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Conclusion

This book has identified the path taken by the presentation of dementia in scientific, medical and literary texts across the twentieth century. It has illustrated that, since the late nineteenth century, when the condition was first described as an organic brain disease, to the present day, when it is viewed as a disorder of cognition, the literary representation of the condition has progressed alongside a continuously evolving medico-scientific discourse about dementia.

The biological psychologies of the late eighteenth century, the somaticization of diseases a century later and the biomedicalization of illness with its pharmacological redefinition of health towards the end of the twentieth century have all led to the objectification of patients, a process not confined to dementia. The memory sciences instigated the systematic neurological study of the dementias at the fin de siècle, thereby creating the patient with a condition of memory loss; the attention of the biomedical sciences, in turn, amplified by sociocultural, political and economic concerns, focused on Alzheimer's disease towards the end of the twentieth century. Yet I argue that the medical sciences' main influence in dementia discourse developments has been of a reinforcing nature. Rather than introducing new metaphorical concepts, on several occasions, medico-scientific language paralleled or followed the wider sociocultural discourse, and was taken to strengthen already existing images. By the beginning of the twenty-first century, this enhancing dynamics had placed the patient in a position from which it was difficult to reclaim a social identity and achieve recognition of their continued self and authority in contributing to healthcare planning.

Scientific, medical and literary iterations have all contributed to the current cultural dementia narrative; and, indeed, it would be wrong to search out an antithetic dualism between the psycho-sciences and the neurosciences in its development. Rather, I see these different disciplines connected by way of a dialogical space occupied by discourses of ageing and memory, and it is in

this space that the narrative has developed. As the layout of this book indicates, at different times the discourses of ageing and memory each held sway over twentieth-century developments. The scientization of memory and its loss and the biomedicalization of Alzheimer's disease have created an object of knowledge which – prior to its naming – had already existed but was dealt with in non-scientific terms in the sociocultural realm. Given that the role of science in discourse is strongly linked to wider cultural changes, the discourse that developed in the medico-scientific field around this new object of knowledge, dementia, fed on the already existing sociocultural images. As the medical sciences developed these images further, their discourse – in the continued exchange with the sociocultural realm – strengthened and reinforced the original images. The images and concepts so developed impinged on the newly created object of knowledge: the dementia patient.

One of my central concerns has been to explore how these dialogical processes affected individuals with neurodegeneration. I wanted to understand why specific notions of Alzheimer's disease are so persistent; why particular themed metaphors continue to reign supreme; and why some research concepts continue to dominate the medical sciences and also the health humanities at the expense of recognizing the patient's individuality and personhood. The foregoing chapters have already answered these questions in much more detail than I can do here.

Concepts of old age and cognitive decline are deeply engrained in the cultural dementia narrative. They are so durable because they formed in a process of reinforcement. The medical sciences adopted images from the sociocultural realm and developed them further; and these images were then taken to corroborate the wider sociocultural ideas about the patient. In the process individuals with memory loss became embedded in a new system of norms and standards in which they could be objectively assessed – a system revolving around antonyms of growth and development versus loss and degeneration, productive versus dependent, young versus old, performing versus passive. The individual turned into an object of knowledge. I argue that Kraepelin's move to focus on neuropathological features and the condition's cognitive component can be taken as activating this process (while at the same time being a representative example of the period's fascination with materialist approaches). The medico-scientific definition of Alzheimer's disease centred on objectively assessable parameters. The patient's thinking mind and feeling psyche were excluded from this focus and as a consequence concepts of passivity and lost agency became manifest in wider sociocultural thinking.

The patient's mind entered the literary arena much earlier and more explicitly as compared to when (only in the 1950s) and how old-age psychiatrists and social medics began to take an interest in this area. The true achievement of modernist narratives, like Hoult's *There Were No Windows*, in relation to dementia discourse developments was their calling into question a 'Cartesian geography of mind'.¹ They challenged old-age psychiatry to aim for an understanding of the patient's mental thought processes and a characterization of the illness from within. My point is not that the psycho-disciplines had a more positive or constructive influence on metaphorical language than the neurosciences; they each emphasized different aspects of the same problem. Rather, meaningful shifts in discourse developments occurred where the human sciences managed to spotlight the patient's subjectivity, where interest was roused in the patient's illness experience and appreciation was able to foster better communication with the patient.

With a steadily growing attention to the patient's narrative – first on the part of old-age psychiatrists, then social scientists, psycho- and sociolinguists, and eventually health humanists – we have witnessed a slow change in discourse. Patients have begun to be seen as individuals with agency, who can contribute to the knowledge to be had about their condition. With a move, in dementia discourse analysis, from a focus on language deterioration to an emphasis on remaining linguistic capabilities, ideas of continued identity and personhood replaced those of communication breakdown. The passive patient turned interlocutor and entered the stage – their own voice being heard in the caregiver's narrative, at the conference podium, and in bookshops and policy discussions. This is a shift with parallels in fiction. Think of Claire Temple, who is being perceived as tedious by her visitors; Faith Gadny not being listened to; later on, Rosemary Travis leads the plot and Maria Merlo challenges how the patient is viewed. Concurrently, we observe that increased value is placed upon the child's perspective on the patient: from Timothy's childlessness and the narrative absence but inferred hostility of Faith Gadny's grandchildren, via Maurizio's valuing the patient outside of memory loss, to Connell Leary's defiance.

Tracing a continuous dynamic between the serious and the comic, the idealist and the derogatory in the history of the novel, Thomas G. Pavel perceives the tension between depiction of 'human isolation' and a 'possible reconciliation between the individual and the world'.² The literary history of dementia appears to be no exception: Faulkner, Bailey, Beckett and Bernlef home in on aspects of isolation, while Hoult, Dibdin, Genova and Thomas see scope for reconciliation with the caregiver and a potential for discourse developments in favour of the

patient's humanity. In this regard, the literary discourse is characterized by poles similar to those observed in the medico-scientific realm. Cure, at the beginning of the twenty-first century, is not only a pharmacological need; it is also a necessity in terms of a 'cure narrative' of and for the self – the ageing self as well as the remembering self.³

I opened this book with a quotation by Claude Couturier from her 2004 diary, in which she advocates the organic paradigm as saving the patient's personhood and agency. A return to the organic paradigm may well restore patients their individuality as elderly citizens with a diseased brain, as long as this does not imply the objectification of the patient. But similarly, to consider dementia as a condition of the failing mind supports the patient, as long as notions regarding, for example, disorientation in space and time solicit supportive healthcare thinking rather than dissatisfaction with the patient's performance and efficiency. Both approaches can turn out to be effective in changing century-old ideas of the patient as cognitively under-performing and the disease as one of old age – especially as long as ageing itself continues to be considered in predominantly negative terms.

Throughout this book, we have encountered sociocultural perceptions of the healthy middle-aged as the only truly productive stratum of the population. Yet, during the past decade or so popular awareness of Alzheimer's disease as a condition that also afflicts the middle-aged has arisen. This is explained by two factors. First, by the decision of scientists to shift both the goal and the interest group of pharmacological investigations towards disease prevention in the middle-aged, and how this move has been reported on in the media. And second, by Richard Glatzer's prominent motion picture *Still Alice* (2014), whose popularizing effect cannot be overestimated, particularly when thinking back to the effect of Richard Eyre's *Iris* thirteen years earlier. This ever-increasing visibility of Alzheimer's disease as a possible condition of middle age has just begun to affect how this younger age group anticipates it will be perceived in the future.

This could prove a turning point in discourse developments, because – as we have seen all through the century-long period under consideration – new ways of classifying may, as Ian Hacking convincingly articulates, 'systematically affect the people who are so classified, or the people themselves may rebel against the knowers, the classifiers, the science that classifies them.'⁴ In exchange with technological and biological domains, the literary and wider cultural realms have questioned archival notions of memory.⁵ This has led to Alzheimer's disease at times being perceived of as a mixed blessing, as possibilities for human

fulfilment begin to be considered possible within or despite memory loss. The response of the human sciences to a growing medico-scientific emphasis on prediction and prevention in the middle-aged will contribute to the conceptual reconfiguration of the future dementia patient.

Caregivers, especially the women (and men) in the middle, have become militant in their writing, with respect to the financial and healthcare support they need, but also regarding their intention to change the dementia narrative itself. With the very recent trends in cultural representations as well as medico-scientific research endeavours that include the middle-aged subject more generally, advocating change is no longer the business of the overburdened healthcare provider and the still underprivileged patient alone. It has become of concern to those middle-aged individuals whose choices define and eventually reinforce the values and beliefs of enterprise societies which continue to have neither space nor place for the condition. But as still productive members are increasingly at risk of the condition, the outlook of these societies will have to change – although this is hard to imagine in practice at the time of writing, when renewed nationalist thinking driven by economic interests seriously damages the slowly rising culture of care and empathy. As those increasingly perceived to be at risk begin to articulate their anxieties about marginalization and illness-related preconceptions, the human sciences will begin to challenge notions of ageing and cognition as the only determinants in the cultural dementia narrative.