

Durham E-Theses

Dementia Narratives in Contemporary Literature, Life Writing, and Film

BITENC, REBECCA,ANNA

How to cite:

BITENC, REBECCA,ANNA (2017) *Dementia Narratives in Contemporary Literature, Life Writing, and Film*, Durham theses, Durham University. Available at Durham E-Theses Online:
<http://etheses.dur.ac.uk/12157/>

Use policy

The full-text may be used and/or reproduced, and given to third parties in any format or medium, without prior permission or charge, for personal research or study, educational, or not-for-profit purposes provided that:

- a full bibliographic reference is made to the original source
- a [link](#) is made to the metadata record in Durham E-Theses
- the full-text is not changed in any way

The full-text must not be sold in any format or medium without the formal permission of the copyright holders.

Please consult the [full Durham E-Theses policy](#) for further details.

Rebecca Anna Bitenc

Dementia Narratives in Contemporary Literature, Life Writing, and Film

This thesis aims to delineate the affordances and limitations of narrative, and narrative studies, for the project of developing new ways of understanding, interacting with, and caring for people with dementia. Engaging with a growing body of contemporary dementia narratives, it investigates the potential of life writing and fiction as a means for exploring the phenomenology of dementia. In particular, the study considers the extent to which dementia narratives align with or run counter to the dominant discourse of dementia as ‘loss of self.’ In considering the question of selfhood and identity, the study highlights the need to attend to embodied and relational aspects of identity in dementia—as well as in the stories we tell about dementia. Finally, even as the thesis disputes the idea that the modes of empathy fostered by narrative lead in any direct or simple way to more humane care practices, overall the analysis suggests ways in which both fictional and non-fictional narratives may contribute to the development of dementia care—particularly to the ethical exploration of caregiving dilemmas. From a broader perspective, in engaging with dementia narratives across genres and media, this thesis demonstrates how ideas from literary narratology bear relevantly on current debates about the role of narrative in the medical or health humanities.

*Dementia Narratives in Contemporary Literature, Life
Writing, and Film*

Rebecca Anna Bitenc

Doctor of Philosophy

Department of English Studies

Durham University

2017

Acknowledgements

I would like to thank my supervisors David Herman and Patricia Waugh. A special thank you goes to my primary supervisor David Herman, for his exceptional supervision, inspiring intellectual curiosity and generosity of spirit.

I would like to thank the Arts and Humanities Research Council for funding my research, as well as the Faculty of Art and Humanities, Department of English Studies and Ustinov College, Durham for financial support over the years.

Thank you to my parents, Karl and Deborah Reichl, and all my friends who have contributed in their own unique ways over the years.

Finally, an enormous thank you to my husband Urban: for sharing your life with me and for your steadfast support throughout this entire venture.

To Clara Maria

Table of Contents

LIST OF ILLUSTRATIONS	3
INTRODUCTION: (RE)CONSIDERING DEMENTIA NARRATIVES	4
THREE STARTING POINTS	4
BIOMEDICINE AND THE CULTURAL MEANING OF DEMENTIA.....	7
THE ALZHEIMER'S 'EPIDEMIC': CONSIDERING CARE, COSTS AND SOCIAL JUSTICE THROUGH LITERATURE	16
WHY NARRATIVE? THE LIFE WORLD APPROACH TO DEMENTIA	23
1 'Illness Narratives': Countering Biocultural Master Narratives and Exploring the Phenomenology of Illness	26
2 Debates in Medical Humanities: Considering Narrative Empathy and Narrative Ethics	29
3 Narrative (and) Selfhood	33
4 Narrative as Tool for Meaning-Making	35
OUTLINE OF CHAPTERS	38
PART I STORYTELLING AND THE PHENOMENOLOGY OF DEMENTIA	41
CHAPTER 1 NARRATING EXPERIENCES OF DEMENTIA: EMBODIED SELVES, EMBODIED COMMUNICATION	42
EMBODIED SELVES, EMBODIED COMMUNICATION	44
INSIDE VIEWS: LIFE WRITING BY PEOPLE WITH EARLY-ONSET ALZHEIMER'S	48
Memory	50
Language.....	53
Bodily Engagements: Perception, Movement and the Senses.....	55
Emotions and Cognition.....	59
Time.....	61
The Social World: Intimate Relationships and Strangers.....	63
Being-at-one-with-the-world: The Experience of Flow in Dementia	66
FROM THE CAREGIVER'S PERSPECTIVE: INTERSUBJECTIVITY IN DAVID SIEVEKING'S DOCUMENTARY <i>VERGISS MEIN NICHT</i>	70
Viewing Symptoms of Dementia.....	71
The Communicating Body in Film	74
Embodied Selves and Relational Selves.....	79
CONCLUSION.....	82
CHAPTER 2 FROM THE OUTSIDE IN? DEMENTIA IN FILM AND THE NOVEL	84
<i>STILL ALICE</i> : FROM FICTION TO FILM.....	86
EXPERIENCING DEMENTIA/EXPERIMENTING WITH THE NOVEL	94
Out of Mind.....	95
House Mother Normal	101
The Unconsoled	110
CONCLUSION.....	117
PART II LIFE WRITING, SELF-WRITING	124
CHAPTER 3 LIFE WRITING AT THE LIMITS: NARRATIVE IDENTITY AND COUNTER-NARRATIVES IN DEMENTIA	125
NARRATIVE IDENTITY IN DEMENTIA	126
RECONSIDERING COUNTER-NARRATIVES	130
READING DEMENTIA AUTOPATHOGRAPHS AS COUNTER-NARRATIVES.....	132
COHERENCE IN 'BROKEN' COUNTER-NARRATIVES: 'MRS MILL' AND OTHER STORIES.....	142

CONCLUSION.....	153
CHAPTER 4 RELATIONAL IDENTITY IN (FILIAL) DEMENTIA CAREGIVERS' MEMOIRS	159
THE AESTHETICS, ETHICS, AND POLITICS OF CAREGIVERS' MEMOIRS	159
GENDER, GENRE AND THE SELF: RETHINKING RELATIONAL IDENTITY IN DEMENTIA.....	170
'My Father's Brain'	171
Do You Remember Me? A Father, a Daughter, and a Search for the Self.....	176
Tangles: A Story about Alzheimer's, My Mother, and Me	183
CONCLUSION.....	192
PART III NARRATING DEMENTIA/RETHINKING CARE	195
CHAPTER 5 CARE-WRITING RECONSIDERED: TOWARDS A NEW PRACTICE OF DEMENTIA CARE	196
EXPLORING CAREGIVERS' DILEMMAS.....	197
IMAGINING ALTERNATIVE APPROACHES IN DEMENTIA CARE	210
CHALLENGING CARE PRACTICE	218
CONCLUSION.....	220
CHAPTER 6 MAKING READERS CARE: BIOETHICS AND THE NOVEL	225
ETHICS AND THE NOVEL: COUNTERING, STEREOTYPING AND DISTURBING	228
Scar Tissue: <i>Biomedicine and the Hermeneutics of Selfhood</i>	230
House Mother Normal: <i>Disturbing Care</i>	240
EXPLORING BIOETHICS: 'THINKING THROUGH' AS 'LIVING THROUGH'	246
Still Alice: <i>(Precedent) Autonomy and Suicide in Dementia</i>	248
Have the Men Had Enough? <i>Gender and the Economies of Care</i>	256
CONCLUSION.....	264
CONCLUSION AND OUTLOOK	270
BIBLIOGRAPHY	278

List of Illustrations

Fig. 1 <i>Evoking ‘parallel experience’ in the reader through photographic style in Henderson (1998: 9).</i>	56
Fig. 2 <i>Using photographic style to elicit imaginative engagement with the ways dementia changes the experience of space in Henderson (1998:10).</i>	57
Fig. 3 <i>Flow and relationality captured in photography in Henderson (1998: 43; 75).</i>	67
Fig. 4 <i>Questioning cultural expectations of filial caregiving in Chast (2014: 146).</i>	184
Fig. 5 <i>The problem of inversed child-parent relations in Haugse (1999: 31).</i>	185
Fig. 6 <i>Interplay of narrative voice and drawing style in the expression of emotion in Leavitt (2011: 66).</i>	187
Fig. 7 <i>Facial expression and gesture indicate emotional distress in Leavitt (2011: 102).</i>	188
Fig. 8 <i>The question of coercion: Nonverbal communication of fear in Sieveking (2012: 30:14; 30:54).</i>	201
Fig. 9 <i>‘Good grooming’: Ethical issues in personal care in Leavitt (2010: 110).</i>	203
Fig. 10 <i>Care as connection in Leavitt (2010: 111).</i>	204
Fig. 11 <i>Figuring the effects of caregiver stress in Leavitt (2010: 116-117).</i>	205
Fig. 12 <i>Drawing style as part of narrative rhetoric in Leavitt (2010: 116).</i>	206

The copyright of this thesis rests with the author. No quotation from it should be published without the author's prior written consent and information derived from it should be acknowledged.

Introduction: (Re)considering Dementia Narratives

Three Starting Points

Consider these three descriptions of dementia:

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain. (ICD-10, *Classification of Mental and Behavioural Disorders* 46)

Mum says ... that she feels lucky and glad and relieved now Grandma is dead. But she says she also feels a coward too because now Grandma is dead she can ignore the problem of all the other Grandmas and she shouldn't, she should be inspired to do something and she knows she isn't going to. She is going to dodge the issue now. She doesn't want to think about senile dementia or hear about it or read about it ever again. She isn't an activist and she can't help it. But somebody, somewhere, will have to do something soon. They'll have to. We've tinkered around enough with the start of life, we've interfered with all kinds of natural sequences, and now we'll have to tinker with the end. Mum says, "Your generation, Hannah, will have to have pro-death marches, you'll have to stop being scared to kill the old." Will we?" (Margaret Forster *Have the Men Had Enough?* 1989: 250)

I've been thinking about myself. Some time back, we used to be, I hesitate to say the word, 'human beings.' We worked, we made money, we had kids, and a lot of things we did not like to do and a lot of things we enjoyed. We were part of the economy. We had clubs that we went to, like Kiwanis Club and Food Bank. I was a busy little bee. I was into all sorts of things, things that had to do with music. Just a lot of things I did back then when I was, I was about to say – alive – that may be an exaggeration, but I must say this really is, it's living, it's living halfway. (Cary Henderson, *Partial View: An Alzheimer's Journal* 1998: 35)

Dementia represents a major public health concern. As our societies age, more and more people are affected by dementia and the number of people involved in providing dementia care—from family members to professional

caregivers—is rising accordingly. Caregiving can constitute a tremendous burden for family members, as they may experience ill health, depression and social alienation due to their caregiving duties. Increasing incidence rates, coupled with restricted financial and human resources, raise moral questions about solidarity and caregiving. How much will future generations be prepared to invest—emotionally as well as financially—in older and increasingly incapacitated generations? At the same time, international reports and local care scandals show that dementia care frequently falls short of what may be called adequate or indeed humane care (see also Burke 2016). People with dementia¹ are disadvantaged, neglected or even abused. Rectifying such situations and creating sustainable and humane dementia care, in which both caregivers and people with dementia can thrive, represents one of the global challenges of the present century.

In this socio-political context, dementia has also, however, become part of the cultural imaginary. Indeed, dementia has become ubiquitous in our times. It features not only in news reports, but in TV series, films, novels, plays,² short stories, autobiographies, graphic memoirs and documentaries. It has become a major theme in poetry and even a topic deemed suitable for operatic exploration (see Maxwell and Langer 2010). Dementia is discussed on radio programmes, via personal blogs and during coffee breaks. It is considered a ‘tragedy,’ a fate ‘worse than death,’ or ‘a death that leaves the body behind.’ Due to the progressive loss of cognitive functions, people with dementia lose their memories and their ability to use language—qualities often viewed as defining ‘what makes us human.’ People with dementia are considered to have lost their ‘self’ and are therefore at risk of being denied personhood. In short, dementia has become one of the most dreaded diseases in Western societies. But what is dementia? Why has it become such a feared disease? What does it mean in the current economic

¹ A note on terminology. First, talking about ‘dementia’ and ‘people with dementia’ may seem to suggest a homogenous group and clear-cut, stable disease category. However, dementia is a progressive disease syndrome with variable patterns of symptom progression. Second, throughout this study I prefer the descriptive term ‘people with dementia’ over the terms ‘victim’ or ‘afflicted person.’ While I use the adjective ‘dementing’ for characters in novels, as it stresses the progressive nature of the disease, I avoid the use of ‘dementing’ or ‘demented’ in relation to actual people with dementia.

² See, among others, Tom Murphy’s *Bailegangaire* (2009), Abi Morgan’s *27* (2011) and Fiona Evan’s *Geordie Sinatra* (2013).

and political climate? And what, finally, can a literary exploration of dementia contribute to our understanding of dementia and of its place in our society?

In this introduction I address these and other questions raised by narratives about dementia while using the three starting points quoted previously as touchstones for my discussion. Exploring first the ways dementia has been configured and reconsidered will enable me to address the question ‘why narrative?’ in terms of four discrete, but interrelated, reasons for examining narrative and concepts of narrative identity when considering dementia in contemporary literature and life writing:

- First, both fictional and non-fictional illness narratives may contribute to a better understanding of the phenomenology of dementia. In this thesis, I explore the possibilities and limitations of narratives of dementia to further our understanding of the lived experience of the disease—especially vis-à-vis narratives told ‘from the inside’—and their ability, or indeed inability, to counter negative stereotypes of people with dementia as ‘living dead.’
- Second, narrative is at the heart of a number of debates within the medical humanities (Charon 2006, Woods 2011), and indeed the role of the humanities in society at large (Nussbaum 1997). The novel, in particular, has been central to discussions about narrative empathy and pro-social action (Keen 2007) and about narrative ethics more broadly (Morris 2002, Nussbaum 1990, 1995,). Issues of narrative empathy and narrative ethics both emerge as important concerns in my study of dementia narratives.
- Third, narrative identity has come to the fore in discussions about what constitutes selfhood and how we claim identity for ourselves. It has been argued that identity is always narratively constructed (Bruner 1991, 2004). Such a view has both positive and negative implications for people with dementia. Determining the limits of the narrative identity hypothesis as well as suggesting the importance of considering the embodied and relational aspects of identity in dementia (and in stories about dementia) constitutes another important strand of my research.

- Fourth, and finally, narrative functions as a sense-making device (Herman 2013). I contend that in order to make sense of dementia we need to consider it at the person-level rather than at (or at least in addition to) a sub-personal level, where phenomena such as neurotransmitters, neurons and fibrillary tangles are situated. Dementia narratives open up the possibility of exploring dementia (and indeed, other aspects of what it means to be human) at the person-level. While I do not mean to suggest that neurological research into the disease does not have its place, given the personal and societal effects of dementia there is also an urgent need to consider this disease syndrome holistically and within the domain of human action and meaning.

A comprehensive analysis of the ways dementia is represented in contemporary film, fiction and life writing is beyond the scope of this thesis. However, by engaging with a range of case studies across different genres, media, and modes,³ I outline ways of understanding the cultural significance of dementia, with a view to developing a more nuanced understanding of how we construct and consequently live with this disease syndrome. My aim is to raise awareness for an underexplored strand of contemporary literature—that is, fictional and non-fictional dementia narratives across a range of media—to situate this literature in contemporary discourses about dementia, and to mine its potential for an as yet imperfectly understood and certainly underfunded area of health care: dementia caregiving.

Biomedicine and the Cultural Meaning of Dementia

Neurobiological disease models of dementia currently underpin our understanding of what dementia is. Indeed, the neurological disease model

³ Usage of the term ‘mode’ differs between theorists but a broad distinction can be drawn between uses of the term in local and global senses (Ryan 2005: 315). In the local sense, mode refers to the different ways or types of representation within a narrative text (such as perspective or focalisation) as well as different types of representation across different narrative media (such as audio-visual in film but not print texts). In the global sense, mode is used as a term for what might be called macro-genres or higher-level text types, such as lyric, epic, and drama. Since the focus of this thesis is on narrative, my chief concern is with mode taken in the local sense.

has come to be the dominant way of understanding dementia. In this thesis, I largely take this model for granted and accept the distinctions between different forms of dementia—among others, Alzheimer’s disease, vascular dementia, fronto-temporal dementia and dementia with Lewy bodies. Rather than delving into state-of-the art neurobiological explanations of the disease syndrome, I here trace the biomedical history and the biocultural meanings attached to dementia, in order to suggest some reasons why dementia narratives—the stories we tell each other about dementia across different media and in different contexts—need to be considered (or perhaps reconsidered) in the first place.

Dementia is a progressive neurodegenerative syndrome. As highlighted in the definition quoted at the outset, common symptoms include a range of impairments to cognitive functions, among them memory and language. Furthermore, dementia can be caused by multiple underlying conditions, such as cardio-vascular dementia, AIDS or Alzheimer’s disease. Since Alzheimer’s currently constitutes the most common cause of dementia it frequently stands in symbolically for the disease syndrome.⁴ Despite difficulties in determining the factors that cause dementia, as well as difficulties in distinguishing ‘normal’ from ‘pathological’ ageing,⁵ the neurobiological explanation of dementia *as brain disease* presents the dominant and accepted mode of understanding the symptoms of memory loss and cognitive decline which frequently accompany advanced old age—and in rarer cases affect young or middle-aged adults.⁶

⁴ In much of the non-medical literature on dementia, ‘Alzheimer’s disease’ is used to refer to all types of dementia, although dementia actually constitutes the umbrella term. I prefer to use the term ‘dementia’ as both the more accurate and more inclusive term. Nonetheless, although dementia represents a disease syndrome, that is, a constellation of symptoms that may be caused by a number of underlying diseases, for ease of reading I refer to dementia as ‘disease’ in the singular.

⁵ See the famous ‘Nun Study’ in which the brains of elderly nuns who manifested symptoms of dementia while alive did not show the characteristic plaques and tangles of Alzheimer’s on autopsy, while conversely, some of the brains that manifested plaques and tangles belonged to individuals who had not shown any symptoms of dementia when living (Snowdon 1997). The study has recently been explored in the stage drama *27* (Morgan 2011).

⁶ For dissenting views compare Whitehouse (2008) who questions the validity of the Alzheimer’s disease category. For other dissenting voices see Holstein (2000: 171).

In the ‘age of Alzheimer’s’ it may be difficult to imagine that cognitive decline in old age was not always considered pathological.⁷ As far back as 2200 BC Egyptian vizier Ptahhotep describes the effects of old age as entailing feebleness, childishness, the loss of language and—significantly—the loss of memory (Wetzstein 2005: 24). Memory loss, lack of orientation and difficulties with tasks of daily living—now considered symptoms of Alzheimer’s disease—were long considered ‘natural,’ that is, expected aspects of ageing. Conversely, some classical writers considered old age itself pathological. The history of medical and cultural attitudes to old age and age-related decline is long and complex (see, among others, Thane 2005). Further, there is significant variability across cultures in understandings of the life-course. Both a diachronic exploration as well as cross-cultural comparisons of attitudes towards people with dementia are worth exploring in their own right—and might shed light on contemporary (Western) constructions of the disease.

Diachronic or cross-cultural comparison, however, would have made this study scientifically unmanageable. I am not concerned here either with tracing a literary history of the disease, or indeed with retrospectively ‘diagnosing’ characters in Shakespeare or Dickens with some specific form of dementia (cp. Douglas 2008). Instead, I consider dementia principally as a contemporary ‘problem’—as it is currently construed in medical, socio-economic and demographic terms—and examine the way this problem of dementia is constructed in the cultural imaginary.

The conceptual history of dementia is well documented (see amongst others Ballenger 2006, Fox 1989, Gubrium 1986, Holstein 1997, 2000, Leibling and Cohen 2006, Shenk 2001, Wetzstein 2005, Whitehouse, Maurer, and Ballenger 2000). Most accounts begin with Alois Alzheimer’s well-known case study of his patient Auguste D.—a fifty-one-year-old woman who presented at his clinic with paranoia and memory problems. After admittance to a mental hospital, Auguste deteriorated rapidly over the next few years, becoming progressively cognitively impaired, disorientated, delusional, and hostile (Shenk 2001: 13). When Alzheimer dissected her

⁷ See Leibling and Cohen (2006) on the pathologisation of senility.

brain post-mortem, he discovered the amyloid plaques and ‘senile’ or neurofibrillary tangles which have since become the hallmark of Alzheimer’s disease. Although Alzheimer presented his work in 1906 and Emil Kraepelin named the disease after him in 1910, the disease category lay more or less ‘medically dormant’ until the 1960s (Gubrium 1986: 1). Even Alzheimer himself evinced some uncertainty over whether his case represented a new disease category or could be equated with the more common form of senile dementia. It was only in the late 1970s and early 80s, due to a complex set of socioeconomic, technological and political developments, that dementia emerged as disease category (Ballenger 2006, Fox 1989, Gubrium 1986, Holstein 2000, Lyman 1989). Alzheimer’s became the dread ‘disease of the century’ (Thomas 1983). It is worth keeping in mind the complex social history of the biomedicalisation of dementia when approaching this disease or disease syndrome as a contemporary problem. Tracing the history of Alzheimer’s highlights the degree to which disease, in general, is always at least partially socially constructed (Hacking 1999a, b) and accrues meaning in its bio-cultural context (Morris 1998).

While demographic changes clearly play an important role in the contemporary ‘rise’ of Alzheimer’s, the particular fear generated by dementia is arguably linked to the fact that this condition threatens core values in contemporary Western societies, such as youth, productivity, autonomy, capability and rationality (Basting 2003a, Snyder 1999). Importantly, the worth of a person, or indeed the status of personhood itself, is determined on the basis of whether or not a person can conform to these values. As ethicist Stephen Post argues, ‘We live in a culture that is, at least in large segments, dominated by heightened expectations of rationalism and economic productivity, so clarity of mind and productivity inevitably influence our sense of the worth of a human life’ (2000: 5). Post calls attention to the risks inherent in such ‘hypercognitive’ value systems, in that people with dementia may be removed from the sphere of moral concern. They frequently become victims of abuse and neglect. In the worst case, their lives might no longer be considered worth protecting and they may be under pressure to consent to ‘assisted suicide’ or may become the victims of

euthanasia or murder. Indeed, as Megan-Jane Johnstone reveals, the way media coverage constructs dementia and thereby influences public understanding of the disease has contributed to what she perceives as a subtle but noticeable shift towards euthanasia as a ‘solution’ for people with dementia at any stage in the disease (Johnstone 2011, 2013).

If people with dementia are dehumanised, the core element of this dehumanisation lies in the fact that dementia is commonly understood to be synonymous with ‘losing one’s self.’ This notion long remained unquestioned and formed the basis of both popular and scientific understandings of the disease (see Millett 2011). Indeed, as Herskovits (1995) argues, scientific literature on dementia tended to enforce the notion that the self is lost, by using such disturbing metaphors as ‘death before death’ and a ‘funeral without end’ (Cohen and Eisdorfer 1986, qtd. in Herskovits 1995: 148). According to the sociologists Fontana and Smith, for instance, in people with dementia ‘the self has slowly unravelled and “unbecome” a self.’ The authors assert that while the caregivers act on the illusion that ‘there is a person behind the largely unwitting presentation of self in the victim ... in reality there is less and less, until where once there was a unique individual there is but emptiness’ (Fontana and Smith 1989: 45, qtd. in Herskovits 1995: 147). Such descriptions of dementia resonate with images that characterise people with dementia as ‘shells,’ ‘husks,’ ‘ghosts of their former selves’ or even ‘zombies’ (Behuniak 2011). Frequently family members will state of a person with dementia that ‘He is no longer there,’ or ‘She is long gone.’ Although such descriptions speak to the experience of loss that family members go through, such statements deny the continuing subjectivity of the person with dementia. Indeed, Herskovits characterises the current construction of Alzheimer’s disease as a ‘*monsterizing* of senility’ (Herskovits 1995: 153, original emphasis) and Wetzstein speaks of a ‘demonisation’ of dementia in public discourse (Wetzstein 2005). Such metaphors as ‘shell,’ ‘husk,’ or ‘vegetable’ are deeply troubling since they risk removing people with dementia from the sphere of personhood and hence moral concern (Post 2000).

Since the 1980s a growing body of research on dementia, especially from a social constructivist perspective, has engaged in what Herskovits

identifies as ‘reparative work’ (Herskovits 1995: 159); this work aims to reconstitute the humanity and dignity of people with dementia and challenges the notion that selfhood is simply ‘lost.’ Karen Lyman (1989) discusses how disease labelling and seeing all aspects of behaviour as pathological facilitates social and medical control (599). The biomedicalisation of dementia may result in, among other things, ‘a self-fulfilling prophecy of impairment’ and ‘excess disability’ (Brody et al. 1971; qtd. in Lyman 1989: 599). In short, the conjunction of labelling and stigma results in the ‘spoilt identity’ of the person to whom a disease label is attached (Goffman 1963).

Tom Kitwood, a pioneer in dementia studies, similarly, draws attention to the way social-psychological factors contribute to the process of dementia and may thereby undermine the personhood of those living with the condition. By highlighting the ‘malignant social psychology’ pervasive in care settings, Kitwood explores the dynamic interplay between neurological processes of degeneration and psychological factors such as disempowerment, infantilisation, labelling and objectification in the progression of dementia (Kitwood 1990, 1997: 45-49). His exhaustive description of the factors which contribute to the dehumanisation of people with dementia in care settings is followed by practical guidance on how to prevent these processes from occurring: his dementia care mapping system has since been implemented in numerous care environments with the aim of developing more ‘person-centred’ care in dementia.

Steven R. Sabat and Rom Harré (1992) also approach dementia from a social constructivist or interactionist perspective. They analyse speech data from people with Alzheimer’s disease to show that ‘(1) there is a self, a personal singularity, that remains intact despite the debilitating effects of the disorder, and (2) there are other aspects of the person, the selves that are socially and publicly presented, that can be lost, *but only indirectly* as a result of the disease’ (444, original emphasis). Their argument is based on a distinction between what they term self¹ and self². Self¹ refers to ‘the self of personal identity, which is experienced as the continuity of one’s point of view in the world of objects in space and time ... coupled with one’s sense of personal agency, in that one takes oneself as acting from that very same

point in time' (445), while self² refers to the number of selves 'that are publicly presented in the episodes of interpersonal interaction in the everyday world, the coherent clusters of traits we sometimes call "personae"' (445). The latter are usually discursively created through narration and declarations and require the cooperation of others in order to exist. Sabat and Harré reveal how the social positioning of people with dementia as confused, and of their behaviour as meaningless, threatens the recognition of their discursive acts as displays of selfhood. In other words, we need to listen to people with dementia in order to recognise them as semiotic subjects (Sabat and Harré 1994). If we fail to do so people with dementia lose their selfhood—not due to the dementing illness but because of the way they are socially positioned.

While setting a laudable example of paying attention to the words and stories of people with dementia—one I intend to follow in this thesis—Sabat and Harré perhaps underplay the role of neurological impairment in the construction or deconstruction of 'selfhood.' Further, their recognition of selfhood overemphasises the 'correct' use of first-person indexicals (such as references to 'I', 'me' etc.) as 'proof' that selfhood persists. Their work suggests that there is nonetheless a cut-off line at which the subjectivity of the person with dementia ceases, and this cut-off line hinges on the use of language. By contrast, Pia Kontos (2003, 2004, 2005) emphasises the role of 'embodied memory' and meaningful behaviour and gestures in people with dementia as examples of the persistence of selfhood. As I suggest in chapter 1, the vexed ontological question of the persistence of selfhood in dementia may perhaps best be understood if we replace Sabat and Harré's self¹ with the phenomenological description of selfhood as the 'first-personal perspectival givenness' of the world (Zahavi 2007). This subjective perspective on the world, I argue, persists until the very end, as people with dementia continue to experience their being-in-the-world as long as they are alive. By contrast, self²—the social identities or personae of a person with

dementia—may indeed be eroded, both by disease processes and social interactions, relatively early on.⁸

More recently a growing literature explores the question of what may actually *constitute* selfhood in dementia. This question has been addressed in, for instance, philosophical and psychiatric practice-based investigations of the disease syndrome (Hughes, Louw, and Sabat 2006). While some work in this area might be classified as ‘reparative’ in that it challenges the construction of people with dementia as non-persons, other studies espouse post-Lockean notions of identity, which posit that to be a person one needs a certain mental unity, and awareness of oneself as persisting in time which is grounded in memory—thereby clearly denying people with dementia a claim to personhood. Of course, simply asserting that self- or personhood persists does not resolve practical or ethical questions around the limits of agency or moral responsibility. While the disempowerment of people with dementia is to be lamented, the safeguarding of people with dementia and of their caregivers clearly requires a difficult balance to be struck.

One of the reparative moves within dementia studies, with particular relevance for this study, has been to see selfhood as narratively constructed. Research on how selfhood is constructed in dementia, both by people with the disease and by their caregivers, has been crucial in drawing attention to the narratives people with dementia tell (Hydén 2011, Hydén and Örvulv 2009, Lyman 1998, MacRae 2010, Phinney 2002, Ryan, Bannister, and Anas 2009, Usita 1998) and also in emphasising the degree to which identity construction relies on the collaboration of others (Sabat and Harré 1992, 1994, Small et al. 1998). However, as previously noted in relation to Sabat and Harré’s work, some risks attach to positing identity as constituted by narrative in the context of neurodegenerative diseases such as Alzheimer’s. People with dementia do experience significant decline in their linguistic capacities and in their ability to remember aspects of their life. Both of these symptoms clearly affect the ability to ‘tell a life story’ and thereby reclaim social identity for oneself. The present study explores this

⁸ The terms ‘self,’ ‘identity,’ ‘person,’ and ‘life’ are frequently used interchangeably not only in public but also in philosophical discourse. I acknowledge the contested nature of all these terms, but for ease of reading refrain from placing them in quotation marks.

very tension, both in the context of fictional writing and in the context of life writing by and about people with dementia. In particular, I investigate how these narratives position themselves in relation to the dominant ‘master narrative’ of dementia as ‘loss of self,’ and to what extent narratives by and about people with dementia may act as counter-narratives to the current Alzheimer’s construct.

In short, the representation of people with dementia is not ‘neutral.’ Biomedicine has created a discourse of ‘facts’ about the disease syndrome, but even this purportedly scientific description is an interpretation of the disease which impacts on the way the disease is treated and experienced. Biomedical approaches to dementia do not pay due attention to the way diseases of all sorts are, in part, socially constructed; nor do they consider the potentially harmful or iatrogenic⁹ effects of biomedical practice itself. However, my focus here is not so much on biomedicine as it is on the way a biomedical category like dementia is wedded to cultural meanings. The damaging effect of disease labels lies not in the labels themselves but in the cultural meaning that, because of these practices of naming and categorisation, certain illnesses accrue (Couser 1997, Sontag 1979, 1989).

There are, as Lucy Burke underscores, ethical consequences that follow from the ‘particular “descriptive” categories’ used to evoke Alzheimer’s ‘and the ways of seeing that they prescribe’ (Burke 2007b: 64). Accordingly, the present study reconsiders the interpretive aspects of the purportedly ‘descriptive’ categories we have developed: not just the biomedical model of Alzheimer’s disease but the metaphors we use and stories we tell to conceptualise dementia in the present age. As David Morris suggests, ‘The stories we tell ... are not just entertainment. They are the material with which a culture redefines its own image and self-understanding’ (1998: 277). Examining the images and stories that have grown around dementia may thus provide an insight into how contemporary Western societies construct human identity. At the same time, understanding ‘how Alzheimer’s is perceived and represented’ will, hopefully, lead to benefits for those living with this disease (see Basting 2003a: 88).

⁹ The term ‘iatrogenic’ relates to illness caused by medical examination or treatment.

The Alzheimer's 'Epidemic': Considering Care, Costs and Social Justice through Literature

This section traces the 'care crisis' narrative that Margaret Forster's novel engages with and in doing so explores further reasons for attending to dementia narratives. These reasons concern how such narratives relate to current ethico-political debates about social justice in the context of a dementia 'epidemic'; how representations of dementia across a variety of media and contexts contribute to the construction of dementia—with very real consequences in the social realm; and how literary narratives can work as a 'moral laboratory' for analysing caregiving dilemmas, thereby fostering new ethical insights into and practices of dementia care.

Let us return to the second 'description' of dementia quoted at the beginning of this introduction. This extract is taken from Margaret Forster's novel *Have the Men Had Enough?* (1989), a novel that explores the difficulties of providing home care for an ageing relative with dementia. The story is told from two different perspectives: the perspective of the daughter-in-law, Jenny, and the granddaughter, Hannah. Neither of these women, although intimately involved in caring for 'Grandma,' is the primary caregiver; rather, that role falls to Grandma's daughter, Bridget. The main conflict in the novel arises from Bridget's desire to keep her mother at home while her mother's ever growing care needs make this increasingly difficult for the family as a whole to sustain. The extract quoted above must be situated in this larger context; rather than being a description of dementia, it is a description of the daughter-in-law's reaction to her mother-in-law's death. More precisely, it represents Jenny's reaction as mediated through her own daughter's perspective and includes a discussion about the responsibility and the limits of responsibility when it comes to caring for people with dementia.

As Lucy Burke notes about this novel, Grandma's death represents a resolution of the care-crisis without actually offering a solution to the problem of how to live with dementia or care for people with dementia (Burke 2015: 39). Heike Hartung (2016: 202-203) goes so far as to suggest that the novel advocates for suicide and euthanasia in dementia. While I

disagree with the latter analysis, the novel clearly does raise questions about the value and quality of life in dementia and about intergenerational justice. In particular, it frames these questions through a feminist enquiry into why dementia care is still predominantly carried out by women. It taps into one of the most prominent narratives about dementia propounded through public media—that is, of Alzheimer's as an 'epidemic' that will lead to an insurmountable 'care crisis.' As a novel, though, Foster's text offers its own vision of this situation and invites its readers to think through some of the complex ethical issues dementia raises. Extrapolating from this novel, I turn now to a discussion of the socio-political context in which debates about dementia care are currently framed, before suggesting, in a second step, how fictional and non-fictional dementia narratives may contribute to this debate.

Dementia has become a major public health concern (World Health Organization 2012). Demographic prognoses of 'graying' societies have led analysts to cast dementia as an 'epidemic,' 'plague,' 'rising tide,' 'wave' or even 'silent tsunami' (Zeilig 2013: 260). Such rhetoric is motivated by statistical estimates presented in the World Alzheimer's Report 2009, according to which the number of people with dementia will nearly double every twenty years, to 65.7 million in 2030 and 115.4 million in 2050 (Alzheimer's Disease International 2009: 8). Dementia is cited as the leading cause of dependency and disability among older people and in 2010 the global economic cost of dementia was estimated at over 604 billion US dollars (Alzheimer's Disease International 2010: 5). Dementia, on these accounts, represents one of the greatest social, health and economic challenges of the twenty-first century.

Although *Alzheimer's Disease International* and related associations have been instrumental in raising awareness about dementia and improving the lives of those affected, there are some negative implications inherent in the plot-lines or master narratives that the association employs in order to justify the urgent need for action. For one, the alarmist notion of an Alzheimer's epidemic or tsunami, fed by demographic statistics, is likely to increase fear and dread of the disease. Such imagery dehumanises people with dementia by turning them into an indistinguishable mass that will 'swallow' the resources of more able-bodied and able-minded sectors of

society. We must therefore question the metaphors used to conceptualise dementia and ask how they make us see, understand and feel about this disease. On a different plane, as a number of scholars have pointed out (Ballenger 2006, Fox 1989), the association's lobbying strategy to increase funding for *research* into the disease is usually based on the projected costs dementia will incur if it is not cured. The advocacy movement uses statistics to support their claim for urgent action, but this use of statistics unwittingly undermines claims for more money to be invested in dementia *care*: supporting people with dementia and their caregivers, or investing resources in developing better insurance care plans and therapeutic interventions is not (yet) a top priority.

Although health care provisions differ greatly between different Western countries, dementia emerges as a problem case in all systems. An in-depth analysis of the situation, specifically in the UK and the US, lies beyond the scope of this introduction, but it is evident that dementia challenges these systems, or rather that health care systems fail people with dementia. In the US, for instance, middle class families affected by dementia frequently fall through the net of insurance policies until they have spent all savings and assets and qualify for state benefits. Furthermore, policies such as Medicaid and Medicare often do not cover the type of care a person with dementia still living at home needs. In the UK, an ailing if not failing NHS struggles to offer the kind of care suitable for a person with dementia. Although all patients suffer from the fragmentation of health services and the lack of communication between different services, people with dementia, in particular, would benefit from having a designated health professional to organise all aspects of their healthcare. Government cuts to the care budget of local councils mean that people with dementia cannot be adequately cared for at home, resulting in increasing numbers of people with dementia in hospital beds. However, hospital visits have been noted to cause rapid decline in the functioning of people with dementia, due to the unfamiliar environment hospitals present. Further, limited visiting hours for caregivers deprive people with dementia in institutions of the familiar faces

and support that would help orientate them and make them feel safe.¹⁰

In sum, institutions are not set up to cater to the needs of the deeply forgetful. Professional carers are underpaid and over-stretched. Agencies send different carers to people with dementia daily, undermining the possibility for a care relationship to form. This means the person with dementia is forced to accept help with dressing, bathing and other intimate aspects of daily living from a string of different individuals. The list of failings is long, perhaps endless. Importantly, besides these local problems, changes to the basic principles of the welfare state over the last decades have presented major challenges for dementia care. As Lucy Burke (2015) notes, the spread of neo-liberalist economic tendencies adversely affects dementia care by turning it into a commodity—one that will not be available to everyone who may need it in the future.

The growing prevalence of dementia together with declining welfare state systems then raises a number of questions. On the one hand, how do we as a society rise to the ethico-political dilemmas dementia raises in terms of social justice? What duty do we have to care for growing segments of dependent people in society? How do we conceptualise people with dementia and what effect does this have on their treatment in society? Are we moving towards political recognition of people with dementia or will euthanasia of the cognitively impaired become the norm in the next decades? (Johnstone 2011, 2013, Kaufman 2006). As Verena Wetzstein (2005) argues, the combination of the biomedical concept of dementia with reductionist notions of personhood has serious implications for how we treat people with dementia. No longer considered a person due to the loss of cognitive functions, a ‘non-person’ may no longer seem to have a life worth protecting. At the same time, the loss of cognitive functions inevitably leads to a loss of autonomy which raises a different set of questions concerning coercion and paternalism. How can the need to protect people with dementia be balanced with the need to respect their autonomy? And what autonomy do people with dementia retain when it comes to making end-of life

¹⁰ ‘John’s campaign’ in the UK (see <http://johnscampaign.org.uk/#/>) focuses on extending visiting hours and generally making family caregivers more welcome in hospital environments with the aim of supporting the well-being of people with dementia.

decisions and to planning ahead through the use of advance directives or the nomination of a proxy?

Fictional and non-fictional dementia narratives, I suggest, provide a means to address, or at least articulate more precisely, questions of this sort. Of course, literature does not provide answers or solutions to all the challenges of dementia care, but it does complement other modes of enquiry and offer a critical contribution to current debates. Critically analysing the representation of dementia in contemporary literature will yield insights into how our society conceptualises dementia, and particularly selfhood in dementia. Fictional representations of dementia may suggest how dementia narratives perpetuate stereotypes of ‘lost selves’ and ‘empty shells’ and thereby confirm the stigma attached to the condition. At the same time, literature may also critically reflect on current discourses, or may function as a counter-narrative to the dominant masterplot of dementia. As the long history of censorship demonstrates, literature is feared or revered—depending on one’s perspective—for its subversive potential. And yet, as my comments about stigmatising narratives suggest, literature also functions as a tool for consolidating cultural attitudes and for legitimating certain social practices.

In recent years, a number of literary and cultural scholars, as well as scholars working in fields such as gerontology, have analysed the way dementia is represented in contemporary literature, film and life writing (see Swinnen and Schweda 2015). Foremost among them, Lucy Burke, a disability scholar, has challenged the representation of dementia in film-poetry (Burke 2007b), life writing (Burke 2007a, 2008) and fictional narratives (Burke 2015, 2016). Burke specifically questions the notion that selfhood is lost in dementia and explores how personhood is constructed (or fails to be constructed) in illness narratives (Burke 2014). Her analysis stresses the socio-political relevance of dementia discourses and the need to challenge cognitivist notions of personhood in the context of neo-liberalist politics. Considering how dementia is represented in contemporary media becomes an ethico-political process geared towards acknowledging the personhood of people with dementia with the aim of recognising their basic human rights to dignity and care.

While scholarship previously focused mainly on representations of dementia in the novel or life writing, it is now starting to catch up with the recent surge of dementia films. Relevant studies range across Japanese film (Asai, Sato, and Fukuyama 2009), Dutch documentaries (Swinnen 2012), non-mainstream films (Cohen-Shalev and Marcus 2012) and British ‘biopics’ (Wearing 2013, Graham 2016).¹¹ Wearing (2013) and Graham (2016), for instance, criticise the stereotypical representation of aged female bodies and voices in biopics such as *Iris* (Eyre 2001), about philosopher and novelist Dame Iris Murdoch, and the controversial film *The Iron Lady* (Lloyd 2011), about Margaret Thatcher’s life with dementia. Wearing argues that the latter film uses dementia as ‘a narrative ploy that legitimises a subjective, one sided, and thereby depoliticised account of British politics’ (321), but does little to further the interests of people with dementia. Graham by contrast draws attention to how cinematic portrayals of the voices of women with Alzheimer’s can enforce damaging stereotypes of dementia as narrative of decline and devastation. Both authors agree that the ways dementia is represented in film, due to the affective potential by which film does its cultural work—with film producing a form of ‘embodied social knowledge’ (Wearing 2013: 323)—has serious implications for how we think and feel about, and therefore how we act towards, people with dementia.

Similarly, Andrea Capstick and her collaborators (Capstick, Chatwin, and Ludwin 2015) have problematized representations of people with dementia in mainstream film. They find that popular TV series and films contribute to the epistemic injustice¹² experienced by people with dementia. Further, they argue that such representations are particularly dangerous, compared to other fictional forms, such as the novel, as filmic representations are more likely to be believed and be experienced as a direct source of knowledge, because film involves ‘a heightened sense of reality’ (235). While such general claims about the reception of film, in comparison

¹¹ David Orr and Yugin Teo (2015), by contrast, explore how dementia films reflect caregivers’ responses to their partners’ shifting identities, rather than discussing the films’ representations of dementia *per se*.

¹² The term ‘epistemic injustice’ was coined by Fricker (2007) to highlight how particular social groups are deprived of their status as ‘knowers’ and may consequently be dehumanised (see Capstick, Chatwin, and Ludwin 2015: 231).

to other media, should be examined more closely, I agree that ‘the benign social realism of a TV drama’ might make ‘its acceptance as a faithful representation of diagnosis, assessment, and prognosis in dementia more likely’ (235). Importantly, because of the way fictional narratives employ dementia to meet their own aesthetic and dramatic ends, Capstick and her colleagues rightly caution against uncritically inserting filmic representations of dementia into curricula for health and social care practitioners on the assumption that this will have a ‘humanising’ effect on future practitioners (238). More could be gained by teaching health practitioners to read such films, and their own preconceptions about dementia, critically.

Yet the focus, both in dementia narratives and in critical analyses of these texts, is not always on the person with dementia. Indeed, it is only recently that the subjective perspective of the person affected has begun to be considered in social science investigations, in life writing by people with dementia, and in artistic explorations of the disease. Most explorations of dementia (both literary and scholarly) focus on the impact the disease has on the family caregiver. Martina Zimmermann’s (2010) article ‘Deliver us from Evil: Carer Burden in Alzheimer’s Disease’ is paradigmatic on two counts: (1) the novels she discusses are written from the perspective of the adult children of a person with dementia, and (2), the focus of her article is on the ‘burden’ dementia constitutes for these adult children. While she rightly suggests that fictional accounts of dementia may contribute to ‘constructive public discussion regarding end-of-life treatment of demented patients’ (101), Zimmermann’s own analysis, however, is insufficiently circumspect about the rhetoric and structures of desire that her two case studies (Christine Devars’ *Le Piano Désaccordé* (2005) and Andrés Barba’s *Ahora Toca Música de Baile* (2004)) may raise in their readers. In both cases, adult children decide to terminate the life of their parent with dementia: in Barba’s account the protagonist first nearly beats his mother to death and then causes her to step in front of an oncoming car. In the narrative, the mother is constructed as no longer human, and her life considered undignified. Zimmermann does not explore the extent to which dehumanising imagery and a hypercognitive approach to personal identity in

the narrative may lead to evaluations of the son's acts as, in her terms, 'positively motivated' (36).

Thus, both the fictional narratives and Zimmerman's reading of these texts highlight what may happen if one doesn't engage critically with the rhetoric of dementia as it is portrayed in discourse concerned with the disease. Attending to the way dementia is constructed in the cultural imaginary is crucial, since it informs the way dementia is lived, experienced and treated. However, my argument is also more specific than that. I suggest that dementia narratives, in particular, provide key insights into the dilemmas of dementia care outlined above—dilemmas having to do with resource allocation, best care practice, questions of autonomy and coercion, and end-of-life decisions. Indeed, novels, films and life writing about dementia may function as a form of 'social phenomenology' (Felski 2008: 89) or 'practical counterpart of phenomenology' (Waugh 2013), offering a means to 'live through' (Rosenblatt 1995) and think through dementia care dilemmas. In short, dementia narratives can work as a 'moral laboratory'¹³ for considering the dilemmas of dementia care, with critical reading of these texts contributing to a new ethics and practice of dementia care. Although the Alzheimer's disease movement since the 1980s has garnered increased research funds in an effort to 'defeat' dementia (Fox 1989)—in the popular militaristic parlance of contemporary illness discourse—a cure for the multifactorial disease processes that cause dementia remains elusive. Since there is no cure in sight, the question remains how people with dementia can best be cared for and, also, how those who provide this care—professional and familial caregivers alike—can best be supported (see World Health Organization 2012: 68).

Why Narrative? The Life World Approach to Dementia

'Some time back,' Cary Henderson tells readers of his Alzheimer's journal, 'we used to be, I hesitate to use the word, "human beings"' (1998: 35). Reflecting on the many ways his life has changed due to Alzheimer's, he contrasts his life as it was 'back then'—full of activities and

¹³ See Hakemulder (2000) for empirical studies examining the effects of reading.

responsibilities—with his current limited horizon: ‘Just a lot of things I did back then when I was, I was about to say – alive – that may be an exaggeration, but I must say this really is, it’s living, it’s living halfway’ (35). Henderson’s journal evokes in a lively fashion how the world of a person with dementia changes—mentally, physically and socially. It is one of a growing number of autopathographies¹⁴ written by people with dementia about what it is like to live with this disease. As such, it is an example of the explosion of contemporary illness narratives, written against the background of biomedical interventions which risk depersonalising the illness experience and reinforcing the cultural stigma associated with disease. Henderson writes about no longer being considered a ‘human being’ because of his inability to be a ‘productive’ member of society. He details how Alzheimer’s interferes not only with his working life and recreational activities but also with his ability to interact with others and feel part of his family and wider social circle. Yet in doing so Henderson seems to have internalised the values of the society he lives in. In describing himself as only partially ‘alive,’ as ‘living halfway,’ he both expresses his subjective experience of living with Alzheimer’s and also confirms stereotypical views of the disease as a kind of ‘living death.’

If Henderson’s journal deals with the phenomenology of dementia and the stigma attached to the disease, it also feeds directly into debates about narrative identity and the politics, ethics and aesthetics of life writing. Henderson’s journal represents a collaborative project: between Henderson and the photographer Nancy Andrews, but also between Henderson and his wife and daughter, who transcribed, organised and edited his many tape recordings. Using a tape recorder allowed Henderson to tell readers about his experience long after he had lost the ability to write. His journal thus points to the limits to life writing in dementia. The episodic nature of the ‘musings’ in his journal also raises the question of how coherent a narrative need be in order to function as an identity narrative—as a means of claiming

¹⁴ For studies of autopathography, defined as life writing primarily about the progression of a disease and written by the person affected directly by the disease, see, among others, Couser (1999) and Graham (1997). Avrahami (2007) uses instead the term illness autobiography. Hawkins’ study (1993) deals with both autopathography and pathography—illness narratives written by the carer of the person affected by disease—under the heading of pathography.

selfhood in the social sphere. More generally, Henderson's autopathography highlights several important roles narrative plays in current discourses about dementia.

Although some of these roles are particular to life writing, others also come into play in fictional dementia narratives, as brought out by the four claims for the study of dementia narratives outlined at the beginning of this introduction:

- First, fictional and non-fictional illness narratives may contribute to a better understanding of the phenomenology of dementia and may act as counter-narratives to the current Alzheimer's construct.
- Second, narrative is central to debates within the (medical) humanities in terms of delineating the potential role of literature—specifically of narrative empathy and the ethics evoked by novels—in relation to pro-social action.
- Third, identity can be considered to be (at least partially) constituted through narrative. There is thus a need to determine the limits of the narrative identity hypothesis—to explore its positive and negative implications for people with dementia—while also considering the embodied and relational aspects of identity in dementia (and in stories about dementia).
- Fourth, narrative functions as a sense-making device that is optimally suited to explore dementia at the person-level.

The latter claim, in particular, resonates with my previous discussion about the biocultural significance of dementia and the way that the conceptualisation of dementia—through medical paradigms, metaphors, or stories—influences the way we see and act towards people with dementia. Rather than reiterating how this argument is relevant to a whole range of cultural productions—including but also extending beyond narrative—I here focus on the primary role narrative plays in human sense-making. In what follows, I outline the broader scholarly debates surrounding each claim in order to highlight the relevance of my approach to current academic discourse.

1 'Illness Narratives': Countering Biocultural Master Narratives and Exploring the Phenomenology of Illness

In recent decades there has been both a surge in the publication of illness narratives and a growing scholarly interest in these stories about illness and disability—from Arthur Kleinman's seminal *The Illness Narratives* (1988), across literary studies of 'pathography'¹⁵ (Hawkins 1993, Wiltshire 2000), to Rita Charon's practice-based *Narrative Medicine* (Charon 2006). While the focus was initially on doctors' narratives of illness (Montgomery Hunter 1993),¹⁶ illness narratives soon became the prerogative of the ill person herself. Indeed, illness narratives may be considered paradigmatic counter-narratives which allow the ill person to reclaim her subjectivity in the face of reductionist biomedical (Frank 1995) and culturally stigmatising constructions of diseases (Avrahami 2007, Couser 1997).¹⁷ There are, of course, problems in defining what constitutes the master narrative of dementia and what may constitute a counter-narrative—as I discuss in more detail in chapter 3. In general, however, counter-narratives become active when one group of society is unduly marginalised or stigmatised (Bamberg and Andrews 2004). While stigma invariably attaches to diseases (Goffman 1963), it seems particularly salient in those conditions that are in some form culturally significant (Couser 1997). I argue that dementia is one such culturally significant disease. As a disease of memory it taps into contemporary Western societies' concern or even obsession with the capacity to remember. More importantly, it attacks those aspects of human cognition that are considered to distinguish humans from other animals—

¹⁵ Auto/biographical illness narratives written, usually, by a family caregiver or by the person affected by the disease (Hawkins 1993). 'Autopathography' was later coined to distinguish the point of view of the ill person from the caregivers' perspective (see, for instance Couser 1991). Given that these texts aim to de-pathologise their authors' experiences, Couser subsequently suggested the term 'autosomatography' (Smith and Watson 2010). I use the term 'autopathography' when referring to life writing by people with dementia and the term 'caregiver's memoir' for dementia pathography written by family caregivers.

¹⁶ See Whitehead (2014: 109-111) on the psycho-analytic focus in doctors' narratives in the UK context.

¹⁷ There is a growing body of literature that deals with illness narratives and other alternative approaches to illness in journals such as *Literature and Medicine*, *The British Journal of Medical Humanities*, *The Journal of Medical Humanities* (US), *The Journal of Critical Disability Studies*, journals in (auto)biography studies, and the online journal *Hektoen International*.

language, higher order thought, and memory. Dementia therefore goes to the heart of discussions of what it means to be human. Consequently, the disease syndrome activates many people's worst fears in today's aptly described 'hypercognitive' society (Post 2000), since it leads to a progressive loss in cognitive functioning—and, presumably, concomitantly to a 'loss of self.'

Although the condition of dementia seems to defy the possibility of expression in autobiographical writing, there is a growing body of texts that tell the experience of dementia from the perspective of the person affected.¹⁸ Karen Lyman's statement that 'people with dementia are largely invisible in most of [the Alzheimer's] literature' (1989:603) fortunately no longer holds—although the representation, and the cultural salience, of the first-person perspective remains low compared to the number of third-person perspectives found in caregivers' memoirs, documentaries, and representations of dementia in mainstream TV series and films. In line with findings about other illness narratives, autopathographies by people with dementia can be seen as a means of reclaiming one's identity and the meaning of one's experience from the biomedical domain (Basting 2003a, Ryan, Bannister, and Anas 2009). Lisa Snyder contends, furthermore, that the narratives of people with dementia present an important means of bridging the gap in communication not only in early but also in later stages of the disease. In a collection of narratives compiled through interviews with people with dementia she writes,

Although the individuals profiled in this book ... are able to articulate their reflections and feelings verbally, in all likelihood their expressions will change over time from verbal to nonverbal – to more behavioural or symbolic gestures. We rely on language as the primary vehicle of communication to bridge minds. And when behaviour begins to speak, it can be seen as a new language – one fraught with confusion and frustration for both the sender and the receiver of the message. ... If we can learn the themes of communication early on, perhaps we can be sensitive to the ways they might be repeated later in the course of the illness. People may continue to experience similar feelings but express them differently as their confusion increases and their capacity to articulate decreases. (Snyder 1999: 10-11)

Autopathographies may, then, have a valuable contribution to make to better communication and care in dementia. Both life writing by people with

¹⁸ See chapters 1 and 3 in particular for an exploration of narratives of this kind.

dementia and by their caregivers may challenge the dominant cultural construct of Alzheimer's disease and question biomedical as well as care practices while providing detailed insight into the experience of living with dementia. These texts have something important to tell us about the phenomenology of being ill (Carel 2008).

Nonetheless, there are inherent problems in dementia life writing. On the one hand, caregivers' memoirs raise ethical issues about representing 'vulnerable subjects', persons who are liable to exposure by an intimate other or caregiver but who are unable to represent themselves or to offer meaningful consent to their representation (see Couser 2004: xii, 2005). On the other hand, people with dementia will eventually struggle to tell their own story in verbally coherent form. Burke (2007a), for instance, suggests that dementia autobiography, or what she calls 'first person testimony' is not a suitable means for challenging cultural constructions of people with dementia as non-persons. Kathlyn Conway (2007) points more generally to the difficulties of expressing serious illness in language, especially in narrative form. Her critique of the dominant 'triumph narrative' in contemporary stories about illness is particularly relevant to neurodegenerative diseases such as dementia. Indeed, I would extend this critique to Frank's elevation of the 'quest narrative' (Frank 1995) over other ways of telling about an illness experience. People with dementia cannot 'triumph' over the disease in the terms of winning the 'battle' against the progression of symptoms. Equally, they are unlikely to arrive at a stage in their disease from which they can comfortably contemplate their experience and share their insights with others, as Frank suggests. Of course, I would not want to deny that people with dementia learn from their experience, and especially that they have valuable first-hand knowledge to share with others. However, questions of form, genre and narrative coherence need to be thoroughly analysed when it comes to making claims about counter-narratives in dementia discourse. To this end, the present thesis explores the emerging genre of dementia life writing with a view to assessing its ability to provide insight into the disease and into embodied selfhood (ch.1), its capacity to act as viable identity narrative and as counter-narrative to social constructions of dementia as loss of self (ch.3), its status as an

underexplored genre that has much to teach us about the relational, political and ethical aspects of life writing more generally (ch.4), and its role as a source of knowledge for rethinking dementia care (ch.5). Chapters 2 and 6, by contrast explore the potential of fictional illness narratives: to provide insight into the phenomenology of dementia and the working of narrative empathy (ch.2), and as a tool for bioethical exploration of caregiving dilemmas (ch.6).

Fictional narratives likewise evoke the life world of the person affected and may potentially allow readers insight into the workings of that person's mind (Cohn 1978). They further raise the possibility of exploring the complex phenomenology of this disease beyond the stage where the person affected might still be able to communicate her experience verbally. The question is then whether such texts may in some way imaginatively explore and fill the epistemic 'gap' in our understanding of late stage dementia. Again, such possibilities raise ethical issues around the representation of vulnerable subjects, and, as suggested previously, dementia narratives may not necessarily challenge but rather enforce cultural stigma surrounding the disease.

2 Debates in Medical Humanities: Considering Narrative Empathy and Narrative Ethics

In her work towards developing a new ethics of dementia care, Verena Wetzstein (2005) suggests that the dehumanisation of people with dementia is fostered by the outside perspective we necessarily inhabit. According to Wetzstein, literature can further our insight into this disease and teach us to value the subjective perspective of the person with dementia (2005: 192). As I have argued elsewhere, fictional representations of dementia open up a new way of relating to the reality of this disease, by simulating insight into the mind of a person with dementia (Bitenc 2012).¹⁹ Wetzstein and I are not alone in claiming that literature, and the novel in particular, provides an

¹⁹ Similar claims about the potential of narrative to further our understanding of the phenomenology of dementia have been made with regard to film, both with a focus on non-mainstream cinematic idioms (Cohen-Shalev and Marcus 2012) and with a focus on embodiment and relationality (Käll 2015).

inroad into understanding the life world of others. ‘Third person fiction’ Rita Felski writes ‘allows the narrator an epistemological privilege that accrues neither to real life nor to the writing of history: unrestricted access to the inner life of other persons’ (2008: 89).²⁰ Further, she argues that the novel ‘unfolds a social phenomenology, a rendering of the qualities of a life-world, that is formally distinct from either non-fiction or theoretical argument’ (89). Similarly, Patricia Waugh speaks of narrative fiction as a ‘practical counterpart of theoretical phenomenology’ (2013: 24). Even scholars outside literary studies, among them philosopher Martha Nussbaum, make claims about the wide-ranging effects of the immersive potential of literature and its ability to render *qualia*, a sense of ‘what it’s like’ to be another human being. ‘The greatest contribution literature has to make to the life of the citizen’ Nussbaum writes, ‘is its ability to wrest from our frequently obtuse and blunted imagination an acknowledgment of those who are other than ourselves, both in concrete circumstances and even in thought and emotion’ (Nussbaum 1997: 111-112). Nussbaum goes so far as to suggest that the ability to empathise with others and meet them with respect is inextricably bound up with, even entirely dependent on acts of storytelling:

For the insides of people ... are not open to view. They must be wondered about. And the conclusion that this set of limbs in front of me has emotions and feelings and thoughts of the sort I attribute to myself will not be reached without the training of the imagination that storytelling promotes. (1997: 89)

While I do not doubt that storytelling plays an important role in shaping the moral imagination and in developing the capacity for intersubjectivity (see also Hutto 2007b), it is equally important to acknowledge the embodied nature of intersubjective experience (Ratcliffe 2007, Zahavi 2007). Different medial representations of dementia—across film, graphic narratives and print texts—might be able to draw on and exploit such embodied intersubjectivity, and not just the resources afforded by storytelling, to further an understanding of others to differing degrees. More importantly, the causal link that has been proposed between the reader’s experience of

²⁰ A key question for research in this area: To what extent does access to fictional minds translate or correspond to access to real-world minds.

narrative empathy and consequent ethical, moral or altruistic action, must be questioned—as Suzanne Keen stresses (Keen 2007). While the immersivity, promotion of perspective taking, and affective richness of novels raises the possibility that fiction may provide a special kind of insight into the phenomenology of dementia, it is important to determine what literature can and cannot do when it comes to enhancing the moral and empathetic capacities of readers. My thesis goes beyond questions of empathy to explore other ways in which narrative fiction may be relevant for dementia care: namely, by opening up, and *keeping open* (see Whitehead 2011: 59), important debates about specific dilemmas relating to the care of people with dementia.

Indeed, the role that literature, and particularly narrative literature, plays in our ethical or moral education has recently become a key topic in debates within the medical humanities (Woods 2011). Angela Woods’ critique of the limits of narrative does not necessarily entail that we disregard the role narrative plays in the medical humanities entirely. Instead, it highlights the need to consider other modes and genres of expression (such as poetry, art, music, craft etc.) as well as the need to closely analyse the form and function of different narratives.²¹ Consequently, the effects of different narrative modes, media and genres on representing the phenomenology of dementia constitute another important strand of my research.²² At the same time, I also acknowledge the need to explore other avenues of expression beyond narrative modes. If I do not address all of these expressive possibilities in relation to the current cultural construction of dementia, this is due to the (necessarily) limited scope of this thesis.

The question of narrative in the medical humanities must also be seen in the context of wider debates about the role of the humanities—its methods and resources—within this emerging field. The first wave of medical humanities research and teaching was primarily concerned with inserting the arts and literary texts into medical curricula in order to ‘humanise’ the

²¹ Whitehead (2014) similarly proposes an opening up towards other genres such as graphic pathography, art, music, and drama since ‘there are dimensions of illness that do not readily conform to conventional narrative modes’ and that remain ‘elusive to expression’ (115).

²² Although there are strong arguments for categorising plays as narratives (Richardson 2007), I do not consider drama in this thesis. The omission was necessary to allow for sufficient space to focus on questions surrounding narrative identity and caregiving.

practice of medicine. This approach has since been joined, and in some cases superseded, by what might be termed second-wave medical humanities. The ‘critical medical humanities’ are coming to the forefront,²³ while, at the same time, the limitations inherent in the disciplinary label ‘medical’ are being challenged. The *health* humanities aim to incorporate a wide set of research questions and practices which include but also go beyond medical settings (Crawford et al. 2010).²⁴ Both within medical humanities contexts that remain concerned with improving the *practice of medicine*—through medical training and by making social science and humanities research relevant to medical contexts—as well as in research that addresses societal concerns around health more generally, debates continue to be waged over the exact role the ‘humanities’²⁵ are to play in these contexts.

On the one hand, teachers, researchers and practitioners working in this area are under pressure to make their work quantifiable according to the standards of evaluation developed in the natural sciences in order for their work to count in medical practice and policy making—in which case they may be criticised for ‘selling out’ their disciplinary aims. From this perspective, doing ‘medical’ humanities research is seen as a strategic means to meet the requirements of Research Excellence Frameworks, in the UK, and thereby survive the economic pressure generated by a global neoliberalist economy (see also Spiegel 2012: 206). On the other hand, medical humanities scholars are sometimes accused of ‘relying on dated notions of humanism’ (Spiegel 2012: 206), in that they may be seen to suggest that exposure to the arts and humanities—and especially narrative—creates more humane, attentive and empathetic health care professionals (Charon 2006, Greenhalgh and Hurwitz 1999).

Additionally, Therese Jones points to the tension between the ‘instrumental justifications for the humanities in medicine’ and the

²³ See, for instance, a special issue in the *British Journal of Medical Humanities* (Viney, Callard, and Woods 2015) and *The Edinburgh Companion to the Critical Medical Humanities* (Whitehead and Woods 2016).

²⁴ See also <http://www.healthhumanities.org/>. Last accessed 26/05/2016.

²⁵ Note that this disciplinary label is also misleading in that the medical humanities include and are even driven by social science disciplines such as (medical) anthropology, psychology and sociology.

‘democratizing energies and dangerous possibilities’ of the humanities viewed as an intellectual practice (2014: 27). Humanities research methods, according to Jones, ‘enable and promote fearless questioning of representations, challenges to the abuses of authority and a steadfast refusal to accept as the limits of enquiry the boundaries that medicine sets between biology and culture’ (Jones 2014: 27-28). Jones’ optimistic evaluation of the almost ‘revolutionary’ potential of the humanities might, however, be challenged in turn. If, as Maura Spiegel suggests, proponents of medical humanities have been accused of ‘retrograde rhetoric regarding the “humanizing humanities”’ (2012: 205), they may also be criticised for assuming a merely oppositional stance to biomedicine—providing an endless ‘critique’ without being able to go beyond that critique. Overall, my thesis focuses on the subversive and empathetic potential of literature but also on the positive contributions critical literary scholarship may be able to make in the context of rethinking current dementia care.

3 Narrative (and) Selfhood

As Amelia DeFalco (2010) has recently remarked, the notion that identity is narratively constituted has become a theoretical truism. A whole range of scholars have probed the extent to which life is narrative and selfhood is constituted through narrative (see Bruner 1991, 2003, 2004, Dennett 1993, Eakin 1999, 2008, Ricœur 1991b, a, White 1984). However, such views have not gone unchallenged (see, for instance, Sartwell 2000, Strawson 2004). In ‘Against Narrativity,’ Galen Strawson (2004) argues, first, against the ‘widespread agreement that human beings typically see or live or experience their lives as a narrative or story of some sort, or at least as a collection of stories’ (428). He calls this the ‘*psychological Narrativity thesis*’ (428; original emphasis). Second, and as it turns out more importantly, he challenges the ‘*ethical Narrativity thesis*’—a normative thesis which holds that ‘experiencing or conceiving one’s life as a narrative is a good thing; a richly Narrative outlook is essential to a well-lived life’ and crucial ‘to true and full personhood’ (428). According to Strawson, the ethical and psychological Narrativity thesis combined ‘hinder human self-

understanding, close down important avenues of thought, impoverish our grasp of ethical possibilities, needlessly and wrongly distress those who do not fit their model, and are potentially destructive in psychotherapeutic contexts' (429). Most importantly he highlights how according to strong narrativist views of identity, such as Marya Schechtman's (1996), he—and with him many others—risk not being considered as persons at all (447).

Without going into all the particulars of this debate, the narrative identity hypothesis is clearly relevant to discourse about people with dementia. I have already highlighted how notions of selfhood become a contested terrain in discourse about dementia. People with dementia will eventually struggle to tell a coherent life story and may risk no longer being considered persons on that ground. At the same time, as discussed in my earlier remarks about reparative moves in dementia studies, the concept of narrative identity has also been employed to draw attention to how people with dementia continue to claim identities for themselves, or how caregivers and others who interact with the person with dementia may contribute to the social construction of identity—perhaps by telling that person's story for them. As Lucy Burke notes, in the personhood movement models of narrative identity have been used in two ways:

First, they have been evoked as descriptive frameworks for the conceptualisation of the relationship between brain, mind, and person and thus for the formation of personal identity in an intersubjective milieu. Second, they have been used in a prescriptive sense as the basis for an ethical argument about good dementia care that points to the importance of the social environment and nexus of relationships in which people live. (Burke 2014: 34-5)

As the latter approach highlights, narrative identity also becomes relevant when considering the extent to which identities are constituted and held in relationships. Relational identity, especially as it has been thematised in life writing studies (Eakin 1998, Friedman 1988, Mason 1980, Miller 1994), plays an important role in understanding how identity, both of the person with dementia and of family caregivers, is constructed and reconstructed in familial life writing about the disease.

The present study explores implications of narrativist accounts of selfhood for people with dementia. I outline both the strengths and limits of the narrative account when it comes to capturing the processes by which

identity is expressed or constituted in the context of dementia. In this way, I adopt a position within the debate that can be characterised as a ‘moderate’ or ‘qualified’ narrativist approach. Narrative is a crucial vehicle for performing and communicating identity. Nonetheless certain aspects of selfhood—understood in phenomenological terms as a persistent point of view and an engaged creation of a life world—are better understood through the lens of embodiment and embodied experience. Narrative can be a means of communicating this changing sense of being-in-the-world—as in the case of narratives told by people with dementia—but it is not constitutive of selfhood as such. The ontological question of whether selfhood persists in dementia cannot easily be answered, and certainly not in this thesis. I therefore propose, with Stephan Millett (2011), that we bracket or even disregard the question of whether selfhood is ‘lost’ and instead concentrate on understanding the *experience* of dementia.

4 Narrative as Tool for Meaning-Making

My fourth claim concerning why we need to consider narrative in the study of contemporary dementia discourses links back to my earlier comments on the bio-cultural construction of dementia. Narrative constitutes a sense-making device. It allows us to learn about how the world, including other people in that world, function (Hutto 2007a, b). Narrative therefore shapes the way we think about things. David Herman writes, ‘a focus on narrative as a means for sense making emphasizes how stories do not merely evoke worlds but also intervene in a field of discourse, a range of representational strategies, a constellation of ways of seeing’ (2013: 13). They also shape what it means to be a person, or to be human. Herman shows how ‘engagements with characters in narratives not only depend on but also have the power to remold wider understandings of persons circulating in a given culture or subculture’ (18; 193-224). Furthermore, he makes a strong case to situate an approach to the study of the nexus of narrative and mind at the level of persons and person-environment interactions (ix). Herman defines the person level as ‘the level of the medium-sized, human-scale world of

everyday experience' (x). He argues that whereas some cognitive narratologists have pursued

a reductionist program of research based on the assumption that the concept of person, and person-level phenomena, must yield to some more fundamental level of explanation, such as neuronal activity, information-processing mechanisms, or other causal factors operating at a subpersonal level, ... it is at the personal rather than subpersonal level that narrative scholars are optimally positioned to contribute to—and not just borrow from—frameworks for understanding the mind. (Herman 2013: ix-x)

While Herman is concerned with a wider programme for illuminating how narrative and the mind interact, attending to the person level, or what might also be described as the semiotic level, in studies of dementia gains support from other scholars. Sabat and Harré, for example, argue that people with dementia continue to be 'semiotic subjects,' 'that is, persons for whom meaning is the driving force behind their behavior' (1994: 145). They contend that

although it is possible to explain behaviour on a chemical or neural level, or by reference to neural dysfunction, considerations on the level of meaning provide ... the best—indeed, the only scientifically respectable—explanation of action. (Sabat and Harré 1994: 147)

In line with such reasoning, I suggest that to understand person-level experiences, it only occasionally makes sense to pursue an understanding at the subpersonal level. In addressing the challenges posed by dementia, the research on neurological disease processes has its place—although in view of the ever receding hope of finding a cure there is an urgent need to also pursue other avenues for treatment and management of the disease. The predominant focus (both of economic resources and research efforts) on biomedical/neurological approaches to dementia occludes other possibilities of engaging with the disease, and significantly the person living with dementia. In dealing with persons and their life worlds, narratives provide a privileged site for addressing the complex effects of dementia on the person. Narratives deal primarily in the medium-sized, human-scale world of everyday experience. In evoking a rich experiential account, similarly to the argument put forth by Havi Carel for phenomenology, narratives may counter and complement biomedical understandings of dementia as a pathology of cognition.

There is considerable overlap between these arguments for *narrative* and the reasons I have provided so far for why considering dementia in and through literature represents an important area of research. Literature shapes the way we think. It not only acts as a ‘mirror’ of current trends and master plots, but also shapes and brings into being social realities.²⁶ There is an urgent need to reconsider the ways dementia is represented in contemporary literature in order to reveal broader cultural attitudes about dementia, and consequently strategies for interacting with the people living with dementia. In what way do dementia narratives reinforce current (mis)conceptions about dementia? If ‘engagements with characters in narratives have the power to remold wider understandings of persons’ (Herman 2013: 18), what do these texts suggest about personhood and selfhood in dementia? Can they act as counter-narratives to dehumanising tropes of Alzheimer’s? And how does public discourse influence public policy, particularly in such crucial areas as the ‘Alzheimerization’ of the euthanasia debate (Johnstone 2011, 2013)?

Since illness is both embodied and socially constructed (Couser 1997, Hacking 1999a, Morris 1998), we must, as Morris argues, explore the ‘complex relations between biology and culture if we hope to understand the contemporary experience of illness and ultimately ... ourselves (Morris 1998: 3). Acknowledging the role culture plays in the experience of illness, as Morris further argues, ‘unavoidably invokes questions and texts lying far outside the ordinary range of medical knowledge’ such as ‘novels, television programs, films, advertising, ...and obscenity laws’ (1998: 43). If this study is limited in its scope in terms of exploring some of these text-types, I nevertheless use a wide range of literary genres and narrative media to suggest how storytelling practices of many sorts help shape what dementia means in contemporary culture and what it may mean in the future.

²⁶ There are risks but also opportunities inherent in this interaction between literature and culture. As a cognitive tool of knowledge transmission, narratives (particularly novels and films) may reach wider audiences than medical or care journals and may thereby contribute to a better awareness of the disease phenomenon. The pedagogical, discursive, and dialogic potential of literary narratives to engage different viewpoints and ‘stage a debate’ offer up possibilities of a more holistic view of the disease syndrome than in more monologic discourses such as scientific reports or newspaper articles. Further, narratives may function as case studies vis-à-vis moral and ethical dilemmas that arise in dementia care.

Outline of Chapters

The chief aim of the present study is to delineate the potential and limitations of narrative, and narrative studies, when it comes to challenging the current dementia construct and developing new ways of understanding, interacting with and caring for people with dementia. I thus move from two opening chapters in part I concerned with exploring the phenomenology of dementia and the relationship between representation and narrative empathy, to two chapters focusing on the aesthetic, ethical and political implications of the emerging genre(s) of dementia life writing in part II, to a final pair of chapters in part III engaging with how fictional and non-fictional narratives may inform the development of dementia care and thereby contribute to on-going debates about the role of narrative in the medical humanities.

Chapter 1 explores how life writing by people with dementia and by their caregivers might contribute to a better understanding of how dementia transforms self-experience as well as one's relationships to the physical and sociocultural world (Carel 2008). To develop this question, I draw, first, on a range of autopathographies by people with dementia. Second, and as a point of contrast, I explore issues of intersubjective understanding in David Sieveking's documentary film *Vergiss Mein Nicht* (2012). On the one hand, I argue that attending to the embodied nature of selfhood can redress the simplistic or reductive notion that the self is 'lost' in dementia. On the other hand, I explore how different storytelling media (especially documentary film and photography) foreground important aspects of embodied selfhood (see Kontos 2003, 2004, 2005) and provide means of exploring the potential of embodied communication in dementia.

Chapter 2 addresses two questions: First, to what extent do fictional narratives (in particular the novel and film) act as a 'practical counterpart of theoretical phenomenology' (Waugh 2013: 24)—or, to put the question another way, how (using what techniques) may they be able to simulate 'what it's like' to be living with dementia? Second, does simulating the experience of dementia lead to an empathetic engagement with the dementing protagonist, and if so, in what way might narrative empathy lead to pro-social action towards real people with dementia? By exploring these

questions across a range of case studies (Lisa Genova's novel *Still Alice* and its film adaptation, J. Bernlef's *Out of Mind*, B.S. Johnson's *House Mother Normal*, and Kazuo Ishiguro's *The Unconsoled*) I aim to suggest how these fictional dementia narratives may contribute to the current theory of narrative empathy while also highlighting the importance of questioning the empathy-altruism hypothesis (Keen 2007), which is commonly invoked in first-wave medical humanities contexts as a reason for incorporating the arts into medical training.

Part II turns to questions of self-presentation and representation in the emerging genre(s) of dementia life writing. Chapter 3 addresses the possibilities and limitations of the notion of narrative identity and narrative coherence in the context of neurodegenerative diseases such as Alzheimer's. I ask to what extent dementia life narratives, like other illness narratives, may function as counter-narratives (Bamberg and Andrews 2004) to the dominant cultural construction of dementia as 'loss of self' and 'death before death' and how genre conventions affect the construction of counter-narratives. To explore these questions I consider two types of case studies: first, autopathographies by people with early-onset Alzheimer's and, second, collaborative life history projects in nursing homes, in particular the collection *Tell Mrs Mill Her Husband Is Still Dead* (Clegg 2010).

Chapter 4 shifts the focus to the genre of caregivers' memoirs. My intention is to highlight the particular political force of as well as the ethical issues raised by dementia life writing—in particular the problem of representing 'vulnerable subjects' (Couser 2004). I then move on to a close analysis of select examples of filial caregivers' memoirs to address the impact of gender, genre and medium on current understandings of relational identity: Jonathan Franzen's autobiographical essay 'My Father's Brain' (2002), Judith Levine's memoir *Do You Remember Me?* (2004) and Sarah Leavitt's graphic memoir *Tangles* (2010).

Part III centres on questions that arise in relation to dementia care. Chapter 5 argues that 'care-writing' may be considered a valuable source of evidence when it comes to theorising and developing dementia care. Caregivers' memoirs explore the dilemmas involved in caring for someone with progressive cognitive impairment. They thereby provide a means for

readers to ‘live through’ (Rosenblatt 1995/1938)—and think through—these difficult issues. The authors of these memoirs imagine and develop alternative treatment and care options which could be adapted to other contexts. Indeed, because they have lived alongside the person with dementia, familial caregivers are ideally placed to identify that person’s evolving needs and to advocate for them when those needs are no longer met—whether in the community or in institutional care. These authors are thus well-positioned to articulate strategies for addressing the needs of people with dementia, and of their caregivers, holistically (see also Greenhalgh and Hurwitz 1999).

Lastly, chapter 6 aims to develop new avenues for thinking about how literary fiction may intervene in medical humanities contexts while problematizing some commonly accepted notions about the link between literature and the provision of empathetic care. First, given the dominant view of the field as driven by an ‘ethical imperative’ (Rees 2010; qtd. in, Jones 2014), I ask whether fictional dementia narratives themselves are necessarily tools for ‘the good,’ or whether they may instead compound the stigma attached to dementia. That is, I investigate to what extent particular fictional dementia narratives live up to, or fail to live up to, the ethico-political standard that the term ‘counter-narrative’ suggests, using Michael Ignatieff’s *Scar Tissue* (1993) and B.S. Johnsons’ *House Mother Normal* (2013/1971) as case studies. Second, I suggest some ways in which dementia novels may engage their readers in considering bioethical questions that arise in contemporary Western care culture(s). To explore how different media and means of narrative presentation affect the process of bioethical decision-making, I discuss the film and book version of *Still Alice* as well as Margaret Forster’s novel *Have the Men Had Enough?* (1989). I contend that these narratives offer special insights into the bioethical dilemmas attendant on dementia care, developing care-oriented thought experiments more fully than would be possible in non-fictional accounts of dementia.

Part I Storytelling and the Phenomenology of Dementia

Chapter 1 Narrating Experiences of Dementia: Embodied Selves, Embodied Communication

In illness our bodies change. Biomedicine attempts to reverse, halt or alleviate the effects of bodily dysfunction. In pursuing this aim, biomedicine treats the body like an object to be fixed, rather than the locus of subjective experience. Accordingly, it has been criticised for paying too little attention to the *person* with disease and the way the identity and life world of the person are changed through the experience of illness (Carel 2008, Frank 1995, Kleinman 1988). Using contemporary phenomenology, Havi Carel (2008) describes how bodily changes in illness radically transform our experience of ourselves as well as our relationships to the physical and sociocultural world. Paying attention to the multiple ways illness transforms subjective experience will not only provide a fuller understanding of a given illness, she argues, but will allow us to develop interventions that go beyond treating the physical body alone (Carel 2008: 73). I argue that life writing facilitates a phenomenological²⁷ approach to illness. These texts provide rich accounts of particular people in a specific context and can therefore contribute to a better understanding of how subjective experience changes in illness. In a second step such knowledge may be used to adapt and develop therapeutic and social interventions.

In this chapter, I explore the phenomenology of dementia through life writing by people with dementia and by their caregivers. I focus on embodied aspects of the disease as they are communicated by a range of narrative media, arguing that these embodied aspects shed a more nuanced light on what is lost, what changes, and what remains. To ground my discussion, I review how phenomenology, and particularly the notion of ‘embodied selfhood’ (Kontos 2005) and ‘embodied’ (or non-verbal) communication (Killick and Allan 2001) have been productively employed

²⁷ The term ‘phenomenology’ is frequently used to describe first-person accounts of ‘what it is like’ to have a certain experience. This usage differs from the technical usage which describes a philosophical discipline that aims to discover the underlying structures that make it possible for *anyone* to experience the world (Gallagher and Zahavi 2008: 10; 20; 26). I use phenomenology both in the non-technical sense, when referring to the description of *qualia* or ‘what it is like’ (Nagel 1974), and in the narrower, philosophical sense, when focusing on structures of experience that are relevant to understanding dementia but that may be masked by approaches that rely on dualistic views of mind-body and self-world.

in dementia studies. I then turn to a close reading of contemporary autopathographies by people with dementia, and conclude the chapter by exploring the potential for intersubjective understanding in David Sieveking's documentary *Vergiss Mein Nicht* (Forget-Me-Not) (2012).²⁸

There are two different aspects to the relationship between embodiment and selfhood that I address. On the one hand, different modal and medial representations of dementia point to changes in embodied (self-)experience in this disease. Relevant changes to self-experience include shifts in consciousness, emotions and cognition as well as body control. Yet these changes to self-experience also extend beyond the boundaries of the body. So for instance, due to both the symptoms themselves and the stigma attached to the disease, relationships also undergo significant changes. The pernicious effect of illness on social interaction, in turn, has serious repercussions on the ill person's sense of self.

On the other hand, attending to the embodied nature of selfhood can redress the simplified notion that the self is 'lost' in dementia. Equating selfhood with high-level cognitive functioning or narrative identity can obscure a) the extent to which memories are embodied (consider, for instance, procedural as opposed to episodic memory) and may thus be 'enacted' even when verbal communication has disintegrated, and b) the extent to which selfhood can be understood as an embodied *perspective* that remains in dementia. This 'first-personal givenness of experience' (Zahavi 2007) may, furthermore, be communicated by drawing on nonverbal 'embodied' forms of communication. A key question is therefore how aspects of 'embodied selfhood' (see Kontos 2003, 2004, 2005) and 'embodied communication' feature in various storytelling environments, including documentary film. Recognising embodied selfhood in dementia has important implications for dementia care, I argue, as it might lead to a more sensitive understanding of what is actually lost in the disease while allowing us to recognise and value the person who remains.

²⁸ For further documentaries on dementia that differ significantly in style see *Complaints of A Dutiful Daughter* (Hoffmann 1994), *First Cousin Once Removed* (Berliner 2012) and *Glen Campbell: I'll Be Me* (Albert and Keach 2014).

Embodied Selves, Embodied Communication

In dementia studies, embodiment has been used to argue both for and against the notion that selfhood is lost (see Davis 2004 and Kontos 2003, 2004, 2005 respectively),²⁹ and also as a means to circumvent the equivocal question of selfhood in dementia altogether (Millett 2011). In this section, I do not intend to arbitrate between these opposing views and provide a definitive answer to what selfhood (or embodied selfhood) *is* or how it is constituted, nor to discriminate among terms such as self, identity, personhood—and also subjectivity (see Millett 2011: 511).³⁰ Instead, I investigate how the notion of embodiment—and relatedly, embodied selfhood and embodied communication—can be productively used to engage with the subjective experience of dementia and, potentially, ground the moral standing of people with dementia not on a cognitive model of personhood, but on our embodied nature as human beings.

The neurodegenerative nature of dementia impacts on memory, language, thinking and reasoning, all of which are traditionally seen to define our personhood. However, less cognitively orientated parameters of personhood, such as emotion³¹ and relationality,³² are also impacted by dementia. Applying the notion of embodiment in dementia allows us to ask a number of questions: What do the changes on a neurological level entail for people with dementia and their experience of their own cognition, as well as their experience of self-efficacy in physical and social environments? How do these changes speak to and elucidate the common understanding

²⁹ Davis (2004) emphasises loss of self to legitimate family caregivers' grief.

³⁰ These terms represent different points on what could be considered a continuum of 'selfhood,' one stretching between a (social) identity and (perspectival) self. In the present thesis, however, I make no hard and fast distinctions among the terms at issue.

³¹ Recent neuroscientific studies reveal the extent to which emotions are a function of the brain and therefore equally prone to be affected by brain damage or disease (Damasio 1994, 2000, 2010).

³² I understand this term to refer to the fact that humans are relational beings—constituted by their relations but also endowed with the capacity for relationships. This notion has gained currency in a range of disciplines and under a number of different guises. Relational models of identity have also figured importantly in life writing studies (Eakin 1998, Friedman 1988, Henry 2006, Mason 1980, Miller 1994, Peaches 2006, Smith and Watson 2010).

that the person with dementia is in some sense ‘losing herself’? And can embodiment perhaps provide a means of sustaining selfhood in dementia?

Pia C. Kontos draws on Maurice Merleau-Ponty’s concept of embodied consciousness as well as Pierre Bourdieu’s concept of *habitus* to argue that the pre-reflective body is fundamental to the persistence of selfhood in dementia (Kontos 2003, 2004, 2005). Her notion of ‘embodied selfhood’ captures the idea that ‘fundamental aspects of selfhood are manifested in the way the body moves and behaves’ (2005: 556). Kontos’s ethnographic study in a Jewish care home provides numerous rich examples to counter the dominant cultural conception that people with dementia experience a ‘steady erosion of selfhood’ (2005: 553). Kontos makes a substantial contribution to dementia studies by bringing to light the continued coherence, purpose, and meaning with which people with dementia engage with the world (2004: 836). The strength of her analysis lies in attending to aspects of behaviour that are pre-reflective, or at least not overly reliant on higher-order cognition, as well as highlighting a multitude of nonverbal elements of communication, such as eye movement, eye contact, gesture, facial expressions and posture. Yet Kontos fails to acknowledge the fact that the brain is part of the body. She argues against cognitivist definitions of selfhood, but in the meantime fails to pay due attention to how aspects of bodily behaviour are essentially orchestrated by the brain and therefore also have a neurological substrate (even if some aspects rely on older brain structures and less on the neo-cortex). As such, the aspects of embodied selfhood she describes are equally at risk of being affected by dementia, and therefore of being eroded—again making people with more advanced dementia open to the risk of being construed as non-selves.

Stephan Millett’s (2011) proposal to ground an understanding of dementia in bio-phenomenology offers an illuminating alternative to Kontos’s account. Millett proposes to leave aside the question of selfhood or personhood in dementia and instead focus on the experience of living with the disease, the continuity over time of an embodied individual, and our attitude toward that individual (Millett 2011: 515). The ‘bracketing’ of the question of personhood, Millett suggests, allows us to ‘focus on the idea that there is a being with an inner life confronting us, a being with value simply

because he or she has a ‘life-world’—a constructed meaningful world revealed to him or her through their senses’ (515). Drawing on Jakob von Uexküll’s biologically grounded phenomenology, Millett emphasises the role of the lived body through which each of us creates a meaningful world (510). This view allows us to recognise that

there is a life-world – or directly experienced world – for people with dementia, who continue to experience the world and create meaning, even in the presence of severe cognitive degradation. It is clear that people with dementia have an *affective* response to certain stimuli: they laugh, cry, express frustration and disappointment, engage playfully with others, and so on. Affective or emotional responses – signs of happiness, sadness, frustration, anger and the like – are indicators of an interior life the extent of which may not be determinable using cognitive criteria alone. From the affective responses we can infer that people with even late-stage dementia still react to, engage with, and co-create a life-world. (510)

Millett harnesses the concepts of von Uexküll’s ethological studies—*Innenwelt*, *Umwelt*, semiotic, ecological and ontological niche value—to his argument that people with dementia continue to create a meaningful world and continue to be of value to others (517). His analysis widens the scope of subjectivity and meaningful interaction with the world beyond the examples of bodily intentionality provided by Kontos, to include ‘bodily reactions of all sorts, to inputs from a range of external sources such as reactions to heat and cold, to smells, sounds and sights’ (517). Millett’s approach thereby suggests that there is a continuing inner world even in the most advanced stages of dementia. This is a rare example of research that disallows positing some kind of ‘cut-off’ point in the progression of dementia, at which stage the person no longer has an inner world and may therefore be considered valueless. Many reparative moves within dementia studies often, inadvertently, serve to enforce stigmatising and dehumanising accounts of the later stages of the disease, while ‘recuperating’ people with less severe symptoms into the sphere of the fully human. By contrast, as Millett states, ‘by employing the concept of bio-semiosis we can acknowledge, with Sabat ... that people with dementia are semiotic subjects—that is, they are ‘driven by meaning’—but without committing to cognition-reliant definitions of selfhood and intentionality’ (2011: 520).

However, despite Millett’s assertions, it is difficult to see how the very basic sense of meaning-making (what he terms semiotic niche value)—such

as reacting to hot or cold—differs from his example of a tick that reacts to warmth and butyric acid (516). Clearly, the moral standing of people with dementia is more closely related to what he terms ecological niche value—‘which is a statement of their value to other organisms’, that is, ‘their social interactions with other humans’—as well as to ontological niche value—‘that is, the [pre-existing] capacity or potential of an organism to interact with its environment’ (517). ‘People with dementia – even severe dementia,’ Millett writes ‘continue to have the capacity to interact with their environment and, simply because they have a body and the capacity to interact, they clearly occupy an ontological niche’ (517). By highlighting ecological and ontological niche value, Millett moves closer to a social constructivist position that focuses on the importance of social interaction and relationships in maintaining the dignity of people with dementia. Furthermore, Millett turns to philosophers such as Aristotle, Jonas, and Levinas in order to argue that ‘each living thing has a unique non-instrumental value-for-itself’ and ‘each human being announces an ought-to-care to the world that places each of us under an obligation to help that being’ (519)—an argument that does not follow from bio-semiosis alone.

Importantly, Millett’s account acknowledges the effects that dementia has, especially on cognition, while productively circumventing the problem of making value-judgments based on aspects of cognition or on the notion of personhood. At the same time, he engages with Davis’s suggestion that ‘Kitwood’s view that it is possible to maintain personhood at the extremes of this condition’ is ‘damaging to those relatives forced to take on the role of primary carer’ (Davis 2004: 369). Millett emphasises that ‘if we take the view that people with dementia maintain a self we may place an unnecessarily high burden on the untrained family carers who do most of the work of care,’ thereby denying them ‘a proper mourning for the loss of their loved one as the dementia progresses,’ inducing ‘guilt or shame at their changed feelings toward the obviously changing “person”,’ and making them ‘complicit in defining those they care for as disabled and as having a progressive deficit’ (Millett 2011: 509-10). Millett’s account indicates how attitudes about people with dementia can shift towards a more sympathetic understanding without having to rely on notions of selfhood. Nonetheless, in

the following discussion I retain the notion of embodied selfhood as a shorthand expression both for embodied aspects of identity and for the way each human being experiences the world—what phenomenologists refer to as the first-personal perspectival givenness of experiential life (Gallagher and Zahavi 2008, Zahavi 2007), which can be claimed to persist in dementia.

Attending to the body in dementia, also opens up the possibility of finding avenues for communication that do not rely heavily on coherent verbalisation. Speaking of ‘embodied communication’ as opposite to ‘verbal’ communication is of course misleading, since verbal communication is very much embodied. However, I use this term to draw attention to other ways that bodies and behaviour may speak. As Lisa Snyder highlights in her collection of interviews with people with dementia (Snyder 1999), because of the way the disease affects cognition, many individuals may not be able to maintain the same insight and verbal abilities as previously. ‘But throughout the course of Alzheimer,’ she writes, ‘each person continues to convey messages through action, gesture, expression and behavior. The disease does not result in a complete inability to communicate. But it can require our time, energy, receptivity, and ingenuity to observe, listen, and comprehend effectively’ (1999: 32-3). I agree with Snyder that the ability to communicate persists, although some forms of life writing may not be able to adequately capture this capacity for communication. Documentary film (and perhaps also graphic memoir, as I discuss in later chapters) offers a mediated opportunity to engage with these ‘embodied’ forms of communication and to train one’s receptivity to channels of communication outside language (see also Killick and Allan 2001).

Inside Views: Life Writing by People with Early-Onset Alzheimer’s

This is my attempt to leave a record of what is going on between my ears.
(Taylor 2007: 3)

Severe illness threatens the production of a life narrative (Couser 1997: 5). In dementia, in particular, all aspects of autobiography seem to be threatened: the *auto*/self in that it is seemingly eroded, the *bios*/life in that

memory loss threatens the ability to remember and coherently narrate life events, and finally the *graphein*/writing is threatened by the erosion of higher order cognitive functions (see Olney 1980). Despite these problems, a number of published dementia autobiographies or autopathographies exist, mainly written by people with early-onset Alzheimer's disease.³³ These accounts have taken the form of articles in Alzheimer's care journals—such as Marilyn Truscott's articles of testimony and advice (Truscott 2003, 2004a, b)—and also of book-length memoirs³⁴ as well as, more recently, blogs.³⁵ Many of the authors also appeared on radio programmes, TV shows, spoke at conferences or participated in documentaries about their experience as part of their fight to raise awareness of this disease and alleviate the stigma attached to dementia. As such, these autobiographical acts have played a crucial role in patient advocacy in the Alzheimer's movement.

In what follows, I draw on a range of autobiographical texts by people with dementia to explore what these texts suggest about the changing nature of embodied self-experience. Engaging with these texts elucidates the range of changes across cognitive, bodily and social spheres of experience, suggesting in turn common structures of experience that can be found across individual experiences of living with dementia. However, this is not to suggest that there is only one type of 'dementia experience.' On the contrary, these autobiographical accounts highlight the extent to which the experience of the disease and the progression of symptoms vary significantly from one individual to the next.

³³ Some of the authors were diagnosed with a combination of Alzheimer's disease, multi-infarct dementia or fronto-temporal dementia. What unites these authors is that the disease manifested itself relatively early in life (before the age of 65).

³⁴ These include, among others, Bryden (1998, 2005), Davis (1989), DeBaggio (2002, 2003), Henderson (1998), Lee (2003), McGowin (1994), Rose (1996, 2003), and Taylor (2007).

³⁵ The number of dementia blogs is too vast to list. Morris Friedell's blog had a significant impact on patient advocacy in the 90s and early 2000s and can still be found at <http://morrisfriedell.com/struggle1.html>. Similarly, Taylor's collection of essays was first published as blog at <http://www.richardtaylorphd.com/blog.html>. An example of a current (23.03.2015) blog by a person with Lewy-body dementia can be found at <http://parkblog-silverfox.blogspot.co.uk/>.

Memory

Memory loss is frequently perceived to be *the* defining characteristic of dementia, especially of the Alzheimer's type. However, memory is not just one thing—a single faculty of the mind—but a variety of processes (Gallagher and Zahavi 2008: 70). Arguably, memory shapes everything the mind does (Fernyhough 2012: 5). Psychological accounts of memory generally distinguish between episodic memory, working memory, procedural and semantic memory (Gallagher and Zahavi 2008: 71). Of course, these categorical distinctions are not necessarily clearly demarcated processes and different types of memory effectively need to work together when an individual interacts with her environment. However, the distinctions can illuminate the different ways dementia affects memory.

Semantic and episodic memory losses are usually the first to become apparent in the disease progression—often manifesting in difficulties with remembering recent events or word-finding difficulties. Later, it can become increasingly taxing to accomplish 'activities of daily living,' such as dressing or cooking, that rely more heavily on procedural memory. Therefore, an understanding of dementia as 'merely' the loss of semantic memory underestimates the profound changes that the disease effects. Christine Bryden succinctly describes this more existential shift in being-in-the-world in her memoir *Dancing with Dementia* (2005):

You see, it is far more than simply memory loss. We are confused, we have problems with our sight, with our balance, with numbers and with direction. ... We have no sense of time passing, so we live in the present reality, with no past and no future. We put all our energy into the *now*, not then, or later. Sometimes this causes a lot of anxiety because we worry about the past or the future because we cannot 'feel' that it exists. (Bryden 2005: 99)

The challenges of living with progressively impaired memory are at the focus of autobiographical accounts of dementia. While these challenges relate to all kinds of everyday activities, one aspect that is thematised in all accounts is the impact that memory loss poses to *communicating* one's experience—both generally and in life writing specifically. In producing his autobiographical journal *Partial View: An Alzheimer's Journal* (1998), Cary Henderson used a tape-recorder to impart his thoughts about what it is like

to be living with Alzheimer's. The use of the tape-recorder is instrumental in his project of contributing to an 'understanding from the patient's point of view' (4) as it provides a 'memory device ... to keep your ideas long enough so somebody else can hear them' (7). At the same time, Henderson's difficulty in learning to handle the tape recorder highlights the extent to which dementia impedes the acquisition of new skills: 'I still haven't mastered this, apparently very simple thing of—uh—pushing down the two sides to get the machine to work. Pushing down two buttons ought to be the easiest thing in the world' (7).

Henderson also describes the disorientating effects of the loss of short-term memory. In doing so he challenges common perceptions about what the behaviour of people with dementia *means*—that is, he suggests that it is meaningful rather than meaningless. As Karen Lyman (1989: 602) notes, one of the adverse effects of the biomedicalisation of dementia is that all behaviour is henceforth interpreted as symptom of the disease pathology, and thereby robbed of its meaning. In particular, Lyman criticises health professionals for misinterpreting 'wandering' as 'deviant' or 'problem' behavior needing to be restrained (1989: 600). Henderson describes what it feels like to forget what you are looking for in the very process of looking for it and how it feels important to keep looking: 'Once the idea is lost, everything is lost and I have nothing to do but to wander around trying to figure out what was it that was so important earlier' (24). While 'wandering' is often considered an aimless and meaningless activity, Henderson's account highlights how, quite to the contrary, it is an attempt to reconnect to the world and recover meaning: 'When I'm wandering around, I'm trying to touch base with—anything, actually' (24). Henderson's strategy highlights the extent to which memory and cognition can be understood as 'embodied, embedded cognition' (Haugeland, 2009, Rowlands 1999, Wheeler, 2005; qtd. in Ratcliffe 2007: 107)), or, in other words, as 'extended' (Clark and Chalmers 1998) beyond the physical mind or brain to include the social and physical environment.

Partial View also highlights the unsettling effects of the loss of procedural memory. Henderson describes his problems with simple,

everyday activities that, coupled with a lost sense of time, lead to a pronounced state of anxiety over the welfare of his dog:

This was a real, first-rate panic. I opened up the can with a—let's see, what did I use for that—uh, well, whatever came at the moment. I had to find some way to give the doggie some food. But this was one of those things you're—must get into if you're going to have a life with Alzheimer's. I'm too clumsy, because of the damned Alzheimer's, my feet and legs, oh well, my hands, to do their job, and the best I can is kind of wiggle them and try to get mad and other silly things. But after tearing up the can, and tearing up a can is a real experience, but maybe my wife, one of these hours, will be feeling better and she can really open the can. Right now, the doggie seems to be in fairly good shape—I am not sure I am. (31)

While this passage evokes the emotional impact of his deteriorating abilities, it also highlights the particular affordances of using a tape-recorder to produce his journal. Contrary to other memoirs, Henderson's narrative arguably 'enacts'³⁶ moments of memory loss. In most other memoirs smooth, coherent, and rhetorically powerful prose starkly clashes with the language difficulties that the authors describe. In fact, the subsequent editing and polishing of the writing usually eliminates the 'diseased' or 'disabled self' from the text itself (Burke 2007a). Symptoms are described retrospectively rather than enacted. This is not only the case for language difficulties but for confusion, hallucination, paranoia, and moments of forgetfulness. In using a tape-recorder coupled with very sensitive editing, Henderson's journal provides rare insights into his experience. His musings reflect word-finding difficulties, the loss of the author's train of thought as well as expressions of anger, anxiety and paranoia. The effect of this closeness between experience and expression is a heightened sense of awareness of 'what it is like' or, at least, what it *may* be like to be struggling with cognitive decline. The more polished accounts, by contrast, may at times make it difficult to imaginatively enter into the troubling experiences of the author as the reader is presented with such a reassuringly competent counterpart.

³⁶ The term 'enacts' is not strictly speaking correct since these are still instances of mimetic verbal representations. In using this term, I mean to highlight the immediacy of the account and the lack of retrospective summary in representing symptoms. Basting (2001) similarly uses the term 'performance' to call attention to this effect.

Language

Words slice through my mind so fast I cannot catch them and marry them to the eternity of the page. (DeBaggio 2002: 27)

The effects of dementia on language production and reception are extensive. Since language provides the primary tool to communicate with others, the impairment of language has serious repercussions within the social sphere. Henderson, for instance, describes the effects of word-finding difficulties and slowed cognition on his ability to take part in conversations: ‘I really can’t converse very well at all. So that’s very limiting. I can’t think of things to say before somebody’s already said it and they’ve superseded what I have to say. The words get tangled very easily and I get frustrated when I can’t think of a word’ (18). However, as Henderson points out, there is also a social dimension to why conversations with others are limited: when you have Alzheimer’s, he notes, ‘nobody really wants to talk to you any longer’ (18). Henderson points out that people with dementia often experience a kind of ‘social death’ (Lyman 1989: 601), as others no longer engage with them, address the caregiver or spouse rather than the person with dementia, and frequently shun interaction altogether (see also Aquilina and Hughes 2006, Kitwood 1997).

Henderson’s journal highlights the importance of slowed ‘interaction’ for people with dementia and the advantages of language production at the sufferer’s own pace. Writing or tape recording can be done as the thoughts occur and the person with dementia experiences a more cognitively alert moment. Furthermore, the process is less likely to be disturbed by time constraints, ‘nervous tension,’ or distractions that occur during face-to-face interaction (see DeBaggio 2002: 180, McGowin 1994, Ryan, Bannister, and Anas 2009: 145). DeBaggio describes the impact of Alzheimer’s on one’s expressive capacity as the experience of living in ‘two worlds:’

In one I am afflicted with Alzheimer’s, gasping as words slip through my lips with effort and suffering imprecision. This is the world in which I have to tell my companion I can’t remember the word to make the sentence. In the other, slower world where I write on paper or directly on the computer, vocabulary is more fluid and I often surprise myself when the perfect word finds its way into the sentence without effort. This has puzzled me from the first sentence I wrote for this book. It is only now eight months later, I

begin to see more clearly how necessary it is to slow the pace to achieve a former normality. (2002: 180)

Not only language production, but language reception become progressively impaired in dementia. As Henderson notes: 'Reading's almost impossible, for one thing—things don't stand still. Words don't stand still. It appears to me that it's wavering. I can't pin it down—the words—they can be over yonder and over yonder and I can't catch them' (Henderson 1998: 23). The link between perception and the ascription of meaning has broken down: 'I can see the words, I can pronounce the words, but they don't seem to mean a whole lot' (23). Henderson, however, has a clear awareness that he has problems understanding what people tell him: 'A lot of things that I don't understand, even after somebody tells me. If I could signal in some way and tell them, oh sure, I heard it, but the ramifications of whatever the heck it was that I heard, I kind of missed' (35). This lack of understanding frequently contributes to a sense of paranoia and a sense of being left out (81). Henderson's thoughts about language point to the fundamental difficulties of communication in general: 'But just keep in mind that everything you say or do is partial—you're probably never going to get a sentence, a nice clean sentence that says everything you want to say' (19).

The effects of dementia on verbal communication call for an exploration of the potential of nonverbal communication (Killick and Allan 2001). As a woman with dementia describes it, 'I'm observing myself and other people a little more closely. I've always been very sensitive to body language, emotions and attitudes. I can tell from how a person moves whether it was a good thing or bad thing that I said. I have to use my intuition a lot more than I used to in order to pick up on the meaning of what people are saying to me' (Snyder 1999: 122). As this quotation highlights, exploring the potential of nonverbal communication is not only relevant for the caregiver, as suggested earlier, but also for the person with dementia who may use nonverbal cues to interpret the meaning of an utterance and draw on nonverbal means to express herself.

I do believe Alzheimer's does include what your feet do and what your hands do, as well as what your brain does. (Henderson 1998: 8)

As will have become clear by now, 'memory' is instrumental in our engagements with the world, including those involving perception and recognition. *Agnosia*, the loss of the ability to recognise visual, auditory or other sensual stimuli due to problems in processing information, is among the symptoms of dementia. As 'Bea,' a woman suffering from dementia, explains: 'Sometimes what I'm looking for will be lying right in front of me and I won't see it. I don't always misplace things; they're right there, but I just don't recognize them' (Snyder 1999: 21). Often these losses go hand in hand with *apraxia*—that is, problems in planning the coordination of movements to accomplish a learned, purposeful task. Previously habitual and ordinary tasks turn into an ordeal, as Bea notes: 'One of the worst things I have to do is put on my pants in the morning. ... I sometimes will have to put them on and take them off half a dozen times or more. ... I think I know the way to do it and I put them on and it's wrong again' (Snyder 1999: 19). Examples of apraxia have already been discussed above as examples of the impact dementia has on procedural memory. Here I explore the far-reaching implications of these losses for sufferers' ability to engage with and make sense of the world.

A key aspect of engagement with the world is the co-ordination of bodily movements in relation to objects as well as broader spatial or geographical environments. In her phenomenological account of illness, Carel (2008) draws attention to the fact that illness changes the geographical landscape one inhabits. She provides the example of how using a wheelchair changes the experience and navigability of a space. As the epigraph by Henderson underlines, the possibilities of bodily movement are curtailed in dementia. Henderson's journal attempts to capture and communicate something of this experience. The words 'I used to be able to talk to people and walk *without wondering if the pavement is actually there*' (8; my emphasis) are accompanied by a heavily unfocused photo of Henderson's

feet walking across a dizzying space of gravel (see Fig. 1).



Fig. 1 *Evoking 'parallel experience' in the reader through photographic style in Henderson (1998: 9).*

The lack of focus and use of perspective seem aimed at creating the effect for the reader that the literary critic Leona Toker has termed 'parallel experience' (Toker 1993).³⁷ Nancy Andrews' photography does not merely accompany the text; nor does it objectify Henderson—although there are some instances of 'uncomfortable' representation. Rather, it provides a parallel, interpretative account of Henderson's words and life. So for instance, a bird's-eye-view shot from the top of a long, public staircase, with Henderson posed at the bottom, gripping the handrail, seemingly hesitant to ascend, communicates something of the emotional tone of Henderson's fear of stairs: 'I'm scared to death of climbing stairs ... I've got to hold on pretty tightly, then I'll go creaming meemies, the uncertainty of one's footage. ... You can't live at the bottom all the time, though' (11). Photography here is used to heighten the reader's awareness of how the subjective experience of space and motion change in dementia (see Fig. 2)

³⁷ Toker's use of the term focuses on placing the reader in a predicament that is cognitively similar to the character's. It is nonetheless pertinent for the way Andrew's photography captures for the reader something of the sensory experience of symptoms of dementia and the dizzying effect of losing control over one's footage.



Fig. 2 *Using photographic style to elicit imaginative engagement with the ways dementia changes the experience of space in Henderson (1998:10).*

Various autobiographical accounts draw attention to the fact that environments with too many stimuli—several people talking at once, background music, noisy restaurants—are impossible for a person with dementia to process (Bryden 1998: 67, Henderson 1998: 68). The difficulties presented by these environments are captured in Henderson’s journal by the photographer Nancy Andrews: during a family gathering Henderson sits at the table, eyes averted, hands clasped, seemingly withdrawn. He is surrounded by several people talking and children who are playing noisily on the floor (Henderson 1998: 68-9). While this outside perspective risks enforcing the stereotype of the person with dementia as withdrawn or an ‘empty shell,’ Henderson’s words lucidly describe the difficulty for people with dementia to process stimuli in such situations—underscoring that the person and mind are anything but ‘empty.’

Whenever there’s a gathering of people, it seems, at least in my mind, to be a lot of confusion. I just feel the need for quiet. ... if there’s not much going on ... I can think better. If there’s anybody else in the room, it seems like—more than just one person—I do sort of lose my grip. (Henderson 1998: 68)

These descriptions of changing bodily and perceptual relations to objects, spaces, sounds and movement underscore the changing sense of being-in-the-world and highlight the extent to which this can have a destabilising effect on one’s sense of self (see also Ratcliffe 2008). Bryden, for instance, when describing the overwhelming confusion of a night out with friends,

emphasises how her difficulties in processing disparate information impact directly on her sense of self: ‘I felt *I was fading*, the sounds were getting distant, faces were difficult to focus on, and I found it harder and harder to concentrate on what people were saying’ (Bryden 1998: 67; emphasis added). As the world fades, or the previously stable relationship to the world fades, the previous experience of self seems to fade with it.³⁸ However, these accounts highlight that while there is a shift in self-experience, it does not make sense to speak of a ‘loss’ of self *per se*.

The visual and auditory senses are not the only ones to be affected by dementia. McGowin provides a vivid account of having olfactory hallucinations; the unpleasant sensation, for instance, of smelling cat pee when others cannot smell anything (McGowin 1994: 125). However, her account also highlights that there at times unexpected pleasures in her symptoms: ‘I can sometimes enjoy the sweet fragrance of night-blooming jasmine, when no one else can. It is my own private sensation’ (125). In fact, McGowin is not afraid to broach the taboo of sexuality in people with dementia when pointing out how dementia has made her more sensual. Realising that she has experienced many ‘last times’ without being aware of it enables McGowin ‘to savor life more openly and ravenously [and to] appreciate all good things more, whether they be trusted friends, cherished memories, nature’s beauty – or physical pleasures’ (87).

Overall, however, these experiences of disruption in habitual encounters with the world have profoundly pernicious effects on the authors’ sense of self. DeBaggio, for instance, describes how after having been baffled and shamed by the failed attempt to use a photocopier, his return home presented a turning point in his (self-)experience: ‘On the way home I had a peculiar feeling that the sidewalk wavered every once in a while. At intersections I was careful to look in all directions. It was a walk in which I lost something I may never get back’ (2002: 116-7). Autopathographies by people with dementia attest to the way in which seemingly effortless processes of sense perception are fundamental in our experience of feeling at home in the world. Such narratives express the loss

³⁸ Similarly, see Ratcliffe (2008) on shifts in ‘existential feelings’ in psychiatric illness.

of this ‘at-home-ness’ and attempt to convey a sense of this experience to the reader.

Emotions and Cognition

Memoirs by people with dementia abound with examples of deeply felt expressions of emotions: from frustration and anger to guilt, worry, appreciation and love. While highlighting the persistence of emotions, these narratives also reflect on the subtle and less subtle ways in which emotions and cognition are changed in dementia—leading to substantial changes in how the authors experience themselves. DeBaggio, for instance, evokes the sense of his mind ‘becoming one-dimensional’ of having ‘almost lost [the] ability to hold two thoughts simultaneously’ (2002: 142). Bryden (1998) similarly describes how her inner thought processes are becoming unfamiliar as they become more ‘stretched out, ... more linear, more step by step’ (48-9). This loss of ‘vibrancy’, ‘buzz’ and ‘interconnectedness’ (1998) is paralleled on an emotional level:

My emotions seem a little awry. Sometimes I am a bit more teary than before, for no apparent reason. But more often I seem to have what feels like a sort of emotional blank, which to my daughters looks like a lack of sparkle, of charisma. I don’t get as excited as I used to, and I just feel a little ‘flat’. It takes too much energy to react with emotion: where once it seemed automatic, now it takes actual mental effort to consider a situation, and then how to react to it. (92)

Bryden’s description highlights the sense in which emotional responses are a cognitive activity (Damasio 2000) and the extent to which this cognitive life is constitutive of her sense of selfhood: ‘I’m like a slow motion version of my old self,’ she writes (Bryden 1998: 49). And yet, Bryden sees some benefits to this change: ‘It’s not all bad, as I have more inner space in this linear mode to listen, to see, to appreciate clouds, leaves, flowers ... I am less driven and less impatient’ (1998: 48-49). Like other authors, then, Bryden suggests that there is potential to live well with dementia and the possibility of positive changes in a disease that is usually described in terms of a ‘living death’ or ‘tragic’ downward spiral.

In one of his essays, Taylor (2007) puts yet another spin on these emotional changes. He describes how he is beginning to care less about his forgetfulness and the lack of correspondence between his world and his caregivers' reality. The feeling of no longer caring is experienced as both threatening and as a relief. It prompts him to ask whether he is 'turning into an android that really doesn't care where it is, what is happening around it, what is happening to it' (57)—drawing on a dehumanising metaphor to conceptualise people with dementia. However, he also depicts his growing lack of concern as positive: 'In the past, behaviour like that would upset me. In the recent past, it would frustrate me. In the present, it just doesn't seem to bother me that much. Why are others around me so concerned? I forgot – so what?' (58). Read alongside his deep expression of fear about the future, this flippant remark does not ring entirely true, but it does speak to the fluctuation in his emotional responses to the lived experience of his disease. It is one of the strengths of the seriality of both essay and blog formats that they allow for varying responses, attitudes and emotions to be registered over time, rather than providing a fixed teleological outlook—as in most retrospective memoirs.

If emotional changes can lead to an increased appreciation of the here and now, Henderson also highlights the negative impact the disease has on his emotional landscape: 'There's so many things about Alzheimer's that are rather bewildering' he writes. 'Sometimes you can have mood swings that are really awful I think. Sometimes I feel on top of the world, a couple of days ago I did and today I just feel absolutely devastated' (Henderson 1998: 32). As DeBaggio recounts, dementia can also have an impact on the (seemingly unmotivated) strength of an emotional reaction:

Strange things are happening. I blew up this morning with surprising force and frustration. The cause? The newspaper hadn't arrived. ... Little things wear down my emotional equilibrium. First vocabulary fractures; then my emotions explode like snowflakes in an angry blizzard. (DeBaggio 2002: 168)

The writers of dementia autopathographies sometimes experience their emotions as alien, out of control, or unmotivated. At the same time, they reflect on the potential benefits of some of the changes wrought by the disease. Importantly, by putting their emotions in the context of their life

experiences, their narratives help to underline the continuity and validity of emotional reactions in people with dementia. As discussed previously, like other behaviour, expressions of emotions are often viewed through the lens of pathology, rather than being seen as legitimate reactions to a frustrating or undignified experience. In particular, the expression of negative emotions, such as anger, is classified as ‘challenging behaviour’ (Killick and Allan 2001). The social context of the situation in which this anger arose is frequently overlooked. A closer look at the experience of living with dementia highlights how these expressions of emotions, while affected by disease processes, remain meaningful. This recognition, in turn, may help attune caregivers to acknowledging what these emotions express.

Time

The scariest thing is, I guess, the fact that I have no sense of time. I have not the slightest idea—my brain doesn’t—what’s ten hours away or two hours away. (Henderson 1998: 47)

Arguably, just like the experience of space, temporal aspects of being are generally changed in illness. As Rita Charon notes, ‘Because the experience of time might be one of the most telling aspects of the divide between the sick and the well, health professionals have an urgent need to examine and make at least imaginative sense of how patients might experience time’ (Charon 2006: 121). In dementia, the experience of time is transformed in numerous ways. The person affected by the disease arguably becomes ‘lost in time,’ due to the progressive inability to remember the current date, month, season or year she is living through. DeBaggio describes this state of affairs while highlighting that certain temporal markers are of less importance to the person with dementia than they are to others (see also Henderson 1998: 44):

I awake in the dark morning without awareness of what day of the week it is. I wait for the newspaper or the radio to locate me in time. The day of the week, the hour of the day has little meaning for me even when I remember. I float in my own chaotic world, grateful to know I am still alive. (DeBaggio 2002: 148; original emphasis)

A person with dementia may also be lost in time in the sense that she may seem to be ‘living in the past;’ in such instances past autobiographical memories are being experienced *as* the present, or they colour the present to such a degree that the person is no longer aware of significant aspects of current reality. Such shifts are unlikely to be represented in autobiographical writing, since the writing project in itself relies on a certain amount of present-day information being available to the author. DeBaggio’s graphic description of a night of delusion, during which he calls out in distress to his wife as his ‘Mommy,’ provides a rare exception to this rule:

I was lost and had begun to regress to another time. I called her ‘Mommy’ and I asked where Daddy was in mantra-like singsong. I saw my mother where Joyce had been. I sat up in the bed and reached out to touch her in the dark air of the room but my tingling fingertips met nothing. My mother had been dead for decades, *but time melted away*. (DeBaggio 2002: 203; emphasis added)³⁹

There is, however, a third way, frequently overlooked, in which people with dementia may become ‘lost in time.’ Temporal units are experienced differently as memory loss significantly loosens the sense of being moored to a particular time and place. Even small units of time can no longer be made sense of as they cannot be linked to a coherent whole, a narrative ‘before’ and ‘after.’ Life writing by people with dementia is rich in phenomenological descriptions of such experiences of being lost in time; such as Henderson’s unsettling experience of not knowing how long his wife has been absent and therefore becoming concerned about the well-being of his dog. Henderson draws attention to the pervasiveness of this temporal unravelling:

No two days and no two moments are the same. You can’t build on experience. You can maybe guess what’s going to happen a little while from now—minutes from now, hours from now—we don’t know what to expect. (Henderson 1998: 47)

It is hard to imagine the disorientating effect such a transformed experience of temporal sequences must have and what the world may look like for a person experiencing these symptoms of dementia. In her memoir, Bryden

³⁹ The discrepancy between narrative voice and narrative experience are noticeable here. It is not clear to what extent this episode is something DeBaggio remembers, from an inside perspective, or presents a reconstructed account of, based on information provided to him by his wife.

quotes an email communication from a friend who is also suffering from dementia, who evocatively describes the effect:

Most of the time I live in the space I can see and the time called 'now' ... it is almost a 'virtual world' ... I move... and a new space opens to view...even my rooted-ness to my place in space feels tenuous ... as if I might be torn loose, uprooted, blown away. (Bryden 2005: 99)

As this extract suggests, living in the 'now' is not a comfortable experience. While a number of memoirs advocate a *carpe diem* approach to life and express their authors' willingness to live each day to the full and make the most of their remaining capacities, Taylor draws attention to the fact that the symptoms of dementia that create this continuous present may in fact undermine the ability to enjoy the present, as 'living in and for the moment assumes the ability to know what is going on, what [one is] doing in a given moment' (Taylor 2007: 131)—an ability that is slowly eroded as the temporal unity of experience is disrupted.

The Social World: Intimate Relationships and Strangers

I'd like a larger world than I have right now. (Henderson 1998: 24)

In many ways, this quotation from Henderson's journal speaks to all the aspects of experience discussed so far that are changed in dementia. In selecting these words as an epigraph for this section on changes in the social world, I aim to underline how this particular aspect of being-in-the-world in dementia is determined less by changes on a neurological level than by changes in other people's reactions. Therefore, it is one of the few aspects of dementia that could be reversed or at least alleviated (see Kitwood 1997, 1990). Many of the memoirs highlight the extent to which interactions with others—strangers, health care professionals, friends and family members—are changed after the diagnosis of dementia. The person with the disease may lose the ability to behave according to social norms (Carel 2008, Goffman 1963) or may become more dependent on others, thereby upsetting the nature of previous relationships. Importantly, research has shown that social relationships are severely undermined, not only by the disease itself, but also by the process of disease labelling (Lyman 1989). The labelling of

their behaviour as pathological results in limited opportunities for people with dementia to assert agency and control over their lives and to interact socially (Lyman 1989: 600-1). One of the most devastating effects of the stigma attached to dementia is that it often leads to social isolation and loneliness, a form of 'social death' (Lyman 1998). Indeed, sufferers describe the stigma attached to dementia as a fear of contagion:

We've never tried to hide that I have Alzheimer's. But everyone acts like they don't want to get near because they might catch it. They don't know how to deal with it. (Snyder 1999: 22)

The authors of dementia memoirs describe the harrowing experience of being ostracised by strangers and friends alike who may be alarmed by their behaviour, verbal mishaps or slowness to respond (see also Snyder 1999: 60). They also express their guilt about how their social isolation impacts on their spouses' lives.

However, diagnosis need not necessarily lead to isolation and abandonment. DeBaggio describes the support and encouragement he received from friends and readers of his botanical newsletter after sharing his diagnosis. Although too often Alzheimer's may curtail the formation of new relationships, the memoirs provide evidence that this is not a necessary consequence of the disease. Henderson describes forming new bonds with health care professionals through being involved in their research project. While appreciating their kindness and personal qualities, his involvement in research also provides him with a new role that boosts his self-esteem. As he writes, 'when I get to Durham and I have something I like to do, I'm kind of on a high. It's something that I can do that not everybody can do, and it makes me feel good about this' (Henderson 1998: 63). Furthermore, many memoirs highlight the importance of forming new relationships through support groups and long-distance communication with other people with dementia. They underline the value of friendships based on a shared understanding of each other's experiences. While the memoirs often criticise health care professionals for callous behaviour, they also describe instances of supportive and lasting relationships with understanding neurologists, family doctors or psychiatrists (Bryden 1998: 4, 6, Lee 2003: 20-21). Indeed, Bryden's autobiographies underscore the potential for

forming significant new relationships despite dementia. Bryden meets and learns to love her husband after having struggled with the symptoms of dementia for a number of years (Bryden 2005). Her experience underscores that people with dementia can form new bonds and maintain personal relationships, if given the chance.

Nonetheless, intimate relationships with partners, children or other family members are bound to be affected by the disease's progression. In some instances, formerly estranged relations between family members may in fact improve due to the way dementia affects both the caregiver and care-receiver. It is a common trope in filial caregivers' memoirs that parent-child roles become inverted by dementia. Sufferers explore their own reactions to this often unwanted inversion of relationships in their autobiographical writing. Their growing dependence on others is frequently coupled with fear, anger and frustration:

Sometimes I give Erika a hard time just to be nasty. I guess it's because I'd like to be doing things myself instead of having someone telling me to do this or do that. I'm a little boy now. I have a mommy to take care of me. It's not a very good feeling. I'd much rather be out there doing something else. (Snyder 1999: 85)

However, the authors of dementia memoirs also express their deep thankfulness and appreciation for the roles their children or partners have taken on: 'My wife is trying extra hard to make things tolerable for me—to give me things to do and make me feel good. I really, really do appreciate that' (Henderson 1998: 28). While occasionally feeling left out in social interactions, Henderson also acknowledges the love and support he has received from his family: 'I think love is the key to all this stuff and love is something that my wife certainly has given to me and the family too and there's nothing that I can see to complain about' (65). Furthermore, he underscores the pivotal role his wife plays in anchoring him in life: 'I'm afraid of losing contact. She's the only one who understands me and I'm hard to understand' (28). Henderson's account, among others, draws attention to the fact that relationships are never one-sided. The authors with dementia frequently voice concern for their loved ones and show an empathetic insight into what their family members may be experiencing. As Henderson notes, 'I think probably all of our caregivers, bless their souls

and hearts, they do go through a little bit of hell themselves—a lot of it—and a lot of it because of us’ (37). Dementia then, changes not only the internal landscape of persons with dementia, but their social world—and with it the worlds of their companions and family members.

Being-at-one-with-the-world: The Experience of Flow in Dementia

I appreciate and sometimes immerse myself in the process rather than only or mostly on the outcome. I like doing things. I like and appreciate the doing. Doing is how I know I am alive, and how I appreciate being alive. (Taylor 2007: 105)

As has become clear from the discussion so far, the experience of being-in-the-world is radically altered in dementia. While the changes wrought by the disease make certain ways of engaging with the world and with others difficult or even impossible, the memoirs also highlight the potential for new or previously unexplored ways of being-in-the-world. The notion of ‘flow’ that the clinical psychologist Kate Allan has recently been exploring in the context of dementia seems pertinent here. Allan describes the experience of flow as being ‘characterised by a total and intrinsically enjoyable focus on an activity that balances skills with challenges, and provides clear and immediate feedback. It results in a merging of action and awareness, loss of sense of self-consciousness, and altered experience of time.’⁴⁰ Life writing by people with dementia provides a number of examples of experience that could be understood in such terms.

For instance, DeBaggio considers writing not only a therapeutic means of distancing himself from the disease, allowing him ‘to leave thoughts of the disease locked up in the computer’ (DeBaggio 2002: 7), but also a means of actually being-at-one-with-the-world. ‘*The only time I feel alive now is when I am writing, under the spell of work and memories*’ (DeBaggio 2002: 121; original emphasis). This sense of ‘feeling alive... under the spell of work’ can be understood in terms of flow experience—of being completely immersed in an (enjoyable) activity. DeBaggio is bound up with his keyboard in this activity of writing rather than constituting

⁴⁰ <http://www.st-andrews.ac.uk/psychology/people/pgprofiles/kma2/> Accessed 31.03.2015

separate subject and object in the world. At this stage, typing still comes automatically and seems to enable his thinking rather than disrupt his relationship to the world around him by interposing a baffling instrument he can no longer use.⁴¹ This sense of being at ease in his body and his environment contributes to the satisfying sense of feeling alive. Similar instances of flow, of being-at-one-with-the-world, are also highlighted in other dementia memoirs.⁴²

Arguably, writing is an unlikely candidate for a sustained experience of flow as the symptoms of dementia progress, and many memoirs—DeBaggio’s included—comment on how the ability to write becomes increasingly impaired. Henderson’s account, by contrast, highlights less cognitively demanding activities that can provide a sense of enjoyable immersion. Music, his ‘only constant companion’ offers such an opportunity:

I’ve whiled away many many hours listening to music. I can just listen to music and feel that I’m doing something that I just love to do. I can’t make music anymore, but I can certainly use it for my own intentions—which are just to be beautiful. (Henderson 1998: 42)

His words are accompanied by this image of him physically expressing his enjoyment of music (see Fig. 3). Overall, Henderson’s account underlines the importance of the appreciation of aesthetic objects, whether man-made or natural. Henderson takes pleasure in the changing colours of autumnal leaves and watching birds in his bird sanctuary. He writes ‘Things are a lot more precious than they were’ (77). In other words, although dementia disrupts his experience of the world it also leads him to a deeper appreciation of all things, great and small.

⁴¹ Compare Heidegger’s distinction between objects being ‘present-at-hand’ (*Vorhanden*) versus ‘ready-to-hand’ (*Zuhanden*) (1962). Objects usually present themselves to us as ‘ready-to-hand.’ Standard examples include the use of a keyboard or of a tool: we do not ‘encounter’ them as objects distinct from our activity, but instead they are bound up in our activity and typically they come to our conscious awareness as ‘present-at-hand’ objects only when they fail to function and therefore become conspicuous (Ratcliffe 2008: 44, 45).

⁴² Truscott (2004a) elaborates ways to achieve such flow in her autobiographical journal article.



Fig. 3 *Flow and relationality captured in photography in Henderson (1998: 43; 75).*

While there are numerous further examples of what Bryden describes as ‘dancing with dementia,’ one final example shall suffice: many authors comment on the value of being in contact with animals. Henderson describes his relationship to his dog as one of care and mutuality.⁴³ The dog provides him with an excuse to leave the house and walk when he is feeling ‘antsy’ (48), but, more importantly, the dog provides a non-judgmental loyal companion, someone to play with, talk to and simply watch. As Henderson puts it, his dog is ‘somebody ... you know is not going to talk back. And you can’t make a mistake that way’ (13). For Bryden stroking a purring cat is an activity that provides her with the kind of ‘brain time-out’ that she finds necessary after being over-stimulated (1998: 82). As with music, there is a certain flow to being with and caressing an animal that is directional but non-instrumental and that does not necessitate the same kind of purposeful planning as other activities. As such, it can provide a reassuring sense of being-at-one-with-the-world, counter to the many examples of shifting self and world experience in dementia.

Thus, life writing by people with dementia offers rich experiential detail on how both self-experience and world-experience are prone to change in dementia. At times, the difficulties of engaging with the world are experienced as attacks on the person’s very sense of self. The memoirs underscore how this sense of ‘losing oneself’ refers not only to the loss of characteristics or abilities that are considered central to one’s sense of

⁴³ Compare, in this connection, research into animal-assisted therapy in dementia (see Marx et al. 2010).

identity, but also to habitual and background ways of being-in-the-world. At the same time, these memoirs underline the fact that there continues to be a certain perspective on the world. *Somebody* experiences these changes, perceives an altered world, feels disorientated or diminished. This person, with all the constantly shifting abilities, continues to be a unique centre of perception on the world. Research suggests that this first-personal givenness of experience continues in the late stages of dementia, beyond the possibility of communicating it in words (Kontos 2003, 2004, 2005).

Furthermore, attending to the ways people with dementia describe their shifting experience in the earlier stages may provide crucial means of interpreting nonverbal expressions of attitudes, preferences and emotions in ‘behavioral or symbolic gestures’ (Snyder 1999: 10) in later stages of the disease. Although the channels of communication may change, Snyder underscores the value of paying close attention to verbal accounts provided by people with dementia as the ‘themes’ in these accounts may in fact provide a basis for interpreting nonverbal expressions of experience later in the course of the illness (11). Furthermore, Snyder highlights the numerous channels of communication that remain open in dementia and the importance of acknowledging and trying to interpret these *embodied* ways of communicating (32-3). Arguably, such embodied ways of communicating are rarely translatable into written accounts of the disease. Although the use of photography in Henderson’s collaborative journal partially explores the potential of embodied expressions of feelings—such as when Henderson strokes his grandchild’s head (see Fig.3), laughs with his wife, sits slumped at the table—written memoirs are limited in the ways they can communicate through the body and communicate embodied selfhood *per se*. In the next section I turn to a different medium, documentary film, that draws on the potential of visual and auditory modes in exploring these aspects of the phenomenology of dementia. David Sieveking’s documentary *Vergiss Mein Nicht* (Forget-Me-Not) provides medium-specific affordances when it comes to representing the embodied nature of the symptoms of dementia, embodied aspects of selfhood, and embodied means of communication in dementia.

From the Caregiver's Perspective: Intersubjectivity in David Sieveking's Documentary *Vergiss Mein Nicht*

Vergiss Mein Nicht (Sieveking 2012) explores the way Alzheimer's changes not only the person with dementia but the entire family. Sieveking is narrator, protagonist, and film-maker alike. The documentary was filmed during several extended periods Sieveking spent living with his parents—during which he at times acted as primary caregiver for his mother Gretel. Due to its mimetic potential the documentary provides abundant material for an investigation of the ways that dementia changes the sufferer's experience of the physical and social world. I examine the portrayal of the symptoms of dementia as entry-point into the documentary itself and into the broader question of how viewing symptoms of dementia on film may be different from reading about them in print.

The documentary also opens up the possibility of representing instances of embodied communication; at issue are various forms of nonverbal communication, such as touch, gesture, facial expressions and posture as well as the role of body movement and tone of voice in nonverbal and verbal humour. What I am calling 'embodied communication' also includes aspects of the voice of the person, such as modulation, tone and intonation, i.e., what linguists call paralinguistic features of communicative acts—features that help constitute the meaning of an utterance in ways that go beyond its semantic content. Documentary film provides the perhaps unique possibility, within dementia life writing, of exploring how people with dementia continue to express themselves through vocal modulations and bodily movements. As the forms of embodied communication just mentioned provide an important means of gaining access to Gretel's state of mind, a large part of this analysis will be devoted to the way the documentary represents and reflects on these means of communication. My guiding questions here include the following: What opportunities do documentary film provide for contemplating aspects of embodied selfhood in dementia? And how do the affordances of film differ from written memoirs by people with dementia?

Viewing Symptoms of Dementia

As hinted at previously, the mimetic quality of filmography allows for a rich representation of the symptoms of dementia. The documentary highlights the ways that the loss of memory impacts on many different areas of human functioning and experience. It is therefore even more difficult than in written memoirs to discuss distinct areas of self-experience affected by the disease. I will nevertheless attempt to draw out some of the relevant areas that the medium of film speaks to in a particular way.

For example, the documentary provides valuable insight into the complex ways that language is affected by dementia. In presenting the viewer with Gretel's speech, rather than an indirect representation of her speech—as in written caregivers' memoirs—the viewer witnesses the repetitions, non-sequiturs, and word-finding difficulties that form the symptoms of Alzheimer's disease. Neurolinguistic research generally corroborates the higher occurrence of discourse deficits in people with dementia, including empty or aborted phrases, indefinite terms—such as 'thing' or 'stuff'—repetitions, referential cohesion errors, and disruptive topic shifts (see Dijkstra et al. 2004: 275). In the first scenes of the documentary Gretel's linguistic impairment seems to 'mark' her as a person with dementia. There is a moment of vicarious shock or empathy with the narrator-figure David who is confronted with a decided change in his mother since his last visit—having just established the opening narrative opposition between 'now' and 'then' that is so typical of many caregivers' memoirs. However, as the narrative progresses, the viewer gets used to the idiosyncrasies of Gretel's speech. So rather than undermining her expressive capacity and marking her as 'demented,' the documentary illuminates the way that language is not simply lost but retains much of its communicative function throughout the course of the disease. The film shows language in context: the setting of the conversational discourse renders intelligible even language that presents syntactical or semantic errors or lapses in coherence or cohesion.

A scene depicting Gretel undergoing neurolinguistic tests—a standard procedure in the diagnosis and tracking of the progression of dementia—

highlights the extent of Gretel's semantic difficulties. More importantly, however, it underscores the degree to which such testing undermines the patient's sense of self-worth. Gretel is clearly baffled by the test procedures. She has been upset by the injunction to hold her peace during the EEG screening and feels put on the spot by word-finding tests she is subjected to, complaining that she is now being asked to speak while before she had been told to keep quiet. She is clearly having difficulties with naming the images presented to her and her attempt to withdraw from the situation by closing her eyes highlights her emotional discomfort. The scene presents one of many instances in which, despite her language impairment, body language and facial expressions clearly express her feelings or attitude.

The documentary also reveals the many ways that bodily engagements with the world are changed in dementia—for instance, by tracking the changes in Gretel's gait. Furthermore, it highlights the importance of haptic relations with the environment as Gretel develops a new way of interacting with the world when walking. In line with Henderson's notion of trying to 'touch base,' it seems that touching objects in her environment helps Gretel to situate herself. So, for instance, the viewer witnesses her sliding her hand along the counter at a doctor's office as she walks along. Much later in the film, she and her husband return to Hamburg, the setting of their budding love story. In a shop, Gretel touches all the sweets on display. Touching seems to allow her to establish a link to the world.⁴⁴ With an understanding of how dementia impacts on habitual ways of being-in-the-world, self-referential tactile behaviour, such as grasping one's own hands or stroking one's legs, can take on a new meaning. Contrary to seeing such repetitive actions as meaningless, they suggest that the person with dementia is attempting to establish a link with the world and familiarise herself with her own body and her environment. Touch, however, as indicated by the image of Henderson stroking his grandchild, and as I suggest below in my analysis of its communicative potential, also has a relational function.

⁴⁴ It is not incidental that the verb 'to grasp'—to understand the meaning of something—is a metaphorical extension of our haptic potential for holding an object. See also Lakoff and Johnson (2003) on the bodily substrates for metaphors that form the basis of everyday language.

The documentary brings to the fore how sense perceptions such as taste and smell may change with Alzheimer's. In additional information on the DVD the viewer learns that Gretel's 'obsession' with butter is a new culinary preference. In Sieveking's discussion of this preference with a gerontologist, it emerges that Gretel's 'butter-addiction' may be in line with recent scientific insights into how early memories may gain importance later in life. It has been shown that in survivors of the Holocaust or of Stalin's work camps the motives, wants and exigencies of this episode of their lives came to be constitutive for the way that motives and needs were structured later in life. The fact that Gretel lived through the war, during which fatty foods such as butter were a scarcity, may therefore account for her growing obsession with butter. This aspect of her conduct also attests to the subtle ways that memories may structure experience and surface in behavioural patterns. This tendency has been highlighted by people working on so-called 'challenging' behaviour in dementia, such as the clinical psychologist Graham Stokes (2010). Stokes provides numerous narrativised 'case studies' of how behaviour that was treated as merely pathological—and seen as 'outlandish and bizarre' (8)—could actually be attributed to individual traits or past experiences and thereby interpreted as understandable reactions to the current situation.

In filming Gretel's daily life, the documentary registers many moments of confusion. Gretel is confused about how to handle objects (such as clearing the table or dealing with dirty dishes), about the identity of the person she is with, and about recent events in her life. So, for instance, after a long car journey to Switzerland to join her husband, she seems to retain no memory of the long hours just spent in the car. Further, she has trouble recognising her husband and distinguishing between her husband and son—presumably because her son had recently taken over the role of primary caregiver. Although she seems happy to be reunited with her husband, her confusion is palpable in her facial expression, tone of voice and bodily movements.

Yet the documentary also registers many moments of being-at-one-with-the-world. As in the autopathographies discussed above, such moments may involve a bodily sense of well-being or a satisfying sense of being-with

another person. Gretel shows a surprising grace, joy and fluidity when she plays ball with her adult children. Further, as I discuss below, she also shares moments of ‘communion’ with others, relying on embodied modes of communication.

In sum, due to its mimetic quality, documentary film can provide insight into a wide array of symptoms associated with dementia. The outside view of the camera may, however, limit an understanding of how these symptoms are experienced by the person with dementia. As hinted at in some of the examples just mentioned, insight into Gretel’s state of mind can, at times, be gleaned not only from her comments but from her facial expressions, gestures and postures. Since paralinguistic information of this sort provides such a crucial form of communication in dementia (Killick and Allan 2001)—and since the documentary captures such paralinguistic cues in a medium-specific way—I turn now to the film’s treatment of nonverbal or more generally embodied communication.

The Communicating Body in Film

In contrast to life writing by people with dementia, which is necessarily confined to the stage when the person can still tell a more or less coherent verbal narrative, documentary filmmaking provides the possibility of providing instances of nonverbal means of expression at later stages in the disease. Although Sieveking’s documentary is of course edited and narratively arranged, it nevertheless provides a mediated space for the presence of the person with dementia. Gretel, the film-maker’s mother, is continuously ‘on scene.’ Her words, gestures, expressions and movements are thus available to the viewer—albeit at one step removed from face-to-face encounter. Given Ratcliffe’s observations on how we understand other people’s states of mind directly through body language and gesture (2007), documentary provides fascinating possibilities to represent the phenomenology of illness nonverbally within a narrative genre.⁴⁵

Sieveking describes how before the onset of his mother’s illness, the family thrived on intellectual discussions. He notes how in his family, ‘the

⁴⁵ Fiction films provide similar affordances. See chapter 2.

word’ was ‘everything.’⁴⁶ This remark echoes Killick and Allan’s observation that ‘Sometimes it seems as if we were all living according to the slogan “Words come first!”’ (44). This way of being and doing things in the world has significant impact on the perceived potential of people with dementia to express themselves, to build social relationships and to affect their reality, as the disease syndrome is linked to various forms of language impairment and the eventual loss of language itself.

No doubt, language plays a crucial role in the way our species engages with and acts in the world. However, in overstating the role of language, or rather in underestimating the contribution of nonverbal behaviour to processes of communicative interaction, we risk missing the continuing expressive potential of people with dementia. Sieveking’s documentary highlights this potential in two ways. First, by portraying how Gretel communicates through and with her body, the film draws the viewer’s attention to the potential of embodied communication in people with dementia. Second, the narrative also traces how the experience of living and communicating with somebody who has dementia brings about a sea-change in the way family members relate to each other. As Sieveking describes it, they learn to relish the potential of touch and physical intimacy, not only in relation to Gretel but also to each other. Sieveking appreciates that through her new way of being-in-the-world his mother was able to teach him a valuable life lesson. Sieveking’s father similarly highlights a positive side to his wife’s illness since, as he puts it, it allowed him to rediscover his love for her anew.⁴⁷ The Sievekings are not alone in seeing dementia as a context for growth and learning, as the words of Michael Ignatieff, author of the novel *Scar Tissue*, confirm:

I learned as much from my mother when she couldn’t speak to me, when she couldn’t communicate, when she simply stared and received our kisses on the cheek, as I learned when she was joking and laughing. (Ignatieff 1994, qtd. in Killick and Allan 2001: 52)

⁴⁶ Sieveking states ‘Alles ging über’s Wort’ in an interview contained in the additional material on the DVD (see ‘Potsdamer Filmgespräch mit Andreas Dresen’). All translations are my own.

⁴⁷ ‘Ich bin der Demenz eigentlich dankbar dass ich die Liebe zu meiner Frau noch einmal neu entdecken konnte’, as quoted by David Sieveking (see ‘Potsdamer Filmgespräch mit Andreas Dresen’).

Yet contrary to Ignatieff's view that not speaking equals not communicating, Sieveking's documentary draws out the many ways that communication is nonverbal. This is not to say that verbal and nonverbal communication are in opposition to each other: 'Although there are forms of nonverbal communication which do not involve words at all, in the majority of instances the two dimensions are intimately intertwined,' Killick and Allan write. 'Facial expression, qualities of voice, and gestures help the listener to decode and interpret words' (Killick and Allan 2001: 45). In normal language use, as in dementia, verbal and nonverbal cues act together to convey the full meaning of an utterance or gesture.

One of the commonplaces in popular understandings of dementia has been that since people with dementia lose the ability to communicate, we have no way of accessing their states of mind, no way of knowing *what it is like* to be living with dementia. Although there are of course limits to intersubjective understanding in dementia, and the loss or impairment of language no doubt plays a contributing factor, it is important to keep in mind what Shaun Gallagher and Dan Zahavi describe as the primordial role of embodiment in intersubjective understanding. Drawing on Max Scheler, Gallagher and Zahavi point out that 'we can perceive the joy, sadness, puzzlement, eagerness of others ... in their movements, gestures, facial expressions and actions' (Gallagher and Zahavi 2008: 182). Contrary to mentalizing accounts of intersubjectivity, they hold that we gain access to other people's minds through perceiving their bodies in a situation or meaningful context (183). Accordingly, a phenomenological account holds that 'we experience the other directly as a person, an intentional being whose *bodily gestures and actions* are *expressive* of his or her *experiences or states of mind*. (183; emphasis added). So for instance, Gretel regularly expresses her disinclination to engage, her tiredness and her need for peace and quiet by closing her eyes and shutting out her surroundings. It would be wrong, however, to presume that when Gretel closes her eyes she is in some sense no longer 'there.' During a conversation between father and son, Gretel expresses her wish to be included both verbally and behaviourally, by squeezing in between the two of them. She then closes her eyes while David and his father continue to talk about the parents' past relationship as if she

wasn't there. However, when her husband Malte hesitates in his narrative, she suddenly interjects with a question, clearly belying the impression that she is unaware that she is the topic of this conversation.

Killick and Allan speculate whether language impairment leads people with dementia to develop a keener sense for engaging in and interpreting nonverbal modes of communication. This hypothesis is corroborated by people with dementia who describe how they have to rely on nonverbal cues to make sense of what others say. Gretel's keen attunement to nonverbal cues and the emotional gist of a conversation comes out in a scene where Malte recounts a quarrel with his wife's professional caregiver, Valentina. Although Gretel may not be able to follow the details of the narrative, she is clearly aware of its unpleasant nature and that it has something to do with her. Furthermore, her partial understanding seems to make her feel responsible for the situation. Her worried look and her query 'What did I do?'⁴⁸ indicate her concern. The scene provides a poignant reminder to caregivers not to assume that people with dementia are oblivious to what is going on around them and that they no longer closely monitor what is said in their presence. As this example highlights, the remaining capacity for understanding can lead to unnecessary negative emotions, a sense of misplaced responsibility, shame or anxiety.

Through her bodily movements, postures and gestures, Gretel clearly expresses feelings of distress, fear or hurt—such as her sense of abandonment when her husband leaves her at the train station, leading her to turn away and avoid his good-bye kiss [22: 48]. However, her bodily movements also express her joy—as when she throws up her hands in greeting her older sister Ise. Gretel's comment 'This is good'⁴⁹ when cuddling with her husband indicates her appreciation of physical intimacy. She reaches out to others, wants to hold hands, and happily links arms with her caregiver Valentina. As Killick and Allan note,

the potential of touch in enhancing well-being and promoting communication with people with dementia has yet to be explored properly. Most of us feel comforted and affirmed by touch which is employed in a respectful way, and for those with the condition it could make all the

⁴⁸ 'Was hab ich gemacht?' [1:20:28].

⁴⁹ 'Das ist gut' [21:54].

difference between being able to remain in meaningful contact with others, and losing a sense of connectedness. (63)

Touch, the documentary suggests, plays an ever-growing role in dementia: as a form of communication and therefore in maintaining relationships.

As many memoirs about dementia indicate, humour remains a crucial means of communicating in the context of dementia. Seeing the funny side of certain situations can help alleviate the stress of dealing with the symptoms of dementia, both for caregiver and care-receiver. Humorous exchanges, as John Bayley recounts in the memoir of his wife's dementia, remain possible when intellectual discussion no longer is. The sharing of laughter, then, is both a means of communication and of maintaining relationships. Gretel signals the humorous intent of her words through facial expressions, such as playfully lifting her eyebrows, as well as through her intonation and the modulations of her voice. On their drive through Switzerland Gretel and David pass 'Die Jungfrau,' a famous mountain named 'the virgin.' After the name has been pointed out to her, Gretel quips: 'And who was that? Well it wasn't me, not me, for sure.'⁵⁰ She places unnatural stress on the 'me' ('ich' in the original) to highlight that by no means could she have been called a virgin. Tone of voice, intonation, bodily language and facial expression all work together to communicate her humorous intent. Similarly, Gretel uses an exaggerated, mock-dramatic tone ('Oh! Who is this Malte?')⁵¹ just before being reunited with her husband, to cover up her confusion about who this person is. Her utterance and tone suggest that she has some awareness that his name should be meaningful to her and she might be using humour to make light of her trouble in remembering the specifics of this relationship. That said, most instances of Gretel's humorous engagements with others do have a strong verbal content. Yet Killick and Allan, in their work on communicating with people with dementia, point out the importance of humour based on bodily movements. They highlight that 'much of what occasions smiling, and even outright laughter, appears to come out of relationship' and they argue that by paying attention to the comical exchanges between people with dementia 'we can

⁵⁰ 'Oh, und wer war das zum Beispiel? Ich war's nicht. *Ich* war's nicht' [42:08].

⁵¹ 'Oh, wer ist denn *Malte*? [42:25].

learn to encourage our own moments of sharing in the sheer fun of existence, often without a word being spoken' (Killick and Allan 2001: 57). Humour, like touch, can provide an important means of being-with and building a relationship with people with dementia. Both remain, also, ways people with dementia can reach out to others and express their subjectivity.

Embodied Selves and Relational Selves

In its mimetic portrayal of living bodies, *Vergiss Mein Nicht* provides particularly rich examples of forms of embodied selfhood. In one sense, the continuing presence of Gretel on the screen as a living body, a unit of identity, strongly discourages viewing her as a non-person, as someone who has 'lost her self.' The documentary allows the viewer to get to know Gretel as a person; she is a person who may be undergoing dramatic changes, but all her potential as human being and her unique subjectivity remain intact. The film also reaffirms the common sense notion of identity that we operate with in everyday life, which is based on the identity of a living body over time. No philosophical concept of identity has ever been able to resolve the paradox between identity and change that living beings present. Gretel's body persists and so does Gretel. While aspects of her social identity—her roles or *personae*—change, at no point in the course of her illness does she cease to be herself.

A key aspect of her embodied identity, as represented in the documentary, is her unique voice. While autobiographies by people with dementia focus on the political notion of voice, in the sense of giving voice to a disadvantaged or stigmatised group, here 'voice' represents Gretel's unique personality in its embodied, literal sense. Her tone of voice, the use of intonation and modulation to convey humour or distress, as well as dialectal influences on her speech all attest to her unique personality. So, for instance, dialectal influences resurface when she returns to her hometown, Stuttgart, and talks to her sister, a strong dialect speaker. The shift to the phonetic variations of the Swabian dialect (in this case replacing the voiceless alveolar sibilant /s/ with the voiceless palato-alveolar sibilant /ʃ/) can be seen as a form of embodied autobiographical memory, that is, a

procedural memory from a former period in her life. However, this shift is also, significantly, a marker of relationship. Dialect speakers will often revert to their dialect when speaking to close family or old friends, even if they otherwise predominantly speak a standard variant of the language. Gretel's shift marks her sense of belonging in relation to her sister. Indeed, Gretel's appreciation of relationships, in her nonverbal gestures, touch and verbal expressions may be seen as a pervasive and important aspect of her continuing selfhood. As mentioned previously, she reaches out to others, and clearly enjoys moments of physical intimacy, compliments and a sense of being included.

The documentary also highlights Gretel's appreciation of physical pleasures, such as eating butter, devouring a waffle, or smacking her lips when drinking a glass of wine. Furthermore, playing ball, going for walks, or listening to music provide moments of engagement with the world through her body and her senses. Some of these may be new developments, some draw on long-term procedural memories or previous habits and preferences, and some may not persist into the later stages of the disease. Nevertheless, these actions on Gretel's part highlight the many bodily and social resources of positive experiences of being-in-the-world that do not rely on higher-order cognitive functioning. As Murna Downs, caregiver and professor in dementia studies, puts it,

I am not so sure that I would hope for a world without dementia, for in a world without dementia we would be without the ones we love who have taught us that remembering and planning and naming and knowing are not the key human activities, but rather that feeling and being and touching and singing have enormous riches and depths that we are often too busy to relish in our race to rationality. (Downs 2000, qtd. in Killick and Allan 2001: 62)

Human activity, as Downs highlights, is embodied, sensual, vocal. People with dementia then retain numerous means of engaging with others.

The documentary also suggests that we understand embodied selfhood not merely as residual body memories that represent core characteristics of the person's previous identity (such as Kontos's examples of someone still being able to read the Torah or of making knitting movements). The film highlights how important it is to recognise the embodied nature of selfhood

in terms of the continuing presence of an inner life world which relies on a continuing first-personal givenness of the world. Gretel's inner life world is continuously revealed through her verbal expressions, facial expressions, gesture and posture. Furthermore, by drawing on Millett's adaptation of the notion of ecological niche value, one can argue that the film represents a woman who despite language difficulties and the growing inability to navigate the world, retains the potential for mutual relationships with other people. Her cognitive disabilities challenge her family to develop new and at times more intimate ways of being together.

The film also underscores that Sieveking's changing relationship with Gretel is not one-sided, based purely on catering to her disabilities, but reciprocal. Too often, a person with dementia is no longer seen for themselves but becomes 'a bundle of needs'—representing a 'burden' for the caregiver. The film underscores Gretel's potential to 'give back' in a relationship. So for instance, in a scene where David has clearly reached the end of his tether in terms of trying to get her to co-operate in necessary activities of daily living (such as going shopping), Gretel's refusal and withdrawal suddenly turn to concern for her son. She opens her eyes to ask him how *he* is doing. When he replies that he is not doing too great, she asks why and then immediately goes on to try and cheer him up and enlist *him* in a joint activity—in this case a trip to her home town, Stuttgart. The scene underscores that people with dementia may often 'develop an especially sensitive facility for reading information which comes through nonverbal channels' (Killick and Allan 2001: 63), given that Gretel's concern is a reaction to David's tone of voice and posture. It also underscores that people with dementia remain relational agents, who are able to show concern and love for others, not just the passive recipients of care. Even in the last scenes of the film that were shot close to her death this dynamic persists. The film movingly closes with Gretel's radiant smile as her husband and son join her at her bedside. Her joyful reaction highlights her continuing recognition of these people as all important to her.

In short, the documentary provides unique ways of conceptualising embodied selfhood in dementia. The body functions as indicator of persistent selfhood that is recognised by others—including the viewer.

Bodily expressions suggest an inner life world and the persistence of a first-personal perspective in dementia—as expressed through ‘embodied communication.’ Bodily expressions also highlight the persisting capacity for relationships in dementia. Documentary film thus provides particular affordances for representing the embodied experience of living with dementia and considering embodied selfhood in the context of neurodegenerative disease.

Conclusion

Dementia narratives, in the form of autobiographical writing and documentary film, are a powerful means of evoking the changing life world of the person with dementia. The authors of autopathographies illuminate how dementia influences their emotions and cognition, and with it, their very sense of self. Furthermore, they describe how the loss of a sense of time impacts on their negotiation of the world, while also highlighting the many ways that they continue to take pleasure in their life and experience moments of feeling at one with the world. The narratives attest to the fact that we do not *have* a body but *are* a body (Carel 2008); the changes illness works in our bodies significantly alter our way of being-in-the-world, and ultimately our sense of self. Life narratives by people with dementia record these changes and the complex ways that body, self and environment interact. Due to the nature of their production and the specific constraints of the genre they adhere to, the narratives cannot, however, address the phenomenology of dementia in the later stages of the disease. While some of the authors cling to a narrative self and fear that there will be nothing left once the ability to speak and remember has left them, others take a more optimistic view of the continuing ability to flourish.

Caregivers’ memoirs provide equally rich accounts of the changes brought about by dementia. However, due to their outside view, they may not provide the same kind of access to the phenomenology of dementia that life writing by those affected clearly does. Nevertheless, despite taking on an outside perspective, the emergence of caregivers’ memoirs that draw on

visual media, such as graphic memoir⁵² and film, speak in illuminating ways to questions of embodiment. Here Sieveking's documentary serves as a counter-point to the written autopathographies. The audio-visual representation allows for detailed accounts of the embodied nature of the disease. More importantly, perhaps, the documentary underscores the potential for embodied communication and the persistence of forms of embodied selfhood in dementia. While I am not suggesting that these are entirely outside the reach of written memoirs, documentary film provides medium-specific ways of conceptualising embodied selfhood in dementia: the body functions as indicator of remaining selfhood that is recognised by others. Bodily expressions suggest an inner life world and the persistence of a first-personal perspective in dementia—as expressed through embodied communication. And this form of communication also highlights the persisting capacity for mutual relationships in dementia.

Life writing both by people with dementia and by their caregivers provides a rich resource to consider the phenomenology of dementia. Grounded in first-hand experience, these texts speak from a position of experiential authority. However, autopathographies in particular are also limited by their mode of production. Due to the nature of the disease, that makes the communication of complex thoughts and emotions difficult beyond a certain stage, and the outside perspective of caregivers, the forms of life writing discussed here may not be able to evoke a sense of 'what it's like' to experience severe symptoms of confusion. In the next chapter, I turn from life writing to fiction, in order to explore how fictional narratives may simulate the experience of dementia. In the process, I investigate the question of how literary representations of dementia shape our understanding of the disease and whether the insight fiction might offer into the mind of a person with dementia is conducive to narrative empathy.

⁵² See chapters 4 and 5.

Chapter 2 From the Outside in? Dementia in Film and the Novel

The present chapter explores to what extent fictional narratives may be able to simulate what it's like to be living with dementia (see also Bitenc 2012). Fiction arguably provides the possibility of allowing the reader insight into the workings of another person's mind (see Cohn 1978, Herman 2011, Palmer 2004) and of conveying 'what it feels like to be alive' (Waugh 2013: 24). Indeed, Patricia Waugh suggests that 'to the extent that the novel creates a pre-reflective place which positions embodied minds in imaginary worlds and confers on them depth and thickness, we might think of it as the practical counterpart of theoretical phenomenology' (2013: 24). Rita Felski speaks of novels as providing a form of 'social phenomenology' (2008: 89). She argues that the technique of 'deep intersubjectivity'—a term borrowed from George Butte—instantiates 'a view of particular societies "from the inside"; we come to know something of what it feels like to be inside a particular habitus, to experience a world as self-evident' (92). In evoking detailed storyworlds, both novels and films provide the possibility of exploring the experience of living with dementia within a particular physical environment and socio-cultural context. Fictional films and novels may, I argue, be thought of as a form of *imaginative phenomenology*.

Furthermore, this chapter considers how, by simulating the experience of dementia, fictional narratives may elicit an empathetic engagement with the dementing protagonist. Novels, it has been argued, elicit empathy for characters by promoting character identification and allowing readers to share a character's point of view. Both in discussions about the uses of literature in relation to global citizenship (Nussbaum 1997) and in the medical humanities (Charon 2006), the view that novel reading promotes empathy has been harnessed to the argument that empathetic engagement with fictional characters will lead to pro-social behaviour in real-life. Charon, in particular, argues that novel reading plays a crucial role in expanding health care professionals' ability to empathise and acknowledge the pain of their patients (see Charon 2006: 233).

However, Suzanne Keen, leading scholar on narrative empathy, challenges the so-called ‘empathy-altruism hypothesis’ (Keen 2007). She also complicates the notion that narrative empathy is simply created by alignment of point of view. Empathic concern, instead, depends on a number of textual characteristics together with the reader’s personal traits and preferences. Keen’s study nonetheless underlines that narrative empathy constitutes a robust element of the experience of novel reading. She therefore explores the ways in which narrative empathy is evoked and its various strategic uses. Overall Keen’s work suggests the value of exploring the formal means by which literary works arouse narrative empathy while remaining cautious about advancing overextended claims concerning narrative empathy’s effects in the socio-ethical domain.

Based on my own corpus of fictional dementia narratives, I argue that further refinements in the theory of narrative empathy are called for if narrative empathy is to capture the full range of storytelling practices. What is needed is an even more nuanced understanding of the spectrum of empathic reading experiences. While I agree with Keen on the previously mentioned points, I demonstrate how a bottom-up approach, one that considers fictional accounts of the experience of dementia, may diversify the notion of narrative empathy. Further, a more fine-grained account of the working of narrative empathy has implications for debates about the value accorded to empathy in medical humanities research and education.

As a route into questions about the potential of fictional narratives to simulate the phenomenology of dementia and evoke narrative empathy, I consider the dementia narrative *Still Alice*: firstly, the novel by Lisa Genova (2007) and secondly, the film adaptation (Glatzer and Westmoreland 2014) with the Oscar-Award-winning performance by Julianne Moore as the title protagonist.⁵³ Does narrative empathy in films, like novels, depend on seeing the world through the protagonist’s eyes? And what distinct

⁵³ Dementia films have seen a veritable ‘boom’ in recent years. See, among others, *Away from her* (Polley 2006) and *The Notebook* (Cassavetes 2004), as well as biopics such as *Iris* (Eyre 2001), *The Iron Lady* (Lloyd 2011), and *Robot and Frank* (Schreier 2012). Furthermore, Alzheimer’s features in a number of science fiction films and sci-fi thrillers, in each case involving the trope of animal experiments for a new Alzheimer’s drug that spiral fatally out of control.

affordances for the arousal of empathy and for exploring the experience of dementia does each medium provide?

After engaging with these questions, I investigate how experimental fiction may be able to expand the limits of representing the symptoms of dementia in narrative form. I address how these texts may contribute to the current theory of narrative empathy via the dementing and partially unreliable narrator in J. Bernlef's *Out of Mind* (1988) as well as the configuration of multiple interior monologues in the stream of consciousness style used by B.S. Johnson in *House Mother Normal* (1971). Then, in the concluding section of the chapter, I discuss the effect of narratives that do not explicitly thematise dementia but may nonetheless be read through the lens of neurodegenerative decline. To this end, I argue that Kazuo Ishiguro's novel *The Unconsoled* (1995), although not explicitly labelled and marketed as 'dementia narrative,' may be productively read as an exploration of the phenomenology of dementia. More specifically, I suggest that this novel's manifold textual ambiguities afford opportunities for empathetic engagement through 'parallel experience' (Toker 1993). I suggest too that the novel's resistance to being fully 'naturalised' as a dementia narrative in fact opens up the possibility for the reader to come close to the existential uncertainty that living with dementia entails. In a condition like dementia, where sufferers may at some stage no longer be able to articulate what it is like to be living with this disease, works of fiction like Ishiguro's may afford special insights into what it's like to have or experience this illness.

***Still Alice*: From Fiction to Film**

Still Alice tells the story of the fifty-year-old cognitive psychology professor Alice Howland who, in mid-career, is diagnosed with early-onset Alzheimer's disease. The narrative explores the link between neurons, memory, and identity. Further, the narrative hones in on how the social world of a person with early-onset Alzheimer's changes: how the disease alters and inverts both professional and personal relationships; and how the entire family is affected by the onset and progress of the disease. Yet *Still*

Alice—both in the novel and to a lesser but still noteworthy extent in the film version—does not focus on the experience of the people surrounding the person with dementia. Although the novel uses a third-person narrator,⁵⁴ events are largely focalised through Alice. Hence the symptoms—such as night-time wandering, confusion, or misinterpretations of reality—are viewed from her point of view.

Alice's symptoms thus enter into the composition of the narrative discourse. For instance, when Alice's thoughts begin to circle around, the narrative mirrors this symptom with almost verbatim repetitions of her thought processes. Yet the reader, briefed by the dust jacket and the prologue, has a better awareness of what is happening than the experiencing protagonist. This set-up frequently leads to instances of dramatic irony, where the reader knows things in excess of what the character knows. Such irony, however, limits the potential of the novel to portray an inside view of living with dementia. The evocation of 'parallel experience,' whereby readers are placed in an 'intellectual predicament analogous to that of the characters' (Toker 1993: 4), is restricted to only very brief moments of confusion, when there is a lack of information about some aspect of the storyworld. Such moments are usually resolved quickly. Generally, Genova uses detailed descriptions of contexts and characters to allow the reader to infer events or to identify characters, even when Alice no longer recognises them.

That said, parallel experience—or feeling 'as' the character does—may not be necessary in order for the reader to feel 'with' and 'for' Alice. Even though the novel does not elicit the *same* mental confusion in the reader as Alice experiences, it nonetheless presents a rich account of how the life world of the person with dementia changes. Seeing and experiencing these changes from Alice's point of view, and being privy to her thoughts and emotions, highlight the psychological impact these changes have on her

⁵⁴ In Genette's terms (1972), this narrator would be categorised as heterodiegetic as well as extradiegetic—that is, as a narrator who is not involved in the events being reported, and who is furthermore not a character in the storyworld who functions as an embedded teller in his or her own right. In this thesis, however, in discussing texts where the finer distinctions Genette's framework offers are not necessary, I mention the relevant narratological descriptors only in passing, while reverting to Genettean terminology when it is required or productive for my analysis.

sense of self and self-esteem. The use of internal focalisation raises the reader's awareness of some of the degrading and painful aspects of living with dementia: the hurt inflicted at being ostracised by her former colleagues and the emotional pain of witnessing her husband's growing estrangement from her, the deflating experience of neuropsychological testing or of being patronised by others, the despair at losing control over her bladder and her words. Indeed, the double perspective of seeing with but also knowing more than the protagonist allows for the reader to engage with the character with dementia while remaining aware of her own perspective. We are offered a certain degree of (imaginative) insight into what it feels like to have dementia, and yet we are the non-dementing other(s) ready to identify also with Alice's family, friends and colleagues. Thus, we are offered an insight into how 'our' behaviour is perceived, critically at times, by the person with dementia (see Bitenc 2012: 315).

The theory of narrative empathy needs to address this double perspective. Rather than defining empathy strictly as the experience of sharing the *same* feelings as the character, the dual perspective that reading narrative fiction promotes may elicit feelings of sympathy, pity or compassion on behalf of the character. Keen, in her study of narrative empathy, acknowledges that the term empathy is frequently used synonymously to sympathy; but she argues for a stricter definition of empathy as a 'vicarious, spontaneous sharing of affect' (Keen 2007: 4) in which 'we feel what we believe to be the emotion of others' (5). That is, she distinguishes between 'I feel your pain' as an example of empathy, and 'I feel pity for your pain' as an example of sympathy, or 'empathic concern' (4; 5). Despite this initial distinction, however, her account frequently conflates the stricter sense of empathy with a broader understanding of the term.

More generally, the current definition of narrative empathy lacks the necessary precision to disentangle the subject position of the empathiser from the 'object' of empathy. As hinted at in my formulation above, I suggest that the stricter notion of empathy may be better defined as feeling 'as' rather than feeling 'with' the character. Such experiences of 'feeling (exactly) as' another are likely very rare—if not impossible. Feeling 'with' or 'for' a character—and here I would use the terms sympathy, pity, and

compassion, despite their current unfashionableness in literary criticism—is a pervasive element of reading fiction. These terms register how the reader necessarily inhabits both her own subject position and that of the imagined other. Since empathy is the accepted term to discuss these types of reader emotions with regard to fictional characters, I retain it in my discussion. Nevertheless, I attempt to clarify when a textual strategy or filmic technique elicits empathy as synonymous with sympathy and when it is more likely to provoke an experience of ‘feeling as’ the character, roughly in line with Toker’s notion of parallel experience—that is, where the narrative discourse is organised in such a way as to evoke a similar cognitive experience in the reader as that of the character. Toker’s emphasis on cognitive experiences is crucial to considering the use of narrative empathy in narratives concerned with representing neurodegenerative decline. Are we made to feel (confusion, frustration, panic) as the character does, or are we, primarily made to feel pity for the character’s situation? At the same time, Toker’s concept highlights that the current theory of narrative empathy needs to address the wide spectrum of emotions and states of consciousness that literary narrative evokes.

Both the film and novel represent a wide array of experiences of living with dementia—both in terms of its symptoms and in terms of its impact on the social sphere. In comparing the two versions, it is productive to focus on select examples that illustrate some of the parallels and the contrasts between the textual and the audio-visual medium. Overall, the 2014 film adaptation of *Still Alice* remains remarkably close to the original text. Some minor changes and a number of omissions necessitated by turning a 300-page novel into a 90-minute film—do not significantly alter the text’s main storyline or its key thematic concerns. What is more, as shown by additional material on the DVD, the producers and director seem to share Genova’s concern with presenting this story from Alice’s point of view. The novel allows insight into Alice’s thoughts through frequent use of free indirect discourse and direct thought representation. Short of using either a narrative voice-over to communicate her thought processes, or filming all scenes as if from Alice’s eye-line, there is no obvious one-to-one method of transposing the novel’s ‘inside view’ in film. Granted, the film does use a number of

over-the-shoulder-shots, which roughly align the viewer with the protagonist's perspective; yet it largely employs medium-distance shots of Alice. We do not literally inhabit Alice's point of view, but instead read her mind and emotions through close scrutiny of her body language, facial expression, or tone of voice. This occurs much in the same way as we read other people's thoughts, intentions or emotions in real life, according to contemporary phenomenologists. The use of close-ups or portrait position in moments of emotional intensity allow the viewer close scrutiny of her facial expressions and gestures. So for instance, during a visit to her neurologist, the camera rests on Alice throughout the entire dialogue. The neurologist's voice comes from off-screen, allowing (or compelling) the viewer to focus on the impact that his words have on Alice. We discern how the questions of the mini-mental state examination (such as, 'Where are we?' 'What day is it?') seem laughable or demeaning to Alice. We also read in her face her embarrassment at being asked to bring someone with her to all subsequent appointments. In the novel, these thoughts and feelings are verbalised, but the visual representation is no less effective.

If we consider recent research on mirror neurons, and Keen's exploration of motor mimicry as a basic form of empathy, we can also see why film may evoke strong emotions in the viewer.⁵⁵ Witnessing Alice's struggle, as she has to inform her three children that early-onset Alzheimer's is genetic and that they have a fifty percent chance of inheriting the disease, is heart-rending. Similarly, her daughter Lydia's pained reaction, as she realises that her mother has just failed to recognise her for the first time, may evoke a strong emotional reaction in the viewer, resulting in empathy not only for Alice's plight but for the ways others are affected by her disease.

Nevertheless, while adept at evoking empathetic concern in the viewer, there are instances where the film seems less effective at portraying an inside experience of the disease than the novel. For example, when Alice loses her bearings while running a familiar route, the film employs a number of techniques to evoke a sense of this experience: the music soundtrack

⁵⁵ For an introduction to mirror neurons see Iacoboni (2008).

becomes eerie and discordant, the sound of Alice's breathing comes to the foreground and communicates something of her panic, and the camera lens goes out of focus [10:05]. However, the sense of being lost—recognising individual buildings but not being able to place them in relation to a mental map—is not very effectively evoked by this representation. The lack of focus in the visual field of the camera is more evocative of vertigo than of the feeling of being lost. And, compared to the novel, the lasting emotional impact of the experience, even after Alice has recovered her bearings, is glossed over.

The novel is also more effective in simulating how Alice becomes lost in time. As described in the previous chapter, one of the challenges of dementia is that, as recent memories become affected, people with dementia may come to live in multiple, competing time frames. Here the novel's use of thought representation is particularly salient. Thus, at one point the narrator reports Alice's thought that '*Anne's going to be so jealous*' (282; original emphasis) when, in fact her sister Anne has been dead for 30 years, thereby signalling that Alice is experiencing life through her childhood time frame. In returning to her childhood, Alice cannot yet know that her mother and sister died in a car crash in her college years. When confronted with the reality of their death, she re-experiences her initial despair and sense of loss: 'Lydia was talking to her, but Alice couldn't hear what she was saying. She could only feel the rage and grief coursing through her every cell, her sick heart, and her hot tears, and she could only hear her own voice in her head screaming for Anne and her mother' (2007: 156). Significantly, this confrontation with what to her is a new piece of information is also one of the instances that suggest that Alice's differing view of reality may lead to a sense of paranoia:

John stood over them, drenched.

"What happened?"

"She was asking for Anne. She thinks they just died."

He held her head in his hands. He was talking to her, trying to calm her down. *Why isn't he upset, too? He's known about this for a while; that's why, and he's been keeping it from me.* She couldn't trust him. (Genova 2007: 156; original emphasis)

While the novel does not explore the problem of paranoia further, it raises the issue of how to deal with situations when the perception of reality by the person with dementia and by family caregivers diverges. The question arises as to whether to ‘go along’ with delusions, misconceptions or confabulated memories or whether to confront the person with dementia with the caregiver’s view of reality. ‘Validation therapy,’ as developed by Naomi Feil (1989, 1992), argues we should acknowledge and validate the point of view and emotions of the person with dementia. However, this may not always be a straight-forward possibility and may, at times, as Sue Miller suggests in her memoir of her father’s dementia (2003), even be harmful. *Still Alice* validates the perspective of the person with dementia by foregrounding her point of view above all others. The novel thereby makes the emotional reactions of a person with dementia understandable. Genova’s strategy here could be described in Keen’s terms as either ‘ambassadorial strategic empathy’ or ‘broadcast strategic empathy’ in that it calls upon readers who are not suffering from dementia ‘to feel with members of a group [here: early-onset Alzheimer’s patients], by emphasizing common vulnerabilities and hopes through universalizing representations’ (Keen 2007: xiv). Most people, at some point in their life, lose a family member. By highlighting how Alice experiences the concomitant feelings of despair afresh due to her memory disorder, readers may come to feel sympathy for her pain, rather than dismissing it as delusional. However, the novel also pinpoints the difficulties of finding common ground in such cases of ‘diverging realities.’ In this example, for instance, it may be impossible for Alice’s husband John to experience, or convincingly feign, sorrow at an event that happened three decades earlier. It remains an open question as to how to respond to the divergent perceptions of a person with dementia; what this novel does suggest is that people with dementia remain ‘semiotic subjects’ (Sabat and Harré 1994) and that their views and perceptions should be taken into account and met with respect.

At the same time, there are aspects of the filmic representation that, arguably, go beyond the limitations of novels. For example, the film can portray the extent to which the physical capabilities of a person with dementia are affected by the disease, leading to apraxia. We witness, for

instance, how Alice eventually requires help getting dressed, since she is no longer capable of planning the order in which to put items on nor the movements required to do so. At the same time, the way her husband John overrides her choice of clothes in this scene, highlights how pervasive the loss of autonomy can be in dementia [1:16:38]. Although Alice can still make a choice and expresses her preferences, her wishes are ignored. The film manages to capture how easily even apparently benign actions, such as helping a person to get dressed, can contribute to the infantilisation of people with dementia.

Further, while the novel glosses over Alice's growing apraxia, the film highlights the extent to which Alice struggles with routine tasks. Towards the end of the film we are shown with what difficulty Alice ties her shoe laces. Her limber and confident movements from earlier in the film have slowed to a shuffling pace. Alice barely speaks and has difficulty getting words out. In the novel, the impact of Alzheimer's on physical abilities is hardly hinted at. Alice seemingly moves without difficulty; at the end she can still carry and handle a small baby without problems. Arguably, the fluent third-person narrative, with but a few hints of Alice's word-finding difficulties incorporated into the discourse, masks the more global deterioration in Alice's abilities. This does, however, allow Genova to avoid stereotypical representations of people with late stage dementia. In this respect, it may be considered either a strength or a weakness of the novel that it ends before Alice enters the final stages of her disease.

The filmic representation, with Alice vacantly shuffling along beside her caregiver, may confirm common stereotypes of people with more advanced dementia as 'empty shells' or 'zombies.' However, the film also works against such assumptions by highlighting how Alice can still recognise and name emotions—significantly, love—in others and in herself. Nonetheless, it is somewhat disturbing that the closing scene in both film and novel suggests that in order for the subjectivity of the person with dementia to be recognised she must still be able to interpret and use words meaningfully. In the epilogue to the book and the final scene of the film, Alice's youngest daughter Lydia acts out a monologue from one of her plays in front of her mother. Lydia then asks her mother to tell her how it

makes her feel, what it is about. In each case, Alice identifies the emotion as ‘love.’ The scene suggests that even a person with limited language capacities can still understand and express emotions. Yet it is problematic that Alice needs to be able to articulate her feelings and her understanding of other people’s feelings in order for her to be recognised as a sentient human being.

Even though *Still Alice* emphasises the importance of linguistic expression, the narrative also asks us to consider more holistically how love and relationships play out in the context of dementia. Alice is still able to feel love and to respond emotionally to her family caregivers. As exemplified in this exchange, Alice’s youngest daughter Lydia finds new ways of engaging with her mother and continues to recognise her mother’s subjectivity. *Still Alice* suggests that our identities, though seemingly rooted in professional roles and our own memories, reside equally in our everyday encounters with others and our capacity for relationships. Relational identity here works in two ways. The daughters not only honour their historic relationship with their mother, but also validate a new form of relationship with her, which is not based on her role as mother or her ability to recognise her daughters. In the novel, Alice is represented as a capable advice giver, despite her otherwise limited capacities, and she provides comfort and love to her grandchildren. The film, perhaps more realistically and less sentimentally, underlines Alice’s capacity to engage with others in the moment. Her relational identity, and her humanity, are enacted in such encounters with others.

Experiencing Dementia/Experimenting with the Novel

In this section, I turn to the question of how certain authors have aimed to extend the limits of representing the experience of dementia, especially the later stages, in verbal narrative. What techniques, within the limits of verbal narration, do these authors find to represent such symptoms as the loss of language, the loss of a coherent life narrative and the loss of the feeling of groundedness in everyday life? What aesthetic and ethical challenges does the imaginative engagement with later stages of dementia pose? Further, I

ask how narrative fiction that engages in more experimental modes of representation may expand the current understanding of narrative empathy. Contrary to Keen's view, which suggests that avant-garde texts, in emphasising defamiliarisation and a shock aesthetic, undermine empathetic reading (or viewing) experiences, I show how literary experimentation may, on the contrary, lead to the kind of empathetic experience, or experience of 'feeling as,' that Toker describes as parallel experience; that is, the reader may be said to experience similar epistemological uncertainty as the character with dementia.

Out of Mind

J. Bernlef's novel *Out of Mind* (1988)⁵⁶ follows a number of months in the life of Maarten, a 71-year old Dutch retiree, who emigrated to the United States during mid-adulthood. It remains one of the few texts that uses a first-person narrator with dementia.⁵⁷ From the start, we are plunged into the immediate thought processes of the first-person narrator, who, even though he is in Genette's terms an autodiegetic narrator telling his own story, remains unsure and indeed wrong about a number of aspects of his situation, such as the time of day and day of the week. In using 'concurrent' present tense narration (see Margolin 1999), the narrative resembles a series of diary entries. The use of concurrent narration has significant effects on the narrative; it contributes, for instance, to a sense of immediacy. More importantly, perhaps, in contrast to retrospective first-person narration, there is no distance between the 'narrating-I' (who has a fuller understanding of events) and the 'experiencing-I.' Yet an organising consciousness can

⁵⁶ J. Bernlef is the pseudonym of Dutch author and poet Hendrik Jan Marsman. The novel was originally published in 1984 as *Hersenschimmen* by Em. Querido's Uitgeverij B.V., Amsterdam.

⁵⁷ See Richler (1997), LaPlante (2011) and Healey (2014). All three novels revolve around a crime story. In each case, the epistemological uncertainty that Alzheimer's entails in the first-person narrator is used to increase suspense. Roy (2009: 50) argues that Richler employs dementia as a narrative device to query, in postmodern fashion, whether there is ever a 'true' version of events. LaPlante and Healey, by contrast, engage more deeply with the question of what it's like to suffer from dementia. Alzheimer's does not function merely as 'narrative prosthesis' (Mitchell and Snyder 2001: 47; qtd. in Roy 2009: 44), but instead the authors employ the murder mystery plot in order to explore the phenomenology of dementia. For a crime story with a heterodiegetic or third-person narrator that uses Alzheimer's as plot device, see Suter (1997).

nonetheless be discerned behind the novel, one which makes the narrative intelligible to the reader.

An example from the text illustrates how the use of present-tense narration and Maarten's lack of insight into the situation affect the narrative. While out for a walk with his dog, the retired Maarten comes to believe that he is on his way to a work meeting. Maarten seems simultaneously aware and unaware of the strangeness of the situation: 'I am the first to arrive, I can tell from the virgin snow all around. It is *perhaps a rather strange* and yet quite suitable place for an IMCO meeting, so close to the sea' (Bernlef 1988: 33; my emphasis); 'from time to time I glance briefly over my shoulder, because for the secretary to a meeting to be forcing a door open is not an everyday event, *I realize that*' (34; my emphasis). When he becomes fully aware of his situation—namely that he is retired and has broken into a holiday residence—he is overcome by nausea:

I just manage to reach the porch. As I hang over the rail my stomach empties itself into the snow, a mucky brown, steaming pulp in which even Robert shows no interest. I feel cold.

What am I doing here? In the summer, people from Boston live here. (35-36)

The present tense here heightens the sense of immediacy and adds to the build-up of dramatic tension. It also allows the reader to follow the workings of Maarten's mind, and emphasises the acute pang he experiences when he becomes aware of his delusion. However, it is important to note here that this is, of course, not the same as not knowing what is going on and therefore experiencing the situation *as Maarten does*. The reader remembers Maarten is a retiree and realises that Maarten's memory loss distorts his reality.

What happens, then, as Maarten's cognitive decline accelerates and his narrative becomes more and more fragmented, enigmatic and idiosyncratic—and therefore more difficult for the reader to decode? Bernlef's narrative techniques could be described as promoting parallel experience: at this stage in the narrative both the reader and the first-person narrator experience a sense of disorientation, the narrator-character with regard to his (fictional) reality and the reader in decoding the narrator's words. Nonetheless, the effect is not perfect since a number of techniques

ensure that despite the narrator's decline the process of narrative transmission does not break down (Bitenc 2012: 308; 309).

Providing detailed descriptions of the storyworld is one such technique. Maarten minutely describes his perceptions and, in that sense, remains a 'reliable' narrator. Given that Bernlef's readers do not suffer from short-term memory loss, they will be able to identify characters by their clothes or other characteristics, or remember what has happened recently, even when Maarten does not. Also, the author uses line breaks between paragraphs to signal that story-time has passed. When Maarten experiences a time shift that returns him to his kindergarten days, this, on the contrary, occurs seamlessly within the space of a short paragraph (Bernlef 1988: 5). Most notably, towards the end of the narrative Bernlef employs the use of brackets to indicate how Maarten retains dual awareness (as expressed, for instance, in second-order thoughts), even as his narrative disintegrates. The narrative voice here becomes split between a more confused version in the body of the text and a more lucid version in the brackets: 'The blonde girl from earlier (so I can remember her for a while at any rate) gets up and goes to the hall.' (104); 'And a chair. (Was it already there or has it just been pushed forward?) I sit down. Notice that the rubbing has resumed. Not unpleasant actually' (100). Here Bernlef begins to drop the first-person pronoun and to employ short and sometimes fragmented sentences in order to mimic the decline in Maarten's linguistic abilities and the growing incoherence in his thought processes.

Towards the end of the narrative the voice in brackets—and the narrative as a whole—increasingly employs the imperative mode. Indeed, as the first-person pronoun is dropped in favour of 'he' or 'it,' the imperative mode seems to indicate the last vestiges of Maarten's first-person narrative voice. It seems as if Maarten is speaking to himself, trying to make his (uncompliant) body do what he wants it to do. The third-person pronoun indicates his growing sense of loss of self, and self-control. Nevertheless, the perspective on the world or, as phenomenologists put it, the first-personal givenness of experience, remains his own: 'Hands and feet it must have ... eyes open and shut: same place ... eyes open and shut again: same place' (122). Despite the technique of fragmentation and the emphasis on

Maarten's dissociation from his body, the way Maarten remains the centre of consciousness and perception—the being that realises that he is in the 'same place'—paradoxically highlights his continuing identity, suggesting that lower-order cognitive functions might be sufficient to accord personhood to a subject. In any case, the reader continues to see him as a character, a 'person' in whom we are interested and with whom we empathise (see Bitenc 2012: 312).⁵⁸

As Maarten's symptoms of dementia progress, the narrative discourse floats in and out of first-person, second-person and third-person narration, highlighting the shifting and unstable nature of Maarten's sense of self. Through this back and forth between the first and third person the narrative does not follow a linear progression towards 'it-ness,' the vacant 'empty shells' of many contemporary representations of dementia, but highlights instead the narrator's persisting subjectivity.⁵⁹ In this part of the narrative, also, embodiment is foregrounded. For instance, Maarten begins to rely on physical sensations to feel himself, to feel at one with his body: by rubbing his hands on his legs, or even pinching himself (see 124). Maarten attempts, even in the later stages of the disease, to make use of any opportunity to recapture his former sense of self, and the 'blissful feeling' of being one with the world:

Get up, *you* ... go and inspect that piano from close by... *he* walks to the little steps by the side of the stage ... toilingly clambers up ... keys that go up and down all by themselves [...] perhaps they can help *your* fingers ... teach them perhaps to play again ... to play from memory again ... that blissful feeling that *your* body is playing you ... that you yourself have become music. (128; my emphasis)⁶⁰

The shift from the third-person pronoun 'he' to the second-person pronoun 'you' and possessive 'your' holds out the possibility that Maarten may

⁵⁸ Damasio's differentiation between 'core' and 'extended consciousness'—and the associated notions of 'core' and 'extended selfhood' (2000)—provide useful concepts to reconceptualise (self-)consciousness in dementia. The concept of core consciousness may however feed into dehumanising discourses about people with dementia, since animals share core consciousness with humans.

⁵⁹ Krüger-Fürhoff similarly argues that the novel imagines 'a view from within that bears witness to the successive breakdown of perception and coherent language, but not of the protagonist's self' (2015: 105). Nevertheless, she asks whether Bernlef's aesthetics—drawing on modern and postmodern literary techniques such as 'stream of consciousness, semantic destruction, and alienation' are convincing 'on an ontological level' (104).

⁶⁰ Since the ellipsis here are part of the original, I use square brackets, here and elsewhere, to indicate where I have omitted text.

overcome his sense of alienation from his own body. However, the pianola, with its own 'agency,' impedes Maarten's attempt to feel at one with the world: 'he sits down on the chair in front of the piano and feels the keys knocking against his fingers ... they push you away ... rebuff you' (128). Right after this passage, in fact, one of the most objectivising moments of the entire narrative takes place:

They take it to a space where there are beds ... they make it sit on the edge of a bed ... they undress it ... they put pyjamas on it that look like the pyjamas of those other men with their big, staring, half-bald heads on the tall, white pillows and all turned towards him ... they push a pill into his throat ... they pour water through it as if he were a funnel ... they lay him in the bed ... they walk past the row of beds together ... they are silent until they reach the door and call out together good night GOOD NIGHT they call and then it is dark. (129)

The next paragraph begins with the eerie sentence 'There is breathing everywhere.' Like Mrs Gradgrind in Dickens' *Hard Times* who on her deathbed pronounces that 'I think there's a pain somewhere in the room ... but I couldn't positively say that I have got it' (Dickens 1854: 191), Maarten seems to have lost the sense of himself and others as distinct persons. Nevertheless, the narrative itself upholds and communicates his subjectivity. The reader continues to read the words on the page as the perceptions, thoughts and feelings of Maarten's consciousness. As Alan Palmer argues in *Fictional Minds* (2004) it takes very little (a personal pronoun, a name) for readers to project the extended consciousness of a character in fiction. Importantly, since readers are given insight into Maarten's thought processes, even as these become less coherent, they are likely to be able to decode the little language Maarten still uses when talking to his caregivers. In narratives focalised through the eyes of the caregiver, such as Michael Ignatieff's *Scar Tissue*, the reader, together with the caregiver, can only speculate on whether the utterances of the person with dementia make any sense. Narratives such as Bernlef's are thus ethically important in suggesting that the enigmatic utterances of people with dementia have meaning when we take into account the person's life history and their current perception of the world. Such narratives suggest that rather than automatically disregarding the seemingly incoherent utterances of people

with dementia, it is imperative to try and make sense of them as best as possible.⁶¹

The closing paragraphs of the novel highlight the important role that respectful and gentle physical contact plays in the care of people with more advanced dementia, while also emphasising the importance of relationships. During the night Maarten seeks the hand of an unnamed woman (possibly Vera or his mother), to find, perhaps the hand of another male patient, or more likely his own. In any case, Maarten experiences the physical contact as reassuring:

... she is among them somewhere... seek her... her hand we must seek ... this takes time [...] her hand will come to you ... here ... first take that hand that gropes aimlessly in the dark ... take it gently ... calm him ... now you no longer need to hold anything yourself ... she will do that from now on ... she carries you ... I carry you ... little boy of mine ... the whole long frightening night I will carry you until it is light again. (129)

Again, the present tense highlights how Maarten experiences the past as the present. He seems to have returned to the scenes of early childhood where a loving female takes care of him. When on the following morning his wife Vera comes for a visit, it is clear that although Maarten does not recognise her voice, he takes comfort in her visit and in listening to her hopeful tale of renewal and repair:

When it is already light and GOOD MORNING and someone says ... whispers ... the voice of a woman and you listen ... you listen with closed eyes ... listen only to her voice whispering ... that the window has been repaired ... that where first that old door had been nailed ... there is glass again ... glass you can see through ... outside ... into the woods and the spring that is almost beginning ... she says ... she whispers ... the spring which is about to begin ... (129)

It is notable that the novel ends with a section that is not only more coherent than many preceding it, but also inherently hopeful. Despite the excruciating pain and confusion that have gone before, the nature imagery which closes the novel suggests a positive outlook on dementia. Arguably, Maarten's increasing loss of self-awareness and return to his childhood self allows for a more tranquil experience of his world. Maarten no longer perceives his environment through the traumatic experiences of World War II. (For a time,

⁶¹ See also my discussion of collaborative life story work in chapter 3.

possibly because they are speaking American English, Maarten mistakes both doctors and nurses for his ‘liberators’ and is worried that they will treat him as a Nazi collaborator.) While the ‘metaphorical spring in dementia’ that the narrative’s ending projects may resemble the more tranquil period towards the end of the disease that many caregivers describe, it also risks underestimating the continued potential for suffering in the person with dementia. Caregivers’ memoirs, such as Sally Magnusson’s *Where Memories Go* (2014), are powerful reminders that the last stages can be anything but painless. Yet, overall, *Out of Mind* questions the commonplace that the person with dementia loses all sense of awareness and the caregiver suffers more than the care-receiver. Fictional and non-fictional dementia narratives alike help expose such preconceptions as misrepresentations of the experience of dementia.

House Mother Normal

If the publication of *Out of Mind* coincides with the rise of the Alzheimer’s disease movement in the eighties, then B.S. Johnson’s experimental novel *House Mother Normal* (1971) predates, by a decade, the growing contemporary concern with dementia. Nonetheless, *House Mother Normal*, in its medicalised understanding of dementia and its acutely contemporary concern over the running of care homes, resonates with contemporary explorations of dementia.

Johnson’s novel consists of a frame narrative by the house mother of a care home and eight twenty-one-page-long interior monologues by the elderly patients in that home, presented in stream of consciousness style. Each of these narratives tells of the same sequence of events: dinner, ‘work’, ‘exercise’ and ‘entertainments.’ As we come to see these events through different characters’ minds, we are able to piece together a sense of the actual events in the storyworld. The technique is similar to that found in modernist texts, such as William Faulkner’s *The Sound and the Fury* (1929/1995), where we come to make sense of the narrative of the mentally disabled character Benjy through subsequent retellings of the same events by other characters in the storyworld. Here, compared to Faulkner’s novel,

the strategy of distributing *fabula* details is inverted, since we start out with the accounts of more verbally coherent characters and move towards those of the most severely cognitively impaired characters, George Hedbury and Rosetta Stanton. Importantly, Johnson exploits the over-determined narrative structure in order to enhance the reader's mental map or situation model of the storyworld (Bernaerts 2014: 298). Not only do all narratives treat the same sequence of events, but the number of pages on which these events are evoked correlate with each other. So page 5 of each narrative relates to the moment in which the house mother gets her patients to sing the 'house hymn.' One of the effects of this '3-D reading experience,' as Lars Bernaerts calls it (2014: 298), is that we can complete the narrative 'puzzle' by referring back and forth between pages. This narrative reconstruction is particularly important vis-à-vis the most fragmented and incoherent narratives towards the end. Johnson's narrative structure also ensures that the reader continues to attribute consciousness to or project 'experientiality' (Fludernik 1996) onto word fragments, nonsense words and even blank pages (see also Bernaerts 2014: 297; 305).

The text further differs in technique from the *Sound and the Fury* in that the patients' narratives are framed by the house mother's prologue and epilogue—the latter providing her version of the evening's events. 'You shall see into the minds of our/eight old friends, and you shall see into my/mind,' (5) the prologue reads. The instances of metalepsis in her narrative, i.e., the moments where different narrative levels and the ontological level occupied by the author get entangled with one another (Pier 2013), draw attention to the ways the supposedly mimetic 'insights' into each character's mind are mediated not only by the house mother, but, in the final instance, also by the author: '(you always knew/ there was a writer behind it all? Ah, there's/ no fooling you readers!)' (204). Each of the patients' narratives is further framed by introductory remarks similar to case notes or patient charts; these notes include age, marital status, percentage of sight, hearing, touch, movement, while also providing a list of the various diseases the patients suffer from. Importantly, a cognitive quotient (CQ) count—which could be compared to a score on a mini mental state examination—indicates the severity of the character's dementia. While,

according to Bernaerts these ‘ironic’ introductions set up ‘a frame through which the fictional minds can be constructed and interpreted’ (300) (since we know that we are moving from the least to the most severely cognitively and physically impaired narrator), this play with genre has the further effect of highlighting the insufficiency of reductionist medicalisations of human experience. The mimicry of contemporary patient charts, which supposedly contain all relevant information about the human subject, is contrasted directly with a rich phenomenological approach to embedded, embodied and extended human minds.⁶²

As is obvious even from this brief description of the text, the novel plays with numerous genres—most notably drama—and is at several removes from the conventions of the realist novel. Through the house mother’s direct address to the reader the novel deliberately draws attention to its constructed nature. Furthermore, Johnson exploits fonts, formatting and numerous other material textual features to explore the ‘qualia’ of the subjective experience of dementia (see also Bernaerts 2014: 305). Line breaks, indents, different fonts and the blank page indicate gaps, jumps, or slowness of processing in the character’s consciousness. Indeed, Johnson uses a number of strategies and techniques, which Monika Fludernik terms ‘typification,’ to create ‘a fiction of authenticity’ (Fludernik 1993: 17, 19, qtd. in Herman and Vervaeck 2005: 95). Typical, clichéd turns of phrase and stylistic means that are supposedly inherent in oral language—such as swear words, exclamations, garbled syntax, hesitation, non-sequiturs and so on—are employed in order to give the reader the sense that a representation is true to life (Herman and Vervaeck 2005: 96); in this case the technique is used to evoke a sense of how the mind of a person with dementia may work.⁶³

⁶² See Charon for the shortcomings of hospital charts in providing sufficient information about the patient as a basis for an empathic healing relationship (Charon 2006: 140-148). Charon develops the practice of ‘Parallel Chart’ writing to address the phenomenology of illness and she demonstrates how this practice yields clinical benefits (173-4).

⁶³ Given that people in the later stages of dementia struggle to verbalise their experiences, it is important to ask: by what standard do we measure the verisimilitude of these interior monologues, or their hypothesised closeness to the phenomenology of dementia? These interior monologues mimic actual speech acts of people with dementia, such as the fragmented speech and repetitive style of reminiscing, recorded in social science research (Hydén 2010, Hydén and Örvulv 2009, Örvulv and Hydén 2006, Usita 1998) and

The narratives represent a blend of immediate perceptions of the character's current environment—those relating to ongoing activities—with what might best be described as reminiscences or associative thought. Bernaerts (2014) notes that earlier readings of the novel may have over-emphasised the element of 'memory narratives' or reminiscence in *House Mother Normal*. His own reading, drawing on cognitive models, instead emphasises the embodied nature of these fictional minds. He argues that by highlighting perception and emotion, Johnson underscores the characters' engagement with their environment and their 'action-oriented thought and plans or scenarios for the near future' (307). 'Memories (in particular memories of relationships and traumatic memories)', Bernaerts writes, 'are an important part of the minds evoked in *House Mother Normal*, but they alternate with thought induced by perception and oriented toward action, which brings the pensioners' minds back to the present' (307). Johnson employs this 'past-present-future' continuum (307) as exploratory modelling of the phenomenology of embodied minds affected by dementia.

The monologues, furthermore, include snippets of direct speech (marked by italics) and highlight the extent to which each fictional mind represents an 'embedded' and 'social' mind (Palmer 2004). Each character's consciousness is shaped by social norms and perceived wisdom and includes the perceptions of other characters' minds. The reader comes to see how characters respond to each other with either sympathy or dislike. Also each character evaluates the same situation differently, based on their personal characteristics and values. As Bernaerts notes, fear and feelings of disgust towards the house mother are among the most pervasive and strongest emotions evoked and 'enhance the dynamics of the characters' mental action' (305). And yet, characters differ significantly in their evaluation both of the house mother and of her sardonic entertainments. These evaluations contribute to the complex individualised portrayal of each character's consciousness, while also shaping the reader's evaluation of the ethics of the narrative.

collaborative life writing (Clegg 2010). The disadvantage of judging verisimilitude of consciousness representation on the basis of actual speech is that it presumes that thought is necessarily or (primarily) verbal.

The novel's focus on a relatively brief space of time in the storyworld allows for detailed, seemingly real-time descriptions of thoughts and events. *House Mother Normal*, compared with other dementia narratives, is less concerned with maintaining a protracted narrative arc in which the character's progressive decline is portrayed. The text can thus explore the limits of language and coherence to a greater degree than other texts. If George Hedbury's narrative is, towards the end, marked by almost blank pages and only a few words, his fragmented language still makes sense insofar as readers have been 'briefed' about what is going on by other narrators. So, for instance, the following fragment refers to the house mother's vile game of 'pass the parcel':

Package

for me pass, parc
 what?
 (152)⁶⁴

Similarly, the following passage may be seen to evoke George's sense of disorientation at suddenly finding that he is being pushed around in his wheelchair during the 'exercise' routine.

name it

moving moving!

everything's moving!

?

(153)

Most notably, perhaps, George's internal cries of pain (155) during the cruel game of a wheelchair tournament starkly emphasise his continuing capacity to suffer. The representation of his pain contrasts with the outside perspectives (both sympathetic and unsympathetic) offered to the reader in previous accounts. Since George does not utter a word he seems, in other narrators' accounts, 'alright' (23).

As noted previously, the narrative progresses from the most mentally able to the most severely demented character. Rosetta Stanton's 'medical

⁶⁴ While my quotations do not represent exact replicas of the original formatting, I follow the original text as closely as possible when doing so is relevant for my analysis.

chart' suggests a drastic stage of decline with her physical capacities ranked around five percent and her CQ count at zero. The first fourteen pages of her account contain only snippets of what to an Anglophone reader appear to be nonsense words, dispersed across an otherwise empty page.⁶⁵ However, on page fourteen, as she is addressed directly by Ivy Nicholls who is pushing her wheelchair during 'exercise,' Rosetta's 'narrative' suddenly becomes coherent: In response to Ivy's question '*How are you Mrs S?*'—which the reader will either have remembered or can return to on the corresponding page of Ivy's account—Rosetta's internal monologue reads:

I a m
t e r r i b l e, I v y.
(175)

Indeed, this passage is in ironic contrast to Ivy's account. Following her questions to Rosetta, Ivy's monologue continues: 'No answer. I have never heard her speak since I came here CAN'T HEAR A THING CAN YOU, MRS STANTON?' (65). However, Rosetta's internal monologue proves Ivy wrong:

N o w I c a n e v e r y
w o r d y o u s a y .. I am a prisoner in my
self. It is terrible. The movement agonises me.

Let me out, or I shall die (175-76)

Here Johnson is drawing on a common trope of dementia narratives. While some accounts argue that the person with dementia has lost her self and resembles an 'empty shell,' other accounts insist that the self is 'locked into' the disintegrating body. Such accounts suggest that the person within persists, much as before, but loses the ability to communicate her subjective experience to others. Becoming a prisoner inside one's body is seen as an even greater 'horror' than the supposed state of selflessness. Johnson draws on this trope in Rosetta's monologue. In fact, he even seems to suggest that

⁶⁵ In fact, the words are Welsh and a translation of the first few words ('galluoag'-*competent/able*; 'lwcus'-*lucky*; 'ynad'-*justice* or *to judge*) suggests that Johnson is adding another layer of meaning to his multi-layered challenge to perceived norms. Johnson throughout the text inverts the sane-insane dichotomy; here by playing with the fact that English speakers without a knowledge of Welsh will read these words as nonsense when instead they make perfect sense.

her loss of consciousness at the end of her narrative—represented by six uniformly blank pages—is a last act of agency, of willed oblivion. In response to Ivy’s further conversational remark ‘DON’T GET ANY LIGHTER, DO YOU, MRS STANTON?’ (66), Rosetta responds in her thoughts:

No, I d o
 n o t g e t a n y
 l i g h t e r, I v y,
 I i n –
 t e n d
 n o t
 t o g e t
 a n y –
 t h i n g
 a n y
 m o r e

 n o
 m o r e
 (176)

How does one read the six blank pages that follow? Do they represent her loss of self? Or do these blank pages, alternatively, constitute an attempt to represent the unfathomable experience of advanced dementia? Within the structure of the novel, with a set number of pages allocated to each character, the blank pages remain significant. They are not merely empty pages but a continued representation of Rosetta’s consciousness. After first experiencing this consciousness through the eyes of others, we then communed with it and continue to engage with it, even in its ‘blankness.’ It is relevant, of course, that Rosetta’s account does not consist of blank pages from the start. We try to parse the information we do get as best we can, using the structural overlay provided by the text. The blank pages may then be read as a powerful representation of the loss of words, which is inexpressible by any other means than silence.

Of course, some readers may simply skip the blank pages; in which case they omit to ‘read’ the marked absence of thoughts or experiences that the author intended to convey. One could also argue that, here, Johnson confirms the trope of loss of self in dementia. Without actual text to represent the character’s consciousness, the character may be considered ‘as good as dead.’ Rosetta may then be seen to inhabit the same space of the ‘living dead,’ on a textual level, that people with dementia are frequently understood to inhabit. That said, in its theatricality and artistically over-determined form, *House Mother Normal* repeatedly draws attention to its constructed nature. The aesthetics embody an ethical value in that the disruption of a ‘naturalised’ or immersive reading strategy repeatedly reminds readers that they are dealing with a *representation* of dementia as imagined by a specific author in a particular cultural and literary context.⁶⁶ The novel is designed to make its readers think about the problems of representing dementia, the difficulties of accessing, inhabiting or understanding the phenomenology of dementia. If, as I have argued in relation to *Out of Mind*, such disruptions of an immersive reading experience have a distancing effect on the reader and impede emotional engagement and empathy with the characters (Bitenc 2012), the foregrounding of the narrative as textual construct nevertheless fulfils an ethical function: by problematizing their own truth-value these novels call the reader’s attention to the risk of effacing the perspective of people with dementia in narratives written as if from their point of view.

At the same time, in providing a number of ‘inside’ perspectives, Johnson not only plays these narratives off against each other, but also orchestrates the novel such that each narrative comes to inform and enrich all subsequent (re-)tellings. Therefore, the configuration of parallel narratives allows readers to develop empathy for even the most severely impaired characters. As Andrew Motion suggests in his introduction to the novel,

⁶⁶ Krüger-Fürhoff similarly draws attention to the culturally constructed nature of dementia narratives: ‘we as readers, together with the literary authors of imaginary inner perspectives, are left with what we *think* dissolution of memory and break-down of language may feel and look like. These expectations are culture-bound’ (2015: 104; original emphasis).

by the end of the book, when we are hearing from characters who are hardly able to speak, and whose states of mind are represented by blank pages, or pages on which only a few words or letters appear, we have acquired sufficient knowledge to sympathize with them despite their inarticulacy – or all the more because of it (Motion in Johnson 2013/1971: vii).

Given that even the least coherent narrative ends with a markedly coherent passage implies that even in this experimental mode, to recognise subjectivity, or to make it ‘readable,’ one must draw on coherent language. Nevertheless, in employing the associative style of stream of consciousness narratives, and emphasising the embodied, embedded and extended nature of fictional minds, Johnson pushes against the limits of conveying an ‘inside’ experience of dementia that apply to realist novels.

In vividly portraying the characters’ personal reactions to events, their likes and dislikes, their moments of pride and their fond or painful memories, Johnson also manages to evoke a deep sense of the characters’ ‘humanity.’ As Motion argues,

as we watch his characters reach into their memories and contend with their losses (of husbands and wives, of places and positions, of physical opportunity and enjoyment), we also see them struggling to preserve for as long as possible the details of their existence. Details that appear humdrum and insignificant, but are a vital means of giving shape and value to their whole existence. (Motion in Johnson 2013/1971: vii-viii)

Of course, the nature and extent of readers’ engagement will depend, as suggested by Keen (2007), both on their personal characteristics and on their reading preferences. For some, an accessible and emotive work, such as *Still Alice*, which draws on the conventions of the realist novel, may be most effective in raising awareness for the experience of dementia. A reader who shares with Alice an academic position as well as attributes of gender and age, may experience more empathic concern for the character than readers who differ from the protagonist in these respects. Similarly, reading preferences—such as disdain for anything smacking of the sentimental, or, conversely, impatience with the modes of (post)modernist fiction—will influence the reader’s manner of engagement with any given narrative. In my own reading experience more ‘experimental’ writing modes at times

turn dementia into a kind of ‘mind game’;⁶⁷ these modes, while raising interest for the symptoms of dementia, are not always conducive to empathy, or sympathy. However, these experimental modes afford innovative ways of representing certain aspects of what it might be like to live with dementia otherwise overlooked. Furthermore, they highlight the difficulties and ethical pitfalls attendant on representing people with advanced dementia who may no longer be able to express their own experience or correct the way they are represented by others. If literature provides a means of experiencing dementia from the inside out, it also suggests how the phenomenological viewpoint of actual others with dementia may be erased. Fictional dementia narratives such as *House Mother Normal* both enact such an erasure (in Rosetta Stanton’s case figured through the blank page) and draw attention to their own participation in this act. Ironically, while potentially effacing or ‘overwriting’ the subjectivity of people with dementia, these narratives also push against the effacement of these others in the cultural imaginary by fictionally giving voice to and imaginatively constructing the embodied consciousness of a subject with dementia.

The Unconsoled

I turn now to a novel that does not signal its status as dementia narrative. In Kazuo Ishiguro’s *The Unconsoled* (1995) the concert pianist Mr Ryder arrives in a central European city to participate in an event which seems of unprecedented importance to the future of this city. The first-person narrative is told by Mr Ryder himself. From the start, his telling is marked by uncertainty: by gaps in Ryder’s knowledge about his situation, his recent past, his relation to others, and the nature of what is expected from him on this visit. While the narrative is presented through the limited viewpoint of a seemingly memory-impaired (autodiegetic) first-person narrator, Ishiguro at times extends the scope of his narrator’s vision or knowledge to include an almost omniscient understanding of other characters’ perceptions, thoughts, and memories. Ryder narrates events that occur in places he is not present,

⁶⁷ Bernaerts uses the term mind-game in his article on *House Mother Normal*. He comments on, but does not explore, how ‘empathy and the attribution of pain are mitigated by irony’ and the tragicomic tone of the novel (2014: 306).

exhibiting the spatio-temporal freedom conventionally attributed to ‘omniscient’ narrators. Even more strikingly, he is privy to other character’s thoughts and memories that cannot be understood or explained within the conventions of a first-person narrator. And yet, in these instances (rather than shifting into a different narrative voice) Ishiguro insistently emphasises Ryder’s perspective through the use of first-person or possessive pronouns. The narrative is marked, therefore by a clash between the narrator’s disturbing lack of knowledge and deficient grasp of his situation and an excess of knowledge about other characters’ perceptions, thoughts, and memories.⁶⁸ One of the effects of this technique is that the reader does not inhabit a stable perspective. Attempts to naturalise the many inconsistencies, incoherencies and sheer impossibilities of the narrative are undermined by the very instability of narrative voice and focalisation. The narrative resists being decoded via the conventions of ‘realist’ first-person narration, while nevertheless drawing on these conventions as dominant mode throughout. We come, therefore, to view the world through Mr Ryder’s limited (and simultaneously incongruously expanded) viewpoint.

What allows a reading of this novel as a dementia narrative is that, on the story level, Ryder finds himself in situations that mirror what a person with dementia can be hypothesised to experience due to the symptoms of cognitive decline. At times, such situations take on a surreal or kafkaesque character. While Ryder does not seem to suffer from word-finding or other linguistic difficulties, he does, at one stage, entirely lose his ability to speak—and, in consequence, fails to speak up for his long-term friend. Ryder, straining to reveal his true identity to a committee of officious local women, can bizarrely emit only grunts. Flushed red by the strain to speak, he presents a disturbing spectacle. Shortly afterwards, he inexplicably regains his capacity for language. While this sudden (and, as it turns out, reversible) language loss is not a realistic representation of dementia, the

⁶⁸ Genette (1972) classified such ‘infractio[n] of the dominant code of focalization in which a narrator provides more information than is licensed by this code’ as ‘paralepsis’ (Dawson 2013: 23). Scholars of ‘unnatural narratology’ propose to classify such cases as instances of an ‘unnatural mind’ (Iversen 2013); as ‘telepathic first-person narrators’ (Alber 2014) or as explained by the concept of ‘impersonal voice’ (Nielsen 2004). Whereas Culler (2004) rejects omniscience as useful category of narrative analysis, Dawson argues first-person omniscience constitutes ‘another category of narrative voice’ (2013: 196).

scene is evocative of how crucial language is in asserting our identity and in positioning ourselves positively in relation to others. Without language, the renowned pianist becomes a no-one, unable to represent himself or intervene on behalf of others. Significantly, he also becomes an object of disgust to those around him.

Ryder also has a less than firm grasp on his recent autobiographical memories. And although the citizens expect him to play an inordinate role in upcoming events—a role which would appear to be in excess of what one might expect from a concert pianist—Ryder remains confused about ‘the precise nature’ (4) of the event as well as his role in it. Indeed, the narrative has, throughout, a nightmarish quality, in that Ryder is continually running late for appointments and never finds himself in the right place. He also frequently loses all sense of time, and since we see events through his eyes the reader cannot unambiguously pinpoint the actual passage of time in the storyworld. The nightmarish quality of the narrative is enhanced by physical impossibilities within the storyworld.⁶⁹ Buildings frequently morph into each other as the protagonist navigates the confusing landscape of the city, and corridors and rooms change their shape as the narrator moves through them or returns to them. In a striking parallel with the experience of people with dementia in nursing homes, who often feel as if ‘traces of ... their childhood home [were] pushing forward under the wallpaper of the care home’ (Clegg 2010: 12), Ryder becomes convinced that his hotel room is one of his childhood rooms:

I was just starting to doze off when something suddenly made me open my eyes again and stare up at the ceiling. I went on scrutinising the ceiling for some time, then sat up on the bed and looked around, the sense of recognition growing stronger by the second. The room I was now in, I realised, was the very room that had served as my bedroom during the two years my parents and I had lived in my aunt’s house on the borders of England and Wales. I looked again around the room, then, lowering myself back down, stared once more at the ceiling. It had been recently replastered and re-painted, its dimensions had been enlarged, the cornices had been removed, the decorations around the light fitting had been entirely altered. But it was unmistakably the same ceiling I had so often stared up at from my narrow creaking bed of those days. (16)

⁶⁹ See Alber (2013) on impossible spaces in narrative worlds.

What is notable about this passage is its assured tone—as expressed through verb tense (simple past, past perfect) and the absence of modal verbs. Contrary to the use of concurrent narration in Bernlef’s *Out of Mind*, Ishiguro uses conventional past tense narration throughout.⁷⁰ Nevertheless, there seems to be very little distance between the narrating-I and experiencing-I. Despite all evidence to the contrary (that he is on the continent and not in the UK, that all aspects of the room have been altered including the ceiling’s dimensions) the narrator is entirely sure of his discovery: ‘the sense of recognition growing stronger,’ ‘I realised,’ ‘unmistakably.’ Indeed, further contemplation of the room triggers a detailed memory of a specific afternoon during his childhood. Arguably, in contrasting the vividness of Ryder’s childhood memories with his recent memory lapses, and in allowing the narrator to experience no sense of contradiction at this superimposition of distinct geographical locations, Ishiguro at this point in the narrative (the conclusion of the first chapter) sets up the possibility of framing the rest of the narrative through the lens of progressive memory loss.

That said, reading this novel as dementia narrative does not provide the reader with an all-purpose interpretative tool which makes sense of the inconsistencies of the storyworld or the narrator’s disorientating experiences. Instead, the narrative places the reader in a situation where she will need to contend with a certain level of uncertainty, disorientation and confusion which may be considered central to the experience of dementia. Similar to the dementia narratives I have discussed previously, Ryder’s loss of the sense of time as well his experience of getting physically lost are enacted in the narrative. Yet here the reader has no possibility of resolving these difficulties—e.g., by naturalising them either through reference to genre⁷¹ or by reading them as indicators of the diseased narrator’s mind. The mental map of the storyworld resists falling into place and the reader is left with a

⁷⁰ An exception is the brief passage at the very end of the narrative which heavily employs the auxiliary modal ‘would’ to indicate the counterfactual, hypothetical future scenario playing out in the narrator’s mind.

⁷¹ The novel, despite many fantastic elements, emphasises the otherwise ‘naturalist’ setting of events rather than invoking the conventions of science fiction or fantasy—conventions which would allow readers to explain incongruous aspects of the storyworld through the possibilities of fantastic storyworlds.

sense of confusion about the world she is inhabiting through Ryder's consciousness. This aspect of the narrative makes it an interesting case for considering the notion of parallel experience in relation to the phenomenology of dementia.

The Unconsoled also resonates with other dementia narratives in that the novel explores how cognitive decline may affect not only one's ability to navigate space and time, but impact on one's social world. So, for instance, Ryder's eminent position as renowned pianist is slowly undermined as he struggles to meet the demands made on him and, finally, fails entirely to fulfil any of his responsibilities. This process is intimated from the start of the narrative in his very first interaction with the hotel's desk clerk. As the clerk begins to chat about the preparations for the elusive 'Thursday night' he mentions how a certain Mr Brodsky, clearly the conductor of the orchestra, has been 'doing splendidly' and is in the process of practicing in the hotel's drawing room. Ryder's response indicates how little he seems to be in the know about events:

'Brodsky, you say.' I thought about the name, but it meant nothing to me. Then I caught the desk clerk watching me with a puzzled look and said quickly: 'Yes, yes. I'll look forward to meeting Mr Brodsky in good time.'
(4)

Ryder, it seems, is astute at reading other people's reactions and quick to cover up any idiosyncrasies in his behaviour due to his failing memory. This behaviour resonates with accounts of people with dementia, who in the early stages frequently report trying to hide their symptoms from others. Even in the later stages, set phrases, which are still accessible, are often used to keep social interactions going and to gloss over the inability to express oneself more precisely. Such set phrases then provide a means to continue functioning on a social level. Ryder, like many people with dementia, despite his often disastrous lack of knowledge, retains the capacity to navigate social encounters relatively smoothly.

Nonetheless, Ryder's relationships to significant others are severely disturbed by his memory loss. In the hotel, Ryder meets an elderly porter named Gustav. As they become more closely acquainted—incidentally, through Ryder's ability to read the porter's mind—Gustav asks him to meet

his daughter Sophie and find out what is troubling her. We then follow Ryder to a café where he meets Sophie and her son, Boris. Initially, seeing events unfold from Ryder's point of view, the reader expects this to be their first meeting.

Turning, I saw a woman sitting with a young boy waving to me from a nearby table. The pair clearly matched the porter's description and I couldn't understand how I had failed to notice them earlier. I was a little taken aback, moreover, that they should be expecting me ... Although the porter had referred to her as a 'young woman', Sophie was in early middle age, perhaps around forty or so. For all that, she was somewhat more attractive than I had expected. ... 'This is Mr Ryder, Boris,' Sophie said. 'He's a special friend. Of course he can sit with us if he wants.' (32)

It soon becomes clear, however, that Ryder is well-known to both Sophie and Boris, and indeed, it emerges that Ryder and Sophie have been in an intimate relationship for years. With this knowledge in mind it is difficult to make sense of why Ryder describes their initial meeting in the way he does, unless one posits that he has temporarily forgotten all about their joint history.

Ishiguro thus largely limits the reader's perspective on events to that of a partially unreliable, memory-impaired first-person narrator. Occasionally, the reader might, as in the passage just quoted, later suspect that Ryder is unreliable when the facts revealed contradict Ryder's reporting: 'Is this really what Sophie said?', one might ask. Since, if Ryder has been acting as something of a father figure to Boris, then Sophie's introduction ('This is Mr Ryder, Boris') is incongruous. Indeed, Ryder's narrative later suggests that a previously harmonious (step)father-son relationship has only recently been disrupted by some unnamed event. In the meantime, Ryder remains fundamentally uncertain about his shared past with Sophie and Boris, and concomitantly about how to behave towards them. This is evident, for instance, when Ryder visits them in their home:

I followed the pair of them up two flights of stairs. As Sophie unlocked the front entrance the thought struck me that I was perhaps expected to behave as though familiar with the apartment. On the other hand, it was equally possible I was expected to behave like a guest. As we stepped inside, I decided to observe carefully Sophie's manner and take my cue from that. (283)

This passage calls attention to the strategies that people with dementia may employ when they are uncertain about their relationship with others. Since the reader never gets the full story of their relationship and is therefore, like Ryder, left to speculate on events, the narrative technique brings readers closer to Ryder's experience of epistemological uncertainty. The parallel experience of uncertainty about the storyworld—about time, space, events and relationships—may then intimate what it feels like to lose a firm grasp on one's life due to dementia. We become, like the narrator lost in time and lost in space, uncertain about our location within the storyworld and the (surreal or real) nature of the events taking place.

If Ishiguro's tale provides a resonant image of the phenomenology of dementia, then it is also about many other aspects of humans' lives as embodied, social agents. Ishiguro, of course, is a master at depicting regret—most notably, the missed opportunities in relationships—the word *not* spoken, rather than the word spoken hastily. This theme resonates in *The Unconsoled*, especially in the relationship between the aged porter and his daughter Sophie. However, the novel also puts a particular twist on the theme of dysfunctional relationships—one that may contribute to an understanding of how relationships may be impacted by progressive memory loss. Ryder seems to have had some kind of falling out with Sophie but cannot remember any of the details. Nonetheless, he repeatedly experiences surges of anger towards her. There appear to be various sources for this anger. On the one hand, his anger seems to be motivated by the underlying reasons for the falling out, even when he cannot remember the details. On the other hand, as events spiral out of control, Sophie becomes a convenient object for his anger at his own powerlessness. Ryder then begins to blame Sophie for everything that goes wrong. As is usual in Ishiguro, the characters never address these issues, never manage to reach an understanding of the other's point of view. In the end, the couple parts ways. Ishiguro's novel suggests how the capacity for misunderstanding is exacerbated when one of the partners suffers from memory loss and may lack insight into his own feelings. Although he does not engage in a direct exploration of dementia, Ishiguro here hints at some of the complexities

inherent in interacting with intimate others when both the memory of recent interactions and even the history of one's relationship have been lost.

Conclusion

In this chapter I pursued two questions: one, can imaginative fiction contribute to a better understanding of the phenomenology of dementia? And two, how do narrative techniques used to project the phenomenology of dementia interact with the reader's experience of empathy—and with what implications for current theories of narrative empathy and its role in the medical humanities?

Much like life writing, fictional narratives evoke the varied life world of the character or person with dementia. They place the character in a specific social and cultural context, while exploring both the character's inner life, her relationship with others and with her physical world. Fictional narratives are therefore well placed to explore how, in Havi Carel's terms, the life world of a person changes due to serious illness (2008). Novels as well as films provide the kind of thick description that is necessary for a full understanding of any socio-cultural phenomenon—including the experience of a neurodegenerative disease. Contrary to life writing, however, fictional narratives, and the novel in particular, may address the experience of the later stages of the dementia by simulating an encounter with the dementing character's mind. Nevertheless, it is important to stress that such representations draw on specific literary techniques and conventions and are based on culturally available conceptualisations of dementia—what dementia is taken to *be* and what it *means*. Narrative technique influences the kind of understanding of the phenomenology of dementia readers and viewers procure. The modes of filmic representation engage, in particular, the possibility of intersubjectivity as grounded in the embodied agency of both the protagonist and the viewer. In the novel, various experimental modes push against the limits of representing serious cognitive impairment within language and narrative. Nevertheless, these narratives continue to act within the bounds of language and at least minimally coherent narrative acts.

Still Alice, *Out of Mind*, and *House Mother Normal* are all recognisable dementia narratives. These texts allow rich possibilities of entering the mind of the character(s) with dementia. They allow numerous possibilities for narrative empathy while also stimulating intellectual curiosity about the limits of seeing the world through the eyes of a person with dementia, since the reader necessarily retains a grasp on the narrative storyworld that exceeds that of the characters. Furthermore, instances of empathic feeling with, or rather feeling as the character, are evoked by creating processes of parallel experience in the reader. Nevertheless, since these narratives are explicitly marked as dementia narratives, and the authors use certain techniques to make their storyworld intelligible to the reader, we, as readers, experience a certain sense of dramatic irony—of knowing more and understanding more than the character with dementia does.

I suggested that the experience of narrative empathy—feeling *as* the character does, rather than feeling *with* (which is more akin to sympathy)—may be rather limited in coherent or ‘conventional’ dementia narratives, such as *Still Alice*. Contrary to Keen’s view that certain literary avant-garde texts, in emphasising de-familiarisation and a shock aesthetic, undermine or actively eschew empathetic reading (or viewing) experiences, I showed how literary experimentation may create processes of parallel experience in the readers; that is, the reader may be said to experience an ‘intellectual predicament analogous to that of the characters’ (Toker 1993: 4). To explore the empathic possibilities of experimental fiction, I considered the use of a dementing and unreliable narrator, such as in J. Bernlef’s *Out of Mind*, as well as the configuration of multiple extended stream of consciousness monologues, such as those employed in B.S. Johnson’s novel *House Mother Normal* (1971). Also, I suggested how a novel which does not announce itself as dementia narrative, such as Kazuo Ishiguro’s *The Unconsoled*, provides means for evoking the parallel experience of certain symptoms of dementia in the reader.⁷²

The potential of narratives which do not provide a clear disease pathology for their characters—that do not name the disease or label the

⁷² There are of course limits to the notion of parallel experience, since the reader retains her capacity to remember what has gone before in the narrative.

character as a person with dementia—need to be explored in more detail. Particularly in the context of the pathologisation of many aspects of human experience, such narratives may allow for an exploration of what it is to be human, without limiting our understanding to supposedly stable disease conditions. I am aware that my reading of Ishiguro's novel as dementia narrative in a sense goes against the possibility of de-pathologising human experience. However, I maintain that the novel provides rich opportunities for exploratory modelling of the phenomenology of dementia, without necessarily having to be 'reduced' to merely being 'about' this condition. Importantly, while the novel opens up a promising means of coming close to the existential uncertainty that living with dementia entails, in the last instance it resists being naturalised as a dementia narrative.

A number of open questions remain about how narrative technique and empathetic feelings interact. For one, the correlation between defamiliarising strategies and narrative empathy may be less straightforward than commonplace literary theorising suggests. It is debatable whether Brechtian shock aesthetics and techniques of defamiliarisation aimed at impeding 'the automatic transfer of the emotions to the spectator' (Brecht 1964: 94, qtd. in Keen 2007: 56) necessarily achieve such an effect. Felski (2008)—in discussing the phenomenon of 'enchantment' that Brecht notably worked against in his audiences (56)—makes the case that contrary to current doxa 'anti-absorptive devices are widely used for absorptive ends; artifice does not exclude immersion' (73). Of course, the link between immersive reading experiences and narrative empathy remains elusive as long as it is unclear what exactly we mean by immersive reading. Contrary to some definitions that suggest we become so emotionally absorbed in the storyworld that our reflective capacities are switched off until we emerge from this moment of enchantment, immersive reading may also include, at times even depend upon, significant cognitive (reflective and sense-making) activity in the reader.⁷³ I would moreover argue that certain modes of

⁷³ Green and collaborators (Green 2004, Green and Brock 2000, Green, Garst, and Brock 2004) by contrast suggest that cognitive scrutiny correlates negatively with the degree of immersion, or what they call 'transportation into a narrative world,' following Gerrig (1993). While their research on how fictional narratives change attitudes and 'real-world beliefs' still leaves many questions unanswered, it strongly suggests that there is a

‘experimental’ fiction have an important contribution to make to the exploratory modelling of the phenomenology of dementia. These texts may be able to probe and extend the limits of engaging with the minds of the severely memory-impaired, or create instances of parallel experience in the reader. The parallel experience of trying to make sense of the narrative world may in itself be considered part of an immersive reading experience which nevertheless demands a high level of cognitive engagement. Furthermore, in its emphasis on deconstructing the illusion of reality, experimental fiction significantly contributes to an ethical probing of the risks of effacing the experience of real others by fictive imaginings.

The ethical problems attendant on representing dementia here become clear. Thus, while the narrative technique of broadcast strategic empathy in *Still Alice* is employed to further the ‘recognition’ of people with dementia and of their continued humanity—in the ethico-political sense of recognition as ‘acknowledgment’ (Felski 2008: 29)—the question arises whether this narrative does not instead contribute to the ‘othering’ of people with more advanced dementia who can no longer use language coherently. As many critics would be quick to point out, representing the experience of another risks obliterating the radical alterity of that other and putting her actual point of view under erasure. Recognising oneself in the other—as when experiencing empathy—is considered a violation of the other’s alterity (Levinas 1961/1990, 1979, Sartre 1943/1976, Zahavi 2007). Indeed, the entire narrative approach to understanding others ‘might be criticized for entailing what could be called a *domestication of otherness*. You reduce the other to that which can be captured in narratives’ (Zahavi 2007: 199; original emphasis). Counter to a number of claims in first-wave medical humanities, literature, like philosophy, biomedicine and neuroscience, may then equally be considered a totalising and reductionist enterprise.

Further, focusing on the other as an *object* of empathy may be seen to deny the other’s subjectivity. Empathetic feelings in the context of literary reading may indeed be considered entirely self-centred, or even selfish: Keen (2007) points out how feelings of recognition in the reader may lead to

correlation between transportation and the extent to which reader’s attitudes shift after reading a narrative. In short, fictional narratives influence readers’ beliefs.

an ‘erasure of suffering others in a self-regarding emotional response that affronts others’ separate personhood’ (xxiv). In this context

Empathy earns distrust for its apparent directional quality—an empathetic performance may appear condescending to its object or to an observer ... Feminists, postcolonial theorists, and critical race scholars in legal studies resist the universalizing of human emotions inherent in much of the commentary on empathy. (Keen 2007: xxiv)

While such a cautionary view is warranted in the context of dementia narratives, due to the vulnerability of people with dementia, a global dismissal of narrative empathy and of the attempt to understand others through narrative perspective-taking may be even more detrimental to people with dementia. Considering the use that narrative empathy has been put to in furthering social causes in the past, it may be premature to dismiss its effects in the current Alzheimer’s advocacy movement. Not to engage with the question of what it may be like for people to live with the symptoms of dementia—and perhaps adapt attitudes and behaviours based on such imaginative exploration—might constitute a greater shortcoming.

Considering that the link between empathy and pro-social behaviour in the real world is tenuous, the social relevance of empathic reading experiences in relation to dementia care remains an open question. Nonetheless, anecdotal evidence suggests that fictional dementia narratives, such as the film *Still Alice*, affect the film-goer’s view of dementia—and even lead to a moral re-assessment of the behaviour of various family members towards a relation with dementia. However, if fictional narratives have the potential to affect people’s views—which I believe they do (see also Green 2004, Green and Brock 2000, Green, Garst, and Brock 2004)—they might equally lead to negative outcomes for certain groups within society. In chapter 6, I therefore return to fictional dementia narratives to explore the possibility that rather than providing counter-narratives to either reductionist biomedical or dehumanising socio-cultural conceptualisations, novels and films may in fact compound negative stereotypes of dementia. Furthermore, I explore in what way fiction intervenes in contemporary debates about dementia care in ways that go beyond questions of empathy. Here I hope to have shown that whatever form of empathy novels or films evoke, and irrespective of whether this may lead to pro-social action on

behalf of others, fictional narratives have the potential to raise awareness about certain aspects of the phenomenology of dementia—some of which may lie beyond the scope of non-fictional dementia life writing.

My overall aim in this chapter was to provide a solid case for literature's value as a 'practical counterpart of theoretical phenomenology' (Waugh 2013: 24) or, indeed, as a form of *imaginative phenomenology*. At the same time, by investigating the literary and filmic techniques that simulate an experiential reading or viewing experience, I not only hoped to underline the potential of imaginative narratives to explore the lived experience of others, but also to emphasise their necessarily constructed nature. In the context of representing people with progressive neurological decline, who at some stage lose the ability to communicate their experience and to challenge the way they are represented by others (see also Couser 2004), it is of no small ethical importance to pay attention to how stories about those persons shape what readers and viewers take to be their experiences of the disease. In part II, I turn more squarely to these questions of self-presentation and representation in the context of dementia life writing.

Part II Life Writing, Self-Writing

Chapter 3 Life Writing at the Limits: Narrative Identity and Counter-Narratives in Dementia

In this chapter I consider dementia autopathographies⁷⁴ as well as collaborative life story work with people with dementia (Clegg 2010) in order to shed light on the possibilities and limitations of the notion of narrative identity in the context of progressive neurodegenerative diseases. I probe the limits of narrative coherence in constructing identity, while also stressing the ethical imperative of attending to identity narratives in the context of dementia life story work and life writing. I suggest that in the context of collaborative dementia life narratives, as compared with other sorts of life writing, a relatively greater proportion of the task of co-creating coherence and co-constituting the interlocutor's identity may shift to the editor, listener or reader.

Further, I investigate how narrative identity links with the concept of counter-narratives which has gained currency across a range of disciplines (Bamberg and Andrews 2004) and which is particularly pertinent in the context of narratives of illness and disability (Couser 1997, Frank 1995). I ask to what extent dementia life narratives may function as counter-narratives to the dominant cultural construction of dementia as 'loss of self' and 'death before death' and how genre influences the construction of counter-narratives in dementia life writing.

To contextualise my discussion, I briefly outline the debates surrounding narrative identity and counter-narratives—while suggesting the implications of these debates for life writing by people with dementia. I then consider two types of case studies—autopathographies by people with early-onset Alzheimer's and collaborative life story projects in nursing homes, in particular the collection *Tell Mrs Mill Her Husband Is Still Dead* (Clegg 2010)—to elucidate how the notions of narrative identity and counter-narrative come into play in these particular life writing environments.

⁷⁴ While I draw on the same corpus of texts discussed in chapter 1, the focus here is on how these texts function as counter-narratives, rather than as means to explore the phenomenology of dementia.

Narrative Identity in Dementia

Life is narrative. It is through narrative that we create selfhood. If we fail to produce an acceptable narrative, our normalcy is questioned. These are some of the tenets and implications of the narrative identity thesis—widely accepted today across a range of disciplines (Bruner 1991, 2003, 2004, Dennett 1993, Eakin 1999, 2008, Ricœur 1991a, b, Schechtman 2007, 1996). Since dementia causes memory loss and severely affects cognitive functioning, the disease eventually erodes the ability to tell a coherent life narrative. If selfhood is tethered to the ability to tell one's life story, people with dementia will be seen to have lost their selves. Consider Jerome Bruner's claim that 'there is now evidence that if we lacked the capacity to make stories about ourselves, there would be no such thing as selfhood' (2003: 86). However, the view that selfhood is constituted through narrative is not without its opponents (see Sartwell 2000, Strawson 2004). Galen Strawson, for instance, challenges both the 'psychological Narrativity thesis'—according to which 'human beings typically see or live or experience their lives as a narrative' (Strawson 2004: 428)—and the 'ethical Narrativity thesis'—a normative view that 'experiencing or conceiving one's life as a narrative' is 'essential to a well-lived life' and crucial 'to true and full personhood' (428). Although Strawson's argument has its problems (see Battersby 2006, Eakin 2006), his work has stimulated a timely debate, relevant to people with dementia, about the ethical implications of the view that identity or selfhood is constituted through narrative. It is certainly questionable whether neurological conditions such as Alzheimer's disease indeed provide evidence for lost selfhood.

In the following, I address the implications of narrativist accounts of selfhood for people with dementia. I outline both the strengths and limits of the narrative account when it comes to capturing the processes by which identity is expressed, constituted, or negotiated in the context of dementia. In doing so, I adopt a position within the debate that can be characterised as a 'moderate' or 'qualified' narrativist approach.

One of the central problems that has emerged from the debate about the narrative constitution of selfhood is that the terms 'self,' 'life' and 'identity'

are frequently used interchangeably.⁷⁵ Critics of the narrativist approach to selfhood have pointed out that not all kinds or levels of selfhood can be adequately accounted for narratively and that to require selfhood to be articulated in narrative can be problematic in some contexts. Expecting life to conform to the genre of a quest narrative (Frank 1995, MacIntyre 1981), and basing an evaluation of this life purely on the success or failure of this quest, places too large a strain on any ordinary human being—if such a being exists. It also places inordinate strain on the lives and narratives of those affected by illness and disability, failing to take into account the natural course of decline towards the end of life—and disqualifying people with dementia from leading any kind of meaningful or valuable existence.⁷⁶

Scholars such as James L. Battersby (2006) recognise the plurality of possible selves and doubt that the notion of self can ever be exhaustively captured in a narrative, or even numerous narratives (37), while still according narrative a central function in human sense-making. Battersby argues that it is important to scrutinise the uses to which narrative is put in the social domain. Paul J. Eakin, similarly, rejects strong narrativist formulations of identity.⁷⁷ He nonetheless pays tribute to the ‘power of narrative not only as a form of self-representation but as an instrument of self-understanding’ (Eakin 2006: 184). At the same time, Eakin underscores ‘the very real imperialism of narrative requirements that structure our social encounters and define us as persons’ (186). Eakin concludes that ‘it’s all very well to attack “narrativity,” but it’s much harder to escape it in self-presentation. We’re part of a narrative identity system whether we like it or not’ (186). Instead of worrying about the ‘lofty norm of the examined life,’ as Strawson does, we need to attend to the ‘deep-seated social conventions that govern narrative self-presentation in everyday life’ (181-2). Eakin points out that in contemporary Western culture we are expected to be able

⁷⁵ An overview of the use of these terms across different disciplines lies beyond the scope of this study. For a historico-literary overview see Oksenberg Rorty (2000). For studies that consider personhood and personal identity specifically in dementia from a psychiatric and philosophical perspective, see Hughes (2011) and Hughes, Louw and Sabat (2006).

⁷⁶ For an exploration of the relation between philosophical approaches to the ‘good life’ and old age see Small (2007).

⁷⁷ Compare Oliver Sacks’ claim: ‘It might be said that each of us constructs and lives a “narrative,” and that this narrative *is* us—our identities’ (Sacks 1985/2015: 110; original emphasis)

to produce a self-narrative and that failing to do so leads others to deny in us the very existence of selfhood. Such social conventions are immensely relevant to people with memory loss. There is a difference, however, between posing narrative as essential to selfhood and recognising its social function in contributing to the formation or articulation of a particular kind of identity. In the context of personhood debates, strong narrativist claims—such as Bruner’s claim that the inability to tell a self-narrative leads to the ‘death’ or ‘loss’ of self—can be detrimental to people with dementia and should be considered ethically suspect.

A further objection that can be levelled at the strong narrativist approach is its lack of attention to the nature of embodiment. Dementia affects all areas of cognition and not just the capacity to tell a life story. Phenomenologist Dan Zahavi therefore argues that *if* selfhood is lost in dementia, the capacity to tell a self-narrative cannot reasonably be considered its sole cause (Zahavi 2007: 192). More importantly, Zahavi queries whether it is accurate to speak of lost selfhood in people with dementia at all. In phenomenological terms, Zahavi conceptualises selfhood as the ‘first-personal givenness’ of experiential life (2007: 188). Selfhood, on this view, is bound up with experience itself and is not constituted through narrative. Thus Zahavi cautions that ‘when speaking of a first-person perspective one should consequently distinguish between *having* such a perspective and *being able to articulate* it linguistically’ (191; my emphasis). Based on this view, he concludes:

It is by no means obvious that Alzheimer’s disease brings about a destruction of the first-person perspective, a complete annihilation of the dimension of mineness and that any experience that remains is merely an anonymous and unowned experiential episode, so that the ‘subject’ no longer feels pain or discomfort as his or her own. (192)

Indeed, the embodied first-person perspective on lived experience persists even into the last stages of dementia. In other words, it is erroneous to assume that dementia entails a loss of self.

In my analysis of stories told by people with dementia I take into account the argument that whatever the ontological criteria for *selfhood*, we are part of an *identity*-system in which ‘identity narratives, delivered piecemeal every day, function as the signature for others of the individual’s

possession of a normal identity' (Eakin 2006: 182). As Eakin highlights, 'The verdict of those for whom we perform [identity narratives] is virtually axiomatic: no satisfactory narrative, no self' (Eakin 2001: 120). In the world we inhabit, narrative plays a crucial role in claiming rights, assigning responsibility and having one's selfhood or identity recognised (see also Ritivoi 2009). Since people with dementia continue to use narrative to position themselves more favourably both in social interaction and through life story work, we need to investigate what these narratives look like and how they are used.

It makes sense to take on Strawson's criticism that a diachronic or narrative self-experience is not necessarily the only or the best way to experience one's being in time. But it equally makes sense to acknowledge the practical importance that both a narrative organisation of memory (Ferryhough 2012) as well as a narrative performance and constitution of identity have both intrapersonally and socially. Not all life experience can or must be narrativised to constitute part of one's life or one's sense of self. However, lacking the means to narrativise one's life experience can put one on shaky terrain when it comes to positioning oneself in relation to others, this process being integral to what it means to be a person.

When considering the question of narrative identity, I am therefore inclined to argue that it is less a question of whether identity *is* narrative or *has to be* but whether we *negotiate* or *perform* identity through narrative. The narrative self is not an ontological given but a social practice and a potential means of self-understanding and understanding others—including the possibility of misunderstanding. The notion of embodied, experiential selfhood as proposed by Zahavi and others usefully adds to our understanding of different levels of selfhood in dementia. The fact that a body-self or experiential self persists in dementia seems out of the question. It also seems clear that the person with dementia can at some point no longer communicate her perspective through narrative or constitute herself narratively in social encounters. Nevertheless, both social science research as well as collaborative life writing projects show that people with dementia continue to attempt to negotiate identity through narrative—and do so further into the disease than may have seemed possible. Such attempts

demand our attention and participation. At issue is an ethical claim in which the task of performing or constituting narrative identity shifts from the teller to the listener (or reader), to a comparatively greater degree than in other storytelling situations.

Reconsidering Counter-Narratives

Life writing studies, the medical humanities and disability studies converge exactly around the issue addressed by Eakin: that is, the question of how people perform identity narratives that serve their tellers. In some cases at least, performing identity narratives may be used to counter disempowering ways in which one has been socially and culturally positioned. Generally speaking, counter-narratives arise in response to a given culture's masterplots (Abbott 2008: 236)—alternatively described as 'dominant discourses,' 'discursive configurations,' or 'master narratives.' Counter-narratives are thus linked to identity politics, in that members of a marginalised group may challenge the way their identities are constructed in the mainstream. In the medical or health humanities, illness narratives are frequently considered paradigmatic examples of counter-narratives since they challenge the dominant discourse of biomedicine (Frank 1995) and the negative cultural constructions of illness and disability (Couser 1997). The question is whether life writing in dementia functions in a similar manner. To address this question I first develop some of the general issues relating to the concept of counter-narratives, and then move on to consider these issues in the context of autobiographical writing by people with dementia.

Scholars working in fields related to gender, ethnicity, or race underscore the extent to which counter-narratives are inextricably entangled in the masterplots they set out to subvert (Bamberg and Andrews 2004). Arguably, by invoking the very masterplots they aim to counter, these narratives contribute to upholding the dominant discursive configurations. Masterplots may also be so ingrained in the ways we think that it becomes impossible to communicate without them. As Bamberg points out, one is forced to enlist masterplots in order to make identity claims that are intelligible (or acceptable) to others (Bamberg 2004: 361). This need to

employ masterplots in one's self-presentation is also evident in dementia autopathographies; and yet by enlisting models of competent and coherent narrative selfhood the authors of these narratives unwittingly undermine their aim to present a counter-narrative to the dominant discourse on dementia.

To increase their heuristic power, developing working definitions of the concepts of master-narrative, masterplot, and counter-narrative will be helpful. Carlos Kölbl has suggested a number of productive ways in which one might define master-narratives. I build on Kölbl's ideas in defining master-narratives about dementia as representing 'a narrative version (or rather discourse) that is most commonly spread within a particular population' (Kölbl 2004: 28)—in this case, high-income Western democracies. As regards the content of this discourse, I argue that the masterplot of dementia can in shorthand form be described as 'loss of self' and 'death before death' (Behuniak 2011, Herskovits 1995). Dementia is seen to equal a tragic progression of losses, in the course of which the person with dementia becomes 'emptied out' and her life and person become of little, if any, value. This view of dementia finds expression in a cluster of pernicious metaphors. Since the dominant construction of dementia is perpetuated and transmitted through 'cultural artefacts such as books, films, [and] newspaper articles' (Kölbl 2004: 28), literary and cultural criticism present productive means for investigating this discursive configuration. Cultural representations of dementia do not operate on their own, of course, but are underpinned by larger ideologies bound up with Western philosophy and contemporary biomedicine. The dominant cultural construction of dementia in the West is informed by cognitivist notions of personhood as well as a reductionist, materialist understanding of how body and mind—in this case the brain and the mind—interact. In short, if the mind is nothing but the brain, then the severe neuropathological breakdown in dementia will entail loss of self. Further, by defining personhood on the grounds of rationality and cognitive capacity alone, people with dementia become non-persons. The dominant discourse on dementia therefore has far-reaching implications for how societies think about and behave towards those who bear this disease label.

I define as counter-narrative any narrative—or in the context of collaborative storytelling, any conversational *move* (Goffman 1981, qtd. in Hydén 2010: 40)—that resists or questions dominant discourses, whether by directly challenging them or by obliquely undermining some aspect of the larger discursive economy in which they circulate. Counter-narratives may also challenge the *effects* of a masterplot, such as infantilisation, neglect or abuse.

Despite the problems attendant on theorising master- and counter-narratives, I argue that they represent valid and important ways to address the question of how dementia is understood in contemporary Western societies. As a neurodegenerative disease that affects language and memory—capacities that are supposedly ‘what makes us human’—dementia raises complex ethical and political issues. In light of recent care scandals in the UK, continuing discussions about the allocation of scarce economic funds, the privatisation and commodification of ‘care’ itself, and ongoing debates about the practice of euthanasia, how we understand dementia and how we define the rights of dementia sufferers are questions that will only become more pressing in the future. By referring to people with dementia as ‘vegetables,’ ‘shells’ or ‘living dead’ we risk stripping these people of their personhood and their human rights (Burke 2007b, Herskovits 1995). By contrast, the stories told by people with dementia show how they may productively use autobiographical and confabulated stories in order to claim identities for themselves, to counter the negative cultural construction of dementia, and to critique the care environments in which they live.

Reading Dementia Autopathographies as Counter-Narratives

In exploring how autobiographical writing by people with dementia may function as counter-narrative, I ask, in what follows, what specific strategies (such as genre, metaphor, plot, or theme) dementia autopathographies employ to counter the stigma of dementia. Other relevant questions are: Can these accounts be considered ‘successful’ instantiations of counter-narratives? How might one assess the success or failure of counter-narratives? Is it even feasible or possible to disentangle masterplots and

counter-narratives from each other—or are they always enmeshed with one another? And finally, do the conventions of autobiography—in that they rely on the narrator’s ability to tell a coherent story and thereby confirm agentive, autonomous and cognitivist notions of personhood—undermine any potential the texts might have for countering the dominant discourse on dementia as ‘loss of self’ (see also Burke 2007a)?

An important first question to consider is how the conventions of autobiography shape the narratives. Autobiography generally demands a ‘comic plot,’ one where the narrator is better off at the end than at the beginning of the story (see Couser 1997). This expectation of a happy outcome, and the predominance of ‘triumph narratives’ in contemporary representations of illness (Conway 2007), prescribe certain forms of closure. Genre may then curtail the possibilities of representing neurodegenerative diseases—here, by demanding that the authors put a positive spin on their illness experience. This is in stark contrast to the progressive decline that the disease syndrome entails. Of course, one may also argue for a converse relation. Authors of dementia autopathographies may be purposefully enlisting ‘the comic plot’ of autobiography in order to paint a more positive picture of dementia and thereby counter the notion that dementia entails a ‘death before death.’ In modelling their life narrative on the *bildungsroman*, shaping their narratives as conversion tale (see Bryden 1998, 2005), or as a quest narrative (see, amongst others, Lee 2003), in which spiritual enlightenment and personal growth constitute the ‘holy grail,’ these authors draw on generic conventions to help them fashion their stories as counter-narratives.

As might be expected in a story about degenerative illness, however, the fit between the genre model and autopathography will by necessity only be partial. With respect to Zen enlightenment, for one, Richard Taylor notes in his autobiographical essays how ‘living in and for the moment assumes the ability to know what is going on, what [one is] doing in a given moment’ (Taylor 2007: 131). Yet this ability is slowly eroded in dementia as the temporal unity of experience becomes fragmented and disjointed—casting doubt on the potentially facile moment of ‘closure’ or ‘redemption’

suggested by either the recurring *carpe diem* motif or the ‘comic plot’ of many of these autobiographies.

In general, Taylor’s essays provide a complex response to the widely employed strategy of countering stigma through a positive reinterpretation of life with dementia. Taylor’s reply to his own rhetorical question in the essay ‘What’s the Upside to Having Alzheimer’s Disease?’ is initially ‘Nothing that I can think of, right off the bat’ (77). And yet he subsequently lists a number of positive changes in his life due to the disease. Among them are an increased closeness to his family, gratitude for all he has and the ‘deeper appreciation of what [he] should and should not respond to emotionally’ (78). However, he self-consciously reflects that while these responses to his disease ‘feel good’ he wonders whether rather than being the ‘upside’ of Alzheimer’s this is in fact how he should have lived his life in the first place (78). He concludes, ‘Still, I couldn’t say, as some others with Alzheimer’s do, that I am glad I know that I have Alzheimer’s, glad that I got the diagnosis early’ (78). Taylor thus cannot participate in the practice of finding, as Couser terms it, ‘redeeming significance even in terminal illness’ (Couser 1997: 16).

Furthermore, as compared with linear narration, Taylor’s collection of essays allows for a more nuanced understanding of how dementia affects experience and especially the author’s sense of self. Thus later essays in the collection frequently undermine the claims or conclusions of previous essays. Rather than presenting the reader with closure and a stable viewpoint, Taylor’s shifting life experience and attitude towards dementia are documented as his life unfolds. Personal essays, as Couser notes about diaries and journals,⁷⁸ may present an advantage over retrospective autobiographies, precisely in that they ‘do not await the resolution—whether in recovery from or accommodation to dysfunction—that seems to license most retrospective autobiographical accounts of illness and disability’ (Couser 1997: 6). Nevertheless, Taylor’s voice and particular style provide coherence to the essays and allow for them to be read as one person’s act of

⁷⁸ Taylor’s essays were initially published as blog posts. Blogging is comparable to journaling in its ad-hoc everydayness.

reclaiming his identity from the dominant cultural construction of Alzheimer's as 'living death.'

Most autopathographers stress the therapeutic quality of writing about their experience, thereby suggesting that narrative self-making can have psychological benefits.⁷⁹ For DeBaggio, for instance, writing not only affords a means of distancing himself from his illness, allowing him 'to leave thoughts of the disease locked up in the computer' (DeBaggio 2002: 7), but also provides a way of feeling at one with the world: '*The only time I feel alive now is when I am writing, under the spell of work and memories*' (121; original emphasis). While some authors stress the importance of writing as a *personal* and *private* process of coping with their experience, others see their writing as an important contribution to the dementia advocacy movement. The memoirs provide rich accounts of how the cognitive, bodily and social world changes after the onset of Alzheimer's. In criticising the callous, unfeeling behaviour of health care professionals and the lack of understanding of friends or strangers, the authors of these memoirs challenge the notion that people with dementia lack insight into their own experience and may therefore be considered unaffected by inhumane or undignified treatment. They write back against the 'epistemic injustice' perpetrated against people with dementia, who are no longer considered experts on their own experience (see Capstick, Chatwin, and Ludwin 2015).

In speaking out against discriminatory behaviour and helping to create a better understanding of the disease, dementia autopathographers therefore aim to alleviate the stigma attached to dementia. Their writing also constitutes a means of reclaiming agency. As Lucy Burke notes, 'to write is to align a person with a narrative voice, and to make a claim for social recognition and personhood' (Burke 2007a). This view is also taken by

⁷⁹ From psychoanalysis to contemporary 'narrative' or 'scriptotherapy,' there is a long line of thought which suggests that telling or writing about one's life may have a beneficial effect on psychological well-being. Without entering into a debate about the pros and cons of these therapeutic interventions, I see no reason to challenge the anecdotal evidence provided by the life writers discussed here that writing had a therapeutic benefit. Beyond anecdotal evidence, see Klein (2003) for a review of how creating narratives about stressful events may lead to health benefits and an improvement in cognitive functioning.

Ryan and her collaborators, who describe how writing provides the authors of dementia autopathographies with the socially recognised roles of writer, storyteller, teacher, advocate, and wisdom figure (Ryan, Bannister, and Anas 2009: 151). These new roles may go some way towards making amends for the loss of other social roles. Indeed, autobiographical writing can be seen as a means of ‘reclaiming social identity’ *per se*. Here the notion of ‘positioning’ comes into play, since the experience of being negatively positioned may, indeed, be detrimental to one’s sense of identity. As Ryan and her collaborators point out, social identity is created, and needs to be constantly re-created, through discourse with others (Ryan, Bannister, and Anas 2009: 146). As these autopathographies attest, certain roles and identities become unavailable to people with dementia due to the progression of their disease, as well the disabling reactions of others. For instance, the authors of dementia autopathographies are often forced into early retirement due to their illness. They struggle with the sense of feeling useless, no longer a ‘fully functioning’ member of society. As Cary Henderson highlights in one of the starting points mentioned in my introduction, the loss of social roles has a deep-seated impact on his sense of feeling fully human:

I’ve been thinking about myself. Some time back, we used to be, I hesitate to say the word, “human beings.” We worked, we made money, we had kids, and a lot of things we did not like to do and a lot of things we enjoyed. We were part of the economy. We had clubs that we went to . . . Just a lot of things I did back then when I was, I was about to say – alive – that may be an exaggeration, but I must say this really is, it’s living, it’s living halfway. (35)

Writing, then, provides a means of self-assertion and self-creation that is immensely important to people with dementia who are being deprived of former social roles (Basting 2003a).

Thomas DeBaggio’s two memoirs *Losing My Mind* (2002) and *When it Gets Dark* (2003) provide illustrative examples of how the cultural construction of dementia informs the author’s self-conception. These memoirs are not merely illness narratives, but come close to being fully-fledged autobiographies. *Losing My Mind* includes three narrative strands; the first concerns his past life experiences from birth to the early 1970s, the second describes the progression of current symptoms, the ‘stories of

humiliation and loss' containing 'the rough details of [his] tangle with Alzheimer's' (2002: ix), and the third is constituted by scientific reports on recent Alzheimer's research. While the first strand is rich in autobiographical details, the second strand outlines the effects of a disintegrating memory on DeBaggio's sense of self: 'This narrative represents a mind-clogged, uncertain present. It is filled with memory lapses and language difficulties and the sudden barks of disappointment and loss' (ix). DeBaggio highlights the importance of memory and of language in his sense of self. In fact, DeBaggio sees the moment of losing language and the ability to communicate as the end of selfhood *per se*, thereby colluding with the dominant conceptualisation of Alzheimer's as 'death before death':

Although my body may still be sputtering along, the day will come when I can no longer write a clear sentence and tell a coherent story. That day will be the actual time of death. The person in me who lives on until natural death occurs is only a show left by the deadly laugh of Alzheimer's. (117)

DeBaggio evidently has a strongly narrativist and diachronic outlook on his life and identity. He describes how the stories he encountered through radio plays, television, and journalism shaped his own identity; how literature provided him with a model for living; and how it continues to provide comfort in his present situation. In Strawson's terms, DeBaggio is living according to the 'psychological Narrativity thesis' in that he seems to 'see or live or experience' his life 'as a narrative or story of some sort, or at least as a collection of stories' (Strawson 2004: 428). Nonetheless, DeBaggio is clearly aware that the imagination and the act of storytelling reshape memory—and thereby the identity narrative one constructs. For instance, DeBaggio ironically comments on the way his parents reconstructed their past as benign, despite the fact that they lived during an era of enslavement, lynching, two world wars, an influenza epidemic, and the Great Depression. Similarly, DeBaggio reflects on the unreliability of his own memories in shaping his sense of personal identity. In this way his memoir not only produces a narrative version of selfhood, but reflects critically on the relation between narrative, memory and self in that production.

Further, despite propounding a narrativist view of identity, DeBaggio also hints at other forms of selfhood. Reflecting on a piece of rock he has been given by a friend, DeBaggio writes:

This coldly solid piece of the explosive past reminded me of the earth's longevity and the firmness of the past in contrast with our ephemeral present. Like many old objects it is without verbal account but nevertheless it is *full of meaning* and a reminder of the permanence of time. Unlike our own wispy recollections, this rock is a survivor of memories beyond our knowledge, a mute reminder that *the past lives silently in the present*. (108; my emphasis)

This passage suggests that memory may be embodied, or that the physical body may provide a base for selfhood. However, the 'meaning' of the object 'without verbal account' depends on a reflexive human Other who can recognise the stone as 'survivor of memories beyond [the perceiver's] knowledge.' Likewise, the person with advanced dementia who is mute and unable to project her sense of self requires another to recognise her past life that continues 'silently in the present.'

This passage in DeBaggio echoes Richard Taylor's conviction that despite biological and psychological changes, at the end of the disease process, he will still be himself: 'I have no idea who I will be when I am wheeled out for the final act on the Alzheimer's stage. But I do know I will *be* ... I will still be me ... perhaps a *me* different from what I have ever been before' (Taylor 2007: 118). However, as noted previously, Taylor's conclusions are never simple. Throughout his essays, Taylor struggles to define the degree to which his brain and his self are one, the extent to which he is Alzheimer's and the disease is him (89). Taylor stresses the impossibility of 'knowing the truth about people with late-stage Alzheimer's.' To claim insight into the later stages, he argues, is like

claiming to know the form and content of the fourth or fifth dimension. We are limited by our own thinking and language to imagining something we cannot see, hear, feel, touch, or taste. We can take what we know and project it, but we are still within the confines of our own minds. (24)

Among other things, Taylor reminds us that due to its progressive nature, dementia is not 'one thing.' Accounts by people with early stage dementia may thus have only limited purchase on what the later stages look or feel like across larger populations. Furthermore, dementia autopathographies are

clearly constrained by the modes and conventions of their production. Indeed, these texts may be seen to compound the stigma attached to dementia, by relegating stigma to the later stages.⁸⁰ The authors claim that although they bear the label of dementia sufferers, they are not (yet) to be equated with ‘vegetables,’ ‘zombies,’ or ‘shells.’ However, by using these negative tropes themselves for their prospective selves (see in particular Davis 1989, DeBaggio 2002), and also by using life writing to assert agency, these authors potentially confirm the masterplot of dementia as ‘loss of self’ and ‘death before death’—suggesting that only when you can tell a (more or less) coherent life story are you still a valuable human being.

The form of autobiography, as dictated by genre conventions, constitutes an ethical problem if we tie narrative form—‘how the subject is realised through writing’—to social recognition in personhood debates (Burke 2007a: n.p.). ‘For it is precisely these fictions of autonomy [perpetuated through the conventions of life writing],’ Lucy Burke writes, ‘that render the vulnerable and disabled beyond the pale of social, political and often legal recognition’ (n.p.). In this context, McGowin’s memoir *Living in the Labyrinth* (1994) has been singled out as an example of how narrative form, and its reception, may be ethically problematic. Basting notes that in McGowin’s account the symptoms of dementia are described rather than ‘performed.’ The language of her memoir is ‘cleansed of the disease ... spelling, grammar and memory of dialogue and events are pristinely intact’ (Basting 2003: 89). The memoir also includes a number of rhetorically powerful arguments. Basting notes, quoting McGowin at length, how well McGowin is able to articulate ‘the contradiction between her own feelings of self-worth and the depletion of her cultural value as a victim of Alzheimer’s’:

If I am no longer a woman, why do I still feel I’m one? If no longer worth holding, why do I crave it? If no longer sensual, why do I still enjoy the

⁸⁰ This move is similar to the one that Leibing and Cohen (2006) describe in the context of gerontology: by way of distinctions between the ‘young old’ or those who are ‘successfully ageing’ and the ‘old old’, the brunt of the stigma attached to old age is shifted to the very old or frail elderly. In a second move, this stigma becomes attached to those affected by a deteriorating mind. In the final move, described above, people with early-onset dementia (or at an earlier stage in the disease) distinguish themselves from the severely demented, by asserting their continuing competencies. The end stages of dementia, in this paradigm, continue to be considered a stage of meaningless existence, a ‘death before death.’

soft texture of satin and silk, against my skin? My every molecule seems to scream out that I do, indeed, exist, and that existence must be valued by someone! (McGowin 114, qtd. in Basting 2003a: 90)

While Basting suggests this passage captures the frustration she has seen in the behaviour of people with more advanced dementia, she nevertheless states that she finds McGowin's eloquence 'almost disturbing' (90)—presumably due to its lack of 'authenticity' as the voice of a person with Alzheimer's.

However, not all contemporary forms of dementia life writing provide coherent narratives promoting fictions of autonomous selves. Cary Henderson's collaborative life writing project *Partial View* (1998) acknowledges not only the collaborative nature of dementia testimony but also the interdependent and relational nature of identity (see also Burke 2007a). Furthermore, Henderson's account, through its repetitive and syntactically flawed style, 'enacts' or 'performs' the symptoms of dementia. Thereby the text fully acknowledges the difficulties Henderson experiences. While Burke is aware that collaborative texts 'raise their own ethical difficulties,' she lauds them for raising the problems explicitly, 'rather than subsuming them behind what has always been a fiction – that of the autonomous, independent subject' (Burke 2007a: n.p.). Burke's discussion of Alzheimer's testimony resonates strongly with Angela Woods's recent challenge to the uses—and potential abuses—of 'narrative' in the medical humanities, in that Woods questions the current promotion of one model of selfhood within medical humanities research—that is, of the self as an 'agentic, authentic, autonomous storyteller' (Woods 2011: 2)—to the exclusion of more shifting, interdependent, relational, or embodied models of selfhood.

By providing a collaborative account and highlighting the process of its production, Henderson's memoir challenges the agentic, authentic and autonomous notion of selfhood. However, it also provokes the reader to reconsider the extent to which narrative 'coherence' in a life narrative is necessary for it to count as a claim to personhood. Henderson's memoir is illuminating, since it lacks any kind of overarching narrative frame and it includes hardly any references to the author's past. And yet his insights into

his current situation, his appreciation of nature and music, his paranoia, anger, and fear as well as his deep compassion for his caregivers provide a powerful sense of self. The inscription of his ‘now-self’ through the use of brief musings is no less powerful than, for instance, DeBaggio’s narrative that is more heavily focused on his ‘past-self.’ Despite minimal coherence between and sometimes within sections, Burke notes how ‘Henderson’s personhood is asserted in the very act of narration’ (Burke 2007a: n.p.). Unlike other dementia life writers, Basting comments, ‘Henderson does not rely heavily on memory to define who he was and, simultaneously, who he is. His narrative voice lives in the present moment, rather than describing the disease with the distance for reflection that more traditional narratives provide’—and, I would add, *require* (2003: 94). In short, small stories (Bamberg 1997) and not just life stories with a protracted narrative arc or in the form of a quest can function as a means for reclaiming identity and countering stigma.

Nonetheless, in relying on the performance of ‘neurotypical’ selves who can tell coherent life narratives, most of these memoirs ultimately reclaim selfhood only for people in the early stages of dementia. They may therefore, as Burke points out, ‘collude with precisely those norms that underpin the stigmatisation of dementia in the first place’ (Burke 2007a: n.p.). Disability scholars question whether autopathographies can ultimately ‘counter’ the dominant construction of dementia as ‘loss of self’ (Basting 2003a, Burke 2007a). Burke worries that in tying life writing to social and political recognition we are ‘still working within a paradigm that potentially robs those unable to produce their own narratives of their personhood’ (Burke 2007a: n.p.). She raises the question whether to tell ‘a good enough story’ about Alzheimer’s may not ‘require a different genre—a new set of conventions—fully to speak to the damage wrought by the condition and to the significance of relationships and intersubjectivity to the illness experience’ (n.p.). I argue that collaborative life story work represents just such a ‘new’ genre of dementia life writing.

Coherence in ‘Broken’ Counter-Narratives: ‘Mrs Mill’ and Other Stories

In this section I argue that collaborative life history work with people with dementia not only extends the possibilities of representing the experience of cognitive decline, but also pays tribute to the intersubjective, interactive and relational nature of identity (see also Basting 2001: 79). I investigate what happens when we shift our attention from the published autobiographies of individuals to seemingly incoherent or ‘broken’⁸¹ narrative told in the context of a collaborative life writing project such as the Trebus Project.⁸² These narratives challenge the extent and the nature of ‘coherence’ expected conventionally of life stories. They alert readers to different *forms* of coherence in collaborative dementia narratives and appeal to readers to actively participate in the creation of coherence.

The artist David Clegg has been producing collaborative life stories with people suffering from dementia since 2001. *Tell Mrs Mill Her Husband Is Still Dead*⁸³ is one of the publications to emerge out of these collaborations. Clegg’s Trebus Project shares certain goals with both life history work and dementia advocacy. In collecting the (life) stories of his participants, Clegg operates somewhere between the practices of ethnography, collaborative life writing and creative writing. The narratives cannot be clearly assigned to any of these genres or disciplines. The very nature of these narratives therefore demands an interdisciplinary approach. In developing such an approach, I map out a framework that leverages the ideas of identity narrative, narrative coherence and counter-narratives to generate new hermeneutic tools for understanding these collaboratively told (life) stories.

⁸¹ I use the terms ‘incoherent’ and ‘broken’ advisedly, since collaborative storytelling is always an ‘interactional achievement’ (Ochs and Capps 2001) and the seemingly ‘whole’ stories published as autopathographies are themselves the product of shared literary conventions. Narrative coherence is, hence, to be understood as a graded quality. In other contexts, the term ‘broken’ is frequently used to indicate a psychological rift or traumatic experience in life rather than, or in addition to, referring to characteristics of a given life narrative.

⁸² See the project website for further information: <http://www.trebusprojects.org/>.

⁸³ Abbreviated henceforth as *Tell Mrs Mill*.

Before I provide examples of how counter-narratives are constructed in collaborative storytelling, a few preliminary notes on the collection as a whole are in order. *Tell Mrs Mill* contains nearly fifty stories by people with dementia. Sometimes these narratives consist of conversations between participants, but usually each chapter is devoted to a single storyteller. Pseudonyms are used in all but one case. Clegg's practice differs here from the usual conventions of life writing. Despite having acquired consent for his work, he shields the narrators' identity—by changing names, addresses and occupations. This practice shows that Clegg is sensitive to the difficult ethical issues attendant on representing 'vulnerable subjects' in life writing (Couser 2004). Nonetheless, it is somewhat surprising that Clegg chooses to obscure the storytellers' identity since, according to his introduction to the collection, many of the participants 'told their stories because they would be published not despite it' (Clegg 2010: 13). Indeed, Clegg adamantly criticises care homes for isolating 'the people it is supposed to be protecting' and for cutting off 'avenues of real communication' (13)—under the pretext of adhering to patient confidentiality. In contrast to the 'institutional need to censor' or to 'sanitise' life stories, Clegg underlines how most of his participants 'insisted that their story be told "warts and all"' (13). By allowing the storytellers' unique voices to shine through, Clegg exposes their disability. By shielding their privacy in order to mitigate the effects of this exposure, however, he undermines the storytellers' authority. Collaborative life writing in dementia raises complex ethical issues not easily resolved by any one set of rules or conventions.

Defining the genre of the collection also poses a problem. Despite its parallels with life history work and patient advocacy, Clegg nevertheless regards his work as artistic practice—describing the words he collects as 'the building blocks' of his sculpture (11). Clegg's procedure raises complex questions about who these stories belong to and how they are to be received. Do we read these narratives as social history, testimony and/or identity narratives? Or do we assess them as collaborative art work? In which case, do we ascribe artistic intentionality to the storytellers or to Clegg (and the numerous other editors) since the editing process gave these stories their final form? Due to the nature of the collaboration process these

questions cannot finally be resolved. Instead I propose an integrative approach that draws on life writing studies, literary criticism and conversational storytelling research to yield strategies for engaging with these accounts—strategies that will need to be further extended and diversified in future work on the narratives at issue.

While ideas from the analysis of conversational storytelling influence my reading of these narratives, my case studies call for distinctive methods of inquiry. The narratives in *Tell Mrs Mill* are, for the most part, a far cry from the detailed transcriptions that appear in conversation analysis. Since Clegg's part in the conversation has been edited out, it is unclear how his contribution shaped the stories. Many stories were, furthermore, elicited over the course of numerous visits. The process of editing may then have rendered the final product either more or, indeed, less coherent. I have no way of reconstructing the editorial process. However, reconstructing this process is not necessary in order to get a sense of how the storytellers use narrative to position themselves both in the on-going interaction and in the context of the publication of their life story (when they retained the sense of this second level of engagement). That said, the editorial process, as I outline below, does play a prominent role in the way we read these narratives as counter-narratives.

The collection is striking for the sheer variety of selves it represents. One is drawn into the storytellers' life histories while also gaining insight into their current situation in the nursing home. Many narrators are openly critical of the care environment and the rigid structure of the institutions they live in. They criticise care staff for curtailing their freedom, denying them their individuality and invading their privacy. On this account alone, these stories can productively be read as counter-narratives to the potentially dehumanising, or at the very least infantilising,⁸⁴ treatment of people with dementia in nursing homes.

⁸⁴ Lyman (1989) cites infantilisation as one of the negative outcomes of the current disease construct. People with dementia are deemed incompetent and irrational, when competence is in fact a local phenomenon and should be assessed case by case. Globally denying people with dementia agency in their lives may lead to excess disability since, as Stokes and Goudie argue, 'people can become de-skilled if their needs are automatically met by others' (Stokes and Goudie 2002: 5-6).

The narrators use autobiographical stories to make identity claims. Sometimes these narratives may lack coherence—when the temporal order becomes disjointed, referents are unclear, or multiple versions of events contradict each other. Yet Hydén and Örvlöv (2009) show how we can understand even such seemingly incoherent narratives by paying attention to how the narrators use the evaluative sections of their narratives to make identity claims. According to Hydén and Örvlöv, evaluation ‘tells the audience something about the teller or the narrator’—significantly about ‘his or her moral standing in relation to what transpired in the story’ (210). Evaluative sections are used to present a continuous identity, to present oneself as the ‘same person’ as previous to the onset of dementia with the ‘same moral qualities’ (212). Many of the stories in *Tell Mrs Mill* function in this identity-building way. For instance, Aidan stresses how he has always been a ‘loner’ and how his independent nature has kept him from becoming an alcoholic embroiled in bar fights—unlike many others from his socioeconomic background. By telling stories about his past and aligning his present self with them, Aidan emphasises continuous traits of his identity. For Isabella, engaging in the Trebus Project represents a continuation of her life-long involvement in political advocacy. Remembering her experience of visiting an abattoir, Isabella notes, ‘But now I’ve seen people with dementia treated just as badly ... people in care... people with dementia... drugged and sedated with a cup of tea and a digestive biscuit’ (Clegg 2010: 111).⁸⁵ The story content (inhumanity towards animals) is made pertinent to her current situation and employed as a searing critique of current dementia care practice. More generally, Isabella calls attention to the vulnerable position of people with memory loss:

Dementia care in this country doesn’t exist... the problem is... a great many people who are supposed to be carers...have contempt... for the loss of memory and the mental problems that that leads to...and take advantage of it. They behave in the most diabolical way and think they can get away with it...because...no one would believe the poor woman with dementia. (112)

⁸⁵ The ellipses are part of the original manuscript. They suggest hesitation in the storyteller’s speech.

In her lively stories about her previous political battles as well as her damning evaluation of the current state of care, Isabella maintains her identity as political activist. Isabella's counter-narrative therefore functions on a number of levels. It undermines the notion that people with dementia undergo a loss of self since her narrative allows Isabella to present a continuous identity. She performs this identity in interaction with Clegg but also through the wider dissemination of her narrative on publication. Furthermore, she criticises the stigma attached to dementia and challenges the way people with dementia are treated.

Autobiographical narratives may also be told to highlight changes over a life time. As the story of a former member of the Hitler Youth suggests, the teller of autobiographical stories can also make identity claims by distancing herself from past actions. Here the storyteller, Eva, dissociates herself from her youthful enthusiasm for Hitler by describing herself retrospectively as 'silly' and 'weak' (23). While her anecdote of offering a bunch of flowers to Hermann Göring may or may not be confabulatory, it vividly evokes her sense of having been swept up in a wave of mass enthusiasm. When it comes to making identity claims in her present situation, though, it is central that Eva retrospectively evaluates her girlhood self, specifically in relation to this incident, as 'proud and stupid' (23). She thereby claims a different moral stance towards her youthful attitudes, resolving the conflict that subsequent knowledge of the Holocaust caused in her sense of herself as moral being. She performs this new identity and highlights her distance from her previous self by integrating self-quotation into her story. As Hydén (2010) notes,

Telling autobiographical stories is a way to expand the present reality and thus expand one's own identity. By introducing new versions of the self, the teller is able to relate to these figures, by identifying with them, by rejecting them, or by claiming that a change or development has taken place, a development that may be continuous or discontinuous. (39)

This 'narrative expansion of identities' through which the teller can introduce new aspects of herself into an ongoing interaction provides the means by which a speaker, as in Eva's case, negotiates her identity with the present audience (Hydén 2010: 39).

Eva's collaboration with Clegg also represents another instance of countering the dominant discourse on dementia. Validating her life experience as part of a life history project, the collaboration underlines that her life is anything but valueless. People with dementia witnessed a time which is slowly passing out of living memory. They have something important to tell us about how things were for them. The stories not only provide counter-narratives to the dominant construction of dementia, but, for instance by describing what it was like to live in war-time London, as a number of stories do, they also challenge the retrospective glorification, or sentimentalisation, of the past.

Although a referential relationship to 'life' is central to autobiography studies (Eakin 1992, Lejeune 1988), the criterion of referentiality may recede into the background in collaborative dementia life writing—without, however, dropping out of the picture entirely. Recent work on confabulation in dementia illuminates how even confabulatory stories are used to make identity claims. To recognise these claims, however, we need to expand the notion of narrative coherence. Maria Medved and Jens Brockmeier's view of narrative as 'primarily a communicative activity' (Medved and Brockmeier 2010: 25) opens the door for recuperating coherence in fragmented and possibly confabulatory autobiographical narratives. They underscore how the narratives told by a brain-injured person may be psychologically coherent, by highlighting a central pre-morbid personality trait. Other authors have stressed the relevance of 'emotional,' 'metaphorical' or 'thematic' coherence in confabulatory stories by people with dementia (Crisp 1995, McLean 2006). Jane Crisp (1995) proposes a framework in which the relevant criteria for evaluating stories by people in advanced stages of dementia 'would no longer be the literal truth or falsity of the details,' but among other things, 'the overall point of the story – the underlying message or thematic and metaphoric meaning it suggests' (135). Crisp underscores that it is important to note 'the qualities to which the storyteller [of confabulatory stories] is laying claim':

Sometimes these are fantasized qualities of strength, activity, resourcefulness and power, which serve to compensate for an actual position of weakness and dependency. ... Less positive stories may present

the teller as ill-treated, trapped, confused and miserable; qualities that make a direct claim on the listener's sympathy, reassurance and aid. (139)

In her case study of the narrative told by Mrs Fine, a woman with dementia, Athena McLean (2006), shows how the tragic plot of 'wronged wife' allows Mrs Fine to make an empathy-eliciting identity claim. The plot segment also helps Mrs Fine make sense of her current living situation—in that the notion of having been disinherited explains why she finds herself in the seemingly reduced circumstances of a nursing home. While details of her story cannot be considered 'true' to real-life events, McLean highlights the 'emotional truth' value of the story (171).

Nonetheless, neither Crisp nor McLean lose sight entirely of the criterion of referentiality in making sense of the confabulatory stories told by people with dementia. (Of course, designating a story as 'confabulatory' already involves a value judgment in relation to 'real-life' referents.) In deciphering the 'underlying message or metaphoric meaning' of her mother's stories, Crisp uses her extensive knowledge of her mother's life. Rather than abandoning 'referentiality' entirely, Crisp instead temporarily brackets it in an attempt to make sense of her mother's stories. At the same time, Crisp notes how confabulation is generally 'very disconcerting to caregivers who know enough about the teller's past life or present circumstances to realize how fantastic many of the claims made in them actually are' (133). Since confabulation presents a major impediment to intersubjective understanding in the context of dementia, Crisp's strategies for meaning-making are vital. Similar strategies can be used in the context of reading the narratives in *Tell Mrs Mill*.

McLean's coherence-seeking analysis of Mrs Fine's story represents a fine balancing act between drawing on biographical 'facts' and not over-estimating the criterion of 'facticity.' Indeed, she alerts the reader to an inherent power dynamic that this criterion sets up. In turning to sources outside the storyteller's narrative, she claims,

we are treading on potentially dangerous territory by risking the elevation of some voices—and narrative truths—over others ... To the extent that additional information can reveal a sense in a story that would otherwise be disregarded as irrelevant, it should be embraced. ... However, when these sources are used to disconfirm (or even affirm) an elder's story on the basis

of its lack (or presence) of correspondence to external indicators of ‘truth,’ it risks disempowering and invalidating that elder. (175)

In many cases external information can help make sense of a narrative and underscore the intelligibility of the storyteller’s claims to a certain identity. Nevertheless, I query the editorial practice, in *Tell Mrs Mill*, of inserting ‘factual’ information in prefaces or footnotes, when the only function of these facts is to highlight the extent of that person’s confusion and thereby undermine her authorial voice. Instead, it seems more productive to follow McLean’s pragmatic suggestion about making use of real-life ‘facts’ and including them in the paratext to help elucidate the metaphoric, psychological or emotional coherence of a narrative. What is at stake here, in short, is how to make sense of confabulatory and fragmented dementia narratives by acknowledging their use in the performance of identities in discourse.

Attending to recurrent or dominant themes, as Crisp suggests, provides another way of reading the narratives in *Tell Mrs Mill* as a means of identity construction (‘self-making’) and ‘sense-making’⁸⁶ (Örülkv and Hydén 2006). Sid’s story, for example, revolves around his survivor’s guilt, a deep admiration for his mother and an overwhelming sense of loss at his close friend Frankie’s death during the war. In Sid’s account, versions of key events in his life (his mother’s death by drowning, various people being killed by a bayonet) contradict each other. However, each version clearly highlights how his life was marked by violence and loss, how he continues to struggle with survivor’s guilt, and how his love for both his mother and his friend Frankie persist. Similarly, Ann repeatedly laments the loss of her doll’s house, which her mother gave away when she was a child. The strong emotion this memory evokes indicates how formative early childhood experiences can be, while also suggesting the extent to which earlier memories may come to dominate the present in dementia. However, in the terms set out in Crisp’s study, the loss of the doll’s house can also be seen as a metaphor expressing Ann’s current experiences of loss.

⁸⁶ See also Herman (2013) for an account of narrative as an instrument of mind and a sense-making practice.

Although much more could be said about the stories in this collection, I will focus on one to elucidate how the ideas discussed thus far may be brought to bear on a more detailed example. I focus on Janet's story, not because it is representative, but to show how narrative identity is constructed in a comparatively fragmented, non-linear, and partly confabulatory narrative. Indeed, this text may not be considered 'narrative' at all if one applies strict criteria of causal linearity and logical coherence. Yet in the context of everyday storytelling, let alone collaboratively produced dementia narratives, such criteria rarely apply (see Hyvärinen et al. 2010, Ochs and Capps 2001). In the following discussion I elucidate how Janet's narrative, though partly confabulatory, functions as a counter-narrative. I engage with the question as to how much context needs to be restored to make sense of her utterances—and what role the listener, editor and reader play in constructing a 'coherent narrative' and possibly by extension a 'coherent identity' for and with Janet.

Unlike most narratives, Janet's story is framed by some introductory information (distinguished from the narrative 'proper' through the use of italics). This introductory information states that she worked as a housekeeper for a large hotel in Great Yarmouth for thirty years and has been living in a modern purpose-built care home for three months (189). The first part seems intended to help the reader make sense of what she says, while the second emphasises the extent of her dementia—since she is uncertain about how long she has been in the care home and whether she lives there permanently. Despite her confusion, her narrative nonetheless highlights how aware she is, both of her dementia and her environment. As she blandly puts it, 'People sometimes think I'm not aware of what's happening but I am' (189). She describes how disconcerting the symptoms of dementia are: 'I feel like I'm out of my depth... like I've been swimming along and suddenly I can't feel the bottom. That's the feeling. It's not my cup of tea at all' (191). Her account is rich in emotional appeal since it evokes her sense of frustration, struggle and loss. Among other things, Janet is aghast at her loss of agency: 'I feel as if the rug's been pulled out from under my feet' (191), she states. Also she feels she has been 'shuffled about a bit,' 'inveigled' or 'hustled into' the care home by her family. Although

Janet acknowledges that her children are trying to protect her from her own frailty she nevertheless states ‘I’d much rather take the risk and stay at home’ (191). Her account closes movingly with the words ‘... all my life has gone now...all my memories are at home...I’m sure all this is with the very best intentions’ (191). Janet’s evocative use of imagery and the insight she provides into her condition allow the reader to get a sense of what it might feel like to be losing all sense of certainty and agency. Her self-awareness clearly undermines the common presumption that people with dementia are ‘mindless vegetables’ unaware of what is going on either ‘inside’ or around them.

Janet’s account also represents a counter-narrative in another, related sense. Her life experience of working in a hotel provides a framework for making sense of—and severely criticising—her care environment. So for instance, she refers to a member of staff as a ‘waitress’ and to the other residents as ‘guests.’

The way that waitress talks to me... she swears... it’s just not the thing. I told the lady last night that she didn’t have to go just because they said it’s time to go to bed. I don’t understand it. They came to the lounge, got hold of my hand and tried to cart me off to bed. I said I don’t want to go to bed. I can go to bed on my own, thank you very much. (189)

By applying the norms of social conduct of a hotel to her environment, Janet starkly highlights how radically social norms shift in the context of dementia care. While her account might be interpreted as a misapprehension of reality, the storyline she employs nevertheless exposes the forms of conduct in care homes as contrary to what is considered acceptable in other social contexts. Common courtesy, respect, and politeness all suddenly go out of the window:

I think I irritate the staff sometimes but some of them are so rough that they scare me. I heard one of them say something to one of the guests the other day and I said, ‘Please, you should say “please.”’ They looked at me as if I’d gone mad because I asked them to say please rather than just pull the lady out of her chair. (190)

In interpreting the care home as hotel Janet uses a dominant storyline from her life history. This storyline helps her make sense of her environment as well as assert her identity by linking the past to the present and by providing an evaluation of the current setting (Örülv and Hydén 2006). Janet’s account

illuminates how residents in care homes are infantilised and robbed of their autonomy in every conceivable instance—frequently unnecessarily. I find it remarkable that this aspect of her narrative, which could easily be dismissed as confusion, instead highlights the persistence of her social identity and provides a damning critique of this so-called ‘home.’

Taken in context, Janet’s narrative suggests more generally how the whole Trebus Project represents a multi-layered and multi-faceted counter-narrative to the dominant discourse on dementia—in large part because of the way Clegg frames his project. The provocative title of the collection derives from what may be considered an exemplary counter-narrative—provided by Clegg himself. Clegg relates how Mrs Mill would camp out in front of the locked door to her residential unit because she wanted to get out to prepare tea for her husband—dead for twenty years. In order to keep her from obstructing the door the nursing staff would pretend her sister was on the phone. Clegg finds that ‘repeatedly tricking a frail old woman and then hoping she would forget seemed so contrary to care, so mocking and so wrong’ that he decides to tell her the truth about her husband’s demise (11). Clegg relates how Mrs Mill, after some initial confusion, visibly relaxed at the thought that her husband was not in fact waiting for her. He manages to persuade the staff to tell her the truth in the future. The next day he finds a message on the notice board: TELL MRS MILL HER HUSBAND IS STILL DEAD. The reader is left to infer with how much sensitivity the staff is likely to have proceeded. Interestingly, when more than a hundred pages later we come to Mrs Mill’s life story there is no mention of these events. Yet what is remarkable is, for want of a better description, how much of Mrs Mill is still there. She remembers her childhood and working life in detail and, notably, cherishes the opportunity to tell her life story: ‘I’m so pleased to do this... I never thought I was popular enough to write a biography’ (157). Clegg advocates a change in the perception of dementia and the treatment of people with dementia and offers his own work as one way such a change can be brought about.

Apart from this introductory anecdote, Clegg’s strongest act of ‘countering’ resides in one of the narratives in which his work as editor is seemingly least pronounced. The middle section of the collection is entitled

(again provocatively) ‘Fun and Games.’ This section is distinguished from the rest by being printed on harder, egg-shell coloured paper and framed by a stripy cover. It includes another introduction by Clegg in which he describes the opportunity to revisit three of his storytellers after a break of five years. Clegg here takes a much more ethnographic approach: describing and transcribing the background details, the date, time of day and the words, actions and gestures of both the residents and their caregivers. Although Clegg here takes *less* licence in editing out sections of the interaction, and therefore, arguably, has less of a shaping influence on the counter-narrative, I consider this section the most powerful counter-narrative of the collection—fittingly placed at its heart. In his transcriptions, Clegg provides context for what may otherwise seem meaningless or incoherent behaviour. Importantly, the detailed description reveals how callously—and sometimes brutally—the care staff respond to the patients in their care. For instance, Clegg queries the enforced cropping of Daisy’s long hair—long hair which had previously been a great source of pride. Although her distress is evident in her words—‘look at what they have done to me’ (XXXVI)—Clegg’s additional description leaves no doubt as to the meaning of her utterance: ‘*(She tugs violently at her cropped hair.)*’ (XXXVI). The image of cropped or shaved hair is in turn reminiscent of other outrages against humanity. In evoking and underlining this image, Clegg highlights the brutality of acts of supposed ‘care’ which instead humiliate and dehumanise the care-receiver.

Conclusion

The question of the relation between narrative and identity remains an open one. In this chapter I have argued that narrative identity is crucial to people with dementia, particularly in the context of dementia life writing. Rather than focusing on the ontological question of whether selfhood is constituted through narrative, I have suggested that narrative is a tool, a means of constructing and negotiating identity in the social world. Writing dementia autopathographies represents one means of making identity claims. In the context of collaborative dementia life writing, narrative is similarly a means of claiming identity, both locally in the context of interactions within the

nursing home and more globally through the publication and dissemination of these texts to a wider audience. In turn, in order to be able to make sense of these narratives and understand their function, we need to expand the notion of ‘coherence.’ In the light of ideas from conversation analysis, ethnographic approaches to narrative and previous research on storytelling in dementia, the narratives in *Tell Mrs Mill* can be read as ‘emotionally/psychologically,’ ‘thematically’ or ‘metaphorically’ coherent. Further, the creation of coherence involves a collaboration among the storytellers, editors and readers.

Coherence, in fact, is the contested backbone around which both identity narratives and counter-narratives are built. Recent work in narrative studies premised on the view that coherence is an interactional achievement opens up new avenues of thought for considering how coherence is constructed in collaborative dementia life writing. The operative terms then become positioning and performance rather than referentiality and factuality. People with dementia continue to make coherent, that is intelligible, identity claims. Whether their claims are recognised or not depends, however, less on the formal criteria of their identity narratives than on the willingness and ability of the people around them to engage with these claims.

By showing how coherence is achieved through a two-way process that involves the coherence-creating capacity of the listener or reader, I have aimed to underline two issues: One, narratives by people with dementia, present an ethical demand or *ought to* for the listener/reader, who is prompted actively to engage with these attempts at meaning-making rather than disregard them as ‘incoherent’—even if this attempt entails the risk of over-reading or misinterpreting certain narratives. Two, not only narrative but identity is interactively and intersubjectively constructed, frequently *through* the exchange of narratives. Dementia life writing, especially collaborative life writing projects, acknowledge our interdependent nature—that we are socially constituted beings—thereby refuting the myth of the self as autonomous agent. Narrative is one means of creating and shaping a social environment (‘world-making’), claiming and negotiating identity (‘self-making’), and making sense of one’s environment and one’s position in the world (‘sense-making’) (Örülv and Hydén 2006)—providing the

answer to such questions as ‘What is this? Who am I? How did I get here?’ Broadening the conception of narrative coherence we can attend to the actual ways people with dementia use narrative and the ‘moves’ they make in social interactions.

Further, I aimed to address the question to what extent life narratives by people with dementia represent counter-narratives to the dominant cultural construction of dementia as ‘loss of self’ and ‘death before death.’ My analysis of dementia autopathographies suggests that the authors of these texts criticise the stigma attached to Alzheimer’s; they reclaim a sense of agency for themselves by becoming writers, advice givers, and dementia advocates (Ryan, Bannister, and Anas 2009) and they revise the view that dementia entails a tragic progression of losses by suggesting ways in which the disease has changed them for the better (see Bryden 2005, Lee 2003, Taylor 2007). But does this really mean they serve as counter-narratives vis-à-vis the dominant discourse on dementia?

By and large, illness narrative by people with dementia represent ambiguous and unsettling examples of counter-narratives. Their authors frequently use the same dehumanising metaphors that circulate in the cultural imaginary to describe those in the later stages of the disease—including their prospective selves. They thereby confirm the dominant trope of dementia as ‘living death’ (see Davis 1989, DeBaggio 2002). Moreover, these memoirs represent remarkably lucid, coherent and rhetorically powerful narratives about dementia (see, in particular Bryden 2005, DeBaggio 2002, McGowin 1994). There is a risk that countering is understood only in terms of resistance and opposition—in the sense of offering a counter-image to the dominant one.⁸⁷ In the case of dementia life writing, there is an inherent risk that by (re)positioning—and therefore valuing—the storyteller with dementia as an autonomous, able-minded, coherent, linguistically expressive person, as many of the above mentioned life narratives do, authors and readers alike continue to stigmatise the

⁸⁷ In the context of disability life writing, Thomas Couser similarly highlights the harmful depiction of disabled people as ‘supercrips’ (Couser 2005). Seemingly ‘positive’ representations according to the norms of the culture do little to question these norms and may place excessive burden on people who fall outside these norms to live up to cultural expectations.

dependent, cognitively impaired persons that people with dementia increasingly become. Together with disability critics I therefore query whether it is appropriate to use this form of life writing in rights-based movements in the context of neurodegenerative diseases.⁸⁸

By writing about their stigmatised diseases these authors entail certain risks. As Einat Avrahami has noted, ‘in a society where health is upheld, paradoxically, both as a normative, regulating category and as an ideal state of personal utopia, the decision to disclose a seriously debilitating illness is itself transgressive, verging on admittance to a state of sin’ (Avrahami 2007: 76). The authors of dementia autopathographies are well aware of such risks. In some cases, by positioning themselves as ‘able-minded’ in their narratives, these authors may therefore be seen as attempting to curtail the risk of associating with dementia. Such a move will necessarily be double-edged.

In any case, neither the narratives nor the identities that these narratives project are untouched by the dominant, and overly negative cultural construction of dementia. This can be seen, for instance, in the reduced levels of self-esteem experienced by most narrators due to the cultural meaning attached to the symptoms of dementia. Even this expression of lowered self-esteem, however, can in itself be considered an act of ‘countering’ in that it alerts the reader to the negative impact of the cultural construction of dementia. ‘Countering’ is never a simple act and reading counter-narratives depends as much on authorial intent as it does on the perspective and values of the reader.

Reading the collaborative life stories in *Tell Mrs Mill* we find that any given narrative may counter a different *strand* of the dominant discourse on dementia. Counter-narratives are also constructed at different *levels*: by the storyteller(s) in the original interaction; by the listener and interlocutor David Clegg; by the numerous editors of the stories; by the general reader; and by this reader and researcher, myself. My own research agenda will, of course, significantly shape the counter-narratives I construct (Jones 2004).

⁸⁸ Autopathography tends to be a white middle class endeavour not representative of other sections of society. While collaborative life writing is more diverse in terms of class and race it runs into similar ethical problems concerning the power dynamics of representation as ethnography.

In the final analysis, counter-narratives—in general and about the experience of dementia in particular—represent a subjective category that depends on the convictions and agenda of all involved, including the beliefs and goals of the researcher studying these stories. What is the story that I myself want to hear? Could it be that I herald certain narratives as counter-narratives because I need reassuring narratives of resilience in the face of cognitive decline (see also Herskovits 1995)? Am I thereby continuing to ignore the essential vulnerability of human life—preferring to ‘erase’ the presence of decline and death in what is already a death-denying society? On the flip side, by criticising the authors of dementia memoirs for using the same devastating metaphors for dementia as are current in popular culture, and by claiming that these narratives on this account partially fail as counter-narratives, am I not denying these authors the right to express their fears about their illness through the means they find most pertinent?⁸⁹ The problem remains too, that by highlighting how people with dementia continue to use narrative to make identity claims, I leave untouched the pernicious effects of the narrative constitution view—that is, the view that identity is not just negotiated but constituted by stories—for those who are no longer able to tell even these minimally coherent narratives. I therefore do not purport to provide here a definitive account of what counter-narratives in dementia look like. Instead, I hope to have opened the floor for further debate about how we think about—and act towards—people living with dementia.

The question of how to represent late-stage dementia remains. While current dehumanising tropes in the media increase fear and anxiety in the population as a whole and increase the stigma attached to the disease, there is also a responsibility to engage with our shared vulnerability. Therefore *not* to represent people in the later stages is equally problematic. Eliding the later stages or ‘putting a positive twist’ on them, furthermore, risks denying the reality of the disease, and may also undermine needs-based advocacy movements that aim to increase funding for this care sector. How can we

⁸⁹ Compare the problem of ‘triumph narratives’ as models for telling about serious illness (Conway 2007). Conway suggests that the triumph plot type suppresses some authors’ need and ability to express the calamity illness may present.

represent people with advanced symptoms of dementia without othering them? Couser (2004) suggests drawing on contemporary ethics of ethnography, and based on his framework I argue that collaborative life writing projects, although clearly not exempt from ethical pitfalls, provide one productive means to attempt to represent dementia, as much from the ‘inside out’ as possible. Whether this view may be able to counter the stigma attached to dementia or not will depend to a large extent on the reader.

Collaborative life story work pays due attention to the interdependent and intersubjective nature of our lives and identities. Maybe the most vital counter-narrative is not the one that asserts agency and autonomy in cases where we no longer expect it but the one that draws attention to our vulnerability and interdependency—in practical matters as well as in matters of identity. The ability to express one’s subjectivity, to tell an identity narrative, is not solely dependent on the individual but is rather a function of a communicative situation, which is co-created. Our identities rely on the willingness of others to engage with us and listen.

Chapter 4 Relational Identity in (Filial) Dementia Caregivers' Memoirs

In this chapter, I investigate what caregivers' memoirs contribute to an understanding of relational identity in dementia, and how genre and gender may modulate this understanding of relational identity. What is at stake in writing about a family member with dementia? Can caregivers' memoirs contribute to a more nuanced understanding of what exactly is lost and what, in fact, remains? To answer these questions, I situate the subgenre of filial dementia memoirs in the wider political and literary context of a fast-growing number of dementia caregivers' memoirs. Genre, as Couser points out, 'is not about mere literary form; it's about force—what a narrative's purpose is, what impact it seeks to have on the world' (Couser 2012: 9). In investigating caregivers' memoir as a genre, and sketching out a number of subgenres, my intention is to highlight their particular political force as well as to explore the ethical issues raised by dementia life writing. I then move on to a close analysis of select examples of filial caregivers' memoirs to address the impact of gender, genre and medium on relational identity: Jonathan Franzen's autobiographical essay 'My Father's Brain' (2002), Judith Levine's memoir *Do You Remember Me?* (2004) and Sarah Leavitt's graphic memoir *Tangles* (2010).

The Aesthetics, Ethics, and Politics of Caregivers' Memoirs

Caregivers' memoirs are by far the most common type of dementia narrative. These autobiographical texts are written by family members, usually spouses or adult children,⁹⁰ who are involved in the care of a family member with dementia. In detailing the progress of the disease, they represent a significant number of narratives of illness and disability that have emerged within the context of the 'memoir boom' of the last few decades (Smith and Watson 2010). The memoirs often deal with the first occurrence of minor symptoms of dementia, the difficult process from denial to diagnosis, and a critique of the failures of the care system, thereby drawing on some of the

⁹⁰ Occasionally they may be written by a long-standing family friend (see Heywood 1994), or an in-law (see Gillies 2010).

staple components of the ‘master plot’ of illness narratives (see Avrahami 2007: 75). At the same time, caregivers’ memoirs are paradigmatic examples of what have been termed *relational autobiographies* (Couser 2012, Eakin 1998, 1999, Smith and Watson 2010). While it has become a critical commonplace in life writing studies that all autobiography necessarily includes the lives of others and therefore is more properly described as ‘heterobiography’ (Couser 2004: x) or ‘auto/biography,’ caregivers’ memoirs, in particular, include significant parts of the life of the person with dementia, while also narrating the shared life history of caregiver and care-receiver.

Caregivers’ memoirs are frequently born out of an impulse to memorialise the parent or spouse,^{91 92} as well as out of the need to make sense of the devastating experience of watching a loved person die with dementia (see also Couser 2009: 223). Indeed, authors frequently comment on the therapeutic quality of writing, both during caregiving and after the family member’s death. In a first step, a diary or journal may provide a coping mechanism: an outlet for negative emotions that arise in the course of caregiving. Later, reworking these diary entries into a coherent memoir is, as Couser notes, ‘a way of grieving, of achieving—or at least approaching—emotional closure on a painful chapter of one’s own life’ (Couser 2009: 228). For literary memoirists the intellectual pursuit of researching and writing about dementia might be therapeutic because it provides a means of distancing themselves from the emotional rawness of caregiving encounters.⁹³ It might also provide the caregivers with a meaningful activity in the face of a neurodegenerative disease that is *prima facie* meaning-

⁹¹ Less frequently, caregivers’ memoirs may aim to settle old scores. When written in a vindictive mood or when gratuitously exposing the dead or dying person, caregivers’ memoirs may be considered ethically dubious. The reception of Tilman Jens’ (2009) memoir about his father Walter Jens, a well-known German intellectual, provides a case in point. In the UK, John Bayley was criticised for publishing his memoir *Elegy For Iris* (1999) about his wife, the writer and philosopher Iris Murdoch, while she was still alive but too advanced in her disease to challenge his representation.

⁹² Memoirs may serve the double function of memorialising a parent and providing an extended family memoir, such as Grant (1998) on her Eastern European Jewish heritage, Appignanesi (1999) on her Jewish family’s history during the Holocaust in Poland, or Gordon (2007) on her mid-century American Catholic working class background.

⁹³ Graham (1997) suggests that writing provides such a distancing effect and a means of coping with illness by allowing the author to remain an authoritative agent in one domain of her life. His analysis is concerned only with autopathographies written by the person affected by the disease but can be seen to apply equally to caregivers’ memoirs.

defying. In many cases, the memoirs allow their authors to maintain a relationship to a declining and finally absent family member, by reconstructing and at times revising or re-envisioning their previous relationship.

At the same time, the status and skill of these memoirists has implications for the political force of their narratives. In the spirit of the second-wave feminist slogan ‘the personal is political,’ professional writers⁹⁴ use their personal struggle with caregiving to engage the wider public in a debate about the ethics and politics of dementia care. Not unlike autopathographies by people with dementia, relational memoirs challenge the stigma attached to dementia, criticise the current health care system and seek to raise awareness for the financial, practical, emotional and ethical problems attendant on this condition. The writers of caregivers’ memoirs also aim to provide solace, support and advice for people who find themselves in a similar situation. As Arthur W. Frank has argued in relation to illness narratives in general, these stories are *for* the other. Frank sees such stories as living up to the moral duty of bearing witness (Frank 1995: 17). However, such texts are not without certain ethical risks themselves.

In fact, Couser identifies intimate life writing—that done within families, couples or close relationships—as particularly prone to ethical pitfalls: ‘The closer the relationship between writer and subject, and the greater the vulnerability or dependency of the subject, the higher the ethical stakes, and the more urgent the need for ethical scrutiny,’ he writes (Couser 2004: xii). People with dementia represent ‘vulnerable subjects’—defined by Couser as ‘persons who are liable to exposure by someone with whom they are involved in an intimate or trust-based relationship but are unable to represent themselves in writing or to offer meaningful consent to their representation by someone else’ (Couser 2004: xii). Indeed, according to Couser, dementia makes a person doubly vulnerable: subject to harm (abuse and exploitation) in their life and, in the context of life writing, vulnerable to being misrepresented (Couser 2004: x)—at times, in such exposing media as

⁹⁴ Authors discussed here are fiction and memoir writers, poets, or work in professions such as journalism, broadcasting or literary criticism.

film or photography.⁹⁵ Furthermore, since people with dementia depend on others for tasks of daily living their caregivers have access to intimate details of their lives. These may be moments of confusion, hallucination, or loss of control over bodily functions. When such intimate moments are exposed in relational autobiographies, these texts violate the privacy of the person with dementia.

Nancy K. Miller picks up on this sense of violation when she claims that writing about a parent's death necessarily entails some form of betrayal (Miller 1996). The authors of filial caregivers' memoirs frequently experience a sense of transgression. Mary Gordon, in describing her mother's bodily disintegration, notably feels like Ham, 'the son of Noah, the betraying son' (Gordon 2007: 216). Deliberating on the conflicting demands of witnessing (and bearing witness in writing) and the injunction not to expose others, Gordon decides that she has made the most dishonourable choice: 'to speak and then to confess one's own (superior) knowledge of the dishonour of speaking' (Gordon 2007: 217). The writers of caregivers' memoirs struggle over the conflicting demands of their own need to tell on the one hand, and, on the other hand, the ethical imperative not to harm the family member with dementia. This conflict becomes particularly pronounced when the narrative reveals transgressions that involve disclosing intimate details that the subject has specifically asked not to be revealed, or when the person with dementia is defined as a private and reticent person—as for instance in Jonathan Franzen's description of his father Earl: 'My father was an intensely private person, and privacy for him had the connotation of keeping the shameful content of one's inner life out of public sight. Could there have been a worse disease for him than Alzheimer's?' (Franzen 2002: 24). The reader may wonder instead whether

⁹⁵ See Tony Harrison's (1993) film-poem *Black Daisies for the Bride* which, while winning a number of awards, was greeted with mixed responses—as can be gleaned from the reaction of one reviewer (Pitt 1993) as well as Burke's discussion of the work (Burke 2007b). The film poem or 'musical docu-drama' displays, alongside actors, the patients of a closed mental ward. These patients were unable to provide meaningful consent at the relative stages of their disease and their representation in the film raises uncomfortable questions with regard to the 'ethics of spectatorship' (Burke 2007b: 62). John Killick's collaboration with a photographer (Killick and Cordonnier 2000) raises similar issues.

there could have been a worse fate than being exposed posthumously by the son's writing.

The possible misrepresentation of people with dementia might not only be harmful to the individual, or the individual person's memory, but also to other people suffering from the condition, in that a gruesome or dehumanising representation might reinforce the stigma attached to dementia (see Couser 2004: 31). As Couser notes, we need to recognise that 'groups, and not just individuals, may have interests, if not rights, and those interests may be harmed by representation' (2005: 20). In this connection, it is important to distinguish between the *mimetic* and the *political* dimension of representation (Couser 2004: x).

The mimetic dimension of representation raises questions about faithfulness to 'reality.' Here the issue of infringing on another person's privacy and dignity, or to put it another way, the problem of voyeurism, is weighed against the writer's need to provide a full account of his or her experience; for therapeutic reasons, because this constitutes part of the writer's own story, or because the writer wants to raise awareness for aspects of dementia care that are silenced by powerful taboos concerning what type of story it is appropriate to tell. As Couser points out, 'memoirists assume two types of obligations: one to the historical or biographical record and another to the people they depict' (Couser 2012: 10). At times these obligations may indeed be diametrically opposed.

Representation in the political sense refers to the notion that in writing *about* certain groups or conditions, writers may actually be attempting to speak *for* those groups, that is, advocate for their rights and interests. A large number of dementia narratives by caregivers, explicitly or implicitly, engage with the politics of care: the insufficiency of care provisions, the callousness or ignorance of care professionals in relation to people with dementia, and the need for better, more sustainable and affordable dementia care. In pursuing better care provisions, writers simultaneously advocate for people with dementia and their caregivers. The question remains, who has the right to speak for a certain group; and what conditions or relationships, if any, confer surrogacy in life writing (Couser 2004: xi).

The hybrid nature of relational life writing makes it difficult to decide to whom a life or life story belongs (see also Miller 1996: 3). Thinking about lives narratives in terms of property highlights that telling another person's life may represent an appropriation of that person's story. Paul J. Eakin has foregrounded the importance of 'the story of the story' (Eakin 1998) when evaluating the extent to which a life narrative represents an appropriation of another's story. Eakin is primarily concerned with memoirs that claim to incorporate their subjects 'own' autobiography, such as 'as told-to' narratives by slaves or indigenous people in the US. The memoirs I am concerned with rarely, if ever, claim to be telling the story from the point of view of the subject with dementia. However, different narratives allow for varying degrees of self-representation, or for the 'voice' or perspective of the person with dementia to shine through.⁹⁶ In representing dialogue with the person with dementia, the person's behaviour, or even attempts at conveying their thoughts, fears or attitudes, these memoirs risk over-writing, misreading or misrepresenting the subjectivity of the person with dementia. The writers of caregivers' memoirs acknowledge the problem of appropriation and of misrepresentation, admitting also the limits of their own faulty memory. Rachel Hadas, in the prologue to her memoir cum poetry about her husband's early-onset dementia, notes:

This story, if it is a story, lacks both a clear beginning and a final resolution. Within the cloudy confines of those years ... I tried to keep track; I tried to tell the truth. Nevertheless, it is largely a one-sided truth ... I can't claim to be telling the story from his point of view. For better or worse, *this is my story*. (Hadas 2011: xi; my emphasis)

Caregivers' memoirs are frequently hedged by such disclaimers. Authors subscribe to an ethics of 'truth-telling' while they simultaneously acknowledge the impossibility of realising such an agenda. At the same time, these memoirs become the stories of their authors not only because they outlive their subjects, but also because of their urgent need to tell:

⁹⁶ I am thinking here, for instance, of the potential of documentary film in contrast to written representations. As discussed in chapter 1, documentary allows for the words and gestures of the person with dementia to be recorded and re-transmitted verbatim. Although editing still raises the possibility of over-writing, the words and gestures of the person with dementia as well as their caregiver remain unchanged. See on this point Couser's discussion of Oliver Sack's television documentaries (Couser 2004).

This is the way I have to tell this story, moving from these details into my parents' lives, my father's history. Into *how it was* for us. And all the while I feel behind me, over my right shoulder and my left, the sense of both my parents, of how differently they would tell it ... Of how my representation itself makes the story mine, not hers or his. But uneasy and unsure as I sometimes feel as I call up the memories and the words to cast them in, I am the one who has the need to do it. (Miller 2003: 48; original emphasis)

Such disclaimers and moments of self-reflection can be seen to represent 'the story of the story' and play into the readers' evaluation of the life narrative.

Caregivers' memoirs also raise aesthetic questions entangled with their ethics: how much poetic licence can one person take with another person's life? Does truthfulness to the biographical record outweigh aesthetic considerations of beauty and balance, on the linguistic and structural plane? Does the shock aesthetic of voyeurism, providing insight into intimate moments of bodily decline and dysfunction (at times going so far as to describe the actual moment of death) gratuitously violate the other person's privacy and dignity? And how does one create a coherent story out of dementia, provide closure in the face of the open-endedness of life? Couser has addressed some of these questions under the heading of the *poetics* of illness narratives (Couser 1997: 13-14). He particularly points to the intertextual nature of illness narratives, asking what genres, conventions, and formulas they employ. These questions of genre bear on how we are to interpret a memoir (Couser 2012: 38).

Caregivers' memoirs can be classified into a number of subgenres based on the type of literary genre(s) and media they draw on. Often this choice reflects the kind of audience the author aims to engage. Memoirs aimed primarily at other caregivers may be closer to advice literature or self-help books (see Alterra 1999). Those engaged in dementia advocacy frequently employ a journalistic style presenting current research into the condition—including demographics, drug research, the history of the disease, and philosophical inquiry (see Gillies 2010, Levine 2004, Magnusson 2014). They may also draw on literary genres such as testimony, apology, conversion narrative, elegy, or the *bildungsroman*. In the latter case, the memoir might enact the author's journey of discovery into the ways in which the potential for relationships and love remains, despite an initially

bleak outlook based on the cultural script of inexorable decline. Filial narratives, in addressing the difficult ethical issues of exposing their parents' lives, frequently draw on confessional life writing genres—not to be judged (and forgiven) by God but by their (secular) readers. Finally, these memoirs also often act as a *memento mori*, a reflection on the author's own inevitable decline and death.

Drawing attention to the aesthetic, mimetic and political aspects of representation should not lead to the erroneous conclusion that these are neatly segregated dimensions. On the contrary, instances of misrepresentation by the standards of the individual with dementia may in fact be a fairly accurate representation of the effects of the disease, and necessary for political advocacy. However, an overly negative or dehumanising representation of people with dementia may reinforce the stigma of the disease and thereby disincline the reader or audience towards engaging with people with dementia—thus indirectly harming the interests of all people suffering from the disease syndrome. Conversely, and somewhat paradoxically, a positive picture of dementia might equally be harmful for the community of dementia sufferers. Highlighting the persistence of personhood and the ability of people with dementia to contribute to society and engage in relationships risks eliding the difficulties both of caregiving and of living with dementia, thereby potentially undermining urgent calls for more support.

It is important to note that caregivers' memoirs are situated in the wider politics of cultural representation which affects whose life gets written (or published) in the first place and whose story gets read, or achieves critical acclaim. There are political (and demographic) reasons, for instance, to support a gender-sensitive approach to caregivers' memoirs. The provision of care remains, globally, 'woman's work' (see World Health Organization 2012: 69). Furthermore, the correlation between old age and dementia coupled with greater longevity in women means that, overall, more women than men are affected by the disease. More mother-daughter pairs, consequently, are engaged in the giving and receiving of dementia care. And yet, the only article to date to address filial caregivers' memoirs notes a 'significant disparity between the demographics of the epidemic as a whole

(and its representation in *all* published life writing) and the demographics of what might be called its *literary* representation' (Couser 2009: 226; original emphasis). Couser remarks that despite a preponderance of women both as subjects and as narrators of dementia memoirs, the most 'visible' memoirs, that is, those 'published by a mainstream press and recognized by mainstream reviewers' (226), concern male subjects (and/or are written by male authors). While his analysis seems a fairly apt description of the North American context—although Couser omits examples of female authorship and female subjects that fall within the domain of 'literary' memoirs (see Appignanesi 1999, Cooney 2003, Gordon 2007)⁹⁷—the situation is somewhat different on the other side of the Atlantic. One of the earliest British dementia memoirs is Linda Grant's *Remind Me Who I Am, Again* about her mother's multi-infarct dementia.^{98 99} The title insistently calls attention to the relational component of identity construction. Equally, the last two memoirs to have achieved wide dissemination and to have won critical awards in the United Kingdom were both by and about female subjects (Gillies 2010, Magnusson 2014). I aim to redress this critical oversight of literary mother-daughter memoirs, by including a case study of Sarah Leavitt's graphic memoir *Tangles*, while also emphasising the complex role of relational identity in any form of dementia life writing.¹⁰⁰

Beside questions of gender, the nature of the relationship to the person with dementia has important implications for the representation of the disease. If life writing can be seen as making identity claims, then one question to consider is what kind of claims are made in relational memoirs for both subjects involved. Are caregivers primarily concerned with the diseased person's loss of social roles—their role as parent or spouse or their professional identity—or are they concerned with the loss of certain characteristics of the person? Do they affirm the relationship and focus on

⁹⁷ A definitive inventory of such a fast-growing genre as filial dementia memoirs lies beyond the scope of this chapter.

⁹⁸ Grant's memoir was preceded by Heywood's *Caring for Maria* (1994), a relatively unusual case of non-spousal male caregiving.

⁹⁹ Compare also the works of the French author Annie Ernaux (1987, 1999).

¹⁰⁰ The limited focus here on white, middle class Anglophone life writing needs to be expanded to take into account life narratives from other cultures and sections of society. A more extensive study would also address 'on-line' and 'new media' acts of self-representation (see Smith and Watson 2009)

what remains, or do they focus on what is lost? Do they help to preserve the individuality of the sufferer in contrast to a medical perspective that tends to conceive of people with dementia as a homogeneous group, or do they accede to the cultural script of dementia as dehumanising ‘death before death’? And how is the caregiver’s identity affected by the family member’s dementia?

With regard to these questions, dementia in a parent might have different effects on a caregiver’s sense of self than if a life partner is losing his or her memory. Filial narratives often comment on the sense that roles have been inverted: parents have become children. And yet they simultaneously assert a continuing need for the parents to act as parents. Couser notes that as the baby boomers assume increasing responsibility for dependent parents, they are ‘stimulated to reflect on the way they were parented and the extent to which they identify with their parents’ (Couser 2009: 227). In my reading, female authors writing about their mothers often identify strongly with them; compare Annie Ernaux’s stark claim ‘I am “her”’ (Ernaux 1999: 17).¹⁰¹ However, gender affiliations may not unfold as expected. John Thorndike, in assuming the role of caregiver for his father, sees himself as taking his mother’s role. He also identifies more strongly with his mother with respect to his temperament and his need for physical intimacy. Franzen, according to Couser (2009: 230), aligns himself with his father against his mother’s materialism and insensitivity. And yet, in emphasising his father’s intensely reserved nature, Franzen, as a writer of autobiography, may also be seen as diametrically opposed to his father. Like many other filial memoirs, Franzen underscores the importance of his father’s role in his life: ‘I was inclined to interpolate across my father’s silences and mental absences and to persist in seeing him as the same old wholly whole Earl Franzen. *I still needed him to be an actor in my story of myself*’ (2002: 15; my emphasis). In considering relationality then, one can ask a number of questions: What is the nature of the relationship between the author and the person with dementia? How is it affected, both positively and negatively by the disease and the process of

¹⁰¹ Burke (2014: 29) argues that Ernaux’s identification with her mother and exposure of painful and undignified experiences in both their lives leads to a reproduction of violence on the narrative plane.

caregiving and care-writing? To what extent is identity, generally, relational? How does the narrative reconstruct, revise or perform relational identity?

Indeed, memoirs can be viewed as enacting a form of relational identity, which is both particularly pertinent and particularly troubled in the context of neurodegenerative disease. Originally proposed as a concept to capture the unique development of female identity in both life and life writing—in opposition to Gusdorfian notions of the autobiographical self as autonomous agent (Gusdorf 1980)—relational identity is now recognised as central to both male and female identity construction (Eakin 1998, Miller 1994, Parker 2004, Peaches 2006). Since our identities are constituted through interactions with others (Sabat and Harré 1992), relational identity, and the ‘telling’ of another person’s life narrative, may present a reparative move to counter the loss of identity in dementia. Significant others, such as family members, are then called on to continue to tell the life story of their loved one (Radden and Fordyce 2006). However, relational identity is a two-way system. Lucy Burke points out that reading dementia narratives highlights ‘the degree to which the task of sustaining another’s identity is problematized by the rupturing of mutual recognition’ (Burke 2014: 45). Burke questions facile recourse to ‘intersubjectivity’ and ‘narrative identity’ as a means of sustaining personhood in dementia. While she acknowledges the importance of ‘telling another’s story,’ she nevertheless cautions that ‘such a task is more complex and potentially more difficult than a simple evocation of intersubjectivity implies’ (45-6). Caregivers’ memoirs bear out the point that the caregivers’ own identity is significantly affected by the onset of dementia in a parent or spouse and that intersubjective understanding is no easy feat. Furthermore, narrativising the other’s life story, while serving the important function of memorialising the other, can never do justice entirely to the subjectivity of a person with dementia. Caregivers’ memoirs explore this complex interplay of memory, narrative and relational identity.

What happens, then, when the person with dementia loses the ability to recognise significant others? Lucy Burke explores this breakdown of intersubjectivity in dementia through a close reading of a *novel*: Michael Ignatieff’s *Scar Tissue*. Burke suggests that the narrator loses his self when

his mother fails to recognise him. I propose that we need, instead, to attend more closely to how the breakdown or, alternatively, the reparative potential of relational and narrative identity plays out in contemporary dementia *memoirs*. Lack of recognition may severely impact on the caregiver's sense of self, irrespective of gender or the nature of the relationship. At the same time, the authors of caregivers' memoirs may develop new and various forms of intersubjective understanding in engaging with their family member. Their narratives bear witness to the importance not only of recognition of historical roles (as parent or spouse) but also of recognition of the evolving personality of the person with dementia, revealing the need for caregivers to find new ways of acknowledging the other's continuing subjectivity.

Gender, Genre and the Self: Rethinking Relational Identity in Dementia

The question of self, or loss of self, is without doubt the central concern of most, if not all, discussions of dementia. Unsurprisingly then, it is also at the forefront of a number of memoirs—as expressed in the subtitle to Judith Levine's memoir: '*a Search for the Self*.' In these memoirs, caregivers explore the question of how pathology and personality interact. The authors also explore how their own identity is affected by their family members' dementia and throw new light on how relational identity plays out in this context. They find that everyday encounters with the person with dementia throw up challenges to previously held beliefs—both about the disease and about the nature of the self. Many authors consequently work towards a new understanding of the disease syndrome: they trace the history of the biomedicalisation of dementia, integrate recent neuroscientific findings, and incorporate critiques of the current model of dementia. In tracking their authors' development towards a more accepting position and a greater sensitivity towards the needs of people with dementia, these memoirs, in a sense, provide a model trajectory for the reader. Part *bildungsroman*, part advice literature (but in a more self-reflective mode), these memoirs fulfil important pedagogical functions. Even if their authors' attitudes (and

behaviour) are frequently less than ‘model’ in the moral sense, these texts register conflicting attitudes towards the question of selfhood in dementia and may therefore spark debate about the complex nature of identity. This is not an insubstantial contribution in a culture where rights-based ethics predominate, and where cognitivist notions of personhood underpin the recognition of these rights.

‘My Father’s Brain’

Jonathan Franzen’s essay ‘My Father’s Brain’ (2002), provides a miniature case study of the effect of cultural scripts, gender and genre on questions of selfhood in dementia.¹⁰² It also highlights some of the ethical pitfalls of writing about a family member with dementia. As the title suggests, the essay explores the nature of the relationship between neurology, memory and identity. It also touches on some of the staples of dementia narratives, such as the history of the disease, the insidious onset of Alzheimer’s and the family’s subsequent slow road toward recognition. Franzen sees his unwillingness to recognise his father’s dementia at least partially as ‘a way of protecting the specificity of Earl Franzen from the generality of a nameable condition’ (Franzen 2002: 19). His attitude also reflects his scepticism of the biomedical model that turns people into patients. Franzen is particularly concerned about the way biomedicine currently holds primacy in explaining human behaviour:

Conditions have symptoms; symptoms point to the organic basis of everything we are. They point to the brain as meat. And, where I ought to recognize that, yes, the brain is meat, I seem instead to maintain a blind spot across which I then interpolate stories that emphasize the more soul-like aspects of the self. Seeing my afflicted father as a set of organic symptoms would invite me to understand the *healthy* Earl Franzen (and the healthy me) in symptomatic terms as well – to reduce our beloved personalities to finite sets of neurochemical coordinates. Who wants a story of life like that? (2002: 19-20)

Franzen, instead, counters the dominant biomedical explanation of dementia by telling stories of his father’s life, of sections where their lives overlapped,

¹⁰² See also Krüger-Fürhoff (2015). I differ from her interpretations of this text as a ‘joint narration between father and son’ (99). Further, there is little critical reflection in her essay on Franzen’s interpretation of his father’s behaviour as a heroic act of asserting his will.

and, significantly, by reflecting on the stories we tell about Alzheimer's in our society. Franzen, for instance, is concerned that scientific research literalises and reinforces the 'Alzheimer's patient as child' metaphor. The disease progression mirrors in reversed order the developmental achievements of a child. David Shenk (2001) has suggested that there may be some redeeming aspects to the reversion to a state comparable with infancy in that it provides a release from responsibility with the concomitant ability to live in—and potentially savour—the present. Franzen invokes the metaphor of 'second childishness,' only to assert his father's individuality and reclaim his identity from the homogenising effect of the disease label. Indeed, Franzen suggests that his father's drive for adult independence is gendered—part and parcel of his *male* identity:

Unlike the female inmates, who at one moment were wailing like babies and at the next moment glowing with pleasure while someone fed them ice cream, I never saw my father cry, and the pleasure he took in ice cream never ceased to look like an adult's. (Franzen 2002: 28)¹⁰³

To Franzen, the persistence of his father's 'will' symbolises the continuing 'essence' of his father's personality. In his son's interpretation, Earl's death from starvation is not a symptom of dementia—in the course of the disease any patient who lives long enough will lose the ability to swallow—but a conscious decision to put an end to his life. Similarly, Franzen sees his father's sudden breakdown on entering hospital—a delirium comparable to the one Sally Magnusson describes in her mother during a stay in hospital—not as a common experience of Alzheimer's patients confronted with an alienating and unfamiliar environment, but as an expression of his father's will to 'crash' (30). Or rather, as Franzen suggests, it is 'a relinquishment of that will, a letting-go, an embrace of madness in the face of unbearable emotion' (30). In other words, Franzen asserts the individuality of his father against a neurochemical understanding of how behaviour is affected by neuronal breakdown.

And yet, Franzen acknowledges that this interpretation of his father's behaviour is a product of his own needs: 'what I want (stories of my father's brain that are not about meat) is integral to what I choose to remember and

¹⁰³ Franzen here repeats long-standing gender stereotypes, which cast childish behaviour as 'female.'

retell' (31). In the end, Franzen remains undecided on the question of selfhood in dementia. While Franzen sees his father's will, and therefore essence, as persisting until the very last moment, this selfhood is always also dependent on the son's perception—or even on his creation. The self arises from the process of seeing a whole where there are only fragments, of 'fashion[ing] stories ... of a man whose will remained intact enough to avert his face when I tried to clear his mouth out with a moist foam swab' (36). In a sense, Franzen's view is overtly and maybe excessively social constructivist; his father's identity is entirely reliant on being constructed in the words and eyes of his family. In response to his mother's words 'I see now ... that when you're dead you're really dead,' Franzen proclaims 'But, in the slow-motion way of Alzheimer's, my father wasn't much deader now than he'd been two hours or two weeks or two months ago. We'd simply lost the last parts out of which we could fashion a living whole' (37-8).¹⁰⁴ However, reflecting on the commonplace trope of Alzheimer's that its 'particular sadness and horror stem from the sufferer's loss of his or her "self" long before the body dies' causes Franzen to wonder 'whether memory and consciousness have such secure title, after all, to the seat of selfhood.' Franzen concludes: 'I can't stop looking for meaning in the two years that followed his loss of his supposed "self," and I can't stop finding it' (30).

Franzen subscribes to a number of dehumanising and infantilising conceptualisations of Alzheimer's, such as using the trope of 'death before death,' invoking the image of his father as 'an unstrung marionette, eyes mad and staring, mouth sagging' (28), comparing his father to a one-year old (28), and his state to an 'unwanted second childhood' (35). And yet he recognises and celebrates lucid moments, comments on verbal and nonverbal forms of communication and continues to 'find meaning' until the very end of his father's life. Indeed, as in other descriptions of dementia,

¹⁰⁴ While Franzen's view risks dehumanising people with dementia, casting them as the 'living dead,' it also points to the kind of pre-death grieving many caregivers experience. Noyes and his collaborators (2010) make the case that the magnitude of stress caused by ongoing caregiver grief is equal to, or even greater than post-death grieving. Franzen's mother, contrary to her son, makes a clear-cut distinction between the actual death and the metaphorical death of a person. Similarly, Sue Miller, present at her father's death, recalls the feeling that 'he was suddenly, palpably, *absent*' (2003: 153; original emphasis).

the disease at times seems to make his father *more* like himself, as when his inability to communicate exacerbates his former characteristic unwillingness to communicate. Significantly, much of the meaning Franzen detects rests in, or is communicated through, the body. He speaks, for instance, of ‘some bodily remnant of self-discipline’ (30) and recognises the importance of bodily identity:

Hour after hour, my father worked his way toward death; but when he yawned, the yawn was *his*. And his body, wasted though it was, was likewise still radiantly *his*. Even as the surviving parts of his self grew smaller and more fragmented, I persisted in seeing a whole. I still loved, specifically and individually, the man who was yawning in that bed. (36)

Somewhat ironically, while Franzen is bent on upholding an individualistic, self-disciplined and mature version of his father’s self, his essay bears witness to the fundamentally relational and interdependent aspects of identity. Relationships are fundamental in re-constituting and recognising his father’s identity. Relationality plays out negatively, in that his father’s confusion and memory loss impact on his mother’s sense of self (25), but also positively, in that his father long continues to perform his role and loving duty as grandfather. Further, despite losing the specific knowledge of their relationship, Franzen’s father never fails to recognise his son ‘as someone he was happy to see’ (27).

In many ways, Franzen’s ambivalence about the effects of dementia on his father’s identity is representative of most caregivers’ memoirs. Many memoirs seem to simultaneously assert and deny the persistence of identity in dementia. By taking into account the autobiographical, relational and embodied aspects of selfhood, Franzen helps the reader understand the complex ways in which the self is constituted and the ways in which it may persist. Franzen criticises overly materialist views of identity—resisting the view that ‘reduce[s] our beloved personalities to finite sets of neurochemical coordinates’ (Franzen 2002: 20). That said, he oscillates between conceding that ‘the brain *is* meat’ (19; my emphasis) and offering the reader stories that challenge neuroscientific understandings of dementia. In a sense, Franzen’s essay both enacts and reflects on the driving motivation of illness narratives to return ‘the voice of the patient to the world of medicine, a world where that voice is too rarely heard, [by asserting] the

phenomenological, the subjective, and the experiential side of illness' (Hawkins 1993: 12). Franzen stresses the need to assert the personal dimensions of illness, not only for the person suffering from a disease, but also for their immediate family members.

As already mentioned, 'My Father's Brain' raises serious concerns about the ethics of recounting events involving a person with dementia whom the author himself describes as 'intensely private' (24). Is he, as Nancy K. Miller claims about Spiegelman's and Roth's memoirs about their fathers, flaunting 'the artist's power to override paternal authority' (Miller 1996: 13)? 'Invariably', Miller notes, 'children's right to produce these representations of their parents raises an ethical problem. The dead instantly lose their entitlement to privacy' (13).¹⁰⁵ What is more, Franzen exposes not his father, but also his mother by criticising her behaviour and publicly proclaiming his parents' an unhappy marriage. He even quotes his mother's letters at length, in a bid to retrace his father's decline. In doing so, he makes a private communication public, exposes her feelings, views and personal style to public scrutiny. As with other memoirs, one is tempted to ask, is there some ethical pay-off for this intrusion on another person's right to privacy?

On a first reading I was tempted to answer such a question in the negative. The author seems to be using his father's disease and demise mainly to pursue an intellectual activity: namely, exploring the link between memory, neurology and selfhood. Furthermore, the relative brevity of the essay, and consequently its focus on a small set of issues, seems to undermine the primary function of many other memoirs to memorialise a family member. Of course, this is not actually a necessary consequence of the essay genre *per se*, but a consequence of the choice of focus. There is too little 'history,' too little of his father's as well as their joint history, for the reader to develop more than a cursory sense of who Earl Franzen was. The essay cannot, therefore, provide the kind of compensation for intrusion

¹⁰⁵ Couser argues that death entails 'maximum vulnerability' (Couser 2004: 16) and, rather than releasing authors from ethical obligations, writing about deceased subjects remains open to ethical scrutiny. I agree with Couser, although I believe the type of harm that can be caused to a person after his or her death is qualitatively different from any potential harm he or she may experience while alive. In the context of dementia life writing, representations may have the most detrimental effect, not on the particular person portrayed, but on people with dementia as a group.

that the inscription of ‘a lasting, if not permanent, account of a life and personality’ may bring (Couser 2009: 229). Unlike other caregivers’ memoirs, Franzen’s essay does not represent an exploration of the dilemmas of caregiving either. This may be a function of the author’s relation to his father, not as primary caregiver but as a son visiting only intermittently. While the essay touches on his father’s unhappiness about being institutionalised, it lacks many of the *topoi* of caregivers’ memoirs, such as incontinence, worries about letting a person with dementia continue to drive or concern about placement in a nursing home (Couser 2009: 230). It does not function as either advocacy, testimony or advice literature. However, while essayistic narratives are typically brief, in narrowing the focus they may also become more accessible to a wider audience. Franzen’s essay is, no doubt, one of the more ‘visible’ memoirs (Couser 2009), read also by memoirists who have written after Franzen. Its main ‘pay-off’ may therefore lie in its potential to spark debate about the nature of the self, the role of relationships in maintaining identity and the types of stories we want and need to tell about dementia.

Do You Remember Me? A Father, a Daughter, and a Search for the Self

Judith Levine’s memoir *Do You Remember Me?* (2004) provides an excellent example of how the topics raised in Franzen’s essay may be elaborated in the context of a fully-fledged memoir. Levine’s research on the disease is representative of a number of recent memoirs that aim to investigate the social, historical, neurological and philosophical underpinnings of dementia. The effect is both to inform the reader and to tie in abstract concerns—about autonomy, the self, memory and identity—with the concrete experience of one family living with dementia. The individualised portrait of Levine’s family is set against the backdrop of dominant values and attitudes in contemporary American society. In fact, Levine’s family’s ‘reverence for the rational’ is entirely in line with contemporary American values: ‘we value, and dread, what our whole culture does,’ Levine writes (30). Levine, who is from a secular, Jewish New Yorker background, describes herself and her family as ‘hyper-

hypercognitive' (36). However, by engaging with the work of the ethicist Stephen G. Post, she comes to reconsider her own and her culture's values. Levine is concerned that in today's hypercognitive society personhood, and with it full moral and legal consideration, is granted only to 'one kind of person—the rational autonomous kind' (30). She traces how her father, Stan, risks losing the status of personhood and how his needs are progressively disregarded as he becomes de-individualised by the Alzheimer's script.

The Levine family values critical thinking above feelings and emotions and the members of the family pride themselves on their intellectual prowess. This is particularly true of Levine's father himself, a former school psychologist, who throughout his career pretended to have a doctorate he hadn't earned. Prior to her father's dementia, Levine's relationship to him was defined by the strength of their intellectual disagreements. As her father begins to lose the ability to engage in verbal disputes, his dementia offers Levine unexpected opportunities to become closer to him—to discover new, non-antagonistic ways of engaging with her father. In a sense, the memoir tells the story of the growing love of a daughter for her father, and how that love allows Levine to revise and repair her former relationship.¹⁰⁶

By contrast, Levine's mother's relationship to her husband undergoes a converse development. As Stan loses the ability to engage in a coherent conversation with his wife, she, in turn, finds it harder to maintain a relationship with him.¹⁰⁷ Not unsympathetic to her mother's predicament, Levine nevertheless finds herself turning into her father's advocate over the question of whether to place him in a home. Levine believes that institutionalising him would lead to him 'decomposing,' as the professional jargon has it, since his attention-seeking personality would not be satisfied in a nursing home environment. Furthermore, Levine comes to challenge what she calls the 'official Alzheimer's story' (119) rehearsed in support groups. This story casts the caregiver solely as a victim in the relationship. On the one hand, her mother feels that Alzheimer's is exacerbating her husband's difficult personality traits to such an extent that she cannot deal

¹⁰⁶ Haugse's graphic memoir (1998) similarly traces how the father-son relationship improves in the course of his father's dementia as they develop new ways of being together.

¹⁰⁷ Noyes et al. (2010) discuss the notion of 'relational deprivation' as a descriptive label for the experience of loss and grief in the caregiver.

with him anymore. On the other hand, she takes consolation in the caregivers' mantra that 'it's not his fault, it's his brain.' Finally, based on this reductionist neurological view, her mother comes to claim that her husband is 'not even a human being anymore' (167). Levine believes that the caregiver support group narrative strips people with dementia of their humanity, turning them into 'creature[s] without ordinary perception or emotion' (167):

I am no longer his wife. Now I am his caregiver. ... to transform him from husband to Alzheimer's patient, Mom is divesting Dad of his former self, even of his capacity for happiness. (Levine 2004: 168; original emphasis)

Levine's interpretation of this narrative is of course influenced by the pain of seeing her mother leave her father when she herself is slowly beginning to love him. However, her analysis does underscore that the narratives we tell about dementia may serve the emotional needs of caregivers, and society at large, better than people with dementia.¹⁰⁸

In her mother's case, Levine believes that stripping her father of his former self allows her mother, to some extent, to divest herself of her guilt at leaving him. Furthermore, as Levine puts it,

The anguish described by many caregivers arises from the persistence of the old self and the old relationship. The new self-free identity of the patient can ease some of that anguish. A creature hollowed out of traits both beloved and reviled, the person with Alzheimer's enters the caregiver's life afresh. Historic ties to the old self dictate obligation, which is of course a kind of relationship. But now that relationship can be cleansed of the sadness of perpetual loss. The "endless funeral" is over. (168)¹⁰⁹

Fontana and Smith (1989), on the contrary, see caregivers as engaged in unduly 'reconstructing' selfhood. In their words, which reflect the stereotype of people with dementia as 'selfless shells,'

¹⁰⁸ See Lyman (1989). The 'medicalization of deviance' as Herskovits notes 'contributes to the erasure of the individual's subjectivity and agency' (Herskovits 1995: 152)

¹⁰⁹ Levine's analysis resonates with the common perception that while family caregivers perhaps are more capable of providing individualised care, they may nonetheless not be ideal caregivers. Magnusson, for instance, concludes that professional caregivers at some point may be better able to provide competent care since they are not burdened by the same emotional anguish family members experience. Also, professional caregivers are not influenced by negative relational patterns that may make the family caregiver more resentful, less patient or otherwise less empathetic towards the needs of the person with dementia. See also Levine's description of the (idealised) 'step family' of professional caregivers discussed below.

The self has slowly unravelled and “unbecome” a self, but the caregivers ... assume that there is a person behind the largely unwitting presentation of self of the victims, albeit in reality there is less and less, until where once there was a unique individual there is but emptiness. (Fontana and Smith 1989: 45, qtd. in Herskovits 1995: 158)

While contesting the point that there can ever be mere ‘emptiness’ in a sentient human being, I agree with Herskovits tentative suggestion that ‘perhaps by re-visioning the self in Alzheimer’s,’ in reaction to this dehumanising view, ‘we (as a society and as individuals) can feel better about being and becoming old’ (Herskovits 1995: 148). The writers of caregivers’ memoirs may be partly motivated to assert their family members’ continuing identity to assuage fears about their own mortality. Indeed, my own reading of these memoirs—foregrounding the ways selfhood persist in dementia—may in fact be an expression of our shared cultural unease with the prospect of losing one’s cognitive functions and of our inability to face up to decline and death. Also, while welcoming the sea-change in conceptualising dementia that Tom Kitwood’s work has brought about, I remain uneasy, as does Herskovits, about reconceptualising dementia as ‘exemplary model’ of how to be human (Kitwood and Bredin 1992: 286, qtd. in Herskovits 1995: 157)—since doing so risks obfuscating the pain and suffering this disease inflicts on both caregivers and people with dementia.

In any case, in providing a detailed description of her father’s life world and his behaviour, Levine’s memoir contributes to a more nuanced understanding of how dementia affects the self. Snatches of dialogue bring home how, while not strictly rational and coherent, her father’s utterances are nevertheless meaningful and to the point, such as when in a struggle with his wife over getting dressed her father laments his loss of independence: “‘I can’t do anything,” he yells at her. *I have no boat. I have no money*’ (116; original emphasis). Furthermore, Levine emphasises the persistence of embodied memory, and with it embodied identity: ‘His personality perseveres in his body: the literally in-your-face aggression, the Catskills comedian shrug, the pipe-smoking intellectual’s eyebrow raise’ (133). It persists in activities, such as rowing, which he continues to be able to do, even as his language skills disintegrate. Above all, however, Levine explores the potential for bodily expressions of meaning. The latter can not

only be seen in instances of aggression, but also in his bodily response to music: using his fingers, arms, feet and rhythm to express the emotional cadences of a Beethoven sonata, from coquettish frivolity to grave sadness (171).¹¹⁰

Levine's memoir also functions as a counter-narrative to the reductionist neurological view of dementia. For instance, Levine challenges a nurse aide's neurochemical view of behaviour when the latter expresses her surprise that Stan apologised for hitting an aide: 'Something in his brain must have done something, and he kept apologizing after that.' Levine wryly replies, 'Yeah ... Like anyone, he feels remorse' (178). Levine attests to the many ways in which her father remains the same, underlining the persistence of—not necessarily positive—attributes in her father that constitute his personal identity. And yet, she also acknowledges the many ways her father is changed and the emotional and practical challenges this transformation poses.

Perhaps the most important contribution her narrative makes is to recognise the many ways relationships constitute identity. Her parents' relationship reveals how gender may influence the ways spousal relationships change in dementia. Social science research suggests that female caregivers are more adversely affected by their partner's decline; perhaps because the necessary prerequisites for intimacy differ between men and women, so that the impact of the disease on communication, for instance, is more likely to deter women from engaging in physical intimacy with their partners than men (Hayes, Boylstein, and Zimmerman 2009).¹¹¹

¹¹⁰ Music has impressive potential to engage people with dementia: as a therapeutic tool, as a means of interacting with others, and as a means to improve memory and cognitive functioning—not to mention as a resource for expressing the inner life-world. See the documentary *Alive Inside* (Rossato-Bennett 2014) and the charity Playlist for Life. For a relational memoir *par excellence* (a you-narrative addressed throughout to her mother) which explores music's potential, see Magnusson's *Where Memories Go* (2014) discussed in chapter 5.

¹¹¹ A cursory comparison of male and female authored spousal caregivers' memoirs seems to support the view that female spousal caregivers are more adversely affected; or rather, that the relationship is more adversely affected when the caregiver is female (Alterra 1999, Bayley 1999, Hadas 2011). That said, caution is necessary when making such generalising claims about the impact of gender configurations. In these cases, as in the sociological research just cited, cultural expectation may cause male caregivers to mask their distress—leading to a skewed representation. Further, in the three memoirs just cited, the age at onset of the spouse's dementia may have had a greater impact on the ability to accept the disease

‘Dementia clearly makes the difference for Mom,’ Levine writes. ‘She cannot have relations with someone who can’t have a rational conversation. The man in the body she knows almost as well as her own had become alien, infantile, an untouchable baby’ (149-150). His desexualisation and verbal impotence has the opposite effect on his daughter. Caring for her father’s body involves a reappraisal of Levine’s relationship with her father and allows her a new kind of physical intimacy: ‘He feels like neither a child, nor a flirt, nor a threat. He feels only like a father. And I feel not like a nurse, a mother, a wife, or a sex object. I just feel like his daughter’ (147). In other words, although he can no longer recognise her as his daughter, his dementia, and the fact that she no longer feels threatened by him, allows Levine to comfortably inhabit, for the first time, her role as daughter. This is not to say, however, that Levine embraces the paternalistic ethics according to which ‘dutiful daughters’ are to be expected to take care of their fathers (see Couser 2009).

Levine not only traces how her own relationship to her father improves in the course of her father’s dementia, but also how new relationships outside the family circle develop. The professionals, hired to look after Stan in his own apartment, form lasting relationships with him. One of the male caregivers comes to assume the role of ‘younger brother’ and, as Levine views it, her father’s ‘nastiness toward Ernesto becomes the time-honored abuse of younger brothers, competitive but affectionate, even protective’ (259). The relationship to his female live-in caregiver, Nilda, not only approximates a spousal relationship, but, in Levine’s interpretation, fulfils her father’s need for the ‘unconditional love’ that his own mother couldn’t provide. In what amounts almost to a panegyric of the professional caregiver, Levine states

Nilda answers Dad’s every need without needs of her own, she loves him openly and without judgment, she neither competes with nor criticizes him, is always there, and (as far as he knows) will never leave him. She lavishes on my father the love sought to no avail from every woman since his tight-hearted mother ... “I was a little, little boy, all alone.” With Nilda in his life, this plaint has ceased. At the age of eighty-three, as the layers of his adult self curl away, Dad has finally been granted his infantile wish ... And besides Dear, Darling, and sometimes Lil, he has another name for her,

than gender, since life course expectations are more radically challenged by early-onset dementia.

which he calls out, almost without guile: “Ma-ma!” ... Finally, my father has a good mother. (261-2)

Contrary to Franzen, Levine interprets her father’s seeming return to childhood as in line with his adult personality and his life-long, deep-seated need for affection. At the same time, she recognises his current state as an opportunity to heal childhood wounds. While making a person with dementia feel safe and loved is of the highest priority, the question arises how such seemingly selfless caregiving can be realised for everyone. The question arises also whether it is fair to expect low-wage professional female caregivers, frequently from an immigrant background, to provide such care ‘without needs of their own.’ Levine raises these uncomfortable issues of social justice—or rather of gender, race and class inequality in the care sector (see Kittay 1999)—while acknowledging her own complicity in the perpetuation of the current care system.

Levine’s memoir also functions as a thoughtful critique of current care practices and the ethics of dementia care. Her discussion of nursing homes and of her father’s specific needs is interwoven with philosophical reflection on how the question of selfhood in dementia directly impacts on the ethics of caregiving. Caregiving dilemmas include how to adhere to advance directives, and the question whether or not the ‘then-self’ before dementia can know what is in the best interest of the ‘now-self’ (Francis 2001). Discussing the bioethical principles of autonomy, beneficence, and justice, Levine laments that autonomy, and the ability to recognise one’s best interests, is not established on a case-by-case basis: *‘Doesn’t know best interest when standing in traffic; knows best interest when refusing to go to a nursing home’* (216; original emphasis). Levine rehearses the current bioethical debate over whether ‘critical interests’ or ‘experiential interests’ of a person with dementia should take precedence in determining treatment options at the end of life (Dresser 1995, vs. Dworkin 1993). Ronald Dworkin (1993) uses the distinction between ‘critical interests’ related to one’s values in life and ‘experiential interests’ related to experiencing pleasure or avoiding pain to argue that critical interests should override experiential interests when making the decision on whether to act on an advance directive. Levine not only offers up a condensed summary of these

difficult debates, through the lens of her reflections on her father's situation, but also a narrative approach to understanding these ethical dilemmas. While not offering a definitive answer, the narrative of her father's life suggests that not only experiential interests but also values may change. Her father of the past, whom she describes as strictly Cartesian and terrified of mental decline, appears in his dementia to be relatively content—provided he receives enough attention—and, as Levine puts it, is 'in no hurry to leave this world' (225).

Levine's account highlights that how we assess and recognise selfhood directly impacts on caregiving decisions. Relational identity can protect and support the identity of the person with dementia and lead to sensitive caregiving decisions. But it can equally lead to the denial of selfhood in the context of a deteriorating relationship. The burden to sustain identity, in the face of a myriad of substantial changes, can become too heavy: 'In losing his memory, the person with Alzheimer's allows his caregiver to lose her memories too,' Levine writes (168). Levine's account, like others, calls attention to both the negative impact of a 'malignant social psychology' (Kitwood 1997) on people with dementia, as well as the continuing positive potential for relationality.

Tangles: A Story about Alzheimer's, My Mother, and Me

Sarah Leavitt's graphic memoir *Tangles* (2010)¹¹² is a relational memoir *par excellence*. It explores the ways that the lives and identities of mother and daughter are 'entangled.' The title takes its name not only from the characteristic plaques and tangles that define Alzheimer's disease on the neurological level, but also from the tangles of curly black hair that characterise the Leavitt family. On one level, then, tangled curly hair signals Leavitt's ethnic roots and genetic ties to her family. In the course of the memoir, however, tangled hair comes to represent the emotional ties, the changing but persisting relationship between mother and daughter. Untangling her mother's hair during the later stages of the disease is an act

¹¹² Currently being adapted into an animated film by Giant Ant. See <http://tanglesthefilm.com/>.

of loving care but also evokes memories of her mother's fierce protectiveness of her daughter as a young girl. Sarah¹¹³ later collects her mother's and her own hair, shelving it in boxes above her bed. The presence of the boxes comes to function almost as a surrogate mother, soothing her to sleep. Insofar as they include Sarah's own hair, the boxes also hint at the ways their relationship has been incorporated into her own identity and will help her thrive even after her mother's death. The metaphorical use of 'tangles' therefore provides a guide to the key patterns of relationality in the text.

While Leavitt underscores the importance of the mother-daughter bond in her life, she also identifies herself in opposition to others, representing herself as autonomous human subject à la Gusdorf. This is brought out, for instance, in an image that positions Leavitt's individualised avatar Sarah against a featureless groups of others huddled in the opposite corner of the panel: 'Hannah and I weren't a unit like my Mom and her sisters. In my mind, there was me and then there was the rest of my family, who I missed and felt liberated from at the same time' (15). This sense of alterity or singularity is at least partly a function of the author's homosexuality. However, as in other memoirs, the very production of the text, modulated by the self-reflexive perspective and voice of the author, even as it includes others' views and memories, in itself underlines the author's singular consciousness. Clearly, even in relational autobiographies the Gusdorfian notion of 'looking-back-over-the-personal-past' (Freeman 2007: 122) to make sense of one's life matters. What differentiates relational memoirs from the Gusdorfian model, though, is their insistence on foregrounding the (life) story of a significant other, or rather a segment of two lives intertwined. While the author 'counts,' so does the Other, and instead of merely bearing witness to herself, the author of relational memoirs also bears witness to the Other. Notably, of course, the notion of what aspects of lived experience are worth relating have shifted remarkably since the 1950s, so that narratives of caregiving, and not just the life experiences of 'great

¹¹³ I use 'Leavitt' to refer to the author and narrator while using 'Sarah' to refer to the author's avatar.

men,' are nowadays considered 'significant to the world' (Gusdorf 1980: 29).

To date, Leavitt's graphic memoir is one of only a handful of full-length explorations of Alzheimer's disease presented in comics format.¹¹⁴ It is situated, however, in a fairly extensive history of autographics,¹¹⁵ and, like these, *Tangles* bears witness to the potential of the medium to provide informative and moving accounts of what it's like to be living with a certain condition (Chute 2007: 414). Though doodle-like in style, Leavitt's simple black and white drawings attest to the effectiveness of combining word and image to engage with the experience of illness, whether one's own or another's. The images sometimes provide evocative illustrations of the sparse prose. In other cases, they serve to undercut the narrative voice-over, adding a layer of ambiguity or irony to the narrative. Finally, the iconographics convey much of the emotional tone, potentially going beyond what can be portrayed in words, or at least opening up a larger spectrum of possible interpretations and emotional responses to the reader (see Figs. 6, 7, below, Figs. 11, 12, ch. 5: 205-6).¹¹⁶

Leavitt's memoir sits squarely within the genre of filial caregivers' memoirs and raises similar ethical issues in relation to the politics of representation. Leavitt grapples with the guilt that attends her writing project, her sense of feeling 'like a vulture hovering and waiting for [her mother] to say or do something [she] could record and preserve' (7). Leavitt relates how her mother at times physically resisted her daughter's project, pulling the paper and pen away from her—whether to gain her daughter's attention or out of an impulse expressing unease at being 'recorded' in this fashion remains open to interpretation. In any case, for works written in the wake of critically acclaimed autographic accounts, such as Spiegelman's *Maus* and Marjane Satrapi's *Persepolis*, the need to defend the comics format as an appropriate medium for such 'serious' autobiographical writing

¹¹⁴ For further autographics that deal with dementia see Chast (2014), Farmer (2010) and Haugse (1998).

¹¹⁵ For a history of the genre of autographics see Gardner (2008).

¹¹⁶ See McCloud (1994) for the argument that the less fleshed-out the drawing of a character, the more latitude there is for readers to project their own situations or responses onto that character.

seems to have receded. However, the form does raise a number of ethical issues particular to its representational mode.

Leavitt clearly wants to memorialise her mother: ‘to remember her as she was before she got sick, but also to remember her as she was during her illness, the ways in which she was transformed and the ways in which parts of her endured’ (7). Like other memoirs, Leavitt simultaneously affirms and denies her mother’s persisting identity. Significantly, both the introduction and the text as a whole bear witness to the importance of relational identity and the complex ways in which it is affected by dementia. As Leavitt states, ‘As my mother changed, I changed too, forced to reconsider my own identity as a daughter and as an adult and to recreate my relationship with my mother’ (7). Even in the way the memoir is framed paratextually, the images insistently draw attention to the intimate nature of the mother-daughter relationship showing mother and daughter holding hands or in close embrace. The first chapter underlines the strength of the mother-daughter bond while also foreshadowing how their relationship will become perturbed by the disease: ‘My mother was floating away from me,’ Leavitt writes about a dream; ‘I woke up crying but she wasn’t there’ (11). While the text never explicitly invokes the common trope of an inverted parent-child relationship, it does highlight Leavitt’s continuing child-like dependence on her mother in adulthood, and suggests that the pattern of dependence and care are finally reversed by the disease.

Other graphic memoirs are more explicit about the role reversal in dementia between parents and adult children. These texts frequently explore the difficulty of becoming one’s parent’s caregiver since former roles, patterns and power relations are not easily shifted. Roz Chast’s graphic memoir *Can’t We Talk About Something More Pleasant?* (2014) indeed suggests that the role of daughter and caregiver are incompatible (see Fig. 4).

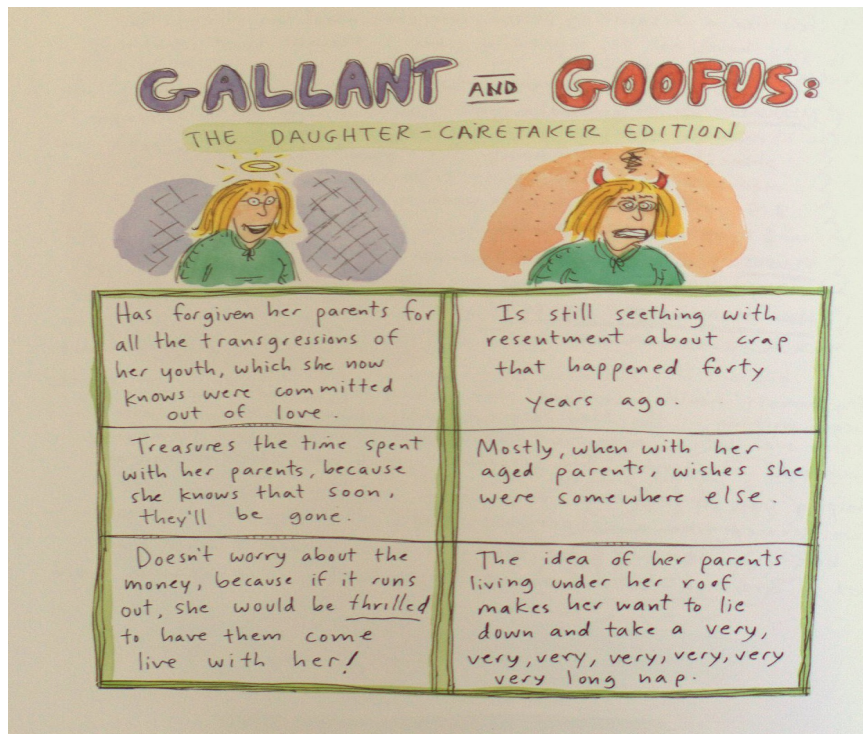


Fig. 4 Questioning cultural expectations of filial caregiving in Chast (2014: 146).

The memoir humorously exploits the conventions of the popular, educational comics genre ‘gallant and goofus’—intended to teach children social mores—to oppose the ideal daughter/caregiver (‘gallant’) with a supposedly more realistic version of what the author feels about her new role (‘goofus’). By drawing on a moralising and at the same time starkly manicheistic genre, Chast also highlights the (partially unrealistic) cultural and societal expectations that arise within the context of familial caregiving.

In his graphic memoir *Heavy Snow* (1998), John Haugse similarly captures this difficult aspect of filial dementia care in the chapter title panel ‘Who gets Dad?’ (31) (see Fig. 5). The image shows the artist interrupted in his work of drawing a nude, while a miniature version of his Dad that barely reaches the doorknob but is nevertheless dressed in formal wear, hat, glasses and the ubiquitous collar of a minister, steps through the door and into his life. The image, by returning the father to the size of a pre-schooler while nevertheless retaining the characteristics of adult attire, brilliantly evokes the fundamental conflict that may arise when ‘parenting’ a parent.



Who Gets Dad?

Fig. 5 *The problem of inversed child-parent relations in Haugse (1999: 31).*

While Leavitt and her mother have a close and supportive relationship compared to what Haugse or Chast describe, *Tangles* nonetheless similarly tracks the ways dementia affects the mother-daughter dyad. On visits home, Leavitt finds herself becoming increasingly involved in her mother's personal care. This new dependence in her mother Midge impacts on Leavitt's sense of self. Having to look after a mother, whom she finds bathing in her own excrement, leads Leavitt to 'feel a new loneliness and a new strength' (60). The change of roles is also expressed in her momentary sense of herself as 'the calmest, most capable nurse' (110). However, the affirmative image of Sarah, smiling in a nurse's uniform, is immediately countered by an image of herself doubled over by nausea and her acknowledgment that she frequently felt unable to cope with the demands of caregiving.

Furthermore, Leavitt's account stresses how her mother's identity is affected by becoming a care-receiver. Leavitt notes, 'It gets hard to see someone as a person when they've become a list of needs: BATH, CLOTHES, BRUSH TEETH, WALK, FOOD ETC.' (85). The exigencies of care can, then, in themselves contribute to the dehumanisation of people with dementia, as highlighted in the work of Tom Kitwood. Kitwood invokes Martin Buber's philosophy of dialogue to elucidate this process of dehumanisation. The Jewish philosopher Buber distinguishes between two ways of relating to

another person: the *I-It* and the *I-Thou* relationship (Buber 1958: 15). ‘Relating in the I-It mode,’ Kitwood writes, ‘implies coolness, detachment, instrumentality. It is a way of maintaining a safe distance, of avoiding risks; there is no danger of vulnerabilities being exposed’ (Kitwood 1997: 10). As Leavitt points out, reducing her mother to a list of needs provides her with a means of coping: ‘If you just think about that list, then you’re not as sad’ (85). However, Buber emphasises the cost of this attitude for both sides of the *I-It* dyad. The ‘I’, Buber maintains, does not exist outside these two ways of relating. And since the ‘I’ is only present in its entire being in the *I-Thou* encounter, arguably not only the Other but also the self is diminished by interacting in the *I-It* mode (see Buber 1958: 15-16; 52). Leavitt’s account brings out the ambivalent effects of these two modes of relating. She describes how her mother’s behaviour, playfully pretending to be a monster while being given pills, prompts Sarah to snap out of her instrumentalised attitude towards her: ‘And she’s a person again and you don’t only love her, you like her’ (85). Here Leavitt highlights not only her filial love, but her appreciation of her mother’s personality. However, the disturbing images of her parents’ despair that conclude this section underline how entering into an empathetic relationship increases not only her sense of her parents’ suffering but also her own distress.

Leavitt’s account also addresses one of the potentially most painful moments in the progression of the disease for the family member: the moment when her mother no longer recognises her as her daughter. Early on in the narrative, Leavitt establishes her mother’s love of nature, animals and children as central to her identity. This finds expression in her ‘undying love’ (66) for her cat. Her mother’s obsession with this rather aloof pet grates on Sarah’s nerves as she experiences a sense of injustice that the cat is so dearly, but undeservedly, cherished. Most importantly, Leavitt recounts, ‘She recognized and talked about Lucy [the cat] even when she seemed confused about who I was’ (66). In contrast to the characteristically understated plain sentences of her narrative voice-over, the graphics express the emotional resonances of this situation in Sarah’s downcast look and resigned and protective pose in the first panel and in her puerile expression of annoyance at the cat in the second panel (66) (See Fig. 6).



Fig. 6 *Interplay of narrative voice and drawing style in the expression of emotion in Leavitt (2011: 66).*

Similarly, in the one instance where Midge actually *asks* her daughter who she is, the images, rather than the verbal track, come to express Sarah's as well as her mother's emotional reaction. With a quizzical, surprised look on her face Sarah replies 'Your daughter. Sarah.' The next panel describes her mother's reaction, but not her own: 'My answer seemed to stress her out. She turned away and started mumbling and breathing heavily.' The image of Sarah included in the panel, however, registers and communicates her pain: in the grieved expression on her face, in her deflated body posture with her arms cradling her stomach, and in her firmly closed eyes—possibly expressing an attempt to block out the reality of the situation (102) (See Fig. 7).



Fig. 7 *Facial expression and gesture indicate emotional distress in Leavitt (2011: 102).*

Leavitt makes use of the expressive potential of the body through posture, gestures and facial expressions in her narrative (Eisner 2008). But she also exploits the potential of visual metaphors, background, typeset, panel size, panel boundaries and other elements of graphic narratives to

communicate the emotional tone of her experiences. Leavitt diverges from the otherwise fairly ‘realist’ mode of representation—within the limitations of the medium and her own drawing style—in moments of intense emotions, such as when her anger at a homophobic attack on her and her mother turns Sarah into a raging monster who explodes across panel boundaries (77). Equally, in describing the difficult decision of placing her mother in a nursing home, she uses evocative surrealist imagery to underline (and convince both herself and the reader of) the necessity of the move (116) (see Fig. 12., ch.5: 206).

Overall, then, the visual track of the graphic narrative opens up a number of communicative and aesthetic opportunities for the dementia autographer. It allows Leavitt to emphasise the importance of nonverbal communication in the later stages of dementia (see also Killick and Allan 2001) and also to foreground the physical closeness that she craves and continues to enjoy with her mother. However, the visual form of representation also raises a number of ethical issues. For one thing, the simplification inherent in the cartoon form, while narratively effective and adding to the economy of the form, risks turning representation into dehumanising caricature. Leavitt’s depiction of her mother with unkempt hair or without eyes behind her glasses is a case in point. Leavitt uses the lack of eyes as metaphor for the increasing sense of her mother’s ‘absence.’ While this metaphor speaks to the author’s emotions, it may enforce stereotypes of people with dementia as ‘living dead’ and oversimplify the issue of (self-)awareness in Alzheimer’s disease. Furthermore, the risk of invading the privacy of the person with dementia, inherent in all caregivers’ memoirs, seems particularly pronounced in the graphic depiction (in both senses of the word) of her mother’s nudity, body hair, and bodily dysfunctions. However, while ‘graphic,’ the comics format ultimately screens her mother from more direct—although still mediated—exposure (as for instance in documentary film or photography) and arguably makes it possible for Leavitt to address the complex ethical issues that arise around personal care. Leavitt does not gratuitously expose her mother to public scrutiny but explores the risks inherent in caregiving of invading another person’s privacy—a point I explore in more detail in chapter 5.

Sarah Leavitt's *Tangles* deals with how Alzheimer's disease affects both the individual and the family. The narrative shares with other memoirs about dementia an emphasis on issues of diagnosis, treatment and caregiving, institutionalisation, death, and mourning. It raises the complex issue of selfhood in people with dementia and it addresses the painful losses that dementia entails. But foremost it asserts on every page the continuing relationship between the author and her mother, their continuing love and the positive influence of that love—even beyond the grave. The memoir is a testament to the primary force of relationality in both shaping and maintaining identity.

Conclusion

In this chapter, I explored the effect of gender, genre and medium on the notion of relational identity; that is, I asked, to what extent the identity of the person with dementia is maintained through relationships and, on a different plane, through relational life writing. What aspects of identity do relational memoirs highlight and what conclusions do these memoirs reach about the persistence of selfhood in dementia? How do formal aspects influence the representation of dementia? And also, how is the caregiver's identity affected by dementia in a close family member? Although dementia caregivers' memoirs are a growing genre across different media and national literatures, and thus require further exploration, the present chapter has sought to answer questions like the ones just listed through a close reading of three filial dementia caregivers' memoirs (and also briefer glosses of other relevant texts): Jonathan Franzen's autobiographical essay 'My Father's Brain,' Judith Levine's memoir *Do You Remember Me?* and Sarah Leavitt's graphic memoir *Tangles*.

In considering gender as a central feature of dementia life writing, my intention has not been to essentialise gender, nor indeed to use gender as an all-purpose 'hermeneutic key' (Peterson 1993: 81, qtd. in Eakin 1998: 67). That said, although debates continue over the relationship between life and art in autobiography, I second Eakin's view that 'autobiography is nothing if not a referential art' (Eakin 1992: 2). In that sense, real-life and re-presented

gender dynamics merit close attention when it comes to examining how relationality is constructed in the context of dementia caregivers' memoirs. As previously mentioned, there are demographic as well as political reasons for considering gender as an important aspect of contemporary dementia care, and consequently caregivers' life writing. At the same time, an in-depth study of the aesthetics, or 'poetics' (Couser 1997), of caregivers' memoirs is crucial, since genre, medium, and other formal aspects crucially shape the way dementia is constructed in relational life writing. Taken as a genre, caregivers' memoirs about dementia in fact incorporate a wide range of subgenres, drawing on a variety of literary conventions and media. The thematic focus and political force of these life narratives depends on formal choices, on the nature of the caregiving relationship (spousal, filial, primary or secondary caregiver), as well as on the author's and subject's gender and professional status. All these factors affect both the ethical difficulties that writing about dementia raises and the tentative conclusions these texts arrive at in relation to the question of selfhood in dementia.

As the present chapter indicates caregivers' memoirs bear witness to the importance of relationships. They are inspired by the writer's relationship to a significant other and they highlight the continuing potential and need for relationships exhibited by people with dementia. Human beings are relational animals that depend on recognition by others. As these memoirs attest, dementia changes many things, but not this.

In the next chapter, I continue my exploration of the ethics of caregivers' memoirs, but with a focus on what these texts suggest about the project of developing a new practice of dementia care.

Part III Narrating Dementia/Rethinking Care

Chapter 5 Care-writing Reconsidered: Towards a New Practice of Dementia Care

Given that a cure for Alzheimer's remains elusive, a key question is how people with Alzheimer's or related disorders can best be cared for and how their caregivers can best be supported (see World Health Organization 2012: 68). Practitioners have developed a range of approaches to improving the delivery of dementia care and to helping people with dementia thrive.¹¹⁷ Current research in the social sciences focuses on unpicking the factors that contribute to the 'burden' of caregiving, with an aim to relieving caregiver stress and preventing 'burn out.'¹¹⁸ Since there is an urgent need for humane and sustainable care, such research is timely. Nonetheless, the methods of social science research—such as questionnaires or semi-structured interviews—leave some vital questions unanswered. In this chapter, I argue that caregivers' memoirs are able to complement such research, by addressing problems that may lie outside the scope of social science methodologies. Further, I argue that 'care-writing' can be understood as a form of caregiving. On the one hand, care-writers are changed by the process of living alongside and writing about the disease in ways that may have strengthened their capacity to provide care locally. On the other hand, by providing insight into the phenomenology of caregiving these memoirs can contribute to the investigation and development of dementia care generally. The aim of this chapter is not only to extract from these narratives widely applicable ways of understanding dementia care, but also to outline how strategies for improving such care can be developed on the basis of studying care-writing in a broad sense.¹¹⁹

Caregivers' memoirs explore the dilemmas involved in caring for someone with progressive cognitive impairment. They thereby provide a

¹¹⁷ See, among others, Basting and Kitwood (2003), Killick and Allan (2001), Kitwood (1997) and Stokes (2010).

¹¹⁸ See, among others, Akpınar, Küçükgüçlü, and Yener (2011), Chappell, Dujela, and Smith (2015), Krause, Grant, and Long (1999), Russell (2001), Wennberg et al. (2015).

¹¹⁹ Published memoirs written by educated, white, middle class persons, often professional writers, do not provide a cross-sectionally representative description of dementia care. Compare Kittay (1999) for an analysis of the problems of social justice that arise within the care sector, especially in relation to gender and racial biases in this undervalued, underpaid and underfinanced service sector. See the World Health Organization's report on dementia (2012) for a cross-cultural exploration of the link between gender roles and care for dependents.

means for readers to ‘live through’ (Rosenblatt 1995)—and think through—difficult issues and complex scenarios. Further, the authors of these memoirs imagine and develop alternative treatment and care options which could be adapted to other contexts. And finally, because they have lived alongside the person with dementia, familial caregivers are ideally placed to identify that person’s evolving needs and to advocate for them when those needs are not being met—whether in the community or in institutional care. These authors are thus well-positioned to articulate strategies for addressing the needs of people with dementia, and of their caregivers, holistically (see also Greenhalgh and Hurwitz 1999).

Exploring Caregivers’ Dilemmas

Dementia caregivers are faced with an array of complex and, due to the progressive nature of the disease, constantly shifting care-decisions. Many of the caregiving dilemmas can be framed as problems of coercion or paternalism (in relation to social behaviour; in relation to practical concerns over personal care such as dressing, feeding, and toileting; in relation to the difficult decision of when, how and where to ‘place’ a person in institutional care; and finally in relation to medical treatment, both during the course of the disease and when it comes to end-of-life decisions about treatment options). Although there may be some overlap with strategies for giving care to persons with other disease syndromes, the care-decisions discussed below are particularly salient in the context of caring for someone who is progressively cognitively impaired. They involve assessing the extent of the cognitive impairment, and the capacity for choice, agency and responsibility in the person with dementia.

This section explores how the authors of caregivers’ memoirs encounter, frame and attempt to resolve some of the above-mentioned caregiving dilemmas. Caregivers’ memoirs not only provide insight into the caregiver’s predicament but may also indirectly benefit others living with or alongside the disease syndrome. These texts model empathetic ways of engaging with people with dementia and of resolving certain caregiving dilemmas, without necessarily representing ‘model’ caregivers. Indeed, the fact that these

caregivers frequently fall short of any ideal (or idealised) standard of care makes their accounts a productive tool for thinking through dementia care. In their failure to find resolutions or in describing the ‘bad choices’ their authors had to face in their roles as caregivers, these memoirs have the potential to provoke debate about what constitutes ethically sound dementia care and what aspects of care urgently need to be addressed by society at large—from policy makers to care managers to taxpayers helping to support care systems.

The most challenging ethical dilemmas in dementia care, no doubt, arise out of the conflicting need to respect the person’s autonomy while also protecting the person from harm and fulfilling his or her most basic care needs. In the case of parent-child relationships, the adult children of people with dementia frequently feel as if roles have been reversed, with the children becoming guardians of their own parents. And with this reversal they enter the quagmire of ethical decisions about the extent of autonomy in dementia. As Sally Magnusson succinctly puts it in her memoir, addressed throughout to her mother who is suffering from dementia:

Ours was the same problem that besets every family trying to look after someone with dementia whom they want to allow to be themselves for as long as possible; how to keep your independent spirit flying and help you feel like a free agent capable of decision, when the decisions you made were so often disastrous (like insisting on walking out on a road shiny with ice) and the decisions you increasingly could not make (to get up, to dress, to eat) were so fundamental. (2014: 148)

This section draws on a number of memoirs which represent not only different genres and media (print, film, and graphic memoir)¹²⁰ but also different caregiving relations and gender configurations, to explore how the authors of these narratives grapple with the difficult issues of coercion and paternalism. David Sieveking’s documentary *Vergiss Mein Nicht* (2012) and John Thorndike’s memoir *The Last of His Mind* (2009) deal with the question of coercion in relation to feeding and ‘activating’ the person with

¹²⁰ Given that genre conventions as well as the properties of storytelling media can significantly shape the representation of caregiving, in my analysis I explore issues of (sub)genre or medium when they bear on the ‘point’ the narrative makes about caregiving dilemmas. By paying due attention to how the narrative form shapes what these authors have to say about the experience of caregiving, I aim to redress the problem of previous approaches to illness narratives that frequently treated these narratives as a ‘transparent medium for the investigation of something else’ (Mattingly 1998: 12, see also Woods 2011).

dementia. Sarah Leavitt's graphic memoir *Tangles* (2010) elucidates infractions in the realm of personal care, while also hinting at aspects of physical coercion and addressing the difficult issue of placing a person in institutional care. Rachel Hadas' memoir *Strange Relation* (2011), which incorporates the author's own poetry, grapples with the guilt attendant on moving her husband into institutional care, while also exploring the 'tipping point' at which home care becomes no longer feasible.

In Thorndike's memoir *The Last of His Mind* (2009) the question of coercion is a recurrent theme. As primary, cohabitating caregiver, Thorndike repeatedly finds that pressurising his father into doing things which he is initially disinclined to do actually helps to improve his father's mood and well-being. Nevertheless, Thorndike remains undecided over when and whether his impulse to care for his father—to feed him, motivate him to go out, get him out of bed—may represent unwarranted instances of overriding his father's wishes. Thorndike explores the moral obligation to feed another who is seemingly unable to remember to feed himself—or who has, on Thorndike's alternative interpretation, consciously decided to forego eating. Evoking the case of an elderly lady who 'was tired and infirm and didn't care about eating,' he quips that, for the caregivers around her, 'food was gospel and eating her duty' (85). Thorndike's choice of words suggests that there is something inherently ludicrous in this demand that the younger and healthier generation places on the old and infirm—to eat, to move, to be active. Thorndike wonders whether showing little interest in food might not be his father's way out, a wish to 'crash for good' (85) as he puts it. However, he doubts his own ability to act on such a view: 'I consider this, but I doubt it will be long before I slide another plate in front of him. It's the habit of care, and the assumption that everyone must eat. Though I question this, I am tied to the wheel myself' (85-6). The ethical imperative to keep a dependent person alive here overrides the conflicting demand to honour this person's choices.

Indeed, Thorndike here taps into the complex debate about patient autonomy in dementia. This debate is usually centred on the question of the validity of 'advance directives' and the question of whether these still hold when the person affected no longer shares the same values or outlook on life

as when these directives were formulated. Here Dworkin's distinction between 'critical interests' related to one's values in life and 'experiential interests' related to experiencing pleasure or avoiding pain come into play. According to Dworkin critical interests should override experiential interests when making the decision on whether to act on an advance directive. That is, if the patient asked to have all life-sustaining measures (including antibiotics) to be withheld once past a certain stage in the illness, it does not matter whether that person still experiences pleasure and satisfaction in the present moment and may benefit from antibiotics, say, in order to sustain her (quality of) life.¹²¹ Whereas Judith Levine's memoir reviews this debate—arguing that 'autonomy' should be assessed on a case by case basis—Thorndike's memoir offers a different tack. In the absence of any advance directives, Thorndike is presented with a different set of dilemmas: how can he reliably know what his father wants? How does he balance his father's apparent wish for autonomy and his own wish to respect his father's preferences with his moral duty to care for him? Can his father's seeming disinterest in food be understood as a genuine 'choice' or is he simply too forgetful to remember about food? In which case, would honouring his father's wishes not represent an instance of inhumane care, of starving a dependent person? And indeed, whose needs do the practices of caregiving actually fulfil—the caregiver's or the care-receiver's?

Thorndike's memoir offers a case study, a practical experiment centred on these difficult caregiving dilemmas. One day, Thorndike undertakes to discover his father's wishes by letting him decide not only whether to get up but also whether to have food at all: 'all offers are coercive and for once I'm not making any' (100). The narrative then moves through the day—torturously, it seems—for the author (and reader) while Thorndike's father shows no interest in getting up or taking any food. The use of mainly one word, end-stopped phrases for time specifications at the beginning of each paragraph (e.g. 'Noon.' 'Three o'clock.' 'Five-thirty.') underlines the slowness of time passing. In addition, Thorndike's agony and insecurity are reflected in the number of questions he asks himself and the reader.

¹²¹ Dresser (1995) takes the opposite view. She argues that 'experiential interests' should take precedence in such cases.

Thorndike finally aborts his plan, without having discovered what the right stance towards coercing a person with dementia might be:

Should I return to my jaunty self tomorrow morning and make him take a shower, make him change his clothes, invite him to sit down to his breakfast and morning medications, urge him to walk to the mailbox, insist on driving him to the ocean, hound him about drinking more fluids? At what point should I let him do what he chose to do today: lie in bed without talking or moving.
(102)

Thorndike is inclined to think that coercion might be a necessary part of caregiving. ‘On the day I give him completely free rein, he winds up with no shower, no breakfast, no lunch, no time outdoors and no conversation. He’s passed *what seems to me* a lost and unhappy day, stretched on his bed’ (102; my emphasis). However, his phrasing is significant in that it introduces the possibility of doubt. It underscores that this is Thorndike’s interpretation of the quality of the day, not his father’s, and leaves open the possibility that to the latter this might have been a satisfying, restful way to spend the day. Chillingly, the passage concludes: ‘And I have to ask: how much did I do this because I wanted a break myself, a day without responsibilities?’ (102). Here and elsewhere, Thorndike repeatedly asks to what extent caregiving (or the absence of providing care) may fulfil the caregiver’s rather than the care-receiver’s needs.

Thorndike’s narrative provides a framework in which the question of coercion is debated, both on the story level and on the discourse level. While the reader is presented with intellectual arguments, the rhetorically arranged ‘argument’ of the story has an affective impact that provides the reader with a sense of ‘what it’s like’ to face the ethical quandaries of dementia care. What is lacking from this narrative, unfortunately, is a clear sense of what the person with dementia needs or prefers. As the situation is presented from the caregiver’s point of view, the reader, with Thorndike, is left in the dark about how his father experiences the presence, or absence, of coercion.

In his documentary *Vergiss Mein Nicht* (2012), Sieveking similarly struggles with the problem that caring for his mother Gretel necessarily involves many instances of overriding her wishes. This issue is brought out in a number of scenes in which health professionals, David himself, or his

father all try to coax Gretel into participating in activities, seemingly for her own good. An encounter with a physiotherapist with a Slavic accent in which Gretel staunchly refuses to do anything takes on an almost comic character. The mood is signalled by Sieveking's voice-over narration: 'Even professional therapists try their luck with Gretel' [15:12].¹²² The subsequent scene, in which a woman sounds a singing bowl, while Gretel lies on her bed, either asleep or ignoring her, takes on an almost absurd quality. Although the lack of comment from the narrator leaves the interpretation of the value of these therapeutic interventions to the viewer, Sieveking's humorous tone in the previous scene is likely to shape viewers' responses. The viewer is left to wonder why older people lose their right to be left alone when they express a wish for peace and quiet.¹²³ And yet, as the quotation from Magnusson above underlines, people with dementia may become unable to make the 'fundamental' decisions necessary for life, with the ethics of care demanding that others prompt, help or even coerce them into these activities.

Although he takes a detached or humorous stance initially, as the narrative progresses Sieveking increasingly finds himself in the role of coaxer and he has to face up to the question of when coercion becomes unethical. The documentary puts the same question to the audience. Compared to verbally mediated accounts of coercion in other caregivers' memoirs, the direct representation of Gretel's expressions of disinterest, or even discomfort and fear, may have a stronger emotional impact on the viewer. Responses of this sort are perhaps most obvious in a scene where David takes his mother to the swimming pool in an attempt to recapture the joy she previously experienced while swimming. His hopes are disappointed as his mother refuses to enter the water. She shields her face with her hands and then turns to the camera, a look of fear on her face, and asks the camera man: 'Can we go sit somewhere where we don't die?' [30:59].¹²⁴ The

¹²² 'Auch professionelle Therapeuten versuchen ihr Glück mit Gretel.'

¹²³ This is not to say that alternative forms of therapy, such as music, arts or physical therapy are not valuable resources in dementia care (Basting 2001, Basting and Killick 2003). Indeed, Sieveking's representation risks undermining the value of such interventions and may contribute to the ageist notion that treatment is futile in such cases and that old people, especially people with dementia, no longer merit medical and therapeutic effort.

¹²⁴ 'Können wir irgendwohin setzen wo wir nicht sterben?' [sic].

semantics of death make sense in this context and clearly express Gretel's fear of the water. More to the point, her facial expression, gestures and bodily movements provide access to her current state of mind to a degree that cannot easily be ignored—and in contrast with the way written memoirs such as Thorndike's may occlude or omit the reactions of the person receiving care (see Fig. 8).



Fig. 8 *The question of coercion: Nonverbal communication of fear in Sieveking (2012: 30:14; 30:54).*

Sieveking's documentary does not offer up a definitive answer to the question of whether coercion is a necessary—and beneficial—aspect of caregiving, and at what point it represents an instance of disrespect or perhaps even potential harm to the person with dementia. The viewer is left to arbitrate case by case, based on the ways that Sieveking frames his material (by scene selection, voice-over narration, use of film music) and also on the bodily and verbal reactions Gretel manifests—be they of joy, pleasure, fear, or annoyance.

Both narratives confront their readers and viewers with the difficulty of ascertaining the limits of autonomy and the legitimacy of coercive caregiving in dementia. They do this by representing complex yet specific situations within the shared life world of caregiver and care-receiver. Both narratives allow a 'living through' (Rosenblatt 1995) of the complexity of day-to-day caregiving decisions and practices. While Thorndike's narrative incorporates to a larger extent his own thoughts, reasoning and emotional responses to these ethical dilemmas, Sieveking's narrative relies more on the process of 'showing' the effects of caregiving decisions, rather than overt reflection or commentary. By representing his mother's disinclination or fear, Sieveking evokes emotions of pity and empathy in the viewer. This emotion, as post-performance discussions of the film highlight, also triggers

viewers to reflect on the ethical problems of coercing a person with dementia, even when it is aimed at promoting their own good.¹²⁵ Thorndike's narrative, by contrast, aligns the reader with the point of view of the narrator. We become privy to the caregiver's conflicting thoughts and emotions, are invited to share his anxiety about doing right by his father, and speculate with him about his father's wishes and needs. Neither narrative achieves a comfortable solution to the caregiving dilemmas they pose. But it is this lack of closure, or lack of clear instructions (in contrast to advice literature), that has the potential to spark debate about ethically sound dementia care practices.

While Thorndike and Sieveking cover a variety of caregiving dilemmas, there are two areas in which they are less instructive—with regards to personal care and to the question of institutionalisation. The latter question barely arises in these narratives since the parents are cared for in their own homes—except for a brief period in Gretel's life. With regard to personal care, Sieveking's narrative is extremely reticent.¹²⁶ While the documentary only alludes to toilet issues metonymically—by filming the father wiping the floor after an incident of incontinence—Thorndike almost seems to revel in a kind of shock aesthetic in exposing his father's bodily decline (compare also the depiction of incontinence in Roth 1991). Thorndike, it seems, uses this stark description of his father's naked, ageing body in an attempt to confront his own fears of mortality and in order to desensitise himself with regard to his anxiety over providing intimate care for his father.

Sarah Leavitt's graphic memoir *Tangles* (2010), by contrast, tackles the question both of personal care and of institutionalisation. On her visits home, Leavitt finds herself taking on an increasing range of 'hands-on' care tasks for her mother Midge. Leavitt's graphic depiction of bodily decline, nudity, and problems with personal hygiene addresses a number of powerful cultural taboos. In the chapter 'Good grooming,' for instance, Leavitt reflects on the taboo of grooming a less and less able-bodied and able-

¹²⁵ See additional material on the DVD 'Filmgespräch mit Andreas Dresen und David Sieveking' (Sieveking 2012).

¹²⁶ Sieveking's reticence may be due to the seemingly more 'immediate' and therefore more starkly exposing nature of documentary film and the worry over violating his mother's privacy. The medial differences in representation here hark back to my discussion, in the previous chapter, of the ethics of representing vulnerable subjects (Couser 2004).

mindful mother. Leavitt notices that as her mother's disease progresses, she becomes more docile and easily submits to being physically cared for. In an attempt to make it easier to keep their mother clean, Sarah and her sister Hannah decide to trim their mother's pubic hair (Fig. 9).¹²⁷



Fig. 9 'Good grooming': Ethical issues in personal care in Leavitt (2010: 110).

The narrative then moves on to a flashback of a similar instance earlier in the disease processes: 'It reminded me of another time,' the narrative voice-over reads, 'when Dad and I tried to shave Mom's armpits so she would smell better. She wasn't as sick then, and she got mad' (111). The image is evocative. It represents Midge's angry facial expression, but also, insofar as her glasses are askew, suggests a struggle, while two de-personified hands reach out toward her—one with a razor, the other seemingly holding her down (see Fig. 9). Leavitt clearly feels distressed by the event as the next panel shows her running from the scene while she considers how the 'secret intimacy' between her parents had been 'breached forever.' She then reflects on how, due to her own homosexual orientation, administering personal care to her mother takes on a particular poignancy and evokes concern over 'being accused of perversion' (111). There is a parallel here between the culturally ingrained notion that it is inappropriate

¹²⁷ As mentioned in chapter 4, the metaphoric omission of Midge's eyes, to suggest her increasing loss of awareness, risks contributing to dehumanising conceptualisations of people with dementia as 'living dead' (see also Burke 2007b, Herskovits 1995). Although it may speak to Leavitt's sense of 'losing' her mother, it represents an oversimplification of the issue of self-awareness in Alzheimer's disease.

for men to care for women, due to concerns over sexual decency (Kittay 1999). However, the main point is that, irrespective of the particular caregiving relation, instances of personal care necessarily (or sometimes unnecessarily) involve violations of privacy. When other family members judge the act of trimming their mother's pubic hair to have been superfluous, Sarah and her sister come to reassess the situation: 'We felt bad then' (111). Moreover, the whole experience leads Leavitt to conclude: 'You get sick and your body is no longer private. Even if none of your caretakers ever hurts you, some basic dignity is lost' (111). Despite these comments about the negative impact of certain acts of caregiving, however, the panel that follows suggests that care can also provide a means of connection. It repeats the image from the front cover of the memoir with Sarah and her mother holding hands, gently smiling at each other. Only at this point in the narrative does it become clear that this is an instance of Sarah providing personal care for her mother (Fig. 10).



Fig. 10 *Care as connection in Leavitt (2010: 111).*

Leavitt's memoir, like many other caregivers' accounts, also addresses a particularly salient dilemma; that is, the question of whether, when or where to 'place' a person with dementia in institutional care. Eleanor Cooney, for instance, in *Death in Slow Motion* (2003), evocatively describes the painful process of moving her mother first from her own home into her daughter's and from there into a series of institutions. Cooney describes the nightmare of negotiating a public health system that invariably represents a number of

Catch-22s. Her anguish grows out of her inability to keep caring for her mother at home while having to acknowledge that ‘there is only one drug in the world that can keep my mother calm and centred, and I am that drug’ (174). However, in taking the reader into the nightmarish world of impossible choices which induce guilt, depression and alcoholism in the author, the narrative may leave its readers feeling overwhelmed or even paralysed when it comes to contemplating the prospect of looking after a family member with dementia. Cooney’s memoir is seemingly trapped within the immediacy of overwhelming caregiving dilemmas. Her memoir then raises the question of how much re-fashioning of a life is necessary for a caregiver’s memoir to turn into care-writing.¹²⁸ Although other memoirs do not present ‘solutions’ for caregiving dilemmas, they provide a working through of these dilemmas, for the authors and their readers, that lead to a place other than despair: acceptance, on the one hand, and the will to look for productive, liveable solutions, on the other.

In her graphic memoir, Leavitt mines the potential of the visual track as a meaning-making device when representing and reflecting on the decision-making process involved in placing her mother in a care home. The physical and emotional effects of caregiving, for instance, are depicted visually without, necessarily, addressing the issue verbally (Fig. 11).



Fig. 11 *Figuring the effects of caregiver stress in Leavitt (2010: 116-117).*

¹²⁸ See also the discussion of the politics of caregivers’ memoirs in chapter 4. The overwhelmingly negative representation of caregiving in Cooney may represent an accurate picture of the phenomenology of unsupported family caregivers and, as a cry for help, may thereby feed into the agenda of the dementia advocacy movement for increased funding and support. However, Cooney’s account does not offer a productive approach to dementia care and may deter people from finding liveable solutions by suggesting that only the death of the care-receiver can relieve the caregiver from her excessive ‘burden.’

Leavitt draws on the potential of facial expressions, body postures and gestures to evoke the emotional reactions to caring for a family member with dementia, while also exploiting the potential for non-realist, metaphorical imagery to convey the intensity of certain emotions (see Fig. 11, rightmost panel, and Fig. 12). In recounting the difficult decision of placing Midge in a care home, Leavitt employs surrealist images in her narrative. The matter-of-fact description of how her father hurt his back helping his wife off the couch is accompanied by two black, tortured, hairless figures, reminiscent of Picasso's *Guernica* or some of Dali's contorted human figures.

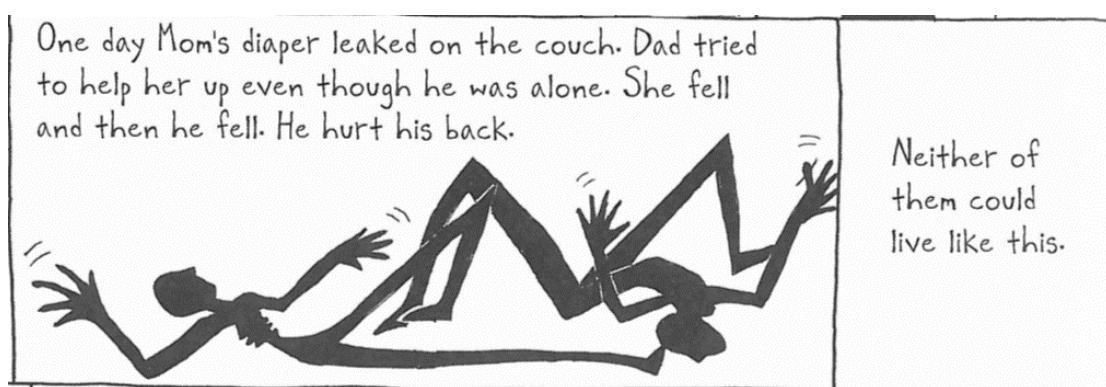


Fig. 12 Drawing style as part of narrative rhetoric in Leavitt (2010: 116).

Every element of these figures spells out the agony of their experience: their emaciated state, their impossible postures, and their over-sized hands grasping at thin air. The next panel concludes: 'Neither of them could live like this' (116). While falling short of any claim to representational 'truth-telling,' this image transmits something of the agony of the experience. Importantly, it is strategically employed to justify (or possibly to persuade Leavitt herself of) the rightness of the decision to place Midge in a nursing home.

If Leavitt's artistic representation makes sense of and justifies her family's decision to place her mother in a care home, Rachel Hadas' memoir, in contrast, highlights how the caregiver can struggle with a distinct lack of clarity about when to move a spouse into an institution. In *Strange Relation* (2011), Hadas explores the tipping point, different in every caregiving relation, at which home care becomes no longer feasible. In her case, this tipping point has to do not with the physical unmanageability of

the disease but with the emotional ‘cost’¹²⁹ of living in a near-state of silence: ‘If there was one reason I decided that I could no longer live with George, that coordinating his care had gone from arduous and unrewarding routine to unbearable pain,’ she states, ‘that reason was the grinding loneliness imposed by his silence’ (133). The emphasis is on how both the decision-making process and the consequent guilt entailed by the decision become a lonely burden for the caregiver to carry. At the same time, Hadas finds solace in poetry, myth, and Greek tragedy, which, unlike caregiving literature that shies away from addressing the ‘salient truth’ (142) of how difficult placement is, offers up its own versions of unpalatable dilemmas. As Hadas points out, ‘when it comes to scooping someone out of the house where they have lived for thirty years and inserting them [into institutional care]—when it comes to doing this, *there are no good choices*’ (142; my emphasis). However, the poetry of others as well as her own helps her make sense of certain aspects of her experience that might otherwise remain incomprehensible, or at least intractable. Poems, in her words, ‘get to eat their cake and have it too’ (24) in their ability to exploit the ambiguous and plurivalent nature of language—and hence describe the ambiguous and conflicting experience of caregiving.

All these caregivers’ memoirs put the dilemmas that dementia care raises in the context of a particular social, cultural and familial configuration. By doing so the reader is immersed in the specifics of each case and can, in Rosenblatt’s terms, ‘live through’ the caregiving experience. And yet, these case studies also offer up generalisable problems—the conflict between autonomy and paternalism in making care decisions, the fine line caregivers must tread between neglect, safe-keeping, infantilising and nurturing. The narrativisation of caregiving dilemmas highlights the complexity of dementia care and the lack of easy solutions. But by giving meaning to particular cases, by making use of the affordances of particular media (be it the audio-visual in film, the visual in graphic memoir or the possibilities of the written word), caregivers’ memoirs structure these dilemmas for their

¹²⁹ See Burke on how the language of economics has permeated caregiving relationships with significant implications for those ‘who are unable to reciprocate according to the logic of this “contract”’ (2015: 28).

readers and signpost pathways towards acknowledging—and perhaps solving—difficult ethical issues in dementia care.

Imagining Alternative Approaches in Dementia Care

Greenhalgh and Hurwitz (1999) suggest that illness narratives provide a framework for approaching patients' difficulties holistically, and that attending to illness narratives may aid with diagnosis as well as with discovering alternative treatment options (48). Along the same lines, moving on from the ethical dilemmas that dementia raises, I now turn to the question of how caregivers' memoirs may contribute to a potential expansion of care options—by questioning common attitudes and care practices and by modelling alternative responses. Caregivers' memoirs detail their authors' own journey towards discovering new ways of seeing and dealing with dementia and how in the process they developed alternative (therapeutic) responses to the person they cared for. My discussion will focus on several representative questions raised by these accounts, including how to respond to confabulation, how to meet the person with dementia in their own world, and how to enhance sufferers' well-being by using music (or other art-related interventions). However, the texts themselves contain a large repertoire of care practices and models. Contrary to care programmes where one method is made to fit all, narrative explorations of care underline the specificity of each person's care needs and describe responses that are designed to suit the situation and temperament of the person affected. At the same time, the memoirs gesture towards therapeutic interventions and everyday responses that may be beneficial for a large number of people with dementia. They can also play an important role in educating readers about what the care needs of a person with dementia may look like.

While reminiscence therapy and so-called 'orientation' exercises (reinforcing the day, time, season and place) may be useful in earlier stages of dementia, practitioners increasingly question the usefulness of such approaches for people with more advanced dementia. People with dementia often start confabulating: telling stories or making comments about a

situation or a memory that does not align with the ‘facts’ as perceived by others. Indeed, confabulation is a typical symptom of dementia; it can be defined as ‘false narratives or statements about world and/or self due to some pathological mechanisms [usually memory problems], but with no intention of lying’ (Örülv and Hydén 2006). Confabulation has been identified as a ‘source of considerable distress to family members’ (Örülv and Hydén 2006: 648) since when confabulation relates to shared experiences caregivers may feel threatened in their own sense of self, or struggle with how to respond to statements that seem fantastical. Caregivers are frequently driven to challenge the confabulatory statement and insist, instead, on their own version of a situation. This insistence may distress the person with dementia and lead to a communicative impasse. However, when caregivers try to enter the world of the person with dementia and ‘go along’ with his or her version of events they frequently have the sense that this move is patronising or deceitful vis-à-vis the sufferer.

In *The Story of My Father* (2003), Sue Miller explores the conflicting impulses she experienced when confronted with her father’s confabulation. ‘My original impulses’, she writes ‘hadn’t been to try and support my father’s delusional life. I’d been fooled by my first few experiences with his hallucinations, when I’d been able to talk him out of them, to reason him back to reality’ (Miller 2003: 119). As the disease advances however, Miller recognises that her reasoning no longer produces the desired response, and she comes to question the effects of her own corrective remarks: ‘It dawned on me that my insistence that what he saw wasn’t “real,” that what he heard was not what he thought it was, was making an insurmountable barrier between us, so I stopped’ (120). She learns to accept his version of reality, to think of him ‘as *having had* the experiences he reported’ (120; original emphasis) and to commiserate with or be pleased for him accordingly. So much so, that it begins to strike her as ‘odd when others didn’t or couldn’t’ (120). Miller openly criticises the nursing staff for their lack of empathy in this respect:

When Dad spoke delusionally to them in my presence, they were openly dismissive. They reported his “mistakes” to me with contempt. This bothered me, more than a little. Had they had no training in the way these

events seemed to occur to a delusional Alzheimer's patient? I wondered. Could they not flex their imagination a little bit? Their compassion? (120)

Indeed, Miller underlines how her father's confabulations may have increased his sense of well-being in that they may have helped him to reconstitute his identity and reassert the patterns that had governed his scholarly life: the nursing home turns into a university, her father reports preparing or attending lectures, and—despite no longer being able to read—he reports on the amount of reading he has to do (121-2). She defends his solitary pursuits (or non-pursuits) and his unwillingness to join in the kind of activities offered at the nursing home, as a means of holding onto his personal identity. Defending her choice to 'lie' and go along with his 'mistakes' to the reader, she argues that his delusional life actually made him 'feel happy and competent in some parallel universe' (123). In her view, supporting his confabulatory or delusional worldview constitutes a better approach than forcing him to take part in activities that she, at least, seems to perceive as mildly degrading. There is a sense, though, in which her acceptance of his confabulations is consoling to her own sense of what her father 'should' be: 'I was glad when he reported he'd done things—familiar Dad-like things—that I knew he hadn't done' (123). It could be that Miller's father does not inhabit a parallel universe in which he feels happy and competent, but his daughter's presence induces him to present this delusional façade as a means of saving face.

In any case, Miller acknowledges that validation of her father's confabulatory comments (Feil 1989, 1992, Feil and Altman 2004) is not without problems. When her father's delusions become painful rather than a source of pleasure, Miller is no longer able to empathise with his point of view. Following a night-time fire drill, her father believes that there has been an actual fire in which children have died. Miller finds it impossible to validate his claim and to act as upset as would be warranted in this situation. Her father, in turn, cannot understand his daughter's or the staff's unresponsiveness. He is appalled by her attempt to empathise with his feelings, rather than acknowledge the tragedy. In fact, the incident impacts on their relationship, until her father eventually forgets about it. Miller is left with the gnawing question of whether she should have reacted

differently, whether there was ‘some lesson [she] could have learned from this’ (125). Miller’s question is in a sense rhetorical. She does not find a definite, ethically sound and unambiguous solution to the question of how to respond to confabulation. But the fact that such a solution does not exist and that one’s response to confabulation needs to be adapted over time and according to the situation and content of the confabulation is the very point of the narrative. Miller learns this lesson and finds a means to share this insight with her readers. In the process she explores how her father’s institutionalisation was not only damaging to him, but also had a significant impact on her own identity:

He changed, and changed again. And in response, often lagging a step or two behind him, I changed also. Slowly, reluctantly, I learned new ways to behave, and I too was transformed, at least with him, as his illness deepened. (119)

While some of these changes are adaptive in the positive sense, and help Miller maintain her relationship with her father, others leave her feeling ‘reduced’ in a way she feels resembles her father’s state.

Sally Magnusson, in contrast, finds new ways of dealing with her mother’s dementia by coming to see confabulation in a positive light. If confabulation is usually seen as fictitious and false—and therefore framed in terms of loss and deterioration on the part of the person confabulating—recent memory research stresses the extent to which all memories and procedures of memory recall are based in processes of narrativisation and confabulation (Fernyhough 2012). By engaging with this research, Magnusson comes to realise that her mother’s confabulations ‘are merely taking to excessive lengths the normal tendency of memory to reconstruct itself’ (238). Memory, according to the research Fernyhough brings together, is a product of the individual’s present needs, created in the moment for the moment. In reconstructing memories, there is a conflict between *coherence* (internal and in relation to the present moment) and *correspondence* to reality: ‘A coherent story about the past,’ Fernyhough writes, ‘can sometimes only be won at the expense of the memory’s correspondence to reality’ (Fernyhough 2012, qtd. in Magnusson 2014: 238). ‘This helps me to understand’, Magnusson writes, ‘the narrative fictions you have been

crafting: your trip to the moon, your matey relationship with Attila the Hun and personal discovery of the New World' (238). Based on these insights from memory research, Magnusson comes to see her mother's confabulation not as a deficit but as a productive means of self-making and sense-making (see also Örvulv and Hydén 2006):

So, you are doing what we all do, and what, as a matter of fact, I am doing right now. You are making sense of your experience by using narrative skills to stitch memory into a story. And you are doing it in the teeth of a strenuous assault on the delicate neural connections that make memory possible at all. I am, as so often, full of admiration. (239)

In fact, Magnusson sees her mother's confabulation not primarily as a symptom of the disease, but as an aspect of her mother's identity. Creating 'a narrative path that makes sense of the moment ... from the memories that do manage to hack their way through the undergrowth' (223) is consistent with her personality:

You are straining to take part in a conversation by appropriating whatever has presented itself to your imagination by way of a story once heard or a snippet of information absorbed. Delving into your own experience is what made you such an engaging conversationalist. You will not give up without a fight your right to keep saying, 'I did that, I saw that, I remember hearing, I was always struck by noticing, it reminds me of the time when...' (224)

Magnusson's interpretation of her mother's behaviour draws support from current research that posits confabulation as a productive means of making sense of the current situation ('sense-making'), maintaining personal identity in interaction with others ('self-making'), and organising and legitimising joint interaction in the world ('world-making') (Örvulv and Hydén 2006: 647). Viewing confabulation in this light also allows Magnusson to respond positively to her mother's confabulation, to acknowledge its function and to recognise in it her mother's persisting identity (see also Crisp 1995). In the process, Magnusson shapes the way we as readers understand confabulation, which in turn, might perhaps lead to less dismissive reactions to this phenomenon in the context of interacting with people with dementia.

Magnusson's memoir is also instructive in that it represents a call for developing more music-based therapeutic interventions in dementia care, since drug treatments are so woefully insufficient. The use of

pharmaceuticals, especially neuroleptics,¹³⁰ to target behavioural disorders—such as wandering, excessive anxiety, lethargy or aggression—has been criticised on the grounds of the drugs’ limited effectiveness, especially considering their severe iatrogenic effects (Samson et al. 2015). There is a growing body of evidence that non-pharmaceutical interventions, including activities related to music, have a positive effect on emotional states and behavioural disorders in people with dementia, and that they can also reduce caregiver distress (Samson et al. 2015: 253). Reviewing the current state of research, Samson and her collaborators call attention to ‘the power of music and its nonverbal nature [as a] a privileged communication medium when language is diminished or abolished’ (250). As Magnusson states of her mother, employing the second-person narration she uses throughout the memoir: ‘Long after your own words have begun to desert you in droves, these familiar songs deliver an illusion of fluency’ (275). Magnusson’s memoir highlights the expressive and relational power of music. Furthermore, since music has always formed a central part of her mother’s identity, singing familiar songs seems to bring her mother back to herself.¹³¹

And it’s instantaneous. Like a switch. Someone starts you on one of your favourites and suddenly you are awake again, alive and remembering who you are. Music, I begin to see, is what rescues you from silence and the bars of the prison-house. (276)

Being able to recognise her ‘mother of old’ in itself has a positive effect on Magnusson. Importantly, however, singing is also a joint activity, helping to strengthen their relationship as well as capable of breaking ‘the monotony of a rainy Saturday afternoon’ (275)—and as Magnusson seems to imply, the monotony of caregiving.¹³²

¹³⁰ Neuroleptic agents, also known as antipsychotics, are frequently used as tranquilisers. While they can reduce confusion, delusions, hallucinations, and psychomotor agitation in psychotic patients, they are increasingly being used in major depression, anxiety, and insomnia. There is controversy over the widespread usage due to the adverse effects of these drugs (see <http://emedicine.medscape.com/article/815881-overview>).

¹³¹ The documentary *Alive Inside* (Rossato-Bennett 2014) demonstrates impressively the power of music to engage people with dementia. However, the rhetoric of ‘awakening,’ the title’s allusion to a ‘dead’ outer shell, and one commentator speaking specifically of people with dementia as ‘living dead’ are detrimental to the film’s aim to improve dementia care.

¹³² For Gordon (2007) singing remains one of the few activities she can do with her mother in the nursing home. In describing this beneficial interaction, Gordon also criticises excessive noise levels in nursing homes, emphasising the ‘ever-present television’ which

In addition, Magnusson's memoir offers moving examples of how music can provide a therapeutic tool to lessen anxiety. In describing a particularly anxiety-inducing area of care, personal hygiene, Magnusson reveals how singing can have a soothing effect on the person with dementia:

You emphatically did not want to get into this bath and I know for a fact that in a moment you won't want to get out either. You are upset and frightened by the transition from towel to water, this awful feeling of vulnerability. I start to hum 'It's a Lovely Day Tomorrow' and in a slightly quavery voice you join in ... You relax. The tension drains from your face. You shut your eyes. You let the water lap around your chin. You begin to smile. It really is a little bit like magic. (281)

Although neuroscientific research supports the view that music has a strong potential to engage people with severe memory loss and improve cognitive and motor functions, a number of scholars have called for more rigorous scientific studies and cautioned against being misled by the 'exaggerated treatment effect' (Samson et al. 2015: 250). They suggest that the social interaction in itself, irrespective of the activity, is likely to contribute to improvements in emotional well-being in people with dementia (253). As Magnusson puts it, quoting the chief executive of Alzheimer's Scotland, 'human intervention is the chemotherapy for dementia' (Magnusson 2014: 282). In other words, while making music or listening to music may not work its 'magic' on every patient with dementia, it is imperative to develop more ways (and make more time) to be with people with severe memory loss.¹³³

Finally, Magnusson's memoir explores how in trying to protect people with dementia from harm, caregivers may be limiting their family members' potential to thrive. Magnusson reflects on her mixed responses of guilt and shame when the address her mother gives at a funeral seems to go fatally wrong. A skilled conversationalist, Magnusson's mother Mamie delivers the

makes it impossible for them to 'sing and hear [themselves]. In peace.' (Gordon 2007: 51). Considering that dementia leads to processing difficulties it seems ill-advised to expose people with dementia to numerous intrusive stimuli. Adapting nursing home environments, by breaking the habit of having the TV or radio run constantly, would represent a first step towards creating a more dementia-friendly environment. See Stokes (2010) for a range of illuminating case studies on how to adapt nursing home environments for people with dementia.

¹³³ In the meantime, Playlist For Life, a charity founded by Magnusson, aims to bring personalised music to people with dementia. For further information see <https://www.playlistforlife.org.uk/>.

talk with conviction and style and it is well received by the funeral audience. However, due to her short-term memory loss, at the end of her speech Mamie proceeds to give the entire speech a second time. Magnusson is mortified for her mother's sake and worries about her own responsibility in leaving her mother open to such public humiliation. However, despite this initial assessment of the event as a failure of caring, Magnusson simultaneously tells another story. She describes how her mother 'revel[s] in the attention of dozens of friendly mourners' (149). The opportunity of giving one more public speech provides her with the 'the chance to be [herself] and feel the adrenaline of performance pumping through [her] veins again' (149). And as the congregation erupts 'in most unfunereal applause'—likely motivated by the joint relief felt at the resolution of an uncomfortable situation—Mamie looks 'thrilled' (150). Initially, Magnusson reflects:

I should have realised that embarrassment had flown to the same place as many of your social inhibitions. But as I steered you between these sympathetic faces, I felt sick with guilt. This was not how you should have left the public stage. (150)

Magnusson later realises, however, that in her ideas and expectations of her mother, she might be holding on to the wrong set of values. In other words, what matters to her—seeing her mother as a supremely competent public speaker who makes no mistakes—may no longer matter in the same way to her mother: 'Serenely unaware of gaffes and social expectations, you drank in only the appreciation. Perhaps it is my own embarrassment I am lamenting today' (152). Her experience leads her to realise that the social environment should be such as to support people with dementia in their current state of abilities, allowing them to flourish, rather than secluding them or restricting their activities for fear of humiliation. Magnusson here underlines the role that the community, and not just specialised care professionals, plays in helping to 'bolster' (385) the person with dementia.

My mother was able to revel in her public self again that day because a community held her in its arms. Imagine the difference if communities in general – churches, shops, offices, buses, hospitals, banks, theatres, schools – were well enough educated in what it means to have dementia (and, crucially, what it doesn't mean) to do the same for the mentally frail in

their midst. No pressure then to hide away. No silly shame at a loved one's social solecisms. No stigma to bring out the cowards in us all. (384)

Magnusson reflects that letting go of her impulse to protect her mother from the risk of public humiliation proved a productive step. Indeed, caregivers' memoirs suggest that at times it may be better to let go of one's responsibilities as caregivers, to lose sight of one's task-focused care agenda and instead follow the person with dementia in their activities. Such moments of 'being-with' the person with dementia, silencing the ubiquitous drive in caregiving to be 'doing-to,' may lead to shared moments of appreciation and joy.

Challenging Care Practice

Caregivers' memoirs—though to varying degrees—function as vehicles of patient advocacy. In criticising the current care system, they raise awareness about dementia as a complex and urgent health priority and may, ultimately, be able to contribute to improvements in the care system. By dint of their form as well as their content, caregivers' memoirs speak not only for people with dementia but advocate on behalf of familial caregivers. They criticise the lack of support for caregivers, and the insufficiency of health care policies in the US and public health care in the UK. Many of the issues discussed so far can be seen in the light of challenging current health care practices. Instead of reiterating these critiques, or indeed exploring the full range of possible relations between these narratives and advocacy work, I limit my discussion to some of the details from Magnusson's memoir that explicitly challenge current care practice.

For one thing, Magnusson's memoir provides a searing critique of the inability of institutions to cater to the needs of confused, elderly patients. The smooth running of the institution constitutes the prerogative of nurses and other professional caregivers—often to the detriment of the people in their care. If institutional care is depersonalised, inflexible, and often debilitating (in that patients are often discouraged from doing things they could well still achieve on their own), it is also hostile to intrusions from the outside world. Family caregivers are seen to disrupt routines, and despite

staff shortages are made to feel unwelcome. After her mother is admitted to hospital due to a broken hip, Magnusson describes her family's sense of helplessness and outrage when they are not allowed to spend the night with her. Magnusson describes her mother's ordeal of waiting several days for an operation (all the while not being allowed to eat for long stretches in anticipation of surgery) and the toll this takes on her mother's grip on reality. In the process, Magnusson questions hospital policies in relation to frail elderly people:

Leaving you to face the night alone in a strange, noisy place, frightened and achingly vulnerable, is like abandoning a scared child. No parent would do it. No parent would be expected to. Can anybody tell me the difference? (162)

Indeed, the unfamiliar environment brings on a state of delirium in her mother. In the rehabilitation centre she is subsequently moved to, Magnusson and her sisters have to fight daily to be allowed to stay with their mother beyond visiting hours, and are criticised by care staff for 'traipsing in all the time' (175)—despite the fact that the care staff itself is overstretched and unable to monitor the movements of a mentally fragile person recovering from hip surgery.¹³⁴ Magnusson and her sisters defy institutional routines and thereby protect their mother from the worst effects of institutional neglect. However, her mother's temporary stay in hospital and a rehabilitation centre allows Magnusson to witness up close how other patients are treated in institutional settings. While Magnusson acknowledges that nursing staff work hard, she reveals how ignorance, power games and lack of empathy can result in dehumanising treatment of people with cognitive impairments and physical disabilities.

Magnusson's critique does not limit itself to the nursing staff, but also flags up how doctors often lack the skills needed to communicate with a person with dementia. She criticises a doctor for reading out all the potential hazards of the impending operation to her mother: 'There is no use abandoning the does-she-take-sugar approach of talking over a patient's head,' she writes 'if instead medics simply read the rulebook to someone whose speciality is missing the point' (167). Furthermore, like many

¹³⁴ See <http://johnscampaign.org.uk/#/>, a UK based campaign to make family caregivers more welcome in institutional settings.

caregivers before her, she emphatically questions the rationale of the Mini-Mental-State-Exam to assess memory impairment—given that the test entails no therapeutic benefits and given that, after it is used to establish her mother’s mental impairment, ‘no-one takes the slightest account of [her] dementia at all’:

asking questions a person is doomed to get wrong is a strangely heartless way to establish someone’s cognitive ability in an alien place when she is already confused and uncertain. It seems almost as mean to measure bafflement in this way as it would be to confirm a weak heart by giving someone an almighty shock. Boo! Yes, as we suspected, heart failure. (173)

Magnusson’s memoir is outspoken about the failings of the current care system. Compared to other memoirs her advocacy aims are also clearer. Especially in the afterword to the second edition of her memoir, she delineates the many ways she hopes to make an impact on dementia care. She outlines care paths and practices based on both her own and her readers’ experiences as caregivers. For one thing, she calls for consistent care in dementia, a professional care manager to support familial care workers and oversee all aspects of health care. Such a role, in her view, would not require ‘more money but more organisation’ (393). She also explores various approaches to ‘integrated dementia care’—institutions that imitate family homes and small-scale community models. And finally, she advocates using music—personalised playlists on iPods instead of antipsychotic drugs—to engage and soothe people struggling with the effects of dementia. Challenging care practice in a first step, these memoirs also move beyond criticism to explore new ways of delivering dementia care.

Conclusion

Caregivers’ memoirs provide valuable resources for developing better dementia care—that is, care practices that fulfil the needs both of the caregiver and care-receiver. Indeed, the process of ‘care-writing’ in itself frequently helped improve the level of care authors were able to provide for their family members. Discovering new ways of seeing dementia, through research and self-reflection, shaped the ways these authors responded to

their family members and may also have enabled caregivers to cope better with the changes that dementia wrought. However, caregivers' memoirs act on more than just a local level. Caregiving grows out of concern for the other, and the authors of caregivers' memoirs frequently aim to enlarge that concern to include others outside the family circle by providing a powerful voice in dementia advocacy. They pinpoint failings in societies, communities and institutions. They challenge current care practices and current attitudes towards dementia which suggest that a person with dementia is already 'gone,' has nothing to contribute, and no longer deserves or is likely to benefit from respectful engagement. If these texts rail against the multiple ways the 'system' fails people with dementia and their caregivers, they do not stop simply at this criticism but also offer up productive new ways of thinking about and delivering dementia care.

Caregivers' memoirs differ in important ways from advice literature or social science reports. While much useful information can be gleaned from the latter, advice literature can feel overly prescriptive and fail to address the ethical issues inherent in dementia care. The narrativisation of lived experience in its complexity, through the eyes of a self-critical and accomplished writer, provides a number of advantages over other sources of information on caregiving. A significant advantage is that these memoirs and documentaries have an aesthetic appeal to them, and as I argue more fully in the next chapter, aesthetically pleasing narrative may make topics like dementia care more palatable. That is, readers may engage with topics they otherwise shy away from when they are embedded in a literary narrative (see also Keen 2007, Nussbaum 1990).¹³⁵ The capacity of literature to appeal to its readers' emotions, to instruct and delight: those are the aspects which distinguish literary narrative (among other art forms) from social science reports. While these memoirs clearly share some of the affordances of imaginative literature, I explore in the following chapter how fictional narrative, free from referential (and arguably, also some moral)

¹³⁵ Keen and Nussbaum are concerned with fictional narratives. Nonetheless, Nussbaum does not rule out that sufficiently *literary* life writing that 'arouse[s] the relevant forms of imaginative activity' and 'promote[s] identification and sympathy in the reader' may function in a similar way as fiction—especially, she writes 'if [it] show[s] the effect of circumstances on the emotions and the inner world' (1995: 5), which these caregivers' memoirs do.

constraints, may provide an even more radical ‘thinking through’ of the implications of the current dementia construct for dementia care. At the same time, differences between literary memoir and literary fiction help give caregivers’ accounts their ethical and political force (Couser 2004). It is the fact that the authors of caregivers’ memoirs speak from a place of first-hand experience that makes their narratives such powerful forces in dementia advocacy. These memoirs are able to expand the horizon of current research agendas on dementia care by opening up questions that previous research never thought to ask. Among these is the realisation that although dementia creates pressing care needs, living with dementia offers up many opportunities for moments of joy and fulfilment—for both caregivers and care-receivers.

Indeed, contrary to Burke’s analysis of current dementia life writing as infused by the ‘language and logic of the market’ (2016: 603), in which authors proclaim ‘my mother’s dementia ruined my life’ (60), many of these narratives underscore the continuing relationality and positive experience of mutual obligation that inhere in personal relationships. Also, rather than focusing merely on dementia as personal tragedy—although these narratives clearly function as means to work through their authors’ own grief and unresolved feelings towards their dead partners or parents—these texts do, in fact, reach out to others with the aim of developing, as Burke demands, a ‘collective societal framework with which to support people with dementia and those that provide their care’ (Burke 2016: 600). *Pace* Burke, then, the subjective and personal do not necessarily undermine or stand in opposition to collective, political action.

Another advantage of memoir over, for instance, specialised nursing literature is that caregivers’ memoirs are likely to reach a much wider audience. (Sales reports suggest even that memoir has nowadays surpassed fiction in marketability.)¹³⁶ Since dementia calls for changes on a societal scale, it is important that the question of dementia care is raised both within and outside specialised contexts. As one of Magnusson’s readers says, these

¹³⁶ Swinnen (2012) argues that documentary may contribute to the personhood movement in dementia since it reaches wider audiences than scholarly work (122). However, she simultaneously draws attention to the need to scrutinise the ethics of representation in films and documentaries used as educational tools.

texts should constitute compulsory reading for a whole range of people, from ‘the highest government minister in the land to the humblest care assistant’ (Magnusson 2014: 381). They should be read not because they present ideal or ‘model’ caregiving, but because, in allowing readers to live through the complexity and ethical murkiness of dementia care, these memoirs stimulate profound debate about the possibilities and problems of looking after people with cognitive impairment. They suggest a panoply of treatment options and stress the importance of flexible care tailored to the needs of individuals, families and communities.

For all their criticism of the current care system, these memoirs are of course not beyond criticism themselves. In exposing the lives of vulnerable subjects they may become ethically suspect. As hinted at in the examples above and discussed more fully in the previous chapter, the writers of caregivers’ memoirs may harm people with dementia by breaching their right to privacy. They may also inadvertently contribute to the stigma attached to the disease. As Magnusson discusses in her afterword, the question of misrepresentation remains complex in dementia. Advocates have long painted a bleak picture of the disease in order to garner more support. Although their aim is laudable, by perpetuating a negative representation of dementia they may also stoke fear of the disease. Conversely, while Magnusson welcomes the change in attitude towards people with dementia—acknowledging what people with dementia can still do, rather than focusing on their deficits—she also warns that this new way of seeing dementia may lead to a ‘revisionist airbrushing of the suffering dementia causes’ (385). What I have argued in this chapter is that some of the apparent shortcomings of caregivers’ memoirs can actually provide food for constructive thinking.

In considering the ethical problems of life writing about vulnerable subjects, Couser asks whether there are any pay-offs which justify or balance out the ethical infractions such writing commits. I suggest that the ethical thinking these texts promote, the imaginative treatment options they develop, and the challenge they pose to current societal responses to dementia care represent such pay-offs. These memoirs offer up multiple new avenues for seeing, responding to and living with dementia. Such

avenues are well worth exploring in light of the pressing need for humane and sustainable dementia care.

Chapter 6 Making Readers Care: Bioethics and the Novel

When we read novels we become immersed in complex storyworlds that may mimic as well as differ substantially from our own world. Whatever the precise relation between the fictional and the real, we make sense of these storyworlds based on our own life experiences, and, in some way or another, will relate our reading experiences back to our lives as embodied, embedded and socially positioned individuals. In the medical humanities—variously described as a discipline, field or meeting point¹³⁷—literary fiction has been called upon to play a number of perhaps surprising roles. In this chapter, I explore and problematize the ways in which literary fiction may intervene in medical or health humanities teaching and research. While the dividends of literary exploration are difficult to quantify or qualify since they lie in the encounter between particular texts and readers, I nonetheless suggest some ways in which dementia novels may engage their readers in considering bioethical questions that arise in contemporary Western care culture(s). I use the term bioethics as a way to describe how novels explore the question of ‘how to live’—including the question of how, when and where to die. In particular, I ask how fictional narratives raise questions concerning autonomy, quality of life, and suicide or euthanasia in dementia. Indeed, a reassessment of cost-benefit understandings of care which underlie discussions around quality of life and euthanasia is central to a number of the narratives I consider in this chapter.

In the present chapter I aim to distinguish my own approach from the practice of ‘narrative medicine,’ as developed in particular by Rita Charon (2006). Charon’s work in this area is concerned to a significant extent with promoting empathy and better clinical skills in health care practitioners. I propose to widen the scope of Charon’s argument in favour of an engagement with narrative in health care settings to include audiences outside the immediate doctor-patient encounter. I by no means intend to devalue Charon’s significant contribution to the medical humanities. Indeed,

¹³⁷ Medical humanities have recently also been described as ‘a series of intersections, exchanges and entanglements between the biomedical sciences, the arts and humanities, and the social sciences’ (Whitehead and Woods 2016: 1).

I find it regrettable that her work is at times held up as a straw figure to represent a type of ‘simplistic’ or ‘naïve’ medical humanities approach, which closer study of the practice she develops does not in fact bear out. However, my approach differs significantly from her work in that I am concerned primarily with the *reception* of texts, and here in particular with the reception of *literary* narratives. Furthermore, I am concerned with all readers—doctors, care home managers, literary scholars and the general public alike. Of course, this does not exclude the possibility that the novels I discuss may speak in particular ways to health care professionals and (family) caregivers, or that they may be used in medical education and training.

While Charon’s work emphasises the clinical benefits of doctors engaging with literary and non-literary narratives, it is imperative to assess whether literature necessarily plays the positive role it is frequently assigned. Current discussions about the medical humanities promote a view of the field as driven by an ‘ethical imperative’ (Rees 2010, qtd. in Jones 2014). On such a view, there is something morally wrong with the current practice of health care, which needs to be redressed. The humanities and social sciences enter to provide a critique of the state of biomedicine and offer new, more ethically sound ways of providing health care. My introduction outlined problems inherent in the argument that the humanities may ‘humanise’ biomedical practice. What I am concerned with here, since I deal with texts that raise issues about well-being and care, is the question whether the literary texts themselves may be seen as tools for ‘the good’ or driven by an ethical imperative, or whether they instead enforce common stereotypes of dementia and thereby contribute to the stigma attached to the disease syndrome.

In considering how dementia is represented in narrative fiction, my approach resembles critical disability studies approaches that aim to outline and frequently deconstruct the way that a ‘disease’ or ‘disability’ has been represented historically in a culture (see, among others, Murray 2008, Stirling 2010). Dementia, like other disabilities, has accrued a host of negative stereotypes and dehumanising tropes that circulate widely in the cultural imaginary (Behuniak 2011, Burke 2007b, Herskovits 1995). The

fact that literary narratives promote these negative representations of dementia seriously undermines the notion that reading literary narratives may promote better doctors, more caring caregivers or more ethical world citizens. Rather than acting, necessarily, as subversive counter-narratives to reductionist and dehumanising biomedical and popular conceptions of dementia, literary narratives in such cases compound the stigma attached to the disease. The question, then, is how particular fictional dementia narratives live up to, or fail to live up to, the ethico-political standard that the term counter-narrative suggests.

Rather than cataloguing numerous stereotypical representations of dementia in fiction—of which there are many—I approach the relation of bioethics and the novel through four case studies. I first consider Michael Ignatieff’s *Scar Tissue* (1993) and B.S. Johnson’s *House Mother Normal* (2013/1971) to reflect on the ways these novels raise ethical problems vis-à-vis questions of selfhood, social stigma and norms of caring. In discussing Ignatieff’s text, I briefly touch on how literary fiction addresses the doctor-patient encounter—long the focus of medical humanities research—as well as on how fictional narratives mediate the contrasting epistemologies of the life world approach versus biomedicine. Johnson’s text, by contrast, addresses the question of how fiction may act both as a dangerous democratising force—though the use of polyphony and dialogism—and as a dangerous rhetorical force, in its ability to sway readers’ views, emotions and attitudes. Literature has the ability to both persuade and disturb. The dangerous and disturbing aspects of narrative rhetoric, I argue, may be productive as well as destructive when harnessed to the ethical imperative of a medical humanities agenda.

In a second step, I explore what fictional dementia narratives bring to the table when thinking through bioethical issues concerning ‘quality of life.’ Judgments about the quality and value of a human life are inextricably linked with making end-of-life decisions. In thinking about the obligations we hold towards more vulnerable members of our society, dementia narratives open up difficult questions about *caregiving* and *withholding* care. In the second section of this chapter, I address how different media and means of narrative presentation affect the process of bioethical decision-

making that these narratives simulate for and perhaps evoke in their readers. To this end, I return to the film and novel version of *Still Alice*, and also to Margaret Forster's novel *Have the Men Had Enough?* (1989). These narratives offer the opportunity to 'live through' (Rosenblatt 1995: 33; 38) as well as 'think through' the bioethical dilemmas attendant on dementia care.¹³⁸ Drawing on Martha Nussbaum's argument that novels provide means of addressing the question of how to live, I explore what type of 'ethical work' (Nussbaum 1990: 47) these narratives may engender in the reader. How may these novels elicit certain responses, without offering pat solutions, to bioethical dilemmas concerning the end of a meaningful life, or the value of one life above, in relation to, or against another?

Ethics and the Novel: Countering, Stereotyping and Disturbing

While I use the term ethics as a way to describe how novels explore the question of 'how to live,' I note that my discussion of ethics is never far from questions of morality and moral action—since the question of how to live invariably involves moral codes as well as individual responses that draw on these codes and personal convictions. As John Guillory acknowledges, a clear demarcation between ethics and morality, or indeed related notions of the aesthetic (as ethical) and the political (as moral), is not possible. Instead, as Guillory proposes in his work, I explore 'the range of possible relations between the ethical/aesthetic and the political/moral' (Guillory 2000: 37).

Furthermore, in approaching the question of ethics from a literary angle, I draw on a range of literary scholars before me who have made questions of ethics a primary concern of their reading practice. My reading of dementia narratives engages most strongly with pragmatist and rhetorical ethics,¹³⁹ represented by such scholars as Martha Nussbaum, Wayne C. Booth and James Phelan, since this strand of narrative ethics is frequently invoked in medical humanities contexts. The work of moral philosopher Martha

¹³⁸ Compare also Morris (2002) on 'thinking *with* stories' (196; my emphasis).

¹³⁹ See Korthals Altes (2005) for an overview of different strands of the 'ethical turn' in the humanities. For further discussion of the relation between ethics and literature see Korthals Altes (2006, 2013, 2014).

Nussbaum supports my thesis that novels provide means of exploring ethical questions and of acting as moral laboratory for the reader. However, I also show how the ethics of alterity and politically engaged ethics subvert more positivist or supposedly morally stable modes of reading, without however subscribing to the notion of an ‘ethics of literature as radical undecidability’ (Korthals Altes 2005: 145), which risks making literature both ethically and morally moot.

In the words of James Phelan, ‘the very act of reading has an ethical dimension: reading involves doing things such as judging, desiring, emoting, actions that are linked to our values’ (Phelan 2003: 132). Phelan and Wayne C. Booth before him show through close rhetorical analysis how literary devices ‘construct value-effects and elicit the reader’s ethical engagement’ (Korthals Altes 2005: 142). Such a focus on the interplay between the author, narrative technique, and the reader emphasises the co-constructed nature of ethical reading practices, referred to by Booth as ‘coduction’ (Booth 1988: 70-75). This process of coduction, which includes discussion with others, is of particular value in the teaching of narrative medicine (see Charon 2006). It is furthermore an integral part of literary criticism in that professional reading, as Guillory argues, constitutes a communal practice. Indeed, in sharing my readings of the novels I discuss in the present chapter, I aim to contribute to a process of coduction which explicitly addresses the ethical dimensions of these texts in relation to dementia care.

Let me turn now to the three verbs of my sub-title: countering, stereotyping and disturbing. In my first case study I ask to what extent dementia novels engage in acts of countering the dominant (negative) cultural construction of dementia. Second, I explore the potential of narrative fiction to disturb its readers, in particular by upsetting moral values. How do polyphony and dialogism in *House*, *Mother*, *Normal* act as a route to questioning and rethinking dementia care practices? Since this novel starkly foregrounds questions of alterity, I here aim to balance and question pragmatist and rhetorical ethics approaches to literature through a text that lends itself to an exploration of an ethics of alterity.

Michael Ignatieff's *Scar Tissue* can best be described as a fictional caregiver's memoir. Indeed, it is stylistically and thematically so close to memoir to be virtually indistinguishable from it. It is therefore perhaps unsurprising that Lucy Burke has recently used it as a paradigm case to discuss relational identity, or intersubjectivity in dementia caregivers' writing (Burke 2014). Although Ignatieff worked aspects of his own life experience, notably of his mother's dementia, into the story (see Arana 2003: 153), the novel departs from the referential stance of autobiographical writing. This departure allows Ignatieff to take a certain licence with his lived experience and to explore other avenues than those derived from his real-life experiences. So, for instance, he is, 'not the son who gave up everything to be with his mother,' like the narrator of the novel, but 'the brother at a distance' (Vassilas 2003: 443).

Writing a fictional memoir further allows Ignatieff to take certain views and experiences to their extremes and to explore the polarity between science and the arts, philosophy and lived experience. Ignatieff contrasts the figure of the unnamed narrator, a lecturer in philosophy and writer of this fictive memoir with the narrator's neurologist brother. In order to explore the question of whether selfhood persists in dementia, Ignatieff almost schematically opposes different characters to show how philosophy, neuroscience, the arts and later religion afford different vantage points on the notion of self. The novel describes the breakdown of the narrator's own identity and of his family relations, especially to his wife and children. As he becomes the 'parent' to his mother (Ignatieff 1993: 96) he neglects his actual parental duties. *Scar Tissue* therefore complicates the view that relational identity is unequivocally reparative in the context of identity crises in dementia. While caregivers are frequently called upon to maintain the identity of their 'loved ones' by continuing to tell their stories for them (Radden and Fordyce 2006),¹⁴⁰ *Scar Tissue* highlights the extent to which the son's own identity is shattered when his mother no longer recognises

¹⁴⁰ Compare Davis (2004), who criticises the demand placed on family caregivers to maintain the identity of the person with dementia.

him: ‘It was as my brother had said: if she failed to recognise you, you ceased to exist. No longer her son, no longer anyone. Acknowledge that I exist. Acknowledge your son’ (Ignatieff 1993: 163-4). In Lucy Burke’s words, the narrative exposes ‘the way in which the narrator’s desire to sustain his mother’s identity is disturbed by her inability to recognise and thus affirm his own sense of self’ (Burke 2014: 45). According to Burke, the narrative thereby takes to their extremes ‘the consequences of the erosion of reciprocal or mutual recognition upon which the concept of intersubjectivity is founded’ (45). In other words, this novel suggests that dementia affects the identity of close family members as well as the dementia sufferer’s.

However, the threat to the narrator’s identity is not only of a relational kind, deriving from his mother’s lack of recognition. Since the narrator believes he has a genetic predisposition to develop the disease—he ironically calls it ‘the family silver’ (1)—he sees the threat to his own selfhood as emanating from the inside, from the supposed build-up of plaques and tangles in his brain. Indeed, the entire narrative is less a coming to terms with his mother’s dementia than a working through of the narrator’s own fears of living with the disease. The narrator self-consciously grapples with ways to confront his supposed ‘fate’—for instance in developing a Stoic attitude rather than relying on the pervasive North-American myth of self-help and positive thinking,¹⁴¹ or in trying to persuade himself that ‘selflessness’ is in fact an enviable state. He develops the first view in a Rotary speech delivered in front of his parents, and the second in his ‘manic treatise’ (179) on selflessness in the wake of grieving his mother’s death—only to partially reject both attitudes later. Towards the close of the novel, the narrator seems to be experiencing the first symptoms of dementia himself. There is some ambiguity, however, whether these symptoms are due to neurological processes or rather to his intense depression and partly produced by his self-willed isolation and almost ‘masochistic’ and certainly ‘narcissistic’ immersion in his own state of grief (see also Burke 2014: 45).

The novel clearly challenges the perceived notion that relational identity

¹⁴¹ See also Hawkins (1993) for a critical reflection on the self-help myth of ‘healthy-mindedness,’ which represents a dominant model for illness narratives in the US.

constitutes an answer to the dismantling of identity in dementia. Apart from focusing on the question of selfhood and relational identity, the novel shares several other themes with those foregrounded by contemporary illness memoirs. Among these, as suggested by its character constellation, is the interrogation of the ‘truth value’ of different master narratives: particularly, philosophy and contemporary biomedicine. The novel challenges the predominance of the biomedical paradigm while also criticising the way health professionals view, and consequently treat, dementia patients. So, for instance, the narrator contrasts the family’s view of dementia with the clinical perspective in what is a staple of most illness narratives: the scene of diagnosis. Although the neurologist is not depicted entirely unsympathetically, the narrator clashes with her from the start. The narrator is ruffled by the neurologist’s patronising language: she uses the first-person plural ‘we’ to ask about his mother’s well-being, refers to ‘Mother’ rather than using her name, and talks about her in the third-person in her presence.¹⁴² From the neurologist’s perspective the mother’s behaviour can be explained through brain pathology: ‘disinhibition begins with disintegration in the frontal lobes. Your mother’s frontal lobes are not yet affected ... which would explain why she is continent and why she is gentle’ (59-60). The narrator, on the contrary, insists that his mother’s behaviour is meaningful and consistent with her personality: “‘She’s gentle,” I say, “because that’s the kind of person she is”’ (60). Frustrated at the neurologist’s cold clinical stance, he eventually blurts out: ‘a lot depends on whether people like you treat her as a human being or not’ (58). That is, the neurologist’s clinical perspective and distancing stance come across as both de-personalising and dehumanising.

Despite the narrator’s attempts to recognise his mother’s humanity and sustain her personhood, he nonetheless struggles to understand the relation between pathology and personality, to separate identity and disease. Later in the novel the narrator explores the notion of embodiment and selfhood, in particular in relation to his mother’s continuing ability to paint, thereby

¹⁴² Aquilina and Hughes (2006: 149) critically reflect on the fact that medical staff often bypass the person with dementia and speak only to caregivers, thereby denying them their status as authorities of their own experience and even denying their personhood. Caregivers’ memoirs suggest this is a common occurrence.

evoking complex questions about the relations among intentionality, representational art, and creativity as ‘expressions’ of selfhood.¹⁴³ Faced with the biomedical narrative of inexorable decline that the neurologist insists on, the narrator struggles to convey his own sense in which his mother’s identity persists in her bodily habits:

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 ... But I stumble along and just stop. (58)

Using metaphor, the novel here develops a more complex vision of selfhood in dementia and opposes it to the reductionist biomedical understanding. The image of the self as feather suggests fragility, lightness, and effervescence as well as durability. But in locating this embodied form of selfhood at the ‘surface,’ the novel also draws on entrenched notions of an ‘inner’ and inaccessible subjectivity that is considered more valuable than ‘outer’ or supposedly superficial manifestations. In the context of the clinical encounter, in any case, the narrator’s views on the ways his mother’s selfhood is embodied remain unexpressed and the two ways of seeing dementia seem irreconcilable:

It is pointless to go on and we both know it. The doctor looks at Mother’s PET scans and sees a disease of memory function, with a stable name and a clear prognosis. I see an illness of selfhood, without a name or even a clear cause. (60)

The narrator is at times critical of both the epistemological validity and the practice of biomedicine. He draws attention to conflicting neuropathological evidence, in which the brains of symptomatically ‘normal’ elderly showed evidence of the plaques and tangles which are commonly held to be the underlying cause of dementia (54). And yet he wishfully envisions a future in which the ‘fate’ of Alzheimer’s will have turned into a manageable disease, fully explained by medical science. Towards the end, the narrator seems to reject his own philosophical and narrativising attempts to make sense of his experience and instead endorses the biomedical understanding of dementia: ‘Human identity is neurochemical’ (193). In a narcissistic reverie he imagines witnessing his own neuropathological

¹⁴³ For a related debate see Selberg (2015).

breakdown with the help of neuroimaging techniques. In an elaborate conceit he (ironically) 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 neurotransmitters ... causing me to forget ... Nothing could be more beautiful than to see this happen: the molecular progress of your dying. Lie back in the scanning room and watch your own neurons watching you, thinking your thoughts, being you, your own forgetting as digital squares of light on a video monitor. (194)

This passage is in direct contrast to an earlier ‘actual’ scene of neuroimaging the narrator describes: the PET scans his mother is subjected to in the process of diagnosis. The earlier scene is offered up as a critique of the humiliating and seemingly futile nature of diagnostic procedures. It also represents one of the moments in the narrative that hint at more basic and productive processes of intersubjectivity in dementia which do not depend on role recognition—that is, the recognition of the other as parent/child or spouse, respectively. Instead, the scene foregrounds how intersubjective understanding depends on our own embodiment and ability to read others’ thoughts and emotions through their body language (Ratcliffe 2007). Strategically placed after the exposition of current scientific uncertainty about the neurobiological underpinnings of dementia, the passage is one in which the narrator questions the validity of biomedical knowledge and criticises ‘inhumane’ medical practice:

Mother was led, naked and uncomprehending, into a tiled room and sealed inside a machine ... I stood in the control room, on the other side of the glass, watching her terrified glances as her head was placed inside an instrument to measure cerebral activity. ... Her legs made small, struggling gestures of fear and a technician flicked on the intercom and told her not to. I stood there beyond the glass, wanting to kill my brother for putting her through this. Then the sedation took hold and she lay awake but motionless, while a stream of images of the neurochemical activity within her brain flowed across the monitors in the control room ... bright blue for the skull casing, red for the cerebral lobes, purple for the tracer. I stood there watching brightly coloured neural images of my Mother’s fear and dread. (55)

The narrator’s insight into his mother’s feelings, based on an interpretation of her body language, is contrasted with the technically possible ‘insight’ into her brain, which only produces seemingly random colour patterns.

According to contemporary advances in neuroscience, cerebral activity registered by neuroimaging techniques reflects our emotions. The narrative emphasises, however, that the gap between understanding (and responding to) these emotions and interpreting ‘coloured neural images’ remains immense. In this instance, *Scar Tissue* underlines how the interpretation of neuroimaging techniques is in itself a hermeneutic process, not a scientific tool that somehow holds a distinct truth value—even if the current neurobiological master narrative of dementia depends on privileging such a view.

What is telling about the narrator’s turn towards biomedical explanations at the end of his narrative is that he sees himself as leaving the territory of figural language, moving from fiction to fact, from a hermeneutic process to some kind of ‘definitive’ form of understanding. Without going into a discussion of the philosophy of science (or indeed of the inevitably metaphoric nature of scientific language), I here want to explore how the narrator’s reflections on the purchase of metaphorical language echoes current debates in the health humanities—since these debates about metaphor and discourse resonate, in turn, with the notion of counter-narratives. In *Illness as Metaphor* (1979) Susan Sontag discusses how metaphors that attach to particular illnesses have pernicious effects for those who suffer from these diseases—paradigmatically tuberculosis, cancer and, later, AIDS (Sontag 1989). Sontag vehemently resists the use of illness as metaphor and claims that ‘the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking’ (1979: 3). She suggests that particular illnesses become synonymous with death. They become mystified, taboo-words that can no longer be uttered, and when they are attached to a person this person is seen to be ‘morally, if not literally contagious,’ and consequently to be ‘shunned’ (6). Arguably, although strenuous efforts to de-mystify and de-stigmatise dementia are underway, this condition remains the ‘dread’ disease of the century. Since dementia is referred to as a ‘living death’ or ‘funeral without end,’ it is easy to see why Sontag’s call for non-metaphoric thinking remains pertinent. Indeed, efforts to rename the disease syndrome due to the inherently stigmatising connotations of the term ‘dementia’ are

underway.¹⁴⁴ In this context, critical disability scholarship, which traces and criticises the representation of a particular condition and the metaphoric meanings attached to it, presents a productive avenue of inquiry.

However, the claim that supposedly non-metaphoric approaches to illness are the best means forward has by no means gone uncontested. As David Morris, in response to Sontag, points out,

There is practical, therapeutic value in calming the imagination of patients gripped by harmful myths. Yet, in her intention to deprive it of harmful meaning, Sontag wants to reduce illness to a scientific, biological fact. Unfortunately, returning illness to science does not deprive it of meaning but simply leaves it in the grip of a reductive, positivist, biomedical narrative that focuses solely on bodily processes ... the effort to cleanse illness of all meaning discounts the therapeutic benefit that positive myths and meanings can supply. It ignores the healing role that stories play ... (Morris 1998: 269-70)

Indeed, the entire health humanities movement is to a large degree founded on the assumption that metaphoric thinking and narrative exploration have beneficial effects for the person living with serious illness. In Morris' words, 'The slippery use of metaphor can be turned to good use as well as ill' (270). The question is, then, how metaphor and narrative are used in *Scar Tissue* to counter or confirm the dominant construction of dementia as 'loss of self.' And what role does narrative play in making sense of the experience of dementia?

To take the last point first: the narrative project, writing a 'memoir' about his experience, provides the narrator with a means of recovering his mother's identity from before her illness, memorialising her as well as others in the family who suffered from dementia (see also Vassilas 2003: 443): 'Memory,' the narrator claims, 'is the only afterlife I have ever believed in. But the forgetting inside us cannot be stopped' (Ignatieff 1993: 4). He accordingly writes in order to defy the 'betrayal' his brain is 'programmed' to enact (4). The fictional memoir represents the narrator's attempts to create meaning out of his experience. As John Wiltshire holds, 'Illness is the stripping of meaning from both person and event' and this 'challenge of non-meaning' is 'perhaps most acutely represented when the

¹⁴⁴ See for instance Hughes' call to replace 'dementia' with 'acquired diffuse neurocognitive dysfunction' (Hughes 2011).

patient suffers ... from a neurological condition' such as dementia (Wiltshire 2000: 413). However, the narrative also registers the many instances in which the attempt to create coherence or master one's 'fate,' as the narrator puts it, is doomed. His mother's death represents such a moment that defies, if not representation, then domestication:

There is only one reason to tell you this, to present the scene. It is to say that what happens can never be anticipated. What happens escapes anything you can ever say about it. What happens cannot be redeemed. It can never be anything other than what it is. We tell stories as if to refuse the truth, as if to say that we make our fate, rather than simply endure it. We live, and we cannot shape life. It is much too great for us, too great for any words. ... there at last in her presence ... I knew that all my words could only be in vain, and that all I had feared and all I had anticipated could only be lived. (172)

Scar Tissue, in striving to create coherence, to find redemption, follows the over-arching goals of most illness narratives. At the same time, the novel enacts the failure of such redemption. In Wiltshire's view, it even comes close to what Arthur Frank somewhat oxymoronicallly terms the *chaos narrative* of illness:

If the mother's illness has led to the loss of "self", as [the narrator] suggests ... something of that loss is passed on, or replicated, in scenes in which the narrator hysterically loses control and [verbally] abuses his wife and brother ending in a period of complete isolation and breakdown. But as well as the narrator the book circles round in bafflement; it manifests a kind of entrapment in the crisis it seeks to understand. Indeed, if the breakdown of boundaries between self and other is characteristic of the material in illness narratives, *Scar Tissue* demonstrates this in pathological form. (Wiltshire 2000: 419)

Although, in my view, Ignatieff's novel is a far cry from Frank's notion of chaos narrative, it does enact the breakdown of relationality. Importantly, the narrative thematises its own failure to create coherence, to provide satisfactory closure. The narrative strand is continuously interrupted by different types of discourses or genres: such as a speech delivered by the narrator, the beginnings of a philosophical tract, excerpts from *King Lear*, a newspaper clipping on suicide in dementia, and an exploration of De Kooning's artwork. These narrative disruptions also represent contradictory viewpoints that the narrator inhabits in relation to the question of selfhood in dementia. In registering the difficulty of arriving at a definitive account of

what dementia entails, both for the sufferer and her caregivers, the novel may offer consolation to others who, as John Skelton argues, ‘may welcome the release that literature brings. They may feel that their own power to express themselves has failed and that there is relief in the words of others and the possibility of saying “This is what I mean”’ (Skelton 2003: 212)—even if in this case the ‘meaning’ would be that the experience of living with dementia or witnessing the death of a parent or spouse cannot be adequately put into words.

Scar Tissue, then, represents conflicting views about the question of selfhood in dementia. On the one hand, the narrator rants at his brother when the latter questions whether there is still any point in visiting their mother:

What you’re asking is “is this a person or is this a vegetable?” ... I would say she is. Definitely. She has personhood. She has the habits a person has. If you say the word coffee, she says “Cawfee”, in imitation of Peg Lawson in Alton. That’s the habit of a person ... Miranda used to say, “She sure is a character.” Do you know what that meant? It meant she hit you if you tried to take her sweater off without her permission. ... Until her fall ... she used to walk six hours a day ... Imagine the determination in all that walking. Imagine what it takes. That’s what I call a person. That’s what I call a character. (159)

And yet, on the other hand, the narrator concludes his rant: ‘She has left her self behind. I sit with her, ... and I think: What’s so good about a self?’ (161). Further, although he feels the need to assert his mother’s identity and acknowledge what remains, he simultaneously reverts to stereotypical representations of people with dementia as selfless beings, with ‘vacant eyes’ (5) that bespeak a lack of interiority. Finally, the narrator tries to persuade himself that the loss of self is in fact, something worth striving for. However, he describes the project of countering the Western ‘obsession’ with individualism as an errant, misguided project: using the terms ‘lunatic’ and ‘manic’ suggests that he feels embarrassed for even entertaining the idea that selflessness might be considered a good, a goal worth striving for. Importantly, the narrative disturbs the view that relational identity is unequivocally restorative. His mother’s lack of recognition leads to his own pathological breakdown of identity. Conversely, the narrator pronounces his mother’s social and spiritual death at the very moment that she fails to be able to recognise him:

This time I was sure that she neither knew me nor cared who I was. ... The eyes that do not see. The eyes that have no memory, the eyes that are dead. I had arrived at the moment, long foretold, hopelessly prepared for, when Mother took the step beyond her self and moved into the world of death with her eyes open. (166)

Scar Tissue here confirms the dominant trope of dementia as ‘living death,’ thereby undermining its status as counter-narrative. However, as suggested previously, counter-narratives are rarely straightforward constructs. They are necessarily entangled in the dominant discourses they set out to subvert. Indeed, seeing counter-narratives as merely oppositional counter-images that rely on invoking the binary opposites of any dominant representation short-changes their potential to question received ideas. *Scar Tissue* challenges current care practices as well as the ‘neurobiological materialism’ (Waugh 2013: 18) which constitutes the dominant mode of understanding dementia—and arguably, what it means to be human. And yet, *Scar Tissue* also promotes the masterplot of dementia as ‘loss of self,’ and compounds stigma through the use of gothic and animalistic imagery. The text may also be seen to reinforce the notion that dementia is a fate worse than death, a dismantling of self and of family relationships. Reading dementia narratives consequently opens up two levels of critique: 1) the potential of the narratives themselves to provide a means to criticise certain aspects of society and 2) the role of the literary critic to elucidate and criticise how novels engage us in ways of viewing and responding to the world.

In *Scar Tissues*, the patchwork of discourses and the narrative trajectory which allows the representation of conflicting views represent a destabilising approach for the reader and ask the reader to join the narrator in his unsettling journey with (and possibly into) dementia. In the end, the novel allows only an imperfect sense of closure. While the narrator seems trapped within the dominant discourses on dementia, the novel as a whole reflects the difficult position dementia inhabits in our society and our minds. It opens up to debate the hermeneutic means—medical, philosophical, artistic, religious or narrative—through which we might approach the questions dementia raises about what it means to be human.

B. S. Johnson's *House Mother Normal*, previously discussed in chapter 2, also sheds light on the relationship between bioethics and the novel. In particular, the text suggests literary fiction's potential to disturb its readers. Martha Nussbaum has suggested that novels have the power to make readers see things differently. Fiction is heralded for its emotive appeal, for making readers feel deeply about characters and plot outcomes (Nussbaum 1990, 1995, 1997). Although Nussbaum acknowledges that fiction's ability to arouse strong emotions entails certain risks, she largely glosses over the dangers inherent in fiction's powerful rhetoric and emotive appeal. *House Mother Normal* can be used to explore these other, less salutary effects of the novel's rhetoric on readers. Such a project does not deny that the 'literary imagination' represents a moral 'good' (Nussbaum 1995), but it more closely delimits what this 'good' may be and contests the claim that reading fiction generally has the effect of morally improving the reader.

In related fashion, Suzanne Keen challenges the argument that reading fiction makes people more caring individuals:

Linking novel reading to a widely shared moral principle—caring—without demanding that fiction be about caring allows broad claims about the medium to exist without evaluating content. This is a neat trick. Novels, by this logic, do not need to articulate the principle that people ought to care for one another. ... the very action of reading fiction—any fiction—supposedly trains people to care for one another. (Keen 2007: 20)

Taking my cue from Keen, I suggest that both form and content need to be taken into account when evaluating the ethics or ethical potential of any given narrative, and particularly the narrative's relation to promoting an ethics of care.

Certain characteristics of literary fiction have been cited as doing ethical work, foremost among them polyphony, dialogism and ambivalence (see Korthals Altes 2006). So for instance, Astrid Erll (2008) describes how from a poststructuralist perspective the ethical value of literature is located in its ambiguity: the 'polyvalency of literary forms,' she writes forces readers 'to acknowledge that reality is a construction' and that 'different, equally valid perspectives on the same thing are possible' (Erll 2008: n.p.). According to Erll this aspect of literature leads readers to 'learn respect for alterity' (n.p.).

When these perspectives become multiplied, as in the insistently dialogic and polyphonic structure of *House Mother Normal*, the ethical effect of ‘respect for alterity’ may be seen to be enhanced. The representation of the events in a care home through the minds of eight different residents allows the reader to appreciate the different meanings each individual attaches to his or her experience. The reader is sensitised to how the house mother’s behaviour impacts on each resident’s well-being and sense of self. By inhabiting each character’s mind, one sees the world through that person’s eyes, appreciates how memories of the past and wishes for the present structure that person’s experience. In representing the consciousness of people with dementia—subjects frequently ‘othered’ in contemporary discourse—and then diversifying this representation through multiple individualised portraits, Johnson seems to be working within or towards an ethics of alterity.

However, some problems remain with interpreting the ethical effect of the novel’s dialogic structure in such a way. For example, taking inspiration from branches of criticism such as feminist, post-colonial or disability studies, one might argue that Johnson’s representation constitutes a misrepresentation or usurpation of the subjectivity of the ‘other.’ In Emmanuel Levinas’s terms the ‘other’ is never fully knowable, and therefore attempting to inhabit the other’s perspective represents an unethical act of appropriation or erasure (Levinas 1979, 1961/1990). Although it is important to bear the complexity of the problem of (mis)representation in mind, Johnson partially circumvents becoming the target of such a critique by drawing attention to the constructed nature of his representation.

It remains a problem, too that assigning a particular ethical value to a particular literary technique, does not pay due attention to how the specific cultural, historical and textual context of a given technique affect its reception. Literary forms do not carry ethical weight in themselves, but contribute to the ethical potential of a narrative in a specific context (see also Erll 2008). *House Mother Normal* lends itself to poststructuralist readings, which value disruption, undecidability, ambiguity and a resistance to closure. At the same time, the text also disrupts hypotheses about the ethical potential of certain literary structures (such as dialogism or the use of

frame narratives). Johnson's work can be read as intensifying the inherent polyphonic and dialogic nature of literature and language (Bakhtin 1981, 1984). We are not presented, as in *Scar Tissue*, with the relatively stable viewpoint of one particular consciousness—no matter how imbued by different discourses—but with a multiplicity of minds which are socially embedded and structurally multi-layered. The patients' interior monologues support each other (by allowing the reader to piece together the events of the narrative), even as they represent different and sometimes conflicting experiential points of view. Importantly, the various interior monologues by the residents are also accorded equal weight and value. So, for instance, despite the narrative trajectory from more cognitively able to less cognitively able minds, each monologue is accorded the exact same number of pages.

Further, if dialogism and democracy are inherently linked, the 'democratic' distribution of narrative space in this case is upset by the house mother's frame narrative. The house mother's story, her point of view, takes precedence over the other accounts on a number of levels. She is after all the eponymous heroine of the novel; and by framing the patients' accounts, her narrative may be seen to determine the interpretive field of the narratives that follow. She is given the 'last word,' literally and figuratively. Her narrative also exceeds the number of pages accorded each patient narrative, as stressed by a significant moment of metalepsis: 'And here you see, friend, I am about to step [page 21] outside the convention, the framework of twenty-one pages per person [page 22]'. That said, Johnson's narrative suggests that her view is not meant to go uncontested. Rather than promoting her views on how people with dementia had best be cared for, the narrative is set up to disturb and shock. As mentioned in my previous discussion of the novel, the house mother provides a number of dubious, humiliating and harmful 'entertainments' for the people in her care. She enlists their labour in manufacturing fraudulent medication, enforces a wheelchair tournament with wet mops that causes at least one of the patients severe pain, and conducts a game of pass the parcel in which the prize is one of her dog's turds. Her final act of entertainment involves pornographic acts with her dog, ending in the 'climax' of her public orgasm. By progressively

revealing the extent of the house mother's shocking behaviour, Johnson subverts the parameters of 'normalcy.'

However, even this reversal of norms and normality undergoes a further twist in the house mother's final address. Her discourse is full of contradictions. It exposes her cruelty, sardonic nature and apparent megalomania. And yet, in the fashion of the court jester, the fool who also speaks truth, Johnson makes her a mouthpiece for criticising care home environments that are, in other ways, worse than or at least as bad as the one she manages. In contrast to the house mother's theatrically and 'over-the-top' immoral acts of 'care,' the deplorable conditions in other institutions she describes, seem plausible, even likely. At once self-absorbed, selfish and in love with her dog, the house mother at times seems to show a real interest in her charges. It thus becomes difficult not to be at least partially persuaded by her argument. She draws an image of mental homes in which people are 'put away ... simply because they are old' and where they are 'stripped of their spectacles, false teeth,/ everything personal to them' (198). Her own 'care', by contrast, provides her patients with 'constant occupation, and/most important, a framework within which to establish/ – indeed, to possess – their own special personalities' (198). However, her means of allowing these personalities expression consists in nurturing petty rivalries among the residents, or giving them reasons to complain. If Johnson uses the house mother to criticise the reality of subhuman care conditions—evidenced nowadays by increasing reports of elder abuse—he also uses her to expose the hypocrisy of a certain 'discourse' that has evolved around care. Her rhetoric evokes the suave language of care home advertising, only to be contrasted immediately with her dismissive attitude: 'Here we respect their petty possessions, so important/to them but rubbish to us' (198). By showing the farcical and sardonic effects of what following the rule-book of what 'person-centred care' could also look like, Johnson invites us to reconsider the very parameters of these care discourses.

In *House Mother Normal* we are confronted with immoral behaviour which is subsequently rationalised and justified. While the reader is unlikely to accept her justifications *tout court*, her arguments nevertheless have an effect on the reader. For instance, when we get to the house mother's

account of the game of 'pass the parcel,' the house mother defends her rationale for using the dog turd as prize:

How disgusting you must be saying to yourself,
friend, and I cannot but agree. But think a bit
harder, friend : why do I disgust them?
I disgust them in order that they might not be
disgusted with themselves. I am disgusting to them
in order to objectify their disgust, to direct it to
something outside themselves, something harmless. (197)

The house mother goes on to argue that her diversion is intended to prevent a deeper spiritual crisis in her patients. This passage reveals a key ethical crux of the narrative. Johnson not only shocks or disturbs the reader in revealing the amoral behaviour of his protagonist, but also disturbs the very norms of what constitutes 'care.' We cannot easily assimilate the house mother's reasoning, but it is not that simple to dismiss her view, either. The logic of the text and the house mother's rhetoric powerfully destabilise the reader's view of what represents morally acceptable caregiving. So, for instance, the patients' monologues bear out the house mother's reasoning that her disgusting behaviour redirects the residents' attention from their own immediate misery. Also, in portraying the differing reactions to her activities, from the 'tournament' to her public masturbation, the narrative underlines the difficulty of pleasing all, or doing right by all. The novel thereby highlights the conflicts between the needs and rights of individuals. What causes one joy causes another pain, what may arouse one person causes another disgust. Balancing these needs cannot ever be simple. What this novel upsets, then, is discourses of care that presume that certain forms of caregiving are uniformly good for all care receivers. In contrast to a moralistic text, *House Mother Normal* does not suggest ideal solutions; rather, it shocks the reader by presenting the effects of a warped care ethic.

In her final address to the reader, the house mother further challenges preconceived notions about what old people, or people with dementia may want for themselves: 'What you do not understand, I think,/friend is that what we imagine they want for them-/selves is not actually what they do want. I do/ not know what they want, either' (193). Although in the next sentence she seems to reject summarily the humanity of the people in her

care ('But I do know/that they are certainly not as we are, and that/therefore by definition they do not want what we want' (193)), her reflections nonetheless point to a distinct ethical problem: 'How does anyone know/what anyone else really wants?' (193). And if we do know what someone wants, how do we balance these needs and wishes against those of others, including, in the context of care, the caregiver's? On my first reading, the house mother's reasoning seemed only to confirm her 'demented' state of mind—structurally contrasted with the supposedly 'dementing' but otherwise mentally 'sane' inmates for a particular stylistic and ethical effect: the novel counters the stigmatising notion that people with dementia are out of their minds. My sensibilities were duly shocked by her cruel behaviour and apparent lack of empathy. However, on my second reading I was more inclined to take her challenges seriously, to be partially persuaded, as I noted, by her logic, or rhetoric. What do we, indeed, know about the needs and wishes of others? How can we provide care for people with dementia? And how can we know which previously stated wishes to fulfil and proclivities to support, when, as the house mother states, these are affected by the 'diffusing effect of time' (193)? Dementia raises, perhaps more than any other condition, ethical dilemmas about advance medical directives and the question of whether we can adequately assess our future selves' needs and wishes.

The effect of staging 'uncaring care' and presenting 'unjust justifications' may be diverse. It may lead certain readers to be shocked and outraged—which in turn may draw attention to actual power imbalances within caregiving environments and highlight the essential vulnerability of those who receive care. It may also lead readers to reconsider dominant humanistic care ethics, to wonder about the rationale behind certain care practices, either to reject them or to re-assert them. What is unlikely, though, is that the narrative will leave its reader untouched. Johnson develops means for us to imagine the phenomenology of dementia and to consider our shared vulnerability as humans. The narrative is perhaps most ambiguous in its representation of the house mother. While Johnson portrays her as a somewhat reprehensible character, he also indicates her isolation, the lack of support she receives from the 'authorities.' Current debates about the

chronically underfunded care sector and the woefully underpaid work of professional carers resonate with this text and add complexity to the house mother's character. Rather than seeing her as a *rogue* character—as Burke suggests frequently occurs in the context of actual cases of abuse by carers (Burke 2016: 596)—we are invited to consider also the systemic failings that may lead to such atrocious 'care.'

Significantly, Johnson puts into the house mother's mouth a lyric and yet melancholy invocation of the *carpe diem* motif.

Still, I'll finish off for him [the author], about the sadness,
the need to go farther better to appreciate the
nearer, what you have now: if you are not like
our friends, friend, laugh now, prepare, accept,
worse times are a-coming, nothing is more sure. (204)

House Mother Normal functions as a *memento mori* for its readers. By evoking the complexity of care home settings, the individuality of people affected by dementia, the vulnerability of not only 'care-receivers' but all human beings, it provides food for thought about what it may be like to grow old with dementia, and how we might prepare, individually and collectively, for the increased dependency that this stage of life inevitably brings.

Exploring Bioethics: 'Thinking Through' as 'Living Through'

In her introduction to *Love's Knowledge* (1990), Martha Nussbaum argues that novels provide important tools for considering the question of 'how to live.' Indeed, she considers novels more productive tools for exploring ethical dilemmas than philosophical examples. Schematic ethical case studies used in bioethics textbooks, Nussbaum argues, are overdetermined in terms of possible interpretations: 'much of the ethical work is already done, the result "cooked"' (Nussbaum 1990: 47). In contrast, literature is open-ended, ambiguous and complex. Due to the particularity, indeterminacy and emotive appeal of literary fiction, Nussbaum argues that novels 'engender in the reader a type of ethical work more appropriate for life' (47). According to Nussbaum, novels both exemplify and approximate experiential learning, that is, learning in concrete situations: they 'exemplify

it in the efforts of the characters and the author, engender it in the reader by setting up a similarly complex activity' (44). In other words, literature provides not only a representation of ethical concerns, but evokes processes in the reader that may be considered a form of ethical deliberation in their own right.

In *Uses of Literature* Rita Felski provides a similar account of the type of learning that fictional narratives promote: 'As a form of context-sensitive knowledge conveyed to readers it is more akin to *connaître* rather than *savoir*, "seeing as" rather than "seeing that," learning by habituation and acquaintance rather than by instruction' (Felski 2008: 93). Indeed, literature's ability to make readers see something in terms of something else, using metaphor and mimesis to make readers see things *differently*, is considered one of its most valuable attributes in the medical humanities (see Jones 2014, Charon 2006). At the same time, most commentators argue that the 'knowledge' or 'learning' that literature promotes is elusive and hard to formulate in discourses other than its particular aesthetic instantiation (see Felski 2008, Nussbaum 1990, Wood 2005). Getting a handle on how novels inform and transform their readers—by providing access into the storyworld's social phenomenology¹⁴⁵ and the protagonists' minds, but also through the use of literary devices, content and structure—requires close narratological analysis.

Lisa Genova's *Still Alice* (2007) and Margaret Forster's *Have the Men Had Enough?* (1989) likewise make their readers in Rosenblatt's terms 'live through' fictional lives affected by dementia, and thereby invite those readers to think through bioethical questions concerning quality of life and end-of-life decisions. Although this chapter focuses on the novel, I include here a discussion of the film version of *Still Alice* in order to address how different medial representations influence the exploration of bioethical

¹⁴⁵ Felski argues that the novel 'unfolds a social phenomenology, a rendering of the qualities of a life-world, that is formally distinct from either non-fiction or theoretical argument' (89). The novel does not only represent social norms, actions and judgments, but 'enfolds readers through the inculcation of countless examples, into an experiential familiarity with the logic of such judgments, with what we may call a feel for the game' (92). While I agree that this experiential familiarity is one of the striking effects of novel reading, one mustn't underestimate that readers do not entirely suspend their own values, norms and experiences and may therefore vary significantly in their response to the social phenomenology rendered in a novel.

questions in fictional narratives. The comparison underscores how each specific narrative environment creates a particular value system in the context of which the reader's or viewer's emotional and ethical responses will emerge.

Before turning to this task of ethico-aesthetic analysis, let me clarify however that 'living through' does not necessarily entail a process of (empathetic) identification in the reader; rather, as Rosenblatt stipulates, it concerns the aesthetic experience of a literary work. (She argues that while others might satisfactorily summarise a newspaper article for us, they cannot summarise a poem: 'If there is indeed to be a poem and not simply literal statement,' she writes 'the reader must experience, must "live through" what is being created during the reading' (1995: 33).) Similarly, I focus here on what aesthetic experiences dementia narratives create and how those experiences pertain, in turn, to larger questions about 'quality of life' in dementia. This approach involves exploring the *ethos* or narrative ethics the novel or film projects, while emphasising that the social or ethical effect in the reader; hence the 'reconstruction' of a narrative ethics, depends primarily on the reader's interpretative stance. In other words, novels suggest certain moral attitudes or (un)ethical solutions to caregiving dilemmas. They rarely, however, offer pat solutions to the reader. Due to the complexity and ambiguity of literary works and the diversity of their readers these texts function as a moral laboratory rather than a moralistic treatise. That said, since 'the implied moral attitudes and unvoiced systems of social values are reinforced by the persuasiveness of art,' as Rosenblatt points out, the systems of beliefs and values that a text projects merit 'careful scrutiny' (Rosenblatt 1995: 8). It is here that the detailed analysis provided by literary critics (and in the case of medical education the teacher's explication) may play a particular role in exploring bioethics in and through literary fiction.

Still Alice: (Precedent) Autonomy and Suicide in Dementia

As noted in chapter 2, in *Still Alice* (2007) Lisa Genova tells the story of a Harvard professor of cognitive psychology with early-onset Alzheimer's. Perhaps unsurprisingly—given the author's background as a pharmacy

consultant with a neuroscience degree from Harvard herself—this novel largely endorses the neuroscientific understanding of dementia. Indeed, Genova's novel is aimed at supporting the Alzheimer's advocacy movement and its call for sustained research into the neuropathology of the disease. The novel does not therefore question the validity of the Alzheimer's disease category. Furthermore, in her choice of protagonist, Genova can be seen to celebrate the common 'virtues' of contemporary Western societies: autonomy, self-reliance, cognitive capacity and a strong drive to achieve. The eponymous heroine Alice identifies herself with her academic persona and struggles to find a new sense of self as her cognitive capacities slowly disintegrate. Even Alice's most intimate relationship, with her husband John, is based on her mental prowess and is therefore fundamentally threatened by the onset of the disease.

Still Alice, then, does not represent a straightforward counter-narrative to the dominant discourse of biomedicine or, indeed, to the cultural norms of hypercognitive Western societies. What it offers is a reflection on how cognitivist values play out in the life course of an individual affected by Alzheimer's disease who, in this case, virtually embodies these values. However, in its narrative logic the novel also offers a subtle critique of the value-system it endorses. The novel highlights the shortcomings of cognitive-skills-based tests to measure quality of life, and concomitantly determine the end of a 'meaningful' life. It suggests that despite cognitive impairment people with dementia have the capacity to enjoy life. By depicting Alice's development from the inside, and her changing perception of the world, the novel raises serious doubt about whether a person with dementia can adequately project herself into her future self. It thereby challenges, albeit without explicitly addressing this topic, the practical and ethical applicability of so-called 'precedent autonomy' and the use of 'living wills' or 'advance directives' to determine treatment options in case of mental incompetence.¹⁴⁶

The narrative logic of *Still Alice* is highly pertinent to bioethical discussions about end-of-life decisions. In tracking the development and

¹⁴⁶ See Davis (2009) on the problems pertaining to 'Precedent Autonomy, Advance Directives, and End-of-Life Care.'

(failed) execution of Alice's suicide plan, the novel raises complex issues surrounding suicide and euthanasia in dementia.¹⁴⁷ In particular, the novel stimulates an imaginative exploration of the question whether so-called 'advance directives' still hold in the context of neurodegenerative disease and whether they should be considered legally and morally binding. Answers to these questions frequently centre on whether a person with dementia remains the same over the course of the disease. If not, changes to the affected person raise the question whether the pre-morbid self, or 'then-self,' can legitimately make choices that affect the 'now-self' in later stages of the disease (Francis 2001). As previously noted, Ronald Dworkin (1993) has famously argued that the 'critical interests' that shaped the life-course and values of the per-morbid self take precedence over the 'experiential interests' of the person with dementia later in the disease. *Still Alice*, however, undermines this argument. Since the entire novel is focalised through Alice, the reader sees how her perception of the world changes over the course of the disease. The narrative tracks this change specifically in relation to Alice's suicide plans. Alice's previous attitude towards the value of a life with cognitive impairment is contrasted with her continuing enjoyment¹⁴⁸ in life, despite significant cognitive disability. So, for instance, the novel emphasises her continuing emotional capacity and her ability to maintain relationships with others, even when she can no longer remember the exact nature of these relationships. More importantly, the novel suggests that the criteria Alice chooses to determine whether her life is still meaningful—and whether to set in motion a suicide plan—are ill-suited to their purpose.

Immediately after receiving her diagnosis, Alice is struck by thoughts of suicide. However, she soon realises that there are still many things worth living for and that the cut-off point for a meaningful life has not yet been reached. In order to determine this cut-off point, she develops a test

¹⁴⁷ A review of the growing literature on this topic lies beyond the scope of this study. For some thought-provoking discussions see Dresser (1995), Hertogh et al. (2007) and Davis (2009).

¹⁴⁸ Simple enjoyment, together with the absence of pain, are usually classed 'welfare' interests in contrast to 'investment' interests such as personal dignity or religious commitment (Davis 2009: 350). These categories seem largely coterminous with Dworkin's distinction between 'critical' and 'experiential' interests.

involving five questions about her life. Failure to be able to answer any of the questions will set a suicide plan in motion. Her suicide plan is hatched during a moment of simple enjoyment—eating ice cream on an unexpectedly sunny spring day—and it is therefore linked to the *carpe diem* motif that runs through the entire novel. In response to her recent visit to a nursing home, Alice decides that ‘she didn’t want to be here ... when the burdens, both emotional and financial, grossly *outweighed* any *benefit* of sticking around’ (116; my emphasis). Notice how Alice’s reasoning represents a cost-benefit analysis and draws heavily on economic language. Her decision is influenced by an economic rationale, which weighs the literal ‘fortune’ of keeping her ‘alive and safe’ against the metaphorical or emotional value of her life and person (116). Alice thinks that when she can no longer recognise her husband, and is ‘in the most important ways’ no longer recognisable to him, her husband’s (financial) obligation to her should cease to exist. Or rather, her reasoning suggests that honouring this financial obligation constitutes a waste of resources. Alice clearly subscribes to a notion of love relationships as forms of exchange. The novel then exemplifies Lucy Burke’s point that the way popular discourse about love and relationships is permeated by the language (and logic) of economics has pernicious effects on care relationships:

... the idea that we must “get something back” from our love object or else move on to a more “profitable” partnership ... has significant implications for attitudes towards care and responsibility for others who are unable to reciprocate according to the logic of this “contract.” (Burke 2015: 20)

Alice envisions a future in which she will not be able to fulfil her side of the ‘contract,’ to *give* ‘something back,’ and she therefore sees no reason for her family members to be obliged to support her—emotionally or financially.

In fact, *Still Alice* might be considered ‘symptomatic’¹⁴⁹ of the trend to view caring as ‘somehow *discontinuous* with normative familial relations and ... an impediment to the flourishing of those around the person with dementia’ (Burke 2015: 25; original emphasis). As Burke points out, this view leads to caregiving itself being perceived ‘as a form of suffering but

¹⁴⁹ According to Abbott ‘symptomatic reading’ refers to the reading strategy of ‘decoding a text as symptomatic of the author’s unconscious or unacknowledged state of mind, or of unacknowledged cultural conditions’ (2008: 242).

crucially one that is often deemed to eclipse that of the disabled or ill person' (28). At this stage in the novel, Alice herself endorses such a view of caregiving as a 'burden' while devaluing the person receiving care. Over the course of her disease, however, the novel develops a different stance. Since the narrative is largely focalised through Alice, her experiences (her thoughts, feelings and responses to a situation) overshadow those of her caregivers. Importantly, as Alice slowly loses her cognitive abilities, they also seem to matter less. Instead, the narrative stresses her capacity to 'seize the day,' to enjoy whatever pleasure comes her way. Her husband John, though, continues to adhere to their previously joint value system. He seems unaware of the extent to which Alice can still enjoy her life, or what matters to her, and instead holds on to the cognitivist values according to which Alice had lived in the past. The couple clashes over the extent to which John will accommodate Alice's needs in his life, and the value accorded to each separate life course.

It is worth considering how a novel that is otherwise so consonant with dominant Western discourses on the value of human life may invite its readers to reconsider some of the implications of these values. Alice's entire self-worth is linked to her IQ. Nonetheless, when she contemplates her future she realises that the things she considers worth living for (holding her grandchild, seeing her children thrive and fall in love, spending one more sabbatical year with her husband) do not require 'intellectual brilliance' (119). Indeed, she expresses her wish for simple pleasures, such as 'more sunny, seventy-degree days and ice cream cones' (118). In view of these life priorities, the questions she generates in order to determine whether this cut-off line to a meaningful life has been crossed are relatively ill-suited. The questions rely entirely on long-term declarative memory pertaining to biographical 'facts' rather than experiences: 'What month is it? ... Where do you live? ... Where is your office? ... When is Anna's birthday? ... How many children do you have?' (119). Such facts represent major co-ordinates of one's life. Nonetheless, this information resembles semantic memory. Semantic memory tests, like the mini-mental state exam, are out of touch with the real-life concerns and important functional capacities of people with dementia. What, one may ask, does it matter whether one knows the

name of the current prime minister or president? Such questions call attention to gaps in semantic memory but do not reveal a person's continuing capacity or incapacity in other areas more (or equally) relevant to everyday life. In defence of such tests, they are not used in order to determine whether the life of the person is still worth living. In *Still Alice*, however, they are. As the novel later highlights, these questions are woefully inadequate as a means of assessing whether Alice can enjoy the presence of her grandchild or the pleasure of an ice cream.

The temporal nature of narrative, in its ability to depict change and to juxtapose contrasting scenes with each other, plays a crucial role in making the reader consider the shortcomings of cognitivist notions of personhood and to 'see things differently.' In a crucial scene, John and Alice return to their favourite ice cream parlour. While John is distressed that Alice can no longer remember what flavour ice cream she likes, Alice is seemingly indifferent to this change. She is enjoying her ice cream, the warmth of the sun and the feel of her husband's hand in hers. According to her life priorities, even at the stage of making her suicide plan, her life is still worth living. However, when John asks her a number of questions from her list, it becomes apparent that she can no longer answer them. (She does make a convincing case that knowing the location of her office is of no practical relevance to her.) It is unclear, here, whether John has discovered her suicide plan or whether he is intuitively using similar questions in order to assess her 'quality of life.' In any case, the narrative suggests that he is trying to assess whether Alice has reached a point where she no longer wants to be alive: 'Alice, do you still want to be here?' (267), he asks in a noticeably serious tone. Alice takes this question literally. However, like his question her answer takes on a double meaning: 'Yes. I like sitting here with you. And I'm not done yet' (268). Since the latter can be seen to refer to her ice cream as well as her life, Alice unwittingly answers his question with a confident 'yes.' Importantly, within the logic of the narrative in which enjoying an ice cream was made *the* criterion for assessing quality of life, this answer is doubly significant. In contrast to Alice's formerly held world-view, this scene represents a serious challenge to the notion that cognitive capacity is the be-all and end-all of human life.

I am taking some time over describing the development of this ‘suicide plot’ to suggest how readers, in the ‘living through’ of a certain aesthetic experience, may come to see things from various angles—particularly since this element of the narrative is so strikingly different in the film version of *Still Alice*. The *carpe diem* ice cream moment shared with John in the book is immediately followed by the chapter in which Alice, by chance, stumbles over her suicide instructions. Although she has serious problems carrying out the instructions, her plan ultimately fails only because the sleeping pills she relied on are no longer in their designated place. The reader is left to wonder whether John, having found her suicide plan (or simply the pills), and having no strong evidence to suggest that Alice no longer wants to live, has quietly removed the pills. In the film, this sequence of events is inverted. The failed suicide attempt comes first and blends into the scene in the ice cream parlour. Further, the emotional undertones and the atmosphere of both scenes differs significantly. In the book, the preceding scene has primed us to believe that suicide at this stage would not in fact be in her best interest. In the film, Alice finds the pills and is only prevented from taking them because her caregiver enters the house at that very moment and the sudden noise causes Alice to drop the pills [1:25:00]. There is a steady build up in tension-creating music until the moment that she finds the pills [1:24:00]. As the pills are scattered on the floor the image blends with the image of similarly fragmentary morsels of ice cream toppings. In contrast to her portrayal in the book, Alice in the film is shown clinging to John. While he does not seem fazed by her inability to remember her favourite ice cream flavour, she is uncertain and in need of emotional and physical reassurance. Alice’s confident sense of enjoyment, which predominates in the novel, is absent in the film. The setting is also markedly different. John and Alice eat their ice cream indoors, in a decidedly cold, almost clinical environment. There is no sense of warmth or enjoyment. There are no geese that prompt Alice to giggle, no pink and white blossoms spread all around.

Interestingly, in the film the ensuing conversation is less close to the questions Alice devised for her suicide plan. Instead, the conversation highlights her distance from her previous role as successful researcher and teacher. When John asks, ‘Ali do you still want to be here?’ his facial

expressions, his fixed gaze on Alice and tone of voice (as in the book) suggest the intent of this question. Here also Alice fails to understand the question. In contrast to her confident answer in the book ('Yes I like sitting here with you.'), Alice is instead perplexed by John's seemingly abrupt suggestion to leave and responds with a troubled 'I'm not done yet, do we need to go?' [1:26:15]. The camera focuses on John's face as he continues to gaze at Alice, herself intent on her ice cream. Tears well up in his eyes as he seems to realise that the moment has passed in which he might be able to have this conversation with his wife; and perhaps also that although she might not want to live anymore (as suggested by the previous scene of her failed suicide attempt) there is now no way out.

These gaps in the film, as well as the sequencing of events, are important. We do not know whether the caregiver or John discovered the pills scattered on the floor, but might presume that one of them did. What is the viewer then led to think or feel? While I cannot determine what any given viewer will feel, I believe that the film does suggest that her failed suicide attempt is 'tragic.' The film presents a much less confident view that her life is in fact still enjoyable to herself. The film also represents her physical deterioration to a much starker degree than the novel. Indeed the representation of Alice is close to that of a 'mindless zombie' as regards her shuffling walk, unfocused gaze and lack of interaction with others.¹⁵⁰ In the novel, on the contrary, Alice 'in the most important ways' (and in contrast to Alice's earlier view cognitive capacity is not paramount) is still functioning emotionally and socially and is 'still' herself—as the title of the novel suggests. She enjoys the music of a street musician, the company of her daughters (despite not knowing their names) and of her grandchildren. One might argue that the novel represents Alzheimer's in a superficial manner here. The impact of the disease goes beyond losing the names of things or people, and as accounts by caregivers suggest, such qualities as caring about children or animals might be drastically altered by dementia.

But if the novel is unrealistically hopeful, the film is perhaps stereotypically pessimistic. What is remarkable is how, despite their

¹⁵⁰ This description pertains to the penultimate scene of the film. As in the novel, the final scene by contrast highlights Alice's continuing capacity to engage with her daughter.

inclusion of similar or even identical narrative elements, these two representations differ significantly in their narrative *ethos*. Not only the sequencing of events—and the emotional reactions that the differing narrational choices elicit—but the ‘sense of an ending,’ the closure each narrative provides, may lead readers and viewers to inhabit substantially different stances towards Alzheimer’s, and the question of suicide in dementia. Both novel and film engage readers and viewers in thinking through bioethical questions by making them ‘live through’ an aesthetic experience. While the novel seems to question the predominant view that a person with dementia has the moral authority to decide her future life, or rather the end of her life, the film by contrast suggests that this moral authority extends into the future.¹⁵¹ Indeed, the film suggests that the ‘tragedy’ of Alzheimer’s lies in the affected person’s inability to assert her right to self-determination and her inability to live out her life according to previously held values. As these narratives bear out, ethics and aesthetics are inextricably intertwined and the aesthetic has a role to play in both moral and political spheres.

Have the Men Had Enough? *Gender and the Economies of Care*

Margaret Forster’s *Have the Men Had Enough?* (1989) is one of the earliest novels which focuses on a character with dementia and the problem of caring for her. The novel’s publication coincides with the rise of the Alzheimer’s disease movement and the biomedicalisation of dementia. Further, as Lucy Burke points out, it appeared during the ‘high point of Thatcherism and the particular form of individualism [Thatcher’s politics] fostered’ (Burke 2015: 37). Accordingly, Burke reads the novel as symptomatic of the effects of the biomedicalisation of dementia and of neoliberalist politics on ‘the concept of family’ and in particular ‘notions of familial obligation, personal choice, and the meaning of care’ (Burke 2015: 25). I extend Burke’s critique by focusing more squarely on the question of gender. In her aim to counter neoliberalist conceptualisations of caregiving,

¹⁵¹ Referred to as the ‘extension view’ in discussions about advance directives (see Davis 2007: 354).

Burke perhaps underplays the important contribution this novel makes to challenging pervasive gender imbalances in the context of both familial and professional caregiving (see also Kittay 1999).

Forster's novel suggests that caring for a declining family member necessarily constitutes an unbearable burden. This view is common in both fictional and non-fictional representations of dementia. The caregiving son in *Scar Tissue*, for instance, rationalises placing his mother in a nursing home by suggesting that at some point 'you have to choose between sacrificing yourself and sacrificing somebody else' (Ignatieff 1993: 97). The decision to institutionalise a family member with dementia therefore resembles an assessment of whose life matters more: the caregiver's or the life of the person with dementia. In *Have the Men Had Enough?* this value judgment is played out through the perceptions of two family caregivers: Grandma's daughter-in-law, Jenny, and Jenny's own daughter, Hannah. Their narratives provide alternating points of view on Grandma's¹⁵² increasing care needs and the relative involvement of different family members in meeting those needs. So, for instance, Hannah repeatedly questions why it is that she, but not her brother, is expected to be involved in her grandmother's care and she challenges her mother's tendency to shield the male family members, including Hannah's father, from becoming involved in 'hands-on' care (see also Burke 2015: 35). Indeed, Grandma's adult son Stuart entirely washes his hands of his mother and Jenny's husband Charlie is only persuaded to manage the financial side of his mother's care because his wife acts as his moral conscience. Significantly, although he doesn't carry the main 'burden' of caregiving, Charlie is the driving force behind his mother's temporary stay in a care home which precipitates her rapid decline, and which in turn leads to her admission into a closed psychiatric ward—represented in the novel as an abject form of purgatory. All this happens in the absence of Grandma's primary caregiver, her daughter Bridget, whose desire to care for her mother at home, but

¹⁵² The protagonist is referred to as 'Grandma' throughout by the narrators and as Mrs McKay by professional caregivers. This lack of individualisation compounds the external view on dementia in which Grandma's existence and care needs are primarily a 'problem' for the family. Although the narrators are concerned about her well-being and are frequently empathetic, Grandma's perspective is not represented—that is, Foster does not focalise events through her.

inability to do this without the support of the wider family, is represented as the main conflict within the novel. Importantly, neither Grandma's own perspective nor that of her primary caregiver is voiced directly. The quality of Grandma's life and the value of caregiving are all viewed from the daughter-in-law's and granddaughter's point of view.

The novel confronts the questions of Who should care? How and how long should we care? And, to a lesser degree, Why should we care for people with dementia? With regard to the first question, Hannah's thoughts about the value of life in dementia are couched, from the start, within a discussion of gender roles in relation to caregiving. Forster's novel is not alone in mirroring, and arguably compounding, widespread views (and anxieties) about male caregiving. The husband in *Still Alice* essentially abandons his wife to the care of his daughters. In the film version of *Still Alice*, he somewhat ironically comments on his guilt at leaving his wife by telling his daughter, 'You are a better man than I am' [1:27:48]. In *Scar Tissue* the son's devotion to his mother unravels his own life, suggesting that a male caregiver cannot retain a sense of self. In contrast, in *The Story of Forgetting* (Block 2008) neither the narrator-son nor his father seem to visit the mother much after admission into a home. In Andrés Barba's *Ahora Toca Música de Baile* (2004) the adult son nearly beats his dementing mother to death, and shortly afterwards causes her to get run over by a car (see Zimmermann 2010). And in Franzen's dystopian analysis of 21st century American family life *The Corrections* (2001), it is the oldest son who pressurises his mother to contemplate admission into a nursing home. The only daughter in the family, in contrast, briefly figures as a potential primary caregiver. That she does not in fact have to take on this role is depicted as a narrow escape from the supposed drudgery and deadening burden of caregiving.

What do these novels then suggest about who should care? And do they not enforce stereotypes about uncaring males and dutiful daughters and wives? Forster's novel challenges the fact that women are expected to and continue to undertake the largest bulk of 'hands-on' care work. That said, nowadays, male family caregivers are no longer as unusual as they once were (Russell 2001). Cultural gender stereotypes, as Russell argues,

frequently make male care work doubly invisible within society. Literary representations, such as those discussed here, may then compound the view of caring as ‘naturally’ female activity and act out societal anxieties and gender stereotypes about ‘uncaring’ males, even as they challenge the unjust distribution of care work.

Forster’s novel also addresses the question of how, and how long, one should care for people with dementia. It explores what different characters consider the ‘cut-off line’ at which home care should end, or, to paraphrase *Still Alice*, the point at which the burdens, both emotional and financial, outweigh the benefits (for Grandma and others) of keeping Grandma at home—or, indeed, alive. At the outset of the novel Grandma is mildly confused, but still a largely functioning and contented person. The novel then follows a tragic downward spiral as Grandma’s dementia rapidly progresses and all the precarious and temporary caregiving arrangements fall apart. Her daughter-in law Jenny is significantly involved in managing Grandma’s day-to-day care. Unlike Bridget, she is not motivated as much by love as by a sense of duty. Nonetheless, she experiences satisfaction and even pride in looking after her mother-in-law, and she clearly voices an ethics of home-care. In a sense, Jenny also sees herself as repaying her mother-in-law for the debt of bringing up children, Jenny’s husband among them, and she tries to compensate for her mother-in-law’s hard life out of a sense of female solidarity. Jenny realises that institutionalising Grandma would deprive her of all the loving attention and ‘all that was meaningful’ to her, and she is therefore racked by guilt at the prospect: ‘How can we ‘put her away’, as she would call it? *How can we?*’ (125; emphasis original). When her husband states that he has ‘had enough’, it is her scruples that prevent him, at least for a while, from placing Grandma in institutional care.

Despite Jenny’s conviction that nursing home care would speed up her mother-in-law’s decline, the latter’s increasing care needs eventually cause a ‘care crisis’ in the family. The novel depicts Jenny’s growing stress and emotional anxiety, and to a lesser extent her daughter’s. Hannah’s narrative, since she is at one remove from the responsibility of caring, represents a more detached and at times critical perspective on the family’s views and actions. She also challenges the hypocrisy inherent in an idealised ethics of

home care, including her own. In these cases, and others, Hannah succinctly pinpoints in lists of (rhetorical) questions the problems and dilemmas that dementia raises. Early in the narrative, Hannah begins to contemplate the question of suicide and euthanasia in dementia:

What I want to know is:
Why don't more old people kill themselves when they get old?
Why do relatives not kill old people more?
What is the point of keeping old people alive anyway?
Haven't the women had enough, as well as the men? (13-14)

Since the questions are left unanswered it is up to readers to develop a response based on the events in the storyworld as well their own life experiences and convictions. While some readers might be categorically against suicide, or euthanasia, others may find themselves contemplating these questions, perhaps for the first time. It is significant that these questions are raised immediately after Hannah's benign description of Sunday lunch dinner, which highlights the many aspects of life that Grandma still enjoys. At this stage, Hannah's provocative questions seem premature. Or rather, the contrast between Grandma's apparent sense of enjoyment and the callous suggestion to murder family members based only on their advanced age provokes a sense of outrage. Nevertheless, derogatory views of old age predominate in contemporary Western societies, and readers may perhaps find that their views chime with Hannah's at times. The expression of such stark views then confronts readers with their own attitudes and may lead them to ask: Do I share this evaluation of old age? Is euthanasia, assisted suicide or murder an acceptable moral stance towards vulnerable dependents? On reflection, is seeing life with dementia as valueless the only way to look at things? The novel sets up such bioethical thought processes by drawing readers into the complexity of caregiving, as evoked by the storyworld, and by contrasting different, at times shocking points of view.

Indeed, the question of euthanasia represents one of the main themes of the narrative and is reframed in the context of Grandma's continuing decline and the increasing pressure this puts on the family. As Nussbaum states,

the novel ... is a morally controversial form, expressing in its very shape and style, in its modes of interaction with its readers, a normative sense of life. It tells its readers to notice this and not this, to be active in these and

not other ways. It leads them into certain postures of the mind and heart and not others. (Nussbaum 1995: 2)

Here, the reader is invited to see the question of care from the point of view of two female family caregivers of different generations. We are asked to note the seeming impossibility of providing home care throughout dementia. Furthermore, Hannah consistently challenges the ethics of caregiving as a natural female duty—a point I elaborate on below. While calling for female empowerment, Hannah also, however, represents the form of consumer-orientated individualism that, according to Burke, neoliberalist economies foster. Indeed, in line with Burke's recognition that care-relationships are imbued with economic rationalising, the value of the person with dementia, as weighed against the 'costs' of caregiving for family members, is what is at issue in this novel.

Hannah eventually draws up such a cost-benefit analysis in order to assess Grandma's quality of life-and concomitantly the question of whether one should end her life. She enumerates the pains and pleasures in her grandmother's life while weighing them against each other and the 'damage' to other people's life (emotional, financial and other) (144-5). Only as an afterthought does it occur to Hannah to detail what Grandma 'returns for what she gets' (146), a revealing list in itself. Entirely within this economic logic, Grandma's daughter Bridget then emerges as the person who both gives and receives most from her mother and who, subsequently, is the most invested in keeping her alive ('*Who gives most to Grandma? Bridget. Who gets most from Grandma? Bridget. Who would never, ever kill Grandma? Bridget*' (146)). Importantly, Bridget is also the one character who resists seeing her mother as a financial and emotional pit. When Grandma finally dies, offering an end—if not a constructive 'solution'—to the family's care crisis, Bridget is the only family member to truly mourn her. To Jenny, and a certain extent her daughter, Grandma's death represents a release from the anxiety and responsibility of caregiving. Indeed, by withholding the severity of Grandma's condition from her sister-in-law, who 'would have had her pumped full with antibiotics' rather than letting nature 'take its course,' Jenny can be seen to be part-responsible for her mother-in-law's death (234). Accordingly, she wants her sister-in-law to experience her mother's demise

as release too, to reap some gain from her passing. Bridget, however, staunchly refuses: ‘no, no gain,’ she asserts ‘only loss’ (249).

The novel closes with Hannah’s thoughts about her own and her family’s reaction to her grandmother’s death. If she feels irked by her mother’s expression of relief and even happiness, she nevertheless expresses an equal relief that, now, with no ‘old person in our family ... There’s no more of that hideous disintegration to watch’ (251). A significant part of her narrative indirectly quotes her mother’s complex reaction to the ethical issues raised by Grandma’s death. If Jenny felt called to look after her mother-in-law out of a sense of familial obligation, her sense of moral duty does not extend to those outside the family circle. Or rather, her guilt at ignoring the needs of others testifies that she may feel a moral duty but does not act on it:

Mum says ... that she feels lucky and glad and relieved now Grandma is dead. But she says she also feels a coward too because now Grandma is dead she can ignore the problem of all the other Grandmas and she shouldn’t, she should be inspired to do something and she knows she isn’t going to. She is going to dodge the issue now. ... She isn’t an activist and she can’t help it. But somebody, somewhere, will have to do something soon. They’ll have to. (250)

If this passage evokes the urgent need to address the challenges that dementia raises, it is also significant—and depressing—that the solution Jenny suggests is to embrace the practice of euthanasia: ‘We’ve tinkered around enough with the start of life, we’ve interfered with all kinds of natural sequences, and now we’ll have to tinker with the end. Mum says, “Your generation, Hannah, will have to have pro-death marches, you’ll have to stop being scared to kill the old.” Will we?’ (250). Note that, as usual, Hannah challenges her mother’s view. The two words ‘Will we?’ open up the question of whether this approach is ethical and whether there may not be other, better solutions. Nonetheless, Hannah does not develop any in the remaining space of her narrative. The novel’s close centres on the desirability of terminating one’s life rather than experiencing the ‘hideous disintegration’ dementia entails—while underscoring the seeming impossibility of such self-determination in dementia:

When my time comes I’m not going to allow it.

When my time comes I won't trust to mystery.
When my time comes I will say I have had enough and go.
That is, if my time comes like Grandma's time, if it is the same sort of time.
But if it is, I won't be able to, will I? (251)

The novel then returns us to the difficulty of developing and executing a suicide plan in dementia, as explored in *Still Alice*. However, within the ethics and logic of *Have the Men Had Enough?* the impossibility of self-determination and individual agency is clearly considered tragic.¹⁵³ Burke argues that the closure the novel provides through Grandma's death 'simply removes the origin of the problem' but does not 'provide any kind of imaginary resolution' (2015: 39). In her view, 'the novel cannot move beyond the cognitive/cultural limits of the model of aging, dependency, and dementia that it – at times – appears to critique' (39). No doubt, the novel does not represent a straightforward counter-narrative to the dominant conceptualisation of dementia. However, I wonder whether the novel is indeed stuck within its own paradigm. It clearly offers material for a symptomatic reading of the neo-liberalist and cognitivist tendencies of its time. As Hannah's disgust at her grandmother's decline or Jenny's dehumanising discourse in relation to the dementia patients in the psychiatric ward highlight (see also Burke 2015: 36), the narrative is suffused with dehumanising tropes of dementia and a valorisation, primarily, of the lives of cognitively functioning individuals. And yet, it is an interesting question whether Forster, or if one prefers, the implied author, here or elsewhere, consistently endorses Jenny's or Hannah's views. Within the novel, Hannah's narrative already acts as a counter-discourse to the narrative her mother tells (and wants to tell) about Grandma's decline and death. But her own view is not left unchallenged either. Indeed, as I suggested above, by making Hannah express at times drastic and disturbing attitudes towards dementia, (and contrasting these with the quality of life that her grandmother actually seems to experience at different stages), Forster may be deliberately confronting and destabilising her readers' received attitudes. As Nussbaum puts it,

¹⁵³ Hartung (2016: 202-3) reads this novel as promoting euthanasia. However, rather than advocating such a practice, the novel plays out conflicting points of views against each other in such a way as to challenge the reader to contemplate the problem of euthanasia.

good literature is disturbing in a way that history and social science writing frequently are not. Because it summons powerful emotions, it disconcerts and puzzles. It inspires distrust of conventional pieties and exacts a frequently painful confrontation with one's own thoughts and intentions. ... Literary works [require] us to see and to respond to many things difficult to confront—and they make this process palatable by giving us pleasure in the very act of confrontation. (Nussbaum 1995: 5-6)

If the use of multiple first-person narrative perspectives 'is indicative of a loss of shared values' (Burke 2015: 38), the use of differing narrators can also be considered one of the advantages of this particular novel. It multiplies opportunities for inspiring 'distrust in conventional pieties,' in Nussbaum's words.

The comments on the dust-jacket of the novel suggest that it is 'not a comfortable novel, but a mighty powerful one.' Or, as another reviewer puts it, the novel 'ends as it begins, with questions ... that spill out over the covers.' Rather than expressing a stable, shared belief system, this novel, like Johnson's, represents a multiplicity of discourses, and allows the reader to linger over uncomfortable questions. It offers a 'pedagogy of discomfort' without offering pat solutions to these difficult questions (Wear and Aultman 2005: 1056, qtd. in Jones 2014: 36). But if the novel is powerful, then in what way? Of what is it trying to persuade the reader? Due to the complexity of the two narrative perspectives, which in themselves incorporate a number of inconsistencies, there may be no simple answer to this question. But the text does highlight the pressing need to address dementia care, voicing this need from a distinctly feminist perspective. While the commercialisation of care is certainly regrettable, the continuing pressure on women to provide care—to the detriment of their own health and well-being and with little appreciation and insufficient remuneration—urgently needs to be addressed.

Conclusion

In this chapter, I have shown how fiction may both counter and conform to dominant discourses about dementia care, how fiction may disturb its readers without this disturbance necessarily acting as a moral good, and how fiction may act as a moral laboratory to assess questions of end-of-life care

in dementia. In situating my discussion of dementia fiction within the debate about the role of medical humanities research in health care practices, I am not proposing that such an approach to narrative supersedes current ones nor that it offers an exhaustive account of the complex interaction between illness narratives, biomedical and popular culture, and the well-being of individuals and communities. Instead, I have aimed to outline, in an exploratory fashion, some ways narratives may work on readers and may thereby contribute to the debate and delivery of dementia care. My aim was to extend the scope of literary reading from the locus of medical training, where Charon (2006) and others situate narrative medicine, to include a wider spectrum of readers. Further, I argue that the discussion of the effects of literary reading in medical humanities should go beyond the question of whether fiction induces empathy. Fiction may act as a source of (elusive) knowledge (Felski 2008, Nussbaum 1990, Wood 2005), as a means of experiential learning and quasi-Socratic thinking about how to live life (Nussbaum 1995, 1990), and as a challenge to dominant discourses. Through the processes of metaphor, mimesis and narrative rhetoric fiction may further engender in its readers new ways of seeing, understanding, and enacting care (Charon 2006).

Stories act as a space to approach and ‘live through’ (Rosenblatt 1995) certain dilemmas without having to take action oneself. Indeed, the counterfactual nature of these scenarios allows novels to probe the boundaries and limits of contemporary understandings of dementia or to follow certain conceptualisations of what it means to be human to their logical conclusion. In accepting reductionist conceptualisations of personhood, rather than necessarily challenging them, these fictions may confront readers with their own implicit views, and raise, as Anne Whitehead puts it, ‘uncomfortable questions’ (Whitehead 2011: 58). I suggest that, in line with Whitehead’s argument, rather than solving or resolving these ethical dilemmas for the reader, the particular value of certain literary representations of dementia may lie in their ability to ‘open up, *and to hold open*, central ethical questions of responsiveness, interpretation, responsibility, complicity and care’ (59; original emphasis). Indeed, the value of much contemporary literature resides in the way it

provides a space for the reader to *be with* uncomfortable questions. Both the process of identification with the non-demented others in fictional worlds (usually the family caregiver) and the process of ‘empathic unsettlement’ (LaCapra 2001: 41-42, qtd. in Whitehead 2011: 58) with regard to the character *with* dementia play out in the reader’s appreciation, understanding and response to the bioethical dilemmas of end-of-life dementia care.

Since these difficult questions are aesthetically mediated, novels have the potential to focus their readers’ attention on issues that they might otherwise be inclined to avoid. While most people do not seek out first-hand accounts about dementia care, dementia films and fiction reach wide audiences. It may be that literary fiction is less likely to cause ‘empathic distress’ in its readers (Keen 2007) than newspaper reports—which, in turn, might lead to a turning away from the issue at hand. The aesthetic mediation of counterfactual scenarios—that we nevertheless bring to bear on our own lives—may then confront us with ethical dilemmas we otherwise tend to ignore until acutely faced with a similar problem. Reading fiction, in its capacity to both ‘delight and instruct,’ to subvert and challenge, to simulate and evoke feelings, to draw in as well as shock, has the potential to make readers care: about fictional worlds, about questions of how we live and die, and about what it means to be human.

Bioethical decision-making concerning end-of-life treatment in dementia cannot be replaced by reading fictional narratives in which similar scenarios play out, in part because these narratives themselves develop an *ethos* that may be opposed to ethical action in the real-world. However, reading such narratives stimulates and simulates bioethical thinking. By emotionally engaging readers, these narratives may move readers to consider previously unthinkable responses and solutions. The counterfactual scenarios may help expand the categories used for bioethical decision-making, and provide a kind of training field or moral laboratory for contemplating the diverse situational, personal, emotional and financial aspects involved in making difficult care decisions. These narratives do not necessarily present ‘ideal’ solutions. Indeed, they may employ narrative rhetoric and dehumanising imagery to condone practices of euthanasia or indeed manslaughter of family members with advance dementia (see

Zimmermann 2010). As Burke suggests vis-à-vis *Have the Men Had Enough?* and as I have indicated in my reading of *Still Alice*, these narratives may be trapped within the predominant logic of neoliberal and also cognitivist notions of the value of human life, promoting ways of thinking about vulnerability and interdependency that may in effect be counter to a responsive and responsible ethics of care which acknowledges the interdependency of human life. If such narratives are therefore to be used as tools within an ethically driven medical humanities agenda, they must themselves be opened up to ethical scrutiny through critical reading strategies.

How do these arguments relate, then, to broader medical humanities agendas and the role of literary critics within them? Theresa Jones argues that much like fiction, the humanities help us see things differently by ‘representing, re-describing and re-contextualizing’ (Jones 2014: 28). Jones, furthermore, points out how the humanities are frequently viewed as a ‘democratizing force’ and a means of challenging the status quo of biomedical practices (28). The traditional mode of ‘critique’ in the humanities is crucial here. I have suggested that while aspects of some fictional accounts act as forms of critique of current dementia care practices, careful literary analysis cautions us against assuming any unilateral democratising or ethical effect of literary fiction. It is here that I locate the need for literary scholars and narrative theorists to engage in debates about the role of narrative in the medical or health humanities. Literary scholars can offer a more complex account of how narratives work on their readers. And more generally, the tools of literary and cultural criticism can help train readers to become critical ‘readers’ or interpreters of culture and cultural productions in their own right. Further, these same modes of critical thinking can be turned on the humanities’ own modes and techniques of producing knowledge. If good fiction ‘opens up and keeps open’ difficult questions about our responsibility to others, then critical thinking about fiction can extend that process of coduction between text and reader to engage wider audiences in a debate about the value of life, end-of-life care practices and how we produce knowledge and protocols in these areas.

A number of problems nevertheless arise in the context of considering literary fiction and literary criticism in the context of the health humanities. For instance, Michael Wood suggests that if we consider critique of hard science the only role of literary critics (a bit like the opposition in politics), then we are selling short what literary critics do, as well as the value of the ‘knowledge’ or ‘understanding’ produced via the study of literary texts (Wood 2005). I have suggested instead that literary analysis offers tools to read fictional narratives, films, and other forms of cultural expression critically for the effects they may have on their readers. Yet even in Wood’s account of scholarly knowledge, ‘understanding’ remains problematically linked to the individual reader or interpreter. How can this understanding be communicable or relevant to others? Perhaps the product of careful literary analysis may communicate understanding between readers. Scholarly publications and conferences in themselves function as forms of coduction, extending beyond the context of medical humanities teaching. However, the crucial question remains how insights from medical humanities research of all kinds, whether literary, anthropological, or other, may be communicated to the relevant actors in health care. Just as doctors may not have the time or inclination to read cutting-edge medical humanities publications, so policy makers, bioethicists or care home designers are unlikely to turn to recent outputs of such journals as *Literature and Medicine* to inform their policies, planning or decision-making.

Guillory warns against exaggerated expectations about the effects of critical ethical readings in the ‘real world.’ In a similar vein, I suggest that further thinking is necessary to translate insights from literary health humanities into policy and practice. Public engagement, reading groups, and consultancy work may offer the beginnings of an attempt to make the reading of dementia narratives relevant to future dementia care. At the very least, I hope to have widened the scope of critical reading of fiction in the medical humanities in emphasising literary criticism’s ability to make us reflect on the social climate we live in, reconsider the modes of knowledge production we use to justify certain treatment measures, and challenge the structures of desire that are aroused by representing dementia as the ultimate tragedy, shattering not only projects of self-fulfilment but ‘the self’ as such.

Conclusion and Outlook

In this thesis, my goal has been to show how both narrative and narrative studies are relevant to the exploration of the phenomenology of dementia, to reconsidering the question of selfhood in dementia, and to the development of dementia care. I have delineated the potential and limitations of narrative, and narrative identity, in relation to challenging the current dementia construct and developing new ways of seeing, acting towards and caring for people with dementia. I contend that narrative remains both a crucial sense-making device and significant form of representation relevant to medical humanities research and health care practices. At the same time, I have aimed to contextualise and correct unilateral arguments about the use of ‘narrative’ in the medical humanities by paying close attention to how different modes, media and genres inflect the various functions narrative may play in the context of dementia studies and dementia care.

Chapter 1 aimed to redress the lack of (critical) attention that has been given to dementia sufferers by exploring, in the spirit of first-wave medical humanities, the potential of illness narratives to contribute to a better, that is more intersubjectively grounded and less medicalised, understanding of the experience of living with dementia. At the same time, by including documentary film from the point of view of the caregiver, I highlighted the importance of attending to embodied selfhood and embodied communication in dementia, in order to refute the claim that people with dementia ‘lose their self’ or can—when they lose the ability to use language coherently—no longer communicate their subjective experience.

Chapter 2 continued the theme of exploring the phenomenology of dementia, in this case not through personal narratives but through imaginative literature—that is, dementia stories presented in novels and films. I argued that fictional dementia narratives act as a ‘practical counterpart of theoretical phenomenology’ (Waugh 2013: 24), while challenging the notion that empathetic engagement with fictional characters necessarily leads to pro-social action on behalf of real-life others with dementia. Through close analysis of a range of fictional dementia narratives, I aimed to provide a more nuanced account of how different local narrative

modes (perspective and focalisation), different media (text and film), and different styles or genres (from realist to experimental novel) elicit various forms of narrative empathy, sympathy or parallel experience (Toker 1993). Further I suggested that a more fine-grained account of how narrative empathy works and a more critical analysis of the empathy-altruism hypothesis (Keen 2007) bear importantly on current debates about the value and function of empathy in medical humanities research and education.

In the second part of the thesis, I turned from the exploration of the phenomenology of dementia to questions of self-presentation and representation. By exploring the emergent genre of collaborative life writing and the flourishing genre of caregivers' memoirs, I aimed to bring to the fore a body of work that has not yet received sufficient critical attention. In chapter 3, by scrutinising the effects of genre conventions on the reading of autopathographies, I challenged the notion that illness narratives act in a straightforward manner as counter-narratives. Not only are masterplots and counter-narratives inevitably entangled in each other, but the strategy of counter-narratives to present a *counter-image* to the one they aim to deconstruct turns out to be problematic in the context of dementia advocacy. Autopathographies that present coherent, autonomous and able-minded selves—in order to challenge the view that people with dementia lose their self or no longer matter—compound the dehumanisation of people with dementia in later stages of the disease. Much like recent directives in the medical profession to speak of 'pregnant people' rather than pregnant women risk—in the name of political correctness—eliding the actual health concerns specific to the female sex, so reconceiving of people with dementia as more 'able-minded' than they are risks denying their progressive dependency and ignoring their actual care needs.

If autopathographies partially fail as counter-narratives in dementia, collaborative life writing may represent a genre of dementia life writing that speaks to the intersubjective nature of identity. Attending to dementia life writing allowed me to interrogate both the usefulness and the limits of narrative identity thesis for people with dementia. Drawing on conversational storytelling research, I showed how people with dementia continue to use narrative to construct identity, while arguing also that such

narrative acts present a call on able-minded listeners (and readers) to be active participants in the co-construction of identity for people with dementia. Reflecting on my own research agenda in this context led me to acknowledge the role of the researcher in assessing counter-narratives in dementia and to question the standards, methods and underlying emotional needs that may have influenced my response and evaluation of current dementia life writing as successful (or unsuccessful) acts of claiming identity and countering the dominant construct of dementia.

Chapter 4 then continued to explore the role of narrative identity in the context of caregivers' memoirs. Here the ethical problems attendant on representing 'vulnerable subjects' (Couser 2004) came to the fore. By first outlining a number of subgenres of caregivers' memoirs, I explored the interrelation of the aesthetic, ethical and political in the context of dementia life writing as well as some of the functions of intimate life writing about a dying parent or spouse. Through close analysis of a range of filial dementia memoirs, I then tackled the question of how relational identity plays out in caregivers' memoirs about a parent with dementia. By contrasting autobiographical essay, fully-fledged memoir and graphic memoir by male and female writers, I focused attention on the potential effects of both genre, medium and gender on our understanding of relational identity. Further, relational identity emerged as both a reparative force in dementia (a means of holding or reconstructing the identity of the person with dementia for them), as well as having nefarious effects (by erasing the subjectivity of the person with dementia, by affecting negatively the identity of the caregiver, or by leading to excess guilt and grief in caregivers who struggle to reconcile historical roles and relations with the changes wrought in the family member due to dementia). Relational identity in these memoirs, however, also emerged as a productive approach to people with dementia when it constituted not so much a re-construction of former identity as a site or opportunity for the person with dementia to assert her current identity and have it recognised by another with whom they are in an on-going relationship.

Finally, although this issue surfaced in preceding discussions, the last part of this study addressed more squarely the role of literature and life

writing in challenging, developing and delivering dementia care. Because of the way that dementia, as Aaron Alterra puts it in his caregiver's memoir, is not usually a 'doctor-intensive disease' (1999: 49) but one where due to limited treatment options and the nature of physiological decline a whole roster of caregivers become heavily involved, dementia narratives speak to current and potential future caregivers. Indeed, they speak to anyone who may one day be afflicted by the disease. Dementia narratives may moreover be valuable to a host of people involved in planning, facilitating, reviewing, and delivering dementia care. An imaginative engagement with the life world of dementia is therefore relevant to politicians, policy makers, care home managers and designers, occupational therapists, and advocacy groups, as well as those providing day-to-day care in the community and institutions. Chapter 5 explored how caregivers' memoirs across a range of storytelling media and modes (from graphic memoir to you-narrative) may contribute to the revision and development of dementia care. Chapter 6, by contrast, suggested some ways in which contemporary fiction may contribute to ongoing debates about dementia care by exploring the interrelation between bioethics and fictional narrative.

As is apparent from this summary, my thesis shares links both to first-wave medical humanities methods and agendas as well as to recent developments in second-wave or critical medical humanities. Exploring the phenomenology of dementia through illness narratives represents a continuation of the aim to make the patient's voice heard. Given the dearth of first-person accounts of dementia, by comparison with outside representations of the disease, I felt compelled to include and re-represent what first-hand accounts are currently available. Further, although the training of health care professionals has not been the focus of this thesis, reading dementia narratives may be beneficial to health care practitioners and their patients. A sustained engagement with the life world of a person with dementia may provide a more holistic view of the patient and her situation and may open up alternative therapeutic possibilities—beyond the limited scope of currently available drug treatments (see also Greenhalgh and Hurwitz 1999: 48). Dementia narratives may contribute, together with other social forces, to a growing awareness of dementia, especially of the

prevalence of early-onset Alzheimer's, which in turn may speed up what is still often a circuitous and drawn-out process of (mis)diagnosis. Narratives that place persons with dementia centre stage, focusing on their intimate experiences of the disease as well their continuing selfhood, may act as a reminder to take the person with dementia seriously—to meet her with respect and include her in the clinical encounter. However, such an effect cannot be predicted for an engagement with any given dementia narrative, nor can it be measured quantitatively. As reader-response criticism highlights, narrative texts offer particular opportunities of engagement for the reader, but each individual 'flesh-and-blood' reader will nonetheless respond differently to these opportunities, based on his or her psychological make-up, social characteristics, and place in time.

In line, also, with first-wave medical humanities concerns, my discussion of illness narratives represents, to a certain extent, a criticism of the neurological approach to dementia and of current medical and care practices. And yet, the intent of this study has not been primarily to write against biomedicine, but to explore avenues of understanding dementia which complement forms of biomedical practice that have, as yet, little to offer to people with dementia and their caregivers. While the notion of criticising biomedicine prevails in mainstream medical humanities, my thesis also activates the notion of the critical and of 'critique' in other ways. I purport a critical need to 1) re-assess the current masterplot of dementia and the way master and counter-narratives are entangled; 2) to recognise personhood in people with dementia in its numerous instantiations (embodied, relational, narrative); and 3) to explore through critical analysis the limits and possibilities of the implications of these different views of selfhood for people with dementia. In addition, if a central element of the 'critical humanities' has been the turn away from the 'primal scene' of doctor-patient encounters to 'new scenes and sites' (Whitehead and Woods 2016: 2), I have extended the scope of the medical humanities, by turning to literary narratives and the public spheres of care—an area that has become increasingly professionalised, but remains enmeshed with private life.

Taking my lead from Keen (2007), I have moreover questioned the notion that empathy leads to pro-social action as well as the notion that

literature is necessarily a good in itself, or acts for ‘the good’ when harnessed to a medical humanities agenda. Among other problems, empathy expended on fictional characters may divert our attention from the needs of real-life others (Keen 2007). Indeed, while narrative empathy has been heralded as a means to extend the moral circle’ to include ‘other clans, other tribes, and other races’ such that their humanity can be acknowledged (Pinker 2004: 48, qtd. in Keen 2007: xix), Keen suggests that empathy might equally lead to the incitement of hatred. For example, the empathy aroused for a character with whom the reader identifies, and who has been harmed by a character who is perceived not to belong to the reader’s ‘in-group,’ may incite that reader to a hateful attitude vis-à-vis the target group in question. Given these problems, I proposed to shift the focus beyond empathy to other ways in which fictional texts may act in the field of the health humanities. I suggested how literature, and literary critics, may contribute to the thinking through of current dementia care. At the same time, I stressed the need to investigate whether the arts and humanities are necessarily ‘supportive’ of a humanist agenda or ‘benign’ in the first place (Whitehead and Woods 2016: 2). Instead, I suggested that fictional and non-fictional narratives shape the way we live in a manner that may at times also be detrimental to individuals or groups within society. Narrativist approaches to medical humanities need to be developed and refined by using the tools of narrative studies and by paying attention to the ways different storytelling environments shape how we come to see and understand things—and ultimately act in the world.

Finally, my work also activates a crucial meaning of the word ‘critical’ as it pertains to the notion of urgency or ‘critical mass’ (Whitehead and Woods 2016: 14). Given current demographic and political developments, we urgently need to address the ways we, as society, want to lead and end our lives. Dementia care, in the community and in institutions, represents a topic currently under-represented in medical humanities research, perhaps because nursing constitutes a separate field. I would venture to maintain that this established discipline could benefit from some of the critical (re)thinking that animates the medical humanities, and in this study I have

outlined some practical ways in which my own literary strand of medical humanities research might contribute to the development of dementia care.

Work in the field of literary approaches to dementia is just beginning, however. The continuing influx of dementia narratives opens up ever new sites of inquiry that raise questions of the sort addressed in this thesis—questions that might be approached through the approach (or approaches) that I have sketched here. Nor does this study represent an exhaustive account of already extant dementia narratives, some of which might suggest both different questions and different preliminary answers to those proposed in my account. What is more, I acknowledge that many of the questions raised in this thesis may also be broached through creative forms of expression other than narrative.

Thus dementia poetry, written by affected family members, professional carers and by people with dementia (see, for instance McNamara, no date),¹⁵⁴ still needs to be explored in detail. A number of relevant questions arise in this context: how do collaborative poetry projects, such as John Killick's (Killick 1997, 2008, 2010, Killick and Cordonnier 2000) differ from collaborative life writing projects, as discussed in this thesis? Compared with life writing, does poetry open up other, less linear, more metaphoric, means of representing the phenomenology of dementia (see also Aadlandsvik 2008) or co-constructing selfhood? What are the ethical implications of refashioning the words of people with dementia into poetry? And does the figurative and often enigmatic language and structure of poetry enhance or deter the reader's engagement with the subjectivity of people with dementia? Also, what potential is there for poetry interventions in dementia care (Petrescu, MacFarlane, and Ranzijn 2014, Swinnen 2016) as compared, for instance, with storytelling interventions (Basting 2001, 2003b) or interventions that draw on the visual arts (see, among others Huebner 2011) or music (Cheong et al. 2015, Liesk, Hartogh, and Kalbe 2015, Raglio et al. 2015, Samson et al. 2015, Unadkat, Camic, and Vella-Burrows 2016)? In short, there is a need to explore more thoroughly how

¹⁵⁴ See also the blog <http://alzpoetry.blogspot.co.uk/>.

aesthetic experience and practice actively enhance the well-being of people with dementia and their caregivers.

Conversely, one might ask how dementia itself acts as a metaphor or narrative device in literary and popular genres. In a previous study, I discussed how dementia may function as a narrative plot device (Bitenc 2011). Wendy Roy elaborates to what extent dementia in novels acts as ‘narrative prosthesis,’ that is, how disability functions either as ‘a stock feature of characterization’ or as ‘an opportunistic metaphorical device’ (Mitchell and Snyder 2001: 47, qtd. in Roy 2009: 44). Hannah Zeilig (2013), similarly focuses on how dementia functions as a metaphor in poetry, plays and film in order to reflect on and criticise aspects of contemporary life. Exploring the function of dementia in literary works and the visual arts is worth analysing in its own right—and might feed back into discussions about the current conceptualisation of dementia.

Drama and opera—narrative genres not explored in this thesis—raise new aesthetic questions due to their multimodal and performative aspects. Moreover, they may open up the possibility of more interdisciplinary and ‘participatory’ research methods. For instance, the performance of dementia plays could be paired with pre- and post-performance questionnaires, post-performance discussions, lectures, or any number of public engagement activities. Integrating social science research methods with a literary approach to dementia studies could yield more diverse and empirically sound results on the interaction, for instance, between aesthetic experience and ethical reflection. Such an approach could also be developed vis-à-vis reading groups with people with dementia and their caregivers, and by taking one’s cue from the participants in these groups, literary dementia scholars might unearth altogether new research questions in relation to dementia.

Finally, I hope to have outlined a framework for a narrativist approach to issues in the health humanities which might be adapted to other contexts and contents. Questions of identity and the problems of care arise in the context of any serious illness. I suggest that these issues might be approached through a literary medical humanities methodology. Simultaneously, a critical literary medical humanities delineates not only the

potential but also the limitations of literature in the context of an ethically driven medical humanities agenda.

Bibliography

- Aadlandsvik, Ragna. 2008. 'The Second Sight: Learning About and With Dementia by Means of Poetry.' *Dementia* 7 (3): 321-339.
- Abbott, H. Porter. 2008. *The Cambridge Introduction to Narrative*. Cambridge: Cambridge University Press.
- Akpınar, B., Ö. Küçükgülü, and G. Yener. 2011. 'Effects of Gender on Burden Among Caregivers of Alzheimer's Patients.' *Journal of Nursing Scholarship* 43: 248-254.
- Alber, Jan. 2013. 'Unnatural Spaces and Narrative Worlds.' In *A Poetics of Unnatural Narrative*, edited by Jan Alber, Henrik Skov Nielsen and Brian Richardson, 45-66. Columbus: Ohio State University Press.
- . 2014. 'Unnatural Narrative.' In *The Living Handbook of Narratology*, edited by Peter Hühn, John Pier, Wolf Schmid and Jörg Schönert. Hamburg: Hamburg University Press. <http://www.lhn.uni-hamburg.de/article/unnatural-narrative>. [last accessed: 22/03/2016]
- Albert, Trevor, and James Keach. 2014. *Glen Campbell: I'll Be Me*. PCH Films.
- Alterra, Aaron. 1999. *The Caregiver: A Life with Alzheimer's*. South Royalton: Steerforth Press.
- Alzheimer's Disease International. 2009. *World Alzheimer Report 2009*. Alzheimer's Disease International.
- . 2010. *World Alzheimer Report 2010: The Global Economic Impact of Dementia*. Alzheimer's Disease International.
- Appignanesi, Lisa. 1999. *Losing the Dead*. London: Chatto & Windus.
- Aquilina, Carmelo, and Julian C. Hughes. 2006. 'The Return of the Living Dead: Agency Lost and Found?' In *Dementia: Mind, Meaning and the Person*, edited by Julian C. Hughes, Stephen J. Louw and Steven R. Sabat, 143-161. Oxford: Oxford University Press.
- Arana, R. Victoria. 2003. 'Michael Ignatieff.' In *Dictionary of Literary Biography: Twenty-First-Century British and Irish Novelists*, edited by Michael R. Molino, 148-156. Detroit: Thomson Gale.

- Asai, Atsushi, Y. Sato, and M. Fukuyama. 2009. 'An Ethical and Social Examination of Dementia as Depicted in Japanese Film.' *Medical Humanities* 35 (1): 39-42.
- Avrahami, Einat. 2007. *The Invading Body: Reading Illness Autobiographies*. Charlottesville: University of Virginia Press.
- Bakhtin, Mikhail. 1981. *The Dialogic Imagination: Four Essays*. Translated by Caryl Emerson and Michael Holquist. Austin: University of Texas Press.
- . 1984. *Problems of Dostoevsky's Poetics*. Translated by Caryl Emerson. Minneapolis: University of Minnesota Press.
- Ballenger, Jesse F. 2006. *Self, Senility, and Alzheimer's Disease in Modern America: A History*. Baltimore: Johns Hopkins University Press.
- Bamberg, Michael. 1997. 'Positioning between Structure and Performance.' *Journal of Narrative and Life History* 7: 335-342.
- . 2004. 'Considering Counter Narratives.' In *Considering Counter-Narratives: Narrating, Resisting, Making Sense*, edited by Michael Bamberg and Molly Andrews, 351-371. Amsterdam: John Benjamins.
- Bamberg, Michael, and Molly Andrews, eds. 2004. *Considering Counter-Narratives: Narrating, Resisting, Making Sense*. Amsterdam: John Benjamins.
- Barba, Andrés. 2004. *Ahora Toca Música de Baile*. Barcelona: Editorial Anagrama.
- Basting, Anne Davis. 2001. "'God is a Talking Horse": Dementia and the Performance of Self.' *The Drama Review* 45 (3): 78-94.
- . 2003a. 'Looking Back from Loss: Views of the Self in Alzheimer's Disease.' *Journal of Aging Studies* 17: 87-99.
- . 2003b. 'Reading the Story Behind the Story: Context and Content in Stories by People with Dementia.' *Generations* 3: 25-29.
- Basting, Anne Davis, and John Killick. 2003. *The Arts and Dementia Care: A Resource Guide*. New York: The National Center for Creative Aging.
- Battersby, James L. 2006. 'Narrativity, Self, and Self-Representation.' *Narrative* 14 (1): 27-44.
- Bayley, John. 1999. *Elegy for Iris*. New York: Picador.
- Behuniak, Susan M. 2011. 'The Living Dead? The Construction of People with Alzheimer's Disease as Zombies.' *Ageing and Society* 31 (1): 70-92.
- Berliner, Alan. 2012. *First Cousin Once Removed*. HBO.

- Bernaerts, Lars. 2014. 'Minds at Play: Narrative Games and Fictional Minds in B.S. Johnson's *House Mother Normal*.' *Style* 48 (3): 294-312.
- Bernlef, J. 1988. *Out of Mind*. Translated by Adrienne Dixon. London: Faber and Faber. Original edition, Hersenshimmen 1984.
- Bitenc, Rebecca A. 2012. 'Representations of Dementia in Narrative Fiction.' In *Knowledge and Pain*, edited by Esther Cohen, Leona Toker, Manuela Consonni and Otniel E. Dror, 305-329. Amsterdam: Rodopi.
- Block, Stefan Merrill. 2008. *The Story of Forgetting*. London: Faber and Faber.
- Booth, Wayne C. 1988. *The Company We Keep: An Ethics of Fiction*. Berkeley: University of California Press.
- Brecht, Bertold. 1964. 'Alienation Effects in Chinese Acting.' In *Brecht on Theatre: The Development of an Aesthetic*, edited by John Willett, 91-99. New York: Hill and Wang.
- Brody, Elaine M., Morton H. Kleban, M. Powell Lawton, and Herbert A. Silverman. 1971. 'Excess Disabilities of Mentally Impaired Aged: Impact of Individualized Treatment.' *The Gerontologist* 11 (2): 124-133.
- Bruner, Jerome. 1991. 'The Narrative Construction of Reality.' *Critical Inquiry* 18: 1-21.
- . 2003. *Making Stories: Law, Literature, Life*. Cambridge, Massachussetts: Harvard University Press.
- . 2004. 'Life as Narrative.' *Social Research* 71 (3): 691-710.
- Bryden, Christine [formerly Boden]. 1998. *Who Will I Be When I Die?* East Melbourne: Harper Collins Religious.
- . 2005. *Dancing with Dementia: My Story of Living Positively with Dementia*. London: Jessica Kingsley Publishers.
- Buber, Martin. 1958. *I and Thou*. Translated by Ronald Gregor Smith. Second ed. Edinburgh: T&T Clark. Original edition, 1923.
- Burke, Lucy. 2007a. Alzheimer's Disease: Personhood and First Person Testimony. In *CDSRN Cultural Disability Studies Research Network*. <http://www.cdsrn.org.uk/ICP.html>.
- . 2007b. 'The Poetry of Dementia: Art, Ethics, and Alzheimer's Disease in Tony Harrison's *Black Daisies for the Bride*.' *Journal of Literary Disability* 1 (1): 61-73.
- . 2008. "'The Country of My Disease': Genes and Genealogy in Alzheimer's Life-writing." *Journal of Disability* 2 (1): 63-74.
- . 2014. 'Oneself as Another: Intersubjectivity and Ethics in Alzheimer's Illness Narratives.' *Narrative Works* 4: 28-47.

- . 2015. 'The Locus of Our Dis-ease: Narratives of Family Life in the Age of Alzheimer's.' In *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*, edited by Aagje Swinnen and Mark Schweda, 23-41. Bielefeld: Transcript Verlag.
- . 2016. 'On (not) Caring: Tracing the Meanings of Care in the Imaginative Literature of the "Alzheimer's Epidemic"' In *The Edinburgh Companion to the Critical Medical Humanities*, edited by Anne Whitehead and Angela Woods. Edinburgh: Edinburgh University Press.
- Capstick, Andrea, John Chatwin, and Katherine Ludwin. 2015. 'Challenging Representations of Dementia in Contemporary Western Fiction Film: From Epistemic Injustice to Social Participation.' In *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*, edited by Aagje Swinnen and Mark Schweda. Bielefeld: Transcript Verlag.
- Carel, Havi. 2008. *Illness: The Cry of the Flesh*. Stocksfield: Acumen.
- Cassavetes, Nick. 2004. *The Notebook*. New Line Cinema.
- Chappell, N. L., C. Dujela, and A. Smith. 2015. 'Caregiver Well-Being: Intersections of Relationship and Gender.' *Research on Aging* 37 (6): 623-645.
- Charon, Rita. 2006. *Narrative Medicine*. Oxford: Oxford University Press.
- Chast, Roz. 2014. *Can't We Talk About Something More Pleasant? A Memoir*. New York: Bloomsbury.
- Cheong, C., Y. Foong, H. Koh, D. Chen, A. Tan, J. Tan, C. Ng, and L. Yap. 2015. 'Creative Music Therapy Improves Mood and Engagement of Older Patients with Delirium & Dementia in an Acute Tertiary Hospital.' *Journal of the American Geriatrics Society* 63: 272-272.
- Chute, Hilary. 2007. 'Book review of *Our Cancer Year, Janet and Me: An Illustrated Story of Love and Loss, Cancer Vixen: A True Story, Mom's Cancer, Blue Pills: A Positive Love Story, Epileptic*, and *Black Hole*.' *Literature and Medicine* 26 (2): 413-429.
- Clark, Andy, and David Chalmers. 1998. 'The Extended Mind.' *Analysis* 58 (1): 7-19.
- Clegg, David. 2010. *Tell Mrs Mill Her Husband Is Still Dead*. No place: No publisher.
- Cohen, David, and Carl Eisdorfer. 1986. *The Loss of Self: A Family Resource for the Care of Alzheimer's Disease and Related Disorders*. New York: W.W. Norton.
- Cohen-Shalev, Amir, and Esther-Lee Marcus. 2012. 'An Insider's View of Alzheimer's: Cinematic Portrayals of the Struggle for Personhood.' *International Journal of Ageing and Later Life* 7 (2): 73-96.

- Cohn, Dorrit. 1978. *Transparent Minds: Narrative Modes for Presenting Consciousness in Fiction*. Princeton: Princeton University Press.
- Conway, Kathlyn. 2007. *Beyond Words: Illness and the Limits of Expression*. Albuquerque: University of New Mexico Press.
- Cooney, Eleanor. 2003. *Death in Slow Motion: A Memoir of a Daughter, Her Mother, and the Beast Called Alzheimer's*. New York: Harper Perennial.
- Couser, G. Thomas. 1991. "Autopathography: Women, Illness, and Lifewriting." *a/b: Auto/Biography Studies* 6 (1): 65-75.
- . 1997. *Recovering Bodies: Illness, Disability, and Life Writing*. Madison: The University of Wisconsin Press.
- . 1991. 'Autopathography: Women, Illness, and Lifewriting.'
- . 2004. *Vulnerable Subjects: Ethics and Life Writing*. Ithaca: Cornell University Press.
- . 2005. 'Paradigms' Cost: Representing Vulnerable Subjects.' *Literature and Medicine* 24 (1): 19-30.
- . 2009. 'Memoir and (lack of) Memory: Filial Narratives of Paternal Dementia.' In *New Essays on Life Writing and the Body*, edited by Christopher Stuart and Stephanie Todd, 223-240. Newcastle: Cambridge Scholars.
- . 2012. *Memoir: An Introduction*. Oxford: Oxford University Press.
- Crawford, Paul, Brian Brown, Victoria Tischler, and Charley Baker. 2010. 'Health Humanities: The Future of Medical Humanities?' *Mental Health Review* 15 (3): 4-10.
- Crisp, Jane. 1995. 'Making Sense of the Stories that People with Alzheimer's Tell: A Journey with my Mother.' *Journal of Narrative and Life History* 2 (3): 133-140.
- Culler, Jonathan D. 2004. 'Omniscience.' *Narrative* 12 (1): 22-34.
- Damasio, Antonio R. 1994. *Descartes' Error*. London: Vintage
- . 2000. *The Feeling of What Happens: Body and Emotion in the Making of Consciousness*. London: W. Heinemann.
- . 2010. *Self Comes to Mind: Constructing the Conscious Brain*. New York: Pantheon Books.
- Davis, Daniel H. J. 2004. 'Dementia: Sociological and Philosophical Constructions.' *Social Science & Medicine* 58 (2): 369-378.

- Davis, John K. 2009. 'Precedent Autonomy, Advance Directives, and End-of-Life Care.' In *The Oxford Handbook of Bioethics*, edited by Bonnie Steinbock. Oxford: Oxford University Press.
- Davis, Robert. 1989. *My Journey into Alzheimer's Disease: Helpful Insights for Family and Friends*. Carol Stream: Tyndale House Publishers.
- Dawson, Paul. 2013. *The Return of the Omniscient Narrator: Authorship and Authority in Twenty-First Century Fiction*. Columbus: Ohio State University Press.
- DeBaggio, Thomas. 2002. *Losing My Mind: An Intimate Look at Life with Alzheimer's*. New York: The Free Press.
- . 2003. *When It Gets Dark: An Enlightened Reflection on Life with Alzheimer's*. New York: Free Press.
- DeFalco, Amelia. 2010. *Uncanny Subjects: Aging in Contemporary Narrative*. Columbus: The Ohio State University Press.
- Dennett, Daniel Clement. 1993. *Consciousness Explained*. London: Penguin Books.
- Devars, Christine. 2005. *Le Piano Désaccordé*. Paris: Editions Anne Carrière.
- Dickens, Charles. 1854. *Hard Times*. London: Thomas Nelson and Sons.
- Dijkstra, Katinka, Michelle S. Bourgeois, Rebecca S. Allen, and Louis D. Burgio. 2004. 'Conversational Coherence: Discourse Analysis of Older Adults with and without Dementia.' *Journal of Neurolinguistics* 17 (4): 263-283.
- Douglas, B. C. 2008. 'Dickens' Characters on the Couch: An Example of Teaching Psychiatry Using Literature.' *Medical Humanities* 34 (2): 64-69.
- Downs, Murna. 2000. 'A World Without Dementia? What Do We Need To Do?' *Dementia in Scotland: Newsletter of Alzheimer's Scotland - Action on Dementia* March 6.
- Dresser, Rebecca. 1995. 'Dworkin on Dementia: Elegant Theory, Questionable Policy.' *The Hastings Center Report* 25 (6): 32-38.
- Dworkin, Ronald. 1993. *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom*. New York: Alfred A. Knopf.
- Eakin, Paul John. 1992. *Touching the World: Reference in Autobiography*. Princeton: Princeton University Press.
- . 1998. 'Relational Selves, Relational Lives: The Story of the Story.' In *True Relations: Essays on Autobiography and the Postmodern*, edited by G. Thomas Couser and Joseph Fichtelberg. Westport: Greenwood.
- . 1999. *How Our Lives Become Stories: Making Selves*. Ithaca: Cornell University Press.

- . 2001. 'Breaking Rules: The Consequences of Self-Narration.' *Biography* 24: 113-27.
- . 2006. 'Narrative Identity and Narrative Imperialism: A Response to Galen Strawson and James Phelan.' *Narrative* 14 (2): 180-187.
- . 2008. *Living Autobiographically: How We Create Identity in Narrative*. Ithaca: Cornell University Press.
- Eisner, Will. 2008. *Comics and Sequential Art: Principles and Practices from the Legendary Cartoonist*. New York: W. W. Norton.
- Erll, Astrid. 2008. 'Naïve, Repetitive, or Cultural: Options of an Ethical Narratology.' *Amsterdam International Electronic Journal for Cultural Narratology* 5.
- Ernaux, Annie. 1987. *Une Femme*. Paris: Gallimard.
- . 1999. *I Remain in Darkness*. Translated by Tanya Leslie. New York: Seven Stories Press. Original edition, 1997.
- Evans, Fiona. 2013. *Geordie Sinatra*.
- Eyre, Richard. 2001. *Iris*. Miramax Films.
- Farmer, Joyce. 2010. *Special Exits: A Graphic Memoir*. Seattle: Fantagraphics.
- Faulkner, William. 1995. *The Sound and The Fury*. London: Vintage Books. Original edition, 1929.
- Feil, Naomi. 1989. 'Validation: An Empathetic Approach to the Care of Dementia.' *Clinical Gerontologist* 8 (3): 89-94.
- . 1992. 'Validation Therapy.' *Geriatric Nursing* 13 (3): 129-33.
- Feil, Naomi, and Rita Altman. 2004. 'Validation Theory and the Myth of the Therapeutic Lie.' *American Journal of Alzheimer's Disease and Other Dementias* 19 (2): 77-8.
- Felski, Rita. 2008. *Uses of Literature*. Oxford: Blackwell.
- Fernyhough, Charles. 2012. *Pieces of Light: The New Science of Memory*. London: Profile.
- Fludernik, Monika. 1993. *The Fictions of Language and the Languages of Fiction: The Linguistic Representation of Speech and Consciousness*. London: Routledge.
- . 1996. *Towards a 'Natural' Narratology*. New York: Routledge.
- Fontana, Andrea, and Ronald W. Smith. 1989. 'Alzheimer's Disease Victims: The "Unbecoming" of Self and the Normalization of Competence.' *Sociological Perspectives* 32 (1): 35-46.
- Forster, Margaret. 1989. *Have the Men Had Enough?* London: Penguin Books.

- Fox, Patrick. 1989. 'From Senility to Alzheimer's Disease: The Rise of the Alzheimer's Disease Movement.' *Millbank Quarterly* 1: 58-102.
- Francis, Leslie Pickering. 2001. 'Decisionmaking at the End of Life: Patients with Alzheimer's or Other Dementias.' *Georgia Law Review* 35 (2): 539-92.
- Frank, Arthur W. 1995. *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press.
- Franzen, Jonathan. 2001. *The Corrections*. New York: Picador.
- . 2002. 'My Father's Brain.' In *How to Be Alone*, 7-38. New York: Picador.
- Freeman, Mark. 2007. 'Autobiographical Understanding and Narrative Inquiry.' In *Handbook of Narrative Inquiry: Mapping a Methodology*, edited by D. Jean Clandinin. Thousand Oaks: Sage.
- Fricker, Miranda. 2007. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.
- Friedman, Susan Stanford. 1988. 'Women's Autobiographical Selves: Theory and Practice.' In *The Private Self: Theory and Practice of Women's Autobiographical Writings*, edited by Shari Benstock, 34-62. Chapel Hill: University of North Carolina Press.
- Gallagher, Shaun, and Dan Zahavi. 2008. *The Phenomenological Mind: An Introduction to Philosophy of Mind and Cognitive Science*. London: Routledge.
- Gardner, Jared. 2008. 'Autography's Biography, 1972-2007.' *Biography* 31 (1): 1-26.
- Genette, Gérard. 1972. *Narrative Discourse: An Essay in Method*. Translated by Jane E. Lewin. Ithaca: Cornell University Press.
- Genova, Lisa. 2007. *Still Alice*. London: Simon and Schuster.
- Gerrig, R.J. 1993. *Experiencing Narrative Worlds*. New Haven: Yale University Press.
- Gillies, Andrea. 2010. *Keeper: A Book About Memory, Identity, Isolation, Wordsworth and Cake*. London: Short. Original edition, 2009.
- Glatzer, Richard, and Wash Westmoreland. 2014. *Still Alice*. Sony Pictures Classics.
- Goffman, Erving. 1963. *Stigma: Notes on the Management of Spoiled Identity*. Englewood Cliffs: Prentice-Hall Inc.
- . 1981. *Forms of Talk*. Philadelphia: University of Pennsylvania Press.
- Gordon, Mary. 2007. *Circling My Mother: A Memoir*. New York: Anchor Books.

- Graham, Megan E. 2016. 'The Voices of Iris: Cinematic Representations of the Aged Woman and Alzheimer's Disease in *Iris*.' *Dementia* 15 (5): 1171-1183.
- Graham, Peter. 1997. 'Metapathography: Three Unruly Texts.' *Literature and Medicine* 16 (1): 70-87.
- Grant, Linda. 1998. *Remind Me Who I Am, Again*. London: Granta Books.
- Green, Melanie C. 2004. 'Transportation Into Narrative Worlds: The Roles of Prior Knowledge and Perceived Realism.' *Discourse Processes* 38 (2): 247-266.
- Green, Melanie C., and Timothy C. Brock. 2000. 'The Role of Transportation in the Persuasiveness of Public Narratives.' *Journal of Personality and Social Psychology* 79 (5): 701-721.
- Green, Melanie C., Jennifer Garst, and Timothy C. Brock. 2004. 'The Power of Fiction: Determinants and Boundaries.' In *The Psychology of Entertainment Media: Blurring the Lines Between Entertainment and Persuasion*, edited by L. J. Shrum, 161-176. Mahwah: Lawrence Erlbaum Associates Publishers.
- Greenhalgh, Trisha, and Brian Hurwitz. 1999. 'Why Study Narrative?' *BMJ* 318: 48-50.
- Gubrium, Jaber F. 1986. *Oldtimers and Alzheimer's: The Descriptive Organization of Senility*. Greenwich: JAI Press.
- Guillory, John. 2000. 'The Ethical Practice of Modernity: The Example of Reading.' In *The Turn to Ethics*, edited by Marjorie Garber, Beatrice Hanssen and Rebecca L. Walkowitz. New York: Routledge.
- Gusdorf, Georges. 1980. 'Conditions and Limits of Autobiography.' In *Autobiography: Essays Theoretical and Critical*, edited by James Olney, 28-48. Princeton: Princeton University Press. Original edition, 1956.
- Hacking, Ian. 1999a. *Mad Travellers: Reflections on the Reality of Transient Mental Illnesses*. London: Free Association Books.
- . 1999b. *The Social Construction of What?* Cambridge, Massachusetts: Harvard University Press.
- Hadas, Rachel. 2011. *Strange Relation: A Memoir of Marriage, Dementia, and Poetry*. Philadelphia: Paul Dry Books.
- Hakemulder, Jèmeljan. 2000. *The Moral Laboratory: Experiments Examining the Effects of Reading Literature on Social Perception and Moral Self-concept*. Amsterdam: John Benjamins.
- Harrison, Tony. 1993. *Black Daisies for the Bride*. London: Faber and Faber.

- Hartung, Heike. 2016. *Ageing, Gender and Illness in Anglophone Literature: Narrating Age in the Bildungsroman*. New York: Routledge.
- Haugse, John. 1998. *Heavy Snow: My Father's Disappearance into Alzheimer's*. Deerfield Beach: Health Communications.
- Hawkins, Anne Hunsaker 1993. *Reconstructing Illness: Studies in Pathography*. West Lafayette: Purdue University Press.
- Hayes, Jeanne, Craig Boylstein, and Mary K. Zimmerman. 2009. 'Living and Loving With Dementia: Negotiating Spousal and Caregiver Identity Through Narrative.' *Journal of Aging Studies* 23: 48-59.
- Healey, Emma. 2014. *Elizabeth is Missing*. St Ives: Penguin Books.
- Heidegger, Martin. 1962. *Being and Time*. Translated by J. Macquarrie and E Robinson. Oxford: Blackwell.
- Henderson, Cary 1998. *Partial View: An Alzheimer's Journal*. Dallas: Southern Methodist University Press.
- Henry, Peaches. 2006. 'A Revised Approach to Relationality in Women's Autobiography: The Case of Eliza Linton's *The Autobiography of Christopher Kirkland*.' *a/b: Auto/Biography Studies* 20 (1): 18-37.
- Herman, David. 2011. *The Emergence of Mind: Representations of Consciousness in Narrative Discourse in English*. Lincoln: University of Nebraska Press.
- . 2013. *Storytelling and the Sciences of Mind*. Cambridge, Massachusetts: The MIT Press.
- Herman, Luc, and Bart Vervaeck. 2005. *Handbook of Narrative Analysis*. Lincoln: University of Nebraska Press.
- Herskovits, Elizabeth. 1995. 'Struggling Over Subjectivity: Debates About the 'Self' and Alzheimer's Disease.' *Medical Anthropology Quarterly* 9 (2): 146-164.
- Hertogh, Cees M. P. M., Marika E. de Boer, Rose-Marie Dröes, and Jan A. Eefstinga. 2007. 'Would We Rather Lose Our Life Than Lose Our Self? Lessons From the Dutch Debate on Euthanasia for Patients With Dementia.' *The American Journal of Bioethics* 7 (4): 48-56.
- Heywood, Bernard. 1994. *Caring For Maria: An Experience of Coping Successfully with Alzheimer's Disease*. Shaftesbury: Element.
- Hoffmann, Deborah. 1994. *Complaints of Dutiful Daughter*. No distributor.
- Holstein, Martha. 1997. 'Alzheimer's Disease and Senile Dementia, 1885-1920: An Interpretive History of Disease Negotiation.' *Journal of Aging Studies* 11 (1): 1-13.
- . 2000. 'Aging, Culture, and the Framing of Alzheimer's Disease.' In *Concepts of Alzheimer Disease: Biological, Clinical, and Cultural Perspectives*, edited by Peter J. Whitehouse, Konrad Maurer and

- Jesse F. Ballenger, 158-180. Baltimore: John Hopkins University Press.
- Huebner, Berna G. 2011. *I Remember Better When I Paint - Art and Alzheimer's: Opening Doors, Making Connections*. Glen Echo: Bethesda Communications Group and New Publishing Partners.
- Hughes, Julian C. 2011. *Thinking Through Dementia*. Oxford: Oxford University Press.
- Hughes, Julian C., Stephen J. Louw, and Steven R. Sabat, eds. 2006. *Dementia: Mind, Meaning, and the Person*. Oxford: Oxford University Press.
- Hutto, Daniel D. 2007a. *Folk Psychological Narratives: the Sociocultural Basis of Understanding Reasons*. Cambridge, Massachusetts: MIT Press.
- . 2007b. 'The Narrative Practice Hypothesis: Origins and Applications of Folk Psychology.' In *Narrative and Understanding Persons*, edited by Daniel D. Hutto, 43-68. Cambridge: Cambridge University Press.
- Hydén, Lars-Christer. 2010. 'Identity, Self, Narrative.' In *Beyond Narrative Coherence*, edited by Matti Hyvärinen, Lars-Christer Hydén, Marja Saarenheimo, and Maria Tamboukou, 33-48. Amsterdam: John Benjamins.
- . 2011. 'Narrative Collaboration and Scaffolding in Dementia.' *Journal of Aging Studies* 25: 339-347.
- Hydén, Lars-Christer, and Linda Örvulv. 2009. 'Narrative and Identity in Alzheimer's Disease: A Case Study.' *Journal of Aging Studies* 23 (4): 205-214.
- Hyvärinen, Matti, Lars-Christer Hydén, Marja Saarenheimo, and Maria Tamboukou, eds. 2010. *Beyond Narrative Coherence*. Amsterdam: John Benjamins.
- Iacoboni, Marco. 2008. *Mirroring People: The New Science of How We Connect with Others*. New York: Farrar, Straus and Giroux.
- Ignatieff, Michael. 1993. *Scar Tissue*. London: Vintage.
- . 1994. 'All in the Mind.' BBC Radio 4.
- Ishiguro, Kazuo. 1995. *The Unconsoled*. London: Faber and Faber.
- Iversen, Stefan. 2013. 'Unnatural Minds.' In *A Poetics of Unnatural Narrative*, edited by Jan Aber, Henrik Skov Nielsen, and Brian Richardson. Columbus: Ohio State University Press.
- Jens, Tilman. 2009. *Demenz: Abschied von meinem Vater*. Gütersloh: Gütersloher Verlagshaus.
- Johnson, B.S. 2013. *House Mother Normal*. Basingstoke: Picador. Original edition, 1971.

- Johnstone, Megan-Jane. 2011. 'Metaphors, Stigma and the 'Alzheimerization' of the Euthanasia Debate.' *Dementia* 0(0): 1-17.
- . 2013. *Alzheimer's Disease, Media Representation, and the Politics of Euthanasia: Constructing Risk and Selling Death in an Ageing Society*. London: Routledge.
- Jones, Rebecca. 2004. "'That's very rude, I shouldn't be telling you that': Older Women Talking About Sex.' In *Considering Counter-Narratives: Narrating, Resisting, Making Sense*, edited by Michael Bamberg and Molly Andrews, 169-189. Amsterdam: John Benjamins.
- Jones, Therese. 2014. "'Oh, the Humanit(ies)!' Dissent, Democracy, and Danger.' In *Medicine, Health and the Arts: Approaches to the Medical Humanities*, edited by Victoria Bates, Alan Bleakley, and Sam Goodman, 27-38. New York: Routledge.
- Käll, Lisa Folkmarson. 2015. 'Intercorporeal Relations and Ethical Perception: Portrayals of Alzheimer's Disease in *Away from Her* and *En sång för Martin*.' In *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*, edited by Aagje Swinnen and Mark Schweda. Bielefeld: Transcript Verlag.
- Kaufman, Sharon R. 2006. 'Dementia-Near-Death and "Life Itself."' In *Thinking About Dementia: Culture, Loss, and the Anthropology of Senility*, edited by Annette Leibing and Lawrence Cohen, 23-42. New Brunswick: Rutgers University Press.
- Keen, Suzanne. 2007. *Empathy and the Novel*. Oxford: Oxford University Press.
- Killick, John. 1997. *You Are Words: Dementia Poems*. London: Hawker Publications.
- . 2008. *Dementia Diary: Poems and Prose*. London: Hawker Publications.
- , ed. 2010. *The Elephant in the Room: Poems by People with Memory Loss in Cambridgeshire*. Cambridge: Cambridgeshire County Council.
- Killick, John, and Kate Allan. 2001. *Communication and the Care of People with Dementia*. Buckingham: Open University Press.
- Killick, John, and Carl Cordonnier. 2000. *Openings: Dementia Poems and Photographs*. London: Hawker Publications.
- Kittay, Eva Feder. 1999. *Love's Labor: Essays on Women, Equality and Dependency*. New York: Routledge.
- Kitwood, Tom. 1990. 'The Dialectics of Dementia: With Particular Reference to Alzheimer's Disease.' *Ageing and Society* 10: 177-96.
- . 1997. *Dementia Reconsidered: The Person Comes First*. Philadelphia: Open University Press.

- Kitwood, Tom, and Kathleen Bredin. 1992. 'Towards a Theory of Dementia Care: Personhood and Well-being.' *Ageing and Society* 12: 269-87.
- Klein, Kitty. 2003. 'Narrative Construction, Cognitive Processing, and Health.' In *Narrative Theory and the Cognitive Sciences*, edited by David Herman, 56-84. Stanford: CSLI Publications.
- Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition*: Basic Books.
- Kölbl, Carlos. 2004. 'Blame it on Psychology?' In *Considering Counter-Narratives: Narrating, Resisting, Making Sense*, edited by Michael Bamberg and Molly Andrews, 27-32. Amsterdam: John Benjamins.
- Kontos, Pia C. 2003. "'The Painterly Hand': Embodied Consciousness and Alzheimer's Disease.' *Journal of Aging Studies* 17: 151-170.
- . 2004. 'Ethnographic Reflections on Selfhood, Embodiment and Alzheimer's Disease.' *Ageing and Society* 24 (6): 829-849.
- . 2005. 'Embodied Selfhood in Alzheimer's Disease.' *Dementia* 4 (4): 553-570.
- Korthals Altes, Liesbeth. 2005. 'Ethical Turn.' In *Routledge Encyclopedia of Narrative Theory*, edited by David Herman, Manfred Jahn, and Marie-Laure Ryan, 142-146. New York: Routledge.
- . 2006. 'Some Dilemmas of an Ethics of Literature.' In *Theology and Literature: Rethinking Reader Responsibility*, edited by Gaye Williams Ortiz and Clara A.B. Joseph, 15-31. Basingstoke: Palgrave Macmillan.
- . 2013. 'Narratology, Ethical Turns, Circularities, and a Meta-Ethical Way Out.' In *Narrative Ethics*, edited by Jakob Lothe, Jeremy Hawthorn, and Leonidas Donskis, 25-40. Amsterdam: Rodopi.
- . 2014. *Ethos and Narrative Interpretation: The Negotiation of Values in Fiction*. Lincoln: University of Nebraska Press.
- Krause, Allison M., Lynda D. Grant, and Bonita C. Long. 1999. 'Sources of Stress Reported by Daughters of Nursing Home Residents.' *Journal of Aging Studies* 13 (3): 349-364.
- Krüger-Fürhoff, Irmela Marei. 2015. 'Narrating the Limits of Narration: Alzheimer's Disease in Contemporary Literary Texts.' In *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*, edited by Aagje Swinnen and Mark Schweda, 89-108. Bielefeld: Transcript Verlag.
- LaCapra, Dominick 2001. *Writing History, Writing Trauma*. Baltimore: Johns Hopkins University Press.
- Lakoff, George, and Mark Johnson. 2003. *Metaphors We Live By*. Chicago: University of Chicago Press.
- LaPlante, Alice. 2011. *Turn of Mind*. London: Harvill Secker.

- Leavitt, Sarah. 2010. *Tangles: A Story About Alzheimer's, My Mother and Me*. London: Jonathan Cape.
- Lee, Jeanne L. 2003. *Just Love Me: My Life Turned Upside-Down by Alzheimer's*. West Lafayette: Purdue University Press.
- Leibing, Annette, and Lawrence Cohen. 2006. *Thinking About Dementia: Culture, Loss, and the Anthropology of Senility*. New Brunswick: Rutgers University Press.
- Lejeune, Philippe. 1988. *On Autobiography*. Minneapolis: University of Minnesota Press.
- Levinas, Emmanuel. 1990. *Totalité et Infini*. Dordrecht: Kluwer Academic Publishers. Original edition, 1961.
- . 1979. *Le Temps et L'Autre*. Paris: Fata Morgana.
- Levine, Judith. 2004. *Do You Remember Me? A Father, a Daughter, and a Search for the Self*. New York: Free Press.
- Liesk, J., T. Hartogh, and E. Kalbe. 2015. 'Cognitive Stimulation and Music Intervention for People with Dementia in Nursing Homes. A Pilot Study, Problems and Perspectives.' *Zeitschrift für Gerontologie und Geriatrie* 48 (3): 275-281.
- Lloyd, Phyllida. 2011. *The Iron Lady*. 20th Century Fox.
- Lyman, Karen A. 1989. 'Bringing the Social Back In: A Critique of the Biomedicalization of Dementia.' *The Gerontologist* 29 (5): 597-605.
- . 1998. 'Living with Alzheimer's Disease: The Creation of Meaning Among Persons with Dementia.' *The Journal of Clinical Ethics* 9 (1): 49-57.
- MacIntyre, Alasdair. 1981. *After Virtue*. Notre Dame: University of Notre Dame Press.
- MacRae, Hazel. 2010. 'Managing Identity While Living With Alzheimer's Disease.' *Qualitative Health Research* 20 (3): 293-305.
- Magnusson, Sally. 2014. *Where Memories Go: Why Dementia Changes Everything*. London: Two Roads.
- Margolin, Uri. 1999. 'Of What Is Past, Is Passing, or to Come: Temporality, Aspectuality, Modality, and the Nature of Literary Narrative.' In *Narratologies: New Perspectives on Narrative Analysis*, edited by David Herman, 142-166. Columbus: Ohio State University Press.
- Marx, M. S., J. Cohen-Mansfield, N. G. Regier, M. Dakheel-Ali, A. Srihari, and K. Thein. 2010. 'The Impact of Different Dog-Related Stimuli on Engagement of Persons with Dementia.' *American Journal of Alzheimer's Disease and Other Dementias* 25 (1): 37-45.
- Mason, Mary. 1980. 'The Other Voice: Autobiographies of Women Writers.' In *Autobiography: Essay Theoretical and Critical*, edited by James Olney, 207-235. Princeton: Princeton University Press.

- Mattingly, Cheryl. 1998. *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Cambridge: Cambridge University Press.
- Maxwell, Glyn, and Elena Langer. 2010. *The Lion's Face*. London: Oberon Books.
- McCloud, Scott. 1994. *Understanding Comics: The Invisible Art*. New York: Harper Perennial.
- McGowin, Diane Friel. 1994. *Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's*. New York: Delta. Original edition, 1993.
- McLean, Athena Helen. 2006. 'Coherence without Facticity in Dementia: The Case of Mrs. Fine.' In *Thinking About Dementia: Culture, Loss, and the Anthropology of Senility*, edited by Annette Leibling and Lawrence Cohen, 157-179. New Brunswick: Rutgers University Press.
- McNamara, Norman. No year. *More Than Words*. No publisher.
- Medved, Maria I., and Jens Brockmeier. 2010. 'Weird Stories: Brain, Mind and Self.' In *Beyond Narrative Coherence*, edited by Matti Hyvärinen, Lars-Christer Hydén, Marja Saarenheimo and Maria Tamboukou, 17-32. Amsterdam: John Benjamins.
- Miller, Nancy K. 1994. 'Representing Others: Gender and the Subjects of Autobiography.' *Differences: A Journal of Feminist Cultural Studies* 6 (1): 1-27.
- . 1996. *Bequest and Betrayal: Memoirs of a Parent's Death*. New York: Oxford University Press.
- Miller, Sue. 2003. *The Story of My Father*. London: Bloomsbury.
- Millett, Stephan. 2011. 'Self and Embodiment: A Bio-Phenomenological Approach to Dementia.' *Dementia* 10 (4): 509-522.
- Mitchell, David, and Sharon Snyder. 2001. *Narrative Prosthesis: Disability and the Dependencies of Discourse*. Ann Arbor: University of Michigan Press.
- Montgomery Hunter, Kathlyn 1993. *Doctors' Stories: The Narrative Structure of Medical Knowledge*. Princeton: Princeton University Press.
- Morgan, Abi. 2011. 27. London: Oberon Books.
- Morris, David B. 1998. *Illness and Culture in the Postmodern Age*. Berkeley: University of California Press.
- . 2002. 'Narrative, Ethics, and Pain: Thinking with Stories.' In *Stories Matter: The Role of Narrative in Medical Ethics*, edited by Rita Charon and Martha Montello, 196-218. New York: Routledge.
- Murphy, Tom. 2009. 'Bailegangaire.' In *The Methuen Drama Anthology of Irish Plays*, edited by Patrick Lonergan, 111-185. London: Methuen.

- Murray, Stuart. 2008. *Representing Autism: Culture, Narrative, Fascination*. Liverpool: Liverpool University Press.
- Nagel, Thomas. 1974. 'What Is It Like to Be a Bat?' *The Philosophical Review* 83 (4): 435-50.
- Nielsen, Henrik Skov. 2004. 'The Impersonal Voice in First-Person Narrative Fiction.' *Narrative* 12 (2): 133-50.
- Noyes, Brigg B., Robert D. Hill, Bret L. Hicken, Marilyn Luptak, Randall Rupper, Nancy K. Dailey, and Byron D. Bair. 2010. 'Review: The Role of Grief in Dementia Caregiving.' *American Journal of Alzheimer's Disease and Other Dementia* 25 (1): 9-17.
- Nussbaum, Martha Craven. 1990. *Love's Knowledge: Essays on Philosophy and Literature*. Oxford: Oxford University Press.
- . 1995. *Poetic Justice: The Literary Imagination and Public Life*. Boston: Beacon Press.
- . 1997. *Cultivating Humanity: A Classical Defense of Reform in Liberal Education*. Cambridge, Massachusetts: Harvard University Press.
- Ochs, Elinor, and Lisa Capps. 2001. *Living Narrative: Creating Lives in Everyday Storytelling*. Cambridge, Massachusetts: Harvard University Press.
- Oksenberg Rorty, Amélie 2000. 'Characters, Persons, Selves, Individuals.' In *Theory of the Novel: A Historical Approach*, edited by Michael McKeon, 537-553. Baltimore: Johns Hopkins University Press.
- Olney, James. 1980. 'Autobiography and the Cultural Moment: A Thematic, Historical, and Bibliographical Introduction.' In *Autobiography: Essays Theoretical and Critical*, edited by James Olney, 3-27. Princeton: Princeton University Press.
- Orr, David, and Yugin Teo. 2015. 'Carers' Responses to Shifting Identity in Dementia in *Iris* and *Away From Her*: Cultivating Stability or Embracing Change?' *Medical Humanities* 41 (2): 81-85.
- Örülv, Linda, and Lars-Christer Hydén. 2006. 'Confabulation: Sense-Making, Self-Making and World-Making in Dementia.' *Discourse Studies* 8 (5): 647-673.
- Palmer, Alan. 2004. *Fictional Minds*. Lincoln: University of Nebraska Press.
- Parker, David. 2004. 'Narratives of Autonomy and Narratives of Relationality in Auto/Biography.' *a/b: Auto/Biography Studies* 1 (2): 137-155.
- Peterson, Linda. 1993. 'Institutionalizing Women's Autobiography: Nineteenth-Century Editors and the Shaping of an Autobiographical Tradition.' In *The Culture of Autobiography: Constructions of Self-Representation*, edited by Robert Folkenflik, 80-103. Stanford: Stanford University Press.

- Petrescu, Ioana, Kit MacFarlane, and Robert Ranzijn. 2014. 'Psychological Effects of Poetry Workshops with People with Early Stage Dementia: An Exploratory Study.' *Dementia* 13 (2): 207-215.
- Phelan, James. 2003. 'Dual Focalization, Retrospective Fictional Autobiography, and the Ethics of *Lolita*.' In *Narrative and Consciousness: Literature, Psychology and the Brain* edited by Gary D. Fireman, Ted E. McVay, and Owen J. Flanagan, 129-145. Oxford: Oxford University Press.
- Phinney, Alison. 2002. 'Fluctuating Awareness and the Breakdown of the Illness Narrative in Dementia.' *Dementia* 1 (3): 329-344.
- Pier, John. 2013. 'Metalepsis.' In *The Living Handbook of Narratology*, edited by Peter Hühn, John Pier, Wolf Schmid and Jörg Schönert. Hamburg: Hamburg University Press. <http://www.lhn.uni-hamburg.de/article/unnatural-narrative>. [last accessed: 22/03/2016]
- Pinker, Steven. 2004. The Seed Salon: Steven Pinker and Rebecca Goldsmith. In *Seed*: 44-49, 97-99.
- Pitt, Brice. 1993. 'Psychiatry and the Media: Black Marks for Black Daisies' *Psychiatric Bulletin* 17: 672-673.
- Polley, Sarah. 2006. *Away from Her*. Lionsgate Films.
- Post, Stephen G. 2000. *The Moral Challenge of Alzheimer Disease: Ethical Issues from Diagnosis to Dying*. Baltimore: Johns Hopkins University Press.
- Radden, Jennifer, and Joan M. Fordyce. 2006. 'Into the Darkness: Losing Identity with Dementia.' In *Dementia: Mind, Meaning, and the Person*, edited by Julian C. Hughes, Stephen Louw, and Steven R. Sabat. Oxford: Oxford University Press.
- Raglio, Alfredo, Lapo Attardo, Giulia Gontero, Silvia Rollino, Elisabetta Groppo, and Enrico Granieri. 2015. 'Effects of Music and Music Therapy on Mood in Neurological Patients.' *World Journal of Psychiatry* 5 (1): 68-78.
- Ratcliffe, Matthew. 2007. *Rethinking Commonsense Psychology: A Critique of Folk Psychology, Theory of Mind, and Simulation*. New York: Palgrave Macmillan.
- . 2008. *Feelings of Being: Phenomenology, Psychiatry, and the Sense of Reality*. Oxford: Oxford University Press.
- Rees, Geoffrey. 2010. 'The Ethical Imperative of Medical Humanities.' *Journal of Medical Humanities* 31: 267-277.
- Richardson, Brian. 2007. 'Drama and Narrative.' In *The Cambridge Companion to Narrative*, edited by David Herman, 142-155. Cambridge: Cambridge University Press.
- Richler, Mordechai. 1997. *Barney's Version*. Toronto: Knopf Canada.

- Ricœur, Paul. 1991a. 'Life in Quest of Narrative.' In *On Paul Ricœur: Narrative and Interpretation*, edited by David Wood, 20-33. New York: Routledge.
- . 1991b. 'Narrative Identity.' In *On Paul Ricœur: Narrative and Interpretation*, edited by David Wood, 188-199. New York: Routledge.
- Ritivoi, Andreea Deciu. 2009. 'Explaining People: Narrative and the Study of Identity.' *StoryWorlds: A Journal of Narrative Studies* 1: 25-41.
- Rose, Larry. 1996. *Show Me the Way to Go Home*. Forest Knolls: Elder Books.
- . 2003. *Larry's Way: Another Look at Alzheimer's from the Inside*. New York: iUniverse.
- Rosenblatt, Louise. 1995. *Literature as Exploration*. New York: The Modern Language Association. Original edition, 1965.
- Rossato-Bennett, Michael. 2014. *Alive Inside*. Projector Media.
- Roth, Philip. 1991. *Patrimony: A True Story*. New York: Simon and Schuster.
- Roy, Wendy. 2009. 'The Word is Colander: Language Loss and Narrative Voice in Fictional Canadian Alzheimer's Narratives.' *Canadian Literature* 203: 41-61.
- Russell, Richard. 2001. 'In Sickness and in Health: A Qualitative Study of Elderly Men Who Care for Wives with Dementia.' *Journal of Aging Studies* 15 (4): 351-367.
- Ryan, Ellen Bouchard, Karen A. Bannister, and Ann P. Anas. 2009. 'The Dementia Narrative: Writing to Reclaim Social Identity.' *Journal of Aging Studies* 23 (3): 145-157.
- Ryan, Marie-Laure. 2005. 'Mode.' In *The Routledge Encyclopedia of Narrative Theory*, edited by David Herman, Manfred Jahn, and Marie-Laure Ryan, 315-316. New York: Routledge.
- Sabat, Steven R., and Rom Harré. 1992. 'The Construction and Deconstruction of Self in Alzheimer's Disease.' *Ageing and Society* 12 (4): 443-461.
- . 1994. 'The Alzheimer's Disease Sufferer as a Semiotic Subject.' *Philosophy, Psychology, Psychiatry* 1 (3): 145-160.
- Sacks, Oliver. 2015. *The Man Who Mistook His Wife for a Hat*. London: Picador Classic. Original edition, 1985.
- Samson, Severine, Sylvain Clement, Pauline Narme, Loris Schiaratura, and Nathalie Ehrle. 2015. 'Efficacy of Musical Interventions in Dementia: Methodological Requirements of Nonpharmacological Trials.' *Neurosciences and Music V: Cognitive Stimulation and Rehabilitation* 1337: 249-255.

- Sartre, Jean-Paul. 1976. *L'Être et le Néant*. Paris: Tel Gallimard. Original edition, 1943.
- Sartwell, Crispin. 2000. *End of Story: Toward an Annihilation of Language and History*. Albany: State University of New York Press.
- Schechtman, Marya. 1996. *The Constitution of Selves*. Ithaca: Cornell University Press.
- . 2007. 'Stories, Lives, and Basic Survival: A Refinement and Defense of the Narrative View.' In *Narrative and Understanding Persons*, edited by Daniel D. Hutto, 155-178. Cambridge: Cambridge University Press.
- Schreier, Jake. 2012. *Robot and Frank*. Momentum Pictures.
- Selberg, Scott. 2015. 'Dementia on the Canvas: Art and the Biopolitics of Creativity.' In *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*, edited by Aagje Swinnen and Mark Schweda. Bielefeld: Transcript Verlag.
- Shenk, David. 2001. *The Forgetting: Understanding Alzheimer's: A Biography of a Disease*. London: Harper Collins.
- Sieveking, David. 2012. *Vergiss Mein Nicht*. Farbfilm home entertainment.
- Skelton, John. 2003. 'Death and Dying in Literature.' *Advances in Psychiatric Treatment* 9: 211-220.
- Small, Helen. 2007. *The Long Life*. Oxford: Oxford University Press.
- Small, J. A., K. Geldart, G. Gutman, and M. A. C. Scott. 1998. 'The Discourse of Self in Dementia.' *Ageing and Society* 18: 291-316.
- Smith, Sidonie, and Julia Watson. 2009. 'New Genres, New Subjects: Women, Gender and Autobiography after 2000.' *Revista Canaria de Estudios Ingleses* 58: 13-40.
- . 2010. *Reading Autobiography: A Guide for Interpreting Life Narratives*. Minneapolis: University of Minnesota Press.
- Snowdon, David A. 1997. 'Aging and Alzheimer's Disease: Lessons from the Nun Study.' *The Gerontologist* 37 (2): 150-156.
- Snyder, Lisa. 1999. *Speaking Our Minds: Personal Reflections from Individuals with Alzheimer's*. New York: W. H. Freeman.
- Sontag, Susan. 1979. *Illness as Metaphor*. New York: Vintage.
- . 1989. *AIDS and Its Metaphors*. New York: Farrar, Straus and Giroux.
- Spiegel, Maura. 2012. 'Rita Felski Uses of Literature: Book Review.' *Literature and Medicine* 30 (1): 203-207.
- Stirling, Jeanette. 2010. *Representing Epilepsy: Myth and Matter*. Liverpool: Liverpool University Press.

- Stokes, Graham. 2010. *And Still the Music Plays: Stories of People with Dementia*. London: Hawker Publications. Original edition, 2008.
- Stokes, Graham, and Fiona Goudie. 2002. *The Essential Dementia Care Handbook: A Good Practice Guide*. Bicester: Speechmark.
- Strawson, Galen. 2004. 'Against Narrativity.' *Ratio* 17: 428-452.
- Suter, Martin. 1997. *Small World*. Zürich: Diogenes Verlag.
- Swinnen, Aagje. 2012. 'Dementia in Documentary Film: *Mum* by Adelheid Roosen.' *The Gerontologist* 53 (1): 113-122.
- . 2016. 'Healing Words: A Study of Poetry Interventions in Dementia Care.' *Dementia* 15 (6): 1377-1404.
- Swinnen, Aagje, and Mark Schweda, eds. 2015. *Popularizing Dementia: Public Expressions and Representations of Forgetfulness*. Bielefeld: Transcript.
- Taylor, Richard. 2007. *Alzheimer's from the Inside Out*. Baltimore: Health Professions Press.
- Thane, Pat. 2005. *A History of Old Age*. Oxford: Oxford University Press.
- Thomas, Lewis. 1983. *Late Night Thoughts on Listening to Mahler's Ninth Symphony*. New York: Viking.
- Thorndike, John. 2009. *The Last of His Mind: A Year in the Shadow of Alzheimer's*. Athens, Ohio: Swallow Press.
- Toker, Leona. 1993. *Eloquent Reticence: Withholding Information in Fictional Narrative*. Lexington: University Press of Kentucky.
- Truscott, Marilyn. 2003. 'Life in the Slow Lane.' *Alzheimer's Care Quarterly* 4 (1): 11-17.
- . 2004a. 'Adapting Leisure and Creative Activities for People with Early Stage Dementias.' *Alzheimer's Care Quarterly* 5 (2): 92-102.
- . 2004b. 'Looks Can Be Deceiving – Dementia, the Invisible Disease' *Alzheimer's Care Quarterly* 5 (4): 274-277.
- Unadkat, Shreena, Paul M. Camic, and Trish Vella-Burrows. 2016. 'Understanding the Experience of Group Singing for Couples Where One Partner Has a Diagnosis of Dementia.' *Gerontologist* 0 (0): 1-11.
- Usita, Paula M., Ira E. Hyman & Keith C. Herman 1998. 'Narrative Intentions: Listening to Life Stories in Alzheimer's Disease.' *Journal of Aging Studies* 12 (2): 185-197.
- Vassilas, Christopher A. 2003. 'Dementia and Literature.' *Advances in Psychiatric Treatment* 9: 439-445.
- Viney, William, Felicity Callard, and Angela Woods. 2015. 'Critical Medical Humanities: Embracing Entanglement, Taking Risks.' *Medical Humanities* 41: 2-7.

- Waugh, Patricia. 2013. 'The Naturalistic Turn, the Syndrome, and the Rise of the Neo-Phenomenological Novel.' In *Diseases and Disorder in Contemporary Fiction: The Syndrome Syndrome*, edited by T.J. Lustig and James Peacock, 17-34. New York: Routledge.
- Wear, D., and J. M. Aultman. 2005. 'The Limits of Narrative: Medical Student Resistance to Confronting Inequality and Oppression in Literature and Beyond.' *Medical Education* 39: 1056-1065.
- Wearing, Sadie. 2013. 'Dementia and the Biopolitics of the Biopic: From *Iris* to *The Iron Lady*.' *Dementia* 12 (3): 315-325.
- Wennberg, Alexandra, Cheryl Dye, Blaiz Streetman-Loy, and Hiep Pham. 2015. 'Alzheimer's Patient Familial Caregivers: A Review of Burden and Interventions.' *Health & Social Work*. 40 (4): 162-169.
- Wetzstein, Verena. 2005. *Diagnose Alzheimer: Grundlagen einer Ethik der Demenz*. Frankfurt a.M.: Campus Verlag.
- White, Hayden. 1984. 'The Value of Narrativity in the Representation of Reality.' In *On Narrative*, edited by W. J. T. Mitchell. Chicago: University of Chicago Press. Original edition, 1981.
- Whitehead, Anne. 2011. 'Writing with Care: Kazuo Ishiguro's *Never Let Me Go*.' *Contemporary Literature* 52 (1): 54-83.
- . 2014. 'The Medical Humanities: A Literary Perspective.' In *Medicine, Health and the Arts: Approaches to the Medical Humanities*, edited by Victoria Bates, Alan Bleakley, and Sam Goodman, 107-127. London: Routledge.
- Whitehead, Anne, and Angela Woods, with Sarah Atkinson, Jane Macnaughton and Jennifer Richards, eds. 2016. *The Edinburgh Companion to the Critical Medical Humanities*. Edinburgh: Edinburgh University Press.
- Whitehouse, Peter J. 2008. *The Myth of Alzheimer's: What You Aren't Being Told About Today's Most Dreaded Diagnosis*. New York: Macmillan.
- Whitehouse, Peter J., Konrad Maurer, and Jesse F. Ballenger, eds. 2000. *Concepts of Alzheimer Disease: Biological, Clinical, and Cultural Perspectives*. Baltimore: Johns Hopkins University Press.
- Wiltshire, John. 2000. 'Biography, Pathography, and the Recovery of Meaning.' *The Cambridge Quarterly* 29 (4): 409-422.
- Wood, Michael. 2005. *Literature and the Taste of Knowledge*. Cambridge: Cambridge University Press.
- Woods, Angela. 2011. 'The Limits of Narrative: Provocations for the Medical Humanities.' *Medical Humanities* 37: 73-78.
- World Health Organization. 2012. *Dementia: A Public Health Priority*. World Health Organization.

- Zahavi, Dan. 2007. 'Self and Other: The Limits of Narrative Understanding.' In *Narrative and Understanding Persons*, edited by Daniel D. Hutto, 179-201. Cambridge: Cambridge University Press.
- Zeilig, Hannah. 2013. 'Dementia As a Cultural Metaphor.' *The Gerontologist* 54 (2): 258-267.
- Zimmermann, Martina. 2010. 'Deliver Us from Evil: Carer Burden in Alzheimer's Disease.' *Medical Humanities* 36 (2): 101-107.