

Reconsidering Dementia Narratives

Reconsidering Dementia Narratives explores the role of narrative in developing new ways of understanding, interacting with, and caring for people with dementia. It asks how the stories we tell about dementia—in fiction, life writing, and film—both reflect and shape the way we think about this important condition.

Highlighting the need to attend to embodied and relational aspects of identity in dementia, the study further outlines ways in which narratives may contribute to dementia care, while disputing the idea that the modes of empathy fostered by narrative necessarily bring about more humane care practices. This cross-medial analysis represents an interdisciplinary approach to dementia narratives which range across auto/biography, graphic narrative, novel, film, documentary, and collaborative storytelling practices. The book aims to clarify the limits and affordances of narrative, and narrative studies, in relation to an ethically driven medical humanities agenda through the use of case studies.

Answering the key question of whether dementia narratives align with or run counter to the dominant discourse of dementia as ‘loss of self,’ this innovative book will be of interest to anyone interested in dementia studies, ageing studies, narrative studies in health care, and critical medical humanities.

Rebecca A. Bitenc completed her PhD on ‘Dementia Narratives in Contemporary Literature, Life-Writing and Film’ at Durham University, UK. Her research interests include critical medical humanities, narratology, and narrative ethics. She is a member of the Dementia and Cultural Narratives Network and the Northern Network for Medical Humanities Research. She has an M.A. in English, French, and Psychology from Albert-Ludwigs-Universität, Germany.

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Reconsidering Dementia Narratives

Empathy, Identity and Care

Rebecca A. Bitenc

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Preface

A few years ago, I was out with my ‘mummy friends’—women I had met through baby groups after the birth of my daughter Clara. At one point, my research, and by implication dementia became the topic of conversation. From the other end of the table one of my friends called, ‘Shoot me if I ever get that way!’ Her comment has stuck with me. Not because it was entirely out of the ordinary. When I tell people about my research, I get one of several reactions: People will tell me about a family member with dementia, who is ‘no longer there’ or ‘no longer herself.’ They will talk about how hard it was (for themselves or someone else in the family) to look after a ‘loved one’ with dementia. Or I might get a comment like the one above, suggesting that life with dementia is not worth living and that the person I am talking to would rather die than lose her cognitive capacity. What struck me was that in 2016, nearly twenty years after Tom Kitwood’s seminal *Dementia Reconsidered* thoroughly challenged the way people with dementia are perceived and treated, negative preconceptions about dementia still prevail.

This book is about the stories we tell about dementia—the ones told by novelists and film-makers, but also by family care partners and by people with dementia themselves. It is also about how these stories interact and become entangled with wider cultural narratives, with the stories we tell about identity, selfhood, ethics, empathy, and care. Dementia, as these narratives demonstrate, is tied up with our value systems—with our notion of who and what matters.

People want to know what drew me to this topic. They ask me whether I have had a ‘case of dementia’ in the family. The simple answer would be ‘No,’ if the question is understood as whether a personal experience has made me so passionate about this topic. The more complex and truthful answer is ‘Yes, but....’ I was drawn to this topic initially by my interest in language—and specifically my interest in what happens when language breaks down. While pursuing a joint degree in literature, linguistics, and psychology, I spent a substantial amount of my time working alongside speech therapists, doing EEG experiments in a neurolinguistic laboratory on speech and language disorders, or completing course work in neuropsychology. Frustrated with the epistemological uncertainties of EEG experiments—as well as, to be honest, the lack of a handy MRI machine to conduct my own study on language pathology—I chose to pursue my interest in neurolinguistics through an entirely different field: literary studies.

This project has morphed many times over the years. Initially concerned with how fictional dementia narratives represent the disease syndrome and what narrative techniques are used to evoke a sense of ‘what it’s like’ to be living with dementia, I later became more interested in the ethics, aesthetics, and politics of dementia life writing. I soon realised that dementia raises a host of philosophical questions (Who am I without my memories?), ethical conundrums (Am I obliged to force my family member with dementia to eat when she no longer wants to?), and political issues (How much money do we allocate to dementia care? And significantly, *who* cares for people with dementia and under what conditions?). Reading widely across media and genres (including theatre, opera, and poetry), I finally returned to my home base—narrative studies—as a lens to approach questions of experience, empathy, ethics, identity, and care.

But like most people I know, I have also had ‘dementia in the family.’ Both my maternal grandparents lived with dementia towards the end of their lives. My grandad’s language became more poetical—but we still tried to make sense of what he said and, I think, even enjoyed the beauty and evocativeness of his language. When I visited, he seemed contented in the nursing home to which he finally moved. Nor—despite his previous intellectual prowess—did his life to me seem tragic, a ‘death before death.’ His death, when it came was absolute and it was then that we grieved.

My grandmother was diagnosed with dementia when she was in her late 80s. She was by then living in Shetland, to where she had removed herself after my grandfather’s death. I never got to visit her at the time. But I got a sense, from other family members, that visiting her and interacting with her actually became easier as the condition progressed. (And this, despite such ‘problem behaviour,’ as the professional jargon has it, as undressing in front of others.) So, yes, professionally and within the context of my own family, I have first-hand experience of dementia—although it goes without saying that this experience is not at all comparable to being a family care partner. But, in any case, my interest was foremost spiked by academic questions: what does it mean to lose language—for the person, her sense of self, and her relationships? And how can one, paradoxically, represent a condition considered beyond language through language? Crucially, too, my own experience departs from dominant narratives about dementia as ‘tragedy,’ ‘death before death,’ and ‘loss of self.’ As this book aims to demonstrate, the stories we tell about dementia are enmeshed with this predominantly dehumanising discourse, but they are also more complex. They tell of relationships improved, of humour, of love, as well as of despair, ethical conundrums, and systemic failings. They explore what it means to be human. They spin yarns in which dementia is the plot-device through which family heritage is unearthed and (murder) mysteries unfold. Others present calls to action to change dementia care. Stories about dementia may solidify stereotypical views of people with the condition, but they may also challenge or surprise. Most importantly, the stories told by people with dementia, I believe, exert an ethical call for those of us not (yet) affected to engage and to listen.

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I would like to thank Sarah Leavitt and John Hauge for their generous permission to reproduce artwork from their graphic memoirs. A big thank you also to David Clegg from the Trebus Project for the permission to use the stories collected in *Tell Mrs Mill Her Husband Is Still Dead*, as well as for his insightful comments on the production, editing process, and initial reception of these stories. Parts of my work on this collection discussed in Chapter 3 have previously been published in an article entitled “‘No Narrative, No Self’? Reconsidering Dementia Counter-Narratives in *Tell Mrs Mill Her Husband Is Still Dead*.” *Subjectivity* (2018) 11: 128–43.

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Many colleagues, friends, and family members have contributed in their own unique ways to the process by which this research has evolved. While too numerous to list, none are forgotten. Special mention is due, though, to my parents, Karl and Deborah Reichl, for being there from start to finish.

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Introduction

Reconsidering dementia narratives

Two starting points

Consider these extracts from two contemporary dementia narratives:

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)

The first extract is taken from Margaret Forster's novel *Have the Men Had Enough?* (1989) and the second from Cary Henderson's *Partial View* (1998), a collaboratively created first-person account about living with Alzheimer's. Forster's novel explores the difficulties of providing home care for an ageing relative with dementia. Henderson, by contrast, explores what it's like to be

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living with dementia for the person affected. Both narratives address the uneasy question of what makes us human and when a meaningful life ends. Both position dementia as a problem case: dementia is seen to threaten the very humanity of the person with dementia, and as the quotation from Forster highlights, may put that person's life at risk.

In the following, I want to use these two examples as entry points into my study of (more or less) contemporary dementia narratives.¹ I ask what questions these narratives raise, and what they tell us about how we conceive dementia, a condition that has increasingly come to the fore of public awareness. I begin with Forster's novel.

Dementia represents a major public health concern. As our societies age, more and more people are affected by dementia. Accordingly, the number of people involved in providing care—from family members to professional caregivers—is rising. Social science research suggests that family caregivers experience ill health, depression and social alienation due to their caregiving duties. Increasing incidence rates of dementia, coupled with restricted financial and human resources raise moral questions about solidarity and caregiving. Forster's novel explores the 'burden' of family caregiving and, as early as 1989, it asks how much future generations will be prepared to invest—emotionally as well as financially—in older and increasingly incapacitated generations.

At the same time, international reports and local scandals show that dementia care frequently falls short of what may be called adequate or indeed humane care (see also Burke 2016). People with dementia² are disadvantaged, neglected, or even abused. Indeed, their life may no longer be considered worth protecting, as the debate about euthanasia in dementia exemplifies (Johnstone 2011, 2013). Rectifying abusive 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 Forster's novel, the major conflict revolves around the problems of providing home care while balancing the needs of all family members involved.

Significantly, the story is not told from the perspective of the person with dementia but from two familial caregivers: Jenny, the daughter-in-law of the character with dementia, and her granddaughter, Hannah. Neither of these women is Grandma's primary caregiver; rather, that role falls to her daughter Bridget. The main conflict in the novel arises from Bridget's desire to keep her mother at home—and her inability to sustain home care without the help from other family members. The extract quoted above must be situated in the larger context of the novel's plot; 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. Jenny's call for urgent action—at first

seemingly similar in nature to the advocacy story Alzheimer's Associations tell—in fact represents a call for political action towards legitimizing euthanasia. However, as is typical of the novel, Hannah's narrative critically reflects on her mother's perspective and ethical stance. 'Will we?' she writes, in response to her mother's injunction that her generation will 'have to stop being scared to kill the old' (250). The novel then, within its narrative plot, opens up for discussion the process of decision-making regarding end-of-life care and the (il)legitimacy of life-ending measures, such as voluntary euthanasia or physician-assisted suicide.

Have the Men Had Enough represents dementia care as a downward spiralling nightmare, impossible to sustain for familial caregivers. 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 this condition (Burke 2015: 39). Heike Hartung (2016: 202–3) goes so far as to suggest that the novel advocates 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 storylines about dementia propounded through public media—that is, of Alzheimer's as an 'epidemic' that will lead to an insurmountable global 'care crisis.' As a novel, though, Forster's text offers its own vision of this situation and invites its readers to think through some of the complex ethical issues dementia raises.

This narrative then both reflects the sociopolitical context of dementia care in the late 20th/early 21st century while raising a number of questions relating to the role of fictional narratives in current ethico-political debates about dementia: How do the rhetoric and aesthetics of a fictional text interact with the ethics of dementia care? How are readers invited to think and feel about the character with dementia, the problem of dementia care, and the question of euthanasia? What role does the mode of representation (narrator, focalisation), the medium (print text vs. visual media), and the genre (novel, autobiography, or documentary) play in structuring the reader's response? What effects might narrative empathy either for the character with dementia or for caregivers have on readers' attitudes and actions towards people with dementia or their caregivers in 'real life'? This study aims to address these questions relating to the role of fictional dementia narratives in the current social and political context of dementia care and thereby contribute to ongoing debates about the role of narratives both in first-wave and second-wave (or critical) medical humanities.³

Despite addressing a broad band of my research questions, Forster's text does not, however, exhaust the possible issues that dementia narratives both raise and attempt to answer. Cary Henderson's autobiographical writing speaks to another dominant storyline about dementia: that is, of dementia

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as a tragic ‘loss of self’ and ‘death before death.’ It is one of a growing number of first-person accounts or autopathographies⁴ written by people with dementia about what it is like to live with this disease syndrome. Like other illness narratives, Henderson’s *Partial View* (1998) writes against the dominant storyline in Western popular and biomedical culture (Swinnen and Sweda 2015), which denies people with dementia continuing subjectivity.

Henderson’s journal evokes in a lively fashion how the world of a person with dementia changes—mentally, physically, and socially. 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 also 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.’ As such, the text problematizes the view that illness narratives act as unilateral counter-narratives to the dominant dehumanising view of a given disease.

If Henderson’s journal deals with the experience of living with 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 expands but also highlights the limits to life writing in dementia. The episodic nature of his ‘musings’ also raises the question of how coherent a narrative need be in order to function as an identity narrative—as a means of claiming selfhood in the social sphere. Critically reflecting on his work therefore draws attention to both the potential enabling and pernicious effects of narrative as a tool for claiming identity or identities in dementia. More generally, Henderson’s autopathography highlights several important roles narrative plays in current discourses about dementia. Problematizing and clarifying the role of narrative in dementia studies and in the medical humanities more generally constitutes the primary aim of the present study.

Why narrative?

Despite recent calls to curtail the role narrative plays in medical humanities research (Woods 2011), narrative remains both an important target of analysis and crucial research tool. In particular, narrative is intimately connected to the debates around dementia. This is not to say that other forms of self-expression, such as music, art, photography, or other literary genres, such as

poetry or drama,⁵ do not represent illuminating areas of study in relation to contemporary representations of dementia. However, including these genres would have made this study scientifically unmanageable. Furthermore, this monograph is based on the premise that narrative and narrative studies have something particular to contribute to public discourse on dementia, to the growing field of literary dementia studies, and to medical humanities research more generally. I present in short my working hypotheses here. The remainder of the introduction will contextualise these claims by providing the background to biomedical and cultural understandings of dementia, literary dementia studies, and the medical humanities. Developing and testing the hypotheses outlined here constitutes the body of this study.

First, narrative functions as a sense-making device (Herman 2013, Hutto 2007a, 2007b). 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 (see also Sabat and Harré 1994: 147). Dementia narratives open up the possibility of exploring dementia (and indeed, other aspects of what it means to be human) at the person level. 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’ (Herman 2013: x). In evoking a rich experiential account, similarly to the argument put forth by Havi Carel (2008) for phenomenology, narratives may counter and complement biomedical understandings of dementia as a pathology of cognition. Further, collaborative life writing projects (Clegg 2010) and conversational storytelling in dementia highlight that narrative remains an important tool for people with dementia to make sense of their environment and of their place in it (Hydén 2018). 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 condition holistically and within the domain of human action and meaning.

Second, both fictional and non-fictional illness narratives may contribute to a better understanding of the phenomenology of dementia. However, narratives, too frequently seen as affording ‘insight’ into a given disease, also need to be scrutinised for the ways they construct and represent the experience of a given disease (Woods 2011). By drawing on the tools of cross-medial narratology, I aim to reflect on how the experience of living with dementia is aesthetically mediated and how the representation of people or characters with dementia is harnessed to the rhetorical aims and affective structures of a given storyworld. I explore the possibilities but also the *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.’

Third, narrative identity is relevant to the discourse about selfhood in dementia. Narrative identity has come to the fore in discussions about what constitutes a ‘self’⁶ and how we claim identity for ourselves. A whole range of scholars from different disciplines have probed the extent to which selfhood or identity is constituted through narrative (see Bruner 1991, 2003, 2004, Dennett 1993, Eakin 1999, 2008, Ricœur 1991a, 1991b)—some arguing that identity is always narratively constructed. However, such views have not gone unchallenged (see, for instance, Sartwell 2000, Strawson 2004). Galen Strawson (2004), in particular, provides a damning critique of the narrativist approach. Most importantly for my argument, he highlights how according to strong narrativist views of identity he and with him many others risk not being considered as persons at all (447).

Without going into the particulars of the debate here, the narrative identity hypothesis is clearly relevant to the discourse about people with dementia in which ‘selfhood’ becomes a contested terrain. 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, the concept of narrative identity has also been employed to draw attention to how people with dementia continue to claim identities for themselves (Hydén 2018), 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. Narrative identity also becomes relevant, then, when considering the extent to which identities are constituted and held in relationships. Relational identity, especially as it has been explored 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 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 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 by me. I therefore propose, with Stephan Millett (2011), that we bracket or even disregard the question of whether selfhood is ‘lost’ and instead concentrate on how narrative is used to claim identities or communicate the experience of living 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) therefore constitutes another important strand of my research.

And finally, narrative is at the heart of a number of debates within the medical humanities about insight or understanding, empathy, and ethics (Woods 2011). These concerns about the role and function of narrative are equally central to my discussion about dementia narratives. At issue is whether narrative, and the novel in particular, provides an inroad into understanding the life world of others (Bitenc 2012, Felski 2008, Waugh 2013), whether narrative empathy leads to prosocial action or more caring health-care professionals (Charon 2006, Keen 2007, Whitehead 2017), and how narrative ethics play out more generally in the context of our social being as moral agents (Meretoja 2018, Morris 2002, Nussbaum 1990, 1995, 1997).

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. More importantly, the causal link that has been proposed between the reader's experience of narrative empathy and consequent ethical, moral, or altruistic action must be questioned (see Keen 2007). Indeed, although empathy has long been heralded as a good to be cultivated, more recently scholars have drawn attention to the nefarious use of empathy as a form of appropriation or as a tool for managing patients (Garden 2007, Hester 2016). Drawing on feminist affect theory, Anne Whitehead (2017) shows how the effects of empathy can divide rather than unite 'us' in a common humanity, or might be damaging to the object of empathy. It is important, then, to determine what literature can and cannot do when it comes to enhancing the moral and empathetic capacities of readers. Further, my study 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.

The aim of this book is not to provide a *comprehensive* analysis of the ways dementia is represented in contemporary film, fiction, and life writing. Nor does it trace the literary history of this condition by providing a *diachronic* exploration of the medical and cultural attitudes to dementia, old age and age-related decline—a history which, as other authors have shown, is long and complex (see, among others, Ballenger 2006, Thane 2005, Wetzstein 2005). 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 in Western, industrialised societies. This focus on issues of identity, empathy, and ethics as they surface and interact with hypercognitive, productivity-demanding capitalist value systems, and specific health-care, political, and academic institutions in the Western world entails that this study also does not offer a *cross-cultural comparative* approach to dementia narratives. Even within the range of countries included (Australia, Canada, US, UK, and Europe) there is huge variability between social care and political systems. To have included dementia narratives from Asian, Middle Eastern, and African cultures alongside the current case studies would have meant disregarding important cultural and economic differences; ignoring different concepts of identity, family, or honour; and neglecting the differences in healing systems and other sociocultural practices that constitute the context for such narratives. A truly comparative approach would necessitate a thorough engagement with the context and culture of ‘non-Western’ dementia narratives.⁷ Both a diachronic exploration and cross-cultural comparisons of attitudes towards people with dementia are certainly worth exploring in their own right, and I hope this study will provide a point of departure for future research.

Instead, by engaging with a range of case studies across genres, media, and modes,⁸ I outline ways of understanding the cultural significance of dementia within a loosely related value system in which dementia is construed as disease syndrome and in which identity is constructed around cognitive functioning, with a view to developing a more nuanced understanding of how ‘we’ (in the global North) construct and consequently live with this condition. My aim is to raise awareness for a strand of literature that is only slowly receiving critical attention—that is, fictional and non-fictional dementia narratives across a range of media—to situate this literature in contemporary discourses about dementia and selfhood, empathy, and ethics, and to mine its potential for an as yet imperfectly understood and certainly underfunded area of healthcare: dementia care. To contextualise my discussion of dementia narratives, I turn, first, to a brief sketch of the biomedical and cultural meanings dementia has accrued, before situating my approach in current literary dementia studies and the medical humanities.

Biomedicine and the cultural meaning of dementia

Dementia is a progressive neurodegenerative syndrome, that is, a clinical term which describes a constellation of symptoms that may be caused by a number of underlying diseases, such as Alzheimer’s disease, vascular dementia, frontotemporal dementia, Lewy body dementia, and others. Common symptoms include a range of impairments to cognitive functions, among them memory and language, as well as behavioural changes. Since Alzheimer’s disease currently constitutes the most common form of dementia, the term is frequently used for the whole disease syndrome in cultural discourses. I prefer predominantly to use the umbrella term ‘dementia’ as

both the more accurate and more inclusive term, unless where Alzheimer's has been diagnosed or is specifically the topic of a given narrative. For ease of reading, however, I at times use the term 'disease,' even though strictly speaking dementia is not a disease but a syndrome.

Despite difficulties in determining the factors that cause dementia, as well as difficulties in distinguishing 'normal' from 'pathological' ageing,⁹¹⁰ neurobiological disease models of dementia currently underpin our understanding of the condition. Rather than delving into state-of-the-art neurobiological explanations of the disorder, I here want to 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.

A brief history of dementia

In the 'age of Alzheimer's' it may be difficult to imagine that cognitive decline in old age was not always considered pathological.¹¹ The conceptual history of dementia is well documented.¹² Although Alois Alzheimer presented his famous case study of Auguste D. in 1906, it was only in the late 1970s and early 1980s, due to a complex set of socio-economic, 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 syndrome as a contemporary problem. Tracing the history of Alzheimer's highlights the degree to which diseases, in general, are always at least partially socially constructed (Hacking 1999a, 1999b) and accrue meaning in their biocultural context (Morris 1998).

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 condition that impacts on the way it 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 iatrogenic¹³ effects of biomedical practice itself. However, my focus here is not on biomedicine but 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 syndrome (Basting 2003a: 88).

Demography and demonisation

While demographic changes clearly play an important role in the contemporary 'rise' of Alzheimer's, the particular fear generated by dementia is due to this condition threatening 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 conforms to these values (Post 2000). Ethicist Stephen Post calls attention to the risks inherent in current 'hypercognitive' value systems, in that people with dementia may be removed from the sphere of moral concern. In the worst case, their lives might no longer be considered worth protecting and they may be under pressure to consent to physician-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 syndrome (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). Popular discourse too is rife 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 or she is 'long gone.' Although such descriptions speak to the 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.

Reconsidering dementia: reparative moves

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 discusses how disease labelling and seeing all aspects of behaviour as pathological facilitates social and medical control (1989: 599). The biomedicalisation of dementia may result in a self-fulfilling prophecy of impairment (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). Sabat and Harré (1992) 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.

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: 45–9). 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.

A growing literature explores the question of what may actually *constitute* personhood or 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). As I suggest in Chapter 1, the vexed ontological question of the persistence of selfhood in dementia may perhaps best be understood if we view selfhood in phenomenological terms 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, the social identities or personae of a person with dementia may indeed be eroded, both by disease processes and social interactions, relatively early on.

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 has been crucial in drawing attention to the narratives people with dementia tell (Hydén 2011, 2018, 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, 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 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 (Chapter 3).

The Alzheimer's 'epidemic': care, cost, and social justice

Dementia has become a major public health concern. 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 apocalyptic 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 21st century.

Alzheimer's Disease International and related associations have been instrumental in raising awareness about dementia and improving the lives of those affected. Nonetheless, there are some negative implications inherent in the plot lines that the association employs in order to justify the urgent need for action. For one, the alarmist notion of an Alzheimer's 'epidemic,' 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 across the board. 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 NHS struggles to offer the kind of care suitable for a person with dementia. Agencies send different carers to people with dementia daily, undermining the possibility for a care relationship to form. 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. Further, limited visiting hours for family caregivers deprive people with dementia in institutions of the familiar faces and support that would help orientate them and make them feel safe. In sum, institutions are not set up to cater for the needs of the deeply forgetful. Importantly, besides these local problems, changes to the basic principles of the welfare state over the last decades present major challenges for dementia care. As Lucy Burke (2015) notes, the spread of neo-liberal 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 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 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. Dementia narratives might then function as moral laboratory to explore dementia care, an idea I develop more fully in Chapter 6.

Literary dementia studies and the medical humanities

Dementia has become ubiquitous in our times. It features not only in news reports, but in TV series, films, novels, plays,¹⁴ 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. But what can a literary exploration of dementia contribute to our understanding of dementia and of its place in our society?

In recent years, a growing number of literary and cultural scholars, as well as academics working in fields such as gerontology, have analysed the way dementia is represented in contemporary literature, film, and life writing. Apart from a number of dispersed articles, three essay collections (Maginess 2018, Ringkamp et al. 2017, Swinnen and Schweda 2015) and by now three monographs (Falcus and Sako 2019, Medina 2018, Zimmermann 2017) attest to the fact that the representation of dementia across literary genres and cultural artefacts is of increasing interest. Many of these essays pursue an ethically driven agenda in suggesting that dementia narratives further our understanding of the phenomenology of dementia and thereby counter reductionist biomedical approaches to the disease syndrome. They also challenge stereotypical representations of people with dementia across different genres, including film, and argue that these representations have serious implications for how we think and feel about, and therefore act towards, people with dementia. Others are concerned with how dementia functions as a metaphor itself to reflect on complex ethical issues of postmodern Western societies. Unfortunately, not all contributions are equally circumspect

as to the language they use to discuss dementia, or the ways their own analysis might at times confirm dominant stereotypes about dementia.

Foremost among the scholars to critically explore cultural representations of dementia, disability scholar Lucy Burke has challenged the representation of dementia in film-poetry (Burke 2007b), life writing (Burke 2007a, 2008), and fictional narratives (Burke 2015, 2016, 2017, 2018). 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 sociopolitical relevance of dementia discourses and the need to challenge cognitivist notions of personhood in the context of neo-liberal politics. Burke's exploration of how dementia is represented in contemporary media represents an ethico-political analysis geared towards acknowledging the personhood of people with dementia. Her aim is the recognition of the basic human rights of people with dementia to dignity and care.

Although I agree with Burke's aim, my work is slightly different in both focus and method. Like Burke, I am interested in how narratives contribute to current debates about dementia. In a second step, however, I am interested in how narrative studies may inform current debates about the role of narrative in the medical humanities more generally. Given my concern with the tools of narrative studies, I pay more attention to how genre, medium, and mode shape the representation of dementia. So, while Burke, in an article on narrative identity in dementia life writing (2014), somewhat incongruously discusses Michael Ignatieff's novel *Scar Tissue* as primary case study, my aim is to explore how genre conventions (e.g. autobiography vs. novel) govern and shape the way we understand narrative identity and other aspects of living with dementia.

As literary dementia scholars demonstrate, attending to the way dementia is constructed in the cultural imaginary is crucial, since it informs the way dementia is lived, experienced, and treated. My study therefore follows in these footsteps, while according more attention to first-person accounts as well as to generic and medial differences between dementia narratives than has, but for some exceptions, so far been the case. However, my argument is also more specific than simply deconstructing the way dementia has been represented in literature in the last thirty odd years. I suggest that dementia narratives 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 [1938] 1995) and think through dementia care dilemmas. In short, dementia narratives can work as a moral laboratory for considering the dilemmas of dementia care, with critical readings 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 primary 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.

Illness narratives: countering master narratives and exploring the experience of illness

Literary dementia studies must also be situated in the context of earlier and ongoing research on illness narratives. 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) and Arthur Frank’s *The Wounded Storyteller* (1995), across literary studies of pathography (Bolaki 2016, Hawkins 1993, Wiltshire 2000), to Rita Charon’s practice-based *Narrative Medicine* (2006, 2017). While the focus was initially on doctors’ narratives of illness (Montgomery Hunter 1993, Whitehead 2014), illness narratives soon became the prerogative of the ill person herself (Vickers 2016). 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).

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 condition. As a ‘disease of memory,’ it taps into contemporary Western societies’ obsession with the capacity to remember. More importantly, it attacks those aspects of human cognition that are considered to distinguish humans from other animals—language, higher-order thought, and memory. Dementia therefore goes to the heart of discussions of what it means to be human. Like other illness narratives, dementia autopathographies challenge cultural and biomedical constructions of the condition while exploring what it’s like to live with a given disease and how this experience affects one’s sense of identity.

These two elements of illness narratives—(1) ‘countering’ and (2) exploring the experience of a given illness with the object of elucidating both health-care professionals and the general public—have been central to the development of the medical humanities. In first-wave or mainstream medical

humanities, such narratives were accordingly integrated into medical training with the aim of broadening health-care professionals' understanding of a disease as more than a set of biomarkers and symptoms. Recently, the critical medical humanities and health humanities alike (Crawford et al. 2010) aim to widen the scope of the field beyond the focus on doctor-patient encounters, on illness experience, and/or on health-care education (Whitehead and Woods 2016: 3). Due to the underlying assumption that engagement with literature promotes more empathic doctors, which may be seen to underpin certain models of health-care education, proponents of the medical humanities have, perhaps rightly, been accused of 'retrograde rhetoric regarding the "humanizing humanities"' (Spiegel 2012: 205). From other sides, the role of the humanities as 'supportive friend' (Brody 2011: 6), in the service of medicine, has equally been challenged (Viney et al. 2015: 3).

In contrast to the supportive role, medical humanities scholars frequently position themselves as opposed to the structures and institutional power of biomedicine. Mobilising the notion of 'critique,' Therese Jones stresses that humanities research methods '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: 27–8). Jones' optimistic evaluation of the almost 'revolutionary' potential of the humanities might, however, be challenged in turn. Medical humanities scholars may be criticised for assuming a merely oppositional stance to biomedicine—providing an endless 'critique' without being able to go beyond that critique. As Viney and his collaborator suggest, 'the arts, humanities and social sciences are best viewed not as in service or in opposition to the clinical and life sciences, but as productively entangled with a "biomedical culture"' (Viney et al. 2015: 2). This monograph problematizes the different ways in which dementia narratives are in opposition, complicit, and entangled with biomedical discourses on dementia. While engaging with themes that have been relevant to both first-wave and second-wave medical humanities, I aim to move beyond dualistic possibilities which set biomedicine up as the main target of criticism. I focus instead on the subversive and problematic 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, as well as in the context of rethinking the role of narrative and narrative identity in the medical humanities more generally.

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. Narrative is examined in its many permutations and with regard to its different functions: as

representational tool, as tool for meaning-making, and as tool for identity construction. But it also emerges as central to two concepts that are at the heart of debates in narrative medicine and the critical medical humanities: (narrative) empathy and (narrative) ethics. To explore these concepts and different functions of narrative, the study moves back and forth between fictional and non-fictional narratives as well as between different media and subgenres within these two categories. The two opening chapters in Part I are concerned with exploring the experience of living with dementia as well as the relationship between techniques of representation, narrative empathy, and understanding. Part II moves on to explore the aesthetic, ethical, and political implications of the emerging genre(s) of dementia life writing. A final pair of chapters in Part III engages with how fictional and non-fictional narratives may inform the development of dementia care and thereby contribute to ongoing debates about the role of narrative and narrative ethics in the medical humanities.

Chapter 1 explores how life writing might contribute to a better understanding of how dementia transforms self-experience as well as one's relationships to the physical and sociocultural world. To develop this question, I draw, first, on a range of autopathographies, that is, illness narratives by people with dementia themselves. 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 aspects of embodied selfhood and provide means of exploring the potential of embodied communication in dementia. While Chapter 1 introduces the important notion of embodiment and relatedly, embodied communication, it is the least theoretical of all chapters, intended to introduce readers to the field of dementia studies, and particularly to the life world of dementia. My aim is to allow the words of people with dementia within the context of this chapter to 'speak for themselves' as entry point into this study. Later chapters more explicitly take up the issue how genre, medium, and the larger discursive culture of a given dementia narrative shape its meaning, as well as its ethical and political impact.

Chapter 2 addresses two fields of enquiry: 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, is it reasonable to assume that narrative empathy translates to prosocial 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 identity, self-presentation, and representation in the emerging genre(s) of dementia life writing. My focus here shifts more squarely to the ethics, aesthetics, and politics 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 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, I return to autopathographies by people with early-onset dementia, and second, I consider collaborative life history projects in nursing homes, in particular the collection *Tell Mrs Mill Her Husband Is Still Dead* (Clegg 2010). Autopathographies emerge as entangled in popular discourses and genre conventions in ways which complicate the notion of counter-narrative. Collaborative life story work in turn stresses the collaborative nature of meaning-making in conversational storytelling while also challenging and redrafting notions of narrative coherence.

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). At the same time, caregivers' memoirs represent ideal case studies to consider the role relational identity plays in dementia. I therefore develop 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: primarily, 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 the context of dementia care. Chapter 5 argues that 'care-writing' (that is, caregivers' memoirs) may be considered a valuable source of evidence when it comes to theorising and developing dementia care. Caregivers' memoirs explore the dilemmas involved in supporting someone with progressive cognitive impairment. They thereby provide a means for readers to 'live through' (Rosenblatt 1995)—and think through—these difficult dilemmas. The authors of these memoirs imagine and develop alternative treatment and care options that can potentially be adapted to other contexts. Indeed, because they have lived alongside the person with dementia, familial care partners 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 can therefore articulate strategies for addressing the needs of people with dementia, and of their care partners, holistically. Extrapolating from these texts, readers gain awareness of key caregiving dilemmas, but may also take away ideas for implementing ways of being with or caring for a person with dementia, based on more open and creative attitudes to communication and care.

Lastly, Chapter 6 aims to develop new avenues for thinking about how literary fiction may intervene in medical humanities contexts by going beyond some commonly accepted notions about narrative as 'humanising' medical practice. While Chapter 2 problematized that there is a link between literature and the provision of empathetic care, Chapter 6 seeks to develop a critical view of fictional dementia narratives that does not simply slot into ethical agenda pursued by the medical humanities. 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 specific 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. Johnson's *House Mother Normal* ([1971] 2013) as case studies. Second, I aim to explore what other role (beyond supposedly creating empathetic individuals) narrative may play in the medical humanities. Returning to an old idea that literature acts as tool for ethical thinking, I suggest some ways in which dementia novels may prompt their readers to engage with 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 insights into the bioethical dilemmas bound up with dementia care, developing care-oriented thought experiments more fully than would be possible in non-fictional accounts of dementia.

Notes

- 1 Since I discuss dementia as it has been constituted in the rise of the Alzheimer's movement in the 1970s and 1980s, I consider narratives from that time period until roughly 2018.
- 2 A note on terminology: First, talking about 'people with dementia' may seem to suggest a homogeneous 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 term 'person with dementia' over the terms 'victim,' 'afflicted person,' or 'patient' that already constitute the person in a reductive way.

- 3 For a critical medical humanities approach see Viney, Callard, and Woods (2015) and Whitehead and Woods (2016). At the same time, the limitations inherent in the disciplinary label ‘medical’ are challenged by the emerging field of health humanities (Crawford et al. 2010). See also <http://healthhumanities.org/>. Note that this disciplinary label is also misleading in that the medical and health *humanities* include and are even driven by social science disciplines such as (medical) anthropology, psychology, and sociology.
 - 4 Autopathography is defined as life writing about the progression of an illness and written by the person affected (Couser 1991, 1997, Graham 1997). Avrahami (2007) uses the term illness autobiography. Hawkins’ study (1993) deals with both autopathography and pathography—illness narratives written by carers—under the heading of pathography.
 - 5 Although there are strong arguments for categorising plays as narratives (Richardson 2007), I do not consider drama in this study.
 - 6 The terms ‘self,’ ‘identity,’ ‘person,’ and ‘life’ are frequently used interchangeably. I acknowledge the contested nature of all these terms, but for ease of reading refrain from placing them in quotation marks.
 - 7 For some cross-cultural or non-Western perspectives across anthropology and literary studies see Asai, Sato, and Fukuyama (2009), Cohen (1998), Holstein (2000), Hussein (2018), Leibing (2002), Nayar (2018), and Traphagan (2006).
 - 8 Usage of the term ‘mode’ differs 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 types of representation within a narrative text (such as perspective or focalisation) as well as types of representation across 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 study is on narrative, my chief concern is with mode taken in the local sense.
 - 9 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).
 - 10 Compare Whitehouse (2008) who questions the validity of the Alzheimer’s disease category. For other dissenting voices see Holstein (2000: 171).
 - 11 See Leibing and Cohen (2006) on the pathologisation of senility.
 - 12 See among others Ballenger (2006), Fox (1989), Gubrium (1986), Holstein (1997, 2000), Leibing and Cohen (2006), Shenk (2001), Wetzstein (2005), and Whitehouse, Maurer, and Ballenger (2000).
 - 13 The term ‘iatrogenic’ relates to illness caused by medical examination or treatment.
 - 14 See, among others, Tom Murphy’s *Bailegangaire* (2009), Abi Morgan’s 27 (2011), and Fiona Evans’s *Geordie Sinatra* (2012).
- 1 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 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.
 - 2 For further documentaries on dementia that present a range of different styles 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).

- 3 Davis (2004) emphasises loss of self to legitimate family caregivers' grief.
- 4 These terms represent different points on what could be considered a continuum on notions of 'selfhood,' ranging from (social) identity to (perspectival) self. While I discuss notions of selfhood and identity across this range of meanings, I make no hard and fast distinctions among the terms.
- 5 Recent neuroscientific studies reveal the extent to which emotions are a function of the brain and therefore also prone to be affected by brain damage or disease (Damasio 1994, 2000, 2010).
- 6 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 guises. Relational models of identity have also figured importantly in life writing studies (Eakin 1998, Friedman 1988, Henry 2006, Mason 1980, Miller 1994, Smith and Watson 2010).
- 7 Apart from Alzheimer's disease, some of the authors were diagnosed with multi-infarct dementia, Lewy body dementia, frontotemporal dementia, or a combination of these. What unites these authors is that the condition manifested itself early in life (before the age of 65).
- 8 The number of dementia blogs is too vast to list. Morris Friedell's blog had a significant impact on patient advocacy in the 1990s 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 www.richardtaylorphd.com/blog.html. An example of a blog by a person with Lewy body dementia can be found at <http://parkblog-silverfox.blogspot.co.uk/>. Wendy Mitchell's blog continues after her memoir was published in 2018: <https://whichmeamitoday.wordpress.com>. Kate Swaffer's blog <https://kateswaffer.com/daily-blog/> provides a forum for the Australian and global dementia advocacy movement.
- 9 These include Bryden (1998, 2005, 2015, 2018), Couturier (2004), Davis (1989), DeBaggio (2002, 2003), Donohue (2009), Graboys and Zheutlin (2008), Henderson (1998), Lee (2003), Mobley (2007), McGowin (1994), Mitchell (2018), Rohra (2011), Rose (1996, 2003), Schneider (2006), Swaffer (2016), and Taylor (2007).
- 10 Although Lucy Whitman's collection of personal stories by people with dementia *People with Dementia Speak Out* (2016) is more diverse in terms of age and ethnicity, she regrets not having been able to include authors from the LGBT (Lesbian, Gay, Bisexual, Transgender) community. In an appendix, she highlights the particular stigma and recurring experiences of discrimination—including in care settings—that people from the LGBT community face and she stresses the need to address the specific care requirements of this group (2016: 289–90).
- 11 See the discussion in Ratcliffe (2007: 107).
- 12 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.
- 13 The recent dementia diaries project—audio diaries that are shared on the website <https://dementiadiaries.org/>—offers another means to allow self-expression and communication in dementia without placing storytellers under the constraints of mainstream publishing.
- 14 See Ratcliffe (2008) on shifts in 'existential feelings' in psychiatric illness.
- 15 The discrepancy between narrative voice and narrative experience is 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 events, based on information provided by his wife.
- 16 www.st-andrews.ac.uk/psychology/people/pgprofiles/kma2/. Last accessed 31.03.2015.

- 17 Compare Heidegger's distinction (1962) between objects being 'present-at-hand' (*Vorhanden*) versus 'ready-to-hand' (*Zuhanden*). 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).
- 18 Truscott (2004a) elaborates ways to achieve such flow in her autobiographical journal article.
- 19 Compare, in this connection, research into animal-assisted therapy in dementia (see Marx et al. 2010).
- 20 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.
- 21 Fiction films provide similar affordances. See Chapter 2.
- 22 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.
- 23 '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').
- 24 'Was hab ich gemacht?' [1:20:28].
- 25 'Oh, und wer war das zum Beispiel? Ich war's nicht. *Ich war's nicht*' [42:08].
- 26 See Chapters 4 and 5.
 - 1 Dementia films have seen a veritable 'boom' in recent years. See, among others, literary adaptations such as *Away from her* (Polley 2006), *The Notebook* (Cassavetes 2004), and *Small World* (Chiche 2010), science fiction comedy drama *Robot and Frank* (Schreier 2012) as well as biopics such as *Iris* (Eyre 2001) and *The Iron Lady* (Lloyd 2011). Furthermore, Alzheimer's features in a number of science fiction films and thrillers. These frequently follow the plotline of animal experiments for a new Alzheimer's drug that spiral fatally out of control, or involve the trope of either a monstrous carer or demoniacal/possessed person with dementia.
 - 2 In Genette's terms (1980), this narrator would be categorised as heterodiegetic as well as extradiegetic—that is, as a narrator not involved in the events being reported and not a character in the storyworld who functions as an embedded teller. When discussing texts where the finer distinctions Genette's framework offers are not necessary, I mention the relevant narratological descriptors only in passing, or simply employ the traditional, but less precise, categorisation of narrators according to grammatical person (e.g., first-person or third-person narrator).
 - 3 Focalisation was introduced by Genette (1980) to distinguish between 'who speaks' and 'who sees or perceives.' This distinction draws attention to how readers may experience the narrative world through a focal character's mind and perception at times distinct from the narrator's vision and voice.
 - 4 For an introduction to mirror neurons see Iacoboni (2008).
 - 5 Of course, all reading experience necessitates cognitive activity. What I mean to highlight are that texts which are challenging because they disrupt 'immersive' reading experiences, by experimenting with form or using gaps, can still further an understanding of the experience of dementia and thereby change readers' attitudes and beliefs—as has been argued for immersive reading experiences.
 - 6 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.

- 7 Recent years have seen the publication of a range of first-person fictional narratives. A number of texts pair the first-person narrative of the person with dementia with other first-person narrators: family members, and others who interact with the person with dementia, see Coleman (2014), Krüger (2018) and Rill (2015). Cavanagh (2015) uses a first-person narrator with early-onset Alzheimer's who insistently addresses his narrative to his teenaged son. For novels with a first-person narrator that employ a crime story plot, see Richler (1997), LaPlante (2011) and Healey (2014). 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 experience of living with dementia. For an earlier crime story with a third-person narrator that uses Alzheimer's as plot device, see Suter (1997).
- 8 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. However, since animals share core consciousness with humans, the concept of core consciousness risks feeding into dehumanising discourses about people with dementia. At issues is of course, whether the respect we accord, or should accord, humans shouldn't also be extended to other species with consciousness.
- 9 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).
- 10 Since the ellipses here are part of the original, I use square brackets, here and elsewhere where this is the case, to indicate where I have omitted text.
- 11 Recent dementia novels, both with first-person narrators (Coleman 2014, Krüger 2018, Rill 2015) and with character focalisers (Downham 2015, Pritchett 2014), use a similar technique, although they vary in the degree of coherence they accord to the perspective of the person with dementia.
- 12 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: 140–8). Charon develops the practice of 'Parallel Chart' writing to address the phenomenology of illness, and she demonstrates how this practice can yield clinical benefits (173–4).
- 13 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.
- 14 In fact, the words are Welsh and a translation of the first few words ('galluoag'-*competentable*; 'lwcus'- *lucky*; 'ynad'- *justice* or *to judge*) suggests that Johnson is adding another layer of meaning to his multilayered 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.
- 15 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).

- 16 Bernaerts (2014) 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).
 - 17 Genette (1980) classified such ‘infracation[s] of the dominant code of focalization in which a narrator provides more information than is licensed by this code’ as ‘paralepsis’ (Dawson 2013: 23). Dawson argues that first-person omniscience constitutes ‘another category of narrative voice’ (2013: 196). 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).
 - 18 See Alber (2013) on impossible spaces in narrative worlds.
 - 19 The end of the narrative represents an exception as it employs the auxiliary modal ‘would’ to indicate the counterfactual, hypothetical future scenario playing out in the narrator’s mind.
 - 20 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.
 - 21 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.
 - 22 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 correlation between transportation and the extent to which reader’ attitudes shift after reading a narrative. Their evidence suggests that fictional narratives influence readers’ beliefs, which, in turn, has implications for considering the role of narrative and narrative ethics in bioethical decision-making, see Chapter 6.
- 1 For a historico-literary overview see Oksenberg Rorty (2000). For studies that consider personhood and personal identity specifically in dementia from psychiatric and philosophical perspectives, see Hughes (2011) and Hughes, Louw and Sabat (2006).
 - 2 For an exploration of the relation between philosophical approaches to the ‘good life’ and old age see Small (2007).
 - 3 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).
 - 4 This is not to say that dementia does not damage the capacity to tell (life) stories.
 - 5 Taylor’s essays were initially published as blog posts. The comments on the advantages of sequential writing can be extended to blogging, since blogging is comparable to journaling in its ad-hoc everyday nature.
 - 6 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 autobiographers 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.

- 7 This move is similar to the one that Leibling and Cohen (2006) describe in the context of gerontology: by way of distinctions between the 'young old' and the 'old old,' the stigma attached to old age is shifted to the 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 impaired, 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.'
- 8 Helga Rohra, for instance, includes scanned images of her notes, what she terms her symptom diary ('Symptomtagebuch'), in her published account (Rohra 2011: 19, 27). In her introduction she also explicitly addresses the process of working with a writing assistant, stressing that it was important to her not to use a ghostwriter which would have masked her need for assistance in creating such a coherent account (Rohra 2011: 11, see also Zimmermann 2017: 112). Bryden similarly recounts how she made a habit of bringing brain scans to her talks in order to counter any challenges as to the validity of her diagnosis.
- 9 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.
- 10 See the project website for further information: www.trebusprojects.org/.
- 11 Abbreviated henceforth as *Tell Mrs Mill*.
- 12 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).
- 13 The ellipses are part of the original manuscript. They suggest hesitation in the storyteller's speech.
- 14 See also Herman (2013) for an account of narrative as an instrument of mind and a sense-making practice.
- 15 In the context of disability life writing, Couser similarly highlights the harmful depiction of disabled people as 'supercrrips' (Couser 2005). Seemingly 'positive' representations according to the norms of the culture do little to question dominant values and may place excessive burden on people who fall outside these norms to nonetheless live up to cultural expectations.
- 16 Moreover, 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.
- 17 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.
- 1 In recent dementia advocacy there has been a call to recognise that people with dementia are not merely the receivers of care and that so-called caregivers are therefore better described as care partners. While I find it important to acknowledge that relationships in dementia, despite certain changes, remain reciprocal, I refrain from using scare quotes to indicate the problematic nature of the terms caregiver and care-receiver in my analysis. I retain the terms not only for ease of reading and disambiguation, but also because I argue that caregivers' memoirs

- have become an established genre in dementia life writing. Nevertheless, in some cases I also use the term care partner to highlight the reciprocal nature of care relations.
- 2 Occasionally they may be written by a long-standing family friend (see Heywood 1994) or an in-law (see Gillies 2010).
 - 3 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.
 - 4 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 are considered particularly ethically suspect. 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 equally 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.
 - 5 Graham (1997) suggests that writing can provide a distancing effect and thereby a means of coping with illness since it allows the author to remain an authoritative agent in one domain of her life. Although his analysis is concerned only with autopathographies written by the person affected by the disease, it can be seen to apply equally to caregivers' memoirs.
 - 6 Authors discussed here are fiction and memoir writers, poets, or work in professions such as journalism, broadcasting, or literary criticism.
 - 7 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 docudrama 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). While caregivers' documentaries certainly raise complex ethical issues, they tend to be fairly thoughtful and at least offer self-reflexive engagements with the problem of voyeurism. Contemporary 'footage' of people with dementia aired on YouTube, without notions of consent or the critical process that a professional production might offer, is certainly highly problematic with regard to violating the affected person's privacy.
 - 8 The poet John Killick's collaboration with the photographer Cordonnier (Killick and Cordonnier 2000), which includes images of people with dementia, raises similar issues with regard to the ethics of representation. Zimmermann (2017) also discusses a number of photographic memoirs by family member, such as Carol Wolf Konek's father-daughter memoir *Daddyboy* (1991) and Judith Fox's spousal memoir *I Still Do: Loving and Living with Alzheimer's* (2009). While Zimmermann judges the latter 'devoid of any voyeurism' (2017: 37) and grounds her appraisal in the beauty of the photographic style, on the one hand, and the nature of a loving spousal relationship, on the other, questions remain as to the nature and content of the images, as well as the metaphors of fading away, darkness, and decline that they evoke.
 - 9 See on this point Couser's discussion of Oliver Sack's television documentaries (Couser 2004).
 - 10 See also Hartung (2016) on dementia narratives as *bildungsroman*.

- 11 A definitive inventory of such a fast-growing genre as filial dementia memoirs lies beyond the scope of this chapter.
- 12 Grant's memoir was preceded by Heywood's *Caring for Maria* (1994), a relatively unusual case of non-spousal male caregiving.
- 13 Compare also the works of the French author Annie Ernaux (1987, 1999).
- 14 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).
- 15 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.
- 16 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.
- 17 Franzen here repeats long-standing gender stereotypes, which cast childish behaviour as 'female.'
- 18 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).
- 19 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, the representation may have the most detrimental effect, not on the particular person portrayed but on people with dementia as a group.
- 20 Hauge'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.
- 21 Music has impressive potential to engage people with dementia: as a therapeutic tool, to improve memory and cognitive functioning, and as a means of interacting with others and expressing one's inner life-world. See Chapter 5 for a further exploration of this topic.
- 22 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 than gender, since life course expectations are more radically challenged by early-onset dementia, by which Hadas's husband was affected. By contrast, June and Brian Hennell's life as related in Lucy Whitman's (2016: 146–55) collection of stories

- by people with dementia may be considered to provide counter evidence to generalising claims about the impact of gender on care relations. The contribution discusses marital problems due to symptoms of early-onset frontotemporal dementia but also bears witness to the strength of the couple's relationship.
- 23 Currently being adapted into an animated film by Giant Ant. See <http://tanglesthefilm.com/>.
 - 24 For further autographics—autobiographical graphic novels or memoirs—that deal with dementia see Chast (2014), Demetris (2016), Farmer (2010), Hauge (1998) and Husband (2014). For a more explicitly fictional graphic novel outside the English-speaking world see Roca's award-winning *Arrugas (Wrinkles)* (2007), which has also been turned into an animated film.
 - 25 For a history of the genre of autographics see Gardner (2008).
 - 26 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.
 - 1 See, among others, Basting (2009), Basting and Killick (2003), Killick and Allan (2001), Kitwood (1997) and Stokes (2010).
 - 2 See, among others, Akpınar, Küçükgüçlü, and Yener (2011), Chappell, Dujela, and Smith (2015), Krause, Grant, and Long (1999), Russell (2001), and Wennberg et al. (2015). Many literary approaches also focus on the 'burden' of caregiving, see, for instance, Zimmermann (2010).
 - 3 For an exception that addresses the care dyad see Whitlatch et al. (2006).
 - 4 Once again, I use the term caregiver and care-receiver advisedly as I am aware these terms might enforce the notion of people with dementia as passive recipients of care who have nothing to contribute to relationships or society at large.
 - 5 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) and Innes (2009) 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 under-financed 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.
 - 6 'Auch professionelle Therapeuten versuchen ihr Glück mit Gretel.' All translations are my own.
 - 7 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.
 - 8 'Können wir irgendwohin setzen wo wir nicht sterben?' [sic].
 - 9 See additional material on the DVD 'Filmgespräch mit Andreas Dresen und David Sieveking' (Sieveking 2012).
 - 10 The medial differences in representation here hark back to my discussion, in the previous chapter, of the ethics of representing vulnerable subjects (Couser 2004).
 - 11 See the joint interview with producer Martin Heisler in the additional material on the DVD (Sieveking 2012).
 - 12 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.

- 13 Arguably, this loss of dignity is perpetuated in dehumanising and exposing representations of the person with dementia by family caregivers. Although, with Burke (2016) and Couser (2004), I worry over the violation of a person's privacy and the symbolic violence inherent in fictional and non-fictional accounts of dementia, I find Leavitt does not gratuitously expose her mother. Although explicit, the narrative does not revel in the kind of revulsion and shock aesthetic mentioned in other accounts. Importantly, her mother's bodily decline does not lead to a turning away from caring, or indeed 'prompt' or 'justify' any form of abuse (see Burke 2016: 598). Though debatable, the narrative medium in its abstract, cartoon form might also be seen to provide a further screen to protect the privacy of the person with dementia. See my discussion in Chapter 5.
- 14 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 to increase 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.'
- 15 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).
- 16 Playlist for Life, a charity founded by Magnusson, aims to bring personalised music to people with dementia. For further information see www.playlistforlife.org.uk/.
- 17 In her memoir *Circling My Mother* (2007), Mary Gordon similarly highlights how 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 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.
- 18 See <http://johnscampaign.org.uk/#/>, a UK-based campaign to make family caregivers of people with dementia more welcome in institutional settings.
- 19 The most well-known and elaborate community approach is the Dutch village Hogeweyk, an institution modelled entirely on village life for people with advanced dementia. See <https://hogeweyk.dementiavillage.com/en/>.
- 20 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). The caregivers' memoirs discussed in this chapter clearly fulfil Nussbaum's criteria.

- 1 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).
- 2 Despite differing from the primary aims and methods expressed in *Narrative Medicine* (2006), my approach shares certain concerns with Charon’s more recent work on ethics, see Irvine and Charon (2017). The latter as well as previous contributions (Charon and Montello 2002), however, focus more on the circumscribed domain of medical ethics and are primarily addressed to clinicians, health professionals, and ethics consultants rather than being concerned with the general public.
- 3 Compare also Morris (2002) on ‘thinking *with* stories’ (196; my emphasis).
- 4 See Korthals Altes (2005) for an overview of the ‘ethical turn’ in the humanities. For further discussion of the relation between ethics and literature or storytelling see Korthals Altes (2006, 2013, 2014) and Meretoja (2018).
- 5 See Hakemulder (2000) for empirical studies examining the effects of reading.
- 6 Compare Davis (2004), who criticises the demand placed on family caregivers to maintain the identity of the person with dementia.
- 7 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.
- 8 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 and autopathographies alike suggest that it is a common occurrence that the person with dementia is bypassed in such interactions.
- 9 For a related debate see Selberg (2015).
- 10 The novel here develops a notion of embodied selfhood akin to Kontos’s approach, as discussed in Chapter 1.
- 11 Hughes (2011), for instance, calls to replace ‘dementia’ with ‘acquired diffuse neurocognitive dysfunction.’
- 12 Felski (2008) 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 ‘unfolds readers through the inculcation of countless examples, into an experiential familiarity with the logic of such judgments’ (92). While I agree that this experiential familiarity is one of the effects of novel reading, one must not 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.
- 13 See Davis (2009) on the problems pertaining to ‘Precedent Autonomy, Advance Directives, and End-of-Life Care.’
- 14 For some thought-provoking discussions on this topic see Davis (2009), Dresser (1995), and Hertogh et al. (2007).
- 15 Simple enjoyment and 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.
- 16 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).
- 17 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.

- 18 Laura Pritchett's *Stars Go Blue* (2014), for instance, develops an entirely different narrative ethos in which the murder-suicide of the character with dementia to avenge his daughter's murder is seemingly lauded as heroic as well as a logical and 'useful' conclusion to his life with dementia—as the character thereby avoids becoming a 'burden' to his family.
 - 19 Referred to as the 'extension view' in discussions about advance directives (see Davis 2009: 354).
 - 20 For a similar view, see the Japanese novel *The Twilight Years* ([1972] 1984) by Sawako Ariyoshi. This novel bears out Innes's point that the cultural expectation that female family members will care for the elderly is 'backed up by the absence of care alternatives provided by health and social care services' (Innes 2009: 48). This situation, she argues, places women who are juggling 'paid work and existing family responsibilities with the new caregiving role' under 'considerable pressure' (48).
 - 21 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 or employ other stylistic devices to communicate her thoughts, feelings, or attitude.
 - 22 By contrast, recent children's and young adult fiction about dementia, such as Lindsay Eagar's *Hour of the Bees* (2016), Jenny Downham's *Unbecoming* (2015), Ruth Eastham's *The Memory Cage* (2011), and Ranjit Lal's *Our Nana was a Nutcase* (2015), to varying degrees portray the second generation—that is, the grandchildren of the protagonist with dementia—as much more willing to take on the role of caregiver than their parents. In the latter two cases the entire plot revolves around the grandchildren trying to keep their grandparent from being institutionalised and to protect them from the seemingly heartless, or at least unemphatic stance of their parents.
 - 23 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
- 1 For a first exploration of children's literature and dementia see Chapter 5 in Falcus and Sako (2019).
 - 2 See, among others, the blog <http://alzpoeetry.blogspot.co.uk/>.
 - 3 See the project website <https://dementiadiaries.org/>.

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