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The dichotomy of Alzheimer's disease

On Christmas Day 2014, the latest film by actor, director and producer Til Schweiger, *Honig im Kopf* (Honey in the head), was released in German cinemas.¹ The movie is about a character called Amandus Rosenbach (Dieter Hallervorden) and his granddaughter Tilda (Emma Schweiger) who are travelling from Hamburg to Venice, where Amandus and his late wife had spent their honeymoon. In picturesque nature shots the sun is seen shining, the beautifully arranged mise-en-scène focuses on the characters' smiles and the rhythmic score carries the audience away. Building on thirty years of public learning about Alzheimer's disease, the film works by merely hinting at the patient's disorientation in stock scenes: the hand fumbling with a door knob, the shaving foam being squirted onto the tooth brush, the aimless searching for the correct word. By the same token, the movie spares us the later stages of the condition: incontinence, aggression, disintegration. More precisely, from the moment Amandus does 'lose it', meaning that he does not recognize his granddaughter any longer (1:58:07), Tilda becomes the narrator (2:01:21). She has told the story all along, but we become aware of the retrospective nature of her account only when Tilda speaks about her grandfather's final happy years in the closing minutes of the film. Emotionally charged slow motion artificially extends these joyful times: Tilda's mother takes time off work so that Amandus can stay with them, and Tilda's father spends more time with the family.

Schweiger's film avoids a deeper consideration of caregiver strain, both physical and emotional. Instead, loss and decline are experienced by others: the patient shooting with a stolen police gun (12:03), the patient pushing the ignition button to set off a firework display at a garden party (56:21), the patient driving the son's car (01:10:05) – all these scenes create mayhem. They produce 'fireworks' in a comedy that additionally relies on a number of sexist and misogynistic clichés: the laid-back son with a high-powered job, the stressed-out daughter-in-law with no sense of humour and her disgracefully ageing mother

with inappropriate sexual drive. Amandus cracking jokes about doing sums in a cognitive testing interview (50:51), or insinuating the sexual symbolism of a cucumber in conversation with a nun (1:47:40) show Hallervorden as the slapstick comedian well-known to the German audience – merely grown old himself.² Given the cinematic memory of the audience, as Raquel Medina would put it, viewers feel all the more emotionally involved in the fate of Hallervorden's Amandus.³ Contrary to what Sally Chivers importantly observes for mass media, literature and film, Schweiger does not use Alzheimer's disease as a magnifier of what people fear most about old age, namely that it 'could manifest itself ... in an apparent loss of sense and self'.⁴ Hallervorden's Amandus has freedom of spirit, lives in the moment and enjoys life. Memory loss – any kind of loss – does not centrally define him.

Schweiger's film was a blockbuster success in Germany. It continued to be on screen eight months after its release, with television talk shows discussing the condition in binary but lively terms.⁵ The film can be criticized as commercially exploiting the socio-economically pressing topic of Alzheimer's disease in a summer's fairy tale for the big screen during the touchy-feely Christmas period. As a comedy, the film lacks any sense of social reality, as Joachim Kurz, who lost his own father to Alzheimer's disease, asserted in a column for the internet presence of German arthouse cinemas.⁶ In response to such criticism, Schweiger explained that he wished to complement the perspective taken by David Sieveking's *Vergiss mein nicht: Wie meine Mutter ihr Gedächtnis verlor und meine Eltern die Liebe neu entdeckten* (Forget me not: How my mother lost her memory and my parents rediscovered their love) two years earlier, a big-screen documentary which had drawn attention to the condition and different ways of approaching care and end-of-life choices.⁷

This cinematic context cannot sufficiently explain how a dementia patient could feature centre stage in a big-screen comedy. *Honig im Kopf* sits with a large body of feel-good films about spirited ageing – including Jon Turteltaub's *Last Vegas* (2013), Dan Fogelman's *Danny Collins* (2015), Nancy Meyers's *The Intern* (2015), Zach Braff's *Going in Style* (2017), Roger Goldby's *The Time of Their Lives* (2017) and Bill Holderman's *Book Club* (2018) – many of which reveal the favouritism towards aged men that Chivers observes in mainstream cinema.⁸ But given how strongly concepts of loss and decline have dominated the cultural dementia narrative across the twentieth century, Schweiger's move must be further contextualized. The final part of this study is concerned with the question of where the disease and its sufferers are located in the first two decades of the new century.

Writing about the immediate present precludes truly historical considerations. However, key concepts can nevertheless be seen developing in medical science, healthcare and cultural representations, even though some of these may not be as durable as what I have referred to as the organic paradigm or the cognitive picture. Schweiger's film is both a product of and a reflection on some changes that have taken place since the start of the new millennium. These changes are partly rooted in postmodern views of the condition as I have illustrated them in Chapters 4 and 6. They are also carried by a rapidly growing marketplace that continues to develop around the condition, especially in rich societies. This marketplace both creates and responds to the priorities of the ultimate consumer – patient, caregiver, the health services, society at large and whoever feels threatened by ageing-related memory loss. It is a space inhabited by various domains that are concerned, each in their different ways, with dementia: laboratory science, the medical clinic, literary scholarship and the human sciences more broadly, as well as cultural productions themselves. And every single domain is subject to economically driven deformations that skew the images and concepts of dementia that this domain projects. This chapter illustrates the increasing fluidity of present-day medico-scientific, healthcare and wider cultural concepts of dementia in this marketplace.

Immunization hope and hype: The patient as non-responder

Following the rise of immunology as a research discipline in the 1970s, a large number of long-identified conditions were redescribed in the 1980s as dysfunctions of the immunity.⁹ The possibility that Alzheimer's disease may be caused by infectious agents like a virus or an abnormal regulation of the immune system was also explored. With the amyloid hypothesis steadily gaining ground, immunological reasoning led researchers to pursue the idea that amyloid could be tackled as if it were an infectious agent – a pharmacological approach that aimed to fulfil the vision of Selkoe and others, introduced in Chapter 5, namely that 'blocking of amyloid will be a therapy'.¹⁰ Accordingly, immunological thinking explored the possibility of 'lowering the burden' of amyloid with a strategy against its production and accumulation.¹¹ This rationale introduced immunological notions of flexibility and spontaneity into the medico-scientific writing about Alzheimer's disease, which, I argue, caught up with budding cultural concepts of the patient as active. Disappointing drug trial outcomes, however, left patients all the more vulnerable, pushing them back into a position

of passive objects of pity waiting for a cure. Pharmaceutical moves happening in the wake of these failed trials in turn reveal how scientific investigations themselves were increasingly driven by societal and cultural expectations.

First research results were based on the concept of what is termed 'active immunization', a strategy that challenges the patient's immune system to produce an active response against a pathological agent within the body (in this case amyloid). The results were collected in a murine model of neuropathological features of the condition and published in 1999.¹² The paper's language conveys the initial enthusiasm for the expected potential of this therapeutic approach. Moreover, its reception by the media bore witness to two developments: a transient conceptual shift in how the general public heard and read about the condition and an ever-stronger reach of scientific research into the mass media, met by the public's growing interest in the disease. The study's outcomes led the authors, based in the pharmaceutical industry, to present the new therapeutic agent as 'disrupting' plaque formation and blocking the pathology (175). The clinical recipient of this treatment was understood actively to develop a reaction against amyloid.

In other words, immunological strategies put amyloid on a par with infectious agents against which the body could mount an active response. They figured Alzheimer's – along with diseases such as cancer and infection – as a beatable condition. This transformed the image of the patient as victim of a killer disease to one enjoined to fight. Anthropologist Emily Martin observes how, during the 1990s, most scientists described the immune system in terms of 'the body at war' and a 'communication system' in which various elements 'orchestrate' cells and 'recognize' enemies; ideas of 'flexibility' and 'individuality' prevailed.¹³ Such notions were contrary to earlier concepts of communication breakdown in Alzheimer's disease. They conveyed an understanding of the patient as active, just as Christine Boden fashioned herself. They credited the patient's body with characteristics that the wider cultural context linked to those of a postmodern self.

Ideas of a postmodern self include that of a self's fragmentation and dislocation as much as its spontaneity and flexibility. Like David B. Morris, I use the term 'postmodern' here to identify the comparatively coherent period in the development of rich societies in the West after the Second World War, 'a period of rapid transition when values and styles are losing their familiar shape', and a social force that evolved in negotiation with these changes.¹⁴ As Arthur Frank argues, these changes also touched on illness. 'The postmodern experience of illness begins,' Frank writes, 'when ill people recognize that more is involved in

their experiences than the medical story can tell.' He then goes on to remark on the availability of 'rhetorical tools and cultural legitimacy' as necessary for the patient's successful expression.¹⁵

With Frank's argument in mind, we could take the increasing postmodern drift as providing both tool and legitimacy for patients credibly to tell their illness experience. The first patient narratives – such as Robert Davis's *My Journey into Alzheimer's Disease* (1989) and Diana Friel McGowin's *Living in the Labyrinth* (1993) – were coherently plotted. They were considered to be inauthentic because, as Anne Davis Basting argues, they described rather than performed the illness.¹⁶ In support of her view, Jesse F. Ballenger expressly terms patient accounts postmodern when they tell their story not in a 'conventional' manner, that is, not in a traditional, well-structured chronological arrangement.¹⁷ Terry Pratchett's television documentary *Living with Alzheimer's* (2009), directed by Charlie Russell, is a case in point. Shooting times could be adapted to the writer's moment-in-time acuity; and episodic reflections portray Pratchett as a spontaneous moderator and presenter.¹⁸ Christine Bryden's *Dancing with Dementia: My Story of Living Positively with Dementia* (2005) articulates such a spontaneous postmodern identity more fully than her earlier account *Who Will I Be When I Die?* (1998). The combination of politically charged essay sections with accounts of her frequent travels acknowledges a short attention span and resulting fragmentation of thought. The same is true for Richard Taylor's collection of essays, *Alzheimer's from the Inside Out* (2007). Their length rarely exceeds two to three pages, but their poignancy regarding, for example, 'nude mice', 'a shell filled with Alzheimer's' or 'feelings of insecurity' made Taylor a prominent patient activist.¹⁹ Finally, the general public's ideas of the immune system included images of 'dancing or playing', rendering Bryden's choice of title particularly meaningful.²⁰

In summary, the pharmacological language related to medico-scientific ideas of Alzheimer's as a condition that could be tackled in immunological terms caught up with, perhaps even sanctioned, what the cultural realm had already worked out: that the patient had continued agency and was active and performing. I do not suggest that these research approaches redefined the condition's pathogenesis.²¹ But immunological thinking in relation to therapeutic strategies introduced language which holds out the possibility of 'blocking' or 'counteracting' the threat from a terminal disease. This is shown by how the media reacted to the data presented by Schenk and colleagues. In the *New York Times*, for example, the results were 'hailed by scientists as a landmark achievement in the battle against Alzheimer's'.²² In the same article, a professor of

neurology considered immunization 'a radical innovation', and the chairman of the scientific and medical advisory board of the Alzheimer's Association judged the findings 'really exciting'.

So, immunological approaches to Alzheimer's disease shifted the condition away from its finality in pharmacological terms, and these concepts began to be picked up by the media. As already mentioned, with Bruno Latour, we should take the scientist's reach into the mass media as part of the strategies that champion the sale, belief in and spread of findings.²³ But such interaction becomes problematic when research results cannot deliver on the hopes held out – in this instance, the drug's safety, tolerability and efficacy in trials with human subjects. These trials, conducted between 2001 and 2003, revealed that cognitive testing scores remained unchanged, that a considerable number of subjects 'did not mount an immune response' to the drug.²⁴ These sobering outcomes left patients all the more vulnerable: they became increasingly exposed to the ups and downs of medico-scientific research and exaggerated reporting – a situation which was also influenced by distorted academic press releases as the pressure on science to find a cure continued to mount.²⁵ In addition, earlier notions of self-inflicted illness appeared to be enhanced by the patient's failure to respond.

Since the early to mid-2000s, a second line of investigation explored the benefits of passive immunization. This strategy does not rely on the body's active response, because an agent raised against the disease-related amyloid within the body is injected directly. In her novel *Still Alice* (2007), the trained neuroscientist Lisa Genova reflects on the patient's and caregiver's dilemma in relation to these drug developments.²⁶ Once an eminent professor in psycholinguistics, 50-year-old Alice Howland has to accept that the 'ability to use language, that thing that most separates humans from animals, was leaving her, and she was feeling less and less human as it departed' (270). As well as reducing mind to brain as other neuronovels, Genova's narrative additionally relies on socioculturally sanctioned stereotypes of science versus arts, male versus female, rational versus emotional, healthy versus sick. This polarization ultimately gears up towards a staging of the all-or-nothing promise of these new drugs. At the centre of her text, Genova introduces the fictional agent Amylix, which it is hoped will 'prevent the disease from progressing further' (139). Alice must decide whether to be included in a further trial of Amylix. Her husband John is not in favour of this option. A high-flying biomedical scientist himself, he has been living (just like Alice) with the conviction that 'anyone could be seduced by research when the results poured in. The trick was to love it when the results weren't forthcoming, and the reasons

why were elusive' (28). That John now prefers an established combination of drugs, rather than helping the cause of science, tells of the helpless situation he is in as the caregiver who loses his partner in life. Alice, in contrast, tries to 'think analytically about her treatment options,' arriving 'at a single, crisp image that made sense. A shotgun or a single bullet' (141). She opts for the trial. As she puts it to John, this 'isn't your one shot. You're brilliant, and you don't have Alzheimer's. You're going to have plenty of shots' (234). As a patient, Alice does not have anything to lose, because the diagnosis has already determined her end.

Genova acknowledges both 'Dr Rudy Tanzi and Dr Dennis Selkoe for an in-depth understanding of the molecular biology of this disease' (x). It is, therefore, unsurprising that her image should echo Tanzi's concept of an amyloid-directed inoculant as 'magic bullet' in his *Decoding Darkness* (246). This link, like Genova's novel itself, points to the increasing confluence of dementia representations in a growing marketplace – a marketplace of service users as well as for accounts about dementia. Medico-scientific, popular and cultural representations all closed in on the same concepts and disappointments. For John, the story ends in tears as he reads the lead article of the *New York Times* Health section, entitled 'Amylix fails trial' (287). Alice, by now looked after by a professional caregiver, continues to live at home together with one of her daughters. For the reader, the story ends on a redemptive note, as Alice cradles her newborn grandchild and we gather her continued ability to read other people's emotions. Sarah Falcus believes that the 'intimate experience of Alice's emotional, physical and intellectual states encourages the reader to construct and reconstruct Alice so that she remains not static, but still Alice'.²⁷ And Rebecca A. Bitenc finds that 'Genova highlights what frequently persists even in the last stages of dementia: the emotional and sensual aspects of relationships that do not depend on higher-order cognitive functioning', and identifies narrative devices in *Still Alice* which convey 'that no clear boundary exists between "self" and "loss of self"'.²⁸ But especially with the drug story in mind, I find it difficult not to agree with Stefan Merrill Block who argues that, 'considering Alice's formerly inquisitive, type-A, tough-as-nails personality, this does not feel like "still Alice". This feels like a transformed self'.²⁹

Two years after Genova's fiction, the outcomes of first clinical trials on the passive immunization prototype drug bapineuzumab were published (its mechanism of action being comparable to the fictional Amylix). Again, research found no significant differences in cognitive testing outcomes.³⁰ Despite ever-intensifying research, Alzheimer's disease remained a condition with no cure in sight; in Genova's words, 'molecular murder or cellular suicide'

(1), with the patient its 'victim' (256). But, in comparison to the 1990s, the patient's perceived loss was amplified several fold: by the pharmaceutical industry's persuasive marketing of potential remedial interventions; by the mass media's exaggeration of press releases; and by the general public's so acquired common knowledge about the disease. I don't argue that science and industry were driving a condemnable profit-oriented campaign. Latour has made it abundantly clear that scientific research can only truly flourish in a marketplace in which different disease hypotheses compete for financial support.³¹ The issue at stake was that Alzheimer's disease had reached an extremely value-laden prominence, and scientific research was expected to offer hope of deliverance from a condition which meanwhile had turned into a major public health issue and inspired fear in large parts of the population. This problematic situation is reflected in the claim made by William Thies, the chief medical and scientific officer of the Alzheimer's Association, at the association's International Conference in Vancouver in 2012, and the research carried out in its wake. Thies maintained that 'earlier detection of Alzheimer's, greater knowledge of dementia risk factors, and better treatments and prevention ... are critical in order to create a future where Alzheimer's disease is no longer a death sentence but a manageable, treatable, curable, or preventable disease.'³² A key trial with bapineuzumab, and two trials with its sister compound, solanezumab, terminated within two months of the conference's end, with researchers having to acknowledge that the agents did not have an effect on cognitive performance.³³

The film *Still Alice* (2014) does not broach the drug story at all, perhaps in view of the sobering appraisal of immunization-related strategies ten years after high hopes for an imminent cure had first been cherished.³⁴ Instead, the movie's energies – mise-en-scène, camera work and score – are all bent towards uncompromisingly depicting the disease progression of Julianne Moore's Alice: her loss of orientation, awareness and language, and her helpless subjection to the clinical diagnosis of memory loss (19:06). If journalist and writer Charles A. Riley is correct that the 'safest nomination bets for Oscar gold, year after year, are disability flicks', we cannot be surprised that Moore's performance earned her the eighty-seventh Academy Award for Best Actress. What I am more interested in, though, is Moore's acceptance speech on the occasion. Riley is convinced that such speeches zero in on the 'victim', who is 'momentarily blinded by flashbulbs', only to be forgotten weeks later.³⁵ Moore expressed the hope that the movie would 'shine a light on Alzheimer's disease', that it would make patients feel 'seen', because 'people with Alzheimer's deserve to be seen, so that we can find a cure.'³⁶

Within two weeks of the film's appearance, news reported that fears 'drive the middle aged to seek checks', affirming how the big screen can help raise awareness (while creating an alarmist atmosphere).³⁷ Yet, the awareness raised was for what the film scholar Lucy Bolton describes as 'an incurable, humiliating nightmare through which we are transformed into a vision of the walking dead, locked into our own heads, unable to think or care for ourselves'.³⁸ The tie between the film's monolithic take on Alzheimer's disease and Moore's call for a cure adeptly condenses the patient's loss as it is societally perceived in the second decade of the twenty-first century. It is no longer only the medico-scientific or sociocultural understanding of the patient's loss of awareness, language and self. It is the absence of a cure that enhances this loss. This is especially the case in capitalist societies, where, according to Dana Lee Baker, we find an 'almost completely unquestioned assumption of superiority of cure over care', as both are treated as parts of one overarching effort: to increase funding for medico-scientific research.³⁹

The political energy of the dementia patient's pharmacological loss becomes apparent from the fact that researchers on solanezumab revisited the clinical data collected up to 2012, and in 2015 published a paper on secondary outcomes. John Abraham's study on policy-related components to pharmaceutical research can help explain this move: specific outcomes may selectively be emphasized to keep drugs in trial for longer after large sums of money have already been invested in their development.⁴⁰ Reviewing clinical data for obtaining secondary outcomes also is (as seen earlier in the medico-scientific history of the condition) a further example of how specialist knowledge establishes the parameters according to which it wants to see its research subject defined. Stratification of subjects in this revision now revealed, in patients with mild Alzheimer's disease, less cognitive decline.⁴¹ These new findings were effectively taken as justification for claims like Thies's that immunization might be beneficial especially in the preclinical stages of the condition.⁴² By what Latour terms inventing new goals and interest groups, researchers began to turn to issues of prevention.⁴³ Overlapping with a slowly rising cultural visibility of the early-onset Alzheimer's patient, this move amplified concerns about health risks in the middle-aged.

Arguments are being made that an earlier diagnosis enables patients to take a more active role, for example, in making their wishes known.⁴⁴ But the film *Still Alice* depicts the deleterious consequences for the patient and her family of what it means to live with this diagnosis. The inheritable nature of the early-onset form of Alzheimer's disease challenges an entire family, and the prospect of inescapable decline leads the patient to consider a radical end-of-life decision.

Alice's conviction, in both book and film, is telling: 'She'd trade Alzheimer's for cancer in a heartbeat ... There was the chance that she could win' (117; 34:59). The continued absence of a cure only enhanced awareness of the patient's loss of memory, awareness and self, after immunological approaches and their representation in the media had begun picturing Alzheimer's as a beatable condition. Even during a period whose fascination with postmodern ways of life both granted and legitimized the narrative tools for fractured selves, a patient like Bryden eventually had to 'move away from the bright lights to a corner of the [dance] floor where the rhythm is slower and the music quieter, but still sweet. All I can do now is sit quietly and listen, and hope for a cure'.⁴⁵

In the meantime, patients continue to rely on care. But, as Dana Lee Baker points out, 'public care is deliberately limited only to those in formally legitimated need ... Victim status is still often considered a necessary condition for provision of care'.⁴⁶ The 2014 UK initiative financially to reward general practitioners for every Alzheimer's diagnosis made has caused controversy across the media, political parties and healthcare associations.⁴⁷ Living with the disease and its label for an extended period can be acceptable for patients and their caregivers only when the label Alzheimer's no longer spoils the individual's social identity.⁴⁸ That is, once sociocultural attitudes to the condition change – under circumstances that Schweiger depicts (undoubtedly too simplistically) in a world ruled by love and empathy.⁴⁹ But reflected against a century-long narrative of dispossession, decline and loss, significant changes are needed politically and institutionally to deliver on the transformative potential of love. In a first instance, attitudes towards the patient must become as unprejudiced as Tilda's appreciation of her grandfather's continued identity outside memory loss and ageing as decline; and healthcare conditions must become more identity-affirming, if not celebratory. These are the issues I develop in the following two sections.

La guardiana di Ulisse: The patient beyond forgetting in children's literature and adult fiction of the new century

The most salient feature of *Honig im Kopf* is that the story is told from the perspective of a child. Moving the child's perspective from an underprivileged narrative space in a mother's account (as I discussed in Chapter 4) to the big screen during peak viewing season – both for that fact, and that it took thirty years to take this step – is noteworthy. First and foremost, this move draws attention to what partly facilitated it: a growing body of dementia narratives

addressing children. In addition, that a dementia patient has become an increasingly prominent figure in books for children and young adults since the year 2000 is further evidence of the condition's popularization.⁵⁰

To some extent, this rise indicates changing caregiver support strategies. Many such books, like those published by the American Psychological Association, were intended as pedagogical tools for caregivers, whose 'child may become stressed and anxious, especially as your family dynamics change'. But in providing support for the caregivers in the middle, they recounted the 1980s and 1990s story of the grandparent whose 'life and memories are leaving him'.⁵¹ They also brought the grandmother as an object of scrutiny to the child, closing, for example, on the narrating child's observation that 'Nana and I can both wear striped shirts and flowered pants, and it will be okay'.⁵² Such an account portrays the child being read about as an American 'improved self', as Lisa Diedrich would say.⁵³ But at the same time, this narrative strategy perpetuates the concept of the patient as child, underpinned by the striking visual resemblance between grandparent and grandchild, including facial expression, head shape and clothing. Such stereotypic representation, so Mareike Hachemer observes, reduces these narratives to didactic texts, without leaving children any room to negotiate with their own grandparent's otherness.⁵⁴ But narratives about dementia for children have also begun rewriting the cultural dementia narrative; they offer the chance to 'take a non-judgemental, unencumbered perspective onto a person, who is different'.⁵⁵ Tilda inverts the adult version of Alzheimer's disease, offering a vision that accepts the patient in all his peculiarity. For her, Amandus is on holiday.

It has variously been argued that applying literary criticism to children's literature demands an analytical consideration in its own right. Yet, I agree with the literary scholar Frank P. Riga that writing for children 'will appeal on a number of levels, eliciting different responses from different readers'.⁵⁶ This is the case, so Riga argues, because authors convey their message in both literal and figurative terms. Any supposedly simplified representation of patient and condition will tell the critical reader what is perceived to be the ultimate truth about illness and sufferer. I read Alessandro Borio's narrative with these genre presuppositions in mind. *La guardiana di Ulisse: Una malata di Alzheimer, un angelo e una domanda* (Ulysses's custodian: An Alzheimer's patient, an angel and a question; 2006) brings home its social criticism to all groups of readers in the form of an allegory.⁵⁷ It can, despite being addressed to children, readily be critiqued as a rejection of contemporary society's lack of reverence for patients – for their identity and personhood, awareness and needs.

Cynthia Marshall illustrates how a story's apparent resonance with a biblical passage will encourage readers to search for its deeper message.⁵⁸ Borio's allegory makes reference to a specific biblical source, alludes to Greek mythology and incorporates poetic symbolism. These heighten the reader's attention to imagery, especially because the narrative's meaning – the guardian angel Ulisse Mantovani's mission – is unclear from the outset. His name lets the reader foresee similarities to Homer's astute hero. But moved to a contemporary allegory the Ithacan king's plot-driving travels turn into Ulisse's (and the reader's) search for meaning. Ulisse is sent to Earth to watch over the Alzheimer's patient Maria Merlo who, he has been told, is a custodian. Ulisse has to figure out why Maria must be protected and what she is custodian of. Focalized through Ulisse, this search for meaning drives the plot. Maria's role on Earth is to preserve civilization and humanity that would be reflected in society's attitudes towards patients like herself.

Borio explicitly removes Maria's condition from its limited meaning as memory loss in the elderly, making it merely a vehicle for a larger truth. Maria stands in for 'individuals of all ages and origins' with a common characteristic: 'a deep suffering had signed them and now they lived in extreme, aggravated weakness. They were all ... "almost vegetables"' (78). Borio's invitation to revere those whose predicament obliterates any difference in age overlaps with Atul Gawande's observation that the current cultural climate has eclipsed the 'veneration of elders'. Gawande comments on the quality of the 'waning days of our lives ... spent in institutions – nursing homes and intensive care units – where regimented, anonymous routines cut us off from all the things that matter to us in life'.⁵⁹ Reflected against Gawande's deliberations, Borio's text revolves around the care for the patient. The power of Maria's status as patient – her name signalling an intercessionary role in the Roman Catholic tradition of Borio's Italy – is conveyed through the biblical source in Borio's text, Abraham's intercession for Sodom (Gen. 18.22-33). God will save Sodom from destruction, if only one righteous person can be found in the city (135–6). In Borio's tale, then, 'the only righteous people in the world ... are those whose condition outruns any possibility to sin, and on them rests the foundation of the world' (82). As Borio assigns this world-saving importance to patients like Maria, he invites us to consider how that world revolves around the patient.

Like Konrad Lang according to Miriam Seidler's critique, Maria herself is a flat character, and it is only through Ulisse's mind-reading (printed in italics) that we become aware of Maria's shrunken world. Still, the emotions and behaviour of all other protagonists develop in negotiation with her. This helps

Borio to develop his social critique, because less emotionally complex characters provoke complex feelings in other characters, and such mental triangulation can 'question existing social hierarchies'.⁶⁰ Maria's son Francesco feels that his mother has become 'her own tomb' (19). This view induces him to place her in a nursing home, and so remove her from any contact with her grandchildren. Maurizio, in particular, misses his grandmother, because for him Maria's memory loss has no negative meaning. It is around the reinstating of contact between grandchild and grandmother that the central message of Borio's text revolves. But how can the contact between two characters without apparent social agency come about? With the help of an angel and an act of faith: Ulisse's dream.

It is in Ulisse's dream that Maria and Maurizio are reunited; that Maurizio relishes his grandmother's hug; that Maria becomes active storyteller. And the story she writes down for Maurizio is the plot- and meaning-driving fable within Borio's allegory. *Il girasole immobile* (The static sunflower; 121–4) tells the reader how society should be thinking about the patient. Rebelling against the sun's lacking recognition of their undivided adoration of her, a field of sunflowers collectively decides that their gaze would no longer follow her rays. But in doing so, they become unpleasant and self-interested. In this climate of utter indifference, a new sunflower grows, who happily follows the sun's trajectory. Challenged by the older sunflowers, this new arrival tells them: 'For me, it is not important to know whether the sun is aware or not of my love, the fact alone of loving her makes me feel good, allows me to receive her vital energy that enlivens my colour and ripens my seeds' (124).

Literally becoming Borio's take-home message, Maria's letter is found, so arranged by Ulisse, in the armchair she occupied in Francesco's home. As a physically tangible object, Maria's story becomes real for those who doubt the truth of dreams, the views of children and the authority of patients.⁶¹ On hearing this fable, Francesco adopts a perspective similar to Maurizio's. He sees his mother 'like a person and not like an Alzheimer's patient', and asserts that 'people are much more than what they manage or do not manage to do, understand, feel or remember' (129). In addition, Borio's choice to tell a tale featuring an angel encourages the reader's creativity.⁶² Or, as sociologist Luigi Berzano suggests, with the return of angels in cinema and literature, the world dominated by technology and rationality becomes recoloured.⁶³ In line with such a reading, Borio lets Francesco learn. He allows Maurizio to see his grandmother again. And, having trusted the authority of an angel in an act of experiential reading, we have learnt our lesson: we are able to see 'something that resembled very much a smile' (141) on Maria's face when Maurizio finally hugs her.⁶⁴

The angel's role in Borio's fiction obtains added meaning when read against Jens Brockmeier's reference to the *Odyssey*. For the scholar of psychology and philosophy, 'the fascination of Homer's epic poem stems ... from its conjuring up the idea of simultaneously moving forward and backward in time'.⁶⁵ Also Ulisse travels in time and space to collect memories of how Maria was in the past. These memories help Francesco to appreciate her in the present of her illness. But the reader does not access the past through Maria, and this helps Borio to remove dementia from notions of memory loss in the first place. Borio's representation of dementia is more in line with recent work that emphasizes the natural function of forgetting and demystifies the idea that the brain stores everything.⁶⁶ Such a change in perspective, what Brockmeier terms 'memory crisis', has developed since the 1990s, as archival notions of memory began to be questioned in social and cultural, literary and biological domains.⁶⁷ Here, I see parallels to the changes in identity-preserving concepts of forgetting which Nicholas Dames detects in the nineteenth century, exemplified in Timothy Forsythe. This dynamic suggests to me that a cultural shift in relation to memory is essential to, and anticipatory of, a cultural change in understanding dementia. This shift is not only seen in children's literature, but also in a growing body of adult fiction that portrays dementia as a mixed blessing: an opportunity for growth and fulfilment, or a condition that can help emotional healing because it entails forgetting.

One recent example that loosens decades-old depictions of dementia is Andrew O'Hagan's *The Illuminations* (2015).⁶⁸ O'Hagan juxtaposes the story of Anne Quirk, a 'wee lady ... [who] knows her own mind' (105), with a growing sense of spatial and temporal disorientation, to that of her grandson Luke, who is out on a mission in Afghanistan, which had turned 'their brains ... soft from months spent doing nothing' (38). Later in O'Hagan's narrative, it is the fighting and killing that 'wears away at you', so that 'there's less of you every day ... Less life. Less cause. Less morality. Less belief. Less judgement. Less energy. Less fucken hope. Just less.' (130). This language strongly echoes war-related imagery that became linked to the illness experience during the 1980s. However, O'Hagan strictly separates two narrative strands that are dominated by Anne and Luke, respectively, in their distant locations. In this way, he removes Alzheimer's disease in general and Anne's condition in particular from such imagery. Once Luke returns from a mission gone wrong the two narrative strands merge. In the conviction that she is 'losing parts of herself and gaining others' (166), Luke identifies 'a trace of something young' (252) in his grandmother. The flexibility with which Anne interprets her past illuminates his own mind, because she had

'preserved what she could of his young mind's entanglements' (255). Drawing on these insights, Luke eventually can 'imagine a future less taken up with loss' (265).

To appreciate that the essence of one's past is central to one's identity in the present has been fundamental to much adult-child caregiver life-writing since the 1990s. In O'Hagan's narrative the patient's regression into the past becomes the healing anchor for the younger generations who run the danger of losing themselves in the traumas inflicted by a fast-living society. Don DeLillo takes a comparable approach in *Falling Man* (2007). He interlaces an account of how individuals grapple with the aftermath of the 2001 terror attacks forever etched in their minds with Lianne's fears of having inherited her father's Alzheimer's disease. In this way, the reader is led to associate the condition with redemptive aspects of forgetting. In essence, narratives like Borio's and O'Hagan's suggest a view of Alzheimer's disease less intricately linked to negative meanings of forgetting, even partly removed from memory loss. They also remind the reader that ageing and old age can embody life experience, wisdom and love.

The concept of dementia as a mixed blessing evolved on the fringes of a cultural dementia narrative that continued to be dominated by notions of loss of self and life. It progressed alongside a rise in popular fiction whose success was at least partly carried by the unbroken fascination with all matters neurocognitive. Such fiction continues heavily to rely on archival concepts of memory. It develops stories of individuals who had been active in their past; and this past dominates both text time and narrative moves: the reader can only access it through and because of the patient's increasing memory loss. Debra Dean, for example, draws out Marina's 'slow erosion of self'; Samantha Harvey shows Jake as 'gone'; and Emma Healey characterizes Maud as 'cut loose'.⁶⁹ All three novels – Dean's *The Madonnas of Leningrad* (2006), Harvey's *The Wilderness* (2009) and Healey's *Elizabeth Is Missing* (2014) – play with the reader's expectation that the patient lives on a rich (but emptying) memory; all headed bestseller lists; all were the authors' debut novels. And this further illustrates how culturally current Alzheimer's disease has become during the past fifteen to twenty years – culminating in its exploitation in a big-screen comedy. But unlike *Honig im Kopf*, many of these narratives appear to propagate the story of the living dead on a mass audience level, writing, like Dean, that 'Marina herself has left ... It is all over but the waiting'.⁷⁰

At the same time, however, this body of fiction has invited more ambivalent readings of dementia. There are gradually dualistic aspects to how the condition is viewed as a mixed blessing. Nicci Gerrard, for example, takes *The Wilderness* to

illustrate that ‘profound loss has a consolation,’ because Jake can forget his past.⁷¹ In a similar fashion, Ian McEwan’s move to let Briony succumb to dementia in *Atonement* (2001) can be read in binary terms. For Laura Salisbury, it serves to ‘displace the question of the unreliability of subjective memory ... with a material form of loss.’⁷² We could also read it as Briony’s final atonement after lifelong efforts to come to terms with her deception. Or, she ‘might not be unhappy – just a dim old biddy in a chair, knowing nothing, expecting nothing’.⁷³ Such an increasingly ambivalent perspective is also found in a number of recent adult-child caregiver accounts, and I will now turn to exploring how this growing ambivalence proves relevant for healthcare considerations.

Alzheimer mon amour: Healthcare changes and patient personality in contemporary caregiver memoirs

On Monday I visited my godmother who has dementia. Her care home has flower-beds and seating at the front. But these are for staff and visitors. Residents have no way into the fresh air. They are imprisoned. It was a palaver to take my auntie through the security door to sit on the (too-low) bench. But outside the stifling day room circle of nodding souls, she brightened.

Janice Turner, ‘I Dreamt of Greek Olives as I Fumed in Munich’⁷⁴

Janice Turner’s frustration about the discrepancy between policy changes and their actual implementation strongly resonates with Scottish broadcaster and writer Sally Magnusson’s account of her mother’s dementia.⁷⁵ Magnusson particularly criticises ‘an under-the-radar culture of poor practice in a system never designed for the longevity we have created for ourselves’ (17) and brands ‘the lack of empathy for confused patients and knowledge about their condition’ (183). Magnusson, who together with her siblings cared for her mother at home, further explicates Alessandro Borio’s idea of the patient as saviour of values, writing that ‘the ultimate guarantee of civilisation for any society in any century ... is that every mind, every person, is regarded as equally precious’ (375). In a similar fashion, the Italian adult-child caregiver, Elena De Dionigi, emphasizes her father’s continued identity in the assisted living facility of Camelot. Her conjuring of associations with the legendary King Arthur locates Alzheimer’s disease in the realm between the real and the imagined. It calls the reader to see in the patient all that remains rather than what is lost, an interpretation encouraged also by the narrative’s title, *Prima di volare via* (Before flying away),

which, like Maria Merlo's surname 'blackbird', alludes to the patient's flying away.⁷⁶

But perceptions of loss continue to permeate caregiver life-writing. Their presence brings home how difficult it is to establish new standards in dementia discourse as much as healthcare practice. Giovanna Venturino, for example, comprehends her parent's condition as an expanding 'sea of nothingness'; Nucci A. Rota writes about her mother-turned-child; and Donatella Di Pietrantonio sees her mother's condition as one of 'lost control'.⁷⁷ Nicola Gardini, by comparison, describes the search for his father as a lifelong process that continues into his illness in *Lo sconosciuto* (The unknown; 2007). Such binary readings at least partly feed on, and also reinforce, celebratory aspects – and these have the potential to push healthcare approaches into new directions.⁷⁸ The relevance for healthcare considerations of this growing ambivalence is perhaps best put into words by Gawande himself: 'We've begun rejecting the institutionalized version of aging and death, but we've not yet established our new norm.'⁷⁹

In this section, I explore what this new norm could be and what institutional and political changes need to happen to deliver on the transformative potential of love. I address how 'a policy bias in favor of a greater emphasis on caring medicine in old age', called for since the early 1990s, eventually began to manifest itself towards the end of the first decade of the new century.⁸⁰ As my example, I take the psychologist Cécile Huguenin's *Alzheimer mon amour* (Alzheimer my love; 2011) and read it in a cross-cultural way.⁸¹ I do so because Huguenin herself thinks about differences in how various cultures understand and deal with Alzheimer's disease and ageing. In addition, the psychologist depicts the import of international research into the French context as influencing how she was advised on caregiving. Sociological research suggests that dementia-related sociopolitical movements in France echo the American model – a connection that points, among others, to the increasing globalization of dementia caregiving issues in the new century.⁸²

Cécile Huguenin writes about her husband's illness in a short volume of not much more than one hundred pages. Divided into three parts, the account changes narrative form and perspective almost as often as the couple do their residence and living arrangements. These different forms mirror Huguenin's search for how to live with, and write about, the condition after having shared thirty years of life and love. In essence, it is a search for the discourse that would help her attitude towards patient and disease, at a time when care and cure policies continued to victimize the patient. As a product of this searching experience, Huguenin's narrative witnesses the life-changing effects of healthcare

approaches that affirm the patient's continued identity and personhood, while leaving reflective space for the caregiver. This space allows for a view of the individual with dementia that is less prejudiced, as we have seen, for example, in the case of Borio's Maurizio.

The narrative's first part covers the years 2006 and 2007: 'Two long years to realize, powerless and lonely, his progressive and unavoidable drowning (*nauffrage progressif et inéluctable*), as if every day a small piece of him was being swallowed by unknown depths' (17–18). It is told in the third person, and its simple language and uncomplicated syntax suggest the story belongs to a fictional world. These formal choices add to the reader's appreciation that Huguenin tells the tale of a couple wandering without hope or direction in the world of sickness. Huguenin describes this narrative choice as allowing her to distance herself from the illness experience.⁸³ More generally, this narrative strategy permits writers, like French TV director Françoise Laborde, in *Pourquoi ma mère me rend folle* (Why my mother drives me crazy; 2002), or the Swiss caregiver Ruth Schäubli-Meyer, in *Alzheimer: Wie will ich noch leben – wie sterben* (Alzheimer's: How will I continue to live – how will I die?; 2008), unflinchingly to reflect on problematic issues, such as challenging family constellations and difficult end-of-life decisions.

Initially escaping to the seaside, Huguenin ponders whether 'one can mourn somebody who is alive' (20). She particularly struggles with her reaction to ideas of self-infliction put forward by Daniel's neurologist: 'her anger, her desire to die, her obsessions to murder, to kill herself' (37). Eventually back in Paris, Huguenin seeks help from medical scientists, wanting to present 'this specimen of an addled (*décervelé*) man, this strong body deserted by the mind' (39). But Huguenin remains helpless in her 'absurd encounters' with the medical profession (43). The narrative's first part closes – in allusion to *Alice's Adventures in Wonderland* (1865) – with her impression that she only comes across 'crazy hatters, queens without a kingdom and rabbits in tails' (43). That Huguenin pictures herself and her husband as lost in an environment that resembles Carroll's nonsense world is perhaps best explained by the insights collected by Charlotte L. Clarke, professor of Nursing Practice Development Research, and her colleagues in a 2011 caregiver manual, namely that

the reciprocity within a care relationship means that both the carer and the person with dementia are working towards keeping some stability, continuity and sense of the normal in their lives. Health and social care interventions, or others outside that caring relationship ... throw a spotlight on the abnormal by focusing on the illness more than on getting on with life.⁸⁴

With her husband's increasing dependence, it becomes Huguenin's responsibility to navigate the world of care; to find the couple's ideal way of getting on with life; to realize their dream 'of a future that would allow us still to live together' (60). Consequently, she tells the second part of her story in the first person.

Based on her experiences in Africa and India, Huguenin idealizes a life in a culture where Daniel's 'condition would be considered a blessing and he like a messenger from the hereafter' (61). Fieldwork in India has revealed that this culture interprets demented behaviour in relation to the patient's social status, and African traditions consider family support a moral norm and emphasize the role of elders. These value systems influence how family caregivers from different cultural backgrounds construct their idea of Alzheimer's disease.⁸⁵ Conversely, 'within an illness culture which emphasises the deficits of people', so observed by Clarke and colleagues, 'options for creative solutions to needs are reduced' (68).

In Madagascar, Daniel 'blossoms' (76). But the couple are forced to return to France, and Huguenin's renewed change of narrative form pinpoints her exhaustion. While continuing to tell her account in the first person, she now addresses her husband directly. Di Pietrantonio and Magnusson also use such a strategy in their stories. But in recounting the mother's past to the mother in the second person, their approach is an attempted 'transfusion of memory', a strategy aimed at writing the parent back to life and identity.⁸⁶ This strategy gains all the more thrust when considering that even patients like Wendy Mitchell use it for holding on to acquired capabilities for as long as possible in the present of their illness. In *Alzheimer mon amour*, by comparison, this narrative choice emphasizes the demands Daniel places on Huguenin, his needs that make her 'prisoner' (82) – that lead to 'the crash that forces [her] to land' (83). But Huguenin lands on her feet. The clinician, who takes care of her husband after a severe fall, points Huguenin to an assisted living facility that enables 'a life put in place (*aménagée*) to take care of those exiled by a society that can no more or does not know yet how to accept them' (93). The narrative's final part is set in that place. A third of the entire text tells about how Huguenin experiences the way of life in this nursing home. Its calm tone and settled narrative perspective bring out the peace that comes with having found this place. The couple have reached their destination – in discourse practised, care received and narrative form enabled.

The place's caring philosophy centres around the understanding that the professional caregivers 'have to adapt to [the patients]' (94). This approach resembles the values pushed by a working group around the geriatrician and president of the francophone association for the rights of the elderly, François Blanchard. Similar to those set down in the 2007 UK personalization agenda and

the National Dementia Strategy in England in 2009, these values centre on the 'imperative of the respect for the individual'.⁸⁷ In the French context, for example, Nicolas Philibert's *La moindre des choses* (Every little thing; 1996) demonstrates that such values – to credit the knowledge of service users – were practised in institutions prior to policy changes. In Germany, policy changes are equally recent, even though initiatives like Demenz Support Stuttgart have promoted the ideal of caregivers as 'companions' of people with dementia since 2002.⁸⁸ But the hands-on implementation of such concepts continues to be slow. Contemporary healthcare keeps privileging, as Clarke and colleagues noted in 2011, 'the knowledge held by health and social care practitioners and underplays the importance of knowledge held by service users' (16).

However, the power of appropriate care is far reaching. Daniel's carers take the view that 'conversation between persons with dementia and their interlocutors is a privileged site for ongoing cognitive engagement'.⁸⁹ Huguenin notices that 'for the first time, every one of his interlocutors has addressed him. Directly looking him in the eyes, without passing via myself as an intermediate and without ignoring him' (99). Her move to mention the caregiver is noteworthy for the fact that scholars of ageing like Kathleen Woodward continue to lament the narrative absence of the frail elderly's professional caregiver.⁹⁰ That said, De Dionigi praises Marco in particular, and professional caregivers in general; and Diane Keaton ponders hospice care and explicitly acknowledges her mother's caregivers.⁹¹ I take their choice as a significant step towards change in prosperous societies, especially because Julia Neuberger, in 2008, called for more respect as well as improved training for healthcare staff, 'who are paid abominably, and are themselves bullied by penny-pinching, technocratic management regimes'.⁹²

The attitude of professional caregivers patterns Huguenin's own narrative approach and her perception of her husband. After she had deprived Daniel of a narrative voice throughout parts one and two of the text, she now includes several of his short poems. These assert his continued identity and personality, as Huguenin sees it (91). Huguenin's choice is encouraged by how professional caregivers themselves 'amass treasures', recording for themselves 'a word, a gesture, a mimic' of individual patients (111). During the first decade of the new century, such person-centred healthcare practices suggest a shift from person with dementia to personality within dementia. Resulting also from such celebratory sociolinguistic approaches, the views and opinions of people with dementia began to be heard. An international journal of social research and practice, *Dementia*, was launched in 2002, inviting people with dementia to contribute or join the editorial board.⁹³ Plays enacting dementia were developed

with educational purpose, with some of these plays originating from interviews with patients and their families; and the patient's perspective was becoming constitutively integrated in the education and training of healthcare staff and students of health-related disciplines.⁹⁴ In the same vein, recent dementia guides address separate chapters to caregivers and the individual with dementia, or include the patient perspective among articles on medical, legal and ethical aspects of dementia.⁹⁵

Also Huguenin herself considers Daniel her teacher. In a short epilogue she thanks her husband for 'having made me go through the hell of your illness so that I would become a different person' (131). Having crossed this hell, she can now – perhaps reminding us of how Borio envisaged his creation of Maria Merlo as custodian of love and empathy – appreciate in other human beings 'the endless power of being' (131). Or, as Magnusson puts it with respect to her mother's continued identity:

You are still you ... You will be you when the last of the fight has left you. You will be you when you no longer know who I am. You will be you even if I can recognise nothing of what you are and connect it with nothing of what you used to be. You will be you, I really do believe, until the last breath leaves your body. (329)

This perspective matches the view patients like Christine Bryden and Claude Couturier increasingly offered about themselves in new forms of patient life-writing.

To assign wisdom and life experience to an individual with dementia reminds us of the positive images that collaborative health humanities projects began to uncover for ageing and old age during the 1980s.⁹⁶ Since the early 2000s, a comparable gradual shift seems to be underway for dementia.⁹⁷ Meanwhile, the popular view that pharmacological research could be closing in on what Huguenin describes as 'this molecule of forgetting that corrodes him inexorably' (39) partly enabled such a change. More obviously and effectively, such a change was supported by narrative medicine-based healthcare approaches to, and a health humanities interest in, ageing, which furthered research projects, for example, on creativity and dementia, and explicitly included elderly people.⁹⁸ Nevertheless, a truly lasting cultural transformation is likely to develop only by incremental steps, because the concepts at stake – loss, decline, passivity, dependence – are particularly resilient as they are embedded within a variety of mutually enhancing discourses.

Take the health humanities as an example. Over the past thirty years, they have been of significant service to people with dementia and their caregivers. But scholarly research has, to a large extent, bought into and further amplified the cultural imperatives about dementia, in this way exacerbating the notion of

Alzheimer's disease as a condition of old age. In the field of literary scholarship, this phenomenon is at least partly explained by a focus on caregiver narratives which, by nature, predominantly feature elderly patients. As I already explained, I believe this focus to be conditioned by an (until recently) almost monolithic attention to John Bayley's account and – maybe unavoidable – its prominent filmic adaptation. But it is also true that, even though films like *Still Alice* (2014) feature the early-onset patient, entertainment culture more generally continues to instil the idea of dementia as a condition of old age. Prominent examples include Sarah Polley's frequently critiqued *Away from Her* (2006) and Phyllida Lloyd's *The Iron Lady* (2012). The latter is a special case in point, because it portrays Margaret Thatcher as young and powerful as long as she is in office; the only 'Thatcher' outside office that the film shows is the former politician in a state of hallucinating dementia in old age.

Revealingly, identity-affirming fiction like Borio's or personality-centred life-writing like Huguenin's leave very little impact on the language used in relation to Alzheimer's disease, regardless of the patient's age. Notions of loss reflect society's deepest fear about the condition: the death of the self and the fear of how a person who is losing their self will be treated by that society. The fear of dying, which Mary Mothersill describes as central to the experience of old age, is aggravated in the experience of Alzheimer's disease – for both patient and caregiver.⁹⁹ Celebratory approaches can do very little to change this, especially in rich societies in which the perceived value of individuals is tied to their productivity. In these societies, so Lucy Burke recently observed, the 'rhetoric of crisis' regarding dementia is closely knitted to financial gain and capitalist marketization.¹⁰⁰ I do not argue that the number of dementia diagnoses has increased with the rise of new capitalism, but I believe that principles of individualism and an atmosphere of entrepreneurialism have contributed to marginalizing people living with dementia even more.¹⁰¹ In the final section of this chapter, I explore more fully the reasons for the persistence of notions of loss and decline in a nearly twenty-year period that has seen tentative shifts in how the person with dementia is viewed in a variety of disciplines and realms.

We Are Not Ourselves: The cultural image of Alzheimer's disease in the twenty-first-century bildungsroman

Edmund Leary's ailment in Matthew Thomas's novel *We Are Not Ourselves* (2014) is Alzheimer's disease as it is perceived and dealt with in current

American culture: a condition of dependence, decline and loss, but most of all of dispossession in both intellectual and economic terms.¹⁰² A century ago, John Galsworthy deployed dementia as a micro-cultural image of macro-cultural concepts of degeneration in order to portray a particular culture. Thomas's early-twenty-first-century narrative, by comparison, tells the story of a character's disease trajectory as degeneration literally rather than symbolically.

It is by way of Thomas's genre-typical scrutiny of family conflict in the bildungsroman that we learn about the culture at large, in which this illness is experienced. I argue that, first, the qualities assigned to Edmund and his illness, and, second, the ways in which this character fits into the narrative form and frame suggest that the condition stands conceptually opposed to all the values held high in twenty-first-century enterprise societies. The account's overt emphasis on loss highlights how an economic dementia discourse may well obliterate the tentative conceptual changes in healthcare and cultural realms.

Thomas neither offers any new images nor describes signature events that would characterize the condition in radically different ways. Instead, it is the sheer number of well-established images and stock scenes stretching out over 620 pages that make it a meticulous study of the condition's insidious nature. For the first time in the literary history of dementia, they make the reader experience the patient's decline in real time. It is ultimately the epic length and consequent detail of Thomas's account that lead reviewers like Nicci Gerrard to assign it a central place in recent dementia fiction.¹⁰³ Stefan Merrill Block, in particular, considers it 'the truest and most harrowing account of a descent into dementia', and ascribes it 'a "Buddenbrooks"-like quality, offering a vision of a society in flux that is at once expansive and tangibly detailed'.¹⁰⁴

I take Merrill Block's association as an invitation to read Thomas's account against sinologist Yi-Ling Ru's work on the family novel, whose first prototype she considers to be Thomas Mann's *Buddenbrooks* (1901). Thomas uses the genre of the family novel to characterize Alzheimer's as a disease. The generic similarities as well as obvious differences bring out the meaning he ascribes to the condition: a disease of decline and degeneration. This is especially true when we look at how Ru, who bases her study, among others, on Galsworthy's saga, sees the family novel defined by four salient features, namely,

first, it deals realistically with a family's evolution through several generations; second, family rites play an important role and are faithfully recreated in both their familial and communal contexts; third, the primary theme of the novel always focuses on the decline of a family; and fourth, such a novel has a peculiar

narrative form which is woven vertically along the chronological order through time and horizontally among the family relationships.¹⁰⁵

For Thomas, Alzheimer's disease impinges on exactly these four elements. I will initially attend to features two and four to show the ways in which *We Are Not Ourselves* methodically aligns with concepts of the family novel. Exploring Thomas's breaking with characteristics one and three, thereafter, will bring out how his novel questions particular conceptualizations of Alzheimer's disease.

Alzheimer's disease disrupts family rituals and the continuity and stability they symbolize. Most obviously, Christmas celebrations change over the years. In 1991, Edmund's wife Eileen has to remind her husband to buy a present for his son; in 1994, she exhorts everyone to 'please have a nice Christmas' (403). One year later, Christmas 'saw no enthusiastic ripping open of presents', and Eileen resolves 'to wring enough perfection out of next Christmas to last her the rest of her years on earth' (430). But throughout 1996, Edmund is 'declining so quickly' (441) that he has to enter a nursing home. The momentousness of this change is signalled by the length of part five that covers the events of a single year, but is nearly as long as part four about the preceding five years. Connell's plan to bring his father home for Christmas fails dismally, because his father 'was gone, gone' (542). Eileen's efforts are reminiscent of Enid Lambert's in *The Corrections* (2001). In light of her husband Alfred's progressing Parkinson's dementia, Enid wishes to bring the entire family together for one last Christmas, but it 'wasn't the Christmas [she'd] hoped for', because Alfred is rapidly 'failing' in body and mind.¹⁰⁶

Change becomes most overtly clear from Thomas's focus on family relationships, as he reverses the roles of husband and wife, and father and son. At first sight, this role reversal merely reflects the actual experience of caregiving, with the account's length allowing for all the excruciating details of Eileen's burden. For Merrill Block, these are 'mostly intimate, domestic scenes, but Thomas understands how the numbing, repetitive minutiae of caretaking are often freighted with unspeakable pain.'¹⁰⁷ That Eileen 'would have to play nursemaid to him' (391) is both subtle and critical given that she is a nurse by profession. And her realization that Edmund 'would have to become something like a child to her' (337) obtains additional meaning, because it is Eileen through whom the narrative is mainly focalized.

The reader, in fact, does not experience Edmund Leary's mind. This move ensures that Edmund does not turn to living in the past, and it matches the genre's concept of driving the plot towards the younger generation's life and

choices. It also means that Thomas does not perpetuate the image of Alzheimer's disease as a condition of ageing and old age. Edmund Leary is only 50 years old, in keeping with the condition (one hundred years after Alois Alzheimer's case of 51-year-old Auguste D.) as it was originally described, as an illness of middle age. Except that anxieties about ageing particularly pervade middle age.¹⁰⁸ In this respect, Thomas's narrative is truly about ageing.

Edmund's age documents the increasing societal awareness of early-onset Alzheimer's disease, as seen with *Still Alice*. But most of all it is an important narrative move. *We Are Not Ourselves* tells of Alzheimer's disease as attacking the middle of life, the time of an individual's prime productivity. Or, as Eileen puts it: "early-onset is the most virulent kind ... It's the true Alzheimer's", she said, with something like pride at the thought that if her husband were to be destroyed by a degenerative neurological disorder, it would be the undiluted article, the aristocrat of brain diseases' (341). Thomas does exactly this: depicting Alzheimer's as the aristocrat of brain diseases – a powerful player outside the common rules, a condition that is beyond the reach of science and medicine, that destroys everything the middle classes have built for themselves. He shows Alzheimer's disease as attacking all that 'capital' has come to embody in rich societies according to Foucault's definition: 'everything that in one way or another can be a source of future income'.¹⁰⁹

In a first step, of course, it is Edmund's capital that is destroyed: his mind. As an 'expert on the brain' (73), an enthusiastic lecturer and dedicated scientist, it is Edmund's profession that makes the horror of his disintegration exceptionally vivid. But Thomas's vision of Alzheimer's disease as the killer of Foucauldian capital goes deeper. In a second, even more powerful way, Thomas uses the theme of role reversal in relation to the narrative scheme of the family novel. To pursue this argument further, consider Ru's definition of family constellations within such a novel:

The husband, just like the father, cares for the family honor and power ... He tries to possess and dominate his wife ... while the wife ... strives for an individual form of freedom just as the rebellious son does. Such a husband-wife conflict is, then, characterized by the opposition between power and will ... there is a clash between tradition and individuality.¹¹⁰

The individualist is Leary. Edmund's name already signals his doom. Notions of *King Lear* as the classical cultural imprint of Alzheimer's disease continue to persist in scholarship, narrative and on stage.¹¹¹ As expounded in the introduction, I disagree with interpretations of *King Lear* as demented, rather

seeing him as an ageing parent gone mad over the consequences of his acting. But here also lies the point of comparison. Edmund's values in life make him unfit for the narrative purpose of a strong father figure, because 'his ambition had never been for fancier titles and fatter pay-checks; he was after something unquantifiable, philosophical, the kind of aim never properly rewarded in earthly terms' (96). These values symbolize 'the grand objectives of the Enlightenment (including Truth, Justice, Reason and Equality)' that, among others, Anthony Elliott describes as dissolving or becoming irrelevant in the dominant presence of corporate capitalism and mass popular culture.¹¹² Thomas brings out precisely this conflict of values through the focus on Eileen as the prototype American middle-class climber. He traces the rise and Alzheimer's-related fall of the Tumulty-Leary clan, and thereby illustrates all that the condition embodies in the rich West.

As a bildungsroman, *We Are Not Ourselves* follows Eileen Tumulty's development and traces her change, as she adjusts her system of values in the confrontation with Edmund's dementia.¹¹³ The novel's first part prepares for an understanding of how Eileen's life – her relationships to her private property, her family, household and retirement – makes her, as Foucault would express it, 'a sort of permanent and multiple enterprise'. It narrates Eileen's harsh childhood in an Irish American household, and portrays her as someone who learns that life was 'what you made of it' (45). It is towards the end of part one that we reach the peak of the Tumulty family cycle, stabilized – again in Foucault's words – by the 'economic rationalization constituted by marriage'.¹¹⁴ Eileen's choice had fallen on Edmund, because the 'men that stirred her [were] reliable ones, predictable ones' (51). But the scene is set for the family's decline, once Eileen realizes Edmund's 'excessive vigilance about the effects of capitalism' (78) that opposes her own strong sense of property.¹¹⁵

The conflict between Eileen and Edmund arises over Eileen's desire to comply with her father's wish to own a house (66). Edmund's opposition is initially related to his disinterest in property and later to his disease-imposed need for environmental stability. This makes it increasingly difficult for Eileen to see Edmund 'as a fully vested partner in her future' (96–7). As Eileen recognizes that Edmund cannot be her capital in marriage, her capital becomes investing in a house. In letting Eileen realize in retrospect that this house contained her 'former *future* life' (575; emphasis original), Thomas very obviously characterizes Alzheimer's disease as severely restricting her entrepreneurial aspirations. What was a minor event in Timothy's final days – the Forsytes' by then eldest member losing the ability to manage his accounts – moves centre stage in this family's

life, creating (as Eileen's surname suggests) disorder and agitation. The novel's two central and longest parts cover the purchase of this house, and illustrate Edmund's rapid decline in it. In keeping with earlier considerations regarding its symbolic nature, Eileen's house embodies her sense of achievement as well as her world of values. Yet, the illness prevents the family from truly owning this house: the rooms remain 'empty spaces' (279). And living in the house – the state of the house itself – becomes one with living with the disease, as 'a lot of her house looked like a waiting room' (314) and Eileen is unable to remedy its 'state of disrepair' (339).

Like the husband–wife relationship, so the father–son relationship takes a special place in the family novel. To quote Ru again, the antagonisms explored are 'the father's thirst for power versus his love for his children, the sons' need for authority versus their rebellion against their fathers, the fathers' dominance versus the sons' disobedience, and the fathers' defense of the old ways versus the sons' quest for the new.'¹¹⁶ Revisiting themes covered in the husband–wife relationship, Alzheimer's disease plays its part in the workings of all these conflicts. Thomas particularly explores the consequences of 'losing a father early, being given all that responsibility' (491). What I want to look at here in more detail is the role of the youngest generation as such in Thomas's family novel, because, as Ru puts it, by 'defying and denying the father, [the sons] are reborn in the end.'¹¹⁷ Connell defies the disease. And in this defiance, he covers the roles of both rebellious outcast and loving son.

Edmund Leary dies in March 1999, the last year of the old century; and the narrative's final part ends with the turn of the millennium. But Edmund's death is not a landmark event. While *The Forsyte Saga* features several significant deaths over time, Thomas's narrative only truly includes Leary's. Its understated singularity within the family novel – Connell misses his father's last few living hours – underpins notions of Alzheimer's disease as a condition of slow dying alive. Shortly after his diagnosis Leary himself claims, 'I *am* dying' (325; emphasis original).

The depiction suggests that the death of the father does not really mark a liberation from the old: Alzheimer's disease lives on in the epilogue set in the year 2011 and remains the challenge of the new century. *We Are Not Ourselves* uses the apparent dissolution of the Tumulty-Leary family to show how family life in the West has been subjected to Alzheimer's disease as one of 'the conditions of postmodern capitalist life.'¹¹⁸ Thomas explicitly lifts Eileen's individual story onto the level of collective, national relevance, when he lets her ponder that we 'move around too much in this country' (575), a thought which evokes a

feature Foucault assigns to capitalist thinking, namely an increasing mobility to improve income.¹¹⁹ Characteristic of capitalist societies, such increased mobility for financial reasons destabilizes the individual as well as the family as a whole. Underlining this argument, Thomas develops the fate of the Tumulty-Leary clan against the backdrop of the intact and extended family of Italian immigrants who make their fortune within the underprivileged environment from which Eileen wants to escape.

It is, therefore, significant that Thomas offers a possible answer in the final ten pages of his account. Again outside the narrative time and frame, the epilogue eventually brings into play the theme of change embodied in the youngest generation: Connell's courage and choice to continue the family line despite a risky gene. Or, as he puts it:

He could honor his father by loving the kid the way his father had loved him. And if he had to be vulnerable in front of the kid, if he had to be defenseless and useless and pathetic, if he had to forget things and piss himself and get lost on the way home, then so be it. If the kid didn't handle it well – well, that was what kids did. (619)

With Connell realizing that '*he* was his father's real estate' (588; emphasis original), this epilogue can be read as an ode to the continuation of the family. As the nineteenth century turned into the twentieth, dementia was an image of degeneration. Two decades into the twenty-first century, Alzheimer's disease is the predominant trope for the decline and loss of the thriving individual as the smallest unit of capitalist societies.¹²⁰ It pictures the fractured lives led in such societies, but concurrently represents the kind of disease for which exactly these societies have neither space nor place.¹²¹

Where *The Forsyte Saga* revolves around the dying out of the clan because of the young generation's individuality, Thomas's account emphasizes the continuity of life granted by that very individuality. This individuality entails an attitude to dementia like that of the child Maurizio who has grown up without having lost his capacity for empathy in favour of the will to 'profit, selfishness, and the drive for ever more bigness'.¹²² Such loss of empathy (already in childhood), according to scholar of psychology Arno Gruen, is particularly encouraged in cultures 'that make it difficult for people to develop the self-esteem that comes from a sense of one's inner worth, which can evolve only if people learn to accept and share their suffering, pain, and adversity'.¹²³ In Borio's allegory, the values of this materialistic culture are embodied by the demon Giancarlo, who seeks to undermine the power of custodians like Maria. Giancarlo focuses his attention

on Maurizio, taking inspiration from a book that instructs how to rob children of their carefree years by letting them watch television programmes where 'children portray the behaviour of adults' (90).

More generally, some recent healthcare initiatives attempt to foster continued empathy from an early age. Sally Chivers, for example, expands on the effects of South Korea's 'interactive and intergenerational social program' directed at dementia care. This social agenda explicitly includes contact between children and people with dementia. As a consequence, Chivers continues, 'alarmist news stories will not be the only source of knowledge these children receive about dementia in late life'.¹²⁴ In reverse, fiction for young adults may contribute, as Clarke and colleagues observe, to 'frequent (mis)representations of dementia that escalate people's concerns'. The authors particularly mention the 'dementors' in the *Harry Potter* series of books, 'which suck the soul out of people and cause a sense of terror in anyone they are near' (87). Borio's book for children genuinely counters this. The careful fabrication of the book – including the use of deckle-edged paper and sewn binding – emblemizes a niche publisher's traditional craftsmanship.¹²⁵ It opposes the fast-lived consumerism encouraged by the story's anti-hero, Giancarlo.

Still, especially in the absence of a cure, the calm acceptance of suffering, pain and adversity appears to be a sheer impossibility; and not enough has changed politically, institutionally and societally that would support such acceptance. The condition will not lose its traumatic connotations – not least if we can read the title of Huguenin's narrative as alluding to *Hiroshima mon amour* (Hiroshima my love; 1959). This French-Japanese co-production tells a story about memory, forgetting and lost relationships during and after the Second World War. Revolving around the harrowing consequences of the first atomic bombing, it explores, as Cathy Caruth contends, the productivity of communicating across cultural boundaries and demands 'a different kind of listening and ... a speaking literally of the body'.¹²⁶ Caruth's perceptions of *Hiroshima mon amour* open an additional perspective on Huguenin's caregiver experience and, I find, they also suggest how Arno Gruen's insights can be implemented in changing healthcare approaches: such approaches acknowledge the patient's inner worth beyond his ability to remember, and the caregiver shares her story in the acceptance of her own risk of dementia. Connell Leary eventually adopts this perspective. But, I reiterate, it is a perspective difficult to imagine in a cultural climate that equates dementia with the death of the self.¹²⁷

How can attitudes evolve in societies that face sharp socio-economic and demographic challenges? This is a question worth asking, especially when media

coverage on ‘dementia levels’ as ‘stabilising’ may easily endanger slowly budding changes, even if this coverage were merely aimed at toning down the populist alarmism we have been witnessing in recent years.¹²⁸ Where families are far flung due to economically imposed mobility, quality healthcare is no longer a matter of choice. It becomes a service many cannot afford. Choice is often about inexpensive deals. Low-cost healthcare is provided by global care chains; yet, as Woodward has remarked, these labour markets ‘move love as surplus value, as a commodity, and as an export from one country to another’.¹²⁹ In addition, quality care is undermined by the profit-seeking exploitation of staff: poor communication skills, high workloads and insufficient training leave little time and space for compassionate attention and dedication.¹³⁰

Compassionate attention and dedication are essential to the caregiving attitude which, during what Gawande describes as a time of transition, Schweiger’s film portrays. The very product of consumerist culture – I especially think about its product placement, its comedy form and its entrepreneurial setting (as well as the fact that Schweiger has filmed a US remake, *Head Full of Honey*, with Nick Nolte as lead character) – it still gives the answer to how society must deal with people with dementia in these circumstances: ‘Amandus’ means ‘to be loved’.¹³¹ But love and empathy can only become transformative on a larger societal scale once political, institutional and cultural values and beliefs about ageing take a momentous turn. For the perceivedly productive part of the population, this means accepting ageing as a natural part of life, and appreciating growth, development and success in ageing and old age. For the elderly and perceivedly less productive, this means bringing their wisdom to bear on value systems that are overly determined by individualism and financial gain.