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The loss of self in healthcare and cultural discourse

Caregiver guides: Helpers in the face of loss and decline

A chronic dementing illness places a heavy burden on families: it may mean a lot of work or financial sacrifices; it may mean accepting the reality that someone you love will never be the same again; it continues on and on; it may mean that responsibilities and relationships within the family will change; it may mean disagreements within the family; it may mean that you feel overwhelmed, discouraged, isolated, angry, or depressed.

Nancy L. Mace and Peter V. Rabins, *The 36-Hour Day*¹

In this section, I focus on how depictions of caregivers in the late 1970s and early 1980s perceived and dealt with dementia in their family, and I study the effects of the NIA's influence on the public understanding of Alzheimer's disease. I explore how caregiver manuals such as *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life* (1981) contributed to the further development of the cultural dementia narrative. I show how these manuals perpetuated into the last decades of the twentieth century the unequal power relations between care provider and elderly individual established in the 1960s and 1970s, as they explored dementia as 'a heavy burden on families'. At the same time, this section explains how the first caregiver accounts contributed to the popular Alzheimer's disease narrative that emerged during the early 1980s. In particular, it illustrates how the language adopted in first memoirs overlapped with that of caregiver manuals, and how such narratives contributed to the cultural persistence of ideas of loss as they told of the involution and slow death of a loved parent or grandparent.

Rosalie Walsh Honel's *Journey with Grandpa: Our Family's Struggle with Alzheimer's Disease* (1988) was the first book-form memoir by a caregiver

accessible to the English-speaking market. It was brought out by the same publisher as the first edition of *The 36-Hour Day*, and endorsed by the manual's co-author, Peter V. Rabins, who wrote the foreword to the caregiver's story.² This constellation underlines the strong educational value old-age psychiatrists saw in this narrative. Beginning in 1978, several years before any healthcare guide became available, Honel recounts her caregiving experience, in which social expectations had thrust the main responsibility for the patient on the family. In the 1970s, a steady rise of hospital costs and the consequential effort to limit costs in service delivery resulted in a growing demand on informal family care.³ At the same time, many families felt an aversion to the 'nursing home', which occupied, as William F. May pointed out in 1986, 'the same place in the psyche of the elderly today that the poorhouse and the orphanage held in the imagination of Victorian children. Even those who never set foot in these facilities fear them as fate.'⁴ This deep-seated aversion is also reflected in contemporary fiction. In Margaret Forster's *Have the Men Had Enough?* (1989), for example, the daughter Briget, who is a nurse, is adamant about the siblings caring for their mother at home, and the layout of the short-term care home Birchholme is reminiscent of Kenneth Hazell's descriptions of houses unsuitable for the elderly in the 1960s.⁵

Rosalie Honel was the primary caregiver to her father-in-law, while still having her own children to look after. She was, as Elaine M. Brody has described such carers, one of the 'women in the middle'.⁶ In their manual, Mace and Rabins acknowledged this position, writing that 'daughters (and daughters-in-law) are "supposed" to take care of the sick. But the daughter or daughter-in-law may already be heavily burdened' (145). Honel's account was both the product and the reflection of this development. It was 'a story of tragedy', but also 'the story of heroism'.⁷ It exposed the link between how the illness affected the patient and how caregiving burdened the adult child, as 'the balance [shifted] between what he could do for himself and what we needed to do for him' (149). In doing so, it set up 'the stereotype of "old people" as objects of care'.⁸

Honel's experiences were representative of contemporary caregiver issues more widely. Mario Monicelli's comedy *Speriamo che sia femmina* (Let's hope it's a girl), for example, broached the female family members' duty to look after an ageing parent with memory loss in 1986.⁹ Elsewhere, the Japanese novel *The Twilight Years* (1972; trans. 1984) by Sawako Ariyoshi, to which Honel refers, portrayed a Japanese daughter-in-law's caregiver burden.¹⁰ And Honel herself discovered during a school exchange event that 'it was obvious that the people in France are as concerned about the problem of Alzheimer's disease care as we are in the United States' (214). From its emergence as a theme of healthcare politics,

Alzheimer's disease posed similar challenges globally. In fact, what the present-day cultural and popular preoccupation with Alzheimer's disease refers to as the phase of Alzheimerization in the history of dementia took place in the early 1980s, and Honel's work is its earliest witness in multiple contexts: in healthcare, in the popular imagination and in medico-scientific discourse.¹¹ Honel's book contributed to the successful advocacy efforts that roused public awareness that change was needed in long-term care.¹² At the same time, it shows how the organic paradigm made its way into an emerging popular discourse.

The history of Frank Honel's diagnosis exemplifies how this advocacy effort turned concepts of ageing-related memory loss, so far termed 'senility' and 'dementia,' into Alzheimer's disease in clinical practice. The initial diagnosis describes him as "senile" and suffering from "hardening of the arteries" (30). A few years later, a neurologist concluded 'that Grandpa did have senile dementia of the Alzheimer type' (164). To this Honel adds, in quoting from *The 36-Hour Day*, that the 'diagnosis confirmed what we had long believed. Parts of Grandpa's brain were being destroyed by some strange accumulation of "plaques" and "tangles"' (164). Mace and Rabins placed strong emphasis on the organic nature of the condition, when they contended that the 'changes that occur are not the result of an unpleasant personality grown old; they are the result of damage to the brain' (9). Such an assertion supported Honel in her conviction 'that Grandpa was not simply old. There was something wrong with his brain that made him forget so much and act so strangely' (90).¹³ This explanation was in line with Butler's anti-ageist interest to counter public misconceptions about senility. With Katzman's political move in 1976, senility became related to a specific disease rather than ageing: to Alzheimer's disease as an organic condition of the brain.¹⁴ In particular, Mace and Rabins wrote: 'The brain is a vast, complex, mysterious organ. It is the source of our thoughts, our emotions, and our personality. Injury to the brain can cause changes in emotions, personality, and the ability to reason' (21). They were using the medical model to preclude judgmental stigma about 'the unpleasant personality grown old'. Their emphasis on the brain as a 'vast, complex, mysterious organ' brought home to the reader how obviously the behaviour of patients had to change as a consequence of organic damage and how this change, therefore, had to be empathized with.

However, the 'empathetic technique' of *The 36-Hour Day* has been described as 'a two-part scheme': 'Only when family members ... have denied meaningful agency and subjectivity to the person with dementia, can these be reintroduced through the superimposition of their own subjectivity onto the experience of the other.' In addition, so the anthropologist Lawrence Cohen argues, the temporal

language of the title of *The 36-Hour Day* conveys that the suffering is not that of the patient, who is here 'the agent but not the subject' of the disease.¹⁵ These observations point us to the perspective from which Rosalie Honel was writing. She was closely watching the changes in personality of a loved and loving parent and grandparent, while having to bear the strain of caring for him. Honel draws us ever more into her burden, when, two-thirds into the text, she begins chapters in the present tense – a narrative strategy we also encounter in later life-writing such as John Bayley's *Iris: A Memoir of Iris Murdoch* (1998) and Andrea Gillies's *Keeper: Living with Nancy, a Journey into Alzheimer's* (2009). In addition, she places great emphasis on the chronology of events. Initially describing Frank as extraordinarily self-reliant and as focused on keeping active and useful, she ultimately depicts Alzheimer's disease as leading to Frank's progressive decline. After Frank's death, Honel ponders the times 'when he lost full human awareness and withdrew into a shell of pure physical existence' (240).

I emphasize Honel's use of the shell metaphor here not only because we already beheld it in the context of Galsworthy's writing. Its full implications were becoming apparent once carried into discussions on advance directives and living wills, which had to consider 'the relationship between the predemented self and the "shell" of that self left since the progression of dementia.'¹⁶ Moreover, social scientists described 'an "unbecoming" process, due to the mental deterioration caused by the disease' in Alzheimer's disease, resulting in the patient being 'increasingly devoid of content.'¹⁷ Notions of the patient's lack of self-recognition and failure to recognize others were reinforced by images of the living dead. These images, albeit in existence since the fin de siècle, obtained further meaning in a wider atmosphere of growing popular fascination with this concept seen in cultural texts such as George Romero's film *Night of the Living Dead* (1968).¹⁸ The image of the patient as victim struck by a killer disease played into the same understanding of the patient as passive.

The idea of the patient as living dead dominated contemporary information campaigns. Such campaigns represented a 'health politics of anguish'.¹⁹ They portrayed poster patients like Rita Hayworth, and in the early 1990s Ronald Reagan himself, as subjected to 'a devastating horror', in this way creating 'a new cultural demon'.²⁰ Celebrity faces successfully drew attention to the cause of Alzheimer's patients. But they were instrumentalized in a way that further stigmatized the condition in the mainstream.²¹ Patients were not allowed to speak for themselves: they were presented as silent objects of pity without agency.²² This agency-denying language rose to prominence once Alzheimer's disease had entered popular print media. An article in the *Washington Post*,

for example, negotiated with Katzman's comparison of Alzheimer's disease to a killer, asserting that Alzheimer's 'changes our very soul, our very spirit. It lessens our humanity ... a person with a serious dementia is no longer human. He's a vegetable.'²³ A weekly news magazine reported on 'a slow death of the mind'.²⁴ In addition, a further caregiver guide propagated 'the loss of self', while claiming that patients 'have a great deal to teach us about living with the anguish of what one man called "a living death"'.²⁵ This contradiction in terms is embodied in the guide itself: it privileges, like *The 36-Hour Day*, the caregiver's perspective and experience.

This observation is noteworthy for the fact that a contemporaneous project paper set out principles of good practice for the care of older people with dementia.²⁶ It pointed out that 'failing mental mechanisms', the failure of coping strategies and the restricted power to communicate were stressful experiences for the patient (10). The paper asserted that, to 'understand the "experience of dementia"', it needs to be seen from the elderly person's point of view – how it disrupts and complicates the process of living a full life' (9). Consequently, the authors matched action points to principles of care for the patient as an individual with human needs and rights (7–8). These action points were formulated in the first-person singular as claims and demands of the patient (14–23). Yet in 1985, family members still described 'care provided [in nursing facilities as] ignorant, indifferent, callous or even destructive'.²⁷ My argument here is not that scientific ways of thinking have influenced specific care habits. I merely suggest that certain habits and attitudes are symptomatic of a specific period, which is marked by particular scientific or medical perspectives on the condition. Take the following example: Sawako Ariyoshi's narrative was originally entitled *Kōkotsu no hito* (ecstasy man). But allusion to the patient's lived experience (and need to be active) was entirely overwritten in the American-published translation *The Twilight Years* from 1984; instead, the translation emphasized the caregiver's view of the patient's dissolution.

Caregiver burden and pain are intensely real at all times. But during the 1980s, they were highlighted at the expense of direct attention to the patient's personal experience. Both contents and layout of *The 36-Hour Day* confirmed the caregiver in their dominance within the carer–patient relationship.²⁸ Mace and Rabins certainly included information relevant to patients, recognizing that 'people, including those suffering from these conditions, may read this book' (xiv). But patients like Larry Rose, who published his illness experience in the mid-1990s, did not see their perspective reflected and needs considered in this manual, writing:

The 36-hour Day was about the best one I read. There was a lot of good information there, but it was mostly for caregivers. I could not see where any of it applied to me. I am just not like most of the Alzheimer's patients I read about. I can still think, talk, walk, write and do almost anything I want.²⁹

We do not gain the impression of such an independent and capable patient from Honel's account. She sees a child in her father-in-law. Among other things, she remarks that 'having Grandpa in our home at this time was like having another baby' (39). In a similar way, advice provided in *The 36-Hour Day* relies on notions of the patient as regressing into a second childhood: 'When we offer to help with something a person has always done for himself ... it is a strong statement that this person is not able to do for himself any longer, that he has, in fact, become like a child who must be told when to dress and must have help' (64). Notions of the patient as child may well originate from earlier medico-scientific as well as fin-de-siècle degenerationist concepts. But when we read from the perspective of the family caregiver we become aware of the full implications and added dimensions of this discourse. Subject to a 'change in roles,' as Mace and Rabins wrote in 1981 (141), and Honel agrees (99), the adult-child caregiver loses a parent and, in turn, becomes, in Honel's words, parent to 'a two-year-old' (210). Engulfed by such feelings, Honel might find it difficult to give space to her father-in-law's own articulations.

Additionally, through a handful of Rosalie Honel's children's diary entries, we behold the pain that comes with Frank Honel's illness. Like her mother, Therese Honel believes that 'Grandpa is ... like a child' (73). But when she affirms that his 'happiness is the best thing about him' (76), she draws our attention more to her grandfather's remaining personality, rather than what the adult child – Rosalie Honel – sees as being lost. It is from the voice of a child – in Honel's account as much as in this cultural history – that we first learn of a positive aspect to the condition. Children share 'marginal positions within the family and society' with the elderly: they also both connect to cultural traditions of the idiot figure.³⁰ Ariyoshi's Shigezō, for example, turns to appreciating his daughter-in-law after having reprimanded her all his life. In a similar way, Pupi Avati's *Una sconfinata giovinezza* (A boundless youthfulness; 2010), though written significantly later, explores positive connotations of dementia within a parent-child relationship. Forster's *Have the Men Had Enough?*, by comparison, gives the narrative voice alternately to the caring daughter-in-law and her daughter. This strategy convincingly captures how the adult child's caregiver burden can lead to negative, identity-denying perspectives on the condition, because this burden obliterates appreciation of possible rewarding aspects of the condition reflected

in the grandchild's thoughts – a perspective Honel (and many a caregiver after her) is able to take only after her father-in-law's death.³¹

The grandchildren's perspective emphasizes the patient's continued abilities rather than losses; its limited availability then reflects the origin of (and reason for) the popular beliefs about dementia in the early 1980s. Just as Rosalie Honel's voice prevails throughout the narrative, so too the caregiver's account about a lost former self took the lead in shaping a popular dementia discourse – which the media supplemented with images of patients as empty shell or living dead. This account was necessarily grounded in the caregiver's experience. But it also strongly related to the language employed in the limited support literature available. That said, caregiver advocacy in the form of printed narratives outside Honel's text and some paragraphs in the two manuals mentioned here, were rare in the 1980s. This means that caregivers during the 1990s not only relied on *The 36-Hour Day* (which by itself suggests the influence on the popular dementia discourse of such manuals). They themselves provided hands-on advice to fellow caregivers in their own writing, among them Carol Wolfe Konek's *Daddyboy: A Family's Struggle with Alzheimer's* (1991), Betty Baker Spohr's *Catch a Falling Star: Living with Alzheimer's* (1995), Frank Wall's *Where Did Mary Go?* (1996) and Ann Davidson's *Alzheimer's, a Love Story: One Year in My Husband's Journey* (1997). In this regard, Arthur Kleinman's *The Illness Narratives: Suffering, Healing, and the Human Condition* (1988) is exceptional in containing a brief account of how a spouse experiences Alzheimer's as 'a disease of the whole family'.³² That the medical anthropologist included this condition in a work that would become canonical to the rising health humanities movement foreshadows the lead this discipline took in helping to reformulate the patient's and caregiver's position during the 1990s and early 2000s.³³

The position of the patient eventually could change because those writing about them came to appreciate their family member's continued identity within a condition of the mind. This shift in emphasis also emerges from *The 36-Hour Day* as notions of the 'damaged brain' became, on several occasions, interchangeable with those of a 'damaged mind' (e.g. 46, 104). These developments suggest that, although practiced for over seventy years, the medico-scientific discourse of dementia as an organic condition of the brain, once imported into healthcare thinking, could not be maintained by those who experienced patient contact on a daily basis. As Cindy Honel wrote of her grandfather, the patient needed to be comprehended as a 'prisoner of the mind' (195), his changed behaviour explained by an illness afflicting the mind. This perspective is similar to Pinel's or Alzheimer's considerations, much in line with psychiatric thinking, and explored in even more detail in prominent fictional accounts of the 1980s.

Out of Mind: The postmodern novel delves into the mind of the patient

The ever-increasing presence of Alzheimer's disease in print media both suggested and stimulated the general public's growing interest in the condition. In 1979, Max Frisch forced the reader into the perspective of a first-person narrator with increasing memory loss in *Der Mensch erscheint im Holozän*, which appeared as *Man in the Holocene* in the *New Yorker* in 1980. In the same year, Samuel Beckett gave an account of an individual's end-of-life experience in the face of his 'mind never active at any time ... now even less than ever so' in *Company*.³⁴ Here, I take a brief look at Beckett's text for two reasons: later Alzheimer's disease life-writing would refer to experiences Beckett described in his work; and Beckett's explorations of consciousness have implications for representations of dementia.³⁵

Experiences expressed in these publications can be said to relate to a transition, during the post-war period, from modernity to postmodernity in the United States and Western Europe. This transition happened, so Jesse F. Ballenger observes, as modern concepts of coherence and ideas of selfhood, space and time became undermined by feelings of disorientation. Ballenger locates dementia patients between modern and postmodern selves, exploring aspects of fragmentation in Cary Smith Henderson's *Partial View: An Alzheimer's Journal* (1998).³⁶ The idea of fragmentation is central to how Beckett explores the protagonist's identity in *Company*. Also, while I do not suggest that Beckett's late prose represents a nosological account of dementia (i.e. one that is exactly true to diagnostic characteristics), its vision of human life is that of a postmodern condition. Dominated by incoherence, confusion and lack of control, this experience convincingly resonated with cultural images of dementia of the 1980s which I shall discuss shortly in this section.³⁷

Beckett sets the 'old man[']s' (8) long-term memories against present-day 'repetitiousness' (9), and describes him 'as huddled with his legs drawn up within the semicircle of his arms and his head on his knees' (17). This portrayal reminds us of Alois Alzheimer's early description of the condition. In Beckett's work, shorter and shorter, less and less complete sentences depict 'mental activity of a low order. Rare flickers of reasoning of no avail. Hope and despair and suchlike barely felt' (29). Concurrently, we feel drawn into the protagonist's return to childhood. Short paragraphs of earliest childhood memories of 'a mother's stooping over cradle from behind' (31) are fused together with those

suggesting the narrator's current lack of mobility, as he is 'crawling again and falling again. If this finally no improvement on nothing he can always fall for good' (31).

Again, I do not suggest that Beckett's *Company* describes an Alzheimer's patient. But I consider it possible that contemporary readers might have mulled over the protagonist's condition in this terminology – especially given how popular this term was becoming. Also, critics wrote of the protagonist as 'victim' within 'the physical confines of this prison'.³⁸ That said, if an association with Alzheimer's disease had been made, the imminent death of Beckett's narrator might have left too little room for the 1980s reader to relate to questions that began to be raised, namely: 'What do demented people experience? What does their condition mean to them? What is their reaction to it? What are their gratifications? What are their frustrations?'³⁹ The neurologist Joseph M. Foley asked these questions as late as 1992 and saw some of them answered in J. Bernlef's bestselling book *Out of Mind*. This fact and the narrative's broad international success invite a close reading of this text.⁴⁰

Originally published in Dutch as *Hersenschimmen* in 1984, *Out of Mind* quickly gained international prominence. It featured in the 'Notable books of the year' section of the *New York Times* on 3 December 1989 and was translated into German as *Hirngespinnste* (1986) and French as *Chimères* (1994). I am particularly interested in the narrative's initial Anglo-American reception following its early translation into English in 1988. Bernlef's novel adopted an unprecedented point of view. It narrated the experience of dementia exclusively from within the patient's mind. As will become clear shortly, the feelings Bernlef created obviously resemble the predicament of Beckett's protagonist. But what I particularly wish to explore is what this account reveals about the cultural image of dementia in the mid-1980s, at a time when a growing body of fictional texts centred around memory, post-war trauma and historical amnesia. I argue that the fictional deployment of dementia for the exploration of such memory imbued the condition with notions of extermination and post-war trauma and determined the use of Alzheimer's disease as a trope for memory loss and forgetting.

In *Out of Mind*, Maarten Klein is in his seventies when he realizes that

year by year things happen to your body. Your feet lose their springiness. You go up and down the stairs once and you have to sit down to catch your breath again. Your eyes start to water when you look at one spot for a long time. The shopping bag moves more and more often from one hand to the other and you

meet fewer and fewer people's eyes. But this is different. More a general feeling of unease than a specific symptom. But no, it would be nonsense to think there is something really wrong. 'I'm still going strong!' (20)

At first sight, Bernlef tells yet another narrative of dispossession, decline and loss in old age. He pushes to centre stage the question of how demented people think and feel, by making it a felt experience for the reader. This felt experience goes further than the empathy solicited by Paul Bailey's or Norah Hoult's narrative strategies, because Bernlef exclusively confines the reader to Maarten's mind. Bernlef experiments with 'how much can be taken away from a human mind and still leave a narrator who can tell a tale comprehensible and attractive to the reader'.⁴¹ He explores, as Steven Connor would say, 'the loose, the contingent, the unformed and the incomplete in language and experience'.⁴² During a period concerned with questions of selfhood at the end of life, this experiment pushed the reader to ponder psycholinguistic implications of denying patients' continued identity once they cannot verbally articulate themselves.

In the absence of chapter headings or distinct line spacing the reader is exposed to the patient's uninterrupted stream of thoughts. The only hiatuses are nine section breaks, marked by their italicized respective first sentences. These sections, in turn, consist of an overwhelming number of longer and shorter paragraphs, whose variable lengths depict Maarten's fluctuating attention span. Across the entire text, paragraph length also mirrors Maarten's decreasing ability to narrate coherently. While the initial paragraphs stretch to up to four pages, the final sections compress the protagonist's narrative (and actual) dying in paragraphs as short as four or fewer lines – a strategy taken up later in life-writing like Thomas DeBaggio's *Losing My Mind: An Intimate Look at Life with Alzheimer's* (2002). The only landmarks of orientation (for the reader just as much as the patient) are Maarten's conversations with his wife Vera, as he 'is begging her to understand something I do not understand myself' (38). These conversations with Vera are the anchor through which we understand what actually happens, one whose representation is grounded in the caregiver-centred approach of the 1980s. But as Maarten becomes less and less able to communicate, Vera's words turn into disconnected echoes in Maarten's mind, and eventually disappear with Maarten's fading awareness, identity and personhood.

Primarily, Bernlef uses the protagonist's loss of language to characterize the patient's dissolution. Maarten Klein gradually loses his fluency in the English language, which he had learned to master when the Dutch couple moved to Boston after the Second World War. At first pleased that he can speak 'in fluent

English' (109–110), he later dissociates from his English-speaking environment, becoming aware that 'only English is spoken' (119). Once moved to a hospital environment he muses that 'the thought of an interpreter doesn't occur to them...I am the only survivor of my own language' (120).⁴³ The loss, also mirrored in the growing number of incomplete sentences as well as suspension points (i.e. '...') in the text, goes further as Maarten has to make a real effort 'to say "Vera", say it, VeraVeraVeraVeraVera until I hear it...hear how my voice drifts away...gone is gone' (121). Such suspension points appeal to the visual imagination; they show 'the pauses, hesitations and endings of dementia', and they reflect how language becomes 'destabilised, fragmented and fractured for dementia sufferers'.⁴⁴

Bernlef wrote his narrative during a period marked by a growing body of psycholinguistic work. In the early 1970s, the literary theorist Luce Irigaray studied how cortical lesions manifested themselves in the patient's production and handling of language, and asked whether specific alterations in the use of language could help distinguish the demented from the psychotic or aphasic.⁴⁵ That a major literary theorist decided to bring dementia into her theoretical project indicates the broadening of disciplines interested in dementia during the 1970s, and further foreshadows the growing attention to narrative in dementia in the 1990s. The worsening of language skills also featured in the 'global deterioration scale (GDS) for age-associated cognitive [decline] and Alzheimer's disease', which Barry Reisberg developed in the early 1980s. On this scale, stages ranged from 'word and name finding deficit[s]' to the point when 'all verbal abilities are lost'.⁴⁶ Bernlef's narrative suggests that with the ability to articulate himself in spoken word severely curtailed, Maarten's self-awareness is quickly lost. The first-person pronoun disappears from the text, as he becomes 'a thin, transparent point in space' (125). The second-person pronoun then strips Maarten of awareness of his identity as a gendered person, completed once 'guards remove this body ... [and] take it to a space where there are beds' (129).

Maarten's perceptions resonate with the feelings of W. G. Sebald's Jacques Austerlitz, whose 'entire life sometimes appeared like a blind spot without continuity', and who 'could not imagine who or what [he] was'.⁴⁷ The purpose of Sebald's *Austerlitz* (2001) is bent towards the protagonist's recovering of childhood memories in search of his parents' fate in Nazi-German occupied Czechoslovakia. But his identity search remains as tentative as the reader's contact with him, which is mediated through the monologue of an unknown narrator talking about him in a text even less structured than Bernlef's. *Out of Mind* and *Austerlitz* both emerged during a period marked by an 'explosion

of memory discourses.⁴⁸ Sebald's narrative, in particular, has been considered 'a literary meditation on the workings, and failure, of memory – a literary reflection on possible modes of Holocaust memory.'⁴⁹

Looking at Bernlef's novel from this angle illustrates how post-war memory discourses added further meaning to dementia. Their language directly related to the imagery of the already existing sociocultural dementia discourse. For Bernlef, dementia becomes the killer that medico-scientific writing had coined and which the popular press perpetuated. More precisely, Bernlef links the long-standing medico-scientific idea that dementia enhances the vividness of long-term memories at the expense of short-term recall to the understanding of dementia-related hallucinations. In this way, he makes Maarten victim to the most troubling and unsettling experiences of his youth, which had been lived in the face of the atrocities committed by Nazi Germany during the Dutch occupation. In hallucinatory associations, Maarten connects present events to past experiences. He mistakes a tranquillizer injection for a liquid food infusion during war time (73) and later for a Nazi's attempt to kill him (110). Such memories visit the patient with increasing frequency and intensity. This process matches the uncontrolled remembering experienced by Saul Bellow's Artur Sammler, a Holocaust survivor, who moved to New York City to forget this 'dead life'.⁵⁰ It also compares to Anton Steenwijk's attempts to forget the assassination of his family by Nazi Germans in Harry Mulisch's *The Assault* (1985).⁵¹ Steenwijk organises his life around '[burying] all that, the way one buries the dead' (61). Yet, his subconscious and chance encounters with others who had been involved in the crime keep confronting him with his past. This very combination of memory triggers matches both the neuropsychological structure and the narrative purpose of Maarten's hallucinations.

Bernlef's war metaphor turned the 1980s dementia patient into the image the NIA had propagated. But it did so by comparing the experience of dementia to that of the Nazi-German occupation and, by extension, the Holocaust, at a time when the fortieth anniversary of the end of war in Europe was being commemorated. Reliving memories of having 'been liberated' (109) towards the end of the novel, Maarten realizes that he has been 'occupied from within...my liberators have occupied me' (124). The condition which has besieged him will lead to his death, and only in his death will he find freedom – like Steenwijk, who reckons that 'life on this planet was a failure ... Not until it ended, and with it every single memory of all those death throes, would the world return to order' (146). Dementia has become the equivalent of both torture of the mind and post-war trauma. Patients like Thomas DeBaggio would later compare their

condition to a 'death sentence' and the 'holocaust of my brain' to evoke the most atrocious objectification of human life and characterize themselves as victims of a terminal disease.⁵²

Bernlef's novel ends as 'spring ... is about to begin' (130), the season symbolizing the renewal of life. This ending provokes the question as to whether the narrative professes a positive view of dementia, given that Maarten ponders 'can this be called progress while in fact it is regression' (125). This question seems pertinent also because the unidirectional nature of the disease pathology would make it difficult for patients to tell triumphalist narratives in the apparent absence of a possibility for satisfying closure.⁵³ Maarten's statement mirrors the kind of 'crabwalk' Günter Grass explored in much of his later writing, namely his narrators' 'steal[ing] ponderously back and forth across characters, plot, and time'.⁵⁴ Maarten Klein's dementia is Bernlef's appropriation of the 'crabwalk' motif, that is, Klein's – as much as Sammler's, Steenwijk's and Austerlitz's – negotiation with the past and his integrating this past into the present.

Bernlef's use of dementia to explore historical amnesia fills the cultural image of the condition with traumatic notions of war, murder, resistance and extermination. At the same time, Bernlef could call on an entire generation's shared understanding of memories to engender empathy for a patient's illness experience. And this experience relates to both the pain and loss remembered and the fragility of identity in the present. As early as 1983, American pastor A. Ralph Barlow likened the effect on family relationships of Alzheimer's disease to a sense of disconnectedness in modern society – a perspective that illustrates how Alzheimer's disease became a metaphor for social ills during the 1980s.⁵⁵ In fact, the major societal anxiety about the ageing population of the 1960s and 1970s had, by the 1980s, turned into a concern for dementia and Alzheimer's disease. For both Bernlef and Galsworthy, dementia reflected large-scale societal concerns. For Galsworthy, dementia was an image. But at the time of Bernlef's writing, dementia had turned into a reality in need of images. In then using the condition as an image in the context of an entire generation's post-war trauma, fiction like Bernlef's prepared its use as a global trope for memory loss and forgetting.

In our efforts to trace discourse developments we also need to be clear about where Bernlef locates dementia in relation to ageing, and how Maarten Klein's dementia differs from Faith Gadny's condition. Bailey's Faith continues to be aware of herself and rejects prejudices about the ageing. Her initial positive self-image, as opposed to how she is perceived by others, resonates with Woodward's observation that there exist 'two contradictory representations of old age – one

which is aggressively negative ... and is projected onto the old by the middle-aged, and one which is fundamentally positive and is *embodied* in the figure of an old person.⁵⁶ Faith's is the lived awareness of what Butler defined as ageism, and her loss of memory is Bailey's way of depicting her surrender to this ageist discourse. By contrast, Maarten is only initially aware of ageist behaviour, noting the 'tone they usually adopt here when they address someone over sixty. Amiable condescension mingled with distaste' (52). Likewise, he loses awareness of his bodily self, becomes a stranger to himself, as he takes his reflection in a window pane for an 'old man in pyjamas look[ing] at me, imitat[ing] a live man with his hollow black eyes' (112). Bernlef's Maarten appears to suffer from a condition of the mind only. Bailey's Faith, by comparison, remains aware of her condition as an embodied person throughout. This gendered representation aligns with one of the main differences between the male and female bildungsroman, namely the 'heroine's manipulation of the gaze of others as well as her control over her self-image'.⁵⁷ And it anticipates how especially female patients will rise to the challenge of writing about a condition that is perceived as afflicting the male associated mind.⁵⁸

We have come across the idea of the patient as stranger and 'other' already in the fin-de-siècle social Darwinist discourse. The abjection of the patient typical of that period was less prominent in the 1980s version of the image of the patient as stranger – both in fiction and the popular press.⁵⁹ By the time the patient was cared for in the family, the personal relationship with that patient came to structure the image: the struggle of family members with 'their commitment to the person they knew and their increasing detachment from the stranger that person has become'.⁶⁰

Two decades after Bailey, Bernlef is only marginally concerned with dementia as a condition of ageing, the protagonist concluding, 'You become forgetful. It's part of old age' (20). Also, Bernlef does not aim to bring out dementia as a nosological entity, as authors would aim to do two decades later. Although the narrative's contemporary reception was quick to describe it as 'a novelistic study of Alzheimer's', it really only prepared the ground for dementia to become a narrative device several years later.⁶¹ But Bernlef succeeded in making the experience of dementia convincing by building on two things. First, he could count on the reader's familiarity with the dementia storyline, which after nearly a decade of information campaigns had reached general awareness. With Bernlef's text, the reader, for the first time, could be forced into the patient's point of view without losing the plot in Vera's disappearance. And second, Bernlef built on the narrative possibilities of modernist and postmodernist approaches to memory

loss. In locating the narrative in the patient's mind, the condition became, on a cultural level perhaps earlier than on a medico-scientific level, one of the failing mind.

Literature creates the terms in which we think about phenomena like decreasing self-awareness and consciousness, and I would not even want to start arguing for the dominance of fiction or linguistics in establishing that, as Paul John Eakin has argued, serious impairment in the ability to tell or understand stories severely impacts on our sense of self.⁶² Suffice to say that Bernlef's depiction of Maarten's continued awareness of his state follows and gains authority from the emerging (though debated) 'evidence of awareness and sensitivity' in advanced Alzheimer's patients.⁶³ Yet, it remains a nagging thought that Bernlef's composition might be flawed due to 'some obvious inconsistencies in the narrative techniques'. Alexander Zweers finds that the reader 'accepts that even within the heavily damaged brain of the protagonist[] an observing instance can "somewhere" remain active'.⁶⁴ And for Anita Desai, the reason why 'we willingly suspend our disbelief in Maarten's ability to narrate so coherently his growing incoherence' lies in Bernlef's prose: it makes us 'participants in [Maarten's] tragedy'.⁶⁵

Be that as it may, with reference to Bernlef's text, the neurologist Foley acknowledged that 'clinical experience is never as deep as fiction'. His contribution to *Dementia and Aging* (1992) virtually invited patients to make their own claims and come out with their narratives, in order to contribute to policy changes:

It is important to identify functions that are lost, but even more so to identify functions that are preserved. Dementia per se does not always deny patients the right to participation in decisions about their own care, their own life, or their own health ... we must recognize that individual demented persons ... each remain a person, with their own gratifications and frustrations, their own unique background, and their own unique destiny.⁶⁶

Such an exhortation is remarkable, especially since, during the period from 1991 to 2001, not a single popular magazine article focused on the perspective of the individual who experienced the disease.⁶⁷

At the same time, the growing need to hear and see the condition more from the patient's perspective is perhaps attested to most clearly by the 1993 television film by Tony Harrison, *Black Daisies for the Bride*. Combining drama, music and poetry, this documentary traced the personalities of three women patients in the Alzheimer's ward of High Royds Hospital in West Yorkshire. The film propagated

the image of the patient as 'baby', 'victim', 'shell' and 'lost self', and the condition as a 'blizzard'.⁶⁸ In frequent above-eye-level takes, it subjected patients to the viewer's scrutiny without definite consent. In addition, a voiceover conveyed the caregiver's perspective, further removing agency from the patient. Considered as a whole, Harrison's work was probing, as Lucy Burke puts it, the boundaries between 'viewer and viewed, subject and object ... carers and patients'.⁶⁹ It was also the first visual narrative about the patient – the caregiver not featuring centre stage in the film recordings themselves, perhaps in response to first-patient narratives appearing in book form from 1989 onwards.

Robert Davis's *My Journey into Alzheimer's Disease: Helpful Insights for Family and Friends, a True Story* (1989), Diana Friel McGowin's *Living in the Labyrinth: A Personal Journey through the Maze of Alzheimer's* (1993) and Larry Rose's *Show Me the Way to Go Home* (1996) pioneered the life-writing of Alzheimer's patients, at a time when the public considered them devoid of a social self and victims of a killer disease. Reflecting the social isolation of patients, the early reception of these texts almost exclusively focused on how their narrators strove to assert their identity as individuals.⁷⁰ These patient-authored publications appeared not only in response to an ageist and caregiver-centred healthcare dementia discourse. They also developed a counter-narrative in response to fast-paced medico-scientific research which had begun to revolve around Alzheimer's disease from the early 1980s onwards. Butler's original desire to move the care for, and curing of illnesses of, the elderly centre stage turned into a development that stigmatized older people even more. It has, indeed, been argued that the response of the healthcare system itself to the increasing older population was partly responsible for catastrophic views of ageing.⁷¹ The early 1990s chastised the curative medicine of the 1980s for not prioritizing enough quality over quantity of lived years at a time when the number of elderly kept increasing.⁷² In the tradition of the grey lobby of the 1970s, which advocated attention to the needs of older people as such, patients would assert themselves increasingly during the 1990s.⁷³

Since the 1960s, medico-scientific research into diseases of old age had steadily intensified, unnoticed by the general public. This changed in the mid-1970s, once medical scientists propagated the single designation of Alzheimer's disease for dementia regardless of the patient's age. In addition, NIA funding strategies, inherently focused on diseases of old age, popularized Alzheimer's disease because it was a disease that is common in old age.⁷⁴ Eventually, the NIA became the most important federal agency of Alzheimer's disease research.⁷⁵ These strategies and events contributed to medical sciences

forming an independent entity. In their growing specialization, they cultivated, as I show in the next chapter, a dementia discourse removed from the patient as individual and separate from geronto-psychiatric initiatives which were beginning to sharpen their understanding of the ageing patient as needing empathetic care.