

**'The Great Dread of our Age':
Reading Alzheimer's and the Gothic.**

Anthony George Austin

Diploma in Social Administration (University College, Swansea)
Diploma in Applied Social Studies (London School of Economics)
B.A. Hons (Cardiff University) M.A. (Cardiff University)

A Thesis Submitted in Candidature for
The Degree of Doctor of Philosophy

Cardiff University
March 2011

UMI Number: U584537

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



UMI U584537

Published by ProQuest LLC 2013. Copyright in the Dissertation held by the Author.
Microform Edition © ProQuest LLC.

All rights reserved. This work is protected against
unauthorized copying under Title 17, United States Code.



ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

**This thesis is dedicated to my family – Rita my wife,
Paul and Sarah my children, and Tomos my grandson.
Also to the memory of Philip and Nessie Hopkins
who first set me on the path.**

Contents

Introduction	1
Chapter 1 Alzheimer's Disease and its Cultural Impact	5
1. Introduction.....	6
2. Late Twentieth-Century Concerns.....	11
3. Nineteenth-Century Concerns.....	23
4. Evolutionary Biology and Heredity.....	35
5. Alois Alzheimer and Alzheimer's Disease.....	39
6. Modernism, Humanism and Posthumanism.....	46
7. Conclusion.....	55
Chapter 2 Alzheimer's Disease: A Gothic Pathology	56
1. The Idea of the Gothic.....	57
2. 'Monstrous Social Exclusions'.....	66
3. The Origins of Fear.....	69
4. Fear, Horror and Terror.....	72
5. Gothicity as Infection.....	79
6. Conclusion.....	85
Chapter 3 Aspects of the Private and the Public	88
1. Epidemics and Pandemics.....	89
2. Imaginative Dread.....	92
3. Biology and Old Age.....	96
4. The Public 'Life' of Alzheimer's Disease.....	97
5. The Private 'Life' of Alzheimer's Disease.....	110
6. Returning to the Body.....	117
7. Hiding and Revealing.....	125
8. Conclusion.....	132

Chapter 4	The Brutality of Fact and the Consolations of Metaphor	135
	1. The Brutality of Fact.....	136
	2. Fact, 'Truth' and Fiction.....	146
	3. Subjective 'Realities'.....	150
	4. The Language of Illness.....	156
	5. Metamorphosing Monsters.....	162
	6. Telling Alzheimer Stories.....	168
	7. Conclusion.....	173
Chapter 5	Buried Alive: Mourning, Gothic Images and Dying Words	175
	1. Buried Alive.....	176
	2. Mourning the Loss of Self-Possession.....	189
	3. Mourning, Melancholia and Alzheimer's Disease.....	202
	4. Exclusion and being Buried Alive.....	206
	5. Conclusion.....	213
Chapter 6	The Struggle between Memory and Loss	216
	1. Bearing Witness.....	217
	2. Pathography as Memoir.....	221
	3. Forms of Representation.....	226
	4. Memory, Loss, Metaphysics and the Supernatural.....	239
	5. Ghost Writers.....	245
	Bibliography	248

Summary

Dementia, particularly Alzheimer's disease, is a defining characteristic of ageing today. Its confusion, disorientation and loss of memory provoke anxiety, dread and fear and its increasing incidence has led, in turn, to a growth in its representation across a variety of literary, cultural and other forms.

This thesis examines Alzheimer's in contemporary cultural and theoretical terms through a reading of a diverse range of texts, arguing that such material can be best viewed through the prism of the Gothic, and that Alzheimer's is informed by Gothicity, rendering Alzheimer subjects and their social world in a posthuman space. Several interrelated themes run throughout - body and mind; psychological and social loss; notions of fear, terror and horror – all addressed by means of theoretical paradigms drawn from psychoanalytic, postmodernist and poststructuralist thought.

Chapter 1 considers the contemporary cultural impact of Alzheimer's disease and, adopting an historical perspective, locates present-day anxieties in nineteenth- and twentieth-century cultural practice. Chapter 2 posits Alzheimer's as a Gothic pathology, profiling Gothic fiction and its contemporary criticism. Chapter 3 contextualises Alzheimer's in private and public spaces.

Chapter 4 sets out the use of metaphor in cultural representations of disease and illness and is followed, in Chapter 5, by an exposition of Gothic imagery and the language of Gothicity in Alzheimer's. The thesis closes, in Chapter 6, with an analysis of imaginative writings about Alzheimer's in contemporary fiction. Extensive reference is made throughout to biography, memoir, poetry, public papers and official reports.

The disintegrating personal and social realms of Alzheimer subjects scarcely feature in representations of dementia in the disciplines of medicine and science. This thesis is the first full-length attempt to fill such a gap and to demonstrate how the Gothic can advance and enrich the understanding Alzheimer's in the contemporary world.

Acknowledgments

This thesis would not have been contemplated and certainly not completed without the practical, emotional and intellectual support of my wife, Rita, who completed her own doctoral work 35 years ago. Knowing the rhythms of the long haul, she withstood all my more gloomy moments and with her usual positive attitudes kept me going. Without her support none of the words written here would be read by others.

There have been many who, over the years, encouraged me into higher education. Two, at either end of my working life, should be mentioned. Philip Hopkins, Warden of Fircroft Adult Education College in Birmingham, where I attended in 1960-61, persuaded me that I could succeed in university level education as a precursor to social work as a career. And Dr. John Pikoulis, at the Centre for Lifelong Learning, Cardiff University, where I attended as a prelude to retirement, encouraged me in a long-standing ambition to return to University and study English Literature.

I owe a considerable debt to Dr. Carl Plasa, my thesis supervisor. I first met Carl when I enrolled at Cardiff University for an undergraduate degree in 1995. His lectures on postcolonial literature were a pleasure to attend and made me curious to explore its notions of 'otherness' in the context of senility, dementia and Alzheimer's. Carl's consistent encouragement gave me the confidence to go on to postgraduate work, branching out from a M.A. with a postcolonial theme which he supervised, to this analysis of 'estranged otherness' which has led me into the realms of the Gothic. He has been a challenging presence in my late-flowering academic interests, testing my abilities to the full and pushing me onwards. I cannot thank him enough for never accepting anything less than his exacting intellectual standard required.

I acknowledge help from Sarah, my daughter, a civil servant, who has kept me up-to-date with public policy developments in health and social services. And Dr. Heather Worthington, a student colleague in 1995, who has gone on to make an academic career, has been a good friend and support over the years.

Finally, I wish to acknowledge and honour the care given by families in the Glamorgan valleys to their relatives suffering dementia, alongside who I worked as a social worker to plan and develop services. This thesis is rooted in their lived experience of Alzheimer's, and the excursion into strangeness of its critical and cultural inquiry has helped me to see their lived experience differently. If only I could have seen then, what I see now...

Tony Austin
March 2011

Introduction

Dementia, with Alzheimer's disease as its most common form, is on the increase within the United Kingdom. Whether written about or spoken, 'Alzheimer's disease' evokes a sense of dread: horror, terror and fear are popular tropes associated with stories about Alzheimer's and its effects and affects in contemporary fiction, popular media commentary, biography as 'pathography' and the so-called 'misery memoir'. Alzheimer's disease is a condition which primarily affects the elderly and, by 2015, the number affected by this disease will have almost trebled in less than twenty years. Faced as they are with the possibility of an exponential increase in expense to the public purse in terms of health and social care, it is not surprising that Alzheimer's disease is also a cause for concern to scientific researchers and public policy makers, whose work is itself not immune to infection by the popular tropes already mentioned. Caused by the gradual erosion of brain cells, Alzheimer's disease leads to a loss of memory, understanding, judgement, language and thinking, and it is primarily with the cultural and literary representation of this loss that this thesis is concerned.

The master narratives of biology and humanism determine the models of old age in their medical, social and economic paradigms, and these narratives have a long and influential history emphasising their powerful cultural effects. However, in their singular and joint dynamics, they cannot entirely resist or deny other narratives which propel different understandings about old age. Dissenting views bring to the surface some of the social contradictions in the master narratives, particularly in relation to our perceptions of disease in old age. For example, biology and humanism are foregrounded, only to be subverted, in Kelly Hurley's *The Gothic Body*, where she describes her main theme as 'the ruination of the human subject'¹ in the late nineteenth and early twentieth centuries. This thesis is a further

¹ Kelly Hurley, *The Gothic Body: Sexuality, Materialism, and Degeneration at the Fin de Siècle* (Cambridge: Cambridge University Press, 2004), p. 3.

excursion into strangeness, and has a similar, if ultimately different, theme to Hurley's text. It attends primarily to the ruination of the mind brought about by the neurological condition of Alzheimer's disease, with the prism of the Gothic summoned into use to view the way this disease is represented in contemporary western society, particularly with regard to the psychological and social constructions inherent in these cultural representations.

Traditional constructions of human identity are undermined by Alzheimer's disease as it insidiously enters the brain to destroy one of the brain's primary attributes - memory. The aesthetic of the Gothic also subverts these constructions so as to delineate the limits of reason and the power of the body, both of which foreground vulnerability to the influence of others. The genre of the Gothic has traditionally shown a horrified fascination with madness as an example of the limits of reason, as also with the terrifying prospect of not having the power to choose reason above non-reason. Such concerns highlight the power of the body and the difficulty of defining a clear boundary between sanity and insanity. Steven Bruhm argues that 'the Gothic graphically renders the body as violently attacked and in excessive pain'² and this notion puts the body not in a sentimental humanistic position, but a posthuman one, without agency. It is precisely because Alzheimer's disease construes its subject as both present and absent, leaving the body in a complex sphere somehow suspended between singularity and generality, that notions of the abject and the posthuman best articulate the private and the public filling of that space with images of abandoned bodies released from anchoring minds.

This thesis argues that Alzheimer's subjects become fear itself as their inner life disintegrates and a dislocation and a fracture of their psychological self becomes apparent. Thus is a psychological structure presented which lends itself, wittingly or unwittingly, to

² Steven Bruhm, 'Gothic Body', in *The Handbook to Gothic Literature*, ed. Marie Mulvey-Roberts (New York: New York University Press, 1998), pp. 267-268 (p. 267).

Gothic language and imagery and, given that the Gothic acts as a repository for our social fears and ills, it is the contention of this thesis that the diverse variety of texts produced in contemporary society concerning old age and dementia possesses a family resemblance to that genre. Alzheimer's disease has become the most representative phenomenon associated with old age, and the condition, probably due to its psychological effect of transforming the human into the posthuman, is open to a dark and metaphorical language reflecting social anxieties as well as personal fears. In this respect, the thesis argues that the subjects become in themselves a kind of metaphor. In other words, materiality substitutes for the embodied self. The self's involuntary retreat, a voyage into the deep space of the body, is a metaphoric understanding of the effects of this increasingly common condition. That this process and its consequences are terrifying and horrific is perhaps understandable given modernity's emphasis on the integrity of the self and the supposed choices and freedoms of action - physical and psychic - that are available. Cultural historians such as Fred Botting and Neil Badmington argue that humanity was invented by modernity, and that to define this concept it had to be held up against a difference. For Badmington this difference can be viewed through the paradigm of posthumanism, and, for Botting, through the notion of monstrosity, both of which might be construed as humanism's darker shades.

It is the idea of difference and how it is represented which is important to this thesis. The term 'Alzheimer subject', or the person subject to Alzheimer's, is used in its postmodern sense to suggest, as David Punter puts it, 'a kind of unificatory power and powerlessness'.³ In other words, a subject in process from being one to becoming another as the condition decentres meaning, the notion being that the immediate identity is processed by the disease - is subjected to Alzheimer's, as it were. The disease, it is argued, signifies the idea of

³ David Punter, *Metaphor* (Abingdon: Routledge, 2007), p. 48.

precedence - someone going on before, ahead, creating a gap - the mind going before the body and leaving a gap between the two that is filled with fears and apprehensions that mobilize the Gothic mode.

Andrew Balfour asks the question ‘how do we think about something we may rather not know about?’⁴ If something is so terrifying that we find it problematic to face, the paradigms of psychoanalysis, within which Balfour’s question is often the opening gambit, suggest we might have to say we resort to the process of projection and displacement to keep the terrifying at arm’s length. This thesis argues that we tend to use the dark language of the Gothic to contemplate a deconstructing disease - one that is always at work within - to balance out our personal fears and social anxieties. However, these forms of psychic defence or evasions are not always easy to achieve, as psychological haunting is a powerful emotion indicating that the dark flaws of whatever it is we call our nature are not to be complacently transcended. If art, as is traditionally argued, is, in its many guises, the human way to contemplate this projection and displacement, then it seems appropriate to explore the forms of fiction, biography and memoir to consider our paradoxical concerns about old age and the loss of capacity Alzheimer’s disease brings in its wake.

⁴ Andrew Balfour, ‘Facts, Phenomenology and Psychoanalytic Contributions to Dementia Care’ in *Looking into Later Life*, ed. Rachel Davenhill (London: Karnac Books, 2007), pp. 222-247 (p. 222).

Chapter 1

Alzheimer's Disease and its Cultural Impact

The great dread of our age is the insidious onset of Alzheimer's disease. The inexorable loss of the very memories that constitute our individuality, our personhood.

Steven Rose

Descartes ... arrived at a new and remarkably influential account of what it means to be human ... Rational thought, quite simply, makes humans human ... Reason not only grants the subject the power of judgment; it also helps 'us' to tell the difference between the human and the non-human.

Neil Badmington

Gothic spaces are simultaneous spaces of being and of self-destruction, resulting in the creation and destruction of the social other.

Steven Bruhm

What particularly fascinated me, because of my interest in the biology of memory, was the possibility that psychotherapy, which presumably works in part by creating an environment in which people learn to change, produces structural changes in the brain and that one might now be in a position to evaluate those changes directly.

Eric R. Kandel¹

¹ Steven Rose, 'Forgetfulness of Things Past', *Guardian*, 29 April 2004, pp.4-5; Neil Badmington, 'Introduction: Approaching Posthumanism', in *Posthumanism*, ed. by Neil Badmington (Basingstoke: Palgrave, 2000), pp. 1-10 (p. 3); Steven Bruhm, 'Encrypted Identities', *Gothic Studies*, 2 (2000), 1-7 (p. 4); Eric R. Kandel, *In Search of Memory* (New York: W.W. Norton & Co., 2006), p. 367. Rose's work concerns the biological processes of learning and remembering, and his research as a neuroscientist is focused on new treatments to counteract Alzheimer's disease and the loss of the human. As such it relates to Badmington's interest in the concept of posthumanism in Western culture, which, it is argued in this chapter, has an association with what Bruhm calls 'Gothic spaces'. Kandel's text relates to the interaction between biology and the environment and their influence in both the private and public arenas. Culture and its practices are encompassed by these epigraphs which broadly frame this first chapter in a reading of Alzheimer's disease.

Introduction

Alzheimer's disease is a neurological condition understood primarily to be caused by structural and chemical changes in the brain creating the loss of brain cells. It is, therefore, considered to be a condition of the brain rather than the mind, a neurological problem rather than a psychiatric one, although it can be accompanied by forms of mental illness such as depression. It is usually indicated to be present when the patient demonstrates several types of symptoms: loss of short-term, and, subsequently, long-term memory; confusion; mood swings; and impairments in language and social functioning. These symptoms commonly anticipate a slow deterioration of mental and physical abilities and tend, in the main, to affect people in the post-sixties age group. Alzheimer's disease is the most common form of senile dementia, afflicting about 62% of the total number of 700,000 subjects in the United Kingdom (a figure now revised, as referred to further below), but its primary cause, as Sherwin Nuland points out, 'has continued to elude scientists since the problem was first brought to medical attention in 1907'.² At the time of writing, there is no absolute test to signify the presence of the disease. It is usually diagnosed during a person's lifetime solely in clinical terms, and even though brain scans are now a common diagnostic tool increasingly used by medical practitioners, they are not commonly used in the diagnosis of various forms of dementia, which diagnosis is confirmed only following autopsy, and even autopsy is not necessarily a regular practice.

Although Alzheimer's disease as a syndrome has been known for more than a

² Sherwin Nuland, *How We Die* (London: Chatto and Windus, 1994), p. 91.

century and forms of dementia for very much longer, its symptoms and effects, including the fragmenting and transformation of identity, suggest a disease which can be tellingly comprehended by means of concepts drawn from a postmodern vocabulary or world view.

The diagnosis of the disease, as Rose's epigraph above suggests, signifies the presence of a developing absence; the progression of a disease which establishes a regression, creating, as it were by appropriation, a fiction out of a fact. In other words, loss of memory, language and functional ability leaves a material fact, the body, without the self-conscious awareness that is assumed, conventionally, to drive it and give it meaning. The epigraph also characterizes the notion of dread in terms of an insidiousness of loss, a kind of erosion of the fullness of being. This fullness relates to a quality of memory which, from Rose's point of view, establishes the idea of self because this quality shapes the history of our minds. The logic of such a view is that memory captures past and present while encompassing an idea of the future, thus establishing the self in time and space, with the loss of such bearings leaving the subject in a kind of void. Configured in this way, the corporeal presence - the body - is a continuous remembrance of a human to whom there once was, and still is, an attachment: a hideous relic of what has been lost. This Gothic image of the hideous memento that is somehow out of time, encompasses a material and experiential reality affecting many thousands of elderly people and those who care for them, and suggestively echoes Badmington's epigraph of a subject losing specificity as a human being once form separates from matter. It is a

disease with an authentic sting, as banal as it is horrible in its theft of human dignity.

Rose's epigraph also implies a divide between the body and the mind's self-consciousness and a dread of the former by the latter. It further suggests that the disease is far more than a singular or personal event by declaring it to be 'the great dread of our age' as the disease creates unguarded emotional responses and the mind shifts from structured to unstructured forms, thus evoking Charles Wright Mills' maxim of private ills being transformed into public issues.³ If the continuity and linearity of memory is interrupted, it becomes a cause not only of personal, but also of public concern and, as the condition becomes widespread, a dynamic interaction between the personal and the public comes into play, a dynamic which will be explored in Chapter 3. The subtext of such an interaction is that the depredations of nature are perceived to be susceptible to public intervention and not simply to be endured in private. But this seemingly optimistic public intervention is often coloured by subversive fears represented in both public and private language as illustrated in Rose's epigraph. Its dark images which reference something threatening and growing within that will eventually consume all before it offer no hope, lifting the veil on a further level of language exposed when faced by such fearful expectations. It is the exploration of the private and public language representing this disease which inhabits the centre of this thesis.

The third epigraph suggests another form of interjection in the discourse of Alzheimer's disease and its cultural impact in that it announces a point of view

³ For a fuller elaboration of these points, see Charles Wright Mills, *The Sociological Imagination* (New York: Oxford University Press, 1967).

about the condition as a kind of infection, thereby making use of one of the popular motifs of the Gothic genre. The Gothic space, suggests Bruhm, is a space within which such infections destroy selves and erode others' identities. In other words, private space is invaded by a disease which transforms identity.

Characteristically the Gothic genre also references terror, horror and notions of monstrosity in both a singular and general sense, all this expressed in a language dark in its sensibilities. The Gothic genre, therefore, is one in which these characteristics relate to matters and events concerning loss, inscribing this loss in what Steven Bruhm calls 'a proliferation of language that borders on obsession - compulsion'.⁴ Michel Foucault, cited by Botting, argues that the genre is exemplified by an excess of language, a fulsomeness which tends to indicate that:

The language of terror is dedicated to an endless expense, even though it only seeks to achieve a single effect. It drives itself out of any possible resting place.⁵

It is not just an excess of language which defines the Gothic; the definition relies heavily on what is stimulated by the Gothic. Terror and horror, which will be considered in the following chapter, are an excess of remembered feeling summarized in Botting's idea that 'Gothic atmospheres ... signal the disturbing return of pasts upon presents'.⁶ Such ideas are also arrived at through a language which alarms that present, a disturbance creating a sense of unrest or excitement, the twin motifs of the genre. The language of loss, often used by Alzheimer subjects and those who care for them, can also be perceived as the language of terror and horror at the prospect of losing a sense of self. As the second epigraph

⁴ Bruhm, p. 1.

⁵ Fred Botting, *Gothic* (London and New York: Routledge, 1994), p. 1.

⁶ Botting, p. 1.

points out, reason enables us to distinguish between what is, and is not, human, and it is the prospect of what is not human that suffuses the descriptive language surrounding those diagnosed with Alzheimer's disease.

The expressions of loss, horror and terror, aspects of the language of the Gothic, seem to emerge from images foretelling a slippage over the boundary of the rational to the chaotically irrational. If one of the ideas of the Gothic is that of excess, it is one which seems to contaminate the image of dementia as expressed by Rose. The apocalyptic nature of 'the great dread' and its fearsome insidiousness, which has within it notions of something lying in wait and seeking to entrap or ensnare, cunning and deceitful, creates images of something incipiently horrible. The disease is seen to menace the body as well as the mind, thus expressing the body's limitations as well as its mutability through the nature of the progress of the disease. The body and the mind are haunted by this movement, turning the subject into the phantom of a once-known identity, a suggestive memento. It seems that within the fabric of the Gothic the fragility and the vulnerability of the body is returned to the horror of the primary position, a body of instinctual feelings and emotional outbursts; a sort of pre- and posthuman condition of the kind explored in Julia Kristeva's *Powers of Horror* which also gives an emphasis to Botting's notion of 'Gothic atmospheres', and her work will accordingly be discussed in later chapters. Framed by these epigraphs, this chapter will examine representations of the neurological condition named as Alzheimer's disease within the cultural history that helped to construct both an understanding and a dread of the condition and the social concerns it has created.

Late Twentieth-Century Concerns

Late twentieth-century concerns with this 'great dread' relate predominantly to the growing volume of people living into old age and the attendant social and economic demands this creates on family structures, health and social care services and on the affordability of pensions. The elderly are seen as heavy consumers of such provision, and it was the twin pressures of a growing elderly population and the consequent demand on services which prompted the Audit Commission to carry out a review of public provision available to the elderly mentally ill, including those with dementia such as Alzheimer's disease - a particularly dependant group. The Commission reported in 2000, publishing a document titled *forget me not*,⁷ which elaborates a connection between private troubles and public issues by asking questions about what it considered to be society's responsibilities to meet the needs of the elderly and, as the report's title suggests, the desirability of recalling former selves destroyed by the condition of dementia.

The question which seems to emerge from this report is: is old age value for money? The question may seem to be heinous to those who belong to religious or humanist groups, as well as to many others of neither persuasion. But it is one that has been asked increasingly in a variety of texts at the latter end of the twentieth and early years of the twenty-first century; texts concerned with the social and health conditions of old age and the consequent socio-economic pressures on the working population, as well as imaginative texts of fiction, drama and poetry. If

⁷ *forget me not* (London: Audit Commission, 2000). A further report was published in 2007 by the National Audit Office, successor body to the Audit Commission, *Improving services and support for people with dementia* (London: National Audit Office, 2007).

there is a value in old age, culturally or otherwise, it is one that appears to be mired in social contradictions. Although there is a sense of congratulation in the way that progress in a range of services has extended expectation of a longer life, dependent old age, in particular, seems to create considerable social and economic stress for western capitalist societies. On the one hand, there are the moral and social demands of compassion aligned with arguments about social justice and human rights, while, on the other, economic self-regard and a distaste for dependency create a tension that seems problematic for the 'private' and 'public' to bridge.

It is not unusual for government or other official reports on public services to be marked by a sense of how the self unravels in the face of conditions over which it has little or no power, and the Audit Commission's report falls into this category, maintaining that 'the prevalence of dementia rises sharply with age, with the proportion roughly doubling with every five years up to the age of 90'.⁸ It goes on to state that '6% of the 75-79 year-olds, 13% of the 80-84 year-olds and 25% of those over 85 have dementia'.⁹ The statistics point toward a paradox and a stereotype: longevity is the successful outcome of better living and economic conditions as well as an improved medical science, yet it is often accompanied by the compromising risk of a diseased old age, which becomes transformed, in its turn, into the very stereotype of ageing. The Alzheimer's Society, a voluntary organization, suggests that there are three-quarters of a million people in the United Kingdom who have dementia and has estimated that this will increase by

⁸ *forget me not*, p. 10.

⁹ *forget me not*, p. 11.

another one hundred thousand before 2010.¹⁰ In a recent report, *Dementia 2010*, produced by the Health Economics Research Centre at the University of Oxford for the Alzheimer's Research Trust, the estimates for those directly afflicted by the condition has risen to some 820,000 in the United Kingdom.¹¹

The implication seems clear: as individuals live longer, so grows the risk of developing dementia as the population as a whole finds itself threatened by the burden of caring for the demented. Andrea Gillies refers to this demographic, in apocalyptic terms, as both an epidemic and a time bomb.¹² Indeed, history has described several periods of demographic pressure, underpinned by the notion of a 'natural' equilibrium of population, which has caused outbursts of moral panic resulting in the identification of groups who were thought to be problematic in causing such a situation. These groups became objects not only of fear but stereotypical constructions and *forget me not* may be construed as a late twentieth-century instance of such a panic and is indicative of a tension which a developing public awareness has created about more people living into old age and its consequent conditions. Time, it seems, is inhabited by the pathological and the language of the Gothic. If three-score years and ten can be considered the measure of God's time, an excess of it might be perceived as unjustified, indecent, unreal and even Satanic. And perhaps it is such possibilities that underscore the symptoms inhabiting this excessive time. Certainly, a return to a primary process

¹⁰ 'Thanks to you', *Alzheimer's Society Newsletter*, 19 (2004), pp.1-6 (p. 1).

¹¹ *Dementia 2010*, Health Economics Research Centre, University of Oxford, 2010.

¹² Andrea Gillies, *Living with Nancy, A Journey into Alzheimer's* (London: Short Books, 2009). Gillies' text describes the emotional and practical aspects of the care of her mother-in-law, who has Alzheimer's disease, against the background of an increase in the number of people suffering from the condition.

in bodies signaling their maturity may seem out of place and out of time, and, therefore, unnerving to others as well as frightening and disturbing to the sufferers themselves. The Audit Commission's description of the process of the disease implies that this return to the body is a kind of unravelling of the mind and the beginning of chaos: intellectual abilities released from anchor seem to return the subject to the pre-human. The higher cortical functions are undone and personality and behavior are no longer controlled by an ego, but left defenceless to the lower cortical instincts. It is these instincts that suggest Freud's model of primary process: a tendency toward an immediate discharge of feeling or emotion.¹³

The Audit Commission's report provides a descriptive account of the process of the disease as presently understood:

Dementia refers to a cluster of signs and symptoms of intellectual and cognitive functioning being disrupted, usually in a progressive way that cannot be reversed. They are also called organic mental health problems, as they are linked to major physical changes in the brain. Four levels or stages have been described, although they merge into each other and individuals will vary in the way in which their condition progresses.

- **Minimal:** where the person has some difficulty in recalling recent events and may mislay or lose things
- **Mild:** where the person's recent memory is very poor and they are sometimes confused or disoriented.
- **Moderate:** where the person is usually disoriented in time and place, and has difficulty in reasoning and or understanding. Sometimes they are incontinent and their emotional control deteriorates.
- **Severe:** where the person is totally disoriented, unable to communicate in normal speech, may fail to recognize close relatives, and is incontinent and completely dependent on others for personal care. Some people with

¹³ Sigmund Freud, *On Sexuality: Three Essays on the Theory of Sexuality*, ed. by Angela Richards, trans. by James Strachey, Penguin Freud Library, Vol. 7 (London: Penguin, 1991), p. 21.

severe dementia may be aggressive or violent to others.
As the dementia progresses, the person can become
immobile and totally physically dependent.¹⁴

In this descriptive account of the process of Alzheimer's disease, the flat administrative prose reminds the reader that it is an *Audit* Commission (deriving from the Latin *audio* 'to hear') that hears the slow, almost measured beats toward the subject's deterioration and dissolution of the mind, a kind of caressing affect inside the idea of insidiousness, as it becomes transformed into its own shadow, gliding ghost-like into a darkened future. What it hears and describes are the pathological outcomes of a disease process, but what it does not hear is what David Lodge calls 'the density of those events as consciously experienced'.¹⁵ Administrative prose carefully hides, or more accurately, veils that psychological experience and thereby avoids its cultural stress except through the arithmetic of what it means economically for public services. It does not seek to 'move' or 'transport' the reader's emotions, but to distance them, unlike works of literature, which 'describe in the guise of fiction the dense specificity of personal experience'¹⁶ and in which the reader may feel the thrill of recognition. But the text does precisely set out how the insidious and transformative nature of the disease emerges over a period of time.

The process is one of the unravelling of the idea of selfhood, a kind of unwinding from the psychological to the biological, a reverse of the usual path taken in personal development, which prompts one subject of the disease to call

¹⁴ *forget me not*, p. 9.

¹⁵ David Lodge, *Consciousness and the Novel* (London: Secker and Warburg, 2002), p. 14.

¹⁶ Lodge, p. 10.

the process one of 'joining a parade of horror'¹⁷ as he is cast off from the human. This idea is explored further in Chapters 2 and 3 through the work of Kristeva, which emphasizes the dark language of the Gothic through the abjection of the body into the symbolic. Personality, temperament and identity are harassed and attacked as the disease begins to bury history, leaving a body at the borders of past and future, existing in a kind of continuous present. The character formed by the disease is delineated through a process of becoming, arrived at through a process of unbecoming. The disease progresses as something secret, illicit in its growth, as the mind yields itself up to an incipient violence. Indeed, in its later stages, Alzheimer's leaves no room for what might be called the clutter of psychology or motivation, those interior niceties that are at the centre of psychoanalytic discourse and literary art. The condition at this stage seems to separate talking and thinking from action and behaviour, indicating that the subject can have no more meaning because it can no longer explore or question its humanity or mortality. Thought, language, questioning or writing are left to die as they are stripped away by the disease leaving something less than human in its wake, a characteristically Gothic predicament. The disease process, as outlined above in the Audit Commission's report, tellingly underlines the way the human is destroyed, its place usurped by the 'not-quite-human subject ... continually in danger of becoming not-itself',¹⁸ a movement that entails a threatening promise as it transforms the usual constructs of human identity to a condition of being fragmented and changeable.

¹⁷ Thomas DeBaggio, *Losing my Mind* (New York: The Free Press, 2002), p. 1.

¹⁸ Kelly Hurley, *The Gothic Body: Sexuality, Materialism, and Degeneration at the Fin de Siècle* (Cambridge: Cambridge University Press, 2004), p.6.

The weight of the incipient violence entailed in Alzheimer's alters the shape of the mind and the body. As cited earlier, Thomas DeBaggio likens the process of being diagnosed with the disease to 'the parade of horror created by Alzheimer's'. But if a return to a primary instinctual existence is perceived in these terms, it is often accompanied with a parallel view about old age in general. Simone de Beauvoir, for example, states that 'society's attitude towards the old is deeply ambivalent'. She goes on to assert 'economists and legislators ... deplore the burden that the "non-active" [have] laid upon the shoulders of the active population'.¹⁹ Similarly, Margaret Simey claims that 'to be old is by definition to be pitiable and poor, to suffer from irreversible decrepitude, to be doomed to go to the workhouse - or to "a home"'.²⁰ De Beauvoir argues that economists and legislators fail to recognize their own future and the need to insure against its depredations. It is a denial and a resistance - a failure to accept and understand mutability and time:

Nowadays we know that it is pointless to study the physiological and the psychological aspects separately, for each governs the other ... this relationship is especially clear in old age ... yet what is termed the individual's psychic or spiritual life can only be understood in the light of his existential situation: this situation therefore, also affects his physical organism. And the converse applies, for he experiences his relationship with time differently according to whether his body is more or less impaired.²¹

This Darwinian interplay between biology and environment is echoed in Tom Kitwood's study *Dementia Reconsidered: The Person Comes First*, when he claims that:

¹⁹ Simone de Beauvoir, *Old Age* (Harmondsworth: Penguin Books, 1985), pp. 8-9.

²⁰ Margaret Simey, 'How, and where, I found my independence', in *Getting a Life: Older People Talking*, ed. by Michael Simmons (London: Peter Owen Publishers, 2000), pp. 133-138 (p. 134).

²¹ De Beauvoir, p. 15.

The brain is now recognized as an organ that is capable of continuing structural adaptation, its circuitry is not static, as in a computer, but dynamic – slowly changing according to environmental demands.²²

The question that arises from these perceptions is how the contradictory social attitudes expressed in western societies affect the elderly. What Kitwood's statement, in particular, begins to suggest is that a condition such as dementia, once thought to be wholly explicable in biological terms of unremitting decay, might now come to be questioned, and that from somewhere in their buried history, subjects may yet be heroically rescued.

In the 1960s and 70s Ronald Laing, an existentialist psychiatrist, propounded the view that some people were sent mad by being placed in what he thought were untenable positions by a contradictory dialectical process. In other words, the person being sent mad was a repository of what might be called contradictory messages. Kitwood argues similarly:

I began to ask myself whether some, at least, of the symptoms [of dementia] that are commonly found might be due more to a failure of understanding and care than a structural failure of the brain. I discovered that a few people had indeed written along these lines, although their work was generally discounted or neglected.²³

Considering whether Alzheimer's is a disease of the brain or the mind, Jacques Maisondieu, a French psychiatrist, begins by examining the confusions which arise in the allocation of such cases between psychiatrist and neurologist. This leads him to the possibility that in some cases dementia may be more socially affected in its origins than medical science to date wishes to acknowledge. This is

²² Tom Kitwood, *Dementia Reconsidered: The Person Comes First* (Buckingham: Open University Press, 1997), p. 2.

²³ Kitwood, p. 3.

clearly not an argument that meets with much understanding or agreement in medical scientific circles, which consider the condition in entirely biological terms as opposed to environmental ones, even though its origins are still not known. Up until the latter years of the twentieth century psychiatric illnesses were classified into two major groups, organic illnesses and functional illnesses based on presumed differences in their origin. Such a classification, which dated back to the nineteenth century, emerged from postmortem examinations of the brains of those suffering from mental illness. But Maisondieu argues that:

Alzheimer's disease has become the nightmare of the third and fourth ages. This disease whose origin is so obscure has now an amazing dominance ... as against a radically biological Alzheimer's there is room for purely functional types which may in every respect look like the same thing. Between these two distinct poles the overwhelming number of cases of senility must be linked to mixed pathological types in which neurochemical lesions, psychic problems and social and linguistic difficulties are linked inextricably with the patient's reactions to his own ailments and with the reactions towards him by those around him.²⁴

On the surface this argument may seem no more than a plea for a more rigorous diagnostic process, involving not only neurology and psychiatry but other kinds of professional workers as well, but its primary message seems to rest with the idea that some of the origins of demented behavior may be found in dysfunctional social interactions, which gives emphasis to the importance of the environment.

But perhaps the clue to it being something more than this rests in the idea that the condition of Alzheimer's has 'become the nightmare of the third and fourth ages', indicating the power of biological medicine to provoke images of monstrous proportions. This telling 'nightmare', another motif of the Gothic,

²⁴ Jacques Maisondieu, 'Alzheimer's Disease: Disease of the Brain, or Disease of the Mind?' *Encephalie*, 5 (1999), 7-10 (p. 9), privately translated by R. H. Spencer.

suggests that de Beauvoir's arguments about the way old age is perceived as a kind of decrepitude, something to be largely ignored or put to the margins as a way of becoming blind to the wretched fate reserved for old age in a society which is only interested in the young, is a very persuasive one. And, if we are persuaded to see old age as burdensome and a kind of mirror-image of the erasure and loss of identity, as implied in *Maisondieu*, why not express despair in losing your wits? Such despair, according to Kitwood, would have its effects on the brain. The subtext of Kitwood's argument is that to reduce everything to matter is to ignore culture and its effects on that matter. Thus, it can be argued that the emerging message in the texts of de Beauvoir and *Maisondieu* concerns both the creation and destruction, in both medical and social cultures, of old age and its ravages. Old age could be construed in terms of the benign, the sagacious and even the active and engaged, but its predominant construction is affected by the anguish of dying, decrepitude and death. This anguish seems, in turn, to fill a space to create images redolent of the Gothic with notions of transformation bred through processes of corruption.

If it is culture that persuades people how to be old, then old age is not necessarily determined by biology: hence, identity need not be buried by age. No doubt the ageing body does become the focus of a discursive project as it is transformed into a site for medical science and its application. Neurological science, in particular, will seek to anchor the ageing and diseased brain in flat, sombre facts. Indeed, as Stephen Katz points out, the National Institute on Ageing in the United States of America has 'been instrumental in publicizing Alzheimer's

disease as a nationwide crisis' and continues by arguing that 'what is the AD movement if not the biomedicalization of senile dementia stripped of its social and economic dimensions?'²⁵ In the United Kingdom, however, as noted earlier, it was the economic consequences of Alzheimer's disease that influenced the Audit Commission's report. But Katz's concern with the social aspects of the disease emphasizes how the mind constitutes an elaborate means of thought and language through which a more imaginative process of being can be conjured and acts of resistance created. What Kitwood, among others, has attempted to do is to focus on 'the person, not the brain'.²⁶ In a sense, he returns old age, and in particular the elderly demented, to a kind of private sphere, thereby undermining the master narrative established by public science. His argument is an anti-reductionist one in which the care and sole treatment of the Alzheimer subject is around physical attention 'based on neurological determinism'.²⁷ Attention only to the body reduces the person to matter, and, alongside care of the body, it is cognitive functioning which needs to be both maintained and improved.

From his experience of working with people with dementia, Kitwood argues that 'the key criteria of personhood are ... subjectivity, relationship and agency'.²⁸ These criteria, as he readily admits, are highly valued in western societies, but would seem to be lacking in people diagnosed with dementia, thereby taking them outside of the human. But he and his colleagues 'place more

²⁵ Stephen Katz, *Disciplining Old Age* (Charlottesville: The University Press of Virginia, 1996), p.5. Katz takes the paradigms of categorization and classification from Foucault to argue against 'the disciplining' of old age by medical and social institutions.

²⁶ Kitwood, p. 3.

²⁷ Kitwood, p. 8.

²⁸ Kitwood, p. 8.

emphasis on feeling than on reason, and interdependence than autonomy'.²⁹

However, such constructions do not necessarily remove the Alzheimer subject entirely from the clutch of the body. Feelings arise from the somatic as well as from the stimulation of the external world and the notion of interdependence may well be a way of ascribing to the master narrative a desire to perceive old age as a stage of dependency. Feelings and interdependency may well be seen as something less than reason and autonomy, and more soft than hard in conceptual terms. Nevertheless, in Kitwood's paradigm they arise out of the continuing psychological needs of the Alzheimer subject underpinning his emphasis on the notion of personhood and the need to maintain identity in the face of a determining biology and the power of medical science. The paradigm invests in the residues of capability, and in the fragments of expression which relate to whole things. This point of view is subscribed to by Mike Hepworth:

Because the self is not a biological entity but a social construct, it is possible to explore the rich variety of ways in which biological changes can be accommodated in any personal life story. The master narrative of decline requires a single self going through a linear trajectory, whilst the portmanteau self is an active concept of ageing as self-narrated experience, the conscious, ongoing story of one's age identity.³⁰

This seems a paradigm which encapsulates Kitwood's philosophy and stands in manifest opposition to the primary concerns of de Beauvoir's economists and legislators in the late twentieth and early twenty-first centuries. These points of argument raise questions such as how much of the behaviour of the elderly can be accounted for by biology, and how much by language, culture, and thought? But

²⁹ Kitwood, p. 10.

³⁰ Mike Hepworth, 'In Defiance of an Ageing Culture', *Ageing and Society*, 19 (1999), 139-146 (p. 146).

such biological and social concerns do not emerge fully-fledged from the constructs of medical and social scientists of this period; on the contrary, they were clearly signposted in the classificatory systems characteristic of thought in the eighteenth and nineteenth century designed to control and regulate a rebellious nature.

Nineteenth-Century Concerns

Social concerns about older people in the community as portrayed in late twentieth-century reports may represent contemporary cultural sensibilities, but such concern should not be seen as a new phenomenon. Anxieties about an excess of population and the nature of that population, and about a return to the body, also marked the social and cultural milieu of the nineteenth century. In particular, a fascination with the mind and a fear of the body was apparent in nineteenth-century psychiatry, which wove a narrative around constructions of mental illness plucked from an inner and private life and thrust into the public arena.

Legitimacy for this narrative was sought by appropriating ideas and analyses from the natural sciences. It has been argued that the eighteenth century foreshadowed 'a dualism that has tended to denigrate the corporeal dimension of human life in favour of the intellectual and cognitive basis of human understanding'.³¹ This hierarchical structure presupposes both human and less than human aspects of our being that appear to arise out of a fear of the body: eighteenth- and nineteenth-century fascination with the mind had to acknowledge the body, but only as a threat to the mind itself, which had to discipline that threat.

³¹ Philip Hancock, Bill Hughes, Elizabeth Jagger, Kevin Paterson, Rachel Russell, Emmanuelle Tulle-Watson, Melissa Tyler, *The Body, Culture and Society: An Introduction* (Buckingham: Open University Press, 2000), p. 121.

Indeed, the dominant lesson of the history of medicine is that it has sought to learn from the body only in order to dominate it and put it in its place in a quest to confront and shape it: 'nature, including the body, has become something to be commanded and disciplined'.³² It is the embodied mind that is projected as commanding and disciplining each individual body, adopting both offensive and defensive strategies as it adapts to its surrounding mass. Later in the nineteenth century, such power was challenged by an evolutionary biology which suggested that the mind might never be entirely the master of its own survival unless it took steps to become the prevailing type which was generally understood as having the capacity to adapt to changing circumstances.

It was in these ways that nineteenth-century medicine constructed the body, working on the assumption that it was 'obedient to the laws of anatomy and physiology'.³³ This conception of the body as a biological and fixed entity, somehow outside of its cultural and historical context, inevitably defines the body as a passive instrument, but as the century progressed and theories of evolutionary biology became more contentious, a redefinition of this perception began to develop, culminating in the twentieth-century belief in the physicality of consciousness. This value structure, when applied to mental health, echoes both the rationalism of the Enlightenment and the discursive nature of the shaping of madness in nineteenth-century psychiatry.

Therefore, it may be argued that the construction of mental illness in this period arose out of opposed possibilities: did the condition result from a

³² Hancock et al., p. 2.

³³ Bill Hughes, 'Medicalized Bodies' in Hancock et al., p. 13.

psychological disturbance, or was it an expression of a material lesion?

Evolutionary biology, with its implied notion of inheritance, pointed toward the latter explanation as a cause of mental illness. However, it could not entirely move away from the necessity of the mind to shape the needs of the body in meeting the social concerns of an increasingly industrialized population. A mind prone to irresolution in the face of bodily demands meant, in the long run, a diminution of the 'quality' of the population. And such irresolution also suggested that the mind could fragment and thus require services that local and national institutions, such as Poor Law workhouses, would find difficulty in providing. It was ideas such as these which developed throughout the twentieth century, influencing medical science and a variety of its clinical practices.

It was Herbert Spencer who first explicated the principle of the survival of the fittest which emerged out of his concerns with evolutionary theories and his interest in their application.³⁴ Evolution was not a new idea as it had been a matter of discussion amongst naturalists and biologists from the late eighteenth century. However, Spencer's article in the *Westminster Review* in 1852 did anticipate some of the basic Darwinian principles of evolution such as the ideas that all organisms can produce more offspring than can survive to adulthood and that like breeds like; and that the best adapted variants are the most likely to survive. Writing in the tradition of Thomas Malthus and advocating moral restraint in the face of demographic pressures, Spencer initially extrapolated a principle of population control from the natural law of animal fertility. What Spencer attempted to

³⁴ Herbert Spencer, 'A Theory of Population Deduced from the General Law of Animal Fertility', *Westminster Review* (April 1852), pp. 468-501.

demonstrate from this law was the transformation of human life from a condition of uncontrolled instinctual impulse to one of self-regulation through the development of higher cortical arrangements arrived at via evolutionary processes.

This transformation from animal instinct to rationality, Spencer maintained, is exemplified in the human species by qualities of swiftness, strength and agility, together with instinct and intelligence. Spencer distinguished between these qualities as displayed in some species of animals, by invoking the more complex physiological and chemical make-up of the human nervous system and the brain which is at its centre. Both human and animal species have an instinct to survive, but human consciousness, arrived at through a highly developed nervous system, enables the human species to cultivate this quality to a higher degree and, in particular, to display a moral sense. Though framed within a scientific discourse, Spencer's paradigm could not veil its moral message:

In the nature of things, only those who advance ... eventually survive. For, necessarily, families and races whom this increasing difficulty of getting a living which excess of fertility entails, does not stimulate to improvements in production – that is, to greater mental activity – are on the highroad to extinction; and must ultimately be supplanted by those whom the pressure does so stimulate.³⁵

The structure of feeling evident here is predominantly one of fear, or at least anxiety, in the face of an excess of population of a type, mainly seen in the notion of the mob, whose behavior exemplifies lower mental activity suggestive of the monstrous. At various times in the eighteenth and nineteenth centuries, moral panics surfaced about demographic pressures. A growing urban industrial class

³⁵ Spencer, 'Theory of Population', p. 499.

brought into play the potential of the mob threatening the middle class with its unruly behavior. Spencer's representation of evolution and population control expresses a fear of the body, and of bodies that were out of control and potentially violent. The representation suggests a body in excess of itself and open to error. Spencer construed the mind, however, as the controlling mechanism for a channelling process of stimulation, one that could ensure that the body was denied. Clearly, the physical 'nature' of the body had to be outwitted by a regulatory mind, a mind that was influenced by a culture turned toward progress. Spencer's model, predating Freud, nevertheless resonates with the structure of the mind elaborated by the latter: ego and superego together smothering libido. Self-denial and self-help were characteristic of the nineteenth-century industrial and commercial middle class to whom Spencer primarily appealed.

It is Spencer's emphasis on 'the nature of things' which calls to mind the idea of biological evolution and materialism - an alteration, indeed a transformation of hierarchy whereby primary processes are shaped and disciplined by secondary ones. The fear of excess was, of course, a fear of instinctual life: a potential animal that required suppression and control, perhaps even a Gothic evolutionary image of unmanageable instincts. In his commentary on demographics, Spencer perceived excess of fertility as subverting progress and undermining the individual because excess produced an inadequate species which was unable to advance progress and was hence a burden to both itself and to society.

As noted earlier, Spencer's ideas pre-dated Charles Darwin's *Origin of Species* published in 1859, in which Darwin took a considered view of excess.³⁶ His theory of evolution by natural selection rested upon three axioms. First, like breeds like, with minor variations. Secondly, all organisms can produce more offspring than can survive to adulthood, and, thirdly, the best adapted variants are most likely to survive to reproduce in turn. Spencer's anxieties related to the notion of a demographic over-production and the idea that evolution could thus be transformed into dissolution; an inevitable carrying forward of a weight from the past to the future: some kind of possession determined in and by history from which there could be no escape except in death. Hence, inheritance became a primary factor in Spencer's notion of self-preservation:

Whilst, on the one hand, it cannot be denied that the increase of tissue constituting growth is self-preservation both in essence and in result; neither can it, on the other side, be denied that a diminution of tissue, either from injury, disease, or old age, is in essence and result the reverse.³⁷

Spencer invariably cast his arguments within notions of the inverse, seeking always a balance of forces in relation to progress which itself, he argued, rested on a balanced population:

Regarded from an abstract point of view, increased ability to maintain life in this case, as in all others, necessarily involves decreased ability to multiply.³⁸

Looking to the future, Spencer perceived a diminishing return in demographics with the 'best' prevailing, and the over-fertile dying away through ill-health,

³⁶ Charles Darwin, *Origin of Species* (London: John Murray, 1859).

³⁷ Spencer, 'Theory of Population', p. 478. Spencer argued that self-preservation of the species was its primary motivating factor, and, therefore, the species had to resist forces that undermined motivation.

³⁸ Spencer, 'Theory of Population', p. 478.

starvation and decrepit old age. In fact, like Malthus before him, he was opposed to state provision for such people, arguing that they should be left to charity and their own devices:

Those left behind to continue the race are those in whom the power of self-preservation is the greatest - are the select of their generation. So that, whether the dangers to existence be of fertility, or any other kind, it is clear that by the ceaseless exercise of the faculties needed to contend with them ... there is ensured a constant progress toward a higher degree of skill, intelligence, and self-regulation - a better co-ordination of actions - a more complete life.³⁹

The qualities of self-preservation, intelligence and self-regulation required a disciplined materiality and an active awareness of time. These qualities typify the liberal bourgeois humanism of the nineteenth century most characteristically illustrated in *Self-Help*, the work of Samuel Smiles, first published in 1859. In other words, the species had to be conscious of the past and its possible effects on the here and now so as to safeguard the future, lest dissolution threaten.

In material terms, Spencer's work described a central nervous system which featured integrative levels, the lower levels corresponding to more primitive functions. Man, with his higher levels, was said to be able to cognize, thereby demonstrating a more refined adjustment to his world than the usual fight-flight behaviour of animals. But the concepts of dissolution and degeneration became central tenets in nineteenth-century psychiatry. In particular, it was Spencer's model of the lower and higher levels of the nervous system which influenced the work of John Hughlings Jackson, a physician and neurologist, who gave considerable emphasis to theories of dissolution, arguing

³⁹ Spencer, 'Theory of Population', p. 498.

that the highest and most recently developed functions dissolve first in the disease process and begin the degenerative transformation toward the less than human.

Jackson maintained that mental illness was primarily the result of some kind of brain lesion, and, in neurological terms, produces an effect that is the reverse of evolution: 'dissolution is a term I take from Spencer as a name for the reverse of evolution'.⁴⁰ In the sense that evolution was reversed if principles of self-preservation were undermined or subverted by forces that damaged the nervous system, Jackson's and Spencer's ideas can be seen to express a mutual pre-occupation with what Kelly Hurley calls a 'prospect of the reversal of evolution' with its possibilities of producing traits in the human species which would prove to be dangerous.⁴¹

However, in perceiving dementia (and epilepsy) as two forms of damage to the nervous system, Jackson's analysis could also be seen as portraying evolutionary biology carrying within itself the seeds of its own destruction. But Jackson distanced himself from Spencer's tendency to apply Darwinian principles universally, seeking instead to focus Darwinian biological propositions on an examination of the nervous system alone:

Evolution is a passage from the most to the least organized; that is to say from the lowest, well organized, centres up to the highest, least organized centres; putting this otherwise, the progress [in the development of the nervous system] is from centres, comparatively well organized at birth up to those, the highest centres, which are continually organizing through life.⁴²

⁴⁰ John Hughlings Jackson, *Selected Writings of John Hughlings Jackson: Croonian Lectures 1884: Evolution and Dissolution of the Nervous System*, ed. James Taylor (London: Hodder and Stoughton, 1931), Vol. 1, pp. 45-75 (p. 45).

⁴¹ Hurley, p. 10.

⁴² Jackson, p. 45.

Jackson goes on to suggest that in the evolutionary process a kind of abnegation takes place materially:

The highest centres, which are the climax of nervous evolution and which make up the “organ of mind” (or physical basis of consciousness) are the least organized, the most complex, and the most voluntary.⁴³

The process of moving to something higher from something lower can be seen as a form of becoming through renouncing the latter for the former. For Jackson, this evolutionary biological becoming was a positive putting together of the nervous system: its negative opposite was the process of dissolution, what Jackson somewhat balefully called a ‘taking to pieces’.⁴⁴ For him, dissolution was:

A taking to pieces in the order from the most complex and most voluntary, toward the most organized, most simple, most automatic.⁴⁵

In other words, the higher cortical arrangements of the brain, those functions that control movement, speech, memory and judgement unravel, leaving the lower arrangements of the nervous system, our instinctual feelings and emotions, open to little or no regulating influence. There is a loss of intellectual functioning in voluntary language, and in logical and reasoned thinking, but there is retention of emotional, automatic language - that is, a language of the body expressing emotion. Jackson concludes his commentary on the evolution and dissolution of the nervous system by asserting:

The doctrine of evolution implies the passage from the most organized to the least organized, or, in other terms, from the most general to most special, ... there is a gradual “adding on” of the more and more special, a continual adding on of new

⁴³ Jackson, p. 46.

⁴⁴ Jackson, p. 46.

⁴⁵ Jackson, p. 46.

organizations. But this “adding on” is, at the same time, a “keeping down”. The higher nervous arrangements evolved out of the lower keeping down those lower, just as the nation controls as well as directs that nation. If this be the process of evolution, then the reverse process of dissolution is not only “a taking off” of the higher, but is at the same time “a letting go” of the lower.⁴⁶

The metaphor of the body politic is one that Jackson shares with Spencer and which echoes the relationship of mind and body. Jackson may concentrate on physiological features, but he makes clear the function or role of mind and body. The mind, fleshed somehow into the brain, is both subject and object to its surrounding mass. It is a consciousness aware of the potential invasion of the mass with all its attendant pleasures and dangers. Within the tradition of humanism, the inclusive compass of ‘normality’ constructs the ‘other’ with its horrific undertones. Spencer’s construction of a duality of mind and body, and Jackson’s primarily physiological model of the nervous system established the mind as a shield against the body, and in evolutionary terms the survival of the best as opposed to the worst of the human species. In psychoanalytic terms, the self’s fear of the body encourages the ego to establish protective forms, and one such defence, observed and noted by Freud, is that of sublimation, a psychological activity in which instinctual tension can be displaced on to objects which appear less threatening. When sublimation occurs, compulsive behaviour - repetitive behaviour - is evidenced against threats and fears.⁴⁷

Within the context of evolutionary biology, Spencer’s anxiety about repetitive behaviour, and the likelihood of its material transmission (‘genetic

⁴⁶ Jackson, p. 46.

⁴⁷ Freud, ‘On Narcissism: an Introduction’ (1991), p. 69.

inheritance' in today's parlance), indicates a fear of man's passage through time being determined by nature, rather than nature being controlled and shaped by man's history. Spencer and Darwin were central figures in the nineteenth-century conceptualization of history as a relation between parental and filial disposition. As the notion of inherited characteristics began to take shape, so the idea of the dependence of the mental faculty on the body's constitution or physical organization began to infuse medical science and the work of physicians such as Jackson. Instances of mental illness provided the most well-known examples to support such beliefs, especially when juxtaposed against cases of 'normal' or positive moral traits evident in families. In his mapping of the body and its responses to the outer world, Spencer's commentary on moral traits argued 'that an impure blood is ... a possible, and indeed, a probable cause of mental illness', and in considering that the blood could be contaminated by the smoking of opium and hashish, Spencer declared that such activities 'exalt the rate of molecular change in the nervous centres, [and] so intensify the feelings and ideas as to cause illusions'.⁴⁸

Good reason, therefore, comes to be smothered by illusions, and, by means of the infusion of consciousness-changing drugs, a poisoned blood-stream permeates into future generations. Furthermore, Spencer argued, repetitive behaviour coalesced into moral traits creating a material memory; and because it is the process of repetition which structures memory, itself embedded within the physical makeup of the brain, its quality diminishes over time:

⁴⁸ Herbert Spencer, *Principles of Psychology* (London: Williams and Norgate, 1881), Vol. 1, pp. 609-610.

If we trace out the successive stages of failing memory ... the earliest among the related impressions which no longer so cohere that one recalls another, are those made by the daily trivialities – those represented in the nervous system by lines through which feeble discharges have but once passed. Interesting statements that are read, and passing events of considerable importance, presently cease: though like statements and events which date back to early life are still recallable: the reason being that the channels of nervous communication long ago made by the strong gushes answering to the vivid feelings of youth, remain more permeable than those lately made by the feebler gushes answering to the fainter feelings of age. Passing over many gradations, we come to the incoherence of thought in which the place now inhabited is confounded with places inhabited long ago, and the business of middle life is referred to as though translated yesterday – incoherences implying that comparatively permeable channels are now so far deserted that the discharges along them do not arouse the elements of these familiar ideas in their proper relations. And eventually we reach the extreme state, similarly explicable, in which even members of the family, who have been companions through life, cease to be recognized.⁴⁹

The nervous system as portrayed here seems a somewhat passive carrier of feelings stimulated from the outside, and because it is constructed in terms of strength and weakness, it is infused with a sense of inevitability through the life span.

Nevertheless, Spencer's description of the process of memory loss from the early to the later stages of the life cycle resonates across time with that described by the Audit Commission in 2000: a remarkable similarity of conceptual thought given the passage of some 120 years. Suggestively, this seems to be a sort of intellectual genetic inheritance. Along with Jackson, Spencer believed that this degeneration involved the loss of the most recently learned and understood functions occurring first, with this followed by the progressive obliteration of longer-term memory and, finally, a failure to recognize others who

⁴⁹ Spencer, *Principles*, pp. 588-589.

have been important in one's life. Jackson's model of the physical evolution and dissolution of the nervous system coincides with Spencer's views in terms both of process and time: the longer one lives, the more likely the loss of a sense of self through a process of mental degeneration. Jackson took the view that:

We develop as we must, that is, according to what we are by inheritance, and also as we can, that is, according to external circumstances.⁵⁰

Jackson's sub-clauses on development seem full of common sense, but beg the question of a mediating form between what we inherit genetically and the environment and culture in which we live our lives. Put differently, what he articulates is a nineteenth-century version of the nature-nurture debate. But Jackson's placement of inheritance over environment and culture suggests that what we are delivered by nature is likely to be the determining factor. For Spencer and Jackson, the body is an integrated system, a harmonious whole containing complex interactions with lower nervous centres receiving and sending messages and images to higher centres, and while these may provide opportunities to adapt to circumstances as they arise, they may also be subverted by the force of inheritance. Nature, it seems, gets in the way of itself through the degenerative process.

Evolutionary Biology and Heredity

Spencer used evolutionary biology to construct a social theory of population, particularly through notions of inheritance and degeneration. These ideas became inserted into the domain of medicine and culture and from the mid-nineteenth century onwards the emergence of heredity in mental pathology became a focal

⁵⁰ Jackson, p. 71.

point of interest. Heredity is essentially a law of succession, of filial disposition to parental traits and as such governs the relations between genealogy and legitimacy of transfer from one generation to the next. In mental pathology, it supposes a possible cumulative effect, damaging generations which follow in such a way as to determine their lives. Spencer's suggestive notion of heredity transmission of acquired characteristics relates to theories of degeneration in the nineteenth century, particularly in the interaction between ideas in medical science and those concerned with social responsibilities. In medical science and pathology, for example, various mental maladies were seen as being inherited and therefore incurable. Time, in such circumstances, had to be left to fend for itself as any intervention seemed worthless to a fledgling profession which could ill-afford to look unsuccessful. Inherited diseases were widely believed to be less amenable to possible cure than those that were acquired, and the locus of hereditary conditions was seen to be the inborn, individual constitution. In fact, the term 'heredity' in clinical medicine and medical pathology was reserved for those conditions largely immune to medical intervention and doctors tended to agree that especially intractable conditions such as consumption, gout and madness were the most likely to have been inherited. The implication is that individual constitutions were relatively unchanging, and faulty constitutions could hardly be expected to be responsive to intervention.

There is, of course, a sense of fatalism in the concepts of heredity and degeneracy, both of which are central to evolutionary biology, as well as in the cultural conceptualization of the Gothic. Such ideas found their way into wider

society, threatening, it seems, the very notion of civilization. Interpretations of these ideas found discursive space in literature and the arts more generally, spaces in which these notions could be culturally represented, struggled with and even contested. Valdine Clemens notes that:

England's late Victorian period was a time of old things passing and new things coming into being. The fin de siècle marked the beginning of the end of British imperial power, but it was also a time of remarkable social and technological newness.⁵¹

Newness such as this threatened traditional ways of understanding the self and the problems and issues facing individuals and society at large. In medicine, for example, as Germaine Berrios and Hugh Freeman argue, 'clinicians mostly accept the textbook definitions of their time, which are seen as reflecting some "given" entity – a disease concept which seems immutable'.⁵² As fresh thinking came to be brought to bear on the subject, so a paradigmatic shift in the consensus of medical understanding began to occur: something different from the 'given' became the focus of evaluation, and, at the turn of the nineteenth century, it was new technology that enabled advances to be made in psychiatry and neurology. In particular, developments in the efficacy of the microscope and new techniques in the staining of brain tissue when carrying out autopsies, gave pathologists and neurologists access to possible causes of mental disease. From the eighteenth century until the early twentieth, dementia had been broadly defined as:

A loss of intellectual function and memory, and divided into congenital, senile, and acquired forms: the causes of the latter

⁵¹ Valdine Clemens, *The Return of the Repressed* (New York: State University of New York Press: 1999), p. 153.

⁵² *Alzheimer and the Dementias*, eds. G. E. Berrios and H. L. Freeman (London and New York: Royal Society of Medicine Services Ltd., 1991), p. 1.

included infections, vascular disorders, sexual excesses, poisons and trauma.⁵³

Within this very inclusive definition, therefore, one could be born with the condition, acquire it through longevity or as a result of accident, or by the consequences of nature or behavioral excess - sex, alcohol, tobacco, narcotics. Such definitional inclusiveness incorporates forms of what would now be defined as psychosis, which also interferes with intellectual function and memory. Anticipated in this definition, with its emphasis on the impairment of intellect, are the nineteenth-century notions of degeneration and degeneracy. Given such inclusiveness, no specific form of brain pathology could be singled out as a cause of the disease. This remained the position until the latter half of the nineteenth century when, according to Berrios and Freeman's history of dementia:

Senile dementia ... was a disease that specifically affected old age ... rarely occurring spontaneously before sixty-five. [Richard Krafft-Ebing] believed that heredity and other external causes were far less important to the development of senile dementia than the natural changes accompanying ageing, including poor cerebral nutrition, anaemia and degeneration of the cortical cells. Clinically, demented patients were distractable, vacant, repetitious, disoriented, showed loss of memory, and could no longer recognize family members or places that were once familiar to them.⁵⁴

This argument clearly sees dementia as a condition of old age, one of 'natural' degeneration unconnected to heredity and it also confidently lists a series of associated physical symptoms which, presumably, might argue a singular disease entity. The argument appears to bring together earlier schools of thought on senile dementia: Jackson's emphasis on 'natural' dissolution which he links to a process

⁵³ Berrios and Freeman, p. 12.

⁵⁴ Berrios and Freeman, p.19.

of ageing, and Spencer's notion of blood flow to which is added symptoms of anaemia and loss of brain cells.

This theoretical argument, clearly establishing a relationship between behavioral symptom and physical condition, was based on the classical anatomico-clinical correlation paradigm of nineteenth-century medicine, which entailed close observation of the patient to see if behaviour fitted certain kinds of clinical facts. In physical medicine, the clinician could also call upon the patient to express a subjective account of their symptoms, but this became more problematic for the psychiatrist or neurologist when facing a dementia patient as very little could be expected from any attempt to elicit subjective experiences of dementia.

The Krafft-Ebing position, which emphasizes cognitive failure as the primary signal for senility, was shared by many because intellect, as evolutionary biology had argued, was the defining characteristic of the human species. In the latter half of the nineteenth century, psychosocial incompetence was perceived to be the result of a failure of mind, and this general belief was, of course, related to theories of degeneration and degeneracy. Therefore, the model of cognitive impairment tended to be promoted in both the clinical and ideological orthodoxies.

Alois Alzheimer and Alzheimer's Disease

As the art and science of medicine developed, signs and symptoms were taken to be representative of some hidden 'truth' or 'truths', and the inner world of the body came to be regarded as a phenomenon which required further exploration, over and above its basic anatomy. But while changes in the tissue and organs of

the body could be expressed in signs and symptoms, an improved detection was necessary to unearth such changes and what may stimulate them. In the nineteenth century, such improvements came to hand in the development of histology: a branch of biology concerned with the minute structure of tissues and, in particular, the study and exploration of diseased tissue. In this way, improvements in both microscopic technology and staining techniques came to be crucial in enabling advances to be made in the understanding of brain disease.

Ernest Jones, in his biography of Freud, offers some detailed commentary on Freud's early interest in histology prior to his stay in Paris and his work with Charcot.⁵⁵ Freud, according to Jones, 'produced some first-class original work'⁵⁶ on this topic and, he goes on to say, 'like all workers in science [Freud] was well aware of the importance of technique'.⁵⁷ Part of what Jones refers to as Freud's 'first-class work' relates to the development of a technique 'to stain nervous tissue with some solution of gold chloride',⁵⁸ which enabled Freud to obtain what he called 'a wonderfully clear and precise picture'⁵⁹ of the cells and fibres of the spinal column.

Developments in the techniques of staining were crucial to the work of Alois Alzheimer. Born in Bavaria in 1864 and qualifying in medicine in Berlin in 1888, he had shown an initial enthusiasm for anatomy and histology, but for some years had worked as a clinician - an assistant medical officer in the asylum at

⁵⁵ Ernest Jones, *The Life and Work of Sigmund Freud*, ed. by Lionel Trilling and Steven Marcus (Harmondsworth: Pelican Books, 1964).

⁵⁶ Jones, p. 187.

⁵⁷ Jones, p. 187.

⁵⁸ Jones, p. 188.

⁵⁹ Jones, p. 188.

Frankfurt. Under the influence of Emil Kraepelin, Alzheimer eventually returned to his former interest, and, in particular, to the study of the anatomy and structure of the brain. Many psychiatrists at this time considered that the dementias of middle age were primarily disorders of the mind as opposed to the pathological or biochemical organic. In 1902-03, Alzheimer moved to Munich to work with Kraepelin, and then, in 1912, three years before his death, was appointed Professor and Director of the psychiatric hospital in Breslau. During his work in the Frankfurt asylum he primarily 'concentrated on mental disorders with clear organic causes'.⁶⁰

In the nineteenth and early twentieth century, this type of work was known as forensic psychiatry and was not considered as a separate or specialized aspect of psychiatry:

The fact that forensic issues were felt then to be of great importance was not only for practical reasons: it was also related to the politically and scientifically influential concept of 'degeneration'. These ideas were prompted by Cesare Lombroso's Italian school of criminology ... Alzheimer's position on this matter was a differentiated one: on the one hand, he rejected the crude and purely speculative statement that the existence of a mental disorder as such proved the degenerate state of the patient. On the other, he defended the concept of inherited degenerative mental disorders.⁶¹

Alzheimer's 'differentiated' position is important in understanding later twentieth-century developments in conceptualizing dementia. He did not hold that someone suffering mental illness was necessarily degenerate because it could be that the illness was inherited from a diseased organ present in an earlier generation. (In fact contemporary medical thinking on the subject of early onset

⁶⁰ P. Hoff, *Alzheimer and his Time*, in Berrios and Freeman, pp. 29-55.

⁶¹ Hoff, p. 41.

dementia is that such patients may carry an inherited cell or cells that may indeed be the cause of the condition). But Alzheimer's differentiation did give emphasis to his quest to reorientate psychiatry away from simply naming symptoms and to move toward the underlying anatomical origins, as he and others saw them, of mental illness.

From this point of view, the post-mortem and autopsy became important methods of investigative research to discover such origins: as Edward Shorter puts it, this type of analysis centred upon 'reasoning back and forth from findings at autopsy to the signs and symptoms displayed before death'.⁶² This methodology gave credence to the notion of scientific evidence in psychiatry and pioneered, to a degree, modern understandings of genetics and biology in the neurosciences. Indeed the approach acted as a counterpoint to nineteenth-century assertions of psychiatry and biology that major mental diseases, although having a biological and genetic make-up, also get worse as they are passed down through the generations. So it came to be that the significance of progressive degeneration as a central concept in the clinical practice of psychiatric medicine began to be challenged by anatomical research.

Although Alzheimer believed mental illness was very likely to be a material disease, he deemed it necessary, in seeking its origins, to base the research on contemporary psychiatric clinical practice. As P. Hoff puts it:

The most urgent task of any medical science is the collection of single cases in the form of diseases, which within certain boundaries are defined by the aetiology of their relevant features concerning clinical phenomenology and outcome.⁶³

⁶² Edward Shorter, *A History of Psychiatry* (New York: John Wiley and Sons, 1997), p. 70.

⁶³ Hoff, p. 38.

For Alzheimer, a prerequisite of the conceptualization of psychiatric illness was that it be merged with the understanding of neurological pathology and the validations of clinical practice: out of this embrace could the collation and categorization of diseases be built. Such an approach emphasized that the signs and signals of clinical practice could be no more than indicators for, and not proof of, the existence of a particular disease. Something else is required in the search for the origins of 'odd' behaviour and this was, and is, at the centre of medical materialism.

Psychiatric practice in the nineteenth century was part of a discourse concerned with the question: does nature change by itself and, if so, what are the laws that govern such change? This question begged another - where did the agency for change lie? Alzheimer, like other medical practitioners of his time, was puzzled by mental diseases that were either in excess of, or an inherent part of nature, and by the manifestations of the signs, images and symbols of that puzzle. Nature's paradox, be it internal or external to the body, is that it is imagined as balanced and harmonious when it can be disturbing and terrifying. Medical practice and medical science are seen as mediating agencies between humankind and nature, and in this mediation both science and practice make use of the notions of 'normality' and 'abnormality' in the materiality of mind and body.

Alzheimer viewed medical research as a kind of superstructure with medical science reliant upon clinical practice. However, clinical work is built upon existing knowledge and practice, both of which are necessarily shaped by

the social constraints and fashions of the period. Medical science and medical practice do not stand outside of society or culture, somehow transcendent of both.

On the contrary, there is an

Interaction between descriptive language on the one hand, and a biological process, bodily changes which emit signals, in the shape of signs and symptoms, on the other. The language of description reflects the beliefs of its users, and so the creation of disease is also a social phenomenon.⁶⁴

The language of description is the diagnostician's primary tool. It is the means of their interpretation of visual data and the patient's explanation of their symptoms, and it is indicative, therefore, of a certain point of view: it is necessarily influenced by existing knowledge, beliefs and attitudes. But what Alzheimer sought, over and above this empiricism, was something else to give substance and credence to the data. This inevitably meant exploring the dead: invading the cadaver to conduct an anatomical investigation of the brain. Developments in microscopic and staining techniques gave Alzheimer's kind of science the means to confirm (or not confirm) empirical diagnosis.

During 1901, whilst at work in the Frankfurt asylum, Alzheimer examined a fifty-one-year-old woman upon her admission to hospital. He closely observed and questioned this patient over a period of four days. She repeatedly said to Alzheimer: 'I have lost myself'.⁶⁵ The patient's behaviour displayed a transformation from an ordered life to one of increasing chaos. Her responses to questions, and her inability to identify objects shown to her, indicated a loss of

⁶⁴ Berrios and Freeman, p. 2.

⁶⁵ Konrad Maurer, Stephan Volk, Hector Gerbaldo, 'Augusta D. and Alzheimer's Disease', *The Lancet*, 347 (1997), 1546-49 (p. 1548).

short-term memory which compounded her agitation. Her speech suggested confusion and disorientation in time and place. She repeated herself and sometimes became mute in the middle of a sentence. When reading, she would omit many lines of text and substituted words in naming objects - a form of aphasia. She also exhibited some forms of delusion and paranoia. Alzheimer carried out a physical examination of the patient, but could find no particular or obvious problem. The patient's behaviour suggested some kind of dementia or psychosis, but a diagnosis of dementia seemed unwarranted in one so relatively young. She remained in hospital, deteriorating gradually both physically and mentally, until she died in 1906.

Following her death, Alzheimer carried out an autopsy on the patient's brain, and, with the assistance of a silver staining technique and technologically advanced microscopic equipment, recorded a pattern of past activity that later came to be named as the disease which bears his name. Alzheimer observed the autopsy to reveal a number of major cell alterations, in particular, the formation of a number of plaques: a kind of chemical protein that had grown and multiplied to the extent that it had stifled living cells. He also observed a number of tangles in the neuro-fibrils: a cell that acts as a kind of communicator of 'messages' between different parts of the brain. Alzheimer hypothesized that these brain lesions might well be the cause or the effect of the disease yet to be named 'Alzheimer's Disease', or possibly a combination of cause and effect.

Current thinking suggests an organic basis for the disease, and notes that the presence of plaques and tangles indicates its onset and severity. It is thought

that genetics may play a part, particularly in those patients where the onset of the disease occurs in middle age. Alzheimer's discovery of the senile plaque and nerve tangles not previously recorded in people of middle age began the process of defining a new disease-structure encompassing both pre-senile and senile stages of the condition. In 1906 Alzheimer gave a report of his findings to a conference of psychiatrists, and in the following year published the contents of his paper. In 1910 Kraepelin proposed that Alzheimer's name be attached to the condition. By naming the disease for Alzheimer, Kraepelin followed a long tradition of medical eponymy which creates the disease as a possession: the giving of a name denoting foundation and conferring a kind of symbolic power. The symbolism of Alzheimer's disease relates to an absence, a lack, a deficiency in being, but conceptually it can also be argued to be an excess or an addition by 'nature' to being. In fact it is these notions of deficiency and excess which emerge as the primary drivers in the argument around degeneration and degeneracy.

Modernism, Humanism and Posthumanism

Although Alzheimer's work demonstrated a shift in medical science, brought about, in part, by advances in technology - from a description of mental states to an analysis of neurological disorders and their origins - the disciplines of psychology and pathology were still used to embrace the idea of evolutionary perfection and imperfection. As Spencer argued, the highest ideal was the struggle for life.

This meant that society as a whole needed to engage with the maintenance of evolutionary health: those who did not participate in a collective social advance

became objects of fear, derision and criticism. Consequently, the basis for the definition of the abnormal or the degenerate was established within the central notion of an evolutionary ideal where 'normal' equalled good, and 'abnormal' equalled bad, constructing a binary which privileged one over the other. The abnormal, of course, fell into the practices of medicine, which helped to create the concept, and with it the incorporation of the idea of monstrosity. Institutional medicine studied illness and the study of illness meant the study of life. It contemplated and pondered the tangible and visible body of man, adopting the role of social interpreter which mediated aspects of the wider culture. Medicine became a site for questions of social value and morality, themes consistently followed in Mary Shelley's *Frankenstein* (1818) which demonised a kind of over-reaching medicine⁶⁶ and a code of attitudes and dispositions to be considered and resolved through the conduct of a social policy which yielded outcomes of the desired good, thus giving substance to Foucault's argument that empiricism and scientific enquiry constitute an exercise in social power.⁶⁷

Such stereotyping of the marginalised in medical science and practice, when set within its symbiotic and diverse relationship with society more generally, also calls to mind Foucault's paradigm of natural and unnatural space. Up until the classical age, the mad circulated within society's physical and moral frameworks. This was because the mad were primarily considered to be custodians of hidden truths about human nature and the human condition. But,

⁶⁶ Mary Shelley, *Frankenstein* (London: Penguin Books, 1994).

⁶⁷ Michel Foucault, *Madness and Civilisation*, trans. by Richard Howard (London: Routledge, 1997). Foucault maintains that in the Enlightenment those considered to suffer from unreason were prohibited entry into the category of the human and, therefore, put away.

being part of a shared 'natural' space did not mean that the mad were not viewed as different – they were so considered, but neither caught up in nor incorporated into any restraining system of medicine or law. However, the cultural shift from medievalism through to the Renaissance and then to the modernity of the Enlightenment, saw such freedoms constrained by the development of a system of asylums which, although originating as benevolent, protective safe havens for the mad in the late eighteenth century, took on a quite different aspect in the nineteenth. Then, as evolutionary biology came to be the dominant cultural measure, bringing in its wake constructions of the mad as degenerate and dangerous creatures, (think of the many texts of the period featuring vampires and devils from whom rational society required protection),⁶⁸ the asylum became a place for well-considered neglect, if not ill-considered punishment.

Two of the founding fathers of degenerationism in the nineteenth century, Benedict Augustin Morel and Cesare Lombroso, adopted evolutionary biology to provide evidence for what they considered to be various forms of mental disorder, criminality and degeneration. As professor of psychiatry and forensic medicine at the Royal University of Turin in the late nineteenth century, specialising in criminology and anthropology, Lombroso developed the idea that degenerates could be identified by certain physical features: a notion which came to be widely used in his specialist area. In the middle part of the century, Morel too pursued the idea of degeneration but particularly as a product of heredity.

⁶⁸ For example, see Hurley, whose *The Gothic Body* illustrates through a number of late nineteenth- and early twentieth-century texts, how cultural anxieties concerning the mind and body were portrayed.

Extending the conceptual analysis, Max Nordau, a physician and social critic of the late nineteenth and early twentieth century, and another who studied with Charcot, appropriated these ideas and translated them into cultural and political criticism. Clemens' argument cited earlier about the *fin de siècle* marking the end of the known and the certain with the 'beginning of the end of British imperial power', can also be seen in Hurley's critical account of Gothic writing in that period, which echoes Clemens and portrays it as a time of considerable upheaval and uncertainty. Hurley argues that the writing of H. G. Wells, Arthur Machen and Bram Stoker, among others, metaphorically reflected this uncertainty by characterising the loss of the human. Hurley claims that Nordau's text

*Degeneration*⁶⁹ of the same period:

was the book of the 1890's, phenomenally popular throughout Europe. It was perhaps the most successful example of that late Victorian sub-genre, the sociomedical text, incorporating biology, evolutionism, psychopathology, moral philosophy, and sociocultural analysis into one sweeping critique of modernity.⁷⁰

What is to be made of such a diverse range of *fin de siècle* subject matter?

Primarily, perhaps, that it reflected the dominant concern of the period: a debate about science and culture's anxieties about the future of civilization and of the human race itself. Nordau characterises this end-of-the-century period as one of decadence and refers to it, in apocalyptic terms, as a

Dusk of nations, in which all suns and all stars are gradually waning, and mankind with all its institutions and creations is persisting in the midst of a dying world.⁷¹

⁶⁹ Max Nordau, *Degeneration* (Lincoln and London: University of Nebraska Press, 1993).

⁷⁰ Hurley, p. 76.

⁷¹ Nordau, p. 2.

Degeneration theory was very much a product of nineteenth-century thought, foreshadowed in the work of Spencer and Jackson, and Nordau's text reflected its concerns about the loss of the human, particularly in relation to a range of aesthetic movements in the late part of the century. Certainly *Degeneration* echoes in its language of biology, evolution and psychopathology the work of Darwin, Spencer, Lombroso and Morel; and in moral philosophy and sociocultural analysis the work of Jeremy Bentham, Samuel Smiles as well as Spencer again. It can be argued that all of these figures were concerned with the establishment and maintenance of the liberal, bourgeois humanism of the nineteenth century which Nordau's text sets out to defend and promote. George L. Mosse, in his introduction to the text, states that:

Lombroso hailed Nordau as the 'true representative of a new humanity'. He might more accurately have said that Nordau was the representative of a century which at that very moment was being freely challenged by men and women who glorified precisely what the two friends castigated as criminal and degenerate.⁷²

And because Lombroso, Nordau and others thought degenerate behaviour 'caused culture to slide back into more primitive behaviours [it became] the particular plague of modernity'.⁷³ Nordau argues that the aesthetic movements of the period emphasised form over substance and from his perspective this menaced the traditional notions of art and literature. Modernity, of course, was characterised by industrialisation, urbanisation, mobility and communication, and in Nordau's view these things were associated with mental disturbances and other illnesses (syphilis, tuberculosis) and vices (drinking and drug-taking); issues of excess in

⁷² 'Introduction' by George L. Mosse to Nordau, pp. xiii-xxxvi (p. xx).

⁷³ Hurley, p. 73.

individual and social behaviour often represented in these movements through visual art as well as literature and drama:

Degenerates are not always criminals, prostitutes, anarchists and pronounced lunatics. They are often authors and artists. These, however, manifest the same mental characteristics, and for the most part, the same somatic features, as the members of the above mentioned anthropological family, who satisfy their unhealthy impulses with the knife of the assassin or the bomb of the dynamiter, instead of with pen and pencil.⁷⁴

Nordau claims that artists and writers of what might be called a modernist persuasion, share not only the same physical features of those he calls 'degenerate', but also some of their 'mental characteristics'. From his point of view, the influence of Tolstoy, Ibsen, Zola and Wilde tended to corrupt rather than enhance 'morality and beauty'. The art produced by such artists, and others, was, according to Nordau, an expression of animal-like instincts, terrorising and exciting readers at the same time, which has also been the intention of Gothic fiction since its development in the eighteenth century. In fact, Nordau argues that the texts of modernist authors perverted reality, reducing it to chaotic features in their manifestations of 'moral insanity, imbecility and dementia', points often made in criticism of the Gothic genre.

If the Gothic genre sets out to awaken a thrilling fear, as will be explored in the next chapter, the aesthetic movements of the second half of the nineteenth century, so Nordau believed, set out to undermine the 'traditional views of custom and morality'.⁷⁵ He believed these movements gave prominence to a 'forgotten, far-away past', one which had demonstrated 'inarticulateness, childishness, and

⁷⁴ Nordau, p.5.

⁷⁵ Nordau, p. 5.

savagery'.⁷⁶ Nordau, therefore, seems to charge this past with what might be called Gothic characteristics: loss of some kind of approved language, immature behaviours and violence. It seems, suggestively, that the Gothic can be seen as a form of degeneration as it brings about a loss, or a gap, in our constructions of the human and, as Hurley points out, 'Degenerationists emphasise the ominous mutability of the human body, [and] its liability to abhuman becomings'.⁷⁷ It may be interpreted that Nordau traced Lombroso and Morel's theories on criminality and degeneration into cultural issues in order to defend and promote the kind of liberal humanism he approved of against an aesthetic which modern cultural critics might term as posthuman; one that acknowledges what Neil Badmington calls 'a crisis' in our conception of the human. Badmington argues that the idea of posthumanism arrives out of the work of Marx and Freud which opened 'up a space'.⁷⁸ If humanism is constructed around the idea of a 'core humanity or common essential feature in terms of which human beings can be defined',⁷⁹ the notion that our world is one of man making meaning now we are emancipated from God, then posthumanism, in the Marxist sense, argues that our 'consciousness ... does not determine a person's social life; it is, rather, social life that determines consciousness'.⁸⁰ Badmington puts it this way:

Subjectivity, in the Marxist account, is not the cause but the effect of an individual's material conditions of existence. The subject is not a given. Eternal man is no more; he now has a history and a contingency denied by humanism.⁸¹

⁷⁶ Hurley, p. 76.

⁷⁷ Hurley, p. 77.

⁷⁸ Badmington, p. 5.

⁷⁹ Badmington, p. 2.

⁸⁰ Badmington, p. 5.

⁸¹ Badmington, p. 5.

Freud took this idea of subjectivity to a more personal level by suggesting that human activity is, to a degree, regulated by the unconscious, thereby throwing our motives into doubt. Such an idea undermines 'the Cartesian model, in which the critical determinant of being is rational, fully-conscious thought'.⁸² Hence, if consciousness is only a part of our mental processes, it must mean we act as de-centred beings, no longer in absolute control of events or experience. Nordau's polemic in defence of a traditional and bourgeois humanism menaced by an aesthetic which might be described, in these contemporary critical senses as posthuman, reflects the uncertainties regarding the future in the *fin de siècle* period.

Hurley argues that 'the last decades of the nineteenth century witnessed the re-emergence of the Gothic as a significant literary form', whose purpose, she goes on to say, functioned 'maximally to enact the defamiliarization and violent reconstitution of the human subject'.⁸³ Nordau's tracing of degeneration theory into culture, which he saw as threatening the traditional perception of the human, can therefore be positioned within Hurley's notion of the Gothic. Certainly Nordau believed that the aesthetic movements of these decades set out to reconstitute the human subject and he argued his point of view in what Glennis Byron called 'one of the most notorious and, in its way, most Gothic texts of the Victorian *fin de siècle*'.⁸⁴ The following extract from *Degeneration* underlines

⁸² Badmington, p. 5.

⁸³ Hurley, p. 4.

⁸⁴ Glennis Byron, 'Gothic in the 1890s', in *A Companion to the Gothic*, ed. by David Punter (Oxford: Blackwell Publishing Ltd., 2001), pp. 132-142 (p. 132).

Byron's point, reflecting, as it does, a crisis of confidence through the language of the apocalyptic, of tragic endings and uncertain beginnings:

One epoch of history is unmistakably in its decline, and another is announcing its approach. There is a sound of rending in every tradition, and it is as though the morrow would not link itself with today ... Over the earth the shadows creep with deepening gloom, wrapping all objects in a mysterious dimness, in which all certainty is destroyed and any guess seems plausible. Forms lose their outlines, and are dissolved in floating mist.⁸⁵

If Nordau sets out to write a socially conservative defence of liberal humanism, his language is graphic and threatening in seeking what Hurley calls 'a more visceral readerly response'⁸⁶ and conjuring up a fear of the new and different. However, Nordau's use of what might be called gothiccity - a use of language to construct dark images - seems, unlike that of authors of Gothic fiction itself, to boil away the excitement and the thrill, leaving merely a residue of existential dread. Appropriating the language of medical science, with an emphasis on its darker Gothic shades, Nordau's polemical text appears haunted by pathology as it seeks to revive a sense of self by invoking tradition to contest the new and the unfamiliar. The concept of pathology, of course, transmutes the familiar into the unfamiliar and this transformation is central to Nordau's argument, reflecting, as it does, the Gothic theme of the loss of the human.⁸⁷

⁸⁵ Nordau, p. 5.

⁸⁶ Hurley, p. 4.

⁸⁷ As Hurley carefully illustrates, Nordau was not alone in appropriating the language of pathology and psychopathology to expose the anxieties of the 'fin de siècle'. The images created by such an appropriation sink into cultural mythologies, and within these DeBaggio's contemporary fears of what Alzheimer's disease will do to his sense of being, have clear Gothic psychological meaning. His presence comes to be re-constituted by the disease as a kind of absence and he expresses his fear of this transmutation in the dark language of the Gothic. Alzheimer's subjects, rather like Gothic subjects, are inserted as unstructured /structured beings into a social order which seeks to deny them. As the disease subverts the rational, what is hidden – our dreams, desires and

Conclusion

While the master narratives of biology and humanism determine the models of old age in their medical, social and economic paradigms, their singular and joint dynamics cannot entirely deny the possibilities of other stories which produce different understandings of this period of life. Some of these dissenting narratives give emphasis to the social and contradictory aspects of old age, particularly in our perceptions of disease in this stage of the life cycle. Alzheimer's disease is one such example as it construes its subjects as both absent and present, leaving the body suspended in a complex sphere somewhere between singularity and generality, the private and the public, filling that in-between space with images of an abandoned body released from an anchoring mind. The images conjure up Gothic forms of transformations of identity 'and the alienation of self from both itself and the social bearings in which a sense of reality is secured'.⁸⁸ This defining characteristic of the Alzheimer's subject, a body in which the self has been lost, exercises a public policy to meet the costs of diagnosis and care within an ethos of dignity and compassion. Such discourse, typically conducted in a private and public language of fear, creates a moral crisis of considerable proportion in our idea of humanism as it confronts a kind of Gothic posthumanism. How this neurological pathological condition establishes dark images of the loss of human specificity is the main focus of the following chapter.

nightmares – is released in the kind of imagery referred to by DeBaggio, and carried into that most telling of Gothic conditions – a living death.

⁸⁸ Botting, p. 157.

Chapter 2

Alzheimer's Disease: A Gothic Pathology

Perhaps we may put it this way: the Gothic and the sublime best encounter each other on the terrain of memory and forgetting.

David Punter

Gothic. This term is ... employed to refer to a cultural discourse that utilizes images of disorder, obsession, psychological disarray and physical distortion [and] the tropes of mental, bodily, and ethical disintegration fostered by the Gothic are inextricably linked to ... ideological, historical and political circumstances.

Dani Cavallaro

'Knowing' is implicitly defined as the setting of limits, and the 'Sublime' as the impossibility of knowledge. So certain kinds of absence, what Burke calls privation, are Sublime – vacuity, darkness, solitude, silence – all of which contain, so to speak, the unpredictable, the possibility of losing one's way, which is tantamount, Burke implies, to losing one's coherence.

Adam Phillips

What remains consistent [in Gothic literature] according to Angela Carter, is the retention of 'a singular moral function - that of provoking unease'. This inflection of Gothic as un-ease or dis-ease invites comparisons with the pathological. Having taken up residence in its host, the Gothic replicates itself throughout our culture like a virus. While resistant to the antidote of realism, it persistently conjugates with the dark side of contemporaneity, at the same time, making a textual negotiation with history.

Marie Mulvey-Roberts

Gothic ... has been theorized as an instrumental genre, reemerging cyclically, at periods of cultural stress, to negotiate the anxieties that accompany social and epistemological trans-formations and crises.

Kelly Hurley ¹

¹ David Punter, *Gothic Pathologies: The Text, the Body and the Law* (London: Macmillan Press Ltd., 1998), p.10; Dani Cavallaro, *The Gothic Vision: Three Centuries of Horror, Terror and Fear* (London: Continuum, 2002), p.vii; Edmund Burke, *A Philosophical Enquiry into the Origin of our Ideas of the Sublime and Beautiful* (Oxford: OUP, 1998), ed. with an introduction and notes by Adam Phillips, p. xxii. *The Handbook to Gothic Literature*, ed. by Marie Mulvey-Roberts (Basingstoke: Macmillan Press Ltd., 1998), p. xvii; Kelly Hurley, *The Gothic Body: Sexuality, Materialism, and Degeneration at the Fin de Siècle* (Cambridge: Cambridge University Press, 2004), p. 5. These epigraphs refer, in one way or another, to the Gothic invocation of a feeling of unease. Mulvey-Roberts's suggestion that this feeling invites comparisons with the pathological conveys a perception of the Gothic as some kind of virus, an epidemic which is somehow resistant to the idea of cure. It is a virus which rests disturbingly inside until ready to

Introduction: The Idea of the Gothic

What is pathology and how can the idea of the Gothic, described severally in the epigraphs above, relate to it? This will be the question addressed in this chapter and it is also one which lies at the heart of this thesis. Medical science needs to define its terms carefully in relation to its investigations and practices, arising, as it does, out of biology and chemistry; and modern medicine, having evolved out of the ‘spirit of Augustan taxonomy’ and the eighteenth century’s need to classify and catalogue, requires these forms of social control.² In his *Dictionary of Human Biology*, Robert M. Youngson defines pathology as ‘dealing with bodily disease processes, their causes, and their effects on body structure and function’.³ Pathology, as a result, and paradoxically, is a way of normalizing a disease, imposing upon it a pattern and a particular determination. Concerned with departures from normality and grappling with abnormalities, pathology in relation to Alzheimer’s disease occupies the gap established between remembering and forgetting: it is concerned with memory, losing it and never getting it back. In a way, Alzheimer’s disease can be described as an elegiac condition, haunted, as it were, by loss. Literature, by contrast, and in this instance the genre of the Gothic, has to shape and control language to give it meaning and effect. Literary works, a term recognized as begging any number of questions, are not, as Terry Eagleton puts it:

break out when circumstances encourage its next arrival at a point of history. As such, this metaphorical disease finds a place, suggests Punter, between memory and forgetting, invoking forms and images of psychological and physical disintegration. It seems impossible to refuse these images cloaked in what Cavallaro describes as dark language. Our embedded anxieties, it seems, are only too ready to be awakened at moments of history that appear to require a discourse which shapes these feelings of awe and fear. In some senses, therefore, it seems unremarkable that contemporary anxieties about dependent old age and loss of self can, or should be, perceived within the paradigm of the Gothic. It is clear, however, from these epigraphs and the texts from which they derive, that the Gothic genre performs a useful and meaningful repository for our fears about mutability and death.

² Mulvey-Roberts, p. xv.

³ Robert Youngson, *Dictionary of Human Biology* (Glasgow: Harper Collins, 2006), p. 370.

mysteriously inspired, or explicable simply in terms of their author's psychology. They are forms of perception, particular ways of seeing the world, and as such they have a relation to that dominant way of seeing the world which is the 'social mentality' or 'ideology of an age'.⁴

Eagleton's point of view, expressed in his book *Marxism and Literary Criticism*, chimes, unremarkably, with the Marxist thesis that products, in this instance texts, and their meaning arise out of a particular historical epoch, and are embedded and reflective of points of history. The base of Marxist ideology is that 'consciousness does not determine life: life determines consciousness'.⁵ This wholly revolutionary understanding of the socialization of man points to a dialectic between authors and the language and culture they inhabit. Eagleton's commentary on language, bodies and culture resonates with the observations noted in the epigraphs cited above by Cavallaro, Mulvey-Roberts and Hurley, all of whom comment on history, ideology and cultural stress within the idea of the Gothic, thus exemplifying with a particular metaphor something more universal.

These epigraphs posit the language of the Gothic as a perspective estranging and defamiliarizing in its effects, perhaps similar to that of disease. They introduce the reader to a vision dark in character and content, subverting a taken-for-granted normality so as to 'speak to the mysterious fears of our nature and awaken thrilling horror' as well as 'to curdle the blood' as if to decompose the body of the reader. Mary Shelley, whose intention this was in writing *Frankenstein*,⁶ saw this fear as something deeply embedded in our being, ready to be awakened by something so horrible that it would capture the reader in a double mix of thrill and fear: this is the Burkean idea of the sublime response,

⁴ Terry Eagleton, *Marxism and Literary Criticism* (London: Methuen & Co. Ltd., 1976), p. 6.

⁵ Karl Marx and Frederick Engels, *The German Ideology*, ed. and introduced by C. J. Arthur (London: Lawrence and Wishart, 1999), p. 47.

⁶ Mary Shelley, *Frankenstein* (London: Penguin Books, 1994); the phrases cited above are taken from Shelley's introduction to the novel (p. 7).

and one which echoes the first of the epigraphs. In other words, the gap between memory and forgetting is filled by this mix of emotions which underlies and provokes a sense of an insecure identity. Howard Phillips Lovecraft, in *Supernatural Horror in Literature*, underlines Shelley's argument, declaring that 'The oldest and strongest emotion of mankind is fear, and the oldest and strongest kind of fear is fear of the unknown'; and what he calls 'the literature of cosmic fear' evokes and resonates with a deep, instinctual awe of the unknown accompanied by a profound sense of dread, emphasizing the power of the body to outwit its rationalizing mind.⁷ Awakening, of course, indicates something forgotten or repressed when confronted by fear. If Gothic literature has an intention it must surely be the one announced by Shelley and Lovecraft, but its appeal, through its variety of hallmarks, particularly the uneasy and ambivalent conversation between anxiety and desire, can also alert the reader to other psychological themes and contexts, such as Alzheimer's, that can evoke terror, horror and other aspects given birth by 'the mysterious fears of our nature'. Overall, fear, it seems, is evolution's way of ensuring our survival.

It is the plasticity of the hallmarks listed in the epigraphs from Cavallaro and Mulvey-Roberts which can be read in both the history of the Gothic and in the contemporary cultural discourses on dementia and dependent old age that is of central concern in this chapter. The contention is that Alzheimer's disease and the Gothic awake

⁷ Howard Phillips Lovecraft, *Supernatural Horror in Literature* (New York: Dover Publications, 1973), p. 12. H. P. Lovecraft (1890 – 1937) first published his long essay, an historical review and critique of what his publisher called 'weird fiction', in 1927. He carried out further revisions and the work, in its final version, was published in 1939, two years after his death. He was a prolific writer of 'weird fiction' which, he argued, was based on something he referred to as cosmic fear. He referenced this fear to things unknown, something mysterious and transcendent of self, a kind of thing-ness which touches the emotion of fear. It is a fear of things transmuted, monstrous and un-human. Lovecraft writes in his introduction 'the one test of the really weird is simply this - whether or not there be excited in the reader a profound sense of dread, and of contact with unknown spheres and powers' (p. 16).

dis-ease and un-ease, gathering together, as it were, those dark intimations which challenge the sensibilities of liberal humanism as each seeks to contaminate and interrogate the other. The language in texts which seek to represent Alzheimer's and decrepit old age in terms of personal pain and the response the community makes to that pain, is an indication of a Gothic space. It may be argued therefore that the disease and the idea of the Gothic interrogate and contaminate each other. As Punter puts it:

By the body we may be all too easily contaminated ... we need to find a form of being which carries all the terrifying weight of infection while eschewing the bodily; thus the haunting, thus the nature of the ghost. The ghost comes to menace the bodily with its limitations; but it also comes to celebrate the loss of the body.⁸

Punter's discussion concerns not only the genre of the Gothic through what it represents and its effects, but by the way it plays with our fears, seeping into our lives as a kind of cultural psychology or pathology of physical and/or mental abuse. Punter argues that it is these forms of abuse which come to haunt us. We recognize 'in Gothic and its traces glimpses of the hidden narrative of abuse'.⁹ But if the Gothic, as suggested in Shelley and Lovecraft, is based in fear, it surely makes the concept timeless. It outgrows, as it were, its history, so as to be ready to be deployed in the present and the future and ready to respond to the anxieties of the moment.

If the idea of the Gothic is timeless, it clearly creates a difficulty for scholars to find an appropriate definition. Fred Botting argues that seeking a rigorous definition for the genre of the Gothic is problematic and that, to compensate, writers resort to categories such as 'early Gothic', 'Victorian Gothic' and even 'modern Gothic', accompanied by

⁸ Punter, 1998, p. 2.

⁹ Punter, 1998, p. 15.

sub-genres which have such titles as ‘female Gothic’, ‘queer Gothic’ and so on.¹⁰ David Punter conducts a similar argument in his introductory essay to *A Companion to the Gothic*, examining critical approaches to the genre. He argues that the Gothic has fragmented to such a degree that it is no longer possible, if it ever was before, to construct a fixed definition or meaning for it.¹¹ Gothic horror and fantasy were popular in the late eighteenth century, originating out of a new interest in medieval architecture and what has become known as romance literature. Its classic textual motifs were castles and dungeons, ghosts, secrets, hidden documents, inheritance, madness, torture and death, and much more.

By the use of the term ‘modern Gothic’, and other sub-categories, of which the sub-title of this chapter - ‘Gothic Pathology’ - is another, there is a clear suggestion that it is a genre that manages to weather time and subject-matter with a suppleness not necessarily given by scholars to other kinds of texts. It can be argued that ‘modern Gothic’ concerns itself more with psychological forces that are problematic to comprehend and seem overwhelming, rather than the generally accepted and traditional hallmarks of the genre, and it is these forces which primarily colour contemporary accounts of Alzheimer’s disease, establishing what might be called a metaphoric Gothic space as a repository for our fears. The Gothic has, as Hurley argues, an ‘instrumental’ plasticity which enables it to re-emerge in different periods of history as a way of negotiating cultural stress; enabling it to speak to contemporary culture’s fears and problems through its particular language and motifs, and it is these which facilitate access

¹⁰ Fred Botting, ‘Preface: The Gothic’, in *Essays and Studies 2001: The Gothic*, ed. by Fred Botting (Cambridge: D. S. Brewer, 2001), pp. 1-6 (p. 1).

¹¹ David Punter, ‘The Ghost of History’ in *A Companion to the Gothic* (Oxford: Blackwell Publishing Ltd., 2001), pp. viii-xiv.

to what Terry Castle calls the 'hag-ridden realm of [the] unconscious'.¹² Hag-ridden, in Castle's sense, indicates that we are tormented and even harassed by our unconscious. Cavallaro and Hurley's epigraphs suggest working definitions of the Gothic, emphasizing that its expressive dark language and history are two of its essential hallmarks which can be used to interrogate any particular historical period. Hurley's *The Gothic Body* is an example of exploring cultural anxieties at the turn of the nineteenth and twentieth centuries through an analysis of fiction and other texts of the period, particularly those representing the degeneration of the body and the disintegration of the mind, two further hallmarks and primary themes in Gothic literature. Hurley's thesis is that the themes of the texts she uses, and their popularity, often shaded by Darwinian evolutionary ideas of dissolution, reflected the concerns of the age, and, in doing so, must have been interrogating those concerns.

In much the same way, Thomas DeBaggio's memoir *Losing My Mind* interrogates, through reflecting upon his life after being diagnosed with Alzheimer's disease, the anxieties of late twentieth-century America about the disease:

It was the day I was diagnosed with Alzheimer's. What time had hidden was now revealed. Genetic secrets, locked inside before my birth, were now in the open. I became a new member in the parade of horror created by Alzheimer's.¹³

The shock and the horror expressed here underline an unbroken distinction between the public and the private, suggesting both a personal and societal sense of disgust and shame. This is a horror that comes from within, recognizing, as it does, the personal and public fear of this disease as the condition becomes the substitute or the metaphor for his

¹² Terry Castle, *The Female Thermometer: Eighteenth-Century Culture and the Invention of the Uncanny* (Oxford: OUP, 1995), p. 5.

¹³ Thomas DeBaggio, *Losing my Mind* (New York: The Free Press, 2002), p. 1.

abjected self as it establishes 'a sense of dissolving a definite identity'.¹⁴ DeBaggio has what is called early onset Alzheimer's, a disease caused, it seems, by a single defective gene thought to be inherited from previous generations, an ironic and paradoxical kind of immortal gene, the outcome of which is similar to that destined for those who develop the disease in old age. The sense of his reaction, as perceived in the language he uses, is that he views his future self as some kind of public horror. He will become estranged from his usual and familiar self and turn into a figure viewed with fear in which the perspective of the Gothic interrogates him as much as he begins to interrogate the idea of the Gothic. That such a condition will 'speak to the mysterious fears of our nature' seems unarguable.

DeBaggio also uses the ideas of secrets and revelations to express his horror, which gives further ballast to the notion of seeing the condition within a Gothic perspective. As indicated earlier, these are often motifs in eighteenth-century Gothic literature which tend to emphasize the breakdown in the distinction between the private and the public (as outlined in Chapter 1 and expanded later in Chapter 3) expressed in concerns about a burgeoning older and dependent population. It can also be argued that this seemingly Gothic disease is, as DeBaggio's memoir illustrates, an attack on the enlightened mind, reducing it to an activity unrelated to a conscious sense of self. He perceives the disease as stripping him of his human qualities, a process of dissolution comparable to that suffered by the Gothic body. And part of his emotional pain is related to the idea of how he will be perceived, anticipating that his disease will spread and, as it were, infect others not only psychologically but materially through his son. This sense of infection wrought by inheritance is, of course, a further motif of the Gothic genre,

¹⁴ Fred Botting, 'Horror', in *The Handbook to Gothic Literature*, ed. by Marie Mulvey-Roberts (Basingstoke: Macmillan Press Ltd., 1998), pp. 123-131 (p. 124).

particularly in relation to madness and infectious disease. DeBaggio's text indicates that writing and reading about Alzheimer's creates an appalled recognition of hopelessness in the face of unfolding events and experiences, as well as providing understanding of a determination to translate our apparent incompetence into a language that somehow distances and encloses us at the same time.

If Alzheimer's disease does suggest dissolution into something akin to the opposite of being human, then it may be seen as somewhat ambiguous. Pain is not peculiar to the human species, but its qualities are obviously expressed and received in a language that can evoke feelings of horror, terror, guilt, remorse, anger and shame, amongst many others. Its physical and emotional torments can outweigh anything else when one is confronted with disease. But being on the wrong side of health may provoke sympathy or empathy on the part of others even when it comes to the notion of monstrosity. Botting makes this point, which perhaps prevents the argument made above in relation to DeBaggio becoming too much of a conceit, when he argues that

Frankenstein

presents a humane and suffering monster, less a figure of vice and transgression and more a figure of monstrous social exclusions. Indeed, blurring the boundaries between good and bad, human and monster, the novel interrogates prevailing value systems to the extent that monstrosity becomes uncannily pervasive, an effect of and intrinsic to the sphere of the human.¹⁵

Frankenstein's stitched-together monstrous creation of bits and pieces may constitute an image of unspeakable horror, but its humane suffering is due to its ambiguous closeness to humanity. The monster becomes a kind of apostle to the idea of self-help, a later Victorian virtue, by learning to read and speak, to become as close to being human as

¹⁵ Botting, 'Monstrosity', in Mulvey-Roberts (Basingstoke: Macmillan Press Ltd, 1998), p. 163.

possible, with language as his doorway to acceptance (but the Alzheimer's subject will eventually lose language). And it is this kind of blurring of boundaries which is eventually rejected as unacceptable to humanity. With or without language, his monstrous image means his social exclusion. Shelley's novel certainly interrogates cultural tensions concerning education and the way certain groups, such as women and the working classes, were excluded from it. Her text also reflected nineteenth-century's medicine's development into different disciplines to indicate its concerns with discrete aspects of the body. Victor Frankenstein's creation, therefore, establishes the idea of the monster and monstrosity as a metaphor which has become a kind of cultural category, as Botting's argument indicates. It is a metaphor for the failure of society to find a space for those who appear less than human and in that sense underlines one of the derivations of monster as a warning.

The word monster derives from the Latin *monstrum*, which in turn comes from the root *monere* which means to warn, and that notion seems to emphasize how metaphors shape our thinking and experiences. But if monsters are threatening they are also disgusting and we seem to be particularly averse to notions of impurity, although not enough, it would seem, not to be still lured towards the horror genre. DeBaggio's memoir also interrogates contemporary value systems and suspects them of falling short of full acceptance of his future self by concluding that he will join a 'parade of horror created by Alzheimer's'. The horrific image he conceives of himself seems to become the point around which his subjectivity unravels, and this is the central theme of his memoir. And his suspicions about the effect his disease has on others can be witnessed by the need to have organizations such as the Alzheimer's Society constantly campaigning both to assist

those with the condition and to underline the continuing ‘humanity’ of the victims of the disease. But Botting’s argument suggests an ambiguity of response: compassion shaded, or shadowed, by both a sense of disgust and shame emanating from a dread of the effects of the disease.

‘Monstrous social exclusions’

Botting’s ironic phrase gives rise to the idea of the Gothic being a paradigm for transgression which leads to social exclusion: an idea with an infectious nature which appears troublesome and creates unease. If we have an ambivalent response to chronic disease and its capacity to undermine our notions of the human, such ambivalences can raise concerns about the nature of cause. Is disease caused by unwitting accident or is it brought on by subversive forms of social behavior (as argued by Max Nordau)? Fear, which seems to give birth to horror and terror, was often used in early Gothic literature as a way of cautioning the reader into what might be called virtuous and proper conduct and therefore underlines their appropriate humanness when indicating disgust at anything which appears to be less than human in conduct and thought. Shelley’s intention, on the other hand, has a more contemporary, psychological and political feel to it. However, it might also be that a mingling of fear and disgust at something which seems less than human may provoke violent reaction, as demonstrated by Alice Sebold in her novel *The Almost Moon*.¹⁶ At the beginning of the story, Helen Knightly, the first-person narrator, murders her mother, who is in the latter stages of Alzheimer’s disease. To the reader, the act may seem inhuman, but Anna Shapiro in reviewing the novel, writes:

The painful ambivalences of mother-daughter relationships are so familiar – and the problems mentally disabled elderly parents can pose for their adult children so well-attested – that I suspect

¹⁶ Alice Sebold, *The Almost Moon* (London: Picador, 2007).

it is a rare person who will not feel a thrill of sympathy for the murdering daughter.¹⁷

Helen's complex relationship in the past with her mother does not disguise her fear and disgust at a mother whose disease tends to magnify the personality she once was: a demanding and quarrelsome parent not attuned to Helen's liberal sensibilities. But Shapiro's review shows a sympathetic understanding of a violent act toward a person who has become less than human. Is this an act of 'monstrous social exclusions'? Does Shapiro's point of view show an intrinsic humanity when she argues that by ridding herself of her mother Helen shows a humane attitude and one with which to empathise? Shapiro takes the novel's sensibilities and indicates that in the real world it interrogates and tests our values concerning 'mentally disabled elderly parents'. She suggests that the familiar and the well recognized are sufficient grounds upon which a sensibility can turn to an act of murder, and notes the thrilling awareness displayed by those who may be in a similar situation. Another way of reading this event, and understanding Shapiro's point of view and Helen's act, is to consider Helen's mother no more than an ambiguous living ghost, possessed, as it were, by a ghostly disease that has transformed her into an uncanny familiar self. She is an abject subject who appears to exist between two worlds and is, therefore, difficult to cope with for an individual like Helen or the wider society implied in Shapiro's review. Has Helen's mother become so like an awkward ghost as to be seen as a kind of interstitial figure, somehow between normal categories of being?

Perhaps it is within the familiar 'ambivalences of mother-daughter relationships', as well as other relationships, that there can be read the psychoanalytic paradigm of the

¹⁷ Ann Shapiro's review article 'Not all there ...' appeared in the *Guardian Review*, 13 October 2007, p. 6.

other. Julia Kristeva's argument concerning abjection puts this paradigm in the following terms:

I experience abjection only if an Other has settled in place and stead of what will be 'me'. Not at all an other with whom I identify and incorporate, but an Other which precedes and possesses me, and through such possession causes me to be.¹⁸

This paradigm suggests a kind of becoming, Kristeva's thesis being that subjecthood arrives out of the primary repression of being abjected from what she calls the *chora*, a state of undifferentiation. However, even as the subject may be abjected and separated from the mother, it lives with an anxious residue that it might slip back into that *chora* and thus lose its sense of individuality. This state of anxiety emanates from the Other, the unconscious, the split within. The paradigm might also be seen as a version of the psychoanalytic model of the death-wish, a powerful psychological drive which runs counter to Freud's 'pleasure principle', which concerns itself with the desire to live and survive.¹⁹ The death-wish rests upon the continuing attraction, or fear, of a return to the darkness and security of the womb.

The unconscious, that 'hag-ridden realm' with its Gothic undertones, can be read into Helen's situation with her mother: the notion of abjection parallels the process of Alzheimer's disease, but in a reverse way. The mother has a presence, but it is one that coexists with an increasing absence, a presence that is on the edge of nonexistence. Alzheimer's disease abjects her self and where her felt borders once were she is now

¹⁸ Julia Kristeva, *Powers of Horror: An Essay on Abjection*, trans. by Leon S. Roudiez (New York: Columbia University Press, 1982), p. 10.

¹⁹ See Suzanne Raitt's essay, 'Freud's Theory of Metaphor: Beyond the Pleasure Principle, Nineteenth-Century Science and Figurative Language' in *Literature, Science, Psychoanalysis, 1830-1970: Essays in Honour of Gillian Beer*, ed. by Helen Small and Trudi Tate (Oxford: Oxford University Press, 2003), pp. 118-130. This essay discusses how Freud sought to develop his notion of the death drive predicated on the research work of August Weismann and others in the late nineteenth and early twentieth century which posited the possible 'immortality' of certain kinds of cell culture.

threatened by dissolution: a kind of return to the *chora* of undifferentiation. Helen's mother, therefore, becomes a foreigner, a stranger, albeit one with a sense of familiarity. And this feeling, almost an uncanny one, can cause, in Kristeva's theoretical paradigm, a reawakening of the sense associated with the loss of the *chora*: a state of anxiety provoked by the lessening of the repressed sense of loss in the face of the abyss suggested by the mother as being a living ghost. To lose that fear of her own potential dissolution Helen destroys the object which causes it.

The Origins of Fear

Kristeva's *Powers of Horror: An Essay on Abjection* examines horror and marginalization, amongst other concepts. Her book, which uses the master narratives of becoming and identity associated with Sigmund Freud and Jacques Lacan, signals one of the major psychoanalytic contributions to the 'mysterious fears of our nature'. She argues that the process of abjection is the psyche's primary repression, with Lacan's mirror stage a secondary process. Repression, of course, acts as a defence against loss. Given that psychoanalytic theory is very much concerned with psychological defences, its theories do not say a great deal about the origins of fear other than that it is a primary emotion dealing with issues of fight and flight, emphasizing the above point about it being evolution's way of ensuring our survival, but Kristeva's dark language concerning the notion of becoming suggests that metaphor is both generated and sustained by fear. Her essay also indicates something more nuanced, resting on the idea of a sublime mix of bodily instincts and psyche in which the body remembers an abjection the psyche has forgotten/repressed. Noelle McAfee puts it this way:

Loss inaugurates being-a-subject, and thereafter abjection marks this loss. Uncanniness is the recollection of that inaugural loss, the reminder of the *chora* that one has forgotten/repressed.²⁰

The fear of a return to the *chora*, undifferentiation, may be seen in terms of a flight from that overwhelming sense of losing oneself. Fear, therefore, is not, as Cavallaro puts it 'a sporadic event but an ongoing condition with eminently ambivalent powers'.²¹ The idea that this emotion is accompanied by 'ambivalent powers' seems to mitigate the possibility that the emotion of fear is one that can transcend modes of representation: if it could, then, presumably, Gothic fiction would never have achieved the popularity it apparently has. In other words, fear is a kind of subliminal feeling of terror and horror. So what psychoanalytic theory has established as a primary emotion confirms Shelley's view of it being part of our nature, ready to be awakened by events or circumstances. Helen Knightly's murder of her mother might also be seen as both fight and flight in the sense that by destroying what she fears most she also takes flight from it, even as Helen's dark act also seems to demonstrate a connection between the visible and the invisible. Put differently, the physical act of murder is prompted by the unseen and repressed fear of nothingness. However, whatever her desires concerning ridding herself of this fear by murdering her mother and the disease, she is unhappily undone by her inability to control the ghostly feel of her mother within as it haunts her for the remainder of the text. Similarly, DeBaggio's fear of his disease haunts him in its increasing manifestations of forgetfulness. Perhaps it is these hauntings that underlie Shapiro's comments above, indicating that the imagination, through invention, can disclose that which exists,

²⁰ Noelle McAfee, 'Abject Strangers: Towards an Ethics of Respect' in *Ethics, Politics and Difference in Julia Kristeva's Writings*, ed. by Kelly Oliver (New York and London: Routledge, 1993), pp. 116-134 (p. 122).

²¹ Cavallaro, p. vii.

suggesting that pain may be shared within the Gothic space. DeBaggio's 'parade of horror', at one level, interprets his disease as one which is shared, but is likely to provoke fear in those who observe the 'parade', suggesting a kind of community of horror which extinguishes the distinction between the public and the private, the visible and invisible and the acceptable and the unacceptable, as the disease and the reactions to it become manifest.

If chronic diseases of the mind, such as Alzheimer's, provoke a cultural discourse which 'utilizes images of disorder ... psychological disarray ... and disintegration' then such a discourse is presumably one which seeks to hide its fear about the prospect of nothingness, except through its occasional outbursts of moral indignation concerning the treatment of the vulnerable elderly. Where the discussion interrogates this hidden fear through various texts concerning this group, it is 'to negotiate the anxieties that accompany social and epistemological trans-formations and crises' of contemporary society. Fear, as Kristeva has argued, is part of our very being, embedded within us to a degree which requires the self and the wider society to be defended from its manifold effects, but defences can be difficult to erect. Certainly DeBaggio finds this problematic, being, as he is, on the cusp between memory and forgetting: his Gothic horror and fear at a point where he is haunted by the prospect of losing his memory as his inner life disintegrates. He believes his true self is to become encrypted by the disease, becoming, paradoxically, a ghostly presence, a form of otherness, a kind of memento of a former self. As Botting puts it, 'the future only presents a dark, unknown space from which horrors are visited'.²²

²² Fred Botting, *Gothic* (London and New York: Routledge, 1996), p. 163.

Fear, Horror and Terror

It may well be argued that the space inhabited by those who have chronic mental conditions, such as Alzheimer's, provides an index of otherness in that Gothic gap which awaits the 'horrors' indicated by Botting's remark above; and what can seem to fill this space is what Hurley calls 'the not-quite-human subject, characterized by its morphic variability, continually in danger of becoming not-itself, becoming other'.²³ What fills the gap between the so-called normal and the abnormal is often occupied first with fear, followed by horror or terror or both. Cavallaro argues that the Gothic genre is 'the textual constellation of the phenomenon of fear' and that terror and horror 'are not antithetical ... but complementary'.²⁴ This suggests that Gothic texts, as with Shelley's intentions, generate fear and do not simply represent them. Ann Radcliffe, one of the early Gothic writers from the eighteenth century, published in 1826 a magazine article 'On the Supernatural in Poetry' in which she argues for a distinction between terror and horror: 'terror and horror are so far opposite, that the first expands the soul, and awakens the faculties to a high degree of life; the other contracts, freezes, and nearly annihilates them'.²⁵ Cavallaro, however, insists that 'these do not constitute fixed and self-contained categories for they incessantly collude [with] and metamorphose into each other as fear's interdependent affects'.²⁶ But, if Radcliffe is correct, it would seem that Shelley seeks to awaken terror rather than horror in the readers of *Frankenstein*, and DeBaggio might be said to freeze at the prospect of annihilation as he writes about the manifestation of Alzheimer's created by his forebears.

²³ Hurley, pp. 3-4.

²⁴ Cavallaro, p. vii.

²⁵ Ann Radcliffe, 'On the Supernatural in Poetry', *New Monthly Magazine*, 16 (1826), 145-152 (p. 150).

²⁶ Cavallaro, p. vii.

However, what DeBaggio anticipates is what Botting claims is a 'sense of dissipation of [his] faculties and physical power, the vampiric draining of energy [which] explains why horror remains ... difficult to dispel'.²⁷ Certainly DeBaggio recognizes the 'vampiric' metaphor when he writes that 'Alzheimer's is the closest thing to being eaten alive' as the disease sucks and eats away at his very being.²⁸ The metaphor is also used in Saul Bellow's *The Actual* when Amy refers to her father's condition - 'Alzheimer's disease has pretty well swallowed up his mind'.²⁹ The idea of being eaten alive, therefore, seems a meaningful one in both fact and fiction. But fear, according to Cavallaro, is 'endowed with ambivalent powers' and the intentions of Shelley and the reactions of DeBaggio may not be as straightforward as suggested.³⁰ Fear can be blinding and numbing in its effects, so the construction of defences, as indicated above, seems to be necessary. Psychoanalytic theory, as Adam Phillips argues, points to

The way we construct our defences [which] tends to suggest that we unconsciously invite, or sustain contact with, whatever we fear ... By constructing fear as a form of desire, by redescribing it as a particular kind of excitement, psychoanalysis has made the object of fear – the place where fear is located – a paradox: both elusive and irresistible ... we can't find it and we can't get away from it.³¹

If the unconscious both lures and repulses, it clearly brought Helen Knightly to an act of what can be called monstrosity, and if fear is somehow embedded within us, then the psyche, it seems, has to find a defence against the body, constructing, as Phillips argues, a kind of psychical shield against a bodily reflex. And this reflex arrives out of a sense of the helplessness of abjection, underpinning, as Phillips writes, 'our fantasies of autonomy

²⁷ Botting, 'Horror', p. 124.

²⁸ DeBaggio, p. 41.

²⁹ Saul Bellow, *The Actual* (London: Viking, 1977), p. 82. Bellow's novel deals with old age, regrets and issues of redemption.

³⁰ Cavallaro, p. vii.

³¹ Adam Phillips, 'Fears' in *Terrors and Experts* (London: Faber and Faber, 1995), pp. 46-63 (p. 48).

[which] are circumscribed by [a] fear'³² that also 'becomes the perception of a truth that inspires tenacious denial' - a psychical defence not uncommon as a reaction to the diagnosis of Alzheimer's.³³ If denial disguises the 'truth' of desire, the lessening of the strength of the ego presumably allows that 'truth' to become apparent and this is, after all, the aim of psychoanalytic treatment.

An example of this failing of the ego, as far as the neurological condition of Alzheimer's is concerned, is the reaction of Fiona, the central character in Sarah Polley's film *Away from Her*,³⁴ a dramatization of Alice Munro's short story, 'The Bear Came Over the Mountain'.³⁵ Fiona begins to lose her memory and eventually goes into a nursing home, but before doing so she tells her husband, Grant, who has had a number of affairs throughout their married life, that there is 'something delicious in oblivion' - not being troubled by the past or worrying about the future but living in the claustrophobic nothingness of the present, unhaunted by memories. DeBaggio understands this as one of the effects of the condition and calls it 'the inevitable self-absorption typical of such a disease'.³⁶ This is the central unease of the film and the story, which uses the idea of Alzheimer's as a metaphor for handling Grant's infidelities. It may be, of course, that the desire for oblivion is the wish the husband projects onto his wife because his disease of unease throughout the drama emanates from shame and guilt. They do not share the secrets of these infidelities, leaving a considerable sense of darkness between them,

³² Phillips, p. 51.

³³ Phillips, p. 52.

³⁴ *Away from Her*, dir. Sarah Polley (Metrodome Distribution, 2007).

³⁵ Alice Munro, 'The Bear Came Over the Mountain', in *Hateship, Friendship, Courtship, Loveship, Marriage* (London: Vintage, 2007). Munro's story is an example of an ambivalence of moral function underlying the deep sense of guilt and unease at the heart of this portrayal of Alzheimer's disease.

³⁶ DeBaggio, p. 7.

emphasized by Fiona's developing loss of memory. Their prospects are an example of a future which will be 'a dark, unknown space from which horrors are visited'.

Radcliffe, as a writer of Gothic texts, thought to stimulate the reader's mind through terror: horror would do nothing for the imaginative engagement which mystery encourages. As Cavallaro argues 'the difference is between awful apprehension and sickening realization: between the smell of death and stumbling against a corpse'.³⁷ The distinction Cavallaro makes here seems to be between the invisible and the visible, with, for readers of Gothic fiction, the reality of the latter having less charm than the potential for imagination in the former. However, she insists that 'terror and horror are closely interconnected and that each is capable of metamorphosing into the other'.³⁸ She argues that:

The interaction of terror and horror is most explicitly conveyed by stories that articulate the experience of fear as an ongoing condition. Such narratives intimate that fear is not triggered by a single disturbing moment or occurrence but is actually a permanent, albeit multi-faceted, aspect of being-in-the-world.³⁹

Clearly Shelley and Radcliffe sense this in seeking to awaken the thrill of terror through their stories, but the horror of something ghostly or monstrous is just as apparent in their work, creating a feeling of unease. Although not using the terms terror and horror, Martin Heidegger, in his text *Being and Time*, suggests a distinction between fear and anxiety: fear is a response to an identifiable threat, and anxiety a response to an unidentifiable one, the danger being nowhere in particular and yet somehow everywhere.⁴⁰ This last notion

³⁷ Cavallaro, p. 3.

³⁸ Cavallaro, p. 5.

³⁹ Cavallaro, p. 6.

⁴⁰ Martin Heidegger, *Being and Time*, trans. by John MacQuarrie and Edward Robinson (London: Blackwell, 1978), Part 1, Chapter 6, 'Care as the Being of Dasein', articulates the distinction between fear and anxiety.

seems to echo Lovecraft's idea of cosmic fear. However, these various responses seem to collide, as may be seen in the two following examples.

The first begins to explore the start of the beginning of the end between memory and forgetting and is from Giorgio Pressburger's short story 'The Law of White Spaces'.⁴¹ Doctor Abraham Fleischmann, the primary character, becomes concerned by losing track of words and attempts to carry out a series of exercises to retain a hold on language:

He repeated over to himself a hundred times the word 'injection', each time scrutinizing every thought and mental association that passed through his head. In this way he alighted on the thought of death, and beyond it, of nothing. For an instant he felt like dying. 'It's obviously a case of an irreversible deterioration of the brain cells', he thought on the subject of his unexpected amnesia, something that had never occurred to him before then. He began to sweat, and felt an emptiness in his stomach.⁴²

Fleischmann's compulsion to repeat is an attempt to retain a hold on things which are familiar and is a common behavioral trope in the various representations of Alzheimer's disease discussed in future chapters.

The second example is drawn from J. Bernlef's novel *Out of Mind*⁴³ where the first-person narrator, Maarten, an elderly Dutch emigrant to America, describes a puzzling state of mind:

Walk, I must get up for a moment and walk about. Then it will ebb away again, this feeling of being absent while being fully conscious, of being lost, of losing your way, I don't know what to call this feeling, which can apparently be aroused by the simplest objects.⁴⁴

⁴¹ Giorgio Pressburger, 'The Law of White Spaces' in *The Law of White Spaces*, trans. by Piers Spence (London: Granta Books, 1993), pp. 13-38. This story, through first-person narration, outlines the narrator's developing terror and horror at his loss of memory.

⁴² Pressburger, p. 18.

⁴³ J. Bernlef, *Out of Mind*, trans. by Adrienne Dixon (London: Faber and Faber, 1998). This novel through first-person narration, details the slow dissolution of the narrator's mind. His total loss of language is demonstrated by the final blank pages.

⁴⁴ J. Bernlef, p. 9.

Things which may have appeared meaningful to the characters begin to be seen as having no meaning at all, and what was once familiar starts to look very strange. In Bernlef's novel the psychoanalytic theory of the uncanny seems to be at work as Maarten is suggestively caught between an inner and an outer state, a realm of the in-between as he engages hidden fears that both recognize and not recognize this mysterious process of 'being lost'.

These two stories do not ordinarily fall into the Gothic genre, but the use of a language of forgetting and the depiction of a vulnerable hold on personal identity, reveal motifs which can claim, as Mulvey-Roberts puts it, 'a family resemblance' to the Gothic as they create senses of terror and horror in confronting the invisible force that will take over the characters' lives.⁴⁵ In both these works, the principal characters describe something invisible, which begins to manifest itself through loss of words and a sense of loss of self: something else takes over the character of Maarten. Bernlef's novel has a kind of dreamlike quality to it as Maarten slips between reality and the indistinctiveness of his life as Alzheimer's begins to take possession of him, and as he seems to observe himself from afar. Fleischmann also begins to recognize his rationality seeping away as it defies and defines his struggle. In effect, these two characters represent and interrogate some kind of lived experience as well as the imaginative capacity of the reader, as they begin to be something other than themselves and the body and the mind mingle in their affects. Both characters might be described as being at the mercy of overwhelming psychological forces that are difficult to comprehend; both are caught within a haunting abjection as the characters begin to realize that their worlds lack the commonly assumed

⁴⁵ Mulvey-Roberts, p. xvi.

secure structure and meaning. In short, both characters may be said to be at the centre of what might be called 'modern Gothic' where 'horror appears when fears come a little too close to home'.⁴⁶ As Cavallaro argues:

If, at the level of everyday lived experience, terror and horror merge in the domain of fear as a persuasive condition, at the level of representation they are drawn together by Gothicity as a cultural discourse that provides the underpinning of disparate narratives of darkness of which terror and horror are the recurring affects.⁴⁷

For Fleischmann and Maarten, as Alzheimer's subjects and objects, abjection moves them from so-called unified beings to an un-restful place of borderline, interstitial figures. It is the phenomenon of Alzheimer's disease which establishes this form of abjection which Kristeva argues 'disturbs identity, system, order' and 'does not respect borders, positions, rules'. Abjection, it seems, creates 'the in-between, the ambiguous the composite'⁴⁸ that Fleischmann and Maarten perceive through their terror and horror that they will become.

So if there is a gap, or distinction, between terror and horror, it is one eradicated by gothicity, which any number of narratives may reflect through their use of language. DeBaggio's reaction to his diagnosis suggests a future mental decline to overlay his physical degeneration. The images he conjures of corruption in his mind and body establish his own Gothic version of his situation, lending a telling personal authenticity to Cavallaro's argument.

⁴⁶ Botting, 'Horror', p. 124.

⁴⁷ Cavallaro, p. 7.

⁴⁸ Kristeva, p. 4.

Gothicity as Infection

But can language horrify and terrorise? Clearly Shelley and Lovecraft thought so and the popularity of the Gothic genre from the eighteenth century onwards indicates the desire to be thrilled and awed at the same time by images either deliberately created or suggested by the author. Punter's *Gothic Pathologies* makes this point and also argues that the Gothic is concerned with 'creating, or recreating, other books'.⁴⁹ In other words, it is an approach which contaminates and infects the language of different texts and can, therefore, horrify or terrorize the readers of such works. In a sense his book appears to interrogate Castle's 'hag-ridden world of [the] unconscious'. His theme seems to suggest that if the Gothic is a kind of literary conceit, its excesses interrogate culture's dark visions, its subversive Other, in much the same way as psychoanalytic practices interrogate the language of the unconscious, hinting at its Gothic nature. The subtitle of *Gothic Pathologies* is *The Text, The Body and the Law*, indicating that the idea of the Gothic runs through all three. This is made clear in the following points:

haunted by a world which comes prior to text yet which we can know only in and through text, a world of oral tradition, of more primal hauntings by word of mouth.⁵⁰

Gothic, then, provides an image language for bodies and their terrors, inhabits a point of undecidability in the area of the growth of self-awareness.⁵¹

Gothic persists in eluding this notion of 'rule' - it consistently subverts rules, the law of things - because it is concerned with the disorder of things.⁵²

⁴⁹ Punter, p. 2.

⁵⁰ Punter, p. 14.

⁵¹ Punter, p. 14.

⁵² Punter, p. 14.

All three notions of the Gothic in text, body and 'the law of things' can perhaps be seen in DeBaggio's both angry and elegiac memoir and the statement he makes after he claims that Alzheimer's was the inspiration for writing his book. The book, he states:

was to be a word picture of the outside and inside, present and past, of a man's naked struggle with the unknown on his way to trembling silence and unexplainable torment without the torturer. It was a story of unleashed anger and beauty brought forth by an unseen illness, incurable and relatively long-term in duration. I knew I was unable to write about all stages of Alzheimer's because the disease causes cognitive decline and I will lapse into a world without language and memory.⁵³

Language, the language of bodies and the disorder of things is suggestively incorporated in DeBaggio's need to explain himself and his disease, and as it horrifies him so it will the reader. Body and mind are clearly under stress in terms of the invisibility of a condition which will torment him, in the end, to silence, but in the meantime anger and struggle provide the impetus to explain and explore his reaction to his daily dissolution. The notion of the struggle also suggests something heroic, but a struggle that fate will destroy, and the intensity and the drama of the language create a Gothic picture. But if the signature of a memoir suggests intimacy, DeBaggio's vivid language of anger and frustration suggests a desire to put the disease outside of himself: to be rid of it. In this excess of anger and frustration, he echoes the language of the Gothic as an internal desire, a desire to return to his former self and escape his oncoming ghostly shadow. Punter explores further how language and the body, through text, might terrorize:

We might take a broad line on this and assert that all texts are instruments of terror. The justification for such a claim would be derived from such thinkers as Heidegger, Blanchot and Derrida, and their arguments about the ways in which text, or 'literature' in their various formulations, represents absence and negativity. In other words, although language may appear to 'represent',

⁵³ DeBaggio, p. 7.

in fact its major effect is to 'stand in for' its absent other; so that when we confront a text we are inevitably confronted in turn by absence, by a sense of loss with which the words we read have a complex relation. Literature, on these readings, would be that which pre-eminently exposes us to the terrors of loss and absence, which threatens our illusions of a fullness of being.⁵⁴

Language, in Punter's view, stands in the gap created by abjection, by underlining that loss of fullness and its representation, and, paradoxically, indicating a fear of its return. As Punter goes on to say, 'Gothic fiction would, on this paradigm, be a model for all literature; precisely because its very subject matter is haunting, which is in the end the station of all writing'.⁵⁵ Absence, it seems, creates the possibility of Gothic speculations especially when rational consciousness is absent during dreams and nightmares.

The process of Alzheimer's disease depicted by the Audit Commission and outlined in Chapter 1, bears out this kind of haunting, albeit in the language of administrative prose. It also illustrates a further point about terror and horror made by Punter: 'Horror, we might say, is a stark transfixed staring; terror has more to do with trembling, the liminal, the sense of waiting'.⁵⁶ The sense of waiting invoked by the insidious progress of the disease is present at each stage as it withholds itself from the next in terms of time and so the reverse abjecting process takes hold, being haunted not only by the bits of the self lost, but also by what is to come. And as language and the sense of self are gradually destroyed by the stranger within, it may be argued that the Alzheimer subject faces what Punter calls 'the terror of incarnation, the fear that bits and pieces of our own ... body ... will receive the gift of "organization" and be returned to us

⁵⁴ Punter, 'Terror' in *The Handbook to Gothic Literature*, pp. 235-240 (p. 235).

⁵⁵ Punter, 'Terror', p. 236.

⁵⁶ Punter, 'Terror', p. 236.

as a fantasized organic whole'.⁵⁷ Such a process appears to be the triumph of the material body over the symbolism provided by language and echoes Kristeva's paradigm of abjection.

But Punter's use of the word 'liminal' in connection with 'waiting' also suggests that waiting has a relationship to the notion of the Sublime and Burke's understanding of it to indicate awe, surprise and terror. Phillips's epigraph conjoins the idea of knowing as implicitly suggesting limits and the Sublime 'as the impossibility of knowledge' and links these to absence and eventually 'to losing one's coherence'. If terror is a kind of waiting, perhaps more accurately described as anticipation, at its heart is what Phillips calls 'vacuity, darkness, solitude, silence', all part of the process of Alzheimer's which is the hidden haunting couched in the administrative language of the Audit Commission's report outlined in Chapter 1.⁵⁸ What this kind of language may wish to hide can be imagined in its description of the unravelling of the mind as it sets out the stages of dissolution. In this sense the Commission's report seems to incorporate gothicity, which may trigger the fear, terror and horror of its readers as they too face the representation of absence underlying the invasive, transpersonal potency of language and disease. This point is marked by Punter when he states of the representation of absence that it:

returns us again to the condition of all textuality, where the free will of the characters is an illusion but one in which we are more than happy to share until the point where we sense that our own freedom as readers is being demonstrably assailed and that we are being led to conclusions which involve death and destruction.⁵⁹

Death and destruction are the end results of Frankenstein's experiments in Shelley's novel. Sir Walter Scott declares something different in the pleasure and thrill of reading

⁵⁷ Punter, 'Terror', p. 237.

⁵⁸ See Chapter 1, pp. 6-10.

⁵⁹ Punter, 'Terror', p. 240.

what Lee E. Heller terms 'philosophical Gothic'.⁶⁰ Heller refers to early reviews of Shelley's text 'as assessing it in terms of cultural concerns about ... character'.⁶¹ However, he also refers to a review of the text which has been attributed to Sir Walter Scott who argued that Shelley's novel is 'more philosophical and refined [in its] use of the supernatural' in which 'the pleasure ordinarily derived from the marvelous incidents is secondary to that we extract from observing how mortals like ourselves would be affected'.⁶² Heller argues that 'the development of Gothic fiction ... takes its meaning from the tensions informing ... cultural concerns about human nature, its potentials and limits, and the forces that go into its making'.⁶³ It seems, therefore, that hidden behind Gothic intentions to thrill and excite is something of the terror and horror concerning 'human nature', the dread of insidious loss and the struggles of identity, all of which speak to Punter's arguments with some resonance and confirm Cavallaro's points about how terror and horror metamorphose into each other. If the intention of 'early Gothic' was to excite, thrill and create a sense of terror, it presumably did so with the idea of resolving such responses by showing that evil designs in the end are happily outwitted by the good in 'human nature', perhaps attempting thereby to shape readers' morality.

Contemporary gothicity may suggest something different. In Hurley's *The Gothic Body*, Gothic literature of the late nineteenth and early twentieth century is examined as interrogating and being interrogated by 'a range of scientific discourses ... rhetoric, modes of imaging, and narrative structures which reveal the surprising compatibility of

⁶⁰ Lee E. Heller, 'Frankenstein and the Cultural Uses of Gothic' in *Mary Shelley: Frankenstein*, ed. by Johanna M. Smith, Case Studies in Contemporary Criticism (New York and Boston: Macmillan Press Ltd., 1992), pp. 325-341 (p. 328).

⁶¹ Heller, p. 329

⁶² Heller, p. 329.

⁶³ Heller, p. 326.

empiricism and supernaturalism' at that time in history. This approach is, as she states, 'more than the formulation of genre-as-symptom'.⁶⁴ Her intention is to show how these various discourses became metamorphosed into Gothic stories and how the language of these other writings were suffused by the idea of gothiccity and the Gothic vision.

Cavallaro's text, *The Gothic Vision: Three Centuries of Horror, Terror and Fear* published two years before Hurley's *id* defines this vision as 'investigating narratives of darkness'.⁶⁵ Cavallaro describes this darkness as being

invested with negative connotations by many mythologies and religions. Frequently, it is associated with the baser instincts, lack of clarity and order, a pervasive sense of fear and a fate of unrelieved sorrow.⁶⁶

She writes later that 'Darkness does not necessarily mask an alluring mystery. It may also, in fact, conceal the absence of anything'.⁶⁷ However, she views the discourse of gothiccity as primarily referring 'to tales of obsession and haunting which employ images of disorder, alienation and monstrosity for the purposes of both entertainment and ideological reflection'.⁶⁸ Her views bear many similarities to Hurley's analysis of Gothic tales in the period of history she covers, and which, she asserts, can also be read in other discourses of that period. So if gothiccity images what Hurley calls 'the ruination of the human subject',⁶⁹ it encompasses, both in the darkness of its language and the terror of its vision, the notions of personal dissolution and struggles with identity that can be recognized in many contemporary accounts of Alzheimer's disease. These fearful sights and sounds come to be incorporated into the 'great dread of our age', where the 'parade

⁶⁴ Hurley, p. 5.

⁶⁵ Cavallaro, p.vii.

⁶⁶ Cavallaro, p. 21.

⁶⁷ Cavallaro, p. 23.

⁶⁸ Cavallaro, p. 8.

⁶⁹ Hurley, p. 3.

of horror' is viewed with considerable unease and terrified impotence. In so far as the Gothic is 'a site of difference', it is only so 'within a panoply of family resemblances'.⁷⁰

Conclusion

If consciousness of self, an awareness of being aware, is considered to be the primary aspect of a civilized and enlightened existence, presumably its lack is seen as something uncivilized, unenlightened and, therefore, abnormal, pathological and probably posthuman. Compacted into the pathological are the dark images of the Gothic seen not only within the literary genre which deliberately accounts for such images, but also in the reactions of those diagnosed with Alzheimer's and in the imaginative narrative descriptions offered by those concerned and interested to create and explore the inner life of the disease.

Furthermore, as Punter has persuasively argued, it seems clear that other kinds of texts dealing with the condition, such as those from the social sciences, medical science and a variety of social policy and administration organizations, cannot entirely escape from these dark visions. The 'ruination of the human subject' comes within the categories and classifications on which all these knowledge repositories rely, and although their respective languages may not be able to indicate the density of lived experience, they find it difficult to avoid the Gothic images and visions ordinarily supposed to be separate from the wider culture. While these areas of knowledge may seek to objectify Alzheimer's disease and its effects and turn them into areas of public concern, they rarely, excepting the products of interest and campaigning groups, are able to get inside the disease. Even memoirs of people who have the condition are written, as it were, somehow outside themselves and in some cases, such as DeBaggio's, very vividly. But the accounts of

⁷⁰ Mulvey-Roberts, p. xvi.

those who write through the creative imagination enable the reader to feel the full sense of fear, terror and horror which the language of other knowledge areas tends somewhat to veil, though not always successfully as the veil often slips, allowing the darker Gothic images to seep through the gaps.

Punter's argument about the Gothic and the sublime meeting on some battlefield between memory and forgetting summons up the notion that within our dreamlike and nightmarish states of mind our fears are, ironically, awakened. It is Alzheimer's disease which creates the terrain between memory and forgetting and establishes the space for the Gothic and the sublime to meet. The Gothic appears out of the language of fear, terror and horror, and if horror seeks to annihilate, it does so through the sublime in the sense that DeBaggio, for example, stands in awesome and stunned fear of being possessed by a disease which will reduce him to silence, eventually rendering him lost for words. This possessive power turns him from one kind of reality to another, in which he will become unrecognizable and a ghostly projection of himself. Punter, and no doubt other scholars recognize this as the psychological embodiment of the Gothic awaiting its release through a language fit for its purposes.

Gothicity, then, enables this language of the 'hag-ridden realm of the unconscious' to contaminate and infect a range of texts concerned with Alzheimer's, but it is the imaginative works of fiction, poetry and drama that manage the cultural stress the condition creates so as to interrogate our fears concerning the disease, and in this sense they fall into the category of works that bear 'family resemblances' to the Gothic genre. The brutality of the fact of the disease provides a basis for the use of imaginative language to explore its subversive reality, and here it seems clear that the tragic drama of

Alzheimer's disease produces a collision of fact and the imagination to a point where the condition might be described as a Gothic pathology 'relevant to a very tangible social reality'.⁷¹ Various aspects of the private and the public within this social reality are considered in the following chapter.

⁷¹ Cavallaro, p. 9.

Chapter 3

Aspects of the Private and the Public

The world seems to be in the grip of a dementia epidemic. There are, as I write, about 24 million dementia sufferers across the globe, with 80 million forecast for 2040 ... That's why the phrase Dementia Time Bomb is beginning to be used.

Andrea Gillies

For the past 2,500 years our understanding of disease has evolved with the state of knowledge about how we are affected by nature, and it has borne a changing burden of anxiety about bodies, souls and the way we live in the world we have made. Prominently, ancient suspicions of contamination, divine punishment, and moral correction have permeated humanity's awareness of disease and continue to influence our grasp of the epidemic.

Philip Alcabes

We humans dread death. It is only natural that the mass mortality brought by a great plague makes us afraid. And besides our dread of death, we are frightened by the prospect of social disruption. To live in a civilised society is to bear a dread that goes beyond the fear of death.

Philip Alcabes

Because there is a silence, a taboo. No one knows how to feel, or what to think because the meteor of dementia that strikes families and wipes out so much is supposed to be part of the realm of privacy.

Linda Grant

The sociological imagination enables its possessor to understand the larger historical scene in terms of its meaning for the inner life and the external career of a variety of individuals ... By such means the personal uneasiness of individuals is focussed upon explicit troubles and the indifference of publics is transformed into involvement with public issues.

Charles Wright Mills¹

¹ Andrea Gillies, *Keeper: Living with Nancy. A Journey into Alzheimer's* (London: Short Books, 2009), pp. 10-11; Philip Alcabes, *Dread* (New York: Public Affairs, 2009), p. 10 and p. 4. Linda Grant, *Remind Me Who I am Again* (London: Granta Books, 1998). Linda Grant is cited by Christopher A. Vassilas, 'Dementia and Literature' in *Advances in Psychiatric Treatment*, 9 (2003), 439-445 (p. 444). Charles Wright Mills, *The Sociological Imagination* (New York:

Epidemics and Pandemics

Earlier chapters have shown how periodic cultural concerns regarding population balance resonate with contemporary anxieties about the social, economic and political effects of increasing numbers of elderly and dependent people, and how cultural commentators have relied upon the Gothic trope and the language of gothicity to respond to and represent these anxieties, taking them beyond the personal ambit into the public scope in a variety of media - official documents, campaigning reports, and works of fiction, drama and poetry. The number of people affected by forms of dementia within the United Kingdom is now estimated to be some 820,000, of which Alzheimer's is considered to be the most common form. Whether or not this can be regarded as an epidemic in strict public health terms, it is clearly seen as such by those intimately involved with the condition such as Gillies. Her stark imaging of an epidemic gripping the world with a potential explosive effect creating disorder and alienation, has its own menacing Gothic undertones, so that, as Linda Grant asserts, the demographic of dementia no longer permits the subject of the disease to remain a taboo. It now spills over into the space of the communal realm, exposing the private troubles of families and friends to a public gaze. Epidemics, of course, have been fellow

Oxford University Press, 1967), p. 5. The several stages of Alzheimer's disease, as outlined in Chapter 1, which will be considered further in this chapter, are marked by loss of aspects of personality and behaviour. These aspects originate within the privacy of individual and family life but the emotional pressure of such a disease, as in epidemics, creates an eruption of fear as the condition socially mutates from the intimate into the public. Private troubles become public issues. These epigraphs, like the texts from which they derive, act as a frame of reference for this chapter as it seeks to illustrate how a disease, such as Alzheimer's, because it is problematic and difficult to understand, becomes, in a sense, a carrier of something we fear - like a spreading dark shadow.

travellers of human civilization for thousands of years, and the realities of infection and contagion have exercised imaginations throughout these times.

If the increasing numbers of the demented reference a kind of epidemic, at least in Gillies' view, then it is an epidemic which seems to create a sense not only of impotent fear, but the possibility of violence, as hinted at by Alcabes in the first of his epigraphs above. Prefacing one of the themes in this chapter concerned with aspects of the private and the public relating to Alzheimer's disease, Alcabes argues that the event of an epidemic is often accompanied by feelings that 'divine punishment' and 'contamination' are at work and requires a response of 'moral correction' to eliminate a suggestive excess.² These responses indicate a need on the part of communities to seek out the agent responsible for such horrific randomness. The gothicity of this language seems to indicate something like a sublime reverence in the face of the disease, and the idea of 'moral correction' echoes the argument used in the late nineteenth century in Max Nordau's *Degeneration*.

However, Gillies' use of the term epidemic to denote the number of people with dementia across the globe is, strictly speaking, misleading. Alcabes, a public health specialist, would insist it is more appropriately called a pandemic, one that crosses borders rather than one isolated in one area or space. William Bynum in *The History of Medicine* argues that because 'public health is about the state and the individual' it is concerned therefore with isolating epidemics to

² Alcabes, p. 10.

prevent pandemics.³ But dementia, again in strict terms, is not an infectious disease, other than in a social sense when its effects on others are socially, psychologically and economically profound. In logic, too, it might be argued that people who contract early onset Alzheimer's (that is, those who demonstrate the symptoms of the disease at a relatively early age), are infected by the condition because it appears to have been inherited. Hence, it is in these interstitial ways that the felt experience of Alzheimer's disease and dementia more generally, crosses the gap between one individual and another and thus moves into the public realm. Wright Mills's argument concerning history and its effect on the inner life of individuals resonates significantly here. An epidemic is one way of reading the Wright Mills' paradigm, being an event which can be perceived as crossing the cultural divide of private and public, not only as a cause in biological biography (as argued later in this chapter from the work of David Shenk), but as an experience that creates social crises. Illness, of course, is a universal as well as an intensely private experience, one where the science and practice of medicine is supposed to act to relieve the tension between the two.

Clearly epidemics generate individual and social fears about what is unknown, undesirable, or misunderstood. In *Dread*, Alcabes writes that:

The way we have responded to epidemics like polio, AIDS ...
and the way we are currently responding to obesity [etc] ...
reveal that we bring fears to the prospect of any sort of epidemic,
deadly or not.⁴

³ William Bynum, *The History of Medicine* (Oxford: Oxford University Press, 2008), p. 68.

⁴ Alcabes, p. 5.

According to Alcabes, our fears and anxieties appear to be manifold, going beyond what is usually seen as normal fear of death:

To judge by our response to epidemics that are less sudden or catastrophic than the black death, we fear much more besides: strangers, flying things, modern technology, female sexual desire, racial differences ... and so on.⁵

One might add to this the fear of a decrepit old age. Of course, the number of people growing into old age has been a matter of knowledge for some time and therefore cannot be as sudden or as catastrophic as some epidemics have been in history, but nevertheless it seems to have taken western culture by surprise with a mix of relief, pleasure and fear at its own success that life now routinely goes beyond God's allotted time of the proverbial three score years and ten. Alcabes underlines this point when he argues that 'besides our dread of death, we are frightened by the prospect of social disruption. To live in a civilized society is to bear a dread that goes beyond the fear of death'. In the land of the living, fear, it is implicitly suggested, is part of our makeup, waiting, as it were, to be awakened. In this sense Alcabes echoes Mary Shelley and Julia Kristeva, indicating that without order, the terrible and the extravagant can be admitted, particularly if the cause is unknown.

Imaginative Dread

But even if the cause is known, it appears our fears and apprehensions can still be stirred into imaginative forms of dread and desire to capture and, to a degree, distance ourselves from these social fears and ills. This might be argued to be the function of the Gothic, a kind of repository and a metaphor for such fears.

⁵ Alcabes, p. 5. These points of fear are implied to be part of 'human nature'.

Illustrative of Alcabes' argument that epidemics have three aspects,⁶ Edgar Allan Poe's story, 'The Masque of the Red Death', registers an event which causes disease and illness, thereby establishing a social crisis. Such crisis disrupts private lives and public institutions and, in turn, becomes transformed into a kind of narrative which knits these several aspects together.⁷ It seems likely that this story may have been prompted by tuberculosis, from which Poe's wife suffered and from which his mother died. Poe is also likely to have witnessed an epidemic of cholera in Baltimore, Maryland in 1831 which could also have helped inspire the story.

There are two protagonists in Poe's atmospheric tale. The first protagonist is the disease which has developed into an epidemic and is mainly illustrated through its symptoms and the death of those who are infected. The second protagonist is a class of people, personified through the Prince Prospero, who attempt to escape the disease by taking refuge in one of the Prince's 'castellated abbeys'. The Prince and 'the knights and dames of his court' believe this self-imposed exile will protect them from the 'Red Death' disease which has caused the demise of half his population.⁸ Place and time suggest something medieval in Poe's story, but what is also discernible is the fabric of William Shakespeare's *The Tempest*, which relates the story of Prospero, the Duke of Milan, who, taking flight to a seemingly deserted island, finds himself troubled by the monstrous

⁶ Alcabes, p. 5.

⁷ Edgar Allan Poe, 'The Masque of the Red Death' in *Selected Tales* (London: Penguin Books, 1994), pp. 192-198.

⁸ Poe, p. 192.

Caliban. Poe's 'Prince Prospero' is also referred to as the 'Duke', and it is he who vividly describes the symptoms of the 'Red Death' at the beginning of the tale:

Blood was its Avatar and its seal – the redness and the horror of blood. There were sharp pains, and sudden dizziness, and then profuse bleeding at the pores, with dissolution. The scarlet stains upon the body and especially upon the face of the victim, were the pest ban which shut him out from the aid and from the sympathy of his fellow-men. And the whole seizure, progress and termination of the disease, were the incidents of half an hour.⁹

This description of the 'Red Death' portrays the victims in a condition of posthuman dissolution with an outpouring of blood creating an image of horrific proportions. Thankfully, the suffering is over in a short time. The Prince and his followers can have no dialogue with this kind of death, it is too horrible and too quick, and they can only take flight from its terrifying manifestations, but epidemics, Poe seems to be saying, are dreadfully democratic.

Poe's narrative language suggests a medieval period which is illustrated by many of the familiar Gothic motifs, particularly of dread, incorporated as an apprehension of an uncertain future with an unknown disease as the object of fear. There is no indication of when the disease will strike, but it is implicit that it will, and escape is not really possible. Fate, therefore, is central to the narrative, as it is to the idea of falling victim to an epidemic. This establishes a sense of both fear and awe. Certainly the pleasures sought by the Prince and his followers at his masked ball in his abbey, as a means of avoiding thinking about the disease, seem to be a kind of fearful indulgence in the face of a terrible death, symbolically masqued to bring the story to a close.

⁹ Poe, p. 192.

If apprehensive dread is endemic in the experience of epidemics, it suggests an uncertain waiting for the disease to strike: a kind of anticipation of an adversary to take on in battle. It can also incorporate the notion of fate. This is something that determines the feelings of the narrator in Michael Ignatieff's novel *Scar Tissue*, whose mother and maternal grandmother have become subjects of the Alzheimer's disease he begins to believe he will inherit - indicating a kind of immortal gene: 'It was as if I discovered in my innocence, that there was such a thing as fate and that it could take a life and dismember it'.¹⁰ The narrator portrays himself as a helpless victim of past generations, fated to be driven asunder into bits and pieces by this immortal gene which will determine the relinquishment of his thinking self. The privacy of his family life is exploded by this understanding and his psyche begins to unravel both in the face of his mother's deteriorating psychological sense of self and his knowledge of maternal family history. He becomes obsessed by the ghosts of his past as they begin to create the sense of chaos that overtakes him, suggesting that he is beginning to feel the effects of this inherited condition by the novel's end. This text will be discussed in a later chapter, but here it illustrates, together with Poe's story, the chilling effect of gothic on the idea of fate destroying people by a masqued disease revealed through symptoms which permeate private and public spheres through its effects on mind and body.

¹⁰ Michael Ignatieff, *Scar Tissue* (London: Chatto and Windus, 1993), p. 64.



Biology and Old Age

As explicated above, it may be argued that disease creates a space in which the private and the public cross over one into the other and collide with some physical and emotional force. Wright Mills uses these terms to suggest both a demarcation and a relationship, and his notion of private troubles being transformed into public issues is illustrated in the Audit Commission's report referred to in Chapter 1.

This is a text which foregrounds a segment of the population as an infectious social problem requiring regulation through statutory and voluntary welfare and medical provision. In doing so, it problematises, and socially constructs, an ageing population as an actuarial one and, in consequence, echoes Spencer's alarmist demographics at the same time as emphasising Darwinian biology as the master of the ageing body. Although the Audit Commission's report gives a due recognition to the social, it establishes a hierarchy of explanation and by giving pride of place to the biological, medicine comes to be offered as the starting point for intervention. Therefore, with old age construed in its terminal stages as a biological process and thus outside the social, the ageing body becomes medicalised as a malfunctioning entity seemingly without emotional and social content. Because precedence has been given to the organic, arguably this puts the aged body into a kind of posthuman condition, given that it is no longer seen as a maker of meaning. Construed thus, terminal old age divides the body from the mind. If memory is crucial to self-reliance, its disappearance signals a journey into the paradox of adult infancy.

In focusing upon loss of function and how this may best be managed, the report, solicitous in tone throughout, advances medical specialities originating in the nineteenth century: geriatrics and psycho-geriatrics. Such specialities have appropriated the ageing body as their particular focus, and have centrally cast that body as pathological and terminal. Much commentary on these considerations is closely associated with loss, and indeed loss is often the dominant empirical experience. And the otherness of the biological aged body is not just a construction of medicine; other discourses - psychology, sociology, public and social administration - have also contributed much of theoretical salience. Managing the otherness of the ageing body has been underpinned by what may be described as welfare narratives, and the explanation afforded by the Audit Commission report is exemplary in this regard in that it evidences the three stages by which the otherness in question is constructed: first, the fact of an ageing population is offered as a problem to be resolved; secondly, the problem is classified and categorised into a body of knowledge; finally, ways and means are outlined of dealing with individuals and their families who present with these problems. The otherness which is to be exposed to the attentions of welfare is construed by the de-anchoring of the social from the biological, and it is to this de-anchoring that this chapter now turns.

The Public 'Life' of Alzheimer's Disease

Within the discursive nature of the paradigm presented by the Audit Commission remains a structural issue. It may be argued that the problematizing of old age, with its emphasis on loss to the point of death, produces welfare capitalism: that is

to say, the 'problem' of old age supports a welfare industry of providers to tend to a malfunctioning, biomedical, aged body set apart from its anchoring social, cultural and intimate self. The Audit Commission report certainly characterizes an elderly population at risk of losing such anchorage through the process of dementia, and in textualising such a characterization, the report argues the necessity for partnerships between public and voluntary bodies and the families and carers of those diagnosed with the condition.

Thus the Audit Commission creates a space in which both private and public are able to meet, but at the expense of a body already marked by the constructions that the report endorses. For those diagnosed with dementia there can be, the report implies, no Cartesian dualism, nor the construction, let alone the maintenance of a sense of self outside the body. Bodily decay parallels mental decay, and, as such, constitutes old age and otherness. Biologically, the body betrays the idea of self. The report's endorsement of the stereotypical medicalised and aged body is an illustration of textualising, of writing on that body. It also indicates that the spaces of the private and the public circulate around this body, considering, examining and often reviling it in its entirety as well as its fragmentation. The body, in this state of disarray, invites further textualisation as illustrated below.

David Shenk's *the forgetting: Understanding Alzheimer's: A Biography of a Disease*, reflects upon and explores the exchange between culture and power.¹¹ Many theoretical constructs explore this tension, but Shenk attempts to consider

¹¹ David Shenk, *the forgetting: Understanding Alzheimer's: A Biography of a Disease* (London: HarperCollins, 2002).

the factual effects of Alzheimer's disease and how it has affected the public domain as demonstrated by comprehensive responses from voluntary bodies, funding organizations, medical and scientific research, the pharmaceutical industry and government as a whole. The text illustrates how a contemporary perception has come about, given the increasing number of people living into old age, the effects of ageing on individuals, families, public and voluntary services, and the need to develop social policies as tensions oscillate between and within these groups. His analysis makes it appear that a single organic condition has spread its effects to a considerable degree as private troubles penetrate and punctuate the domain of the public and vice versa. Shenk foregrounds Alzheimer's disease and its history from its naming in 1910 to the present day. He entitles his text a 'biography' of the disease, suggesting to his readers that not only does he wish them to understand this subject as a disease, a scientific as well as a social one, but as a character that has a life of its own, and a singular one encompassing many other bodies. It is a 'life' that emerges as a kind of serial killer: a 'life' that is decadent and promiscuous in its 'purpose', indicating a text which may be read as a kind of Gothic thriller. By giving due weight to the most extreme effects of Alzheimer's disease, Shenk's text evokes a double response of horror and compassion: fear of the condition, and sympathy for those who suffer from its 'purpose'.

Its 'purpose' may be described as driving out the inner life, derived from internalizing 'civilization', and creating another form of self-presentation: that of someone living in space rather than time. The conventions of restraint taken more

or less for granted in most social interaction are lost, and, as regression sets in, a private self becomes a public problem due to the body's capacity and ability to disturb the order of time. Perhaps it is the notion of the regression of the adult body and mind that provokes fear, bringing in its wake a transforming counteraction: in this instance it is the forces of modern medical science which bring the transformation into focus. Medical science, in particular, based on the principle of law and certainty and the absence of doubt, comes to be centrally challenged by the discovery of a condition such as Alzheimer's, which confounds the law as manifest in known diagnostic labels. Shenk's text shows how 'objective' science and 'subjective' experience are brought together within the space of a tension between mind and body. What really troubles the laws of medical science is the idea of randomness: people suffering from Alzheimer's disease reveal no established pattern of the invasion of the disease other than the symptoms of the condition themselves. Therefore, such 'accidents' suggest those diagnosed with the disease are victims, and this seems to make it both unfair and unreal. Such randomness also elicits a fear of the disease as uncontrollable, and in this sense it haunts a wider public domain in much the same way as any kind of epidemic will, which is vividly illustrated and gothically represented in Poe's story.

This invasive 'life' has a haunting effect in its very insidiousness; a growing blight from which, apparently, it is impossible to escape until it devours the very thing which keeps it alive: memory. Shenk quotes Ralph Waldo Emerson's argument that memory brings us into being, shapes our consciousness,

and that 'without it all life and thought [is] an unrelated succession',¹² and he accentuates the biological process of memory:

New memory traces are laid down on top of a foundation of old memories, and old memories can only be recalled in context of recent experiences ... because of this, no recorded experience can ever be fully distinct from anything else. Whether one likes it or not, the past is always informed by the present, and vice versa.¹³

Shenk's definitive statement of how biology affects the processing of memory fits comfortably within the assurances of neurological science, and can be traced back to Spencer and Jackson's nineteenth-century views that the latest memories will be the first to be contaminated by earlier ones, and would be the first to be lost in the process of dementia. Shenk's description of a biological process uses a language which explains its complexity in simple images. His description constructs a metaphor imaging memory as architecture that changes with time as repairs and new materials are added to build upon the original structure. Shenk declares that biology determines the processing of our memories. Old memories mixed with fresh ones are clearly malleable, and if our identities are so reliant on this mix (as his citation from Emerson seems to suggest) it follows that memories can never really be fixed and permanent. Here, it appears, biology meets poststructuralism with its notions of identity also being something which shifts and is reshaped with passing experience.

These notions of shifting and re-shaping clearly complicate the idea of laws and the culture of medical science, but, at the same time, such notions have to be quelled so as to quieten the apprehensions and costs that disturb the private

¹² Shenk, p. 6.

¹³ Shenk, p. 55.

and the public. In this sense, medical science finds it problematic to ignore the social, and maybe Shenk's metaphor underlines the necessity to reshape science's laws which, in most cases, offer rewards (in medical, social and economic terms) if such reshaping takes place. The medicine of old age is not a 'glamorous' aspect of medical science, but, as Shenk points out, the discovery of a mitigating drug or a cure for Alzheimer's disease will make those involved very rich indeed.

Neurological science is particularly well placed to prosper from reshaping the paradigm. Consequently, research on the mind and the brain faces many tensions.

Memories are an aspect of our consciousness and hence of our mind. Paul Broks's belief is that:

Minds emerge from process and interaction, not substance.
In a sense, we inhabit the spaces between things. We subsist
in emptiness.¹⁴

Broks seems to be arguing that minds are primarily the result of culture although clearly we need to have the basic physical machinery with which to interact. It seems to Broks that the mind fits a space somehow between the body and the space within which it moves or operates. But once the mind, however formulated, begins to be taken over by bodily processes, it stops interacting, and the body appears to become an empty space. When Alois Alzheimer carried out an autopsy on the brain of Auguste D. in 1906 and discovered the condition which thereafter carried his name, was he considering a piece of machinery devoid of self, mind and soul? Auguste D. had stopped interacting with the world in any comprehensible way several years before her death, which would indicate that her

¹⁴ Paul Broks, *Into the Silent Land* (London: Atlantic Books, 2003), p. 56.

mind was beginning to disappear, or regress, at a stage earlier than her death. As

Broks argues:

The self is not an intrinsic feature of the brain and it is possible to become derailed – through psychosis ... and as a result of brain damage.¹⁵

Hence, our consciousness of things and ourselves can be ‘derailed’ by any number of unpredictable, random ‘accidents’. As Shenk points out, such ‘accidents’ demonstrate both that ‘the disease [Alzheimer’s] was emerging as one of the largest causes of death in the United States’¹⁶ and, that, prior to death, the number of bodies outliving their minds was creating a level of dependency that society felt it could not contain: ‘the unique curse of Alzheimer’s is that it ravages several victims for every brain it infects’.¹⁷ Here, Shenk’s language conflates demographics and classifications to create, perhaps unwittingly, a transformative Gothic image of unrestrained, cursed and infected bodies, such as the victims in Poe’s story, which are forms with no content: the ‘parade of horror’¹⁸ or zombie-like monstrous images so feared by Thomas DeBaggio. Alzheimer’s disease is turned into a curse and an infection that ravages a decrepit old age as it sits at the edge of the formlessness of old age, and confers another identity and a representation of monstrosity.

Certainly it is others, who are forced to confront this process of regression, who need somehow to compensate for the witness with which they are challenged. Shenk’s language, however, suggests some transcendental malign

¹⁵ Broks, p. 42.

¹⁶ Shenk, p. 62.

¹⁷ Shenk, p. 62.

¹⁸ Thomas DeBaggio, *Losing my Mind* (New York: The Free Press, 2002), p. 1.

force concerning the disease, which seems to be incisive in its 'purpose', for to be cursed, infected and ravaged is to be taken over by the other within and typical, as such, of subliminal fears demonstrated in Poe's story. And the number of bodies outliving their minds drives the condition into the public arena as individual stories add up to such significance that they become public concerns underlined by these Gothic images:

The disease name is public recognition of a shared affliction. The name says, this is what you are suffering from. You are not alone. Others are suffering from the same thing ... once accepted, specific names quickly come to dominate social reality.¹⁹

Shenk maintains that names become emblematic of a process, not a thing, and it is this transformative process which is, paradoxically, fixed by one name - Alzheimer's. The reality of the disease to those so diagnosed, and their families and carers is inevitably shifted into the social and public arena through the intervention of diagnosis and the subsequent prognosis which seeks to identify a range of services in an attempt to combat the disease: public recognition and social reality are indeed defining aspects of the public and the private. For all engaged with the 'victim' there may be opportunities to share common experiences of loss or care; but as the disease progresses the patient, as 'victim', moves beyond any notion of shared interaction, moving into a state of isolation from others and themselves. Many simply become lost, to themselves and to others, behind the symbol of the name, and although medical science is underpinned by an optimism that believes that in the end 'nature' will give way to

¹⁹ Shenk, p. 80.

man's intervention, it seems that there is a chasm between that optimism and the mournful world of sufferers of the disease. Broks, however, argues that:

We must try to understand what mechanisms might be operating at the intersection of the biological (the brain) and the social (the self).²⁰

Such Cartesian dualism perceives the biological in terms of mechanisms and the self as something quite different and distinct from it. This is akin to the idea of the ghost within the machine, but it is also suggestive of a descending mist. Certainly many who suffer from Alzheimer's disease describe their state of being in these terms as the disease makes its insidious progress with the protein plaques and tangles smothering and hiding the mechanisms associated with storing memories. But in the initial stages of the disease process another psychological aspect tends to come into play. Shenk records how some patients resist the changes which they are undergoing:

Denial is an important part of the Alzheimer's experience, very commonly employed as symptoms first appear, or at any juncture where a truth is so horrifying that the most emotionally healthy choice is to pretend that it does not exist. The poisonous reality is pushed back into the recesses of the mind and only slowly, in small drips, is it allowed to seep back into consciousness.²¹

Shenk's interpretation, following interviews with patients and staff, suggests a continuing but steadily reduced consciousness of self, which eventually goes beyond reach. He suggests that this consciousness is still psychologically aware enough to deny the condition and its effects, and he expresses, in some dramatic terms, the way patients demonstrate such attitudes. Logically, it would appear that

²⁰ Broks, p. 52.

²¹ Shenk, p. 115.

a remaining self-consciousness uses the space between the mutability of the disease and the residual sense of self to express a kind of illusionary dream as a form of defence. It is as if the subject is stranded in time between the past and the future, an unbecoming in prospect, uncertain of place or status and unanchored. The subject is both touched and untouched within the denial.

The Freudian psychological model of the mind argues that the ego is driven by ego-reality, a consciousness of the objective world. In this sense, the ego is primarily concerned with self-preservation and part of that instinctual drive is to deny the objective world. Freud argued that it was necessary for the organism to seek a state of constancy, a state of equilibrium by discharging tensions, maintaining that:

The nervous system is an apparatus which has the function of getting rid of the stimuli which reach it, or of reducing them to the lowest possible level; or which, if it were feasible, would maintain itself in an altogether unstimulated condition.²²

Denial seems to be a defence which seeks to prevent an estrangement from oneself. If the defence process proves insufficient it means the subject becomes separated from himself and a split occurs. The subject's hold on their linear narrative becomes dream-like as their edges and boundaries grow blurred and indistinct as represented in the characters of Maarten and Jake in, respectively, *Out of Mind* (see Chapter 2) and *The Wilderness* (see below). The apparent trauma of the condition, with all its emotional consequences, seems to establish a kind of internal silence. Alzheimer subjects who use denial as a defence,

²² Sigmund Freud, 'Instincts and their Vicissitudes', in *On Metapsychology: The Theory of Psychoanalysis*, ed. by Angela Richards and trans. by James Strachey, Penguin Freud Library, Vol. 11 (London: Penguin Books, 1991), pp. 107-138 (p. 116).

something that might be called a protective shield, suggest a psychic splitting whereby two 'people' are created: one of these seeks to be part of the world, and the other acts as if they have no contact with it at all. What Shenk refers to as the 'truth' seems to be accompanied through the process of diagnosis, with the subjects coming to realise that they will disappear into their own futures which will bring a first death - loss of self, before the second physical death. Moreover, Shenk regards such denial as an 'emotionally healthy choice', echoing Freudian notions of defence as a developmental and evolutionary idea, with sublimation, in this sense, viewed by Freudian analysts as 'normal'.

However, the basis of defence is in the instinctual drives, and the ego, seeking equilibrium, has to displace such instinctual energy elsewhere, and Shenk is clearly committed to the view that the ego energises the defence mechanism of denial, suggesting a circular or repetitious process. The desire for equilibrium is driven by a search for security, for peace, for not wanting to be troubled; but such a desire is, in itself, akin to the surreal, unworldly, somehow out there and, in a Lacanian sense, Real. But the fear of disappearance hangs uncomfortably within the notion of denial. Such feeling creates something of the sense of the uncanny, Freud's psychological notion which has its own Gothic fabric as Nicholas Royle claims:

The uncanny entails another thinking of beginning: the beginning is already haunted. The uncanny is ghostly. It is concerned with the strange, weird and mysterious, with a flickering sense (but not conviction) of something supernatural. The uncanny involves feelings of uncertainty, in particular regarding the reality of who one is and what is being experienced.²³

²³ Nicholas Royle, *The Uncanny* (Manchester and New York: Manchester University Press, 2003),

Samantha Harvey in her novel *The Wilderness* describes some of these uncanny uncertainties through Jake, an architect, who is beginning to become exposed to the symptoms of Alzheimer's:

He stares at the drawing; it is not his, it was done by one of the junior architects and he has been asked to check it ... A simple two-storey building whose only design hurdle is, as ever, the budget; but even so he has been gazing at it all afternoon, his pencil in hand, a stream of coffees getting cold as he tries to remember what it is one is supposed to do. Should he change the lines somehow (but how)? Should he put a tick in the corner?²⁴

Jake refuses to acknowledge his symptoms until events and experience overtake him and Shenk describes this point in the process of the disease as a kind of middle stage:

The middle stages bring the end of ambiguity. The subtle clues that something was not quite right - so easy to miss a few years ago - are now bright, self-reflecting signposts of decline, impossible to avoid. Conversation is now pockmarked with lost names and empty recollections. Times and dates have become fungible. Concentration wanes. The mind is clearly ebbing.²⁵

It is paradoxical of course that the manifestation of decline should be both 'bright' and 'pockmarked' and full of 'empty recollections' so that it cannot be misjudged in any way, illustrated, curiously, using the language of contamination and epidemic. However, this odd oscillation between knowing and not knowing who one is emphasizes Royle's conception of the uncanny in its 'strange, weird and mysterious' formulation.

p. 1.

²⁴ Samantha Harvey, *The Wilderness* (London: Jonathan Cape, 2009), p. 35.

²⁵ Shenk, p. 117.

For the Alzheimer's disease patient it is a process of exile, being separate from oneself as if the patient is doubled, inside and outside of the self as something akin to emptiness begins to occur. Denial of this estrangement can be construed as a form of silence: it speaks only in its symbolism as it meets, in secret encounter, with ego-reality. Shenk indicates that denial is passed once the second stage of the disease arrives. It is, he declares, an end to any ambiguity of the condition. As the process of the disappearing self gains ground, it may be viewed as some sort of return, albeit an unwelcome one, to innocence, represented in an unprotected vulnerability: no defences, no boundaries, no edges, just a blur as the disease announces the end of psychology and the beginning of neurology. The paradox, sublimely, is both beautiful and horrifying as this unprotected vulnerability makes a claim on whatever it is we call humanity. Shenk comments that Barry Reisberg, neurologist at New York University and a 'pioneer in defining stages and substances of Alzheimer's',²⁶ once noticed:

That there were precise inverse relationships between stages of Alzheimer's disease and phases of child development in the areas of cognition, coordination, language, feeding and behaviour.²⁷

Such an inversion echoes Jackson's nineteenth-century view that dementia, once on its journeying trajectory, was noticeable by its dissolution of the human personality. All the skills, knowledge, feelings and facts that a person has learned are steadily eroded as the process of becoming inches towards unbecoming.

²⁶ Shenk, p. 122.

²⁷ Shenk, p. 122.

The Private 'Life' of Alzheimer's Disease

Not all 'victims' of Alzheimer's disease await its insidious coming in a passive way. Some struggle to hold on to whatever it is they consider themselves to be, in attempting to stem the coming of the other within. The Alzheimer Disease Society has brought together some personal accounts of those taken up with such endeavour, and one such account states:

Every morning when I wake up, I'm unsure where I am and feel anxious. But when I see familiar things, I know I'm at home. At night I try to take all my important things into the bedroom with me. It's reassuring to know everything is in place when I get up in the morning. It helps me feel calm if I know what time it is and what day it is, so I have the TV guide and clock next to my bed. Some mornings I forget to look and consequently get up very early.²⁸

The organisation of space and materials to anchor time and self is clearly very necessary for this person, in the struggle against forgetting and being a 'victim' about to be swept up into a void. There is no apparent denial here, only an admission of the disease and its effects which provokes both a defensive and proactive response.

Such a struggle, moreover, exemplifies the notion of the uncanny in its exposition of the compulsion to repeat. To stem his anxiety about forgetting, 'John', whose account this is, devises a set of repetitive behaviours to reassure him of being himself. The essence of repetition rests not only upon the idea of familiarity but, in psychoanalytic theory, the need to resolve a problem. But what does it hide? As Freud puts it, if an emotional impulse is repressed:

into anxiety, then among instances of frightening things
there must be one class in which the frightening element can be

²⁸ *In Memory of Memories*, Alzheimer Disease Society (London, 2003).

shown to be something repressed which recurs. This class of frightening things would then constitute the uncanny.²⁹

A number of selves appear to be operating in 'John's' account. There is the conscious self, seeking to handle the anxiety of another self which is so threatening. The anxiety seems to be related to a form of living death. In this void, the private and the public necessarily meld into each other. There are no more nuances or ambiguities (essentially forms of privacy), just an emptiness which is, paradoxically, the enclosed space of the material organism. According to Freud such doubling of self originates in the development of the ego and acts 'against the destruction of the ego, an energetic denial of the power of death'.³⁰ The ego seems to hold this doubling in some kind of balance through the process of repetition which, moreover, symbolically brings to light what Freud calls 'the uncanny harbinger of death'³¹ in the form of the representation of the double within the repetitive behaviour.

Royle's construction of a transcendent uncanny as 'strange, weird and mysterious' may be thought to be akin to magic by Freud - a product of the enlightenment project in medicine. However, Freud's work in the First World War on the process of the uncanny and primary instincts draws attention to the internal pessimism of the enlightenment project as he emphasises a further collapse of the private and the public within the paradigm of biology and culture with meditations on the death instinct. Freud published his essay on 'The

²⁹ Sigmund Freud, 'The "Uncanny"' in *Art and Literature*, ed. by Albert Dickson and trans. by James Strachey, Penguin Freud Library, Vol. 14 (London: Penguin Books, 1990), pp. 335-376 (p. 363).

³⁰ Freud, (1990), p. 356.

³¹ Freud, (1990), p. 357.

“Uncanny” in 1919, but while working on these ideas was also developing his thoughts on the subject of primary instincts which were eventually published in 1920 under the title ‘Beyond the Pleasure Principle’. Both works meditate on how the mind protects itself from reality, particularly the matter of death. But within the biological paradigm of the primary instincts, a parallel exists between the sexual instincts, which, Freud argued, are concerned with the preservation of life, and other instincts which apparently lead to a form of regression and eventually death - an inorganic state. In his account of keeping anxiety at bay, ‘John’s’ conscious self depends on repetitive, habitual behaviour as an expression of mastering the anxiety created by what Freud calls a ‘truth’:

If we are to take it as a truth that knows no exception that everything living dies for internal reasons - becomes inorganic once again - then we shall be compelled to say that *‘the aim of all life is death’* and, looking backwards, that *‘inanimate things existed before living ones’*.³²

This evocation of Darwinian biology underscores an uncanny concealed desire to cease living; that nothing can gainsay the desire to return to this inorganic state. Simultaneously, however, an equally powerful instinct for self-preservation has to be accommodated. ‘John’s’ account of his desire for self-preservation conceals, in Freudian terms, the symbol of the death instinct, that internal desire to die seemingly created in the form of an organic disease which is ‘determined’ to kill off itself as well as the body which incorporates it. However, ‘John’s’ remaining conscious self demonstrates an equal determination to stave off his anxiety and maintain his independence:

³² Freud, ‘Civilisation and its Discontents’ (1991), pp. 310-311.

My independence is hugely important to me. I might seem a prisoner of my routines. I can't just pop out. I can't do my job or go for a drive. But I still manage to live on my own.³³

This paradoxical independence caught within the structured routines of a prisoner, is suspended within the interstices of the private and the public, giving a greater significance to the private against the encroaching public as biology and culture begin insidiously to merge.

The importance of personal privacy finds an emphasis in Jonathan Franzen's book about his father:

My father was an intensely private person, and privacy for him had the connotation of keeping the shameful content of one's interior life out of public sight. Could there have been a worse disease for him than Alzheimer's? In its early stages, it worked to dissolve the personal connections that had saved him from the worst of his depressive isolation. In its later stages it robbed him of the sheathing of adulthood, the means to hide the child inside him.³⁴

Franzen renders his father's privacy public, presumably to make the point that Alzheimer's disease destroys such distinctions in much the same way as it destroys the distinction between what 'John' sees as independence and dependence. The psychological attributes of privacy and independence seem conjoined and are probably perceived as central aspects of the notion of self, which is seemingly buried beneath them. However, in Julian Barnes's short story 'Appetite', the first-person narrator, discussing her husband's dementia, says:

When it began, I thought, well it's better than some things he could have got. Worse than others, better than some, and though he'll forget things, he'll always be himself, there,

³³ *In Memory of Memories*, p. 19.

³⁴ Jonathan Franzen, 'My Father's Brain', in *How to be Alone* (London: Harper Perennial, 2004), pp. 7-38 (p. 24).

underneath, through and through. It may be like second childhood,
but it will be his childhood, won't it?³⁵

The narrator perceives her husband's dementia in relative terms, but argues that his essential self is still 'buried', ghost-like, within and remains somehow in his ownership, notwithstanding that this self is locked in by the disease. Indeed the 'selves' of 'John', Franzen's father, and the narrator's husband in Barnes's story share the common experience of this locked-in privacy.

Privacy is at the compelling heart of psychoanalytic theory: so private that it is unknown to itself except in occasional acts of unwitting revelation, either in deeds or in words, asides at the edges of things. But Alzheimer's disease seems promiscuously to conflate the private and the public and in so doing reduces the human to its basic elemental being. Franzen and Barnes elaborating from their personal and imaginative spheres conjure this humanity and posthumanity into our presence and render the conflation into a recognisable private and public persona. Barnes's narrator, with regard to her husband, and Franzen with regard to his father, perceive the self as owner of their experience and narrative: aged bodies carrying on through the agency of much younger ones, ones which return their owners to a childhood stage through the passage of the disease. For the narrator, her husband's past is another country. Between her and that place is an almost impenetrable hurdle, which she can rarely cross to be able to get a glimpse, through his confusions, of what that place may have been like for him. Demands are made upon the imagination if the demonstrable confusions of the veil are to be seen through, and the occasional rushes of memory which visit the demented

³⁵ Julian Barnes, 'Appetite', in *The Lemon Tree* (London: Picador, 2005), pp. 159-173 (p. 164).

patient may well seem phantasmagorical to the carer or observer. Body and mind are written upon by Alzheimer's disease as memories are insidiously written off.

Exploring the 'mystery' of this writing, Tobias Wolff notes:

Below the mind's business and noise, in deep unlit shafts
where phantom messengers struggle towards us, [they] kill
one another along the way.³⁶

What is left resembles a rush of phantoms, breaking the surface of a dying consciousness. Wolff's interest is in another form of what might be called the creative instinct which, he suggests, arises from the depths of consciousness, arriving unannounced and in unexpected or unpredictable forms. The anticipatory fascination of this has its own kind of rhythm but is, no doubt, again as Wolff hints, tinged with anxiety because of something concealed being revealed.

Franzen, in discussing the importance of privacy to his father, draws attention to the notion of concealment as some sort of condition of civilization. The term is a broad one, which covers not only secrecy and deception, but also, as in Franzen's father's case, reticence. Social conventions precede legal rules, and, as a social convention, an attitude of reticence clearly fights shy of the excessive revelation. But the subject of Alzheimer's disease displays no such consideration and the boundaries of mind and body break under the strains of the excessive. The disease may well be thought of as an act of material violence by the body on its seemingly separate mind - a mind vulnerable to material violence - and the weight of that violence alters the shape of mind and body alike. The disease may also be seen as a space occupied with dead time, memory and anticipation having no grip

³⁶ Tobias Wolff, *Old School* (London: Bloomsbury, 2004), p. 156.

on 'reality' and no anchorage. The subject becomes the other and falls into another narrative discourse. The mind, no longer able to edit or censor, cannot muster the defences of social convention, and, if Franzen's father had any right to concealment, it was thoroughly abused by Alzheimer's disease.

Furthermore, the condition is one which does not allow for a relationship between an inner world and the public domain, a domain that regulates social relationships and unspoken contracts. Indeed the condition veils the capacity to imagine the self, looking, as it were, inside from the outside. The abuse of the disease robbed Franzen's father, as it will inevitably 'John', of an interior life, that concealment of experiences owned by him. Inexorably, the disease will reduce adulthood to that of the vulnerable child within. Such representations of the disease call to mind Jackson's notion of dissolution, more than Spencer's or Freud's construction of an animal-based biology imposed upon by an editing and censoring mind, regulating the material embodiment and permitting the 'contractual' relationship with the public domain. Without such regulation, Franzen's father, together with all who endure the disease, become marginalized 'children' within mature bodies.

Wolff's interest in the creative instinct and the rhythm which accompanies it is echoed, in a different sense, in 'John's' repetitions. The interim for him and others like him is that period between the diagnosis of Alzheimer's disease and the onset of the final phase of loss of function and memory. What is woven into 'John's' repetitious rhythms is also an inevitability as to outcome. His repetitions form an incantatory rhythm in that period between diagnosis and the final phase.

It is a time which is indicative of a future squeezed into a present - a future occupying the performance of the present. The repetitions may seem to keep time at bay, but paradoxically bring the future into the present. They echo 'John's' sense of foreboding, like some haunting of the other self to come. Viewed from the perspective of Alzheimer's disease as the harbinger of the birth of a contracting old age and a dependent childlike state, the repetitions are also reminiscent of childhood itself. The repetitions are, of course, important to 'John' as a way of keeping a grip, a purchase, on both his present and his presence. But the haunting of that self to come clearly marks the existence of the disease which begins its own *tabula rasa*. The repetitions draw attention to the self's incipient disappearance as the disease begins to write itself into the self, to determine and shape the story of another self to come.

Returning to the Body

The idea of incipency and a state of being incipient becomes the paradigm in Julia Kristeva's *Powers of Horror: An Essay on Abjection* (see Chapter 2).

This notion is central also to Freudian psychoanalytic theory in so far as that theory is concerned with the trauma of origins and the passage, or, in Kristeva's paradigm, terrifying journey of the primary instincts or drives into the realm of language: put another way, from the biological to the psychological or from the private to the public. The process is one in which the body seems to be expelled by the power of language, which resonates with Terry Eagleton's argument that the Western aesthetic has primarily ignored the body.³⁷ Kristeva's title indicates

³⁷ Terry Eagleton, *The Ideology of the Aesthetic* (Oxford: Blackwell Publishers, 1996). Eagleton's

her concern with origins, boundaries, change and mutability. She perceives abjection as some sort of motif for these concerns - a form of casting off: a rejection as well as a refusal:

There looms, within abjection, one of those violent, dark revolts of being, directed against a threat that seems to emanate from an exorbitant outside or inside, ejected beyond the scope of the possible, the tolerable, the thinkable.³⁸

The essence of the paradigm seems to be the struggle between becoming 'I', and hence a subject and object in relation to others, and what is left behind in the deep unconsciousness of the body from its earliest and most vulnerable time.

But what is the 'nature' of this period? Kristeva argues that it is a time of non-existence: a body incorporated into a world full of needs and wants and the satisfactions and disappointments that these desires and their fulfilment bring. It is a world of the exorbitant outside and inside, an undifferentiated being. Noelle

McAfee refers to it as:

The pre-oedipal undifferentiated stage, one in which the child experiences itself as the receptacle of all being.³⁹

As previously described in Chapter 2, McAfee characterises this undifferentiated state as 'the chora: this state of being one with all'.⁴⁰ Kristeva explains the splitting of the becoming subject from the wholeness of a maternal envelopment in terms of the spasms and vomiting out of food:

text attempts to reveal the body within European thought from the Enlightenment to the twentieth century.

³⁸ Julia Kristeva, *Powers of Horror: An Essay on Abjection*, trans. by Leon S. Roudiez (New York: Columbia University Press, 1982), p. 1.

³⁹ Noelle McAfee, 'Abject Strangers: Towards an Ethic of Respect' in *Ethics, Politics, and Difference in Julia Kristeva's Writings*, ed. by Kelly Oliver (New York and London: Routledge 1993), p. 117.

⁴⁰ McAfee, p. 117.

During the course in which 'I' become, I give birth to myself amid the violence of sobs, of vomit. Mute protest of the system, shattering violence of a convulsion that, to be sure, is inscribed in a symbolic system.⁴¹

Here Kristeva gives an emphasis to the primary processes of the body as a power that incorporates itself into the deep recesses of the developing psyche, which, represented in a violent gothicness, acts as a preamble to her evolving thesis about the nature of the abjecting process. Symbolically, subjectivity becomes formed in the process of expelling and spitting, and such expulsion encompasses becoming 'I' as well as refusing and rejecting the hitherto all-encompassing maternal. This passage of unconscious but bodily actions creates the demarcation of the self and the other. But although the 'chora' is rejected and repulsed in this becoming,

Kristeva alerts us to its nature as a boundary:

Abjection is above all ambiguity, because, while releasing a hold, it does not radically cut off the subject from what threatens it - on the contrary, abjection acknowledges it to be in perpetual danger.⁴²

By using the term 'ambiguity', Kristeva underlines the basic nature of abjection as a form, or as a capacity to migrate back to the past from a present situation, with the past having the capacity to infiltrate the present. Abjection as a form is both a presence and an absence, and has the power to cross boundaries depending on the psychical condition and situation of the subject. Kristeva emphasises this point about its nature thus:

Abjection preserves what existed in the archaism of pre-objectal relationship, in the immemorial violence with which a body becomes separated from another body in order to be.⁴³

⁴¹ Kristeva, p. 3.

⁴² Kristeva, p. 9.

⁴³ Kristeva, p. 10.

Abjection is argued here as a condition which precedes memory, but which is nevertheless preserved within the experience of separation: an experience so powerful in its effects that it waits dormant, veiled, as it were, until the potential of its return is conjured by circumstances. Kristeva claims that these circumstances emanate from the ambiguity giving rise to a sense of 'discomfort, unease and dizziness'.⁴⁴ Perhaps, above all, abjection indicates helplessness and powerlessness stirred with a considerable sense of anguish underlying the emotional, instinctual, pre-linguistic, non-cognitive aspects of horror which settle, from a psychoanalytic point of view, into the unconscious.

The ambiguity, moreover, releases a balancing desire to resist such states of unease by marking out a space in which resistance and refusal can take place to minimise the seductive pull of the return: a return to a state of homogeneity from a condition which Kristeva calls 'heterogeneous' - the space of diversity and difference which collapses such seductions. Essentially, the paradigm indicates a repression of the sense of undifferentiation to enable the self/other model to be created. In her commentary on Kristeva's paradigm, McAfee states:

The abject comes back in fleeting encounters, fleeting because we flee, horrified at falling back into the maternal body, where no difference - and thus no subjectivity - is possible.⁴⁵

Kristeva's model of abjection speaks of a moment when the subject becomes human: an apartness that 'legitimises' the paradoxical and apparently violent moment. Clearly Kristeva's view of the body is that of something which is

⁴⁴ Kristeva, p. 10.

⁴⁵ McAfee, p. 118.

powerful and dark, as it is expelled by culture (echoed in Eagleton's argument above), to await the inevitable opportunities to come to re-assert itself through disease.

In contrast to Kristeva's dark view of the expulsion of the body, Kitwood perceives the body in benign terms, almost romantically welcoming its return at the behest of dementia:

People who have dementia, for whom the life of the emotions is often intense, and without the advisory forms of inhibition may have something important to teach the rest of humankind. They are asking us, so to speak, to heal the rift in experience that western culture has engendered, and inviting us to return to aspects of our being that are much older in evolutionary terms: more in tune with the body and its functions, closer to the life of instinct.⁴⁶

Here instincts are being suggested as an essence and a chora of being which is supporting an innocence derived from being transcendent of culture. Moreover, language is seen as an inhibiting form causing a rift between body and mind. It may also be argued that this return to an intense body, with its seeming excess of instincts, has echoes of the Gothic body, which as Kelly Hurley illustrates, is also unrestrained by language - a kind of surrender to the flesh.

But McAfee's point hints at the seduction of a personal nothingness, which is evoked by a sense of something familiar but forgotten. Such an idea has some of its origins in the work of Melanie Klein, and in presenting a critique of her ideas, Darian Leader describes Klein's 'interest in the way a child may think, at some level, that it contains ... another human being or part of a human being'.⁴⁷

⁴⁶ Kitwood, pp. 5-6.

⁴⁷ Darian Leader, *Freud's Footnotes* (Faber and Faber: London, 2000), p. 70.

Leader explores Klein's theory of introjection and the philosophical conundrums that underlie it. He finds some possible explanation of the theory in Paul

Schilder's work on body image:

Schilder argued that children tend to identify their interior with food substances, so that in the deep infantile strata of our minds we are not perfectly certain whether there is anything inside us except what is crammed into us from outside.⁴⁸

This argument indicates a tension between empiricism and symbolism in so far as it resists the notion of internal objects other than those which infiltrate from the outside. But to make sense of this infiltration, Klein's psychoanalytic theory rests upon the idea of an imagination which conjures up internal objects, much as children do when Schilder questions them about body image and they imagine their bodies 'crammed' with food. Schilder's use of this term is suggestive of too much: it is an excess which bloats the image of the body. And, what is excessive can be ejected. From the points of view of Klein and Kristeva, this form of something extra is perceived in symbolically punitive terms yielding negative results on the developing psyche in its archaic period. The Kleinian paradigm views this punitive process as the cause of later depressive conditions, but Kristeva's argument relates the symbolism of the ejection to the passage of becoming. Moreover, Kristeva adds the notion of sublimation – the sublimation of the ejection experience into what she calls 'a structure within the body'.⁴⁹ It is this process which enables the subject to control the seduction and to reduce the return to undifferentiation.

⁴⁸ Leader, p. 73.

⁴⁹ Kristeva, p. 11.

Kristeva's point about sublimation echoes the earlier discussion about Shenk's views on the middle stages of Alzheimer's disease and the many ways patients will deny or sublimate their fears and anxieties about the effects of the condition. To develop the point further, Shenk reports on the work of the neurologist, Barry Reisberg, who suggests an 'inverse relationship between the stages of Alzheimer's disease and the phases of child development'.⁵⁰ The Alzheimer subject becomes so full of fear about a return to absolute dependency that, most commonly in the middle stage of the disease, he sublimates or denies his fears. Kristeva's thesis on becoming underlines the power within the notions of splitting and difference, and the strangeness of the paradox. Sublimation, therefore, appears to be a necessary defence against the force of this power. But differences are essential to the creation of individuals, and identities create groups and categories. Identities are by their very nature reductive, because, as Klein and Kristeva intimate, an identity is not needed to become oneself: indeed, one needs an identity to become like someone else. However, the mythical power of the idea of unity and wholeness of self attempts to resist the return of nothingness, or the 'chaos' referred to by Jacques Lacan:

The illusion of unity, in which a human being is always looking forward to self-mastery, entails a constant danger of sliding back again into the chaos from which he started.⁵¹

This chaos is similar to Kristeva's notion of abjection in that it refers to the experience of spiralling into or out of subjectivity. Furthermore, alongside the idea of being on one's own there is a necessity, or a desire for self-mastery,

⁵⁰ Shenk, p. 122.

⁵¹ Jacques Lacan, 'Some Reflections on the Ego', *International Journal of Psycho-Analysis*, 32 (1951), 11-17 (p. 15).

wholeness and unity - a phenomenon Lacan describes as illusory. But this desire is a marked characteristic of those who are lodged within the confines of Alzheimer's disease. 'John's' repetitions are just one such illustration of the struggle which is shared also by Robert Davis in his personal account of his spiralling descent into the condition:

Now that I am developing a ritual with which I can be comfortable, I begin to see the great value of establishing a routine within my limits. My experience has taught me that if I want to function at the top of my limited capacity, I must establish a routine and keep to it.⁵²

It is Davis's limits which frame his need for routine and ritual, and which confine his ambitions. They are also expressions of sublimation, of pushing back the encroaching psychic encryption of his notion of self-mastery. He goes on to record his fear of nothingness:

As soon as I let go of my concentration to try and fall asleep, there is nothing there. This vacuum was filled with terrifying blackness. Blackness and darkness of the worst kind.⁵³

Nothingness, it seems, is filled with blackness which creates Davis's anxieties about 'sliding back ... into the chaos' as he becomes some formless void of matter. He gives additional emphasis to his understanding of the process of his condition and such understanding underlines the paradigms of Kristeva and Klein in an inverse manner:

Alzheimer's disease is like a reverse ageing process. Having drunk from the fountain of youth one is caught in the time tunnel without a stopping place at the height of beauty and strength. Cruelly, it whips us back to infancy. First the memories go, then perceptions, feelings, knowledge, and,

⁵² Robert Davis, *My Journey into Alzheimer's Disease* (Illinois: Tyndale House Publishers, 1989), p. 88.

⁵³ Davis, p. 48.

in the last stage, our ability to talk and take care of our most basic human needs.⁵⁴

This inverse return to what Lacan has called a premature state resonates substantively with many theoretical themes alluded to hitherto: Jackson's concept of dissolution; Reisberg's notion of an inverse relationship between the development of Alzheimer's disease and the stages of a child's maturation; and Kristeva's abjection paradigm. Davis's statement reveals the possibility of the body's potential return to an undifferentiated state, where subject and object are strangely entwined. For Davis and 'John', and many others, there is a sense of losing habitual bearings and having to institute different and new living regimes to structure daily lives. A kind of constant copying is apparent which assists in holding on to an image of themselves as subjects with boundaries and edges. But by these activities is also revealed an existential feeling of becoming unmoored from everything that they have taken for granted, cut adrift in an outer space of strangeness - a kind of traumatised irrationality.

Hiding and Revealing

The idea of the wholeness and unity of the self is crucial to the classical paradigms of psychoanalysis. It is the central point of departure in its challenge to the powerful Cartesian myth. Of course, the process of psychic concealment is, as has been argued earlier, essential to the concept of privacy, but the task of psychoanalysis is to search out the unspeakable secret and make it public. Often what is concealed seems strange, unruly and anarchic, but analysts mark the symptoms of a hidden trauma which are only revealed in linguistic or behavioural

⁵⁴ Davis, p. 86.

encodings. Kristeva and Klein, in their psychoanalytic paradigms, reveal the strangeness of the Other which is often projected outwards as both a form of defence and attack: a combination of fight and flight. Disease can be interpreted as the Other within; the hidden, awaiting through encoded symptoms, its 'real' revelation in the books of medical science. As a stranger within, disease creates a situation whereby the subject becomes a stranger to himself. Davis, for example, is acutely aware of becoming a stranger not only to himself but to others as well. Shenk writes that 'as the illness progresses [the carer] will struggle to look through the disease and recognise the person inside'.⁵⁵ The person on the outside is, presumably, perceived as some kind of strange and uncanny double of the person on the inside.

Shenk also reports on some biochemical changes that occur in the process of what may be called the shaping of Alzheimer's disease, which mirror, metaphorically, the psychological alterations he has already noted. These changes refer to the effects of a protein - prion - that destabilises other nearby proteins, causing them to adapt to a shape and form more like prion itself. Ultimately this process yields the sticky sheet of protein tangles which acts as one of the main results of the condition.⁵⁶ This biochemical process of shaping, or more properly reshaping, may construct similarities on the inside, but, paradoxically, it over-determines a difference on the outside. Although Davis is aware of his developing difference and becoming more and more a stranger to himself, it is this very awareness which gives credence to Shenk's point that:

⁵⁵ Shenk, p. 160.

⁵⁶ Shenk, p. 149.

One essential component of self that Alzheimer patients do not come untethered from early on is their own emotional reservoir.⁵⁷

It is this emotional reservoir of awareness of what is to come which begins the initial psychological process of the over-determination of the self in acts of repetition and ritual, and:

As the plaques and tangles proliferate and the brain begins to shrink, a psychic barrier arises between the victim and the outside world. The Alzheimer sufferer becomes an island.⁵⁸

The imagery of an island portrays an aspect of being a stranger to oneself and others with which 'John' and Davis are familiar. Both protagonists are painfully aware of a different kind of self to come and the sense of strangeness this evokes. Their ideas of their selves and their very egos are disturbed and it is in this process that they appear to detect a strangeness activating the sense of the uncanny. Additionally, the fear of the potential loss of their ego and a return to something familiar but frightening becomes more and more apparent. Full of fear, both protagonists are stranded at the edge of several forthcoming diminutions from their hitherto familiar lives; as McAfee puts it: 'dread (or anxiety) signals an encounter that threatens the border between undifferentiated being and subjectivity'.⁵⁹ Encountering the foreign other within underlines the beginning of indeterminacy.

The concept of the uncanny, with its sense of something familiar but concealed, suggests an experience, a feeling or event waiting to be revealed and in this way it can be seen as a bridge between the private and the public. In

⁵⁷ Shenk, p. 202.

⁵⁸ Shenk, p. 204.

⁵⁹ McAfee, p. 122.

psychoanalytic theory such revelations arise out of the leavening process of analysis as forms of repression are slowly brought to the surface in the interaction between the analyst and the analysand. The process in itself may seem uncanny as 'secrets' are moved out of the private into the public. The endeavour of psychoanalysis is to search for and expose the origin of a symptom within a language which not only names the symptom but the origin as well. It is therefore not only a science of biology, but also of metaphysics, a kind of science of forgetting and remembering. This paradoxical 'losing' something and 'gaining' something else - the economy of psychoanalysis - is also at the centre of the activities of evolutionary biologists. Shenk reports:

Evolutionary biologists are also fascinated by the rapid increase in longevity and its unintended consequences. From their perspective, the central concept here is one of hidden disease - disorders that have always existed for human beings in a potential state, but that have never been fully realised until recently ... The long term frailties are there somewhere, but they cannot be seen.⁶⁰

These hidden diseases, potentially, seal the fate of an individual at the moment of conception, and genetic research in the area of what was once known as 'pre-senile dementia' and now as early onset Alzheimer's, suggests a strong defective gene component as the cause of the condition, a kind of immortal gene referred to earlier. It also suggests a gene preserved, ironically, by 'memory' within its own material home.⁶¹

Shenk's description of the interests of evolutionary biologists indicates a structural concern with the material body and its secrets that may ensure, once

⁶⁰ Shenk, pp. 164-165.

⁶¹ Shenk, p. 165.

revealed, the emergence of a difference to be transformed into sameness by medical classification. This idea is not unlike that of psychoanalysis in seeking out conditions which await a realisation into another world. Both relate also to the 'nature' of frailty, something not quite right, or odd or strange in relation to the norm. What he also describes is the body's relative success in keeping its frailties hidden, but with the condition of dementia this cannot fully succeed:

perhaps the most remarkable thing about the history of senile dementia is that it has been so conspicuous. In practical terms, it was a hidden disease with very few victims before the twentieth century, and yet references to senility are strangely ubiquitous throughout recorded history – not just in medical records, but also in legal, political, and cultural terms.⁶²

Given its symptomatic relationships, the disease could hardly have remained hidden, as neurological degeneracy outs itself in such dramatic symptoms by returning its 'victims' to their material embodiments, and in the process 'hiding' their minds within that embodiment. However, as argued earlier, the symptoms were perceived in history as a disease of old age and therefore a precursor to death. Shenk provides two literary examples of neurological degeneracy from the eighteenth and nineteenth century – Jonathan Swift and Ralph Waldo Emerson. In recording their diminishing later lives Shenk argues that 'in myth and fable, senility often intersects with immortality'.⁶³ He refers to the Greek myth of Tithonus, desired by the goddess Eos, who asks Zeus to give him immortality but, ironically, forgets to ask him to be provided with immortal youth. So Tithonus ages and becomes decrepit and senile. Swift's deep personal fear about his loss of

⁶² Shenk, p. 165.

⁶³ Shenk, p. 166.

mental faculty seems to be represented in *Gulliver's Travels* which provides a further example of immortality and senility in the form of the Struldbruggs 'a subrace of immortal beings born at random among the mortal Luggnaggians'.⁶⁴ It is the Luggnaggians who disabuse Gulliver of the so-called advantages of immortality by pointing out that it is 'in fact the worst imaginable curse'.⁶⁵

A further paradox for evolutionary biologists in this history of hiding and revealing, and in the transformation of private ills into public issues, is, in Darwinian terms, the law of natural selection and the principle of adaptation. The latter is a requirement if long-term survival is to be achieved. However, if diseases and frailties are hidden, it would seem that they subvert the forces of natural selection. Longevity, it may be argued, rests upon what epidemiologists call 'manufactured time' - a phenomenon created by medical, environmental and technological advances. This same phenomenon suggests the uncanny and the strange as it outmanoeuvres God's time. Furthermore, this manufactured and excessive time seems to have created opportunities for these hidden frailties to appear and to merge the private and the public in ways which provoke what Kristeva argues was the fundamental revelation of Freud's work on the uncanny - the idea of anguish. As an emotion, anguish arises out of shock and astonishment as a private response to being diagnosed with Alzheimer's disease and conjures up a public response to its widespread and apparently sudden appearance as a major health and social care problem in the latter half of the twentieth century.

⁶⁴ Shenk, p. 167.

⁶⁵ Shenk, p. 167.

As a biography of a disease, Shenk's text reveals its birth, life and 'suicidal' death. The disease haunts its embodied state, contaminating its material surroundings and, in the process, creating a ghost-like self. It menaces, and eventually expresses the limitations of the body by producing and controlling the distortions it creates. It may be said that the disease subverts the meaning of medical science in its law-making desire for control and recovery. Longevity, as Shenk suggests, has outwitted the manufactured time it has created for human life. What Davis and others know is the command that the condition exercises on empty minds: a haunting prospect, with Gothic resonances because it appears to be a disease of excess. It is an excess in the sense of it being something additional to the body, arriving, as it often does, from the added-on time of longevity. Paradoxically, its effects are also excessive, notwithstanding that it diminishes our cognitive abilities and capacities and all that we may need to construe our sense of self. It is excessive, moreover, in terms of its overwhelming 'nature', not only in the private sphere of intimate and domestic concerns, but also, according to Gillies, in its global impact on the public mind, policies and purse.

These forms of extravagance, as Fred Botting points out:

reflect wider anxieties which, centring on the individual, concern the nature of reality and society and its relation to individual freedom and imagination.⁶⁶

Botting goes on to argue that these forms contain the 'disruptive return of archaic desire and fears'.⁶⁷ In fact it is these fears of a return to 'emptiness' or 'nothingness' which are the essential fears of the 'victims' caught up in the

⁶⁶ Fred Botting, *Gothic* (London and New York: Routledge, 1996), p. 11.

⁶⁷ Botting, p. 11.

transgressions of Alzheimer's disease; fears which are, furthermore, almost universally considered to permeate the Western world.

Conclusion

Disease is a transformative space within which, in Western culture, reside notions of both good and evil. Alzheimer's disease is so shocking in its nature that it tends to evoke feelings and attitudes which suggest that its degree of otherness generates fear because it transforms its 'victims', by destroying their natural inhibitions, into something very threatening. Disease, and certainly one that is defined as a state of being out of one's mind, can, as Marina Warner puts it 'sew and weave and knit different patterns into the social fabric'.⁶⁸ Here, Warner's figurative pattern relates to her argument about the making of mythical monsters, but myths are often perceived as being synonymous with fantasy and hence having no basis in reality. However, in the transforming space of disease, there are clear ties with a grounding material, where both reality and the myths emerge out of the circumstances of a described shared world.

Myths also, of course, very often account for experiences which may be viewed as otherwise incomprehensible, and the incomprehension can be attached to circumstances which seem so shocking as to evoke the most Gothic of dreams and nightmares. The apparent excess which arises out of the loss of inhibitory boundaries or borders can be threatening, and it is this fear of being transformed into somebody or something different - to 'die', in fact - which animates 'John's'

⁶⁸ Marina Warner, *Managing Monsters: The 1994 Reith Lectures* (London: Vintage, 1994), p. xiv.

and Davis's actions and underlines Jonathan Dollimore's illuminating point about the concept of the death drive:

Death is not simply the termination of life (that being the mystifying banality by which we live) but life's driving force, its animating dynamic principle.⁶⁹

What appears to animate 'life's driving force' is the fear of the paradoxical transformation into a kind of 'living death' for the 'victims' of Alzheimer's disease. It is also this fear which animates the development of organisations to raise funds for the care of Alzheimer patients, to research the condition, to lobby and to inform; in short, to clamour for something to be done and cures to be found before an epidemic turns into a plague. These activities, certainly in the United States of America and in the United Kingdom, become part of Warner's imagined pattern by weaving themselves into the social fabric and cultural practice. Shenk comments of America in the mid 1990s:

It seemed Alzheimer's disease was everywhere. Nursing home dementia units were filling beyond capacity. Middle-aged children were moving back home to take care of their parents. Community police were regularly being phoned to help track down wandering relatives. The disease was cropping up continually in newspaper articles and everyday conversation.⁷⁰

This graphic description underlines the complex private and public anxieties and fears about the disease and the ways in which it gets represented. Shenk continues:

As the twentieth century came to a close, a shadow legacy was rapidly becoming apparent – the dark unintended consequence of the century's great advances in hygiene, nutrition, and medicine ... the number of cases of senile dementia mushroomed.⁷¹

⁶⁹ Jonathan Dollimore, *Death, Desire and Loss in Western Culture* (London: Penguin Books, 1998), p. 192.

⁷⁰ Shenk, p. 29.

Such a point of view suggests that by playing against nature, our interventions through progressive developments in environmental and technological knowledge have brought about these paradoxical problems that may otherwise have lain dormant. Shenk's voice at the end of the twentieth century seems to echo, uncannily, Max Nordau's scepticism with regard to modernity at the end of the nineteenth century.⁷² It may also be that it is these excesses that are, as Botting points out, at the very heart of the idea of the Gothic.⁷³ Shenk's use of language, its gothicity, dramatically represents the Gothic woven into the private and public visions of Alzheimer's disease in a language that seems to conjure reason's surrender to the flesh and the brutality of that fact.

⁷¹ Shenk, p. 31.

⁷² Max Nordau, *Degeneration* (Lincoln and London: University of Nebraska Press, 1993).

⁷³ Fred Botting, *Gothic* (London and New York: Routledge, 1996).

Chapter 4

The Brutality of Fact and the Consolations of Metaphor

Diseases whose cures have been found become mere diseases; those we do not yet understand become metaphorical carriers of everything we fear and loathe.

Michael Ignatieff

The classical goal of science has been to eliminate the personal subjective quality of language and replace it with the public voice of claimed objectivity.

Steven Rose

Literary imaginings in literary form, continue to haunt science, its demons, it seems, too intensely embedded in culture to expel.

Fred Botting

The damnable fact – and possibly the saving grace – of serious illness is that it has the power to strip away the evasions that mask the human soul ... this stripping away has revealed a delicious gift for storytelling and a conspicuous passion for living.

Meg Rossof

When illness becomes metaphor ... it is wiser to acknowledge that such metaphors have proven irresistible to societies under stress.

Arnold Weinstein

Must the life of the body be given up on, as the sheer unthinkable other of thought, or are its mysterious ways somehow mappable by intellection in what would then prove a wholly novel science, the science of sensibility itself?

Terry Eagleton¹

¹ Michael Ignatieff, *Scar Tissue* (London: Chatto and Windus, 1993), p.67; Steven Rose, *The Making of Memory* (London: Vintage, 2003), p. 6; Fred Botting, 'Metaphors and Monsters', *Journal for Cultural Research*, 7 (2003), 339-365 (p. 342); Meg Rossof, 'Passion for Life', *Guardian*, 31 March 2007, G2 section, p. 10; Arnold Weinstein, 'Infection as Metaphor', *Literature and Medicine*, 22 (2003), 102-116 (p. 103); Terry Eagleton, *The Ideology of the Aesthetic* (Oxford: Blackwell, 1996), p. 14. These epigraphs suggest an ambiguity between a kind of certainty concerning the body and doubtfulness about language. Disease, particularly chronic and mental disease, requires language to establish their meanings. We become alienated from and lose our material embodiment in such circumstances, and here, as Catherine Belsey puts it in *Culture and the Real*, 'language will always come between us and ... the real' (p. 5). These epigraphs introduce the primary theme of this chapter which considers the collision of the body with language in relation to illness and disease.

The Brutality of Fact

Alzheimer's disease is a condition in which the body corrupts the mind, dismissing it, as it were, from its material presence and, moreover, exiling it from any semblance of a self-presenting language. Thus the condition creates and enables surrender to the flesh and to the brutality of fact. It allows for the triumph of the body in which few consolations appear to be available. In the space established by disease and illness, the body speaks for itself, and others have to seek a language to respond and to create a relationship. Very often for the old, language has already imprisoned them within the commonplaces of social constructs that have them readily defined. So when the bodies of the old begin to tell stories which seem to fit these constructs, clearly something else is necessary to free them from the prison of the stereotype. Body and the imagination both have to be reconfigured somehow in the spaces of consolation and understanding, and such transformation has to seek an outlet for a challenging escape through a language that traces both light and darkness.

For the subject diagnosed with Alzheimer's disease, this trace, as has been seen in previous chapters, is a crucial aspect of the descent into the body, a body which Freud and his successors, such as Lacan and Kristeva, perceive to be one of material sensibility: in other words, a body alive with instincts which create forms of incompatibility requiring reconciliation through language. Alzheimer's disease, however, breaks up the classifications of presence essential to psychoanalysis such as self-consciousness, self-reflection, self-awareness and self-censorship as, in its final stage, it returns the self to a body which then requires others to speak

for it. Kristeva's paradigm, outlined in Chapters 2 and 3, suggests that the subject of the disease has a body that is both past and present; one which brings its knowledge, its material sensibility to a performance that seems to others to be strange and dislocated, and for which they have to seek a meaning. The absence caused by Alzheimer's disease can, therefore, be read as a social text as the other writes on the body, rather like reading a first-person narration in a novel. And how that body is to be written upon, as the epigraphs to this chapter suggest, is one of the primary themes of this chapter.

If, as Foucault argues,² terror is necessarily characterized by an excess of language, Susan Sontag's *Illness as Metaphor* is a text concerned to curtail a form of language which, from her point of view, is one that seeks to hide the brutality of fact. There are, perhaps two senses in which it can be said that her text is concerned with the related questions of surrendering to the flesh and rendering that flesh into fantasy. First, the text seems to argue the primacy of the diseased body over language, transforming each into a kind of fantasy, and, secondly, the text indicates some fascination with the idea of a corrupting disease being corrupted further by language.

Furthermore, within this second sense, a concern with strangeness is implied: that if disease is a familiar part of our lives it is somehow made unfamiliar by the use of figurative, metaphorical language which transforms flesh into a kind of fantasy. In this sense the body becomes estranged from language as language becomes separated from the body. Illness, it seems, is both deafened and

² Foucault's argument is cited in Fred Botting's *Gothic* (see Chapter 1, p. 4) and Botting makes the point to indicate that the genre of the Gothic 'signifies a writing of excess' (Botting, p.1).

exhausted beyond all language. However, the space of illness is one in which we become aware of how apart we are within ourselves as well as from each other, and it is the breakdown of illness which affords opportunities for reconstruction, with language, in all its variety, as the means by which reconstruction can be effected. Metaphoric language may, from Sontag's point of view, disrupt meaning, but the argument in this chapter is that it opens the way to a range of new meanings and even to new ways of understanding, with metaphor enabling experience to be produced meaningfully. Medicine, in its institutional power, assists in the creation of this sense of estrangement through its ability and capacity to appropriate the materiality of the body at the expense of the subject. As Judith Butler puts it, the body becomes 'the site of the transfer of power itself'.³ Being, therefore, is reduced to materiality and becomes the image for the gaze of the other, particularly if that body is demonstrating a diseased condition. Havi Carel points out that the concept of illness 'originates in a naturalistic approach', within which physical facts are explained, particularly in the objectifying and, supposedly, neutral language of medical experts who tend to focus on the body, in its illness, as biologically dysfunctional.⁴ This approach marginalizes the lived experience of illness which usually gets represented in a more subjective language. But illness and disease do not stand still, they are protean, travel and journey and attack and defend, and their very description is migratory and difficult to pin down. Therefore language has to travel with these trespassing movements in turn.

³ Judith Butler, 'Bodies and Power, Revisited', *Radical Philosophy*, 114 (2002), 13-19 (p. 15).

⁴ Havi Carel, *Illness: The Cry of the Flesh* (Northumberland: Acumen Publishing Ltd., 2008), p. 8.

However, in Butler's paradigm, the body becomes classified. Her conception of power and the body resonates with the work of Michel Foucault who, like Sontag, but from a different theoretical point of view, has a major concern with the language of appropriation and power. Sontag's central argument is that metaphorical language has the power to make the subject powerless: a victim of that language, rather than one with the potential to master and transcend a physical condition. From her point of view, metaphorical language is dangerously subversive of the physical condition and her text argues the need for it to be excluded in any understanding of the meaning of illness. Pain, seemingly, is beyond discourse and language breaks before it.

It may be argued that Sontag's thesis itself arises out of a late Renaissance view that matter is rooted in reality; put differently - that matter is a thing and not a collection of words. Things rather than words became the objects of observation and fascination in eighteenth- and nineteenth-century medical science, and it was through a process which observed things as objects that symptoms of disease were described and ordered into classificatory syndromes. As Foucault puts it:

By limiting and filtering the visible, structure enables it to be transcribed into language. It permits the visibility of the [patient] to pass over in its entirety into the discourse that receives it. And ultimately, perhaps, it may manage to reconstitute itself in visible form by means of words.⁵

It would appear that Foucault perceives a gap between words and things - a gap which becomes filled with names which pattern the representation of both the

⁵ Michel Foucault, *The Order of Things: An Archaeology of the Human Sciences* (London: Routledge, 1997), p.135. This translation was first published in Great Britain in 1970 by Tavistock Publications Ltd. Foucault's argument relates to the history of natural science, but it has its echo in the human sciences which are main themes in his text.

things and the words. In this respect, Alzheimer's disease may be understood as illustrative of Foucault's paradigm. It is also illustrative of the power to name; a power that is jealously guarded by medical science and its practitioners. Language and power come to be intimately connected in Sontag's text and, as such, are primary points for consideration in this chapter.

It is Sontag's contention that diseases 'thought to be intractable and capricious' are, by definition, mysterious.⁶ Tuberculosis in the nineteenth century and cancer in the twentieth are the two conditions cited in her text as diseases which began, and continue to begin, with a puzzle: they are diseases without any known cause, but with many effects. Her text argues that this gap in knowledge invites the use of metaphor and metaphorical language to fill this emptiness. Catherine Belsey makes a similar point in her interpretation of Jacques Lacan's concept of the 'Real'. Lacan argues that this idea refers to what we do not know and as such 'the real enlists speculation'.⁷ If the idea of mystery is what we do not know, it clearly invites speculation. The Lacanian 'Real' is, of course, primarily concerned with what is not known to our conscious selves, that which is buried, hidden in our unconscious. Sontag's text seeks, as she states, 'a liberation' of the disease from metaphorical speculation,⁸ whereas Belsey's interpretation of the Lacanian 'Real' sees it as an opportunity, a quest, for personal and social change. Nevertheless, the quest in seeking to reveal this mysterious gap and bring it into everyday speech and discourse is as much at the heart of medical science as of psychoanalysis. As Sontag states, once a cause of a disease is revealed and

⁶ Susan Sontag, *Illness as Metaphor* (Harmondsworth: Penguin Books, 1983), p. 9.

⁷ Catherine Belsey, *Culture and the Real* (Abingdon and New York: Routledge, 2005), p. xii.

⁸ Sontag, p. 8.

established in what may be spoken, the mystery is solved; the speculation and speculative language is likely to become redundant and the patient liberated from its 'secret invasion' of both cause and effect.⁹

The argument that gaps, spaces, voids and other lacunae invite the use of figurative and metaphorical language, as it were, to advance into silence, suggests a need to combat fear, and the fact that there is no marked and defined origin such as a cause for the many symptoms of Alzheimer's disease clearly provokes considerable fear. But would the language of loss and substitution be rendered redundant by conjuring a known cause into reality? The assumption on which the Sontag thesis is predicated is that once cause is known, cure cannot be far behind. However, it may be argued that Sontag's text demonstrates a kind of utopian desire in that it seeks a clarity and self-sufficiency for the disease itself; in other words, that the disease should be purified of metaphorical language so that it can be seen for itself alone, somehow decontextualised or figuratively uncontaminated.

It is as if metaphor itself is a disease of language which requires to be expelled. Her commentary suggests a need to establish authenticity for a thing rather than to rely on language. Thus she argues for a closure - to close down articulation and to discourage interpretation, reinterpretation and ambiguity. However, the subject diagnosed with Alzheimer's disease is already being shifted to the margins of the symbolic order and, therefore, at the mercy, or otherwise, of the other's symbolism. Their body has become a kind of concrete abstraction, a sort of facsimile - like, but unlike, themselves, no more than a vitality of signs that

⁹ Sontag, p. 9.

require interpretation by others. In effect, the Sontag text seeks to put all this and the realities of human foible and frailty, as well as reassurance, in their place.

But such commentary passes over the real possibility that disease always teeters on the brink of another kind of narrative. Barbara Clow argues that Sontag's

solution to the problems posed by disease metaphors was simply to eliminate them from the discourse ... she believed that, once the disease had been stripped of symbolic association, sufferers would realize cancer was a biological phenomenon rather than a social or moral one.¹⁰

In this analysis, biomedicine appears set on desocialising disease, its proponents arguing that disease is defined solely by impersonal, natural laws, rather than moderated also by social ties and interests. This is exemplified in the title of Sontag's text, which suggests a body not only weighted by disease, but also encumbered by an extra and burdensome language. The weight of the disease and an unfitting language, which is often used as a response to the condition, can be cleansed and purified of its subjective nature, argues Sontag, so that it can be returned to a perception of the thing-in-itself. Whether any disease of a transforming nature (tuberculosis, cancer or Alzheimer's), can be purified of a language which articulates that transforming experience seems unlikely given patients' need to make sense of their condition.

Sontag's argument is that metaphors hide the 'truth' of a disease and so disable the patient's resources to resist the ideas and images created by that language. The idea of purification and therefore of being released from a shroud

¹⁰ Barbara Clow, 'Who's Afraid of Susan Sontag?', *Social History of Medicine*, 14 (2001), 293-312 (p. 297).

which hides the 'truth', a form of redemption, invokes a religious iconography which, paradoxically, is supposed to reveal a truth. But what is it that is supposed to be hidden here? Sontag argues that metaphor is not only an extra, an addition, a substitution, a moment of excess, but a very unwelcome filler of space. The dark and hidden space of the body, it seems, suggestively requires no other meaning than the condition in which it finds itself. Ironically, Sontag's text begins with a metaphor incorporating images of identity, place and journeying between bodily spaces:

Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds a dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.¹¹

The metaphor's metaphysical notions are of a body born into shades of light and darkness, but with a paradoxical fixed identity that is somehow sovereign in both places. But a disease creates a difference, an estrangement from the idea of normality and a different passport seems to be required, not a fixed one. The subject inhabits a strange location with a language of difference in the ascendancy where the idea of darkness is indicative of the mysterious void, that space which is strangely inhabited by an illegitimate illness, illegitimate in the sense that it has no known cause and hence is unnamed. Drawing upon the Lacanian 'Real' to illustrate this void, Belsey asserts:

The real is not reality, which is what we do know, the world picture that culture represents to us. By contrast, the real, as culture's defining difference, does not form part of our culturally acquired knowledge, but exercises its own, independent determination even so.¹²

¹¹ Sontag, p. 8.

The question here is what, if anything, is on the other side of language? Sontag's metaphor clearly hints at the other side, this space of darkness which hides away from revelation, but which, as she argues, once revealed and brought into the discourse of acquired knowledge, will be set in the language of cause and effect. Her metaphor is also indicative of strangeness, of being a stranger in another place and at a distance from whatever or wherever may have been one's origin, which may arouse 'punitive or sentimental fantasies' in the new location.¹³ Illness, then, seems to create a psychological sense of apartness, not only within but also outside. It drives the sick body from the 'norm', so that it becomes detached, unanchored from its usual state of being. Illness, whatever its form, makes a further space for language to give meaning to this different experience. Therefore, changes in identity require a continual process of 'retranslation', of reconstructing the self depending upon social context. It is this process of distancing and strangeness, and what it may evoke or provoke, which is of major concern to Sontag in her inquiry into the forms of language which address particular diseases:

My point is that illness is not a metaphor, and that the most truthful way of regarding illness - and the healthiest way of being ill - is one purified of, most resistant to, metaphoric thinking.¹⁴

Metaphor and metaphoric language, it is suggested, is not only the language of strangeness, but also of deceit, of cheating, of lying. It is a language, in fact, not to be trusted. Such configurations are clearly ones which seduce, in essence, the pure

¹² Belsey, p. xii.

¹³ Sontag, p. 8.

¹⁴ Sontag, p. 8.

and truthful, and, therefore, have to be resisted so as to enable the patient to be returned, via their good passport, to their former self. This suggests that the journey between light and darkness and back again, has no psychological or material effect which needs to be given meaning by those who make the journey as well as by those who act to assist.

Although in making her argument Sontag insists metaphorical language colours the experience of illness to the detriment of the patient's capacity to deal with its reality, it is this very colour that is welcomed by Virginia Woolf.¹⁵ She argues that illness needs a language to reveal itself and its effects upon the body and mind, and to enable the sick to feel that they remain in the world and that they are not to be silenced by the condition or any attendant shame. Illness, it seems, can be one of those moments for reconstructing the self. For the Alzheimer subject, however, it is materiality which outwits the self by putting that subject outside the norm and at the mercy of a language which lays claim to its essential monstrosity in personal and social contexts.

Sontag's argument does give an emphasis, and preference, to a medical discourse which invariably claims to seek a detachment in its quest to be specific and not to generalize. Certainly such a discourse aspires to employ and display a more concrete and less figurative language. The very idea of something more and something less is expressive of the values of medical discourse and therefore underpins the level of its importance in Sontag's text. In other words, medical discourse seeks to place a so-called objective science over and above that of

¹⁵ Virginia Woolf, 'On Being Ill', in *The Crowded Dance of Modern Life: Selected Essays*, ed. by Rachel Bowlby (London: Penguin Books, 1993), Vol. 2, pp. 43-53. Woolf's ironic essay, first published in 1926, debates the question about why illness is ignored as a major theme in literature.

subjective experience, which is often expressed in figurative language and which establishes the metaphorical myths that Sontag so disapproves of. To pursue the economic trope a little further, Sontag's analysis suggests that metaphorical language has no surplus value as far as the discourse in which to understand disease is concerned; in fact, from her viewpoint, it holds no exchange value at all. If subjective experience is to be characterized by metaphorical language, it clearly cannot hold any substantial value within the discourse of medical science and the reality of the material diseases with which it deals. In these circumstances it can be argued that illness itself is, metaphorically, asking for the body to be abandoned by language and to be left to its own factual suffering. However, what is apparent in the narratives of those suffering from Alzheimer's disease is the evacuation of the peculiarly human ache of longing, the base of the Lacanian 'Real' and the need to try and express this, perhaps romantically, within the language not only of loss and fear, but also of love and hope.

Fact, 'Truth' and Fiction

For those with the condition, as well as those who observe them, Alzheimer's disease creates a space which is eventually to be occupied by dead time, reached when the regulatory relationship we all have with temporality comes to be destroyed. This kind of reality, both for the observer and the patient, creates the sense of illness and disease re-constituting the subject. As Jacques Derrida puts it, 'the place of the subject is ... taken by another, it is concealed'.¹⁶ In other words,

¹⁶ Jacques Derrida, *Of Grammatology*, trans. by Gayatri Chakravorty Spivak (Baltimore and London: Johns Hopkins University Press, 1998), p. 315.

the identity of the subject, unlike the fixed identity in Sontag's metaphor, is transformed: taken over and concealed, by the illness.

This seems to be as factual as the fact of the disease itself and such a change in the subject suggests the need for a different form of language as the subject is translated into another sort of narrative. Alzheimer's disease creates one such narrative in its process of distancing the subject from a state of well-being to one that, in prospect, will lose that subjectivity and thus become not only strange, but come to be seen as somehow outside of nature. The disease is indeed one in which an involuntary exchange takes place, a kind of mutation of identity which is neither sought nor asked for, but is an illustration of a trick of nature. And it is the disease itself which procures the displacement of body and mind, requiring a different sort of language to that of medical scientific discourse with its concerns for the material specificities of the body, and requirement that form and function go together: a reflection of its modernist philosophy, with its emphasis on paring down to the essentials.

Such an approach does suggest a distrust of additions, of excess, of other things getting in the way of those essentials - and one of those things is the idea of metaphorical language. Sontag argues that tuberculosis in the nineteenth century and cancer in the twentieth were and continue to be perceived as 'obscene ... ill-omened, abominable, and repugnant to the senses'.¹⁷ Sontag's interpretation of the responses to these two diseases does underline the use of excessive, inflationary language, but it is a language clearly embedded in the social fabric. It is also a response to conditions that are both painful and terminal, and in which

¹⁷ Sontag, p. 12.

the idea of rationality, of objectification, seems to wither in the face of a gothicness of language. Indeed until cellular pathology became established in the late nineteenth century, tuberculosis and cancer were seen as diseases which corrupted and consumed, the body somehow being eaten away. These metaphors were, as Sontag points out, arrived at by people's perceptions of those suffering from such conditions, in much the same way that language is used to interpret and give meaning to Alzheimer's disease in contemporary society. If tuberculosis and cancer can be perceived within a language fuelled by a sense of something monstrous, such a situation resonates with Thomas De Baggio's fearsome foretelling of his future after being diagnosed with Alzheimer's disease - that he will join a 'parade of horror'.¹⁸

Certainly Sontag's text does argue for a resistance to metaphorical language in relation to illness, displaying a wariness of the imagination, at the very least, as a way of defending fact against fiction. The impression imparted is that one form of language is more truthful than another. She sees fact as an asset and fiction as a liability when it comes to handling and understanding illness and disease. Her text suggests that the limiting of the imagination is to be provided, and bound, by scientific discourse. But in the face of something as desperate and intractable as Alzheimer's disease, and other terminal conditions, another kind of language appears to be needed to establish understanding and meaning between communicating human beings. In any event, fiction can also be a place of truth, articulating fears that are generally suppressed and conveying emotional certainties that are usually based on facts which provide their context. Indeed it

¹⁸ Thomas DeBaggio, *Losing my Mind* (New York: The Free Press, 2002), p. 1.

can be argued that facts only have meaning if they are shaped by the emotional truths which underlie them.

Kristeva's concern with sub-verbal codes is suggestive of a way of approaching the theme of the imagination and the language by which it may be understood, and of exploring the ambiguities of the private and the public. From this theoretical point of view, the real work of the imagination is carried out by considering the gaps between words and their meanings, or the boundary between body and culture. These fascinations with the pre- and sub-verbal are an indication of the power of the body and its capacity to somehow speak for itself even when clothed with language and speech. This notion comes very close to Sontag's textual argument. Illness and disease are spokespersons for the body, making visible the invisible. In Alzheimer's disease, for example, there is something buried and hidden which then appears in the subject's formless behavior outside of time and space. It becomes a visible language making present what is absent, or speaking its absence through its presence, all of which seems to underline the tension between body and mind and its private and potential public exposure.

However, the gaps present the possibility of a mix, the fluidity of which may emerge in the work of the imagination. One way this is done is explained by Terence R. Wright:

If narrative is the way we construct our sense of identity, metaphor is how we think, especially in areas in which we need to build our knowledge of the unknown by comparison with the known.¹⁹

¹⁹ Terence Wright, *Theology and Literature* (Oxford: Blackwell, 1989), p. 11.

Wright's explanation of the purpose of metaphor goes part of the way to support Sontag's view, but crucially departs from her position by suggesting that metaphorical language may enable the subject to meet and explain the unknown and thus bring it into the domain of what may be said. Wright goes on to argue that the devices of such language, figurative and poetic, tend to de-familiarize the familiar, an understanding arrived at out of the work of both the Russian formalists and Kristeva. Wright argues:

Paradox and ambiguity, like metaphor, symbolism and other poetic devices, are an admission of the limits of logic, an expression of the contradictory nature of experience.²⁰

The body, as matter, is, of course, there, a thing, but it can never have a fixed meaning in either health or disease, or science and reason because it is constantly subverted by the imagination. Belsey asserts that:

A certain discontent inhabits the organisms-in-culture that we are: a dissatisfaction with the present state of things, an imperative to do better, or to change the world; above all a capacity to dream up alternatives to the way things are.²¹

Indeed both Wright and Belsey indicate that the way we are, and could be, is primarily a matter of the way we think: the way of the imagination.

Subjective 'Realities'

For the subjects of Sontag's text, those suffering with the physical diseases of tuberculosis and cancer, their personal images of reality lie, as it were, beneath the level of discourse inhabited by the body in medical science, dreaming of alternative ways of thinking about themselves. Belsey sustains an affirmative

²⁰ Wright, p. 152.

²¹ Catherine Belsey, 'Biology and Imagination: the Role of Culture', in *Human Nature: Fact and Fiction*, ed. by Robin Headlam Wells and Johnjoe McFadden (London: Continuum, 2006), pp. 111-127 (p. 125).

attitude toward the discourse of the body against the reductionism of science with its deterministic ideas of evolution, claiming that such views are often undermined by the very mechanism which is supposed to separate the unfit from the fit. We struggle with our own biology and give degrees of respect to our 'natural' world, but we also have a need to 'figure' it with imaginative language so that it may become embedded in our culture. To find and say something different is, in Belsey's argument, 'an imperative'. In other words, it becomes necessary to re-define, to renew and to re-write. To re-define is an important concept in this analysis. Steven Rose, a neuroscientist, has argued for such an understanding of the use of the imagination in shifting perspectives:

Yet I have to accept the limits of neuroscience, to concede that it has so far been left to the other half of our fragmented culture, the terrain traditionally inhabited by poets and novelists, to try to explore the subjective meanings of memory.²²

There is a note of regret and reluctance in the tone of Rose's admission of the limits of the objective science of neurology, that capacity to distance the activity from the effects of a damaged memory, but he still seems to insist on its primary role over 'the subjective meanings of memory'. The emotional nuance in the face of scientific fact is still regarded as secondary in what is seen as our two cultures. But the power of memory is in its capacity to drive the imagination in its associative abilities, and it is through language that this association is best seen and heard. The character and dynamic of metaphor is in its potential to get ideas to interact and therefore go beyond the literal. Metaphorical language suspends the literal sense and shifts it to a new level of reference so that a different

²² Steven Rose, p. 8.

understanding comes into effect. In this way a re-defining of the literal takes place.

This process of re-defining and re-writing neuroscience is one which Rose seems to applaud, but of course this objective science is concerned with a language that describes Alzheimer's disease as a primary degenerative dementia, a disease of the brain. But another way of considering this is to view such a dementia not just as a cerebral deterioration, but as a complex disease which is a disease of the brain with a parallel resonance for the mind, the mind being essentially a social construct. And, not surprisingly, it is the mind which is of most concern to the subject. It is the language of the 'other half of our fragmented culture' which seeks to imagine what this experience of deterioration is like, and what it is most like is most often expressed and represented in the language of difference, strangeness, loss and death: the language of the Gothic.

As Alzheimer's disease tends to be an effect of old age, its symptoms can be regarded as constituting not only a disease but a stage of being. Illness and ageing are drawn inevitably together in the terminal stages of life's cycle. Perhaps just as inevitably, the way Alzheimer's is represented can be seen as figures of metaphor. The language used for its representation suggests that metaphor becomes, in a sense, the public face of private ills. The very elemental rawness of disease seems to demand the shelter of metaphor, a language of both tragedy and comedy, to ease the rawness of the condition. Metaphor, in fact, hides and reveals the ghosts of the literal, suggesting both mastery and loss. DeBaggio, in his autobiography, writes:

There was something else that spring and it was unnamable.
 As with all unknowns, it was unsettling and had nothing to do
 with the weather. It was something that gentle rains, bright
 sunny days, an optimistic outlook would not cure. It was an
 anonymous presence, yet I could feel its uneasy cadence ...
 I might be tied to a teetering mind that had begun a slow
 descent into silence.²³

This ghost-like presence of a Lacanian ‘Real’ in the springtime of DeBaggio’s year evokes a subliminal fear of something to come, a fear of Gothic proportions. The juxtaposition of an anonymous ghost-like presence with a world bright with prospect has its own poignancy, but to DeBaggio, a market gardener, the language is full of meaning and understanding of his situation. Each turn of the year brings prospects of different kinds, but here the spring holds within it the seeds of something much darker and less generous as it progresses into summer, autumn and winter. The apparently normal rhythm of an external nature which touches the inner is to be disrupted by an insidious internal presence which will eventually strike out a perception of that nature in both its understandings.

DeBaggio’s metaphor strikes a note of the sublime, that mix of terror as well as pleasure, but at the same time seems a clear example of what Wright alludes to - a language is sought which indicates ‘the limits of logic and an expression of the contradictory nature of experience’. Early in his text, DeBaggio depicts himself as joining a group paraded as something horrific - bodies without minds, zombie-like in appearance and behavior and therefore outside the norm. Indeed, the parade is one full of horrific, posthuman substitutions, a series of metaphors for the so-called real selves. DeBaggio’s use of nature as a metaphor is indicative of a living in language: it is what he does as a horticulturist that attunes

²³ DeBaggio, p. 3.

him to the language of the nature which surrounds and influences him. It is this experience which makes things comprehensible to him, but the language of horror is a shift of perspective and register which relates to a wider cultural understanding and is the language of de-familiarization and exile. His condition first breaks a silence, and then descends into silence in his parade of horror. This is a text which readily suggests a redrawing of personal boundaries not unlike the process described by Kristeva where the subject is returned, at one and the same time, to a sense of nothingness and wholeness. Anna Smith argues that Kristeva:

appeals to the visionary language of epiphany and apocalypse to elaborate the earth-shaking nature of those borderline states of language and human experience.²⁴

DeBaggio's moment of epiphany comes in knowing the prospect of that descent into silence and of recognizing the apocalyptic nature of his existence between language and body: that teetering at the edge of his mind descending into something dark. The words he uses describe what is happening to him as a result of the attentions of his internal rhythmic ghost, marking its life to the point where all understanding of time and space is lost to an eternal present. Although there is a clear and profound difference in kind, there is also a resonance with the idea of the eternal present in Oscar Wilde's *The Picture of Dorian Gray*. The book is invaded by a sense of fatality as the primary character, Dorian Gray, leads what can only be described as a double life. On the one hand he remains constantly young, enclosed in an eternal present, while his portrait demonstrates the corruption brought about by time. At the completion of the portrait he states:

²⁴ Anna Smith, *Julia Kristeva: Readings of Exile and Estrangement* (London: Macmillan Press, 1996), p. 6.

How sad it is! I shall grow old, and horrible, and dreadful. But this picture will remain always young. It will never be older than this particular day of June ... If it were only the other way! If it were I who was to be always young, and the picture that was to grow old! For that – for that -- I would give everything! Yes, there is nothing in the whole world I would not give! I would give my soul for that!²⁵

The images of duality, a familiar motif in the Gothic genre, also seem to have an echo in DeBaggio's memoir in the sense that he sees himself in two situations; one as himself and the other as an Alzheimer subject, the latter becoming the metaphor for the former in the same way as the portrait of Dorian becomes the substitute for himself. But given DeBaggio's very human experience, the shelter of a metaphor seems a small thing, an inflation easily forgiven and understood. If language is to be so objectified as to rule out the human and the posthuman, and to be given always as a kind of understatement, it surely follows, as Adam Phillips points out, that there is something under the statement which needs to be addressed.²⁶ If Sontag does contrast the visible characteristics of disease with an uncalled for and unfitting language, does it not beg the question posed by Phillips? Some kind of answer is supplied in DeBaggio's response to his disease, which is the language of personal imagery layered beneath the bodily facts of his diagnosis.

As Sontag's opening metaphor suggests, we are all likely to journey into periods of disease and discomfort of various kinds; we all die of something. And as we are all part of our cultures we must be part of its ways and meanings of understanding and coping with such predicaments. But Sontag seems to argue the

²⁵ Oscar Wilde, *The Picture of Dorian Gray* (London: Penguin Books, 1985), p.31.

²⁶ *The Penguin Freud Reader*, ed. and introduced by Adam Phillips (London: Penguin Books, 2006), p. xi.

American dream, that of overcoming, of transcending such cultural meaning as we give to disease so as to combat and defeat it: 'the person dying of cancer is portrayed as robbed of all capacities of self-transcendence, humiliated by fear and agony'.²⁷ Sontag's son, David Rieff, has written that:

My mother, Susan Sontag, lived almost her entire seventy-one years believing that she was a person who would beat the odds. Even during the last nine months of her life, after she was discovered to have myelodysplastic syndrome ... a particularly virulent blood cancer, she continued to persevere in the belief that she would be the exception ... her positive denial ... whether with regard to her health, her work as a writer or her private life, had not been extinguished by the hard facts of her MDS.²⁸

This kind of optimism and belief in the face of the inevitable is often seen in cultural terms as brave and courageous, and Rieff's description of his mother's attitude indicates her own desire to transcend her disease, and the language of robbery, corruption and being consumed by the fire of cancer.

The Language of Illness

The vocabulary of illness is replete with language which locates and spaces the subject who becomes ill. We often use the term 'to succumb to disease', to describe the idea that we are laid low beneath it, and when we say that we are 'afflicted by a condition' the metaphor is that we are brought down by it. We are often said to feel 'low', 'run down' or 'under the weather', or, when in a terminal condition, 'to be sinking fast'. All such language spells out as fact that illness is 'down' and being healthy is, conversely, 'up'. We say also that the body is 'attacked', either by an internal organ such as the heart, or an outside virus such

²⁷ Sontag, p. 21.

²⁸ David Rieff, 'Illness as More Than a Metaphor', *New York Times*, 4 December 2005, p. 4.

as influenza, sustaining an assault which in both cases has to be 'fought off'. If we 'fight off' influenza we can prevent ourselves from becoming ill. These military metaphors are well established in our cultural understanding in which they signify the meaning of disease. The 'fighting' and 'defending' metaphors are particularly well worn and welcome because they tend to resist the idea of the sick person as victim, the theme uppermost in Sontag's text and clearly a dominant idea both in her life and in her writing about disease.

To resist the idea of being a victim, it is necessary, in Sontag's argument, to use one's sense of self to transcend the condition which, it seems, fate has handed one. To be sick is to be at the disposal of accident, perhaps even necessity, both concepts, paradoxically, arrived at through evolutionary biology. But Sontag also cites aspects of the social fabric which suggest that personal characteristics may be responsible for the conditions she explores in her text. Similar social constructions have also been made in relation to Alzheimer's disease. Sontag takes issue with the Romantic period's depiction of tuberculosis as a disease affecting those who may be described as refined, sensitive, interesting, genteel or delicate. Incorporated in these personal characteristics is the notion of passion, either too much or too little:

As once tuberculosis was thought to come from too much passion, afflicting the reckless and sensual, today many people believe that cancer is a disease of insufficient passion, afflicting those who are sexually repressed, inhibited, un-spontaneous, incapable of expressing anger ... as much as tuberculosis was celebrated as a disease of passion, it was also regarded as a disease of repression.²⁹

²⁹ Sontag, p. 26.

Sontag cites the infamous psychoanalyst, Wilhelm Reich, as someone who associated 'cancer with the repression of passion',³⁰ making it seem that those who sublimate their passionate natures are vulnerable to these diseases and she comments further that 'the Romantic treatment of death asserts that people were made more singular, made more interesting, by their illness'.³¹ However, she goes on to state:

Doctors and laity believed in a TB character type – as now the belief in a cancer-prone character type, far from being confined to the back yard of folk superstition, passes for the most advanced medical thinking. In contrast to the modern bogey of the cancer-prone character - someone unemotional, inhibited, repressed - the TB prone character that haunted imaginations in the nineteenth century was an amalgam of two different fantasies: someone both passionate and repressed.³²

Here the imagination is aligned with fantasy, the latter apparently dominating and promoting the idea of particular personal characteristics being open to certain diseases. Sontag appears to divide the organic from the psychological, the body from the psyche and language. But presumably, and paradoxically, the sick body has to be mediated to enable it to transcend and combat its condition; nevertheless, Sontag insists that 'psychological understanding undermines the "reality" of a disease'.³³ In other words, fantasy, driven by metaphor, is an illusory cloak to cover 'the obscene mystery' of death.³⁴ Such fantasies are also seen by Sontag 'as forms of self-judgment, of self-betrayal',³⁵ as the self is unable to resist the power of cultural metaphor. In such instances the mind can betray the

³⁰ Sontag, p. 27.

³¹ Sontag, p. 35.

³² Sontag, p. 43.

³³ Sontag, p. 59.

³⁴ Sontag, p. 59.

³⁵ Sontag, p. 44.

body: Sontag refers to the case of Franz Kafka, suffering from tuberculosis and writing to a friend - 'my head and my lungs have come to an agreement without my knowledge'.³⁶ This tripartite God-like imagery seems to suggest a body and mind co-operating against some other spatial self; but it is a readily understood image, confronted, as it were, by a form of difference within.

But the imagery is indicative also of what seems most to interest Sontag in relation to the idea of being a victim: powerlessness. The argument, however, is not one of helplessness in the face of the authority of an appropriating medical discourse inhabiting the terrain of the power of life and death and the language of the body, but against the cultural metaphors of the Romantic period and their successors in the late twentieth century. Sontag maintains that such forms of language create the idea of victims that are somehow to blame for the conditions from which they suffer. Her argument is that such language establishes a nonsensical mythology that acquiring cancer, for example, is the result of sublimating one's desires, the mind resisting the body. These cultural metaphors, arising out of speculation concerning unknown causes, are, according to Sontag, driven by sentiment and sentimentality which deny the 'realities' of terminal, or potentially terminal, conditions. Sentiment can, of course, be a disengaging emotion, polluting the events and experiences of disease and illness. However, these experiences are, as DeBaggio's responses indicate, a fluid mix of the real and unreal as they are traced into cultural metaphors. In this way the brutality of fact shades into the consolations of metaphor even where it is coloured by

³⁶ Sontag, p. 44.

gothic. Sontag's position is most clearly stated at the close of her polemical text:

The modern metaphors suggest a profound disequilibrium between individual and society, with a society conceived as the individual's adversary. Disease metaphors are used to judge society not out of balance, but as repressive. They turn up regularly in Romantic rhetoric which opposes heart to head, spontaneity to reason, nature to artifice, country to city.³⁷

Here the private and the public are seen to be opposed, and the oppositional mode of Romantic rhetoric, which indicates a critique of society, is one that, as argued earlier, Belsey applauds as acts of the imagination, acts of potential progression. But Sontag's position is also one that echoes Freud's 'Civilization and its Discontents', a discontent which is paradoxically unveiled in cultural metaphors.

The primary theme of Freud's text is the tension between the demands of the body, its instincts, and the prohibitions of the external world. Illness, particularly mental illness, seems to isolate and detach the subject from what might be called their 'real' life, their condition throwing into relief the tension between body, mind and the wider environment. It might be argued that the use of figurative and metaphorical language actually minimizes, mitigates or explains such a tension. Freud's text does suggest how a sense of the public, or in his terms civilization, imposes a need for the individual to sublimate instinctual drives into the private, producing guilt as an inhibiting factor, an argument also used by Lord Henry Wotton in Wilde's novel.³⁸ However, it may be that it is through Romantic

³⁷ Sontag, p. 77.

³⁸ Oscar Wilde, p. 23. Wotton argues a case for the freedom of instinctual life - 'The bravest man amongst us is afraid of himself. The mutilation of the savage has its tragic survival in the self-denial that mars our lives. We are punished for our refusals. Every impulse that we strive to

rhetoric that such inhibitions can be released, which is only another way for the body to speak its inhibited desires. As Freud's text points out, the body's pathology subverts the belief in the unitary idea of the ego and blurs the perception 'between the ego and the external world'.³⁹ Freud goes on to argue that:

Life, as we find it, is too hard for us; it brings us too many pains, disappointments and impossible tasks. In order to bear it we cannot dispense with palliative measures.⁴⁰

If life is so full of discontent, some forms of mitigation have to be established and Freud suggests that there are three such palliative measures, one of which he calls 'substitutive satisfactions'.⁴¹ These tend, he argues, to mitigate these many pains and disappointments. He goes on to state:

The substitutive satisfactions, as offered by art, are illusions in contrast with reality, but they are none the less effective, thanks to the role phantasy has assumed in mental life.⁴²

If art is a form of metaphorical illusion, then Sontag's thesis would have Freud's support in its contrasting relationship with the 'realities' of science. Certainly if fantasy is an aspect of the imagination, it is one that blurs the ego's relationship with an external world and may well be effective in handling and understanding disease and illness. Sontag and Freud seem to agree that metaphor acts as a creator of illusions, reminding us that they were both creative artists in their own spheres of art. But if fear and desire are aspects of illness, this fear, as described

strangle broods in the mind and poisons us.' Wotton's argument seems to summarise Freud's central point in his 'Civilization and its Discontents'.

³⁹ Sigmund Freud, 'Civilization and its Discontents', in *Civilization, Society and Religion*, ed. by Albert Dickson and trans. by James Strachey, Penguin Freud Library, Vol. 12 (London: Penguin Books, 1991), pp. 243-340 (p. 255).

⁴⁰ Freud, p. 262.

⁴¹ Freud, p. 262.

⁴² Freud, p. 262.

by Derrida, is ‘the mistaken face of pity ... pity is the force of reconciliation and presence’.⁴³ Such a model reconciles substitutive satisfaction, in the form of metaphor, in conciliating the subject to a terminal condition, particularly when read alongside the language used by DeBaggio when describing his impending destination.

Metamorphosing Monsters

Illness, as a distancing from the self, requires a language of reconciliation which the use of metaphor appears to meet. DeBaggio’s situation is both real and unreal as the spectre of the ghost to come invades his sense of reality with its promise to return him to nothingness. His apprehension of what is to come is revealed in his response. The image of horror and the spectre embedded in his reaction to his diagnosis of having Alzheimer’s disease is his way of imaging the consequences of that disease. The metaphorical language he uses indicates both resemblance and substitution to the literal condition - the name of the disease which conjures up such images. The literal is also the disease of the brain itself; the mind however stretches its understanding of this literal condition through a language of the imagination. DeBaggio’s language has an emotional reality as it explores, explains and recognizes the reconfiguration of his situation. In a sense, such language becomes an act of faith, a transcendental terminology arriving out of the psyche which has psychological meaning. In these ways is it seen that metaphorical language is also a response to ‘contemporary western medicine’s

⁴³ Derrida, p. 278.

emphasis on biochemistry and technology in neglecting personal and social dimensions of illness'.⁴⁴

However, Fred Botting is one who takes issue with Freud's views on the role of art as simply a substitutive satisfaction:

Monsters give form to fears, desires and anxieties, allowing the channeling and expulsion of emotional energies. In its infectious myth-making, art, it seems, does not simply conjure up and circulate a series of colourful representations of science that develop independently and according to their own generic and cultural momentum: science is implicated in and affected by the process since it never remains outside the cultural sphere.⁴⁵

Botting is concerned to argue that Frankenstein's monster remains a persistent myth within the activities of scientific research, and claims that it has a 'monstrous metaphorical resonance'.⁴⁶ Science and art are not necessarily separate Botting argues, in contradiction to Rose's notion of a 'fragmented culture', but involved in a symbiotic and dialectical relationship, each using the other to ease the 'many pains, disappointments and impossible tasks' of the Freudian imagination. DeBaggio's vision of his future illustrates both a lack as well as a substance within that vision. The lack relates to a named diagnosis which offers nothing, and the substance refers to a loss as becoming drawn prospectively out of nature. His emotional reality is one which can be explored within the images conjured by his response. In this instance the language used implies science and art: the reality of the limits of medicine and the emotional reality of his metaphors.

⁴⁴ Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography* (West Lafayette, Indiana: Purdue University Press, 1999), p. xi.

⁴⁵ Botting, p. 341.

⁴⁶ Botting, p. 339.

Botting agrees with the view that biochemistry and technology have shifted the ground away from the human subject and argues the reverse of Rose's hierarchy in so far as Rose grudgingly admits to the imaginative power of the language of the arts, but still insists on the superiority of science. However, Botting maintains that 'the language of the arts supplies the moral vision lacking in science'.⁴⁷ He goes on to say that this is an attempt 'to return technological innovation to an older framework based on the bounded opposition of humanity and nature'.⁴⁸ In line with DeBaggio's response, a similar idea is advanced by Anne Hunsaker Hawkins when she argues a necessity which puts 'the welfare of sick persons',⁴⁹ over and above that of technology and by so doing hears the voice of the subject. Carel, too, seeks to establish a voice for the subject who becomes ill. She argues that illness is 'accounted for by physical facts alone' and these facts are described in 'objective and objectifying' ways by medical science which ignores the 'first-person experience'. She argues a phenomenological account of illness in response to the objectifying medical process - a philosophical model which enables a description of the lived experience of sickness that transcends the 'biological dysfunction'.⁵⁰

Illness, of course, is experienced subjectively, which gives an emphasis to our perception that at such times we tend to believe we have been betrayed and alienated from ourselves by a foreign body. Carel's argument primarily concerns those who are physically sick, but can a similar account be made for those

⁴⁷ Botting, p. 340.

⁴⁸ Botting, p. 340.

⁴⁹ Hawkins, p. xi.

⁵⁰ Carel, p. 8.

alienated from their minds? Maarten, the narrator of J. Bernlef's novel *Out of Mind*, seems to suggest so. He attempts to describe his experience in the early middle stages of Alzheimer's disease and his struggle to understand and keep in touch with himself, wrestling between presence and absence. At one point, in describing the process of the condition, he hints at a ghostly metaphor: 'to see something you must first be able to recognize it. Without memory you can merely look, and the world glides through you without leaving a trace'.⁵¹ It is as if experience floats, ghost-like through him, a ghost within a ghost and the very opposite to the fact of the flesh. It can be argued therefore that metaphorical thinking and figurative language may be seen as attempts to humanize a disease sent by 'nature'. Metaphors, as a language of fear, anxiety and desire, clearly shape our perceptions as Mary Shelley intends when she writes in her introduction to *Frankenstein* that her story was 'one which would speak to the mysterious fears of our nature and awaken thrilling horror'.⁵² But from Sontag's point of view, such perceptions do not fit the reality of disease.

Metaphors, moreover, as Maarten's description of his illness emphasizes, can be said to interrogate the very thing which creates them, and the response to illness and disease is indicative of this process. DeBaggio writes about his situation as someone with Alzheimer's disease in the following terms:

Now we know it [Alzheimer's disease] was not undefined evil, profligate activity, or witchcraft causing the strange behavior created by the disease. We are close to understanding mechanisms triggering this ghostly malady. The disease, or its potential, appears to rest secretly inside us until its evil time arises and a languid torture begins. This is a disease probably not

⁵¹ J. Bernlef, *Out of Mind*, trans. by Adrienne Dixon (London: Faber and Faber, 1989), p. 41.

⁵² Mary Shelley, *Frankenstein* (London: Penguin Books, 1994), p. 7.

caused by something you did to your body. It is, most likely, a consequence of bad luck, subtle effects activated in the brain, and parents who carried corrupted genes.⁵³

DeBaggio moves from a speculation about the possible causes of Alzheimer's disease to its effects:

The disease works slowly, destroying the mind, stealing life in a tedious, silent dance of death. Slowly the memory is impaired, and you wander in a world without certainty and names. Yesterdays disappear, except those long ago. Eventually there is a descent into silence and a dependence on caretakers ... a cipher takes your place ... by the end Alzheimer's leaves its victims silent, quivering in their flesh.⁵⁴

Although in his speculations as to the cause of Alzheimer's disease DeBaggio rejects the classic Gothic metaphors of evil, witchcraft, ghosts and decadent living, as does Sontag with tuberculosis and cancer, these cultural metaphors remain part of his developing understanding of his condition and its effects on him. He sees it as a secret and ghostly disease which tortures and then reveals its evil nature in its own time, gradually diminishing his own life force. Nature seems to have played this ghostly trick of fate upon him through the possible inheritance of immortal but 'corrupted genes'. The disease puts him under some kind of siege, destroying and stealing his life from him to the point where he becomes homeless and without anchorage of any kind: his undefended identity is taken from him. Is such a Gothic language an excess of categorization, out of proportion to his situation, or does it reveal an emotional, psychological reality which underlines the limits of medicine and the 'facts' of the disease?

⁵³ DeBaggio, p. 5.

⁵⁴ DeBaggio, p. 5.

The facts are that his brain is becoming neurologically damaged and re-making him as a human subject, but his mind is still embedded in culture. This is not to argue an artificial Cartesian division between brain and mind, a relationship remaining to be revealed, but to underline the fact of matter and the apparent tangibility of a consciousness which seems undefended in its symbiotic relationship with that matter and with culture. DeBaggio's cultural metaphors charge his neurological condition with reducing him, his mind, to a cipher, an unreal image hiding his real self. In fact the language of metaphor charges the name, Alzheimer's disease, with a kind of murderous intent. Matter, in the form and production of disease, is about to destroy the intangibility of his mind, that which makes him human and different at the same time. In DeBaggio's language, Alzheimer's disease becomes monstrous: it is a form which creates formlessness and, as in the genre of the Gothic, DeBaggio is aware of mutability and is in awe of it as there are no sure anchors to which to cling. If, at the end, the subject of Alzheimer's disease is perceived as a silent, quivering victim, the condition seems to usher in a language to accompany such perceptions. Botting explains the language thus:

Metaphor - and hence its monstrosity as well as creativity - is not just restricted to a realm of poetry and rhetoric, it is pervasive in everyday life, not just in language but in thought and action, crucial in structuring how we perceive, how we think, and what we do ... metaphor exploits the creativity of language ... [it] does not merely actualize a potential connotation, it creates it.⁵⁵

DeBaggio's language emphasizes that talking and writing about the experience of illness and disease can never be isolated from existing cultural ideas, and certainly

⁵⁵ Botting, p. 346.

being sick cannot be considered as some kind of pre-linguistic fact. If there is such a thing as ordinary language it needs the supplementation of metaphor to create a sense of understanding of the experience of illness. Western medicine, however, continues to have a powerful effect on individual subjectivity, and biological medicine, in particular, clearly locates pathology within that individual body, thereby handing authority to its practitioners. The medicalised body, therefore, has to become passive and disciplined as it becomes transposed into an object, a circumstance implicit in Sontag's analysis.

Telling Alzheimer Stories

There is, however, a connection to be made here in relation to metaphor as a form of resemblance. There are both subjective and objective elements in the imaging of similarities between one thing and another, a resemblance in the pursuit of understanding. Such a paradigm is also to be noted in classificatory science, a certain requirement of repetitiveness involved in establishing similarity or resemblance. But DeBaggio's responses are an example of a form of resistance to this objectifying by medicine. He explains his situation in terms which indicate the limits of biological medicine by its failure to be able to 'normalize' his experience by cure: they cannot bridge the gap, the void, and his language gives an emphasis to this as he mutates from being in 'nature' to being somehow outside of it. His language clearly attunes itself to this movement, re-describing his reality. Botting cites Paul Ricoeur as stating 'with metaphor we experience the metamorphosis of both language and reality', in other words a form of

defamiliarization: as Botting argues, Ricoeur seems not to believe it possible 'to produce a transparent language'.⁵⁶

Responses to illness and disease can be as varied as disease patterns. As needs change so will the accompanying language, as the subject attempts to adjust or reconcile itself to these needs. Subjects have a vision of their circumstances enlivened by their experience of culture, but the language they habitually employ may seem deficient to explain and explore their situation. In particular Alzheimer's disease subverts the idea of a benign 'nature' and all that such a concept represents, thus provoking the kind of responses made by DeBaggio. This is a 'nature' making a lived life strange not only in mind and body but also in language. Alzheimer's disease, it might be argued, promotes a sense of hyper-reality on the one hand and leaves a kind of simulation of a self on the other, a memento as argued in Chapter 1. This seems to underline DeBaggio's responses to his circumstances in which he senses a difference from others.

DeBaggio's responses exemplify Botting's argument that language contains resources which allow it to be used creatively. Two such methods of creativity, as he points out, are, first, the coining of metaphor, and, second, the fashioning of narratives. The first can both generate and regenerate meaning and therefore alter our understanding of reality. Disease acts as a kind of referent giving birth to metaphors and metaphorical language, and as such is a maternal offering which both gives and takes at the same time.⁵⁷ DeBaggio's response certainly indicates two archetypal metaphors with his disease as the reference

⁵⁶ Botting, p. 347.

⁵⁷ Botting, p. 365.

point. One is the idea of journeying provoked by cause, and the other is of death at the end of the journey. He makes both a reference to the past and prognosticates about what is likely to happen to him and such language enables him to order and cope with his situation. As he points out:

The inspiration for this book appeared a few days after I was diagnosed with Alzheimer's disease. It was to be a word picture of the outside and inside, present and past, of man's naked struggle with the unknown on his way to trembling silence and unexplainable torment without the torturer ... Writing about it may be a way to legitimize my almost continuous contemplation of the subject.⁵⁸

Here DeBaggio invokes a third archetypal metaphor, that of struggle; to fight and to do battle with his disease: in fact to fashion combat and to resist the disease by ordering it through writing. His struggle is nakedly elemental, and only language can help him in his fight. His tormentor obsesses him and this can only be made lawful by writing, and it is here that we have an interesting juxtaposition of an illegitimate disease facing a lawful writing: it is literally being brought to book. The archetypal myths, however, are invoked because they tend to represent shared cultural phenomena, the ways in which we have come to understand such experiences over time. In other words, they are universal myths. For DeBaggio such myths explain his idea of reality because he feels this is grounded in his experience. For the practitioner of biological medicine, reality is a kind of abstraction - a thing; but for the subjects of Alzheimer's disease, such as DeBaggio, the disconnecting experience can be made to connect through metaphorical language.

⁵⁸ DeBaggio, p. 7.

Disconnection and connection are, after all, the essentials of metaphor.

Somehow the gap between self and body created by disease has to be made meaningful for that self, and for DeBaggio only the invocation of metaphor can bridge such a gap. However, Ricoeur cites Gérard Genette as saying that metaphor is the 'inner space of language',⁵⁹ and, in this sense, while such language may not be able to bridge the gap, it may create a condition which enables a connection to be made.

In terms of function, metaphorical language appears to be one in which connections can be both possible and impossible. Robert Davis' autobiography, *My Journey into Alzheimer's Disease* illustrates this. He writes in the prologue that he wants:

To give to the concerned families some insight as to the devastation felt by the Alzheimer patient. Perhaps understanding the blackness and lost feelings will help families to be more understanding of the unreasonable actions they must deal with.⁶⁰

Davis sees his journey as arriving into a space, a gap, a void of blackness, engendering a sense of considerable loss. These metaphors are pervasive in the writings about Alzheimer's disease as they seem to describe the effects of the condition with some accuracy through the use of dark language. If memory is a kind of Freudian container, the emptying of it leaves a void, a nothingness, a matter without past, present or future. Later Davis describes his sense of fear of this void:

⁵⁹ Paul Ricoeur, 'The Metaphorical Process as Cognition, Imagination and Feeling', *Critical Inquiry*, 5 (1978-79), 143-159 (p. 144).

⁶⁰ Robert Davis, *My Journey into Alzheimer's Disease* (Wheaton, Illinois: Tyndale House Publishers, Inc., 1989), p. 17.

I am alone in the blackness. Suddenly, ridiculous, absurd fears creep into my mind. I know they are ridiculous and unreal, but they still come. Suddenly, in spite of my best efforts my mind becomes fixed upon these things – glued to them so strongly that I do not have the power to get my mind off these absurd, ridiculous, devastating, fearful things.⁶¹

Here the gothicness of the language seems only too apparent and the mind seems divided between Davis as a self, and something else that is being invaded by some kind of ghostly fear which Davis is conscious of but can do nothing to evade. It is reminiscent of DeBaggio's tormentor, breaking into a consciousness to empty it of its contents and leaving behind the other pervasive metaphor, that of the paradox of the living corpse. These metaphors shape the psychological space of Davis and DeBaggio, as well as their language. They expose and connect with the idea of the gap, the spaces between the memories of past and present and thoughts of the future, which are interfered with by neurological disasters that reduce the power of Davis's mind to resist the fears of the void. Their lived experiences of an Alzheimer's journey, marked by metaphors, end by what Iris Murdoch called 'entering a dark place', one in which the self has been wiped away.⁶²

The accounts that DeBaggio and Davis both give of Alzheimer's disease, are examples of that same self-combat which Sontag desires: of resisting, by writing, the notion of becoming a victim. Language for them defines their knowledge rather than simply reflecting it, and their stories unfold between the spaces of their descent into silence. In particular, these metaphors express un-sublimated fears as the gaps, spaces and voids are perceived in terms of

⁶¹ Davis, p. 107.

⁶² Murdoch is reported to have used this phrase in talking to Martin Amis about losing her memory. He reports this in the *Guardian*, 25 January 2010, p. 3.

corruption: of a body corrupting its driving forces - consciousness and memory.

DeBaggio's obsessive contemplation of his condition is almost Gothic in its concerns with horrific ugliness as well as the mortality of the human body. It suggests an awareness of how his condition is announced in language while, at the same time, the language begins to displace him, in the sense that it emasculates him and moves him out of nature by cutting him off from his past, his history. Suggestively, both Davis and DeBaggio, in telling their stories, attempt a kind of body suicide by scooping out from the memories of their lives a substance which seems to create a hollow within the body; a grave in which another will dig even deeper to encrypt them. In the face of all this - the blackness, the gaps, the spaces - Sontag's clinical rationalism rejects the very messiness and anguish of life, in which, she readily admits, illness and disease play such a large part.

Conclusion

Language meets the needs of both rationalism and the imagination, but it is evident that it is imagination, in the early stages of the disease, that seems to assist the subjects of Alzheimer's in ameliorating and accurately describing their circumstances in a way that, for them, authenticates their situation. If language is desire, then Davis, DeBaggio and others seek to hold on to it for as long as possible to assist in continuing to define themselves as subjects still within nature and culture, until the life-threatening condition which makes them strange finally overtakes them and moves them into a void. Their texts occupy a kind of emotional twilight, a space of eclipsed intensity and identity. The disease, suggestively, writes a concluding chapter of lived lives and as such that space is

haunted by a lost past; matter becomes a kind of empty house, no longer accommodating a life that has been lived. As subjects who have lived and continue to live through the void, their texts indicate their presence as well as foretelling their absence. In a sense they write what Hilary Mantel calls a ghost story:

A ghost story always exists on the brink between sense and nonsense, between order and chaos, between the rules of existence we know and the ones we don't know yet.⁶³

Their texts rest uncannily upon this cusp of being between one sense of self and the ghost of the one to come, and this metaphor seems central to their personal and social predicament. As their notion of being an 'I' disintegrates, it becomes, paradoxically, displaced as an existence in their texts as their writing attempts to keep them on the right side of being human, emphasizing that language, as a symbol, acts in their place.

⁶³ Hilary Mantel, 'Ghost Writing', *Guardian Review*, 28 July 2007, pp. 4-5.

Chapter 5

Buried Alive: Mourning, Gothic Images and Dying Words

The psychoanalytical experience has rediscovered in man the imperative of the word as the law that has formed him in its image. It manipulates the poetic function of language to give to his desire its symbolic mediation ... It is in the gift of speech that all the reality of its effects resides; for it is by the way of this gift that all reality has come to man and it is by his continued act that he maintains it.

Jacques Lacan

Like the half-dead, I hug my last secrets ... I fall, more and more into my own silences.

Theodore Roethke

Alzheimer's disease is worse than death. It leaves bone and flesh intact while it erases judgement and memory. I could live with death. Death is part of the cycle of life. It's like spring, the end of winter. But this disease – it's unnatural. It's the end of hope.

Jim Evans

The human problem: having a mind, being a body, is nowhere quite so painfully and clearly apparent as in medicine. Painful, because to be a body means you must die. Clear, because to have a mind means you know this.

Bert Keizer

we need to pay attention not only to an already conventional dialectic of civilization and barbarism ... but also to a phenomenon of inner exile, in which whatever melodramatic scenario the spurned ego enacts for itself on the cave walls can be seen, under certain cultural circumstances, as a potential for acting out.

David Punter

No longer something to be dispatched, mourning becomes more amorphous and fluid, more interminable as one might say.

Jacqueline Rose.¹

¹ Jacques Lacan, *Ecrits: A Selection*, trans. by Alan Sheridan (London: Tavistock, 1977), p.106; Theodore Roethke, 'Old Lady's Winter Words' in *The Collected Poems of Theodore Roethke* (London: Faber & Faber, 1966), p. 103; Jim Evans, cited in Donna Cohen and Carl Eisdorfer *The Loss of Self* (New York and London: W. W. Norton & Co., 1986), p. 60; Bert Keizer, *Dancing with Mr. D: Notes on Life and Death* (London: Black Swan, 1997), p. 1; David Punter, 'Introduction: the Ghost of History' in *A Companion to the Gothic*, ed. by David Punter (Oxford: Blackwell, 2001), pp. viii-xiv (p. xiii); Jacqueline Rose, *On Not Being Able to Sleep: Psychoanalysis and the Modern World* (London: Chatto and Windus, 2005), p. 73. The slow psychological dying brought about by the neurological pathology of Alzheimer's disease - a kind of Gothic premature burial - is the main theme of this chapter. The epigraphs which introduce this

Buried Alive

If postmodernity can be said to be framed and characterised by forms of fragmentation, division, separation, space, void, incompleteness, remnants, repetitions, fracture, circularities, disappearance, ambivalence, ambiguity, depth, surface, absence and so on, then it may be observed that these concepts conform to the symptoms and effects commonly relied upon in the representation of Alzheimer's disease. The concepts also seem to have contracted a place within the genre of the Gothic, in so far as all of them are concerned with the dissolution of boundaries, both of self and of society, as meanings and identities are broken up. In particular, the space created by the disappearance of a personal history wrought by the disease resonates suggestively with the idea of being buried alive. This is a common theme in many Gothic texts, most notably in stories by Edgar Allan Poe as the commentary below sets out. Elaborated here in relation to Alzheimer's disease, premature burial refers to the psychological self insidiously disappearing into the materiality of the remaining body which comes in turn to be seen as the remnant of that self: the surface of a buried self. Thus the reality of the material body seems to encrypt the illusion of that self and the space created by a lost history is one in which a mourning for the death of a psychological self precedes and shapes the transitional space before material death. In fact, as much as in representation, Alzheimer's disease takes you to the very edge of your mind and then tips you over that edge into darkness. And it is perhaps at this point that we have to accede to Freud's exhortation that we look to the language of the poets to supplement, as it were, what we may think we know about this space of absence

notion signal emotional and linguistic responses inhabiting the space between the diagnosis of Alzheimer's disease and the eventual loss of self. The vulnerability of the Alzheimer subject to the possibility of abuse within this space is also discussed.

and darkness. This chapter will attempt to explore such a space and the psychological issues which arise, for individual, family and wider society alike.

Spaces, and how they are framed in meaning, are the primary themes in Catherine Belsey's illuminating essay 'Making Space: Perspective Vision and the Lacanian Real'. Belsey takes this 'Real' as a starting point to consider issues of reality and illusion, particularly in the form of visual art. She argues that the perspective of space is crucial to our understanding of reality and illusion, and asserts that 'Truth exists in culture, at the level of the signifier, in this instance as a painting which denotes a building'.² Architecture and buildings become objects of our perspective with their scale and drama as forms that tend to signify power, and Belsey tellingly uses Elizabeth Bennet's first sighting of Pemberley, in Jane Austen's *Pride and Prejudice*, to illustrate this point and to begin her explication of space, reality and illusion. Her primary argument about architecture and buildings is that in so far as they are constructions that seem to speak to us not only of history and power, they also enclose emptiness; an emptiness, perhaps, of power and sterility which asks to be relieved by interpretation, which in the case of Austen's novel, occurs through the alchemy of romantic love.

This emptiness is invoked in Hilary Mantel's notion of the ghost story, referred to in the previous chapter, as something in-between, a story which has spaces between the forms which structure it, 'between sense and nonsense, between order and chaos, between the rules of existence we know and the ones we don't know yet'.³ It is within these spaces, perhaps, which bring to mind paralysis or redundancy, that we begin the transformation from fact to artwork which gathers to itself the signifiers of emotional truth. Mantel's structuring of the

² Catherine Belsey, 'Making Space: Perspective Vision and the Lacanian Real', *Textual Practice*, 16 (2002), 31-55 (p. 38).

³ Hilary Mantel, 'Ghost Writing', *Guardian Review*, 28 July 2007, pp. 4-5.

ghost story indicates that one of the ways we collide with the Real is through this form and what we do not know yet may be journeyed towards through the mysterious genuflections of the Gothic ghost story as it explores ways to write about non-beings. The space which Mantel's structured forms surround is, in the Lacanian Real, 'the place of the lost object ... impossible to symbolize and equally impossible to forget'.⁴ In the psychoanalytic paradigm, this lost object is created by our abjection into a world of difference and therefore 'formed at the expense of the little human organism that knows no distinctions'.⁵ But, so argues the paradigm, once the notion of difference is introduced, desire follows as a form in which to search and seek out the lost object. The theory seems to owe a good deal to Aristophanes' story in Plato's *The Symposium*.⁶ However, the Lacanian Real, being 'beyond the signifier and beyond pleasure',⁷ can only, it seems, be attained in death, in annihilation:

To be united with the lost object even if it were possible,
would be to surrender our existence as subjects, dissolving
into the real itself. We need, therefore, to keep our distance.⁸

If it is in difference that we become subjects then a fall into the Real is when we dissolve into nothingness, the abjection in reverse of the body. The Alzheimer's disease subject seems to be no more than an object, lost in the space of materiality. But the desire that has a need to seek this Real creates the language which Susan Sontag takes issue with in *Illness as Metaphor*. In the instance of

⁴ Belsey, p. 32.

⁵ Belsey, p. 35.

⁶ Plato, *The Symposium*, trans. by Walter Hamilton (London: Penguin Books, 1951). Plato's text is a discourse on love in its several forms and guises. The text is presented in the form of a conversation between various members of the Athenian elite, mostly friends of Plato. Aristophanes' contribution seems a satire on the notion of desire and its origins which involve, at the beginning of creation, a set of spheres sliced in two by their creator, Zeus, the consequence this being that the spheres search for their severed other half throughout their existence.

⁷ Belsey, p. 33.

⁸ Belsey, p. 33.

Alzheimer's, desire has a need to fill this enclosed space with a metaphorical language of sorrow, anger, regret, loss, consolation, fear and horror in that transitional mourning period between diagnosis and the onset of the worst effects of the condition. In a sense, it can be said that Sontag's argument leads us towards burying alive the metaphor, leaving bodies to fall into a void and to resolve emotional truths concerning illness and disease by returning them to the brutality of fact. The metaphor, for Sontag, may be considered a difference too far, but for Lacan it becomes the essence of the psychoanalytic paradigm. And for those writing about the disease in a personal sense, or for those who pursue it through fiction and other genres, figurative language seems to authenticate the experience of this condition.

The desire for the lost object might also be construed as the metaphor for the death wish which was once a central motif of the psychoanalytic paradigm. Certainly, as Nicholas Royle remarks, the fear of being buried alive is a well established 'literary preoccupation';⁹ it is also one of the opening points in Freud's 'The "Uncanny"'. How the past has become buried is, of course, the central preoccupation of psychoanalysis, as it attempts to uncover emotional truths between the spaces of language offered up by analysands. However, it is the spaces left by the consequences of Alzheimer's disease which are the primary focus here, as existence is dissolved into the Real in much the same way as the Gothic 'is always on the point of dissolving into something else, as are phantoms and spirits'.¹⁰

⁹ Nicholas Royle, *The Uncanny* (Manchester and New York: Manchester University Press, 2003), p. 155.

¹⁰ David Punter, *Gothic Pathologies: The Text, the Body and the Law* (Basingstoke and London: Macmillan Press Ltd., 1998), p. 200.

As Alzheimer's disease progresses, it creates in the mind a sense of living between two worlds and being driven remorselessly out of one and becoming more and more entombed in the other. Earlier chapters have indicated something of the relationship between the disease and the discomfiting, disorientating and fragmented language which often accompanies it. Following diagnosis and the early effects of the condition, there appears to be both a literal and a metaphorical truth in the reactions to the disease of Thomas DeBaggio, Jim Evans and Robert Davis among others. And if Freud's exploration of the sense of the uncanny can be read as a way of systematizing the experience of anguish and Julia Kristeva's paradigm of abjection can be read as an experience of the apocalyptic and epiphanic, then it seems that in the reactions of those diagnosed with Alzheimer's disease, as well as those who care for such subjects, the deep structures of the language of the Gothic can also be read. To begin with, Sherwin Nuland argues that:

It is probably a universal teaching of all cultures that putting a name to a demon helps to decrease its fearsomeness. I sometimes wonder whether the real, perhaps culturally subconscious, reason that medical pioneers have always sought to identify and classify specific diseases is less to understand than to beard them ... when we give sickness a name, we civilize it - we make it play the game by our rules.¹¹

Naming is an instrumental process and, as Lacan points out in the first of the epigraphs to this chapter, creates images, and the image of the self being buried alive by dementia is a fairly common one. But being named as a subject of Alzheimer's establishes that the demon is alive and well, establishing a fear of the potential to kill twice: once psychologically and then materially. The narrator in Damon Galgut's novel *The Good Doctor* exemplifies this hidden fear:

¹¹ Sherwin Nuland, *How We Die* (London: Chatto and Windus, 1994), p. 105.

I didn't see it, I sensed it: a sudden little burst, a flexing
in the dark. It had a will and life of its own. And in a second
all my terror was back. Everything I most feared and dreaded,
all the phantoms of the mind, had drawn together into a knot -
a presence that had risen out of the dark.¹²

This is the kind of embedded fear shocked into wakefulness by something
unknown which Shelley and Lovecraft attempt to prise open in their work.

But naming in medicine has established its own law-giving practice, and
as Nuland indicates, provides some certainty that consequential action will follow.
Lacan's playful psychoanalytic rewriting of the essence of the Bible as the
defining law of the Word of God is central to the idea of postmodern humanness
in that the reality of life and death is mediated by language. We are speaking
beings and construct in language our narratives of life and death. There is,
however, a paradox within 'the imperative of the word as the law'¹³ and the law
of naming in medical science and it is this: if certainty is at the heart of law, then
it must allow for an absence, what Lacan might call the Real, that speculative
other side of language, something unknown but ready to come to the surface. The
certainty of becoming absent and being removed from language with all its
mediating efforts is what follows being named as a subject of Alzheimer's
disease. Absence may also be recognised within the motifs of the Gothic: for
example, the unseen virus in the epidemic of death in Poe's 'The Masque of the
Red Death', written about also, as with Alzheimer's disease, with the certainty of
an unreal existence yet to come. But if naming is seen as a civilizing process,
Alzheimer's disease is perceived as a kind of death sentence, as Jan Prescott's
reaction to her diagnosis indicates:

¹² Damon Galgut, *The Good Doctor* (London: Atlantic Books, 2003), p. 179.

¹³ Lacan, p. 106.

A sense of utter helplessness swept over me when the doctor said that I probably had Alzheimer's disease. The very words "Alzheimer's Disease" sounded harsh and unreal. I wanted to believe that he was talking about someone else - not me ... I thought if I didn't hear the words then I couldn't have the disease.¹⁴

And Joan Didion's memoir of her reactions to the death of her husband, John Gregory Dunne, recalls not wanting to believe his death and her emotional reaction to it as a kind of magical thinking, a way of substituting one form of language for another in a further avoidance of reality. She quotes the response of a mother to the news that her army son has been killed:

'I opened the door and I seen the man in the dress greens and I knew. I immediately knew. But I thought that if, as long as I didn't let him in, he couldn't tell me. And then it - none of that would've happened'.¹⁵

It appears that if you do not hear the fact of death, or its approach, it assists with the illusion that living seems to need. Didion's recollection of her experience during the year following her husband's death is focused on how she reacted to certain experiences, such as not wanting to get rid of his shoes in case he may need them on his return. She is, so to speak, brought up short against these ideas of his return, and it is this experience that she calls magical, a desire not only to disbelieve the fact of his death but also, paradoxically, a kind of need to re-awaken him from the dead. Both she and Prescott react to loss in ways that display omnipotent thinking: a kind of magic-making. Prescott's reaction to her diagnosis, however, is far from 'decreasing its fearsomeness' because this particular 'demon' refuses to be bearded. Her reaction is structured with a sense of shame, which from a psychoanalytic point of view would, paradoxically, be seen as a civilizing process. But this is compounded by a feeling of undergoing a

¹⁴ Cohen and Eisdorfer, p. 58.

¹⁵ Joan Didion, *The Year of Magical Thinking* (London: Harper Perennial, 2006), p. 13.

terrible trauma, a trauma which seeks to escape the evasion of the truth of the disease so as to ensure that her imagined completeness of self remains intact. The trauma makes her acutely aware of her self. Cathy Caruth describes the pathology of trauma as an event which:

Consists solely in the structure of its experience or reception: the event is not assimilated or experienced fully at the time, but only belatedly, in its repeated possession of the one who experiences it. To be traumatized is precisely to be possessed by an image or event.¹⁶

The words 'Alzheimer's disease' which Prescott hears, but seeks to be deaf to, are a death sentence to her sense of being somehow complete. She wants to deny it, but this particular demon infiltrates and then destroys her sense of wholeness and opens her up to a transformation which will place her in DeBaggio's parade of horror. Trauma is experienced as a fragmenting of identity having a profound effect on the ways in which the self is constructed. The trauma of hearing the words seems to split Prescott's oneness into dislocated segments as the self attempts to defend itself. Within the psychoanalytic paradigm the defensive drive paradoxically comes up against the Real itself, the fear of dissolving into nothingness. Prescott, at this early stage of her condition, is her own witness to the horror of a disease which seems beyond explanation or rationalization and which exposes human vulnerability as it encounters such estrangement. Prescott's language can be seen to be replete with the demons which cause her body to feel helpless against an estranging power destined to divorce her from herself and bury her within. Her attempted defence is a psychic one, the mind taking the primary defensive role, with the body in a state of tension, helplessly struggling against the words she does not want to hear. This reading relies on a construction of

¹⁶ Cathy Caruth, 'Trauma and Experience: Introduction' in *Trauma: Explorations in Memory*, ed. by Cathy Caruth (Baltimore and London: Johns Hopkins University Press, 1995), pp. 4-5.

Freudian drives which places them at the interface of the inside and the outside; hovering in a somewhat ghostly manner between the two, located neither within the mind nor the body.

Jim Evans, in the third of the epigraphs which open this chapter, seems to predict his future as somewhere between life and death, seeing himself as a kind of living corpse, in a manner illustrative of the construction set out above. He, like Prescott, indicates an acute awareness of self and sees Alzheimer's disease as robbing him of his self-awareness by removing his history and destroying his capacities, thereby abjecting him back to his body which will no longer seem to be his own. His despairing cry that the disease gives no hope is underscored by Nuland who states that it creates an 'excruciating cul-de-sac', an aporia with no signs to indicate a way forward.¹⁷ Evans claims the disease undermines a proper nature which recedes before its very un-naturalness, and he resents the reality of transience, becoming angry, despairing and fearful of the future in much the same way as Prescott. Both Evans and Prescott's reactions to the trauma of diagnosis seem to incorporate feelings not only of horror, rage and a kind of shame, but the idea that they are being robbed of that capacity which Lacan argues is distinctively human. In other words, the loss of the possibility to manipulate language with all its poetic and symbolic potential, the opportunity to dwell in the imagination, something that Theodore Roethke's epigraph illustrates, as it prefigures Evans, imagining the half-dead and half-alive state as the poet slowly falls into his own silences.

¹⁷ Nuland, p. 105.

This lived-in space between life and death is evidenced not only by carers but also by psychologists such as Steven Sabat and the late Tom Kitwood.¹⁸ They argue that the reality of the self, although imprisoned by disease, is still to be found within this constructed space. In Julian Barnes's short story, 'Appetite', the narrator discusses her husband's dementia as if in conversation with another, and declares 'he'll always be himself, there, underneath, through and through'.¹⁹ Here a buried self is clearly being suggested. By contrast Kitwood and Sabat advocate relating to parts of the former self through the use of focused listening and observational skills concentrating on the dislocated, fragmented language and behaviour of the Alzheimer subject. This conjuring of aspects of the former self is similar to the idea of linking the past to the present through the wraith-like figure of the Fetch who is conjured from the past into the present, portending death.²⁰ This is an idea tellingly used in A. S. Byatt's story 'The Pink Ribbon', when the husband is visited by the figure of his wife from earlier years portending her death in the present from Alzheimer's disease.²¹ To many carers of those with Alzheimer's disease, the subject seems to have an uncanny likeness to their former selves, but only in the sense that they have become a kind of ghostly resemblance to it.

Evans's judgment about an un-natural nature is echoed in Freud's short essay 'On Transience' which was written in response to an invitation from the

¹⁸ Steven Sabat, *Experience of Alzheimer's Disease: Life through a Tangled Veil* (Oxford: Blackwell Publishers, 2001); Tom Kitwood, *Dementia Reconsidered* (Buckingham: Open University Press, 1997). Both these clinical psychologists have investigated the extent to which an essential self remains embedded notwithstanding a dislocated and dislocating language, and the relationship of that essential self to the language it speaks and hears.

¹⁹ Julian Barnes, 'Appetite', in *The Lemon Tree* (London: Picador, 2005), p. 169.

²⁰ Fetch - a word of uncertain origin - refers to the disembodied ghost of a living person. Fetches most commonly appear to friends and relations at the very moment before the death of those they represent.

²¹ A. S. Byatt, 'The Pink Ribbon', in *Looking into Later Life: A Psychoanalytical Approach to Depression and Dementia in Old Age*, ed. by Rachel Davenhill (London: Karnac Books, 2007), pp. 246-268.

Berlin Goethe Society in 1915.²² Freud was an admirer of the work of Goethe and in 1930 received the Goethe Prize, the highest literary award in Germany at that time. It seems the genesis for the subject of the essay arose out of a meeting that Freud had had with the poet Rainer Maria Rilke and his companion, Lou Andreas-Salomé, a psychoanalyst and writer, in 1913, a year before the outbreak of the First World War. The essay and its history chime with Freud's 'Mourning and Melancholia',²³ published in 1919, but written earlier in the war. Both works reflect Freud's feelings of sadness and despair during a period of considerable social and economic upheaval and the death of many millions of people, but a period which also, paradoxically, fostered substantial creativity in his written work. At the beginning of this essay, Freud writes that he and his companions were out walking in the countryside where:

The poet admired the beauty of the scene around us but felt no joy in it. He was disturbed by the thought that all this beauty was fated to extinction, that it would vanish when winter came, like all human beauty and all the beauty and splendour that men have created or may create. All that he would otherwise have loved and admired seemed to him to be shorn of its worth by the transience which was its doom.²⁴

Freud's response to what he called 'the proneness to decay' of all that lives, was to maintain that Rilke's attitude could be said to arise from 'two different impulses in the mind'. One of these was Rilke's despairing reaction, and the other was to feel that something as beautiful as life, in all its facets, 'must be able to persist and to escape all the powers of destruction'.²⁵ The questions which seem to arise out of both impulses are ones that are of central concern to psychoanalysis:

²² Sigmund Freud, 'On Transience', in *Art and Literature*, ed. by Albert Dickson, trans. by James Strachey, The Penguin Freud Library, Vol. 14 (London: Penguin Books, 1990), pp. 287-290.

²³ Sigmund Freud, 'Mourning and Melancholia' in *On Metapsychology*, ed. by Angela Richards trans. by James Strachey, The Penguin Freud Library, Vol. 11 (London: Penguin Books, 1991).

²⁴ Freud, 'On Transience', p. 287.

²⁵ Freud, 'On Transience', p. 287.

how do we attempt to survive dissolving into the Real? How do we struggle against, or with, a return to death? The first of these questions carries aspects of mourning which Freud developed further in his later essay on 'Mourning and Melancholia', while the second continues his concerns with the denial of death and feelings of immortality as he goes on to say:

Mourning over the loss of something that we have loved or admired seems so natural to the layman that he regards it as self-evident ... we possess ... a certain amount of capacity to love ... which in the earliest stages of development is directed toward our own ego.²⁶

Given that psychoanalytic theory suggests that nothing is lost, only psychically buried, this love of self presumably remains and, at times of crisis or trauma in the face of impending loss, is psychologically re-activated, as illustrated in Prescott's reaction to the words of her diagnosis. She, Evans and DeBaggio are clearly emotionally involved in their psychic demise, and their potential extinction seems to bring images of decay in its trail. Of course, if nothing is lost but simply buried, it presumably has the potential to be re-awakened. In the psychic topography of Nicolas Abraham and Maria Torok, images of phantoms and crypts proliferate and these are the very materials which also flourish, of course, in the Gothic genre.²⁷

In psychoanalytic terms, Abraham and Torok's work seeks to provide both a meaning for repressed emotional problems and to exorcise these awakened phantoms; but the buried self created by Alzheimer's disease resists this priestly approach. Freud's argument in 'On Transience' is that the value of life and nature

²⁶ Freud, 'On Transience', pp. 288-289.

²⁷ Nicholas Abraham and Maria Torok, *The Shell and the Kernel*, edited, translated and with an introduction by Nicholas T. Rand (Chicago and London: The University of Chicago Press, 1994). Rand writes that 'The broadest aim of *The Shell and the Kernel* is to restore the lines of communication with those intimate recesses of the mind that have for one reason or another been denied expression' (p. 4).

rests within what he calls its 'scarcity value', which should increase the possibility of enjoyment.²⁸ However, the transient and transitional time and space between the symptoms of Alzheimer's disease appearing and the burying of self-consciousness is seen by both Evans and Roethke in much the same way. Both begin to show the symptoms of mourning the loss of themselves and that process continues in a different kind of way as the disease makes its inevitable progress. In that buried state, the Alzheimer subject will often cry out in bewilderment at the loss of their self and often physically wander about in ways which suggest they are seeking the consciousness of themselves, reflecting a desire to return from the underworld to which they have been confined by the disease. Alzheimer's own patient, Augusta D., during a clinical examination, told him repeatedly that she had lost herself, and it was following her death that Alzheimer described the condition which subsequently came to bear his name.

In a sense Alzheimer's name entombs all those who are diagnosed with the condition, as all proper names do according to Royle in his commentary on 'The Premature Burial', a short story by Edgar Allan Poe, where the narrator describes what he thought was his own burial while still alive.²⁹ However, the story turns back on itself as a work of the imagination by suggesting to the reader the drawbacks of a too vivid, excessive and, more tellingly, morbid imagination.³⁰ The power to think such things, it is being suggested, must be met equally with the power to overcome them and so enable one to return to reason - a theme pursued by Freud in 'The "Uncanny"'.³¹ Poe's narrator suggests at the beginning

²⁸ Freud, 'On Transience', p. 288.

²⁹ Nicholas Royle, p. 145.

³⁰ Edgar Allan Poe, 'The Premature Burial' in *Selected Tales* (London: Penguin Books, 1994), pp. 322-336.

³¹ Sigmund Freud, 'The "Uncanny"' in *Art and Literature* ed. by Albert Dickson and trans. by James Strachey, Penguin Freud Library, Vol. 14 (London: Penguin Books, 1991), pp. 335-376.

of his account of his own and other people's experience of being buried alive, which is told in the form of a kind of reportage, that the subject is such that it is 'too horrible for the purposes of legitimate fiction'.³² The idea of legitimacy returns us to the law and the issue of examination which is at the centre of Freud's essay on 'Mourning and Melancholia'.

Mourning the Loss of Self-Possession

If Poe's story relates to a fear of being buried alive presaging the arrival of ghosts between 'the boundaries which divide life from death',³³ then 'Mourning and Melancholia' speaks of Freud's profound despair at the loss of western enlightenment values during the First World War and the transience and fragility of all cultures. Ostensibly the paper traces the similarities and differences between mourning and melancholia, but with 'On Transience'³⁴ and 'Our Attitude towards Death',³⁵ 'Mourning and Melancholia'³⁶ struggles to hold the centre against the ghosts and the influences of the past and their re-appearance in the present and the future. In the early part of the paper Freud proposes that:

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.³⁷

The ghosts that have arrived out of the loss of ideals, liberty and reason and the necessity to return to them, are essential components of the psychoanalytic paradigm fashioned and polished within the trauma of the First World War. The primary distinction that Freud makes between mourning and melancholia is that

³² Poe, p. 322.

³³ Poe, p. 322.

³⁴ Freud, 'On Transience', pp. 287-290.

³⁵ Sigmund Freud, 'Our Attitude Towards Death', in *Civilization, Society and Religion*, trans. by James Strachey, ed. by Albert Dickson, The Penguin Freud Library, Vol. 12 (London: Penguin Books, 1991), pp. 77-89. The essay argues that 'in the unconscious everyone of us is convinced of his own immortality' (p. 77), but in relation to other people's death, from primeval man to the present, we construct the notion of spirits to accommodate loss.

³⁶ Freud, 'Mourning and Melancholia', pp. 245-268.

³⁷ Freud, 'Mourning and Melancholia', p. 252.

mourning is a conscious emotional piece of work which has a beginning, middle and an end so that at its conclusion those who have mourned a loss have regained their emotional equilibrium once more. Melancholia, on the other hand, is pathological in that it has unconscious elements that help sustain the relationship with the dead object, a kind of unwillingness to shake off the ghosts of the past and so retain some emotional contact with them for reasons which need to be examined if that stasis is to be relieved or removed.

The work of mourning, it seems, is normal and in the end can be driven away with the mourner returned to a state of normality; melancholia, by contrast, suggests some blind identification with ghosts as a way of living, as it were, with what Freud terms 'the shadow of the object'.³⁸ However, where mourning comes to an end followed by an emotional rapprochement, it indicates that we can live without the ghosts of the past. But in practice, as the work of Abraham and Torok suggests, to be a subject in difference means continuously to be haunted and to be able to accommodate such ghosts. It seems clear, from the various remarks of Alzheimer's disease subjects quoted elsewhere in this and earlier chapters, that they are only too conscious of death as the absent presence which stalks them in the transitional space between diagnosis and the onset of the worst features of the disease. In fact, the Alzheimer subject deals not so much with the taboo of death as with the taboo of dying, being held, as it were, on the threshold of death. James Thomas puts it this way:

No theory of medicine can explain what is happening to me.
Every few months I sense another piece of me is missing.
My life ... myself ... are falling apart. I can only think

³⁸ Freud, 'Mourning and Melancholia', p. 258.

half-thoughts now. Someday I may wake up and not think
at all ... not know who I am. Most people expect to die some day,
but who ever expected to lose their self first.³⁹

Thomas sees his psychological self slowly disappearing into his body and his sense of himself seems to be breaking into bits, but do the pieces fade away or do they fill and expand the space of the body? The narrator of J. Bernlef's novel, *Out of Mind*, Maarten, subject to Alzheimer's, states:

No way back, no way forward. Fill this space more and
more. (Breathe as little as possible, therefore, so as not
to expand even more in the emptiness around me.)⁴⁰

The speaker seems to see himself in a state of aporia, but in danger of filling up his inner space with nothingness. Putting the last sentence into parenthesis seems to emphasise Maarten's desire not to expand because as the story goes on the words get less and less. Both Thomas and Bernlef's narrator see no way out of their predicament and no opportunity to re-arrange or re-transcribe their problematic situation. Clearly, from Thomas's point of view, the disease has created within him something strange and unfamiliar, and he has been uprooted from his sense of self and reconfigured into 'half-thoughts'. So the mourning of these subjects for themselves inevitably entails a language of loss and, as the sense of their ideal wholeness is undermined by the disease, that language speaks out of the body. Moreover, the sense of loss of the Alzheimer subject is exacerbated by a search for the lost self: those pieces which Thomas says he is losing and which seem to elicit the frustration and poignancy in his language as the image he has of himself begins to fragment.

Darian Leader represents this in a psychoanalytic paradigm by suggesting it is a depressive position. It is:

³⁹ Cohen and Eisdorfer, p. 22. The authors quote a patient, James Thomas, writing a year after his diagnosis.

⁴⁰ J. Bernlef, *Out of Mind* (London: Faber and Faber, 1989), p. 113.

One linked to the destruction of the Ego and one linked to pining, reparation and the wish for the whole and complete object ... there is the fragmented state of the body and then there is the wholeness promised by the image.⁴¹

Leader argues a theoretical point of view concerning a notion of identity and how we only sense wholeness through an image of ourselves, which is reminiscent of Lacan's mirror stage when the child perceives the reflection of its body as whole and mistakes it for a psychological sense of oneness. However, there is an inverse to this youthful illusion when old age arrives, as Kathleen Woodward points out:

As we age we increasingly separate what we take to be our real selves from our bodies. We say that our real selves - that is our youthful selves - are hidden inside our bodies. Our bodies are old, we are not. Old age can thus be described as a state in which the body is in opposition to the self, and we are alienated from our bodies. This is a common psychological truth.⁴²

Both Leader and Woodward argue that mirror images at either end of the age spectrum establish and create illusions about the self. However, in old age the elderly recognise themselves in the other and are, as Woodward points out, 'compelled to acknowledge ... the other which has, as it were, installed itself in our body'.⁴³ But the image of wholeness is seemingly transformed by the disease and the representation becomes one of being less than human: creating, as it were, something of the posthuman.

So in the period between the diagnosis of Alzheimer's disease and the inevitable decline into its dislocating effects, a space exists within which the experience of the subject invariably seems like something else. Unsurprisingly, the language of metaphor and simile is often used in such instances as when the

⁴¹ Darian Leader, *Freud's Footnotes* (London: Faber and Faber, 2000), p. 201.

⁴² Kathleen Woodward, 'The Mirror Stage of Old Age' in *Memory and Desire*, ed. by Kathleen Woodward and Murray M. Schwartz (Bloomington: Indiana University Press, 1986), pp. 97-113 (p. 104).

⁴³ Woodward, p. 104.

subject is attempting to understand this transformation of self while simultaneously trying to keep in touch with a fading memory of both that self and others. In the epigraphs which open this chapter, for example, both Evans and Roethke resort to the use of simile as a means of describing this mutation and the prospect of death. The disease and the prospect of death put their experience at the disposal of the mourning process as their dying selves begin to grieve over their forthcoming demise. In a sense, one form of death precedes the other and the passing of the self, uncannily, becomes a substitute during this transitional period for the other physical death. The space occupied by Alzheimer's disease is a space of suspension, the subject being both dead and alive, or neither dead nor alive, and a space, also, within which mourning and, maybe, reconciliation occur.

Donald W. Winnicott's theoretical work on object-relations opens up what he called an 'intermediate area': spaces and stages in suspension in a child's development. These areas, he argues, are times for reconciling the various stages of maturation, in a way tracing maturational developments from one stage to another. Transitional objects such as toys, play and stories are taken gradually into the child's psyche and are forms of introjection which become part of their self-fashioning processes and create a sense of difference from others. All of which, according to Winnicott, enables the child to 'link with the past and with the future'.⁴⁴ This process of self-fashioning and differentiation, forming a sense of self and a belonging to self in tandem with an appreciation of being different from others, may also be understood in relation to Alzheimer's disease. In other words, the time between diagnosis and the appearance of the worst features of the condition, can also be seen as an 'intermediate area'. In the child's development,

⁴⁴ Donald W. Winnicott, *Playing and Reality* (London: Penguin Books, 1964), p. xii.

Winnicott states, 'the infant's capacity to recognise the object as "not me"' ⁴⁵ is a crucial stage in the differentiation between it and the external environment in its becoming world. He also states that:

The object represents the infant's transition from a state of being merged with the mother to a state of being in relation to the mother as something outside and separate. ⁴⁶

Winnicott first wrote about transitional objects in 1951 and Julia Kristeva's ideas about abjection were published some thirty-two years later. Her much later concerns about the effects of this differentiation and its power were only partially conceptualised by Winnicott when he states that objects are transitional, but assist as 'a defence against anxiety, especially anxiety of a depressive type'. ⁴⁷

The power of loss, of abjection and the establishment of a lack and its effects upon the psyche and the body do not seem to hold the same terror for Winnicott as they do for Kristeva. However, the 'not me' process within the 'intermediate area' for Alzheimer subjects seems to be at the centre of their mourning for a lost self. Any understanding of wholeness in Alzheimer disease subjects bifurcates what they consider to be the real self as it gets buried by the condition. The objects which seem to act against the anxiety of this burial process are ones of repetition and obsession as described by Davis and others, but this merging back into the body, and being buried within it, is an experience that cannot be prevented by objects of any kind, as neurology outwits psychology.

When Auguste D. says she is lost, she not only expresses the paradox of her sense of subjectivity but also acts out the loss in her behaviour. The narrator in

⁴⁵ Winnicott, p. 2.

⁴⁶ Winnicott, p. 17.

⁴⁷ Winnicott, p. 4.

Samuel Beckett's *The Unnamable* declares: 'Where I am there is no one but me who am not'.⁴⁸ Here, as Gabriele Schwab points out:

Is not only the expression of a paradoxical subjectivity beyond the notion of a self, [but] also the expression of a voice that is conscious of the paradoxes of its own performance ... destroying our ease with such basic categories as life, death, time, language, and other.⁴⁹

Auguste D. has, as others in a similar position, an awareness of herself in a predicament of loss, but it is an awareness which will inevitably fade during this 'intermediate' phase as she and they are propelled into a space of unbecoming. They all seem to express a fear of the abject:

The place of the abject is where meaning collapses, the place where I am not. The abject threatens life, it must be radically excluded from the place of the living subject, propelled away from the body and deposited on the other side of an imaginary border which separates the self from that which threatens the self.⁵⁰

For the Alzheimer subject, however, whatever is left in the mind is slowly deposited into the body. But, rather like the child in Winnicott's theoretical space, there appears to be a need for transitional objects to enable Alzheimer subjects to cope with the anxiety of becoming separated from themselves, and such objects tend to be expressions of what may be described as mourning, particularly in relation to repetitious behaviour. The disease and the language used to describe it create the image of the dying subject: the psychological death. If denial, say in the form of Didion's 'magical thinking', is performed in terms of repetitious and obsessive behaviour, it seems also to be an illustration of mourning and a way of adapting to the loss of oneself. In *The Loss of Self* Cohen and Eisdorfer record the response of a patient recently diagnosed with Alzheimer's disease:

⁴⁸ Samuel Beckett, *The Unnamable* (New York: Grove, 1958), p. 94.

⁴⁹ Gabriele Schwab, 'The Intermediate Area between Life and Death', in *Memory and Desire*, ed. by Kathleen Woodward and Murray M. Schwartz, pp. 205-217 (p. 206).

⁵⁰ Barbara Creed, *Horror and the Monstrous Feminine: an Imaginary Abjection* (London: Routledge, 1993), p. 27.

One patient, a physician, told us that he wanted to develop “the courage to make a series of silent retreats”. He spoke of his need to gain power over his disease and to die a little each day without losing the desire to live.⁵¹

This patient’s effort to transcend the liminal dimensions of Alzheimer’s disease and survive in the living world is an attitude welcomed by the authors and one they adopt in providing a context to support families who care for those with the condition.

Of course, immortality and death can only be imagined and being out of one’s mind, that feeling of not being where one thinks one ought to be, is a repetitious thought in the early to middle stages of dementia and one very familiar to the Alzheimer subject, its refrain haunting the subject’s imagination. Thomas DeBaggio asks the question of his imagination in this way:

How do you express the true nature of tears in words?
How do you define the limits of evil born of a secret disease?
These thoughts lie silently on my mind and work their way
through my body.⁵²

For DeBaggio, evil arises out of secrets which seem to be buried within the body. Their revelation spells out his psychological demise as language begins to lose its mediating effects; and this loss, as language seeps away into the body, relates to another loss upon which DeBaggio also remarks:

Getting used to the idea of dying is difficult, emotionally and physically, but what awaits me is losing the idea of dying and that is incomprehensible and at the same time may be liberating.⁵³

To be conscious of your future demise is central to the condition of being human; it is a realisation which guides the very forms of life which differentiate humankind from the rest of the animal world. When that awareness fades and disappears and the Alzheimer subject is left without the knowledge of their future

⁵¹ Cohen and Eisdorfer, p. 65.

⁵² Thomas DeBaggio, *Losing my Mind* (New York: The Free Press, 2002), p. 9.

⁵³ DeBaggio, p. 18.

fate, does it liberate the subject, or does it put the subject outside of human nature, reduced to an animalism suggestive of the Gothic? As Neil Badmington's epigraph to Chapter 1 points out, it is Descartes' philosophy which distinguishes mind and body, with the former enabling us 'to tell the difference between the human and the non-human'.⁵⁴ But where language seeps away into the body, it would seem to find the internal grave of the lost self as it filters and fades into that nothingness. The remnant which is left behind suggestively searches for itself, striking, as it were, the very chimes of John Donne's bell with its vivid realisation of mortality:

any man's death diminishes me, because I am involved in
mankind, and therefore never send to know for whom the bell
tolls; it tolls for thee.⁵⁵

The Alzheimer subject, located within the 'intermediate area', is split between being in the living world and existing in the world of the dying. David Shenk reports that it is usually at this stage that the subject is most likely to make what he calls 'the most emotionally healthy choice' of being in denial.⁵⁶ Nicolas Abraham's essay, 'The Illness of Mourning and the Fantasy of the Exquisite Corpse', focuses on this matter from a psychoanalytic point of view. He identifies various forms of unconscious motivational denials within the psychoanalytic paradigm and states that his clinical experience suggests that one such form occurs in the process of mourning. He maintains that following the death of someone close, the subject often reports a sharpened sexual appetite, but the sense

⁵⁴ Neil Badmington, 'Introduction: Approaching Posthumanism', in *Posthumanism*, ed. by Neil Badmington (Basingstoke: Palgrave, 2000), pp. 1-10 (p. 3).

⁵⁵ John Donne, *Selections from 'Divine Poems', Sermons, 'Devotions', and Prayers*, ed. and introduced by John Booty, in the Classics of Western Spirituality (Paulist Press: New York, 1990), p. 272. Donne's well known lines are from a Devotion, a meditation on the Divine and its relationship to humankind. The theme of death in the particular moves on to death in general, to give emphasis to the notion of the universality of humanity as sewn together by death wrought by the Divine.

⁵⁶ David Shenk, *the forgetting: Understanding Alzheimer's: A Biography of a Disease* (London: Harper Collins, 2002), p. 115.

of such a bodily excitation at a time of mourning creates a feeling of deep shame which is consequently repressed. Abraham writes:

The illness of mourning does not result, as might appear, from the affliction caused by the objectal loss itself, but rather from the feeling of an irreparable crime: the crime of having been overcome with desire, of having been surprised by an overflow of libido at the least appropriate moment, when it would behoove us to be grieved in despair.⁵⁷

Nicholas T. Rand, Abraham and Torok's editor, comments that this desire focuses:

On the psychological weight of unwanted, shameful, or untoward reality and our tendency to isolate painful realities ... This removal of an unbearable reality and its confinement to an inaccessible region of the psyche is what Torok calls ... "preservative repression".⁵⁸

It would appear from these representations, that those with Alzheimer's disease desire to hold on to and preserve as much of themselves as is possible for as long as possible, poised at the margin between awareness and denial and in a space which secretes that awareness into another part of the psyche, at least for a period of time.

With the 'intermediate area' signified by mourning and the 'not me' phase of losing a sense of self-possession, it is also a period when the realisation of what its outcome is to be can encourage thoughts of suicide. DeBaggio, Evans, Prescott and Thomas structure an understandable feeling of depression about their situation, and this mood is a common precursor to thoughts of suicide and the possibility of its realisation. In so far as postmodern culture can be characterised by a loosening of bonds between the individual and society through a greater emphasis on social mobility and changing family structures to meet the needs of a

⁵⁷Abraham and Torok, p. 110.

⁵⁸Nicholas T. Rand, in Abraham and Torok, p. 102.

post-industrial capitalist system, it would seem to create an increase in normlessness and a sense of helplessness which underlie issues of personal and family stress. This is clearly a broad sociological generalization and not an unfamiliar political argument, but earlier analyses about the status of and attitudes towards the elderly as a group, particularly the dependent elderly, signify this to be a matter of considerable concern, as witnessed by any number of official reports in recent years from both national and devolved governments and a variety of voluntary organisations acting as a voice for the elderly such as Age Concern and the Alzheimer's Society. At best these reports express disappointment, and at worst horror at the way the elderly and the dependent elderly are treated by a whole cluster of service providers. Derek Beeston, who has compiled a report entitled *Older People and Suicide*, comments on how the devaluation of the elderly can have serious effects upon their mental health and states that:

Syndromatic factors refer to the presence of a cluster of symptoms strongly related to suicide ... these include: depression accompanied by anxiety, tension, agitation, guilt and dependency; rigidity, impulsiveness and isolation; changes in sleep and eating habits.⁵⁹

Such a concentration of symptoms is often seen as simply being age-related and therefore somehow acceptable, but how the issues of old age are reported will, as Beeston argues, write its effects into culture more generally by demonstrating the ambivalences and ambiguities about older people which it contains. Kitwood underlines these points when he argues that:

Many cultures have shown a tendency to depersonalize those who have some form of serious disability, whether of a physical or psychological kind. A consensus is created, established in tradition and embedded in social practices, that those affected are not real persons.⁶⁰

⁵⁹ Derek Beeston, *Older People and Suicide* Centre for Ageing and Mental Health, Staffordshire University, December 2006), p. 16.

Generally speaking such groups are powerless and therefore liable to be particularly devalued. Kitwood further argues that the United Kingdom is ‘permeated by an ageism which categorises older people as incompetent, ugly and burdensome’,⁶¹ all suggesting a form of dehumanisation or what may, in the context of this thesis, be termed as a kind of Gothic posthumanism. Beeston points out that one of the consequences of this devaluation is that ‘people over the age of sixty-five are more successful than any other age group at taking their own lives’.⁶² This age group, it appears, are not only more successful at growing older than those in any other decade, they are clearly more efficient at killing themselves than any other age group too. Beeston reports that ‘in the general population the ratio of suicide attempts to completed suicides is approximately 15:1’; among the elderly, however, ‘this ratio is approximately 4:1’.⁶³ People diagnosed with Alzheimer’s disease, as one study carried out in 2002 points out, are at more of a risk of a suicide attempt in ‘the less severe stage of the disease’,⁶⁴ and Beeston agrees with this assessment:

It may be the case that Dementia is a risk factor for suicide in older people early in the course of the disease, when insight and the ability to plan and act are still present. Later in the course of Dementia the presence of the disease may be protective insofar as insight may be lost.⁶⁵

As Alzheimer’s disease begins to erode any sense of self-regard, the subject may not wish to continue living in the face of such depletion. Christopher Manthrop writes that the condition is so ‘frightening for people to encounter ... it frequently

⁶⁰ Tom Kitwood, *Dementia Reconsidered: The Person Comes First* (Buckingham: Open University Press, 1997), p. 12.

⁶¹ Kitwood, p. 12.

⁶² Beeston, p. 10.

⁶³ Beeston, p. 10.

⁶⁴ Yoram Barak and Dov Aizenberg, ‘Suicide amongst Alzheimer’s Disease Patients: a Ten-Year Survey’, *Dementia and Geriatric Cognitive Disorders*, 14 (2002), pp. 101-103 (p. 103).

⁶⁵ Beeston, p. 151.

terrifies those undergoing its early stages [to the extent that]... dementia has a higher suicide rate than any other mental illness'.⁶⁶ The name and the diagnosis frame the subject's reality, supporting the identity which has been, unwelcomely, given to him or her. The name stays the same as identity changes and, in a sense, a surplus of self occurs which cannot be relieved; so it is carried about - inside, a constant and palpable absence. This diminishing experience echoes Roethke's simile of being half-alive and half-dead, creating, as it were, a kind of hybrid. Nuland cites the Roman orator Seneca concerning the loss of mental faculties and suicide:

I will not relinquish old age if it leaves my better part intact.
But if it begins to shake my mind, if it destroys its faculties
one by one, if it leaves me not life but breath, I will depart from
the putrid or tottering edifice ... I know that if I must suffer
without hope of relief, I will depart.⁶⁷

Seneca sees his mind as his better half, but if it should begin to erode he sees being half-alive as no life at all and indicates he is prepared to destroy himself if such a situation should arise. For Seneca, as for others, the idea of depersonalisation, of un-becoming, is not something he feels he can tolerate. The insidious nature of this loss of self, becoming less and less of a recognisable human being, was not something that Seneca felt could be sustained. Depression, as a precursor to attempted or successful suicide, may, of course, be remediable, but if it is a reaction to a condition which will kill you in the end, it could be argued to be a rational response.

⁶⁶ Christopher Manthrop, 'Living in Fear of the Kindness of Strangers', *Guardian*, 13 December 2006 (Society section), p. 6.

⁶⁷ Nuland, p. 151.

Mourning, Melancholia and Alzheimer's Disease

By calling mourning an illness, Abraham radically departs from Freud's view that it is a common and understandable emotional response to the death of another who is dear to the mourner. But if such a loss is a traumatic event it seems psychologically unlikely that the mourner can return to an integrated and complete self, to make a return to what we might be called a 'normal self'. Freud sees the emotional work involved as having a beginning, middle and, most importantly, an end which enables mourners to return to being themselves. However, by claiming that the mourning process is an illness, Abraham designates it as a pathological psychic problem and, therefore, something to be cured only through the psychoanalytic method. It is melancholia which Freud sees as a problem needing to be explored through these methods, but as James Strachey points out:

In very early days (probably in January 1895) Freud had sent Fliess an elaborate attempt at explaining melancholia ... In purely neurological terms ... this attempt was not particularly fruitful, but it was soon replaced by a psychological approach to the subject.⁶⁸

Eventually, in 'Mourning and Melancholia', Freud draws a comparison between what he viewed as the two psychological processes:

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 ... 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. We rely on its being overcome after a certain lapse of time, and we look upon any interference with it as useless or even harmful.⁶⁹

⁶⁸ Editor's note to 'Mourning and Melancholia', p. 248.

⁶⁹ Freud, 'Mourning and Melancholia', 1991, p. 252.

From Freud's point of view, mourning is a process when, for a period of time, the ego devotes itself entirely to the painful feelings related to loss. Mourning is a private experience and it can be no other: it is a kind of narcissism which eventually releases itself back into the public world to relate to new objects of interest. The loss of an abstract idea, such as a country, suggests Freud's preoccupation at that time with the tragedies of the First World War. Freud argues that the characteristics of the mourning process are a loss of interest in others and the outside world, and an inability to adapt to changed circumstance.

Anna Aragno, in a contemporary account of her reaction to a personal loss, relates to this argument and views it as a traumatic and transforming experience, one that can change the mourner:

It is, however, the personal encounter with death and its severance of a cherished relationship that hurtles us into an adaptive crisis from which we cannot emerge but transformed.⁷⁰

Aragno views the mourning process as having an inherently potential opportunity to be arrived at out of loss, but like Freud also suggests its other and darker side which creates obsessive and repetitive behaviour, denial and avoidance and displacement activities. The issues at stake in these emotional responses to loss are, of course, ones of identity. Aragno, herself a psychoanalyst, declares that:

The predominance of ambivalence and hostile reproach turned against the self in [melancholia] precludes the smooth transition from object cathexis to identification.⁷¹

Freud, as Aragno acknowledges, is the father of this notion of melancholia, but she sees it within the relatively new diagnosis of depression rather than the much older melancholic paradigm. Freud puts it this way:

⁷⁰ Anna Aragno, 'Transforming Mourning: a New Psychoanalytic Perspective', in *Death and Endings*, eds. by Brent Willock, Lori C. Bohm and Rebecca Curtis (London: Routledge, 2007), pp. 21-41 (p. 21).

⁷¹ Anna Aragno, p. 24.

The melancholic displays something else besides which is lacking in mourning - an extraordinary diminution in his self-regard, an impoverishment of his ego on a grand scale. In mourning it is the world which has become poor and empty; in melancholia it is the ego itself.⁷²

It has already been noted that denial and avoidance can be features in the response to the diagnosis of Alzheimer's disease when awareness of the effects of the condition are well known, or explained for the first time; or they may arise at a later stage as the disease progresses. Denial and avoidance are not dissimilar to the early responses in the mourning process when disbelief characterises the initial response to the death of someone very close. Bodily responses such as weeping, moaning, restless yearning for the person who is dead later give way to anger, blame, anxiety and so on.

With Alzheimer subjects this cluster of responses may well be traced into a kind of melancholia as they lose their sense of self. DeBaggio, Evans, Prescott and Thomas all seem to indicate in their responses a fear for the loss of their reason as well as feelings of shame, anger, anxiety and restlessness about themselves akin to both processes of mourning and melancholia. In their personal response to Alzheimer's disease, they seem to reflect Aragno's view on how identity is affected by loss:

Identity ... is in disarray, the self depleted and deprived of familiar narcissistic comforts and sustenance. Suddenly, the self-with-other identity has been supplanted by a self that is without. Initially, and for a long time, we are defined by what we have lost ... Neither what we were, nor yet what we will become, we hover uncomfortably in the disintegrative space of liminality.⁷³

For them, and many others who have the condition of Alzheimer's, it seems that reason is both a separate and an integral part of each of them, and its potential

⁷² Freud, 'Mourning and Melancholia', p. 254.

⁷³ Aragno, p. 35.

absence is reconfigured in a variety of ways in their language as they, uniquely, experience its insidious loss as a kind of vanishing. And because experience is defined and influenced by language which organises it around the social constructs of loss, those subjects who have ‘vanished’ continue to demonstrate some of the features of mourning and melancholia.

Absence, it seems, defines us. Nuland, for example, in writing about Alzheimer’s disease, cites the 1838 text of Jean Etienne Esquirol’s *Des Maladies Mentales*, concerning the behaviour of patients suffering from dementia. Nuland argues that the French physician’s description of the clinical course of his patient’s behaviour can be seen as much in the twentieth century as in the nineteenth. Esquirol is quoted as stating that his patients:

Rejoice little at the pleasures which are procured for them. What is passing around them, no longer awakens interest [and they cannot connect] with any hope. They are irascible [and] their anger ... is only of a moment’s duration ... some are constantly walking about as if seeking something they do not find ... words succeed words.⁷⁴

In considering the history of dementia, Nuland also cites James Prichard, a noted English physician of the period, whose 1835 text, *A Treatise on Insanity*, argues that there are, in the clinical course of dementia, ‘several degrees of incoherence’ which include impaired memory, irrationality, incomprehension and a loss of reasoning power.⁷⁵ Clearly these are patients who are at the latter end of the disease, but who continue to display a kind of searching for their lost selves; but, as Nuland points out, the language used by Esquirol and Prichard will be just as familiar to those who practice within psychiatry today.

⁷⁴ Nuland, pp. 109-110.

⁷⁵ Nuland, p. 109.

Such language speaks of ghosts, the loss of a self to be searched for restlessly in a quest to be released from a kind of claustrophobia. Modernism is, as David Punter argues:

... [a] movement of the mind that seeks to exorcise the ghost, to clean out the house, ruined though it may be, and assert the possibility of a life that is not haunted as it situates itself resolutely in a present that strains towards the future.⁷⁶

But then postmodernism subverts it by its own assertion which declares that life is so full of fragments, dislocations and remnants, that ghosts will be with us in our mortal existence, particularly when forms of mental distress accompany so many events in our lives. The Gothic speaks of crypts, ghosts, phantoms and demons, and all such linguistic forms play their part in our cultural practices of meaning and all suggest that there is no sure foundation, only different kinds of distortion. Gothic ideas, encapsulated within a literary genre, may well have been understood at one time as a kind of escape from social concerns, but as Punter argues:

Gothic was, from its very inception, a form that related very closely to issues of national assertion and social organisation, and which, on occasion, could 'take the stage' in foregrounding social issues and in forming social consciousness.⁷⁷

Social concerns, of course, can create a plague of images and a terror of repetition, which are the very materials of the Gothic and which can be argued to constitute the subtexts of several official reports which follow, all dealing with the condition of the elderly within contemporary culture.

Exclusion and being Buried Alive

If Enlightenment values can be seen as inscribing the administrative and legal regulation of official and semi-official documents relating to the health and

⁷⁶ Punter, 'The Ghost of History' (2001), p. ix.

⁷⁷ Punter, 'The Ghost of History' (2001), p. xi.

welfare of an older, and apparently virtuous, generation, they also describe what Punter calls a Gothic which:

Has come to serve as a kind of cultural threshold, or as a repertoire of images that fatally undercut the ‘verbal compact’ on which, among other things, the modern state rests.⁷⁸

The Audit Commission report of 2000 and that in 2007 of its successor organisation, the National Audit Office, both critically evaluate the shortcomings of the modern state’s institutional practices and provision of health and social care services for the elderly mentally dependent.⁷⁹ Adding to these concerns the Parliamentary Joint Committee on Human Rights proceedings on the human rights of older people being treated and cared for in the National Health Service and other services, states that ‘There are concerns about poor treatment, neglect, abuse and discrimination’ and considers ‘that an entire culture change is needed’.⁸⁰

Neglect, abuse and discrimination underline Beeston’s points about how the elderly and the vulnerably dependent are devalued and put to the margins in contemporary cultural practices, resulting in depression and possible thoughts of suicide. Examples provided to the Joint Committee of the ways in which an older and generally dependent group of people are devalued suggest a proliferating repertoire of images which subvert the Enlightenment values of our twenty-first-century state. Furthermore, these publicly announced anxieties by the Committee about the abuse of the elderly sick, infirm and demented, underline the psychological loss of self generated by these types of oppression. Certainly such images test enlightened attitudes. They attack and undermine perceived values of

⁷⁸ Punter, p. xiv.

⁷⁹ *forget me not* (Audit Commission: London, 2000); *Improving Services and Support for People with Dementia* (National Audit Office: London, 2007).

⁸⁰ *The Human Rights of Older People in Healthcare* (London: The Stationary Office, 2007), p. 3.

a civilized national identity, with its incorporated progressive welfare aspirations and, suggestively, they haunt the myths of progress by burying this oppressed demographic alive. Buildings house the elderly demented subject, and the space within can emphasise their sense of loss and emptiness. The abuse of older people clearly does not attract as much attention as the abuse of children; in fact it is a hidden problem:

Reporting on elder abuse in 2004, the House of Commons' Health Committee found that abuse of older people was a hidden, and often ignored, problem in society, and was a violation of their Human Rights. It concluded that, unlike child abuse, whose profile had been dramatically raised in the past few years, abuse of older people remained hidden.⁸¹

The images of such a group suggest dissolution, instability and fragmentation which clearly challenge the idea of the integrity of the human subject and consequently symbolise the darker side of progress. Perhaps, too, the reports reflect an introspective modern state which looks, as it were through Caliban's mirror, to see only the darkness within. Certainly those responsible for elder abuse in contemporary society appear to pay no heed to Donne's exhortation cited earlier, or could it be that being faced with the void in the Alzheimer subject, they see only their own nothingness?

The condition of Alzheimer's disease in the elderly creates a void which excites a desire in others to seek a response which cannot be made, thus exposing the essential vulnerability of the subject. The 'dead' cannot be brought back to life by magical thinking, and this mirroring of non-existence suggestively creates in those who are supposed to care for and understand the demented, a sense of frustration acted out in ways which are heavily criticised by the Joint Committee. Freud argues that:

⁸¹ *The Human Rights of Older People in Healthcare*, p. 11.

We have recognised our mental apparatus as being first and foremost a device designed for mastering excitations which would otherwise be felt as distressing or would have pathogenic effects.⁸²

Echoing Herbert Spencer's nineteenth-century argument about the mind's primary task, Freud visualises the mind as a piece of machinery designed to control the excitations of the body, to understand and delay its needs. The Joint Committee makes no reference to the possible causes for abusing the elderly buried psychologically within their dementia, other than the lack of adequate and appropriate training of staff.

But Freud, in quoting Heine about the beginning of creation, might offer up a clue: God is imagined as saying: 'Illness was no doubt the first cause of the whole urge to create. By creating, I could recover; by creating I became healthy'.⁸³ If neither the carer, nor the Alzheimer subject, is able to establish or create their sense of self through the mirror of the other, then it seems quite possible to feel under threat and to respond with aggression.⁸⁴ Punter's remarks quoted above encapsulate this idea, and the Audit Commission and Joint Committee's reports are, arguably, part of what he calls 'the conventional dialectic of civilization and barbarism'. Moreover, the Joint Committee's report exemplifies what he describes as a 'phenomenon of inner exile' demonstrated in

⁸² Sigmund Freud, 'On Narcissism' in *On Metapsychology*, pp. 65-97 (p. 79).

⁸³ Freud, 'On Narcissism', p. 85.

⁸⁴ The narrator of Michael Ignatieff's novel *Scar Tissue* refers to differential qualities of caring in the Home where his mother, diagnosed with Alzheimer's disease, is a resident. He distinguishes between carers and nurses who have a 'secret capacity' or 'the gift' of 'an intuitive natural tenderness' to assist such vulnerable and difficult residents, and those who 'are just doing a job'. The former, he argues, 'know how to feel the pain of their patients' and not to be frightened of it whereas the latter have to keep such pain 'at a distance'. The narrator claims that those who have a 'natural intuition' could 'hear the messages my mother tapped out through the walls of her prison'. The metaphor of imprisonment can, it seems, only be understood and responded to if carers have this gift. Distinguishing the capacity to care in this way emphasises the propensity to mental and physical abuse by those who cannot empathise with the pain of that imprisonment. Ignatieff, *Scar Tissue* (London: Chatto and Windus, 1993), p. 110.

the neglect, abuse and discrimination of the elderly demented - a condition which buries them alive. To emphasise this point Punter also points out that 'representations do not "hold" in the cultural psyche unless they find an answering response'.⁸⁵

If the Gothic of the eighteenth century signified a lack of reason, morality and beauty, it 'resonates as much with anxieties and fears concerning the crises and changes in the present as with any terrors of the past'.⁸⁶ It can be argued that these various official reports are indicative of a contemporary crisis of reason and morality, but as Scott Brewster indicates in citing Derrida, 'madness can be thought within reason, but only by questioning, or thinking against, reason'.⁸⁷ This opposition to alienation, within and against, may well be an element involved in the various forms of abuse reported by the Joint Committee, and such a list of shortcomings in care indicates a lack of touch and understanding of the other. It is likely that the elemental behaviour of Alzheimer subjects at the latter end of their condition might well provoke fear in carers resulting in abuse because the subject, existing within a mature body, seems well beyond reason. The writings of DeBaggio and others in a similar situation are examples of minds dying, but still working to find some kind of reason for their predicament; but as Jacqueline Rose points out 'there is ... no rhyme or reason to death'.⁸⁸

However, the forms of conduct by carers reported to the Joint Committee might well be considered to be a type of mourning - mourning for their own selves seeing a possible future that is too frightening to contemplate. Indeed these

⁸⁵ David Punter, p. xiii.

⁸⁶ Fred Botting, 'In Gothic Darkly: Heterotopia, History, Culture', in *A Companion to the Gothic*, ed. by David Punter (Oxford: Blackwell, 2001), pp. 3-14 (p. 3).

⁸⁷ Scott Brewster, 'Gothic and the Madness of Interpretation' in *A Companion to the Gothic*, pp. 281-292 (p. 82).

⁸⁸ Jacqueline Rose, 'Virginia Woolf and the Death of Modernism', in *On Not Being Able to Sleep* (London: Chatto and Windus, 2003), pp. 72-88 (p. 82).

various Reports may also be read as demonstrating a similar contemplation in relation to a wider culture. Rose's epigraph, with which this chapter begins, suggests that mourning is part of our lives, announced and accounted for, perhaps, by abjection, and therefore, to be lived with. Mourning is not necessarily recognised until events and experience conspire to bring the feeling to life, provoking the darkness within. It is, perhaps, this conspiring of events which also stimulates the desire to strike out against its overpowering insistence. In so far as language helps to organise and define experience, what may be understood from the Joint Committee's following statement?

Older people in healthcare are especially vulnerable to ill-treatment because of their dependency on others for their basic needs ... It is by no means all older people who are vulnerable to human rights abuses, but some groups are more vulnerable because of ill-health, disability or dementia.⁸⁹

It appears that abuse of older people is relative – some older people are more vulnerable than others. Vulnerability, in the form of physical and mental dependency, is conjoined with ill-treatment as cause and effect. The Joint Committee defines the experience of ill-treatment as discrimination towards the dependent elderly. Hence, vulnerability is something that must be protected against, as if in itself vulnerability invited abusive behaviour. As an act of exclusion, discrimination creates a space for a sense of loss of self; a sense of being devalued, of not belonging and of being of low worth. Dependency, which it may be argued invites compassion, sympathy or even empathy, is viewed as also being able to invite anger, aggression, assault, and other forms of hostility.

Dependency may also be understood through the language of loss when the language of protective power is diminished by 'ill-health, disability or

⁸⁹ *The Human Rights of Older People*, p. 19.

dementia'. Vulnerability defines dependency before, in relation to Alzheimer's disease, it defines a return to archaism in the body which has, in turn, to speak for its loss through its 'basic needs': a form of dying words. In the pre-socialised stages of becoming, the affiliative needs are dependency, succour and attachment and such needs remain within the body, in relative terms, throughout life, demanding a basic rapport with the world. Dependency in old age returns the body to this pre-socialised kind of need if it is not to be buried alive by those who carry out a caring role and who face the prospect of their own nothingness which may be too fearful to contain.

This combination of losses is compounded by evidence provided to the Joint Committee about other forms of discrimination and devaluation which suggest that institutional rights have priority over the rights of individuals. Given an ageing population and the increase in the number of people diagnosed with Alzheimer's disease, it is clear that they must be significant users of health and social services, but they appear to be given no priority and even less service than other heavy user groups. The Joint Committee reports that witnesses giving evidence to them 'criticised the poor provision for mental health of older people' and goes on to state that:

Older people do not have access to the range of specialist mental health services, such as talking treatments, available to younger adults despite having the same, and often greater, need.⁹⁰

The report goes on to indicate further forms of age discrimination in the provision of services:

⁹⁰ *The Human Rights of Older People*, p. 22.

Younger people receive higher levels of community services than older people. Older people are moved into residential care even though a small amount of additional support at home could help someone to maintain their independence in the community for far longer.⁹¹

Identifying these gaps and spaces within our health and social care system, the Joint Committee's report tellingly announces a policy subtext to all our futures which seems to sustain Simone de Beauvoir's argument that:

We carry this ostracism so far that we even reach the point of turning it against ourselves: for in the old person that we must become, we refuse to recognise ourselves ... nothing should be more expected than old age: nothing is more unforeseen.⁹²

Conclusion

What is seen in dependent old age is a mirroring of a self to come which can be denied through systems of personal and institutional abuse. This is the structure underlying de Beauvoir's argument: one of private and public paradigms and the complex nature of their interrelationship. If old age can be expected or anticipated because it is preferable to death, its depredations are too horrific to contemplate and thus have to be denied even by public agents in the public realm. The young, who enjoy the privileged priorities of service provision, are, of course, the dwelling place of their own future old age. But, as de Beauvoir points out, 'age is removed from us by an extent of time so great that it merges with eternity',⁹³ appearing unreal; except when one is faced with age and all its vulnerabilities and dependencies, its realities so awful to look upon that it must be put far from the private and the public gaze. As de Beauvoir indicates, to contemplate this otherness as oneself is clearly too problematic; it is a mirroring of the future

⁹¹ *The Human Rights of Older People*, p. 22.

⁹² Simone de Beauvoir, *Old Age* (Harmondsworth: Penguin Books, 1985), p. 10.

⁹³ De Beauvoir, p. 11.

which the imagination seems to need to deny. And once denied, the experiential void which follows permits a tolerance of the devaluation and discrimination of the elderly dependent in both the private and public realms of service provision; this is the state of affairs to which public commentators take such official exception.

In the vacuum of reason which is created by Alzheimer's and given emphasis by the notion of the subject being buried alive by the effects of the disease, there is the added horror of this mental disability inviting denial, devaluation, deprivation, exclusion, discrimination and other forms of abuse. In such situations the dependent body is left to try and indicate its own dying words, usually in the most elemental of forms. That these dying words are not responded to in any language other than the horror of others, gives emphasis to the self's mourning as it expresses its being as buried alive. It may be said that the dependent body underlines the paradox of modern medicine in that medical development has assisted in extending God's time, but has failed to find the solution to the many conditions which have turned 'acute death' into 'chronic death', leaving the final stages of life to a condition of acute dependency, particularly for those with neurological problems such as Alzheimer's disease. In these circumstances it may be argued that it is in the interests of pharmaceutical companies to maintain the status quo whereby drugs which mitigate conditions rather than cure them continue to be developed, produced and sold. The emphasis given to biomedicine with its priorities towards curing disease rather than mediating illness (in other words the dominance of a paradigm which focuses on singular disease conditions affecting one or more bodily organ rather than the holistic notion of illness encompassing the whole person), underlines the very

dependency of the body. The fact of illness may prefigure both meaning and unmeaning in its 'chaotic and incoherent quality',⁹⁴ and it is in the various forms of chaos demonstrated in dementia that the discourse of being buried alive, its Gothic images and its mourning for a lost self, are played out.

⁹⁴ John Wiltshire, 'Biography, Pathography and the Recovery of Meaning', in *The Cambridge Quarterly*, 29 (2000) 409-422 (p. 413).

Chapter 6

The Struggle between Memory and Loss

People with Alzheimer's ... are on a voyage into deep space,
sending back messages that it is our job to decipher.

Linda Grant

In its causes and effects ... imagination finds itself inextricably
bound up with, even as it remains in excess of, reality.

Fred Botting

The self of pathographical writing is the self-in-crisis: when
confronted with serious and life-threatening illness, those
possibilities, fictions, metaphors, and versions of self are
contracted into a "hard" defensive ontological reality.

Anne Hunsaker Hawkins

Imagination provides models for reading reality in a new way.

Paul Ricoeur

Remember, God of history, that you created man to remember.
You put me into the world, you spared me in time of danger and
death, that I might testify. What sort of witness would I be without
my memory.

Elie Wiesel

The pathologist's identification of senile plaques in my father's
brain served to confirm, as only an autopsy could, the fact with
which [my mother] struggled daily for many years: like millions of
other Americans, my father had Alzheimer's disease ... This was
his disease. It was also, you could argue, his story. But you have
to let me tell it.

Jonathan Franzen¹

¹ Linda Grant, *Remind Me Who I Am, Again* (London: Granta Books, 1998), p. 42. Grant cites an address given to the Alzheimer's Society by the Canadian author, Michael Ignatieff; Fred Botting, 'Metaphors and Monsters', *Journal for Cultural Research*, Vol. 7, No. 4, (2003), 339-365 (p.340); Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography* (West Lafayette, Indiana: Purdue University Press, 1999), p. 17; Paul Ricoeur, 'The Metaphorical Process as Cognition, Imagination, and Feeling', *Critical Inquiry*, 5 (1978/1979) 143-159 (p.157); Elie Wiesel, *The Forgotten* (New York: Schocken Books, 1995), p. 10; Jonathan Franzen, 'My Father's Brain' in *How To Be Alone* (London: Harper Perennial, 2004), pp.7-38 (pp. 10-11). These epigraphs encapsulate notions of memory and loss. How they are represented in contemporary and other fiction and genres such as poetry and memoir is the theme of this final chapter.

Bearing Witness

To go ahead evokes the notion of precedence, and echoes Jacques Derrida's idea that 'one must always go before the other', thus creating a hiatus in the space between one and another. Within this hiatus Derrida establishes a discourse on death and mourning. And it is the concept and inhabitation of mourning² which takes forward reading Alzheimer's in theory, literature and culture. The texts considered in the last chapter illustrated how the loss of the mind through Alzheimer's disease preceding the death of the body, rooted the Gothic motif of being buried alive in a process which itself inaugurated mourning for the loss of self. Writing *The Work of Mourning*, as his friends and relations predecease him, Derrida comments that the gap will be filled by a mourning which, as Wiesel's and Franzen's epigraphs imply, becomes the expression of fidelity – the quality of being faithful to a person or to a set of ideas or beliefs. This idea echoes Freud's definition of mourning as a 'reaction to the loss of a loved person, or the loss of some abstraction which has taken the place of one'.³

Of all the epigraphs cited above, it is Wiesel's that most clearly seeks some kind of fidelity, pleading that memory exist to establish such a possibility. Without memory, he argues, one cannot testify or honour what has gone before. Only memory can bear witness to the past and anticipate and imagine the future, and the loss of memory means neither past nor future can be accommodated. Franzen's epigraph implies a similar, but slightly different, point. His father's loss of memory, through Alzheimer's, fathers his own sense of being faithful to that memory and, with his father no longer master of his own identity, compels him to become responsible for

² Jacques Derrida, *The Work of Mourning*, ed. Pascal-Anne Brault and Michael Naas (Chicago and London: The University of Chicago Press, 2001). The idea is discussed in the editors' introduction 'To Reckon with the Dead: Jacques Derrida's Politics of Mourning', pp.1-30 (p. 1). The text brings together, as an illustration of fidelity, Derrida's reflections on the death of a number of his friends.

³ Sigmund Freud, 'Mourning and Melancholia', in *On Metapsychology*, ed. Angela Richards, trans. by James Strachey, Penguin Freud Library, Vol. 11 (London: Penguin Books, 1991), pp.245-268 (p. 252).

telling his father's story. As we have already seen, Thomas DeBaggio's memoir makes clear that in the social formation of Alzheimer's disease, the illness is such that the Alzheimer's subject is frightened of being frightening. Seeing a living image construed in this guise tends to evoke the uncanny, and the elderly patient, in particular, becomes, in biomedicine, an anatomy of disgust. Franzen has witnessed his father's decline and seeks to memorialise him and the effects of the disease as an act of fidelity, as a way of reckoning 'with death, or with the dead'⁴ in the sense that his father somehow remains in him.

Wiesel also bears witness in his plea with God that he live with the victims of the Holocaust. Linda Grant, in her story about her mother's decline into dementia, adds a paradoxical turn to Wiesel's plea when she writes:

I don't know if it is a tragedy or a blessing when Jews, who insist on forgiving and forgetting, should end their lives remembering nothing. My mother, the last of her generation, was losing her memory. Only the deep past remained, which emerged at moments in bits and pieces.⁵

Such ghosts within inhabit the work of Franzen and Wiesel, DeBaggio and Robert Davis, as they too mourn their own ghosts to come, bearing witness and being faithful to the loss of their own selves:

Fidelity thus consists in mourning, and mourning – at least in a first moment – consists in interiorising the other and recognising that if we are to give the dead anything it can now be only in us, the living.⁶

Perhaps it is not only a fidelity to the other that matters in mourning and memorialising, but also a fidelity to oneself. Derrida, ironically, rephrases Descartes' 'cogito ergo sum' by stating that 'I mourn, therefore I am'.⁷ Mourning, it is argued here, constitutes

⁴ Derrida, p. 2.

⁵ Grant, p. 15.

⁶ Derrida, p. 9.

⁷ This is cited in Sean Gaston, *The Impossible Mourning of Jacques Derrida* (London and New York: Continuum, 2006), p. 6.

selfhood because it is a feeling of life, a jokingly paradoxical twist of imaginative language putting Derrida inside of oblivion if not quite of it.

But fidelity as practised by the narrator of Michael Ignatieff's novel *Scar Tissue* seems to edge into a kind of chaotic melancholia as he struggles to believe in his mother's continuing awareness of what is happening as Alzheimer's disease takes its malevolent hold and she slips deeper and deeper into oblivion. It is a disease which frames the narrator's sense of both the real and the unreal as his self-knowledge and self-possession crack under its weight. Paradoxically, this textual act of faith, or fealty, is also to the idea of betrayal inherent in a disease where the body betrays the mind and which requires, as the memoirs of DeBaggio and others bear witness, a voice to articulate the betrayal. As in Wiesel's novel, there is also a fidelity in Ignatieff's work to the idea of humanity subverted by a Gothic pathology as well as to the inhumanity of the Holocaust.

Possibly the most defining characteristic of ageing in the latter half of the twentieth and early twenty-first centuries is dementia, particularly Alzheimer's disease, which is its most common form. Literary depictions of this condition may be described as forms of witness to the needs of the ghosts created by the disease as they fall out of this world and into another. Grant's citation, taken from Michael Ignatieff's address to a conference of the Alzheimer's Disease Society, suggests that since Alzheimer subjects can no longer bear witness to their own life, others have to take up that responsibility. The disease, seemingly, wipes the mind clean for others to write on it and for it in a process resembling a palimpsest. Ignatieff's metaphor of the body being a 'deep space' into which the dissolving mind travels, creating a distance that makes the messages more and more difficult to decipher, is one whereby the recipients of the message have necessarily to use imagination to interpret and provide meaning.

A 'deep space' also suggests, or hints at, fears buried in the awful unconscious, a cave-like location holding within it the scattered bits and pieces of a life now lost except to those who may have shared parts of it. The facts and the effects of the disease, are, of course, ultimately bigger, bolder and more disastrous than can be expressed in stories, either metaphorically or plainly, entailing, as they do, the triumph of the body over language.

Nevertheless, as earlier chapters have indicated, this uniquely suffered condition spills over into the public realm to exercise the broader cultural, economic and political discourse to a degree which suggests an anxious desire to fill the space created by the disease. Genres as varied as autobiography, biography, drama, fiction, memoir, poetry, policy papers and scientific research reports are all summoned to reflect the struggle of memory and loss in narratives which give voice to public concern and personal fears. All of this varied discourse bears witness to these concerns and fears either through the pedestrian language of the bureaucrat, the scientific language of the medical researcher or most tellingly, through the language of fiction, poetry and drama, precisely because when Alzheimer's subjects can no longer themselves bear witness, the word of others is pressed into the service of that responsibility. Indeed writers such as Ignatieff, J. Bernlef and Samantha Harvey, who bring their imagination to the task of deciphering the latter stages of the disease, may be read as keeping a hold of something of the mind as it seeps into the body.

Botting seems to suggest that the Gothic, as a genre, tends to emphasize the needs of a body which creates the reality the imagination tests. But, as Suzanne Raitt points out, 'we have no language for our own mortality. We die at the limits of our

own observable experience’⁸ and so it would seem that it is only in the imagination that we can explore what it is like to have Alzheimer’s and the imagination is only too aware of the horrors which the condition and its effects bring. Contemporary novels which concern themselves with representations of Alzheimer’s disease, particularly those referred to above, tend to be primarily character-led rather than plot-driven and such texts typically explore and express the disintegration of the mind. If the purpose of forgetting, within the psychoanalytic paradigm, is to escape from uncomfortable ‘truths’, then it may be said that the purpose of writing about Alzheimer’s through the various imaginative genres, is to reveal the realities of those truths brought about by neurological forgetting.

Pathography as Memoir

Pathography, argues John Wiltshire, has become ‘a new form, genre, or sub-genre of biography’ and memoir.⁹ Texts such as the writings of Thomas DeBaggio, Robert Davis, Havi Carel among others referred to in earlier chapters, foreground personal experiences of illness, and there are also first-person accounts of the illness of a family member such as John Bayley’s narrative of Iris Murdoch’s journey into a dark space. And fiction, of course, has something of a long history of covering matters of ill-health, and has, claims Wiltshire, been the means:

by which the patient’s view can enter the public domain and contribute to the understanding of medical issues. Moreover, contemporary illness narratives are rarely self-consciously and exclusively about illness: pathography appears in different forms, nestled into a book about something else, disguised as a novel, philosophical meditation, or sociological treatise, or offered as instructional handbook.¹⁰

⁸ Suzanne Raitt, ‘Freud’s Theory of Metaphor: Beyond the Pleasure Principle, Nineteenth-Century Science and Figurative Language’, in *Literature, Science, Psychoanalysis, 1830-1970: Essays in Honour of Gillian Beer*, eds. Helen Small and Trudi Tate (Oxford: Oxford University Press, 2003), pp.118-130 (p. 128).

⁹ John Wiltshire, ‘Biography, Pathography and the Recovery of Meaning’, *The Cambridge Quarterly*, Vol. 29, No. 4 (2000), 409-422 (p. 422).

¹⁰ Wiltshire, p. 410.

Hawkins's view about the writing of pathographies, arguing that they demonstrate 'the self-in-crisis', might also be suggested for Gothic tales and for Ignatieff's *Scar Tissue*, which is a kind of dialogue with death. Wiltshire suggests that this text 'looks like a memoir ... presented as fiction', showing the impact of the mother's dementia on the unnamed narrator and the rest of the family.¹¹ Helen Small agrees with this point of view when she writes that 'Ignatieff's first-person narrator is sometimes hard to distinguish from Ignatieff himself', and such a form does have a sense of immediacy and intimacy for the reader.¹² Hawkins and Wiltshire both argue that pathographical writings have become a popular genre due to the rise of biomedicine, which tends to disregard the experience of illness, particularly the chronic kind, and concentrate much more on the disease. The discussion earlier in Chapter 4 set out how biomedicine seems to ignore the needs of the body to be touched, loved, cared for in response to illness, signalling thereby the loss of the human in medicine. In other words, patients, and their carers and relatives, are trying in these texts to wrestle back some humane control over the body, to reach a kind of rapprochement and meaningful understanding of it in its diseased form. So, if pathography is a genre for the forgotten subjective experience of illness, it is clearly one in which disease, the unforgiving interpellator, is challenged.

To the extent to which the genre seeks to re-establish the subject as being in control of his or her own life, it speaks up for the human in the context of a biomedicine where, as Wiltshire and Hawkins claim, the human is absent. The genre's popularity seems to have something to do with a curiosity in how others overcome very difficult circumstances. But, it may also be argued, underlining Botting's point, that such a genre 'supplies the moral vision lacking in [science]' by providing a human response to a disease sent by nature.¹³ It

¹¹ Wiltshire, p. 410.

¹² Helen Small, *The Long Life* (Oxford: Oxford University Press, 2007), p. 255.

¹³ Botting, p. 340.

is this human moral response which forms the major theme of this final chapter, which will also examine how self-knowledge and self-possession are taken apart in various texts.

Cryptomimesis is a neologism suggested by Jodey Castricano, a term proposing making present that which is absent. It is a notion with classic Gothic overtones evident in Franzen's account of his father's disintegrating mind, where, in keeping with other similar accounts in fictional form, the purpose is to write the other into being, bringing them back to a kind of life and in a sense mimicking such lives. Steven Bruhm comments thus:

To write the other in a Gothic mode is not only to draw upon spectres that may already be said to exist [such as those who might be considered to be buried alive due to Alzheimer's]; it is also to create those spectres, to construct ... the spectralization of the other, by which elements of culture are imbued with a haunted, supernatural presence where only materiality [exists].¹⁴

Furthermore, texts, such as those of Ignatieff, Bernlef and Harvey, among others, which have Alzheimer's disease as their primary theme, are not necessarily pure creations by their authors, but representative productions of the society within which they work, a point made by Terry Eagleton and elaborated earlier in Chapter 2. These writers create texts which are within the social praxis of modern medicine and provide a social and psychological commentary on it. For example, Ignatieff's *Scar Tissue* displays a close familiarity with Alzheimer's disease revealing an acute understanding of the space between the 'actual experience and the written narrative' which shapes that experience.¹⁵ The text shows how the familiar, in the person of the narrator's mother, becomes unfamiliar and how meaning becomes meaningless. And if the Gothic genre is one that explores the limits of human reason, it would seem that *Scar Tissue* fits within this model, especially given its unforgiving meditation on the processes of losing one's mind.

¹⁴ Steven Bruhm, 'Encrypted Identities', *Gothic Studies*, Vol. 2, No. 1 (2000), 1-7 (pp. 4-5). This is an introduction to a number of other articles on the theme of writing the dead which includes Castricano's neologism – cryptomimesis.

¹⁵ Wiltshire, p. 410.

Ignatieff's text may be placed, ambiguously, between novel and personal memoir, as the narrator, who never identifies himself by name, describes his mother's decline into Alzheimer's, a disease which first threatens and then destroys her character. Unlike Oscar Wilde's *The Picture of Dorian Gray*, the narrator's mother cannot trade off her situation for something different. She cannot be doubled except in the sense that her narrator-son tells her story through the chaos of his emotional reactions which, uncannily, parallel the effects of his mother's disease. In this way he seems to be inside her biological disaster. There is, of course, both an irony and a paradox in a story told by an anonymous narrator who, by not naming himself, suggests he has no meaning, but whose narrative is meaningful in its creation of a subject who loses a named identity, meaning and purpose just as the unnamed narrator seems to do in the telling of her story, one ghost seemingly creating another. And although Wilde's novel is a fictional account of a character in fear of growing old, it also reflects the author's interest in biology. Suzanne Raitt argues that

The curious replication of Dorian by the portrait whose existence keeps Dorian's death at bay echoes Weismann's account of the amoeba, whose division gives rise to two new individuals, as if death and reproduction were the same thing.¹⁶

Ignatieff's novel, or memoir, also reflects and displays an interest in neurological science and medicine. Small calls his text 'a meditation on both literature and philosophy in relation to science' through its representation of personal fears and social concerns as the narrator 'puts into words ... what it is like to be on the inside of biological disaster'.¹⁷

Mary Shelley's *Frankenstein* displays similar interests. And it is such representations of Alzheimer's which provide an opportunity for gothicity to infuse the condition and yield imitation – true reality in the form of material and appearance, an echo of Victor Frankenstein's creation. In other words, the Alzheimer's subjects appear no longer to have

¹⁶ Raitt, p. 126.

¹⁷ Small, p. 260.

a clearly defined place other than one of appearance as they become a replica of themselves, a disorganised creation organised by the disease. This kind of imitation suggests that if the Alzheimer's subject is not enough of the same, which defines a kind of acceptable difference, then they may well appear 'monstrous, queer, or socially catastrophic'.¹⁸

Ignatieff's text indicates that the narrator's mother is somehow both herself and other as he seeks to gather together her history as wife and mother in order to hold her, as it were, in one piece. But Ignatieff's unnamed narrator finds himself on the inside of biological disaster and suffers a kind of trauma in the face of his mother's dementia as his personality divides between a dutiful and loving son and the container for her fragmentation, which eventually creates a terrible breakdown. It is as if his mother's disease has reconstituted itself within him and therefore destroys the role of being her thinking apparatus. The narrator expresses a Gothic transgenerational haunting of inheriting a gene which will tip him over into the dementia suffered by his mother and maternal grandmother. This seems to be a legacy which awaits him and perhaps his children as a biological law of previous generations indicates a vitality which destroys. It seems in *Scar Tissue* that the dead and the dying can shape the lives of the living as the narrator goes back to his childhood to trace the beginning of his grandmother's and mother's disease. As the narrative unfolds, the unnamed narrator seems to have inherited the immortal gene, and so is not only inside his mother and grandmother's biological disaster but his own as well. This situation creates, as it were, two images; one that exists in the past and present and the other in a displacing future. As referred to in earlier chapters, this immortal gene also creates a demonic metaphor – its vampiric nature. Frankenstein, talking about his own disastrous relationship with his creature, says it is his

¹⁸ Bruhm, p. 5.

‘own vampire, my own spirit let loose from the grave and forced to destroy all that was dear to me’.¹⁹ The creature becomes the metaphor for the darker elements in Frankenstein’s personality, a grave that has been opened up to create his other, and, similarly, the immortal gene is carried within for Ignatieff’s narrator until it too begins to express itself in the personality of its carrier.

As explicated in *Scar Tissue*, the narrator’s role is to take on responsibility for the story telling when the other can no longer think for themselves, taking on, as it were, a Frankenstein-aspect in recreating this other. The narrator, in *Scar Tissue*, becomes a character driven by events rather than attempting to control them, but he, like Maarten in Bernlef’s *Out of Mind*, Jake in Harvey’s *The Wilderness*, all dealing with states of Gothic chaos, has to take cognisance of that chaos in representing that condition.²⁰

Forms of Representation

Texts that deal with the chaos of dementia represent these chaotic, traumatic states, experiences and events within an ordered language which takes cognisance of such conditions in clear and structured ways that endow them with sense and meaning. Such texts remind us that this kind of language arrives out of the ‘other half of our fragmented culture’ which seeks to imagine what the experience of mental deterioration is like; and what it is most like is often expressed and represented in the language of difference, strangeness, loss and death, the language of the Gothic. But whether such an ordered representation is always necessary is brought into question by the work of Bryan Stanley Johnson and Bernlef. In particular, Johnson’s *House Mother Normal* demonstrates through forms of typography the regressive nature of what he calls senility. The word ‘senile’

¹⁹ Mary Shelley, *Frankenstein* (London: Penguin Books, 1994), p. 74.

²⁰ Samantha Harvey, *The Wilderness* (London: Jonathan Cape, 2004). Harvey uses a third-person structure in the present and past tense. Using the present tense enables Jake to inhabit his experiences, thoughts and feelings. And sections written in the past tense allow him, and the reader, to get inside his fragmenting memory as he reviews his life. Such shifts of tense symbolise the nature of Alzheimer’s disease. Jake’s professional life also symbolises the building of his narrative life and its disintegration, and how in that disintegrating space fractured memories appear.

comes from Latin and refers to age, but with no negative significance. The word became extended to 'senility' to cover the effects of mental and physical deterioration in old age in later times. Its use is still not uncommon, but Alzheimer's disease and the names of other forms of dementia are more widely used in contemporary society to cover such states of deterioration and to ease the negative images of the term (as Franzen points out 'senility is not merely an erasure of meaning but a source of meaning').²¹ Johnson's use of the word 'senility' in his text, first published in 1971, would have been negatively understood by his readers at that time and left in no room for ambiguity by the way he represents the condition as death's portent. The novel does not show any particular interest in deciphering the messages being sent back from 'deep space', but portrays the rawness of human existence at the edge of such a space. The text begins with an ironic introduction by the House Mother to the reader as if they were a visitor to the old people's home of which she is in charge:

Friend (I may call you friend?), these are also our friends. We no longer refer to them as inmates, cases, patients, or even clients. These particular friends are also known as NERs, since they have no effective relatives, are orphans in reverse, it is often said.²²

The attempt to establish a kind of humanity is clearly subverted by the language of dehumanisation indicating the isolation of the residents of the home. This welcome introduces several monologues by the 'friends', with each showing a developing regression as one follows the other with gaps increasing in the typography to indicate their mental confusions. In the later monologues, the 'friends'' loss of coherence is represented by the typography straying over the page, leaving large gaps between words which bear little relation to each other, until the final pages become blank.

²¹ Franzen, p. 25.

²² Bryan Stanley Johnson, *House Mother Normal* (London: Picador, 2004), pp. 5-204 (p. 5). *House Mother Normal* is published with two other novels by Bryan Stanley Johnson in the B.S. Johnson Omnibus.

To indicate the narrator's deteriorating mind, Bernlef's novel *Out of Mind* also leaves the final pages blank. This visual and graphic way of representing the loss of self can be very discomfoting for readers, putting them, as it were, in a position of being in front of the demented person, trying to make sense of their incoherencies. To be faced with gaps, a series of white spaces, between un-joined up writing can be bewilderingly fearful, as if one is confronting a void or a thing seeming less than human, and Johnson's text shows the importance of language in all its human and dehumanising effects, making use of blank spaces and random typography to represent how the mind disintegrates. But in these gaps and voids there seems to be a return to the pre-linguistic and the maternal, as well as an escape from the paternal law of language and culture as dementia loosens the purchase on the symbolic. No doubt for Johnson, who was considered to be an experimental novelist in his time, *House Mother Normal* is a realistic representation of dementia, an act of fidelity, a mimetic but truthful account of its effects on the human condition.²³

A more ordered way of representing disintegrating and disintegrated minds and decrepit old age is portrayed graphically in Philip Larkin's poem 'The Old Fools'. The 'old fools' are also residents in an old people's home and, like Johnson's 'friends', seem to be incarcerated within a space in which Gothic horrors are locked away to be occasionally visited and gazed upon, as if these places were utilitarian institutions rather like Jeremy Bentham's Panopticon, where residents are under constant observation. Larkin's fearful anticipation of how time corrupts is graphically described in this poem, which is a raw and elemental work about dementia foretelling death, and uncompromising in its description of

²³ Aristotle argues in *Poetics* that mimesis represents men in action, in the process of doing. The concept is central to the notion of representation, particularly in what is called realist fiction. Michael Taussig argues in *Mimesis and Alterity* (London and New York: Routledge, Chapman and Hall, 1993) that 'the wonder of mimesis lies in the copy drawing on the character and power of the original, to the point whereby the representation may even assume that character and that power' (p. xiii). This comment is well made in respect of Johnson's novel.

decrepit old age. The poem's opening lines set a scene of Hogarthian terror in their posthuman depiction:

What do they think has happened, the old fools,
To make them like this? Do they somehow suppose
It's more grown-up when your mouth hangs open and drools,
And you keep on pissing yourself, and can't remember
Who called this morning?²⁴

As Small comments, this opening indicates 'the absolute loss of agency [which is] for Larkin the defining characteristic of being human'.²⁵ But it is not only the loss of agency that causes Larkin anxiety, it is also the loss of body control. Such a loss parallels abjection and Dani Cavallaro makes an interesting point when she states that:

Especially threatening are those borderline parts of the physiological apparatus through which abject materials pass and the materials themselves: blood, semen, urine, faeces, tears, milk, sweat. These question the body's self-containedness, for they are neither totally contained within the organism nor fully external to it.²⁶

Larkin's repugnance and disgust at the loss of body control in decrepit old age underlines the fear of being menaced from inside. The narrator's interrogation and fearful anticipation of a dependent old age is distanced at the beginning by the use of 'they', 'them' and 'your', but the emphasis is upon loss and the mutability of the body:

Not knowing how, not hearing who, the power
Of choosing gone. Their looks show that they're for it:
Ash hair, toad hands, prune face dried into lines –
How can they ignore it?²⁷

It seems clear that Larkin's speaker cannot ignore it and the images created by this almost visible documentation of dried-out skin create and portray bodies *in extremis*, at the end of

²⁴ Philip Larkin, 'The Old Fools' in *Collected Poems*, ed. and introd. by Anthony Thwaite (London: Faber and Faber, 1990), pp. 196-197 (p. 196).

²⁵ Small, p.139.

²⁶ Dani Cavallaro, *The Gothic Vision* (London: Continuum, 2002), p. 200.

²⁷ Larkin, p. 196.

their tether. Choice, it seems, has been overtaken by disease, a predicament about which the narrator of Ignatieff's *Scar Tissue* gives due warning:

You can choose to die, or you can choose that life beyond selfhood, the life beyond the gates of truth. How you choose ... depends on the value you place on self-consciousness. No one can decide that for you. You can choose life or you can choose consciousness ... the illness does not allow you both. If you do not act ... on the first signs of its presence within you, the illness will not even allow you the dignity of a choice.²⁸

Larkin's old fools have gone beyond making such a choice, as has the narrator's mother in *Scar Tissue*, but Ignatieff's narrator meditates more on this moral issue as he becomes convinced he has inherited the disease from past generations. However, within the image in Larkin's poem lies a fearful preparation for extinction, what Julia Kristeva calls 'a vortex of summons and repulsion'. It is a kind of revolt of being by Ignatieff's narrator, who is at once haunted by what he sees in his mother and fearful of old age drawing him to a 'place where meaning collapses' and where he gazes at living corpses which are, as Kristeva argues, at 'the utmost of abjection'. In Kristeva's paradigm, abjection is 'at the border of my condition as a living being. My body extricates itself, as being alive, from the border'.²⁹

The border for the 'old fools' has been crossed by the disease of dementia which 'lives' in that gap between mind and body, leaving the latter helpless and without direction and purpose. The disease becomes the object which has caused body and mind to be rent asunder, leaving the Alzheimer subject living between the borders of past and future. If one shudders at the image, this suggests not a failure of transcendent imagination, but a clear hold on a palpable reality, at least on the part of Larkin's narrator, who acknowledges that, in some, the process of ageing is akin to an act of violence whereby the

²⁸ Michael Ignatieff, *Scar Tissue* (London: Chatto and Windus, 1993), pp.185-186.

²⁹ All the brief citations here are taken from Julia Kristeva, *Powers of Horror*, trans. Leon S. Roudiez (New York: Columbia University Press, 1982), p. 4.

body turns its owner into a thing. As Susan Sontag puts it in relation to particularly violent photographic images, the narrator's shocking and mocking images, 'arrest attention, startle, surprise'.³⁰

It is as if Larkin's narrator has burnt these images within his memory, and his point of view is one of fearful and horrific anticipation of decrepit and disintegrating old age. These 'old fools' are like 'the corpse, seen without God and outside science [and are] the utmost of abjection. It is death infecting life. Abject'.³¹ But although the narrator is acutely aware of what he observes, he also attempts to imagine what it is like to be old and inside the head of those he gazes upon in such terror:

Perhaps being old is having lighted rooms
 Inside your head, and people in them, acting.
 People you know, yet can't quite name; each looms
 Like a deep loss restored, from known doors turning,
 Setting down a lamp, smiling from a stair, extracting
 A known book from the shelves; or sometimes only
 The rooms themselves, chairs and a fire burning,
 The blown bush at the window, or the sun's
 Faint friendliness on the wall some lonely
 Rain-ceased midsummer evening. That is where they live:
 Not here and now, but where all happened once.³²

These metaphors of lightness and space inside the head of the 'old fools' underline the absence of cognition and language, but ghosts somehow stir within these metaphors, as whatever memories are left restore them to some kind of life - like actors whom one 'can't quite name'. Small remarks that Larkin imagines in this stanza that old age 'is not really a psychological state [but] a condition of alienation from one's own psyche'.³³

Lightness, space and rooms echo the dreamlike spaces of Poe's castellated abbey in his 'The Masque of the Red Death', referred to in Chapter Three, in which the inhabitants also lead a life of exile in order to escape the contagion of the 'Red Death'. They, like the

³⁰ Susan Sontag, *Regarding the Pain of Others* (London: Penguin Books, 2004), p. 20.

³¹ Kristeva, p. 4.

³² Larkin, pp.196-197.

³³ Small, p. 139.

‘old fools’, find that they cannot escape rooms, disease or death. Larkin’s narrator both witnesses physical and mental deterioration and imagines what such an absence of self might be like, and then completes his witness with the overhanging threat that ‘We shall [all] find out’ what it will be like to be an ‘old fool’.³⁴ This third verse in Larkin’s poem is a reminder of what Steven Bruhm refers to as the Gothic aesthetic concern ‘with the phenomenology of loss’, and that this loss has usually to be accompanied by the idea of resurrection, ‘to conjure up from the crypt’ a kind of ghost that must be made visible in language.³⁵ What Larkin’s verse does is to make visible, paradoxically, a kind of dream which conjures up ghosts of the ‘old fools’ encrypted past, half-revealed associations from a sleepless psyche. Larkin’s ‘The Winter Palace’ also shapes the fear of growing old into six two-line stanzas, the last three indicating an ambiguity concerning the loss of mind:

And [I] am starting to give offence by forgetting faces
And swearing I’ve never been to certain places.

It will be worth it, if in the end I manage
To blank out whatever it is that is doing the damage.

Then there will be nothing I know.
My mind will fold into itself, like fields, like snow.³⁶

The mind folding into itself seems to bring a sense of relief from knowing, to be absent from the anxiety of what is happening to the self. It is the knowing, the anticipation of ageing with all its losses and depredations, which causes Dorian Gray to be absent from the process represented in his portrait. If ‘The Winter Palace’ is a metaphor for an absent mind, Dorian Gray’s portrait is a metaphor for an absent mutable life, with both the poem and the story revealing, in different ways, an uncanny troubling presence as well as absence. But these notions of presence and absence are also a demanding reminder to

³⁴ Larkin, p. 197.

³⁵ Bruhm, p. 1.

³⁶ Larkin, p. 211.

Dorian Gray and to Larkin's narrator of extinction and death, about which they both feel angry and fearful.

'The Old Fools' clearly has a relationship with the Gothic genre's fascinated obsession with the ugliness and mortality of the human body, giving it what some contemporary cultural critics call a posthuman quality. However, the first-person narration of Bernlef's *Out of Mind* and Harvey's third-person narration in *The Wilderness* also show the drift between presence and absence as the narrators struggle with the effects of a seemingly malevolent and indifferent disease. Jake's drift in *The Wilderness* between the two is emphasised when he states 'that it is not the happiness of a memory that he is looking for, it is the memory itself; the taste and touch of it, and the proof it brings of himself'.³⁷ And later, 'How strange, then, was memory – that a whole interval of one's life could be blotted out like the sun behind the moon, and then emerge again so intact'.³⁸

Scar Tissue also represents these notions. His narrator's fatalism, derived from believing he has inherited the disease that eliminated the mind of both his mother and grandmother, is accentuated when his brother, a neuroscientist, shows him scans of a brain attacked by Alzheimer's disease. He subsequently realises that the scan is of his mother's brain:

We are standing side by side, and I am looking down the eyepiece of an electron microscope ... The cells have been stained in order to highlight neurons, axons and dendrites, the structural architecture of the brain. My brother is guiding me through these regions of inner space. The blurred brown oblongs are normal neurons. The dark blotches with long curving tails are called neurofibrillary tangles. At the centre of the image is a compacted black mass surrounded by a halo of inflammation. This is a deposit of amyloid protein, a form of scar tissue deep within this patient's brain. Under the microscope, it resembles a galactic storm, a starburst from an extinguished universe.³⁹

³⁷ Harvey, p. 3.

³⁸ Harvey, p. 24.

³⁹ Ignatieff, p. 130.

The narrator's perception of these images of his mother's brain seems suggestive of mysterious passageways which, in the story, he peoples with ghosts, in a manner akin to Poe's 'Masque'. He and Poe perceive the mind filled with irrational thoughts, a weird place in which sensations arrive at a surface that can no longer regulate them and where reason has seemingly given way to the uncontrollable and the frightening. Both these texts suggest an awe-fulness in the face of a seemingly evil disease. Ignatieff's narrator, a teacher of philosophy, uses language to create images of a cosmic space, darkness and light and the metaphor of 'an extinguished universe' to show both a presence and an absence in relation to his mother. This seems to echo H. P. Lovecraft's idea of cosmic fear, that unknown thingness which touches, from his point of view, most of us and which seems so unsettling in its compulsive pull. The paradoxical juxtaposition of evil and goodness, 'black mass' and 'halo of inflammation', is striking in its Gothic overtones within the centre of this image. Later in the text, when Ignatieff's brother points out a defect in one of the chromosomes, similar dark images are created:

The cascade begins there, he says. To my brother the word cascade means only the sequence of pathological effects, but for me the word has menace. I see a body tumbling down a black, liquid-filled shute.⁴⁰

Ignatieff's narrator points out the clear differences between the languages of medical science and philosophy, one seemingly distanced and the other responsive to the human tragedy of someone losing their mind as it slips into a black morass. The notion of falling in 'cascade', is particularly apt in the philosopher-narrator's telling of his mother's disease, as his emotional life, in response, spreads and infects his family and others. But how are he and others to deal with chronic and terminal disease? The narrator is grief-stricken by his mother's insidious demise and turns in hope, relative to the pessimism since her diagnosis, to what he refers to as 'health and personal growth' texts, which argue that the power of

⁴⁰ Ignatieff, p. 131.

the mind can overcome physical states and improve the body's immune system.⁴¹ He sees a particular cultural trend in North America with these sorts of texts as they fit the notion of idealism and individualism which inform the American dream. Such texts can also, in a sense, be seen as concerned with loss and resurrection; the transcendence of the body in order to conjure up a new self and the power of the mind to put the body in its place. Self-help texts do tend to 'shuttle between physical and psychological wholeness', emphasising 'the consciousness of loss, absence and dismemberment' and therefore may be seen as one kind of definition of the uncanny.⁴²

Certainly such texts seem to hint at Freud's idea of formlessness, a sense of falling apart. Jake, in Harvey's *The Wilderness*, places considerable emphasis on trying to retain memories and plays memory games in the same way as Dr. Fleischmann does in Giorgio Pressburger's *The Law of White Spaces*, stating that 'he simply must not fly apart'.⁴³ He also attempts to establish patterns in his life to put 'limits on chaos'⁴⁴ and believes his memory games helps this process and feels that 'there is a satisfactory quality about gathering the words into his mind, filling him like stones filling his pockets'.⁴⁵ Like other narrators in these meditational Alzheimer texts, Jake clutches at words in a way which suggests that they weigh and hold them together. This appears to give them a sense of wholeness that, for Jake, is undermined when he recollects the feeling of terror and 'the utter blankness' of what he was supposed to do next.⁴⁶ But for the narrator of *Scar Tissue*, the words of the self-help texts have only a brief influence before something else is written in their place, overwriting such desire. The philosopher-narrator turns instead to Stoicism - indicating acceptance of any misfortune without complaint, particularly if that misfortune

⁴¹ Ignatieff, p. 62.

⁴² Bruhm, p.2.

⁴³ Harvey, p.74.

⁴⁴ Harvey, p.85.

⁴⁵ Harvey, p. 98.

⁴⁶ Harvey, p. 41.

cannot be understood -and it is the narrator's struggle to understand and believe which is at the centre of his imprisoning grief and melancholia.

The narrator states his need to remember his mother, her disease and its effects, 'to rescue her from her dying'.⁴⁷ This form of fidelity is also concerned with, and expressive of, his sense of fatalism:

When does dying begin? It was within her from the beginning, an illness passed from cell to cell, from mother to daughter. In my brother's job I have seen those cells, the dark starbursts of scar tissue, invisible to the naked eye. I have seen the inheritance, the family silver.⁴⁸

His mother is a painter who paints a portrait of him as a young man, an image which he says did not make him feel himself: 'It is a portrait of a child watching his childhood vanish before his eyes'.⁴⁹ This echoing of Basil Hallward's portrait of Dorian Gray and the mutability and corruption of time symbolises the gradual vanishing of his mother's skills and personality under the duress of the inherited disease. As his mother's condition worsens, his own reluctance to admit to this is expressed in his irritation with her forgetfulness: 'Her absences can be uncanny. Sometimes it is as if she has decided to take a vacation from me'.⁵⁰ Unlike Helen, in Alice Sebold's *The Almost Moon*, he does not murder his mother, but contemplates such an act. Helen uses her mother's dementia to excuse her motivation for killing her: 'When all is said and done, killing my mother came easily. Dementia, as it descends, has a way of revealing the core of the person affected by it'.⁵¹ The narrator of *Scar Tissue* thinks about smothering his mother with a pillow while she sleeps, feeling that he has 'the right to save her' from her disease.⁵² It seems that, as in Larkin, the narrator believes that agency is the central value of life and once it is gone

⁴⁷ Ignatieff, p.1.

⁴⁸ Ignatieff, p.1.

⁴⁹ Ignatieff, p. 16.

⁵⁰ Ignatieff, p.48.

⁵¹ Alice Sebold, *The Almost Moon* (London: Picador, 2007), p. 3.

⁵² Ignatieff, p.51.

there is only materiality left. What seems to stop him joining Helen's murderous route is a belief in the mother's intactness as a person:

I want to say that my mother's true self remains intact, there at the surface of her being, like a feather resting on the surface tension of a glass of water, in the way she listens, nods, rests her hand on her cheek, when we are together.⁵³

Jake too believes in his essential intactness:

The old man who looks in the mirror and sees an old man beholds also a man who has given up. This is not him. There are vast tracts of his life which he believes unassailable by disease, and strings of days in which he is no less coherent and lucid than he was as a twenty- or thirty-year old. He is amazed, thus far, at the banality of this land of forgetfulness.⁵⁴

For Jake there is both denial and stoicism in these inner thoughts, but for the narrator of *Scar Tissue* this belief in his mother's intactness takes him to the self-help texts, which creates a tension between him and his wife, who feels that his mother's illness is taking him over while he feels he 'was struggling to work [himself] free'.⁵⁵ This notion of freeing himself sets up a kind of ambiguity. Is he attempting to free himself from the idea of his mother's intactness and thus understand her condition and situation more clearly and truthfully, or struggle with the hand that fate seems to have dealt him? This latter notion seems to be the key when he lectures about illness and declares that:

Living an illness without giving it meaning would seem to require us to be as individualistic as we can, refusing to succumb to the contagion of fear which sweeps through everyone when we learn that we are ill. Living without metaphor also means trusting the doctor, because only medicine approaches disease non-metaphorically.⁵⁶

The language of medical science, it is being suggested here, is a neutral tool that does not match our feelings and thoughts, but as Karl Marx and Frederick Engels argue in *The German Ideology*, language is as a thing in itself, as capable of creating our thoughts and

⁵³ Ignatieff, p.58.

⁵⁴ Harvey, p. 43.

⁵⁵ Ignatieff, p. 63.

⁵⁶ Ignatieff, p. 67.

feelings as it is of reflecting them. Meaning, in illness, it seems, is established in metaphoric language: it has to be like and unlike other things otherwise materiality is left to its own devices. And this is an argument with which Sontag would agree, as, in the end, language is there to save us from our own flesh, a point which Ignatieff's narrator underlines when he states:

When you strip us right down, when illness pares us back to our core, we remain creatures of the word. Nothing can save us but the word, the messages we send in the shaft of sickness.⁵⁷

What we know of ourselves, and others, is the result of additions, the extras and excesses of materiality and it is out of this that we weave our meanings about our bodies and the defects it imposes upon us, physically and psychically.

Memory, Loss, Metaphysics and the Supernatural

The values of self-mastery are, of course, subverted by neurological conditions such as Alzheimer's disease. They were also challenged in the nineteenth century when Victorian society showed considerable interest in matters such as phrenology, vitalism and magnetism - forms of pseudo-science which had some influence in that period. George Eliot shadowed these interests in the story of the narrator, Latimer, in *The Lifted Veil*.

As with the narrator of *Scar Tissue*, Latimer too is fated to know his forthcoming death, not through inherited disease but through what he calls a 'superadded consciousness'.⁵⁸

Waiting brings considerable apprehension and anxiety to both narrators as an unalterable and pre-determined fate awaits them.

If, as David Punter has suggested, the Gothic genre is where memory and loss meet, then Latimer and the narrator of *Scar Tissue* meet in a space where the metaphysical and the supernatural collide. Ignatieff's narrator is concerned with the issues arising from a

⁵⁷ Ignatieff, p. 140.

⁵⁸ George Eliot, *The Lifted Veil* (London: Virago Press, 1985), p. 19.

and the supernatural collide. Ignatieff's narrator is concerned with the issues arising from a disease which confuses time and space and Latimer, in *The Lifted Veil*, the metaphoric title for his 'superadded consciousness', has visions of future events and experiences as well as the ability to see into other minds: it is a story of serious uncanniness. Latimer has an intense dislike of his body and nature. He seems to represent an androgynous figure and character, seen as poetic, with a sensibility prone, it is suggested, to visions; seeing and hearing other people's thought-processes, which take him into experiences beyond the reach of the ordinary and familiar and into something 'real'. It seems, at times, that he becomes a kind of alternate self, an uncanny configuration outside his usual self. This is also the condition which the narrator of *Scar Tissue* inhabits, and, as his first-person narrative progresses, both narrators seem to be in the process of falling apart. However, Latimer, in *The Lifted Veil*, comes to believe the characteristic poetic visions he has are the result of a diseased consciousness and they become burdensome for him:

... my diseased participation in other people's consciousness continued to torment me; ... The weariness and disgust of this involuntary intrusion into other souls.⁵⁹

Latimer longs for a release from these visions and perceptions of other souls and desires to abandon them. Similarly, Ignatieff's philosopher-narrator meditates on self-knowledge and the abandonment of self in seeking transcendence as depression overtakes him. He refers to Melanie Klein's notion that depression is

a longing for the lost oneness with the maternal breast. The individuation of adult life is thus haunted by a preconscious memory of a time when we had no selves at all ... [a] longing for a return to the beginning.⁶⁰

This idea is clearly in tension with that of Kristeva's paradigm of abjection. She argues that there is a horrific ambivalence in this longing, one from which fear grows at the

⁵⁹ Eliot, p. 26.

⁶⁰ Ignatieff, p.181.

prospect of losing the self. She claims that we do not wholly seek this form of self-abandonment.

The narrator's depression in *Scar Tissue* may, of course, be perceived as a kind of abandonment of self as he returns to and struggles with his emotions concerning his mother. His descriptions of these struggles for self-mastery are echoed by Latimer in *The Lifted Veil* who feels that he has been somehow abandoned by his real self and given over to something diseased and terrorising. These notions of abandonment reverberate within the Gothic genre, as, for example, in the reckless psychological and social abandonment by Victor Frankenstein of the creature he has created and the terrifying and horrific consequences it sets in train. And the psychological and social consequences of the self being somehow forsaken and renounced through the process of Alzheimer's disease have been at the centre of most of the texts referred to in this and preceding chapters.

Maarten in *Out of Mind* begins to feel this sense of being abandoned when he declares that 'it worries me that you can suddenly be so cut off from the most ordinary actions. I have no explanation for it'.⁶¹ As his disease progresses, he states:

I can think of nothing but vanished memories and therefore dare not think of the past anymore. Even less dare I talk to Vera [his wife] about it. Perhaps it is only temporary, perhaps they will come back. Memories can sometimes be temporarily inaccessible, like words, but surely they can never disappear completely during your lifetime? But what are they exactly, memories? They are a bit like dreams. You can retell them afterwards, but what they really are, whether they are real, you don't know, no one does.⁶²

Maarten's rhetorical questions are clearly difficult for him and reflect the mind's gradual disappearance. This form of disappearance is rather like a dream as he oscillates between periods of absence and presence. For Maarten, loss, longing and memory tussle for ownership. These notions can be applied to naming – and the possessive noun of

⁶¹ J. Bernlef, *Out of Mind*, trans. by Adrienne Dixon (London: Faber and Faber, 1989), p. 13.

⁶² Bernlef, p. 15.

Alzheimer's disease indicates foreclosure on meaningful life. A noun connotes possession: it clutches at the loss and longing that announces a departure from memory.

But there seems a strange and uncanny similarity between the three narrators of *The Lifted Veil*, *Scar Tissue* and *Out of Mind* in referencing the mind and its surrounding material mass. Latimer's mind is lit up with visions and the thoughts of other people; Maarten declares, after waking from a dream, 'My head was one large brightly lit space, completely empty. And outside it, there was total calm'. Ignatieff's narrator emphatically states

I want to be done with metaphors. I want to see the thing itself. I want to see deep into the hippocampus, deep into the parietal and occipital, down into the brainstem itself to the places where the protein deposits are building up, millisecond by millisecond, forming plaques and tangles, shutting down the neurotransmitters, causing the circuits to close down, causing me to forget, more and more every day ... This dream of the transparent body, of seeing inside yourself, has always been the fantastic underside of the official history of the self.⁶³

This is an intensely poignant and desperate description of an internal landscape of character, some kind of search for origins with its own dark message from the deep, both like and unlike the metaphors of light for Latimer and Maarten. It also alludes to the Gothic idea of the brain as an essential betrayer of the mind as the seat of self: once Alzheimer's destroys the neurotransmitters, the brain and self both begin to fold and shrivel together, creating a posthuman self.

But if this is a search for the rational based upon a neurobiological certainty, it is one that arrives out of the terrifying messiness and anguish of life. The search seems to be a quest for a re-connection to nature, and in this way Ignatieff's narrator desires to cross the divide between medical science and the humanities. In a sense he and his brother stand on either side of their mother as the twin interpreters of her condition; one seeks the secrets

⁶³ Ignatieff, p. 194.

of death, the other the secrets of life. However, although Maarten and Ignatieff's narrator are beginning to lose consciousness of self and Latimer has an excess of consciousness, they remain within culture, within language and therefore metaphor. Furthermore, as Catherine Belsey points out in somewhat a materialistic Gothic idea, 'we are inescapably rooted in biology as products of evolution',⁶⁴ a point exemplified by Marx and Engels when they argue that 'The phantoms formed in the human brain are also ... sublimates of their material life-process'.⁶⁵ Belsey writes further in relation to the disciplines of the humanities, that:

The days of the free-floating consciousness as the determinant of human nature are gone, and yet this recognition does not necessarily diminish the importance of human culture. On the contrary, it locates and grounds the processes by which we come to make sense of our world. For example, developments in neurobiology, by showing that thoughts, perceptions and feelings have a material existence, which can be mapped as the actions and interactions of neurons, give those supremely human experiences more weight, not less. The scientific challenge to Cartesian mind-body dualism takes ideas out of a nebulous realm of unearthly abstraction and gives them substance, the same substance as the materiality of the organisms that human beings also are. Culture – as the virtual world produced by the physiology of the brain – is real.⁶⁶

Belsey's rational and enlightened view of the inter-connectedness of biology and culture, the propensity of the Humanities' disciplines to analyse and comment on this, underpins a diversity of textual practices critically to expose our fearful differences. Culture, fiction and other genres illustrate Belsey's thesis and Latimer in *The Lifted Veil* is an example of a materiality which creates a virtual as well as a hyper-reality.

Neurobiology, it is being argued here, provides us, almost invites us, to begin the journey of self-invention, where the subject, as it were, arises out of the body: the very

⁶⁴ Catherine Belsey, 'Biology and Imagination: the Role of Culture' in *Human Nature: Fact and Fiction*, eds. Robin Headlam Wells and John Joe McFadden (London: Continuum, 2006), pp.111-127 (p. 111).

⁶⁵ Karl Marx and Frederick Engels, *The German Ideology*, ed. C. J. Arthur (London: Lawrence and Wishart, 1999), p. 47.

⁶⁶ Belsey, p. 111.

stuff of the birth of the Alzheimer's subject. It also suggests that culture is a result of a biologically based psychic structure. So, if Ignatieff's narrator seeks some kind of certainty in biology to escape the unease which the language of metaphor seems to bestow on him, Belsey's commentary, in 'Biology and Imagination: the Role of Culture', indicates that while there may be a sympathy and understanding for such a search, history and culture reveal in their human waywardness that the search for certainties can be a very troublesome journey. Can one be sure, Belsey postulates, that we all know fact from fiction in the way, for example, Ignatieff's narrator seems to suggest? Or does he confuse the two? Latimer and Maarten both begin to understand that they have diseased minds, but rely on culture, in the form of words, meanings and cultural understandings, to reach this point. And Ignatieff's novel/memoir arrives out of a philosophical meditation on modern medicine to reach a similar point, giving an emotional and subjective account of fear - an instinct seemingly embedded in biology - in the process. Indeed it may be argued that modern medical science, with its emphasis on biomedicine, demonstrates an acute fear of the body, a desire to conquer and put it in its place as an accompaniment to the mind.

Ignatieff's *Scar Tissue* is a story which tracks not only a mother's death but also the narrator's, as Alzheimer's disease shadows them both, and shows the twin faces of tragedy -- pity and terror -- as its power creates the narrator's emotional chaos. His mother no longer carries the weight of her own history, but the narrator-son takes this weight on as an act of fidelity in the same way as, within the biographical genre, Franzen does for his father and Grant for her mother in turn. Each carries the weight of pity for a parent and a terror of what has happened to them, a terror which may be described as a kind of tyranny created by the parent's dementia. Michael Berkeley, writing about his father, the composer Lennox Berkeley, states:

I encountered death in an emotionally involved way
(for the first time) in 1989 when my father was admitted

to hospital [he had Alzheimer's] ... I was strangely relieved that 'the old man's friend' pneumonia, would finally release him, with relative tenderness, from the tyranny of dementia. He had always been so quietly spoken, modest and private that the descent into Alzheimer's, with its rampant invasion of privacy, seemed to be particularly monstrous.⁶⁷

Berkeley echoes the distressed anger of the narrator of *Scar Tissue* about Alzheimer's and what he calls its 'monstrous' effects, the tyranny of the condition, its overwhelming power to foreclose life and its capacity publicly to expose that tyranny. The fact that his father is released into death by another condition is welcomed with relief and the tyranny passes, but for the Jake of Harvey's *The Wilderness*, it is a continuing threat:

He pauses, interrogating his brain aggressively for the clarity that sometimes comes out of temporary confusion, but this time it doesn't come. After a lifetime of well-founded reliance on things just fixing themselves, he finds it disturbing to accept that they are more likely, now, to stay broken.⁶⁸

Ghost-Writers

The gaps that occur in Jake's and others' memories are widened as the disease inserts itself as a kind of ghost-writer, moving through the gaps that it has created, leaving the body to its unmediated and lonely self. What becomes broken is the links between the past, the present and the future which normally ground the self in time and space. It is a loss of narrative, but what is the interplay between absence and presence in these various characters' lives? What hovers in that space when the links are broken?

What may be suggested here is a ghost-writer, one who creates a self out of a ghost and makes animate the inanimate, but who, paradoxically, cannot do so without unlocking deep fears about such representation. This is because the organising principle of writing as a medium and literature as a genre is a responsibility to organise reality, to give it an extra depth and dimension in exposing the differences which make us afraid. Each of the

⁶⁷ Michael Berkeley, 'Lennox Berkeley', *Guardian* 2, 10 February 2003, p. 7.

⁶⁸ Harvey, p. 61.

characters examined above are represented in our culture through language which considers Alzheimer's disease in seismic terms precisely because it creates a non-identity and an unnatural body out of a natural disaster: a movement out of one space into another, like some kind of migrant from culture. And it is this fear of exile which stirs within the sentences of these ghost-writers. The disease establishes a kind of stilled life, a silence within a space, but literary art can recover and conquer time to bring a language and a life and thus break the silence, recovering meaning and understanding in recreating something akin to authenticity. These ghost-writers may be described as explorers of 'deep space', filling it with the imaginative language of cryptomimesis.

Castricano's neologism seems an appropriate paradigm for the works of biography, autobiography and memoir concerning Alzheimer's disease and is particularly apt in relation to fiction, poetry and drama which also cover this subject-matter, providing emphasis to Hilary Mantel's notion of the ghost story and the way such stories live on the brink of the in-betweenness of things. The stories of Ignatieff's narrator, Jake and Maarten move between these gaps, exploring the depth of their own and others' messages and certainly the work of carers such as Franzen, Grant and John Bayley, is one of deciphering the messages that come through these ghostly gaps as they reconstruct their relatives' lives. This notion of recovering and deciphering messages underlines Punter's statement about metaphor, that it is 'an innate property of language' and therefore an expression 'of constant excess or dissemination'.⁶⁹ In other words, the imagination can represent our fears through the language of fiction and other literary genres, but whether the imagination can also invite positive social action concerning the mitigation or cure for forms of dementia seems doubtful.

⁶⁹ David Punter, *Metaphor* (Abingdon: Routledge, 2007), p. 144.

The dark language which often describes the lives of the elderly can often also fill their lives. The language may shade from the bleakly humorous to the tragic and it may describe a caring aspect anywhere on a continuum from empathetic and loving to distant and cruel. But the public language could not be clearer in its recognition of how contemporary culture handles old age and death. There are almost daily reports in broadsheet and tabloid newspapers alike which, in terms of horror, terror and fear, voice the parlous condition of the elderly and the demented in today's society. For example, a national newspaper with a large circulation reported recently a poll of some 2000 people which found that 31 per cent 'feared dementia above all else as they grow older, compared with 27 per cent who were most scared of cancer and 18 per cent who feared death itself more than anything'.⁷⁰ The headline and the report were swathed in the concept of fear and Terry Pratchett, a contemporary author who has early onset Alzheimer's, was reported as saying that 'Alzheimer's is a large number of small tragedies usually played out behind closed doors, so in spite of the numbers living with it, the world still doesn't take much notice'. The idea of a number of small tragedies growing into a large one has something of an image of a Greek tragedy, one that builds up until a chorus announces the dreaded arrival of a fated end created by an unseen malign force.

In the same news item, Alzheimer's Research UK suggested that dementia costs the economy some £23 billion a year, giving this newspaper (but it could have been any other) a platform to publicise the connectedness of private tragedies and public economy framed by the concept of fear. This research also indicated that around 10 million people in the United Kingdom carry the apoE4 gene creating a risk of early onset of Alzheimer's. That the general public are ignorant of these large numbers of personal tragedies seems

⁷⁰ Martin Beckford, 'Britain Faces Dementia Catastrophe', *Daily Telegraph*, 9 February 2011, p. 1. This newspaper article was based on a research report by Alzheimer's Research UK publicising the growing numbers diagnosed with Alzheimer's disease and particularly people at risk of early onset Alzheimer's. Terry Pratchett's comments were reported within this news item.

unlikely given the amount of general media and literary interest in the subject in recent years, the number of carers actively involved in families and many others in the caring professions and the health care economy. It seems more likely that the horror and the fear expressed about the condition are woven into the various texts referred to in this thesis and the increasing number of accounts outside of it. Thus are the psychological and social effects of Alzheimer's disease comfortably, and paradoxically, hidden out of sight in the gothicity of the language within the genres referred to, underlining the internal menace which threatens our fearful natures and our fearful differences. As the texts used here have indicated, such fears are well grounded because the tragedy of Alzheimer's disease is that it truly casts us off, abjects us out of our bodies and out of culture, into a posthuman state.

Ghost-writers work within a concept of change and how change occurs through the emergence of substitutions, displacements, disguised conquests and various reversals. These writers show how changes come about through the appropriation of the defects of neurobiology, how the body is a conduit of a terrible power shifting us from one set of images to another. Their texts arrive producing sentences of a life within, announcing a fidelity to humanity, but with such dark undertones that the reader is taken into the arenas of the Gothic. And these life-sentences illustrate and represent an emotional twilight, leaving a body shorn of the intensity of self-knowledge and self-possession. In itself the disease writes a final chapter of lived lives in an empty house no longer able to accommodate the life except through the empathetic imagination of ghost-writers seeking to recapture those lived lives. The 'I' of the texts of *Scar Tissue*, *Out of Mind*, *The Wilderness* and *House Mother Normal* is a voice which represents many other voices suffering loss of self and of sovereignty and compromised by gothicity.

Bibliography

Works Cited

- Abraham, Nicholas and Maria Torok, *The Shell and the Kernel*, ed., trans. and with an introduction by Nicholas T. Rand (Chicago and London: University of Chicago Press, 1994).
- Alcibes, Philip, *Dread* (New York: Public Affairs, 2009).
- Alzheimer Disease Society, *In Memory of Memories* (London: Alzheimer Disease Society, 2003).
- Anon., 'Thanks to You', *Alzheimer's Society Newsletter*, 19 (2004), 1-6.
- Aragno, Anna, 'Transforming Mourning: a New Psychoanalytic Perspective', in *Death and Endings*, ed. Brent Willock, Lori C. Bohm and Rebecca Curtis (London: Routledge, 2007), pp. 21-41.
- Audit Commission, *forget me not* (London: Audit Commission, 2000).
- Badmington, Neil, 'Introduction: Approaching Posthumanism', in *Posthumanism*, ed. Neil Badmington (Basingstoke: Palgrave, 2000), pp. 1-10.
- Balfour, Andrew, 'Facts, Phenomenology and Psychoanalytic Contributions to Dementia Care', in *Looking into Later Life: A Psychoanalytical Approach to Depression and Dementia in Old Age*, ed. Rachel Davenhill (London: Karnac Books, 2007), pp. 222-247.
- Barak, Yoram and Dov Aizenburg, 'Suicide amongst Alzheimer's Disease Patients: A Ten-Year Survey', *Dementia and Geriatric Cognitive Disorders*, 14 (2002), 101-103.
- Barnes, Julian, 'Appetite', in *The Lemon Tree* (London: Picador, 2005), pp. 161-173.
- Beckett, Samuel, *The Unnamable* (New York: Grove, 1958).
- Beckford, Martin, 'Britain Faces Dementia Catastrophe', *Daily Telegraph*, 9 February 2011.
- Beeston, Derek, *Older People and Suicide* (Centre for Ageing and Mental Health, Staffordshire University, 2006)
- Bellow, Saul, *The Actual* (London: Viking, 1977).
- Belsey, Catherine, 'Biology and Imagination: The Role of Culture', in *Human Nature: Fact*

- and Fiction*, ed. Robin Headlam Wells and Johnjoe McFadden (London: Continuum, 2006), pp. 111-127.
- Belsey, Catherine, *Culture and the Real* (Abingdon and New York: Routledge, 2005).
- Belsey, Catherine, 'Making Space: Perspective Vision and the Lacanian Real', *Textual Practice*, 16 (2002), 31-55.
- Berkeley, Michael, 'Lennox Berkeley', *Guardian* 2, 10 February 2003.
- Bernlef, J., *Out of Mind*, trans. Adrienne Dixon (London: Faber and Faber, 1998).
- Berrios, G. E. and H. L. Freeman, ed., *Alzheimer and the Dementias* (London and New York: Royal Society of Medicine Services Ltd., 1991).
- Botting, Fred, *Gothic*, (London and New York: Routledge, 1994).
- Botting, Fred, 'Horror', in *The Handbook to Gothic Literature*, ed. Marie Mulvey-Roberts (Basingstoke: Macmillan Press Ltd., 1998), pp. 123-131.
- Botting, Fred, 'In Gothic Darkly: Heterotopia, History, Culture', in *A Companion to the Gothic*, ed. David Punter (Oxford: Blackwell, 2001), pp. 3-14.
- Botting, Fred, 'Metaphors and Monsters', *Journal for Cultural Research*, 7 (2003), 339-365.
- Botting, Fred, 'Monstrosity' in *The Handbook to Gothic Literature*, ed. Marie Mulvey-Roberts (Basingstoke: Macmillan Press Ltd., 1998), 163.
- Botting, Fred 'Preface: The Gothic', in *Essays and Studies 2001: The Gothic*, ed. Fred Botting (Cambridge: D. S. Brewer, 2001), pp. 1-6.
- Brault, Pascal-Anne and Michael Naas ed., *The Work of Mourning*, Jacques Derrida (Chicago and London: University of Chicago Press, 2001), pp. 1-30.
- Brewster, Scott, 'Gothic and the Madness of Interpretation', in *A Companion to the Gothic* ed. David Punter (Oxford: Blackwell, 2001), pp. 281-292.
- Broks, Paul, *Into the Silent Land* (London: Atlantic Books, 2003).
- Bruhm, Steven, 'Encrypted Identities', *Gothic Studies*, 2 (2000), 1-7.
- Bruhm, Steven, 'Gothic Body', in *The Handbook of Gothic Literature*, ed. Marie Mulvey-Roberts (New York: New York University Press, 1998), pp. 267-268.
- Burke, Edmund, *A Philosophical Enquiry into the Origin of Our Ideas of the Sublime and Beautiful*, ed. with an introduction and notes by Adam Phillips (Oxford: Oxford

University Press, 1998).

Butler, Judith, 'Bodies and Power, Revisited', *Radical Philosophy*, 114 (2002), 13-19.

Byatt, A. S., 'The Pink Ribbon', in *Looking into Later Life: A Psychoanalytical Approach to Depression and Dementia in Old Age*, ed. Rachel Davenhill (London: Karnac Books, 2007), 248-268.

Bynum, William, *The History of Medicine* (Oxford: Oxford University Press, 2008).

Byron, Glennis, 'Gothic in the 1890s', in *A Companion to the Gothic*, ed. David Punter (Oxford: Blackwell, 2001), pp. 132-142.

Carel, Havi, *Illness: The Cry of the Flesh* (Northumberland: Acumen, 2008).

Caruth, Cathy, ed., *Trauma: Explorations in Memory* (Baltimore and London: John Hopkins University Press, 1995).

Castle, Terry, *The Female Thermometer: Eighteenth-Century Culture and the Invention of the Uncanny* (Oxford: Oxford University Press, 1995).

Cavallaro, Dani, *The Gothic Vision: Three Centuries of Horror, Terror and Fear* (London: Continuum, 2002).

Clemens, Valdine, *The Return of the Repressed: Gothic Horror from The Castle of Otranto to Alien* (New York: State University of New York Press: 1999).

Clow, Barbara, 'Who's Afraid of Susan Sontag?', *Social History of Medicine*, 14 (2001), 293-312.

Cohen, Donna and Carl Eisdorfer, *The Loss of Self* (New York and London: Norton, 1986).

Creed, Barbara, *Horror and the Monstrous Feminine: An Imaginary Abjection* (London: Routledge, 1993).

Darwin, Charles, *Origin of Species* (London: John Murray, 1859).

Davis, Robert, *My Journey into Alzheimer's Disease* (Illinois: Tyndale House, 1989).

De Beauvoir, Simone, *Old Age* (Harmondsworth: Penguin, 1985).

DeBaggio, Thomas, *Losing my Mind* (New York: The Free Press, 2002).

Derrida, Jacques, *Of Grammatology*, trans. Gayatri Chakravorty Spivak (Baltimore and London: John Hopkins University Press, 1998).

Didion, Joan, *The Year of Magical Thinking* (London: Harper Perennial, 2006).

- Dollimore, Jonathan, *Death, Desire and Loss in Western Culture* (London: Penguin, 1998).
- Donne, John, *Selections from 'Divine Poems', Sermons, 'Devotions', and Prayers*, ed. and introduced by John Booty, in Classics of Western Spirituality series (New York: Paulist Press, 1990), pp. 271-275.
- Eagleton, Terry, *The Ideology of the Aesthetic* (Oxford: Blackwell, 1996).
- Eagleton, Terry, *Marxism and Literary Criticism* (London: Methuen, 1976).
- Eliot, George, *The Lifted Veil* (London: Virago Press, 1985).
- Evans, Jim, in Donna Cohen and Carl Eisdorfer, *The Loss of Self* (New York and London: Norton, 1986), 60.
- Foucault, Michel, *Madness and Civilization*, trans. Richard Howard (London: Routledge, 1997).
- Foucault, Michel, *The Order of Things: An Archaeology of the Human Sciences* (London: Routledge, 1997).
- Franzen, Jonathan, *How to be Alone* (London: HarperPerennial, 2004).
- Freud, Sigmund, 'Civilization and its Discontents', in *Civilization, Society and Religion*, trans. James Strachey, ed. Albert Dickson, Penguin Freud Library, Vol. 12 (London: Penguin, 1991), pp. 243-340.
- Freud, Sigmund, 'Instincts and their Vicissitudes', in *On Metapsychology: The Theory of Psychoanalysis*, ed. Angela Richards and trans. James Strachey, Penguin Freud Library, Vol. 11 (London: Penguin, 1991), pp. 107-138.
- Freud, Sigmund, 'On Narcissism', in *On Metapsychology: The Theory of Psychoanalysis*, ed. Angela Richards and trans. James Strachey, Penguin Freud Library, Vol. 11 (London: Penguin, 1991), pp. 65-97.
- Freud, Sigmund, 'Mourning and Melancholia', *On Metapsychology: The Theory of Psychoanalysis*, ed. Angela Richards and trans. James Strachey, Penguin Freud Library, Vol. 11 (London: Penguin, 1991), pp. 245-268.
- Freud, Sigmund, *On Sexuality: Three Essays on the Theory of Sexuality*, ed. Angela Richards and trans. James Strachey, Penguin Freud Library, Vol. 7 (London: Penguin Books, 1991).

- Freud, Sigmund, 'On Transience', in *Art and Literature*, ed. Albert Dickson and trans. James Strachey, Penguin Freud Library, Vol. 14 (London: Penguin, 1990), pp. 287-290.
- Freud, Sigmund, 'Our Attitude Towards Death', in *Civilization, Society and Religion*, ed. Albert Dickson and trans. James Strachey, Penguin Freud Library, Vol. 12 (London: Penguin, 1991), pp. 77-89.
- Freud, Sigmund, 'The "Uncanny"', in *Art and Literature*, ed. Albert Dickson and trans. James Strachey, Penguin Freud Library, Vol. 14 (London: Penguin Books, 1990), pp. 335-376.
- Galgut, Damon, *The Good Doctor* (London: Atlantic Books, 2003).
- Gaston, Sean, *The Impossible Mourning of Jacques Derrida* (London and New York: Continuum, 2006).
- Gillies, Andrea, *Living with Nancy: A Journey into Alzheimer's* (London: Short Books, 2009).
- Grant, Linda, *Remind Me Who I Am Again* (London: Granta Books, 1998).
- Hancock, Philip, Bill Hughes, Elizabeth Jagger, Kevin Paterson, Rachel Russell, Emmanuelle Tulle-Watson, Melissa Tyler, *The Body, Culture and Society: An Introduction* (Buckingham: Open University Press, 2000).
- Harvey, Samantha, *The Wilderness* (London: Cape, 2009).
- Hawkins, Anne Hunsaker, *Reconstructing Illness: Studies in Pathography* (West Lafayette, Indiana: Purdue University Press, 1999).
- Health Economics Research Centre, *Dementia 2000* (University of Oxford, 2010).
- Heidegger, Martin, *Being and Time*, trans. John MacQuarrie and Edward Robinson (London: Blackwell, 1978).
- Heller, Lee F., 'Frankenstein and the Cultural Uses of the Gothic', in *Mary Shelley: Frankenstein*, ed. Johanna M. Smith, Case Studies in Contemporary Criticism (New York and Boston: Macmillan, 1992), pp. 325-341.
- Hepworth, Mike, 'In Defiance of an Ageing Culture' *Ageing and Society*, 19 (1999), 139-146.
- Hoff, P., 'Alzheimer and his Time', in *Alzheimer and the Dementias*, ed. G. E. Berrios and H.

L. Freeman (London and New York: Royal Society of Medicine Services Ltd., 1991), pp. 29-55.

Hurley, Kelly, *The Gothic Body: Sexuality, Materialism, and Degeneration at the Fin de Siècle* (Cambridge: Cambridge University Press, 2004).

Ignatieff, Michael, *Scar Tissue* (London: Chatto and Windus, 1993).

Jackson, John Hughlings, *Selected Writings of John Hughlings Jackson: Croonian Lectures 1884: Evolution and Dissolution of the Nervous System*, ed. James Taylor (London: Hodder and Stoughton, 1931).

Johnson, Bryan Stanley, *House Mother Normal* (London: Picador, 2004).

Joint Committee on Human Rights, *The Human Rights of Older People in Healthcare* (London: The Stationery Office Ltd., 2007).

Jones, Ernest, *The Life and Work of Sigmund Freud*, ed. Lionel Trilling and Steven Marcus (Harmondsworth: Pelican Books, 1964).

Kandel, Eric R., *In Search of Memory* (New York: Norton, 2006).

Katz, Stephen, *Disciplining Old Age* (Charlottesville: University Press of Virginia, 1996).

Keizer, Bert, *Dancing with Mr. D: Notes on Life and Death* (London: Black Swan, 1997).

Kitwood, Tom, *Dementia Reconsidered: The Person Comes First* (Buckingham: Open University Press, 1997).

Kristeva, Julia, *Powers of Horror: An Essay on Abjection*, trans. Leon S. Roudiez (New York: Columbia University Press, 1982).

Lacan, Jacques, *Écrits: A Selection*, trans. Alan Sheridan (London: Tavistock, 1977).

Lacan, Jacques, 'Some Reflections on the Ego', *International Journal of Psycho-Analysis*, 32 (1951), 11-17.

Larkin, Philip, 'The Old Fools', in *Collected Poems*, ed. and with an introduction by Anthony Thwaite (London: Faber and Faber, 1990), pp. 196-197.

Leader, Darian, *Freud's Footnotes* (London: Faber and Faber, 2000).

Lodge, David, *Consciousness and the Novel* (London: Secker and Warburg, 2002).

Lovecraft, Howard Phillips, *Supernatural Horror in Literature* (New York: Dover, 1973).

McAfee, Noelle, 'Abject Strangers: Towards an Ethics of Respect', in *Ethics, Politics and*

- Difference in Julia Kristeva's Writings*, ed. Kelly Oliver (New York and London: Routledge, 1993), pp. 116-134.
- Maisondieu, Jacques, 'Alzheimer's Disease: Disease of the Brain, or Disease of the Mind?', *Encephalie*, 5 (1999), 7-10 (privately translated by R. H. Spencer).
- Mantel, Hilary, 'Ghost Writing', *Guardian Review*, 28 July 2002.
- Manthrop, Christopher, 'Living in Fear of the Kindness of Strangers', *Guardian Society*, 13 December 2006.
- Marx, Karl and Frederick Engels, *The German Ideology*, ed. and introduced by C. J. Arthur (London: Lawrence and Wishart, 1999).
- Maurer, Konrad, Stephen Volk and Hector Gerbaldo, 'Augusta D. and Alzheimer's Disease', *The Lancet*, 347 (1997), 1546-1549.
- Mosse, George L., 'Introduction', in Max Nordau, *Degeneration* (Lincoln and London: University of Nebraska Press, 1993), pp. xiii – xxxvi.
- Mulvey-Roberts, Marie, ed., *The Handbook to Gothic Literature* (Basingstoke: Macmillan, 1998).
- Munro, Alice, 'The Bear Came Over the Mountain', in *Hateship, Friendship, Courtship, Loveship, Marriage* (London: Vintage, 2007), pp. 275-323.
- National Audit Office, *Improving Services and Support for People with Dementia* (London: National Audit Office, 2007).
- Nordau, Max, *Degeneration* (Lincoln and London: University of Nebraska Press, 1993).
- Nuland, Sherwin, *How We Die* (London: Chatto and Windus, 1994).
- Phillips, Adam, 'Fears', in *Terrors and Experts* (London: Faber and Faber, 1995), pp. 46-63.
- Phillips, Adam, 'Introduction', in Edmund Burke, *A Philosophical Enquiry into the Origin of Our Ideas of the Sublime and Beautiful* (Oxford: Oxford University Press, 1998), pp. ix-xxiii.
- Phillips, Adam, ed., *The Penguin Freud Reader* (London: Penguin, 2006).
- Plato, *The Symposium*, trans. Walter Hamilton (London: Penguin, 1951).
- Poe, Edgar Allan, 'The Masque of the Red Death', in *Selected Tales* (London: Penguin, 1994), pp. 192-198.

- Poe, Edgar Allan, 'The Premature Burial', in *Selected Tales* (London: Penguin, 1994), pp. 322-336.
- Polley, Sarah, dir. *Away from Her* (Metrodome Distribution, 2007).
- Pressburger, Giorgio, 'The Law of White Spaces', in *The Law of White Spaces*, trans. Piers Spence (London; Granta, 1993), pp. 13-38.
- Punter, David, ed., *A Companion to the Gothic* (Oxford: Blackwell, 2001).
- Punter, David, 'The Ghost of History', in *A Companion to the Gothic* (Oxford: Blackwell, 2001), pp.viii-xiv.
- Punter, David, *Gothic Pathologies: The Text, the Body and the Law* (London: Macmillan, 1998).
- Punter, David, *Metaphor* (Abingdon: Routledge, 2007).
- Punter, David, 'Terror', in *The Handbook to Gothic Literature*, ed. Marie Mulvey-Roberts, (Basingstoke: Macmillan, 1998), pp. 235-240.
- Radcliffe, Ann, 'On the Supernatural in Poetry', *New Monthly Magazine*, 16 (1826), 145-152.
- Raitt, Suzanne, 'Freud's Theory of Metaphor: Beyond the Pleasure Principle, Nineteenth-Century Science and Figurative Language', in *Literature, Science, Psychoanalysis, 1830-1970: Essays in Honour of Gillian Beer*, ed. Helen Small and Trudi Tate (Oxford: Oxford University Press, 2003), pp. 118-130.
- Rand, Nicholas T., 'Editor's Note', in Nicholas Abraham and Maria Torok, *The Shell and the Kernel* (Chicago and London: University of Chicago Press, 1994), pp. 99-106.
- Ricoeur, Paul, 'The Metaphorical Process as Cognition, Imagination and Feeling', *Critical Inquiry*, 5 (1978-79), 143-159.
- Rieff, David, 'Illness as More Than a Metaphor', *New York Times*, 4 December 2005.
- Roethke, Theodore, 'Old Lady's Winter Words', in *The Collected Poems of Theodore Roethke* (London: Faber and Faber, 1966), p. 103.
- Rose, Jacqueline, *On Not Being Able to Sleep: Psychoanalysis and the Modern World* (London: Chatto and Windus, 2003).
- Rose, Steven, 'Forgetfulness of Things Past' *Guardian*, 29 April 2004.
- Rose, Steven, *The Making of Memory* (London: Vintage, 2003).

- Royle, Nicholas, *The Uncanny* (Manchester and New York: Manchester University Press, 2003).
- Sabat, Steven, *Experience of Alzheimer's Disease: Life through a Tangled Veil* (Oxford: Blackwell, 2001).
- Schwab, Gabriele, 'The Intermediate Area between Life and Death', in *Memory and Desire*, ed. Kathleen Woodward and Murray M. Schwartz (Bloomington: Indiana University Press, 1986), pp. 205-217.
- Sebold, Alice, *The Almost Moon* (London: Picador, 2007).
- Shapiro, Ann, 'Not all there ...', *Guardian Review*, 13 October 2007.
- Shelley, Mary, *Frankenstein* (London: Penguin, 1994).
- Shenk, David, *the forgetting: Understanding Alzheimer's: A Biography of a Disease* (London: HarperCollins, 2002).
- Shorter, Edward, *A History of Psychiatry* (New York: John Wiley and Sons, 1997).
- Simey, Margaret, 'How and where I found my independence', in *Getting a Life: Older People Talking*, ed. Michael Simmons (London: Peter Owen, 2000), pp. 133-138.
- Small, Helen, *The Long Life* (Oxford: Oxford University Press, 2007).
- Smith, Anna, *Julia Kristeva: Readings of Exile and Estrangement* (London: Macmillan, 1996).
- Sontag, Susan, *Illness as Metaphor* (Harmondsworth: Penguin, 1983).
- Sontag, Susan, *Regarding the Pain of Others* (London: Penguin, 2004).
- Spencer, Herbert, 'A Theory of Population Deduced from the General Law of Animal Fertility', *Westminster Review* (April 1852), 468-501.
- Spencer, Herbert, *Principles of Psychology* (London: Williams and Norgate, 1881).
- Taussig, Michael, *Mimesis and Alterity* (London and New York: Routledge, Chapman and Hall, 1993).
- Warner, Marina, *Managing Monsters: The 1994 Reith Lectures* (London: Vintage, 1994).
- Weinstein, Arnold, 'Infection as Metaphor', *Literature and Medicine*, 22 (2003), 102-116.
- Wiesel, Elie, *The Forgotten* (New York: Schocken Books, 1995).
- Wilde, Oscar, *The Picture of Dorian Gray* (London: Penguin, 1985).

- Willock, Brent, Lori C. Bohm and Rebecca Curtis, ed., *Death and Endings* (London: Routledge, 2007).
- Wiltshire, John, 'Biography, Pathography and the Recovery of Meaning', in *The Cambridge Quarterly*, 29 (2000), 409-422.
- Winnicott, Donald W., *Playing and Reality* (London: Penguin, 1964).
- Wolff, Tobias, *Old School* (London: Bloomsbury, 2004).
- Woodward, Kathleen and Murray M. Schwartz, ed., *Memory and Desire* (Bloomington: Indiana University Press, 1986).
- Woolf, Virginia, 'On Being Ill', in *The Crowded Dance of Modern Life: Selected Essays*, ed. Rachel Bowlby (London: Penguin, 1993), pp. 43-53.
- Wright, Terence, *Theology and Literature* (Oxford: Blackwell, 1989).
- Wright Mills, Charles, *The Sociological Imagination* (New York: Oxford University Press, 1967).
- Youngson, Robert, *Dictionary of Human Biology* (Glasgow: HarperCollins, 2006).

Works Consulted but not Cited

- Asma, Stephen, *On Monsters: An Unnatural History of Our Worst Fears* (Oxford: Oxford University Press, 2009).
- Bayley, John, *Iris: A Memoir of Iris Murdoch* (London: Duckworth, 1998).
- Bayley, John, *Iris and the Friends: A Year of Memories* (London: Abacus, 2000).
- Beckett, Samuel, *The Complete Dramatic Works* (London: Faber and Faber, 1990).
- Belsey, Catherine, *Desire: Love Stories in Western Culture* (Oxford: Blackwell, 1994).
- Bentham, Jonathan, ed. *The Limits of Human Nature* (London: Allen Lane, 1973).
- Centre for Policy on Ageing, *Dementia in Focus: Research, Care and Policy into the Twenty-First Century* (London: Centre for Policy on Ageing, 1998).
- Davies, Tony, *Humanism* (London: Routledge, 1994).
- Derrida, Jacques, *Specters of Marx: The State of the Debt, The Work of Mourning, and the New International*, trans. Peggy Kamuf (New York and London: Routledge, 1994).

- Evans, Dylan, *An Introductory Dictionary of Lacanian Psychoanalysis* (London and New York: Routledge, 1996).
- Forster, Margaret, *Have the Men Had Enough?* (London: Penguin, 1990).
- Illich, Ivan, *Limits to Medicine* (London: Marion Boyars, 1976).
- Jennings, Kate, *Moral Hazard* (London: Fourth Estate, 2002).
- Johnson, Julia, *Writing Old Age* (London: Centre for Policy on Ageing, 2004).
- Kermode, Frank, *Shakespeare's Language* (London: Penguin Press, 2000).
- King, Nicola, *Memory, Narrative, Identity: Remembering the Self* (Edinburgh: Edinburgh University Press, 2000).
- Kristeva, Julia, *Strangers to Ourselves*, trans. Leon S. Roudiez (Hemel Hempstead, Harvester Wheatsheaf, 1999).
- Laing, Ronald David, *The Divided Self: An Existential Study in Sanity and Madness* (London: Pelican, 1965).
- Lechte, John, *Fifty Contemporary Thinkers* (London and New York: Routledge, 1994).
- Levin, Samuel R., *Metaphoric Worlds* (New Haven and London: Yale University Press, 1955).
- Margalit, Avishai, *The Ethics of Memory* (Cambridge, MA: Harvard University Press, 2002).
- Martin, Paul, *The Sickening Mind: Brain, Behaviour, Immunity and Disease* (London: HarperCollins, 1997).
- Phillips, Adam, *Winnicott* (London: Fontana, 1988).
- Pollen, Daniel A., *Hannah's Heirs: The Quest for Genetic Origins of Alzheimer's Disease* (New York: Oxford University Press, 1993).
- Porter, Roy, *Flesh in the Age of Reason* (New York and London: Norton, 2004).
- Ricks, Christopher, *Beckett's Dying Words: The Clarendon Lectures 1990* (Oxford: Oxford University Press, 2001).
- Rose, Steven, *The Twenty-First Century Brain: Explaining, Mending and Manipulating the Mind* (London: Vintage Books, 2006).
- Rycroft, Charles, *A Critical Dictionary of Psychoanalysis* (Harmondsworth: Penguin, 1972).
- Rycroft, Charles, *Viewpoints* (London: Hogarth Press, 1991).

- Rycroft, Charles, *Psychoanalysis and Beyond* (London: Hogarth Press, 1985).
- Ricks, Christopher, ed. *Tennyson: A Selected Edition* (Harlow: Longman, 1989).
- Smiles, Samuel, *Self-Help* (London: The IEA Health and Welfare Unit, 1997).
- Snowdon, David, *Ageing with Grace: The Nun Study and the Science of Old Age* (London: Fourth Estate, 2001).
- Von Unwerth, Mathew, *Freud's Requiem: Mourning, Memory and the Invisible History of a Summer Walk* (London and New York: Continuum, 2006).
- Winnicott, D. W., *The Family and Individual Development* (London: Tavistock, 1965).
- Young, R. M., 'The Human Limits of Nature', in *The Limits of Human Nature*, ed. Jonathan Benthall (London: Allen Lane, 1973), pp. 235-274.

