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Neurotechnologies and narrative examine the failing mind

The visual exploration of the brain and fascination with the mind

In the 1990s, Alzheimer and his disease have become the flavour of the decade ... Clinicians increasingly face demands from basic scientists to provide subjects for research studies who meet 'strict DSM III-R diagnostic criteria' of the disorder. The race between pharmaceutical companies to find the 'cure' for Alzheimer's disease is fierce, and established scientists have been recruited to the tasks.

G. E. Berrios and H. L. Freeman, *Alzheimer and the Dementias*¹

Since the early 1980s, medico-scientific research had been working at an international level towards elucidating the condition's pathogenesis. With new imaging technologies becoming available for medical practice, a patient's biochemical and genetic make-up could now be assessed in conjunction with real-time observation of functional and structural changes in the brain. In the wake of these developments, as summarized by G. E. Berrios and H. L. Freeman, the medico-scientific narrative of decline and loss attained a new level of perceived truth. Visually observable brain shrinking became the correlative, if not surrogate, of a patient's decreasing performance, because cognitive functioning scores could be correlated to data collected from the brain at work.

Imaging methods led to an ever more detailed study of the mind, while conditioning and enhancing a growing preoccupation with cognitive prowess. A US government initiative additionally heightened public awareness of brain research during what George W. Bush had proclaimed the 'Decade of the Brain', the period spanning 1990 and 1999.² The emergence of the first drugs used for the treatment of Alzheimer's disease also furthered this cognitive focus. (These drugs were intended to counter neurochemical deficits while enhancing cognitive

performance, but they would reveal themselves as largely ineffective: they did not halt disease progression and alleviated cognitive symptoms only to a limited extent. Yet, essentially they continue to be the only drugs available for Alzheimer's disease.) These developments, I argue, reformulated dementia as a cognition- and performance-limiting process, based on organic changes now observable *in vivo*.

The imaging techniques of particular relevance are: computer tomography (CT), a method building on X-ray technology; magnetic resonance imaging (MRI), which assesses the environment of hydrogen atoms in the body; positron emission tomography (PET), which traces the uptake of specifically labelled glucose (abbreviated FDG), and hence cellular activity; and single photon emission computed tomography (SPECT), which measures blood flow. When these methods started to gain prominence in the 1980s, CT and MR images were considered to represent tissue anatomy and biochemical make-up, while the PET-FDG image was taken as a 'map' that reflected neuronal activity.³ The implications that Van Dijck has identified regarding the meaning and effect of the map metaphor where it applies to genetics are relevant here too: its equating to a map underlines how the research community increasingly considered the visual image as the most reliable form of evidence. MRI technology in particular represented, as sociologist Kelly A. Joyce elaborates, a '*cultural icon* – a sacred object' on which questions about personal health and identity revolved.⁴ Early MRI studies provided evidence of the patient's shrunken brain.⁵ And, in 1990, a group of US scientists around William Bondareff advocated the use of MRI for 'following the course of dementia' over time, because they saw differences in disease severity.⁶ Such work was seminal in discourse developments, because medical images were valued 'as Evidence in its quintessence'.⁷

In keeping with Foucault's insight that the clinical gaze detaches the body from a person, this research brought home how patients could be turned into abstract entities. Presenting assessment scores and computed lesion-brain ratios, three tables and six graphs adumbrate, in the paper by Bondareff et al., the complex procedures of weighing, measuring, dividing and multiplying that yielded the numbers standing in for the individuals subjected to these procedures. The imaging specialists' focus on visually collected and mathematically processed ratios of brain measurements further distanced the observer from both specimen and individual. I emphasize that, despite the perceived reductionism of these procedures, I do not attribute to them any particular role *per se* in discourse developments. Bruno Latour and Steve Woolgar convincingly present the data processing as part of a creative process and explain that, for the scientist, the

outputs obtained in such a process remain in 'direct relationship to "the original substance."' ⁸ Rather, I am interested in how these procedures contributed to what Ian Hacking would term new ways of classifying and knowing patients, and how such classification played into concepts of loss related to archival notions of memory.⁹

The resulting diagrams suggested potential correlations of each individual's lesion-brain ratio to various cognitive test scores. Specifically, the 'magnitude of these lesions ... correlated closely with the severity of dementia indicated by scores on the Blessed Dementia Scale and the Folstein Mini-Mental State Examination' (47). These cognitive tests were intended to quantify the 'degree of intellectual and personality deterioration' in elderly individuals, as they categorized the cognitive performance of patients along a numerical scale.¹⁰ Originally developed in 1968 and 1975, they came to be prominently used once pharmaceutical compounds required assessment. Tacrine and donepezil were the first drugs (termed pro-cholinergic because they were designed to support cholinergic activity) approved in the United States and other countries, in 1993 and 1997, respectively. A pharmacological study of one of these compounds illustrates how the language evolving around these drugs (and the testing of their efficacy) heightened concepts of dementia as a cognitive condition and the patient as under-performing.

In a US report from 1998, S. L. Rogers and colleagues evaluated the efficacy and safety of donepezil.¹¹ Their description of inclusion criteria and methods for assessing drug efficacy brings home two points: the language regarding Alzheimer's disease had become strongly performance focused, and the description of the patient followed principles of systematic clinical categorization and classification. The diagnosis of 'probable AD' was made

according to criteria outlined by the National Institute of Neurological and Communicative Disorders and Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA), with patients also fitting DSM-III-R illness categories ... Patients had scores on the Mini-Mental State Examination (MMSE) of 10 to 26, and a Clinical Dementia Rating (CDR) score of 1 (mild dementia) or 2 (moderate dementia) at both screening and baseline. (137)¹²

Also clinical outcomes were expressed in strictly standardized terms based on a battery of five different tests: 'the cognitive portion of the Alzheimer's Disease Assessment Scale (ADAS-cog) and a Clinician's Interview-Based Impression of Change scale that included caregiver supplied information (CIBIC plus) ... the MMSE, patient-rated quality of life (QoL) scale, and the Sum of the Boxes of the

CDR scale (CDR-SB)' (137). The authors dedicated almost a quarter of the eight-page-long paper to the description of these research methods, and I have quoted from them at length to convey their style and purview.

For the purpose of Bondareff's research, patients were tested similarly (47). Based on mathematical and statistical operations, the authors hypothesized that the visible changes they observed 'might affect cognitive functioning; perhaps ... by interrupting networks [that] are the subject of contemporary discussions of the neurophysiologic basis of learning and memory' (51). With such speculations, the authors took a significant step towards the claim that visual data that reflected a loss in brain cells could stand in for cognitive performance and memory capacity. Five years later, in a Japanese study, Kazunari Ishii and colleagues explicitly linked visually collected information to impairment in a brain area involved in memory operation (the hippocampus).¹³ This step deserves particular mention because they published their evidence in colour.

The use of colour rather than grey scales to display differences in recorded intensities in the brain had been in use since the early 1980s. But only when scientific journals supported publication in colour, and such publication became affordable for research labs, did coloured brain sets become the norm. Anthropologist Joseph Dumit points out that choosing a specific set of colours to represent linear activity values in specific brain regions is entirely arbitrary. For him, this very arbitrariness reinforces the sense that 'these regions are internally coherent, separate from their neighbors, and therefore able to adequately represent the "functioning of the task" in question'.¹⁴ This means that colouring per se added to the perception that a specific area of the brain was structurally damaged and its function impaired in Alzheimer's patients. In reverse, the image could be seen as the correspondence of patients' cognitive impairment. Ishii and colleagues opted for a scale ranging from blue to red, with red representing the highest degree of intensity. The absence of the signal colour red in those areas where 'decreased' cerebral blood flow was observed (1163) visually determined the loss in the research subject's memory.

The images were selected with the aim of enhancing textual arguments in both scientific and popular articles.¹⁵ Colour made research results more easily accessible to mass media exploitation, but this process was reciprocal, as researchers soon felt the pressure to make their scientific publications more engaging. Lisa Cartwright has superbly illustrated how, across the twentieth century, knowledge and subjectivity in science are 'entangled with a broad range and mix of cultural and representational practices'.¹⁶ Her insights inform my understanding that images of the living brain opened up medico-scientific

descriptions of Alzheimer's disease to largely unfiltered mass media use of the condition as meaning cognitive deficit. Articles frequently incorporated colourful brain images or, at least, made reference to the usefulness of imaging technologies to 'detect progressive brain cell degeneration' in the brains of patients in very early stages of Alzheimer's disease.¹⁷

Like the general public, researchers were convinced of the 'certainty' conveyed in these visible findings, which was 'heightened by the 'status attributed to large, expensive, complex technologies.'¹⁸ Lennard J. Davis has made the important observation that science and scientific medicine are themselves not objective disciplines of knowledge acquisition but part of a 'new problematics of obsession'.¹⁹ By the turn of the century, the evolving technology could generate dynamic blood volume images to assess brain activity during stimulation, such as cognitive testing. In keeping with Dumit's statement that brain areas circumscribed by colour were taken as functional units, the image itself now answered for the subject's cognitive performance.²⁰ But such brain imaging also revealed the sobering fact that long-term treatment with drugs like donepezil did not improve 'regional cerebral blood flow' in patients.²¹

This brings me back to the clinical trial conducted by Rogers and colleagues in 1998. Their study concluded by stating that future trials were 'necessary to determine if donepezil has significant effects in delaying deterioration or actually improving functional outcomes for AD patients' (144). Cognitive abilities had become the all-encompassing parameter by which to define patient well-being. In fact, for Hacking, one of the reasons that memory loss in Alzheimer's disease is so emphasized in the final decade of the twentieth century is that objective quantitative tests for memory loss can be so easily defined.²² This is especially important because once so tested, therapeutic approaches proved largely unsuccessful – counter to expectations nourished by the myth of the transparent and knowable body, resting on the assumption 'that seeing is curing'.²³ Based on similar assessments, a British long-term clinical trial found donepezil not to be cost effective in 2004.²⁴ This study eventually led the National Institute for Health and Care Excellence (NICE) to no longer recommend the use of pro-cholinergic drugs in mild to moderate cases of dementia in Britain.²⁵ During a period marked by a prominent fascination with the brain, whose visual scrutiny seemed to give access to the 'neural correlates of the activities of mind itself in real time', cognitive performance had become a question of healthcare budgets.²⁶

Such decisions were influential for the further development of the status of patients. They were made at a time when, as we have seen, cognitive health and performance in older people was increasingly promoted in public health

strategies such as the US Healthy Brain Initiative in 2005.²⁷ Caregivers witnessed their parent's or partner's loss of memory and mourned their social death. These losses appeared sanctioned by imaging data and testing outcomes, and they were enhanced by a popular fascination with cognitive performance and the visual representation thereof. As Stephen G. Post observed, 'Nothing is as fearful as AD because it violates the spirit (*geist*) of self-control, independence, economic productivity, and cognitive enhancement that defines our dominant image of human fulfillment. Deep forgetfulness represents such a violation of this spirit that all those with dementia are imperiled.'²⁸

Post's deliberations on the situation of Alzheimer's patients in a 'hypercognitive society' are particularly poignant when considering that imaging technologies grappled with the same question: the separation of normal from pathological processes of ageing. In the search for diagnostic tools with which to distinguish between 'normal age-related cognitive decline' and levels of cognitive performance 'that precede the onset of dementia', a series of constructs had been devised since the mid-to-late 1960s. The most durable term, 'mild cognitive impairment', entered the lexicon of literature on ageing and dementia in 1988.²⁹ The move to introduce a category of 'mild' impairment enabled practitioners to lift the ensuing stigma of lacking cognitive performance from the ever-growing number of older people, who feared the diagnosis of Alzheimer's disease, because the demented individual was – as popular writing had brought home – less able, less independent, less productive and less conforming with society's expectations of performance.

The growing cultural interest in these neurotechnologies both paralleled and conditioned a marked increase in literary explorations of a broad range of neurological conditions from the late 1990s onwards. For American literary critic Marco Roth, this rise of the 'neurological novel' was closely linked to the fact that the press, like the *New York Times* in its sciences pages, eagerly took up the reductionism of mind to brain.³⁰ Ian McEwan's *Saturday* (2005) is a good example.³¹ It centres around the psycho-neurologically challenged Huntington's disease patient Baxter, whose disease-typical behaviour becomes indistinguishable from that of a socially disadvantaged criminal aggressor (91). Baxter falls short in terms of intellectual abilities. He becomes a mirror in which the values of a cognition-driven society are reflected – those of his opponent, the high-performing and successful brain surgeon Henry Perowne. For Perowne, Baxter merely has 'a diminishing slice of life worth living, before his descent into nightmare hallucination begins' (278).

This fictional representation brings home the deleterious impact on personhood of what Raymond Tallis termed the 1990s ‘culture of neuromania.’³² With the biomedicalization of Alzheimer’s disease, Joseph M. Foley much earlier had seen that the dementia patient’s chances to be considered an individual with personhood and identity were at stake. He wrote that ‘we must know not just about cognitive capacity but also about awareness, feelings, and emotional reactions to the personal and social consequences of dementia.’³³ He had expressed these concerns as early as 1992, which signals how anxieties about identity in dementia foreshadowed the exponential rise in medico-scientific research on Alzheimer’s disease and its coverage by popular science and mass media throughout the 1990s.³⁴

The patient’s feelings and experience, eventually, attracted increasing attention in the final decade of the twentieth century. Partly, this change was conditioned by the said cultural fascination with ‘neuronovels’ and a rising number of genre novels, among them ‘thrillers[] of amnesia.’³⁵ Countless popular novels (including detective fiction) and an endless number of televised serials continue to bring out the condition as a mirror, in which values of the cognitively, romantically or economically excelling chief protagonist are reflected. Still, I contend that the narrative exploration of Alzheimer’s disease as one of the failing mind, especially during the 1990s, eventually opened the way for patients to articulate themselves and reclaim their authority and identity. I cover such patient life-writing more fully in the final section of this chapter. First, I will examine three early pieces of dementia detective fiction. Their unreliable narrators keep these narratives anchored in the tradition of the novel of consciousness. Yet, it is through their renewed focus on plot as tracing mindful performance that these narratives would be of notable service to patients and their care.

The Dying of the Light: Detective fiction claims back patient authority

In 1992, one of the first narratives carrying ‘Alzheimer’s’ in their title appeared in print – Hans Dieter Mummendey’s *Claudia, Alzheimer und ich: Kriminalroman* (Claudia, Alzheimer’s and I: A detective novel).³⁶ Judging from the core image explored in the narrative’s opening chapter, the story did not promise a radically different approach to dementia: an allusion to the patient’s living death as the 64-year-old narrator, undergoing a scanning procedure, wonders, ‘Is this

already the scenario of interment, of cremation?’ (10). But the story’s subtitle opened the condition to an entirely new genre. Mummendey develops his mystery consistently from the perspective of an ageing person, whose reliability is questionable from the outset. The narrator himself explicitly ponders, ‘Does my brain keep up with reality?’ (10), and later comments on his forgetfulness (15) and age-related chattiness (15). In this narrative mode, the patient turns to telling of his much younger wife Claudia’s death. He expands on how Claudia perceived increasing signs of ‘imperfection, lack, weakness, illness’ (61, 87) in him and how she created situations which suggested his inability to remember (69). Based on such information, the reader begins to wonder how Claudia might have died, especially since the narrator keeps emphasizing her sportiness and robust health.

Bernlef’s narrative is also told from the patient’s perspective, but Maarten’s reliability is never an issue for the reader – both for Vera’s presence and because we are led to read *Out of Mind* as a convincingly charted documentation of the narrator’s Alzheimer’s disease.³⁷ The narrative’s free indirect style reinforces this perception. In comparison to Bernlef’s Maarten, Mummendey’s narrator is both actor and witness, and therefore has control over the truth or not that is revealed. With a detective novel in hand, the reader relies on the patient-turned-narrator to solve the mystery. But anxious to see its solution before Alzheimer’s has gone too far for the narrator to impart his knowledge, the reader experiences a completely new feeling with a dementia novel in hand. We read for the plot, against the disease and its trajectory.

Between the 1940s and the 1980s, the tools and strategies of modernist and postmodernist fiction enabled the narrative exploration of the workings of the patient’s mind and emotional experiences. These approaches were, as Peter Brooks has argued, permeated by a suspicion that ‘plot falsifies more subtle kinds of interconnectedness.’³⁸ This means that modernist writing narrated the condition from within the patient’s mind, relying on the condition’s own plot, which medical and social scientists as well as psycholinguists had characterized in terms of decline and loss. Paralleled by the growing emphasis – by both medico-scientific research and the adult child’s memory work – on chronology, genealogy and temporality during the 1990s, plot re-emerged as a structuring principle in narrative. In this context, no narrative relied more on plot than the detective story, given that ‘everything in the story’s structure ... depends on the resolution of enigma.’³⁹

Lisa Zunshine points out that ‘we open a detective novel with an avid anticipation that our expectations will be systematically frustrated, that we

will be repeatedly made fools of, and that ... we will be fed deliberate lies in lieu of being given a direct answer to one single simple question that we really care about (i.e., who done it?).'⁴⁰ Put differently, the questionable reliability of dementia patients makes them characters highly suitable for detective fiction. At the same time, detective fiction, in driving towards dénouement, is perhaps the genre most suited for challenging this supposed lack of reliability. I here advance the argument that it was exactly such plot-related expectations that encouraged the reader to question societal preconceptions against patients as unreliable and lacking in authority. The genre's requirements for red herrings as well as dependable clues led authors to appreciate dementia patients' narrative possibilities. By the same token, it opened readers to the narrative capabilities of patients and heightened societal responsibilities for listening and granting authority to their accounts. In short, beginning with Mummendey's novel, the plot-reliant detective story of the 1990s returned agency and control to the patient.

Plotting is the narrative's core device and the patient's central pursuit in Michael Dibdin's *The Dying of the Light: A Mystery* (1993).⁴¹ Rosemary Travis dictates the plot, and she misleads detective and reader. In so doing she awakens fellow patients 'from their catatonic stupor and paranoid delusions' (132), instigating their improved care and awareness of continued agency. Dibdin's mystery is both hilariously funny and playfully critical. It reveals itself as a parody on the continued lack of quality care, a satire on society's views on the elderly and memory loss as their main condition, and a (Travis's) travesty of the contemporary form of the detective novel. First and foremost however, *The Dying of the Light* can be read as an allegory for memory loss in the elderly – a cognitive condition where fact and fiction merge. To identify the murderer of Rosemary Travis's friend Dorothy Davenport, the reader's interpretive ordering must achieve more than sifting reliable from unreliable figures. It must probe the relevance of different narrative layers dominated by these figures: Rosemary Travis's fanciful storytelling; detective Stanley Jarvis's unenthusiastic investigating; both their impressions conveyed in free indirect style; and, perhaps the only layer in which to find trustworthy clues, the views of a hardly perceptible narrator.

From the outset, Dibdin plays with the reader's expectations. He portrays Rosemary and her friend as the elderly storytellers, who are perceived as tedious by those who are young. Yet, the narrative's first part is set in an environment in which storytelling becomes a necessary pastime. Befitting its name, Eventide Lodge is a place where time stands still. The clock on the mantelpiece has stopped

at ten past four, preventing the plot from moving forward, like the darkness which engulfs the place when lights are turned off at 9.30 every night. Rosemary and Dorothy 'make a fictional virtue of the factual necessity' (49), taking to plotting their own 'comforting narrative' (45). For their 'murderous web of intrigue' (56), they turn their fellow inhabitants 'into cardboard characters whom they manipul[at]e to suit their whims and the twists and turns of the story' (59). In this diversion between the friends, 'it was always Rosemary ... who kept all the strands of the plot in play while still managing to accommodate – and thus to some extent control – the real horrors which surrounded them' (44). However, once Rosemary is removed from conversational interaction, she feels her control – her identity as plotting individual – slip away. With the news of Dorothy having to go to hospital for cancer treatment her sense of audience drops, because Dorothy's part was 'to fill in the gaps ... to spot the errors ... to approve and criticize, suggest and reject' (45). But Rosemary does not give up at the loss of her social network. She does 'rage against the dying of the light', as the book title's allusion to Dylan Thomas's 1937 poem for his dying father anticipates.

On the day Dorothy is found dead, Rosemary's ability to plot reaches a new level. She becomes the narrative interface in Dibdin's network of fact and fiction, relaying between the different fictional layers. With Dorothy's death, a real mystery needs to be solved in part two of the novel, requiring an actual detective, who would separate clues from red herrings – in an environment whose closed society makes all its members potential suspects and unreliable.⁴² An avid reader of detective fiction (65), Rosemary is aware of the rules of the genre and sees the need to assert her selfhood in a plot apparently no longer of her own design. Put differently, the reader replaces Dorothy as Rosemary's audience, observing the altercations ensuing between Rosemary and detective-inspector Stanley Jarvis.

But if the pleasure in reading detective fiction derives from 'observing the mastermind's work', Dibdin dashes his readers' hopes for an authoritative inspector entirely: Jarvis has no interest in the case.⁴³ Uninspired, 'he consulted his thoughts. They were empty' (78), 'executed a doodle in his notebook' (79) and later 'added an elegant curlicue' (81). As an invisible narrator observes Jarvis, the reader, like Rosemary, begins to wonder: 'You *are* in charge, aren't you?' (93; emphasis original). And Jarvis's authority is fully undermined when he feels the need to 'tower[] over the elderly woman, swaying back and forth in the manner cultivated by the constabulary for the purposes of impressing the populace' (96), and silently prays 'Don't let me hit an old lady' (98). Thrown back onto Rosemary's initiative, the reader begins to appreciate the patient's

resourcefulness. Rosemary coordinates her fellow patients' interrogation by the detective, setting the scene for a 'classic English detective story, with its unique blend of logic and fair play' (98), in which all are 'gathered together in the lounge of this isolated country house to face the detective's probing questions. One of us is guilty, but which? Can the sleuth succeed in unmasking the murderer before he – or she – strikes again?' (112–13).

Rosemary positions herself as the centre of a network of information. In this network, she regains dominance through language, because, as Otis would express it, she 'tries to know and control others by controlling their words'.⁴⁴ Her threat – 'if you leave now, I will be the next to die' (120) – forces Jarvis to take the matter in hand, even though convinced of Dorothy's suicide (87). As the narrative accelerates towards the mystery's dénouement, Jarvis returns to Eventide Lodge in the third and final part of the narrative, to identify the testimony of one of Rosemary's fellow residents as 'fiction from beginning to end' (135) and Rosemary as 'the author' (135) of it. As it turns out, Rosemary has been plotting the case all along, putting Dorothy's suggestions in her suicide note into action, namely 'to make it look as though I were the victim in one of our whodunnits' (142).

Rosemary is the real mastermind of the piece of fiction in hand. She plotted the case and laid out the clues for Jarvis to pick up and the reader retrospectively to arrange. She performs theory of mind. She uses – I am adapting Alan Palmer's definition here – her awareness of the existence of Jarvis's mind, the knowledge of how to interpret her own as well as the detective's thought processes.⁴⁵ But Rosemary's design is not only the key to the reader's pastime. We honour her plotting, because we have to go over the story again to revise our interpretations; we have to use our own theory of mind, aiming to follow Rosemary's as well as Jarvis's mind to avoid losing the plot.⁴⁶ In this regard, our readjustment goes beyond the separating out of witnesses and culprits: like Jarvis, we must come to terms with the fact that Rosemary does not fit our preconceptions of an unreliable, because elderly and perhaps forgetful, storyteller.

Confirming this reading, Dibdin presents Jarvis and Travis as plotting equals in their animated conversation covered in the novel's final part. For Rosemary, Jarvis turns out to 'be someone of a rather higher calibre' (147); and Jarvis explicitly tells Rosemary of the moment when he 'first started to take [her] seriously' (137). Once the inspector – as the detective fiction's key integrative figure – values the patient, Rosemary is lifted onto a higher level of authority. This ingenious change in dynamics invokes notions of whole-person approaches to dementia care, which advocate that 'much of personal identity belongs ... to

the mutual recognition between two people'.⁴⁷ It also forms the centre of Dibdin's social criticism. With her newly gained authority, Rosemary can finally live her social self, which goes far beyond that of a cardboard character in a piece of detective fiction: she can lecture Jarvis for not having approached the 'case in the open-minded and impartial manner befitting a detective' (136).

But it is the joint action of Travis and Jarvis – the phonetic similarities between their names anticipating their cooperation – that solves the narrative's real concern, after we have followed the red herring of Rosemary's plotting: the patients' well-being. It is through Jarvis's actions that Rosemary becomes aware of Eventide Lodge's true impact on the patients' mind and spirit (131). In keeping with W. H. Auden's view that 'the job of detective is to restore the state of grace in which the aesthetic and the ethical are as one', Jarvis, at last, turns out to be the perfect inspector.⁴⁸ Initially sorry for the home's director Anderson 'stuck out here in the middle of bloody nowhere with a bunch of oldies well past their sell-by dates' (87), he eventually charges him and his sister for 'wilful cruelty and gross neglect' (132). He brings home the narrative's core message that care is, to some extent, a cure. However, it is only through Rosemary's plotting that Jarvis is led to expose himself and the reader to the patients' environment in the first place. Through his focus we appreciate the home's smell of mould (77). We suddenly see everywhere 'the same miscellaneous assortment of third-hand furniture, the same oppressive volume of chilly grey light, the same sense of desolation and decay' (107). Together with Jarvis, we hear Anderson and his sister Letitia Davis considering the elderly 'dribblers and bed-bespatterers' (80), with 'brains in their bums' (91) and without any future, let alone credibility:

All the residents of this establishment are shortly destined to become the victims of a ruthless and anonymous killer against whom the combined forces of civilization have so far proved powerless. What more natural than that they should seek to contain their terror by recasting themselves as characters in a nice cosy whodunnit, threatened not by impersonal oblivion but a fallible human murderer, acting in a recognizable manner and for comprehensible motives, whose identity will be revealed in the final chapter? (81)

Dibdin also satirically overstates Anderson's and Davis's alcohol abuse and their physically and verbally abusing the patients. In this way, he satirizes the continued lack of quality patient care in the 1990s. Dorothy's choice to end her life could also be read as a response to the bleak outlook drawn, and caused by, caregivers like Anderson.

In Dorothy we encounter Dibdin's other powerful patient advocate. Her right to self-determination could be taken as a fictional response to contemporary evidence suggesting an increasing trend in elder suicide.⁴⁹ As such, Dibdin's choice with Dorothy and Rosemary to explore both end-of-life possibilities is most effective. In conjunction with the novel's ending – Rosemary asks explicitly, 'How's that for a happy ending?' (151) – Dorothy's choice may be viewed in relation to David C. Thomasma's argument that while 'a good death is a benefit to all of us, the duty to help bring it about can be fulfilled through loving care of individuals, proper control of our medical technology, and community support through hospice programs'.⁵⁰ The ending makes for a comedy of manners, given that it 'contains an expulsion of the socially undesirable which insures the continued happiness of those remaining'.⁵¹

We could read *The Dying of the Light* as a response to the National Health Service and Community Care Act from 1990, which regulated the assessment of patients' needs and abilities as a precondition for them to receive care and services. It suggests that many institutionalized individuals could live within the community for longer, if adequate healthcare were provided in that community and if healthcare were more focused on communicating with the patient. This perspective is in line with agendas, developed since the 1990s, that centred on care and campaigned for the celebration of neurodiversity. According to Dana Lee Baker, both agendas connect to the question of personal identity and promote patient-centred care. Dibdin's narrative appears exceptionally well placed to bring home the potential of celebrating neurodiversity: it develops the individual with the condition into a three-dimensional character with continued capabilities and identity.⁵² The play-like narrative relies on the continued interactional abilities of older people. Almost entirely set in the home's lounge, the narrative's confined space of action encourages the reader's perception of a drama unfolding in the continued present tense of a play on stage with a central focus on conversation. Dibdin's emphasis on verbal exchange appears particularly pointed at a time when a growing body of work developed around differences between psycholinguistic concepts of breakdown and sociolinguistic appreciation of continued abilities in cases of dementia.⁵³ As explored in Bernlef's *Out of Mind*, psycholinguistic studies had particularly concentrated on language breakdown, explained by worsening cognitive skills. Sociolinguistic studies, from around the mid-1990s, rather emphasised remaining linguistic capabilities and assigned an important role to the patient's environment in sustaining these abilities.

Still, the question arises as to how realistically patients can be portrayed in their progressive decline, if they are meant to represent proactive characters.

Baker, in fact, cautions that celebratory agendas frequently emphasize the higher-functioning individuals, while excluding those who appear less capable.⁵⁴ Accordingly, the argument could now run that the condition of Mummendey's narrator or Dibdin's protagonist simply had not gone far enough so that these patients could still be presented as active. In line with sociolinguistic approaches to dementia, psychologist Steven R. Sabat would, I believe, counter this objection, arguing that patient understanding comes down to appreciating remaining abilities and to figuring out how those abilities 'can be recognized and supported by others'.⁵⁵ Martin Suter appears to take this issue to heart in *Small World* (1997), while similarly broaching the topic of improved patient-centred care.⁵⁶

The Swiss writer credits a vulnerable patient with continued abilities, even though Konrad Lang is much less able than Rosemary Travis to perform theory of mind. Without dedicated support, the secret Konrad holds would not be revealed. At the same time, the disease trajectory drives the plot: the mystery can only be uncovered once Konrad accesses his earliest childhood memories (51). Miriam Seidler considers Konrad to be a flat character, because his condition represents the continuation of his lifelong subjection to the stepmother.⁵⁷ But he is at the centre of all other characters' attention. The matriarch Elvira Senn, 'alarmed by his detailed memories' (45), wants to murder him before he can reveal her crime; his stepbrother Thomas tries to escape him because Konrad's detailed memories make him doubt his own cognitive abilities; and Simone, the young wife to unfaithful Urs, Elvira's heir, focuses her caring instincts on Konrad once she notices the growing tension in the Senn clan.

Related to Simone's efforts, a large part of the narrative explores Konrad's recovery of memories, particularly in response to the study of photographs from his own past. This therapeutic approach had featured in the clinical literature since the mid-1990s, and was part of what developed as patient-centred care towards the turn of the century.⁵⁸ Together with Simone, the reader sides with Konrad, who needs 'to be treated like a human being' (23), rather than sent to a nursing home. Simone arranges for highly qualified day- and night-care personnel, a dietician, physiotherapist, occupational therapist and a neurologist in the Senn villa's guesthouse. Konrad 'blossomed' (170) from the first day in this caring environment, 'showing longer phases of presence, improved ability to concentrate and communicate' (171). As care becomes key to Konrad's memory recall, the reader becomes privy to the crucial need for patients' dignified care.

Accomplishing the 'fusion of the popular in terms of subject, audience, and form', a piece of detective fiction could impart this message on a much larger

scale than caregiver manuals like the revised 1999 edition of *The 36-Hour Day* could do with its 'Guidelines for Selecting a Nursing Home' (464–75).⁵⁹ Dementia detective fiction was, in its reach as much as in its cognitive approach, the cultural reflection of two trends: significantly intensifying dementia research and an expanding body of interdisciplinary work centred on cognitive sciences.

In the final section of this chapter, I show how patients themselves attempted to influence the dementia narrative at the interface of science, medicine and the arts towards the turn of the century; how they located themselves in a slowly changing atmosphere that credited them with continued capabilities; how they fashioned their 'return from the living dead'.⁶⁰

Who Will I Be When I Die? Patient life-writing around the year 2000

For Christine Boden, writing *Who Will I Be When I Die?* (1998) is her reaction to the fact that 'sufferers seem to be ignored – on the assumption, perhaps, that we are "too far gone" to care'.⁶¹ She is mindful that there are not many books written by people with Alzheimer's disease, 'as generally they tend not to be aware of their gradual deterioration, nor to be able to document the changes happening to them. There are several written by carers', she emphasizes, but these 'have a very different perspective' (ix–x).

As part of a slowly growing body of patient life-writing, Boden's narrative strongly emphasises the patient's continued agency and voice in a discourse that, for twenty years, had been dominated by the caregiver's view of the patient as passive. Eleanor Cooney and Margarita Retuerto Buades perhaps told narratives of the patient as living dead, because they experienced the loss of a parent or partner. At the same time, accounts about a patient can perpetuate ideas of the patient's social death, because the existence of these accounts per se embodies the unspoken assumption that the patient is unable to communicate. Only once patients began to occupy centre stage in fictional texts did their autonomy and independence become more visible. The emphasis on self-determination in these texts is shared with that in patient accounts which appear towards the end of the century. Written with the purpose of self-affirmation in a cultural climate that hails cognitive prowess, the tone and intent of such life-writing significantly differ from that of genre fiction. But like the examples of detective fiction I discussed, these texts imply that Alzheimer's disease is not necessarily a

condition of loss alone and restore patients' narrative and social identity.⁶² They emphasize 'that the self persists in dementia.'⁶³

Who Will I Be When I Die? affirms the patient's continued personhood, just like the three early patient accounts introduced in Chapter 4 – Robert Davis's *My Journey into Alzheimer's Disease* (1989), Diana Friel McGowin's *Living in the Labyrinth* (1993) and Larry Rose's *Show Me the Way to Go Home* (1996). Like Davis, McGowin and Rose, Boden challenges the perception of patients as losing the plot and needing to be written for. But she goes further in her direct negotiation with objectifying healthcare practices and in her claim on a say in healthcare policymaking. In particular, Boden's demand for the patient to be seen as a person with continued identity and voice strongly resonates with contemporary biopsychosocial approaches to Alzheimer's disease, approaches that attend to the biological, psychological and social dimensions of the condition and inform interaction with the patient. At the same time, Boden's narrative illustrates how the patient's voice continued to be squeezed between popular concepts of the condition as performance-limiting and societal images of Alzheimer's disease as pertaining to old age: diagnosed with Alzheimer's disease in 1995, at the age of 46, the Australian civil servant felt 'far too young to get an old people's disease' (3).

Reading Boden's account in the context of the growing interest in narrative in medicine and healthcare in the 1990s shows how the growing attention to discourse analysis by healthcare professionals and linguists began to change the view of the patient, as patients themselves asserted their continued identity in reliance on an organic understanding of their condition. Boden's wish for patients to be treated 'very much as people, not just as medical cases' (31) matches concerns, raised by medical humanities and bioethics scholar Kathryn Montgomery Hunter in 1991, about 'the professional shortsightedness that sees maladies rather than people as the objects of medical attention.'⁶⁴ Boden voices the value to the patient of an empathetic doctor, when she illustrates her encounter with the practitioner, who provided a second opinion on her diagnosis: 'He sat behind a desk in a small but comfortable office, listening, asking, rather than expressing immediate opinions and statements' (8). This characterization of a clinician comes close to Rita Charon's later depiction of narratively trained medical doctors, who should 'donate [them]selves as meaning-making vessels to the patient.'⁶⁵ It also underlines Boden's continued ability meaningfully to articulate herself – a perspective taken up by Malcolm Goldsmith, who asserts that 'communication with people with dementia is possible' and advocated by

healthcare professionals such as the Australian nurse Julie Goyder, who seeks time for conversation with her patients.⁶⁶

As early as 1987, social psychologist and gerontologist Tom Kitwood (1937–1998) had propagated ideas of a ‘malignant social psychology’ that amplifies the ill-being of individuals with dementia.⁶⁷ In *Dementia Reconsidered* (1997), Kitwood contended: ‘Alzheimer victims, demented, elderly mentally infirm – these and similar descriptions devalue the person, and make a unique and sensitive human being into an instance of some category devised for convenience or control.’⁶⁸ These concerns invited the patient to take control of developing a counter-discourse. And patients were, indeed, beginning to achieve a real shift in perspective. Goldsmith cited earlier patient narratives – Davis’s *My Journey into Alzheimer’s Disease* (1989) and McGowin’s *Living in the Labyrinth* (1993) – and Boden, in turn, praised Goldsmith’s study for his attention to patients’ accounts in her second narrative (she was by then remarried and called Bryden).⁶⁹ In this awareness, Boden becomes an instructor herself, directly addressing the reader and caregiver with the claim that proper care and support can turn patients into proactive people: ‘Don’t hide us away – involve us, let us still experience the joy of living, with the help of your memory, your abilities, and your patience’ (53).

Boden strongly relies on an organic definition of the disease as explaining behavioural changes. Her account builds on the understanding that ‘some cells of the brain become diseased and tangled, confused and no longer able to function. The cells affected are those making up our personality, our behaviour, our thinking, our memory’ (51). She uses such descriptions to emphasize that ‘we are not mad, but sick’ (169). In this way, she attempts to claim back (as in many pathographies of the 1990s) the grounds for the patient’s individuality within the process of biomedical labelling.⁷⁰ Boden’s claim is especially noteworthy because it highlights her struggle to position herself between a materialist explanation for her symptoms and an appreciation of her identity through a whole-person approach. She fears the reductive nature of the former, wondering whether her remaining personality would still be recognized as an entity separate from the condition. At the same time, she is afraid of potential stigma entailed in whole-person approaches, because she could be reduced to an unpleasant person grown old.

Boden clearly acknowledges: ‘I have lost that vibrancy, the buzz of interconnectedness, the excitement and focus I once had. I have lost the passion, the drive that once characterised me. I’m like a slow motion version of my old self – not physically, but mentally’ (49). That a patient in 1998 should adopt

the century-old language of loss and decline brings out how difficult it was for individuals with dementia to assert themselves authoritatively without having developed a language of their own. More so, it brings home the core of the patient's experience. Alzheimer's disease is a condition that imparts feelings of losing one's self – as Auguste D. had told Alois Alzheimer in one of her many interviews: 'I have, so to say, lost myself.'⁷¹ Boden fears 'that slowly there might be less and less of "the old me"' (47). In the face of this imminent loss, Boden shares the understanding that a patient's lived past structures their illness experience in the present. This perspective formed the core of the psychosocial efforts made by Kitwood and the Bradford dementia group – and informs patient-centred care to the present day.⁷² Asserting her unbroken identity and personhood despite Alzheimer's disease, she explains:

These memories form the kaleidoscopic perspectives of all the many expressions of my being over my lifetime: as a child, daughter, grand-daughter and sister, as a student and young adult, as a wife and mother, as a friend, as a researcher, an editor, an information officer, policy manager and senior public servant, as a member of St George's church and a Cursillo team member, and as a writer of this book. (49–50)

This statement imparts the central claims made by geriatricians and psychologists, who increasingly advocated whole-person approaches to dementia, namely that 'people should be treated as wholes, with attention not only to their biology, but also to their psychology, their social and ethical concerns, and the cultural and spiritual aspects of their lives.'⁷³

It is exactly Boden's spirituality around which her understanding of a continued identity and biography centres. This understanding helps her to give an account that entirely offsets Arthur Frank's view of Alzheimer's disease narratives as representing 'chaos' narratives.⁷⁴ Boden's telling about her 'emotional, physical and spiritual journey with Alzheimer's disease' (ix) underscores how little she is "losing it" (58, 60, 65), how much she is aware of a plot in her life. The journey myth Hawkins identified in much illness life-writing does not easily hold for people with dementia, since the illness experience is one of no return, into darkness.⁷⁵ Except that Boden explicitly pictures her illness as 'an adventure into the unknown' (85). The narrative's final part, 'Thank God God's in charge' (125–46), is Boden's life review as much as it is her search for continuity in a life history disrupted by illness.

Like the Miami pastor Robert Davis in *My Journey into Alzheimer's Disease* (1989), Boden sees continuity in her growth as a Christian within and through

her illness. She considers her purpose in life to be 'to explain Alzheimer's in a way that lots of people might be able to understand this physical disease' (137). By integrating her condition into a belief system, she deflects, as Claude Couturier would do in *Puzzle: Journal d'une Alzheimer* (Jigsaw: Diary of an Alzheimer's patient) six years later, any responsibility for her condition. Couturier lifts the cause of her memory loss onto a literally unreachable level, when she expresses the hope that 'God at least knows what becomes of my lost neurons and that, above all, he makes good use of them'.⁷⁶ This is an important step if we consider that notions of self-infliction emerged in epidemiological research at this time and how genetic and visual evidence was seen as equating patients as specimens to their very illness.

The dualistic purposes of Boden's narrative position her text at a turning point in dementia life-writing: the move from assertions of biographical continuity to increasingly sophisticated purposes in the new century.⁷⁷ More and more, patients presented themselves as authority on and within their condition. Christine Bryden's most recent *Will I Still Be Me?* (2018), for example, reads like a manifesto for the patient's continued sense of self in the lived experience of dementia.⁷⁸ As such, people living with dementia first relocated themselves at the centre of a cultural dementia discourse, supported by a growing interest in psychosocial approaches to the condition; and thereafter they repositioned themselves in a healthcare discourse. But although vocal writings like Bryden's are on the increase, this shift continues to be slow in coming. Wendy Mitchell's very recent experiences suggest exactly this. Diagnosed with dementia at the age of 58, Mitchell had been working with the British National Health Service for twenty years, but still cannot get the support she needs. 'What chance do others with dementia have?', she wonders; 'I still have a valuable contribution to make and I'm not ready to write myself off'.⁷⁹

In an environment of multiplying patient assertions, from around the turn of the century, more and more caregivers incorporated accounts by the told-about patient within their narratives – a phenomenon mirrored in fiction where caregiver and patient become narrative equals. In Wolfgang Held's *Uns hat Gott vergessen* (God has forgotten us; 2000), for example, fictional diary entries alternate between the husband Markus and his wife Monika with dementia. Or take one of Ulrike Draesner's short stories. The reader plunges into a patient's ruminations, piecing their meaning together only once the narrative voice shifts to the caregiver in the second half of the account.⁸⁰ One of the earliest caregiver memoirs of this kind was Kim Howes Zabbia's *Painted Diaries: A Mother and Daughter's Experience through Alzheimer's* (1996).⁸¹ Zabbia includes entries

from Lou Howes's notebook, which she kept from the time of her diagnosis to 'record her feelings and her constantly changing symptoms' (54). In essence, these entries trace, as Vaidehi Ramanathan notes, 'a mental disappearance [which] is an analogy of death but far worse, for while the body lives some sense of an "essential self" has gone'.⁸² Zabbia herself offers an alternative view on the condition not only by letting her mother speak for herself. She develops the story of caregiving in parallel to her struggling to excel as an artist, in which she gains support from her mother, 'soak[ing] up some of her positive attitude' (139). Similarly, Reeve Lindbergh offers extracts from the pilot's former writing in *No More Words: A Journal of My Mother, Anne Morrow Lindbergh* (2001); Elinor Fuchs includes snippets of conversations with her mother at the beginning of each chapter in *Making an Exit: A Mother-Daughter Drama with Alzheimer's, Machine Tools, and Laughter* (2005); and Arno Geiger reports page-long conversations with, and aphorismic wisdom imparted by, his father in *Der alte König in seinem Exil* (The old king in his exile; 2011).

The cultural fascination with the visual helped these developments. Zabbia wanted to paint what her mother felt (124), supplementing her book with drawings about the stages of her mother's condition, drawings which she herself described as 'art with an emotional impact' (73). Jeannette Montgomery Barron, in turn, published a kind of fashion diary of her mother. Each double page shows an item of clothing or accessory of her late mother, accompanied by Barron's personal reflections on the opposite page. These reflections tell of Barron having 'missed her [mother] for years before her death'.⁸³ At the same time, this memoir celebrates the mother's life: printed on glossy paper throughout, Eleanor Morgan Montgomery Atuk comes to life on every page as Barron tells of her mother's love for a particular piece of clothing or a special occasion when a sparkling accessory was used. Similarly, Phillip Toledano records *Days with My Father* (2010), the photographs focusing on interaction with, rather than the passive portrayal of, the parent.

In the wake of a growing body of patient life-writing, patient portrayals would become more identity-affirming, both in textual and visual representations, with photographs shifting (though not exclusively) the emphasis from chronicling to moment-in-time recording. An increasing body of artistic work concerned with Alzheimer's disease, inter alia, in the framework of exhibitions, as well as attention to late-life creativity further enhanced a dualistic perspective at the turn of the new century.⁸⁴ By contrast, I am not aware of contemporaneous visual productions by caregivers that centre on brain recordings that imaging studies produced. Considering their increasing presence in popular science writing and

mass media reporting, I take the carer's choice not to rely on raw medical scans as further evidence of the identity-affirming dimensions increasingly found in visually enhanced caregiver writing.

But in making these arguments, I would caution that an ambivalent or more positive interpretation of visual representations is perhaps only possible once the beholder of these images is aware that a shift in cultural discourse is taking place – or, as John Berger puts it, 'the way we see things is affected by what we know or what we believe'.⁸⁵ Already in 1991, Kathleen Woodward had claimed that 'socially, politically, physically – the meanings of old age are changing. On the whole our literary tradition has lagged behind, continuing to produce predominantly dark portraits of aging'.⁸⁶ Both Dibdin's portrayal and Boden's narrative illustrate the dichotomous terms in which dementia increasingly came to be understood – at a time when scientific research correlated visual brain recordings to the patient's cognitive loss, as caused by guilty genes, articulated in failed network concepts and recounted in a growing body of caregiver life-writing. We first beheld such ambivalent views in relation to redemptive takes on forgetting in some caregiver narratives of the 1990s, and I consider this growing sociocultural ambivalence towards the condition in more depth in the final part of this study.