there were any previous tests done on my thyroid. I could not remember any. For months I was distantly angry that this had not been caught earlier. Even though I did not want bitterness, it remained as an undertone. I later found out it had been tested and

come back inside the acceptable range. My life and treatment have changed again, this time for better and worse, because of this most recent diagnosis. I am not exhausted. My mind feels clearer than it has in a long time, but it wants to be away from poetry and thesis writing. This is not born from a renewed lease on life, instead it is because to look at this thesis is to look at my illness. In a way this is a new shift in the way *différance* relates to me. I differ from being in the category of illness that I was (severe with potentially fatal outcomes), and consequently I am deferred still from wellness, but also from the way I was ill.

Illness is illness is a lovely sentiment that sought to eliminate blame, but I have found ‘the-experience-of-illness is illness’ to be equally true. In that sense my experience was metaphorical. Metaphors are not lies – they are a valid basis for comparison. It is strange to have lived the life of someone who for many years is sick only to find out that, in all likelihood, the diagnosis was a mistake. From here my relationship with my creative practice changes again, but my diagnosis and years of living with a chronic disease will always be a part of it.

And so the potential for that illness stays with me and I am cautious about being well. In some sense my current state could be expressed through the idea that, 'not-illness is illness' because my relationship to my health is measured against my experience of being unwell (even though it was misdiagnosed). While I have explored the difference between writing about illness and being a writer who is ill (and the intersection of this), the relationship of creativity and illness is very difficult to define. The inter-relatedness of living and expressing that experience makes it extremely hard to separate the elements.

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Appendix – Information sheet provided to me about methotrexate from the pharmacy.

METHOBLASTIN® TABLETS

Methotrexate

Consumer Medicine Information

What is in this leaflet

Please read this leaflet carefully before you start taking METHOBLASTIN.

This leaflet answers some common questions about METHOBLASTIN. It does not contain all the available information and it does not take the place of talking to your doctor or pharmacist.

All medicines have risks and benefits. Your doctor has weighed the risks of you taking METHOBLASTIN against the expected benefits it will have for you.

If you have any concerns about taking this medicine, ask your doctor or pharmacist.

Keep this leaflet with the medicine. You may need to read it again.

What METHOBLASTIN tablets are used for

METHOBLASTIN is used to treat severe psoriasis (a skin condition) and severe rheumatoid arthritis. It is only used to treat these conditions if other treatments have not worked.

It is also used to treat some types of cancers.

The medicine contains methotrexate, which belongs to a family of medicines called antimetabolites. It may also be called a chemotherapy medicine.

The medicine works by blocking an enzyme needed by the body cells to live. This interferes with the growth of some cells that are growing rapidly in psoriasis and cancer. In rheumatoid arthritis, this medicine reduces the overactivity of the immune system leading to less pain, swelling and damage to the joints.

Ask your doctor if you have any questions about why this medicine has been prescribed for you.

Your doctor may have prescribed it for another reason.

This medicine is not addictive.

It is only available with a doctor's prescription.

Before you take METHOBLASTIN tablets

When you must not take it

Do not take METHOBLASTIN if you have an allergy to:

- any medicine containing methotrexate
- any of the ingredients listed at the end of this leaflet.

Some of the symptoms of an allergic reaction may include:

- shortness of breath
- wheezing or difficulty breathing
- swelling of the face, lips, tongue or other parts of the body
- rash, itching or hives on the skin.

Do not take the medicine if you have:

- severe kidney problems

- lowered immunity due to diseases such as HIV/AIDS or due to other treatments
- blood disorders, including anaemia (low iron in the blood) and reduced number of red or white blood cells or platelets
- bone marrow disease
- severe liver disease
- stomach ulcers
- ulcerative colitis, inflammation of the bowel
- an infection
- an alcohol dependence (alcoholism).

Do not take the medicine if you are pregnant or trying to become pregnant.

Do not take the medicine if your partner is trying to become pregnant.

The medicine may cause birth defects if either you or your partner is taking it.

Do not take the medicine if you are breastfeeding.

It passes into the breast milk and may affect your baby.

Do not take this medicine if you are taking acitretin or etretinate, medicines used to treat psoriasis and other skin conditions.

Do not use METHOBLASTIN after the expiry date printed on the pack or if the packaging is torn or shows signs of tampering.

If it has expired or is damaged, return it to your pharmacist for disposal.

If you are not sure whether you should start taking this medicine, talk to your doctor.

Before you start to take it

Tell your doctor if you have allergies to any other medicines, foods, preservatives or dyes.

Tell your doctor if you have or have had any of the following medical conditions:

- kidney problems
- liver problems
- lung problems
- diabetes
- folate deficiency
- lactose or galactose intolerance (Methoblastin tablets contain lactose).

Your doctor may do tests to check your blood, liver and kidneys.

Tell your doctor if you have an infection or high temperature.

Your doctor may decide to delay your treatment until the infection has gone. A mild illness, such as a cold, is not usually a reason to delay treatment.

Tell your doctor if you or your partner becomes pregnant while you are taking or just after you stop taking the medicine.

The medicine may cause birth defects if either the male or female partner is taking it. Use a proven method of birth control, such as the contraceptive pill or a condom, while taking the medicine and for at least 12 weeks after you stop treatment.

If you have not told your doctor about any of the above, tell them before you start using the medicine.

Taking other medicines

Tell your doctor if you are taking any other medicines, including any that you get without a prescription from your pharmacy, supermarket or health food shop.

Some medicines and this medicine may interfere with each other. These include:

- aspirin and other pain relievers or anti-inflammatory medicines
- some antibiotics

- phenytoin, a medicine used to treat epilepsy
- sulfonylurea medicines used to treat diabetes
- diuretics, also known as fluid tablets
- probenecid, a medicine used to treat gout
- pyrimethamine, a medicine used to prevent malaria
- cholestyramine, a medicine used to lower blood cholesterol levels
- theophylline, a medicine used to treat asthma
- azathioprine, a medicine used to prevent transplant organ rejection
- amiodarone, a medicine used to treat heart disorders
- leflunomide, a medicine used to treat rheumatoid arthritis
- sulfasalazine, a medicine used to treat Crohn's disease, ulcerative colitis and rheumatoid arthritis
- retinoids, medicines used to treat skin conditions
- folic acid, a vitamin that may be present in multi-vitamin preparations (take your folic acid preparation on a another day of the week, separate from Methoblastin)
- some medicines used to treat cancers such as mercaptopurine, cisplatin, asparaginase
- methoxsalen, a medicine used with UV light (PUVA therapy) for skin conditions, such as severe psoriasis
- vaccines
- nitrous oxide anaesthesia
- packed red blood cells, blood transfusions.

Tell your doctor if you drink alcohol.

Alcohol may affect how well METHOBLASTIN works.

Your doctor has more information on medicines to be careful with or avoid while using this medicine.

Talk to your doctor if you are not sure whether you should be taking this medicine.

Taking METHOBLASTIN tablets

Important Dosage Instructions

Always read the pharmacist's label to check the exact dose and how often to take it.

The dose depends on the condition this medicine is being used for.

Make sure that you understand how often your doctor wants you to take METHOBLASTIN to treat your condition.

There are different doses for rheumatoid arthritis or psoriasis, and cancer. It is important not to take Methoblastin more often or in higher doses than your doctor has prescribed for your condition. Overdoses of methotrexate may cause serious illness or death.

If you are unsure about the dosage, ask your doctor or pharmacist.

Never take it more often than your doctor has told you to.

Your doctor will tell you how much to take and when to take it.

How to take it

Do not crush or chew the tablets.

Swallow the tablets whole with a full glass of water.

Rheumatoid arthritis and psoriasis:

- **Take the tablets ONCE A WEEK on the same day each week for rheumatoid arthritis and psoriasis.**
- Only take your dose on the day agreed with your doctor or pharmacist.

Cancer:

- **For cancer, take the tablets at the same time of day and only on the days specified by your doctor.**

- Taking the tablets at the same time of day will have the best effect. It will also help you to remember when to take the medicine.

How long to take it

Continue taking the medicine for as long as your doctor tells you to.

Ask your doctor if you are not sure how long to take it.

If you forget to take your METHOBLASTIN tablets

If you forget to take a dose, contact your doctor or pharmacist for advice.

Never take a double dose to make up for the dose you missed.

If you have any trouble remembering when to take your tablets, ask your pharmacist for help.

If you take too much (overdose)

Immediately telephone your doctor or the Poisons Information Centre (telephone 13 11 26), or go to Accident and Emergency at your nearest hospital, if you think you or anyone else may have taken too much METHOBLASTIN. Do this even if there are no signs of discomfort or poisoning.

You may need urgent medical attention.

While you are taking METHOBLASTIN

Things you must do

Tell your doctor or pharmacist if you are taking any other medicine.

Check your tablets very carefully each time you collect them from your pharmacist.

METHOBLASTIN tablets are made in two strengths. You should check to make sure that you are given the correct strength.

Wash your hands immediately after taking the medicine.

Drink plenty of water on the day you take the medicine.

The recommended daily intake is 8 glasses per day.

Keep all of your doctor's appointments so that your progress can be checked.

You will need to have regular blood and urine tests. Regular blood tests will show any abnormal effects of METHOBLASTIN on the blood cells and the liver. As you may not get symptoms of these problems, you must have regular blood checks. Your doctor may also want you to have some other tests.

Use a proven method of birth control, such as the contraceptive pill or a condom, while taking the medicine and for at least 12 weeks after stopping treatment.

The medicine may cause birth defects if either you or your partner is taking it.

If you become pregnant while using this medicine, tell your doctor immediately.

Tell any other doctors, dentists, or pharmacists who treat you that you are taking this medicine.

If you are about to be started on any new medicine, remind your doctor, dentist or pharmacist that you are taking this medicine.

If you are going to have surgery, tell the surgeon, anaesthetist or dentist that you are using this medicine.

It may affect other medicines used during surgery.

Things you must not do

Do not go out in the sun if possible.

If you need to be in the sun, use a 30+ sunscreen and wear a hat and shirt to protect your skin from the sun.

This medicine may make your skin more sensitive to sunlight. This means your skin may burn more quickly than usual. Some signs are:

- redness
- itching
- swelling
- blistering
- rash.

Do not use sun lamps.

Do not drink alcohol while taking the medicine.

Alcohol may increase the side effects of the medicine.

Do not stop taking the medicine, or change the dose, unless your doctor tells you to.

Do not start to take any other medicine before talking to your doctor or pharmacist.

Do not use this medicine to treat any other conditions unless your doctor tells you to.

Do not allow pregnant women to handle this medicine.

Do not give your medicine to anyone else, even if they have the same condition as you.

Things to be careful of

Be careful driving or operating machinery until you know how the medicine affects you.

It may cause dizziness, drowsiness or tiredness in some people. Make sure you know how you react to the medicine before you drive a car, operate machinery, or do anything that could be dangerous.

Carers and other people who handle the tablets should wear disposable gloves to avoid contact with the skin.

Pregnant women should not handle the medicine at all.

This medicine may cause harm to the unborn baby.

Because this medicine can reduce the ability of your immune system to fight infections, try to reduce the risk of infection. Maintain good hygiene. Some ways you can do this are:

- avoid people with infections if possible
- be careful when using a tooth brush, toothpick or dental floss
- be careful not to cut yourself
- avoid activities where you might be injured or bruised
- wear disposable gloves when cleaning, especially when cleaning up body fluid or waste
- dispose of gloves, rags or other items safely in a sealed plastic bag.

Side effects

Be aware that taking more than the exact prescribed dose can be dangerous.

Tell your doctor or pharmacist as soon as possible if you do not feel well while you are using this medicine.

This medicine may have unwanted side effects in a few people. All medicines can have side effects. Sometimes they are serious, most of the time they are not. You may need medical attention if you get some of the side effects.

Do not be alarmed by the following lists of side effects. You may not experience any of them.

Ask your doctor to answer any questions you may have.

Tell your doctor or pharmacist if you notice any of the following and they worry you:

- upset stomach, stomach pain, vomiting, nausea, loss of appetite
- headache, dizziness
- hair loss, nail changes, dark or light patches on the skin
- mood changes, depression or confusion
- ringing in the ears

- sore eyes, blurred vision
- increased sensitivity to sunlight
- unexplained weight loss
- tiredness or drowsiness
- weakness, difficulty moving one side of the body
- unusual or excessive thirst
- breast enlargement
- impotence or loss of interest in sex
- painful muscles and joints
- changes in menstrual cycle or unusual vaginal discharge.

The above list includes side effects that are usually mild.

Tell your doctor as soon as possible if you notice any of the following:

- headaches, shortness of breath when exercising, dizziness, looking pale - signs of anaemia
- bleeding or bruising more easily than usual
- seizures, fits or convulsions
- blurred vision, short term blindness
- difficulty speaking, writing or understanding language

The above list includes serious side effects that may require medical attention. Serious side effects are rare.

If any of the following happen, tell your doctor immediately or go to Accident and Emergency at your nearest hospital:

- persistent diarrhoea
- skin disorders, such as rash, ulceration, blistering; hives or itchy skin; infections
- chest pain
- dry, non-productive cough
- shortness of breath, wheezing or difficulty breathing
- swelling of the face, lips, tongue or other parts of the body
- mouth ulcers, sore throat, fever or chills - signs of infection
- pain or difficulty urinating, lower back or side pain - signs of a possible kidney disorder

- yellowing of the skin or eyes, light coloured bowel motions, dark coloured urine, generally feeling unwell - signs of possible liver disease
- blood in urine or bowel motions, black tarry bowel motions, black vomit, pin-point red spots on the skin - signs of internal bleeding or other bleeding disorders
- swelling and pain in the legs - signs of a blood clot in the leg
- fast heart rate, shortness of breath, sharp chest pain that worsens with deep breathing, or coughing up blood - signs of a blood clot in the lungs.

The above list includes very serious side effects. You may need urgent medical attention or hospitalisation.

Tell your doctor if you notice anything else that is making you feel unwell.

Other side effects not listed above may also occur in some people.

Some of these side effects can only be found when your doctor does blood, urine or other tests from time to time to check your progress.

Tell your doctor immediately if you notice any of the side effects even after you have finished your treatment.

The side effects of METHOBLASTIN may occur after you stop taking it.

After taking METHOBLASTIN

Storage

Do not store METHOBLASTIN or any other medicine in the bathroom or near a sink. Do not leave it on a window sill or in the car.

Heat and dampness can destroy some medicines.

Keep it where children cannot reach it.

A locked cupboard at least one-and-a-half metres above the ground is a good place to store medicines.

Disposal

If your doctor tells you to stop using this medicine or the expiry date has passed, ask your pharmacist what to do with any medicine that is left over.

Australian Registration Numbers

2.5 mg: AUST R 15418

10 mg: AUST R 15417

This leaflet was revised in March 2010.

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Product description

What METHOBLASTIN tablets look like

METHOBLASTIN 2.5 mg tablets are round, pale yellow tablets marked with "M 2.5" on one side. Available in packs of 30 tablets.

METHOBLASTIN 10 mg tablets are capsule shaped, pale yellow tablets marked with "M10" on the same side as the score line. Available in packs of 15 and 50 tablets.

Ingredients

Active Ingredient

- methotrexate

Inactive Ingredients

- maize starch
- lactose
- pregelatinised maize starch
- polysorbate 80
- microcrystalline cellulose
- magnesium stearate.

This medicine does not contain sucrose, gluten, tartrazine or any other azo dyes.

Supplier

Pfizer Australia Pty Ltd

ABN 50 008 422 348

38-42 Wharf Road

West Ryde NSW 2114

Australia

Toll Free number: 1800 675 229

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