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Notes

1 Introduction

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2 From brain inspection to cell death

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- 2 Earl Eugene Stevens, 'John Galsworthy: An Annotated Bibliography of Writings about Him. Supplement I', *English Literature in Transition, 1880–1920*, 7 (1964): 93–110; see therein, for example, Stevens's summary of Ione Dodson Young, 'The Social Conscience of John Galsworthy' (PhD thesis, University of Texas, 1955); Tracy Hargreaves, "'We Other Victorians': Literary Victorian Afterlives', *Journal of Victorian Culture* 13 (2008): 278–86.
- 3 *The Complete Forsyte Saga*, directed by Andy Wilson (2002; ITV Studios Home Entertainment, 2003), DVD.
- 4 On notions of decay and degeneration in England, see Pick, *Faces of Degeneration*, 153–221.
- 5 A specific 'battle' centres on the consequences of Timothy's nephew Soames's failed love life. As a 'Man of Property', he is unable to consider his wife anything other than a further possession. Irene's consequent adultery, later divorce from Soames and marriage to his cousin Young Jolyon are central to the Forsytes' fragmentation.
- 6 William Greenslade, *Degeneration, Culture and the Novel, 1880–1940* (New York: Cambridge University Press, 1994), 2.
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- 8 Galsworthy specifically alludes to Darwin's theories on *The Descent of Man, and Selection in Relation to Sex* (1871), which had, among others, emphasized the female's dominant role in selecting mating partners. This further accentuates Soames's perceived failure to maintain his family line.
- 9 Karen Chase, *The Victorians and Old Age* (Oxford: Oxford University Press, 2009); on the 'consciousness of senescence' at the time of Queen Victoria's Diamond Jubilee, see pp. 197–8.
- 10 Charles Booth, *Pauperism: A Picture, and the Endowment of Old Age: An Argument* (London: Macmillan, 1892), 167–8. Booth's reference to 'a more perfect nerve' suggests the growing popular awareness of research that related neurological health to bodily performance.
- 11 Thomas R. Cole, 'The "Enlightened" View of Aging: Victorian Morality in a New Key', in Cole and Gadow, *What Does It Mean to Grow Old?*, 125.
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- 15 Helen Small, 'The Unquiet Limit: Old Age and Memory in Victorian Narrative', in Campbell, Labbe and Shuttleworth, *Memory and Memorials*, 62, 63–4.
- 16 Laura Otis, *Organic Memory: History and the Body in the Late Nineteenth and Early Twentieth Centuries* (Lincoln: University of Nebraska Press, 1994), 34.

- 17 Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (New York: Oxford University Press, 1985), 32–3; William F. May, ‘The Virtues and Vices of the Elderly’, in Cole and Gadow, *What Does It Mean to Grow Old?*, 46. The 1960s screen adaptation brings Timothy to life faithfully in Galsworthy’s narrative up to this last appearance. However, John Baskcomb’s Timothy dies lying in bed in his last appearance, rather than performing his cognitive state; *The Forsyte Saga*, directed by David Giles and James C. Jones (1967; BBC Worldwide, 2004), DVD.
- 18 Timothy has remained excluded from the Forsytes’ gossiping throughout. Gossip has been described – in relation to George Eliot’s earlier social realist novel *Middlemarch* (1871–2) – as ‘the fundamental linking force’, the tool with which ‘characters articulate both their individual and communal identity’. Timothy’s silence induces the reader to question his identity: we perceive him as an outsider, if not a stranger throughout. As such, Timothy has always been a symbol for the Forsyte clan’s undermined situation, a living dead. Soames seems to imply this. When he asks his sister whether she did ‘ever know a publisher’, Winifred suggests ‘Uncle Timothy’ and Soames retorts with ‘Alive, I mean’ (803); Sally Shuttleworth, *George Eliot and Nineteenth-Century Science: The Make-Believe of a Beginning* (Cambridge: Cambridge University Press, 1984), 147–8; see also Laura Otis, *Networking: Communicating with Bodies and Machines in the Nineteenth Century* (Ann Arbor: University of Michigan Press, 2011), 81.
- 19 Heike Hartung, *Ageing, Gender and Illness in Anglophone Literature: Narrating Age in the Bildungsroman* (Abingdon: Routledge, 2016), 23; consider also Thomas R. Cole, *The Journey of Life: A Cultural History of Aging in America* (Cambridge: Cambridge University Press, 1992), ch. 4.
- 20 Havelock Ellis, *The Criminal* (New York: Scribner and Welford, 1890), 212, <https://archive.org/details/criminal00elli/page/212>. Sally Shuttleworth illustrates how nineteenth-century research projects ‘locate the human infant in the pre-human sphere’; Sally Shuttleworth, *The Mind of the Child: Child Development in Literature, Science, and Medicine, 1840–1900* (Oxford: Oxford University Press, 2010), 255, 181–206.
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- 24 Jill Matus, ‘Emergent Theories of Victorian Mind Shock: From War and Railway Accident to Nerves, Electricity and Emotion’, in Stiles, *Neurology and Literature*, 163–83.
- 25 Marrot, *The Life and Letters of John Galsworthy*, 426.
- 26 McDonagh, *Idiocy*, 79–101.

- 27 Philippe Pinel, *Nosographie philosophique ou méthode de l'analyse appliquée à la médecine*, 6th edn (Paris: Brosson, 1818), 3:127, <https://archive.org/details/nosographiephilo03pine/page/126>; Jean Étienne Esquirol, *Mental Maladies: A Treatise on Insanity*, trans. E. K. Hunt (Philadelphia: Lea and Blanchard, 1845), 422; originally published in French in 1838. The Scottish physician William Cullen (1710–1790) first defined 'amentia' as a loss of memory and intellectual faculties; Berrios and Freeman, 'Dementia before the Twentieth Century', 12.
- 28 James C. Prichard, *A Treatise on Insanity and Other Disorders Affecting the Mind* (Philadelphia: Haswell, Barrington and Haswell, 1837), 17, <https://wellcomelibrary.org/item/b21007597#?c=0&m=0&s=0&cv=0&z=-1.0448%2C-0.0907%2C3.0895%2C1.8137>.
- 29 Ibid., 76.
- 30 Bénédict-Auguste Morel, *Traité des Maladies Mentales* [Treatise on mental illnesses] (Paris: Librairie Victor Masson, 1860); Samuel G. Howe had expounded theories of moral degeneration in the United States before Morel advanced his treatise, but his work appeared only the year after Morel's publication in the United Kingdom; McDonagh, *Idiocy*, 264–5.
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- 36 On clinical observations and experimental work supporting localization theories carried out, inter alia, by Franz Josef Gall (1758–1828), Paul Broca (1824–1880),

- Gustav Fritsch (1838–1927) and Eduard Hitzig (1838–1907), David Ferrier (1843–1928) and Carl Wernicke (1848–1905), see, as previously referenced Young, *Mind, Brain and Adaptation*, and Clarke and Jacyna, *Nineteenth-Century Origins of Neuroscientific Concepts*.
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 - 39 Michael J. Clark, ‘The Rejection of Psychological Approaches to Mental Disorder in Late Nineteenth-Century British Psychiatry’, in *Madhouses, Mad-Doctors, and Madmen: The Social History of Psychiatry in the Victorian Era*, ed. Andrew Scull (Philadelphia: University of Pennsylvania Press, 1981), 287, 298.
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 - 42 Clark, ‘The Rejection’, 271.
 - 43 David Shenk, *The Forgetting. Alzheimer’s: Portrait of an Epidemic* (2001; New York: Anchor Books, 2003), 77.
 - 44 The lectures on brain pathology, which Alzheimer attended at the Charité Hospital in Berlin, had been devised by Griesinger and further developed by Westphal. Griesinger’s textbook *Die Pathologie und Therapie der psychischen Krankheiten für Aerzte und Studierende* (Pathology and therapy of psychiatric diseases for practitioners and students; 1845) was a cornerstone in the emerging scientific epoch of psychiatry which sought to characterize brain damage in psychotic conditions; Clarke and Jacyna, *Nineteenth-Century Origins of Neuroscientific Concepts*, 133–8.
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 - 46 Thomas Schlich, for example, shows how international German surgery was in its approach to innovation and how British and German research communicated; Thomas Schlich, ‘Farmer to Industrialist: Lister’s Antisepsis and the Making of Modern Surgery in Germany’, *Notes and Records of the Royal Society* 67 (2013): 245–60.

- 47 P. Hoff, 'Alzheimer and His Time', in Berrios and Freeman, *Alzheimer and the Dementias*, 49.
- 48 Otis, *Organic Memory*, 113; Silvia Acocella, *Effetto Nordau: Figure della degenerazione nella letteratura Italiana tra Ottocento e Novecento* [Nordau effect: Figures of degeneration in Italian literature between the nineteenth and twentieth centuries] (Naples: Liguori Editore, 2012), 105–24.
- 49 Samuel Wilks, 'Clinical Notes on Atrophy of the Brain', *Journal of Mental Science* 10 (1864): 382–3; Torack, 'The Early History of Senile Dementia', 26.
- 50 James Crichton-Browne, 'Clinical Lectures on Mental and Cerebral Diseases', *British Medical Journal* 1 (1874): 601, 603.
- 51 Alois Alzheimer, 'Neuere Arbeiten über die Dementia senilis und die auf atheromatöser Gefässerkrankung basierenden Gehirnerkrankheiten' [Recent work on senile dementia and brain diseases based on atheroma], *Monatsschrift für Psychiatrie und Neurologie* 3 (1898): 101–15.
- 52 Lauren Berlant, 'On the Case', *Critical Inquiry* 33 (2007): 666; Alois Alzheimer, 'Über eine eigenartige Erkrankung der Hirnrinde' [On a peculiar illness of the cortex], *Allgemeine Zeitschrift für Psychiatrie und Psychisch-gerichtliche Medizin* 64 (1907): 146–8; all references from this edition are incorporated in the text. Consider also the paper's two present-day translations: 'A Characteristic Disease of the Cerebral Cortex', in *The Early Story of Alzheimer's Disease: Translation of the Historical Papers by Alois Alzheimer, Oskar Fischer, Francesco Bonfiglio, Emil Kraepelin, Gaetano Perusini*, ed. Katherine Bick, Luigi Amaducci and Giancarlo Pepeu (Padua: Liviana, 1987), 1–3; and Alois Alzheimer et al., 'An English Translation of Alzheimer's 1907 Paper, "Über eine eigenartige Erkrankung der Hirnrinde"', *Clinical Anatomy* 8 (1995): 429–31.
- 53 The Swiss psychiatrist and neurologist Otto Ludwig Binswanger (1852–1929) used the term 'presenile dementia' already in 1894; Otto Ludwig Binswanger, 'Die Abgrenzung der allgemeinen progressiven Paralyse' [Differentiation of general progressive paralysis], *Berliner klinische Wochenschrift* 31 (1894): 1181.
- 54 Michael Lynch, 'Discipline and the Material Form of Images: An Analysis of Scientific Visibility', *Social Studies of Science* 15 (1985): 43; emphasis original.
- 55 Melissa M. Littlefield, 'Matter for Thought: The Psychon in Neurology, Psychology and American Culture, 1927–1943', in Salisbury and Shail, *Neurology and Modernity*, 269.
- 56 Together with the neurologist Max Lewandowsky (1876–1918), Alzheimer later co-edited the newly established specialist journal *Zeitschrift für die gesamte Neurologie und Psychiatrie* with the aim of bringing the fields of psychiatry and neurology closer together.
- 57 Konrad Maurer and Ulrike Maurer, *Alzheimer: Das Leben eines Arztes und die Karriere einer Krankheit* [Alzheimer: The life of a physician and the career of a disease] (Munich: Piper, 1998), 73, 128.

- 58 Already the nineteenth-century clinical case study had seen remarkable textual and formal changes: the autopsy report refocused the case history on a 'narrative of causality instead of analogy', and statistics gained in value; Meegan Kennedy, *Revising the Clinic: Vision and Representation in Victorian Medical Narrative and the Novel* (Columbus: Ohio State University Press, 2010), 57, 76.
- 59 Francesco Bonfiglio, 'Di speciali reperti in un caso di probabile sifilide cerebrale' [Concerning special findings in a case of probable cerebral syphilis], *Rivista Sperimentale di Freniatria e Medicina Legale delle Alienazioni Mentali* 34 (1908): 196–206; all references incorporated in the text. Translations of Bonfiglio's as well as Perusini's cases are included in Bick, Amaducci and Pepeu, *The Early Story of Alzheimer's Disease*, 19–31, 82–128.
- 60 The pathologist Rudolf Virchow (1821–1902) used the term on several occasions in his textbook on *Die Cellularpathologie in ihrer Begründung auf physiologische und pathologische Gewebelehre* (1858); translated into English in 1860 with the title *Cellular Pathology as Based upon Physiological and Pathological Histology*. Also Alzheimer had observed 'degenerative alterations' in relation to nerve cell morphology in a patient with atrophy of a muscle at the base of the thumb in 1892; Alois Alzheimer, 'Über einen Fall von spinaler progressiver Muskelatrophie und hinzutretender Erkrankung bulbärer Kerne und der Rinde' [On a case of spinal progressive muscular atrophy with additional affliction of bulbar marrow and cortex], *Archiv für Psychiatrie und Nervenkrankheiten* 23 (1892): 465 *et passim*.
- 61 Foucault, *The Birth of the Clinic*, 146.
- 62 Gaetano Perusini, 'Über klinisch und histologisch eigenartige psychische Erkrankungen des späteren Lebensalters' [On clinically and histologically peculiar psychiatric illnesses of later life], in *Histopathologische Arbeiten über die Großhirnrinde unter besonderer Berücksichtigung der pathologischen Anatomie der Geisteskrankheiten* [Histopathological studies on the cerebral cortex with particular reference to the pathological anatomy of mental illnesses], ed. Franz Nissl and Alois Alzheimer (Jena: Gustav Fischer, 1910), 3: 297–352.
- 63 G. Macchi, C. Brahe and M. Pomponi, 'Alois Alzheimer and Gaetano Perusini: Should Man Divide What Fate United?' *European Journal of Neurology* 4 (1997): 210–13.
- 64 Emil Kraepelin, 'VII. Das senile and präsenile Irresein' [Senile and presenile dementia], in *Psychiatrie: Ein Lehrbuch für Studierende und Ärzte* [Psychiatry: A textbook for students and practitioners] (Leipzig: Johann Ambrosius Barth, 1909–10), 627; all further references from this edition are incorporated in the text. Chapter VII (533–632) contains three sections: 'A. Das präsenile Irresein' (presenile dementia; 534–54), 'B. Das arteriosklerotische Irresein' (arteriosclerotic dementia; 554–93) and 'C. Der Altersblödsinn' (senile dementia; 593–632).
- 65 In this section, Kraepelin elaborated on 'depressive madness' particularly in women between 45 and 50 years of age. He described these presenile cases as 'very

- considerably mentally deficient, poor in thought, without judgement, unreasonable, dull and weak in will' (548).
- 66 Note that *Rückbildung* can be translated as 'regression' or 'involution'.
- 67 Thomas S. Kuhn has illustrated the role of textbooks in establishing a 'paradigm for granted'; Kuhn, *The Structure of Scientific Revolutions*, 20.
- 68 Mary Boyle, 'The Non-discovery of Schizophrenia? Kraepelin and Bleuler Reconsidered', in *Reconstructing Schizophrenia*, ed. Richard P. Bentall (London: Routledge, 1990), 10, 5, 13.
- 69 G. E. Berrios, 'Alzheimer's Disease: A Conceptual History', *International Journal of Geriatric Psychiatry* 5 (1990): 363; Lawrence Cohen, *No Aging in India: Alzheimer's, the Bad Family, and Other Modern Things* (1998; Berkeley: University of California Press, 1999), 79–80. Kraepelin treated 'Das arteriosklerotische Irresein' (arteriosclerotic dementia; 554–93) in a separate section, even though vascular phenomena had in fact been described, but with less detail, by Alzheimer, Bonfiglio and Perusini.
- 70 Hacking, *Rewriting the Soul*, ch. 5.
- 71 Kraepelin's haste has given rise to a series of historical hypotheses that could account for the selective emphasis on characteristics when establishing Alzheimer's disease in these terms. The medical historian G. E. Berrios convincingly discards all of them, including those concerning rivalry with Arnold Pick (1851–1924), who researched on dementia in Prague, and Sigmund Freud, who was known for his non-materialist views; Berrios, 'Alzheimer's Disease', 362–3.
- 72 Guenther, *Localization and Its Discontents*, 65–7.
- 73 Ibid., 81; Berrios, 'Alzheimer's Disease', 362. Also Sander L. Gilman notes, inter alia, Freud's work on neurological diseases like multiple sclerosis as related to 'the endogenous decay of the cell'; Sander L. Gilman, *The Case of Sigmund Freud: Medicine and Identity at the Fin de Siècle* (Baltimore: Johns Hopkins University Press, 1993), 157–8.
- 74 Sacks, *The Man Who Mistook*, 91. Neurobiological concepts of 'excess' – as with increased levels of the neurotransmitter glutamate or genetic explanations of loss of function through gain of function – have, as far as I am aware, not reached the popular dementia narrative. I note that the justification for the pharmacological inhibition of acetylcholinesterase (which breaks down the neurotransmitter acetylcholine) I discuss in Chapter 6 is not its excess, but rather insufficient substrate (i.e. acetylcholine).
- 75 Alois Alzheimer, 'Die diagnostischen Schwierigkeiten in der Psychiatrie' [Diagnostic difficulties in psychiatry], *Zeitschrift für die gesamte Neurologie und Psychiatrie* 1 (1910): 1–19; references incorporated in the text.
- 76 Nordau took inspiration from England's Henry Maudsley (1835–1918), Italy's Cesare Lombroso (1835–1909), France's Auguste Morel and Germany's Richard von Krafft-Ebing (1840–1902); Dowbiggin, *The Quest for Mental Health*, 59. At least

- on three occasions, Alzheimer set himself apart from the kind of degenerationism that fed into criminal anthropology and, later, eugenicist healthcare politics. In the publication 'Ein "geborener Verbrecher"' (A 'born criminal'), Alzheimer asserted himself against the contemporary conceptualization of the genetically predisposed as criminal, as propagated in Lombroso's 1876 *L'Uomo Delinquente* (The criminal). In 1907, he argued against increasing eugenicist tendencies in Germany, and, supporting notions of regeneration, Alzheimer's stance echoed diatribes like Egmont Hake's, published in response to Nordau's *Entartung*. Finally, in his speech 'Der Krieg und die Nerven' (War and nerves), Alzheimer vehemently opposed himself to views that modernity in all its facets would lead to degeneration; Alois Alzheimer, 'Ein "geborener Verbrecher"', *Archiv für Psychiatrie und Nervenkrankheiten* 28 (1896): 327–53; 'Über die Indikationen für eine künstliche Schwangerschaftsunterbrechung bei Geisteskranken' [On the indication for induced abortion in the mentally ill], *Münchener medizinische Wochenschrift* 54 (1907): 1617–22, cited in Maurer and Maurer, *Alzheimer*, 185; Egmont Hake, *Regeneration: A Reply to Max Nordau* (Westminster: Archibald Constable, 1895), cited in *The Fin de Siècle: A Reader in Cultural History, c. 1880–1900*, ed. Sally Ledger and Roger Luckhurst (Oxford: Oxford University Press, 2000), 17–19; Alois Alzheimer, *Der Krieg und die Nerven* (Breslau: Verlag von Preuß und Jünger, 1915), https://digital.staatsbibliothek-berlin.de/werkansicht?PPN=PPN716104202&PHYSID=PHYS_0001&DMDID=DMDLOG_0001.
- 77 Alois Alzheimer, 'Über eigenartige Krankheitsfälle des späteren Alters' [On peculiar illness cases in later life], *Zeitschrift für die gesamte Neurologie und Psychiatrie* 4 (1911): 356–85; references incorporated in the text.
 - 78 Gonzalo R. Lafora, 'Beitrag zur Kenntnis der Alzheimerschen Krankheit oder präsenilen Demenz mit Herdsymptomen' [Contribution to the understanding of Alzheimer's disease or presenile dementia with focal symptoms], *Zeitschrift für die gesamte Neurologie und Psychiatrie* 6 (1911): 16.
 - 79 Ernst Grünthal, 'Klinisch-anatomisch vergleichende Untersuchungen über den Greisenblödsinn' [Comparative clinico-anatomical examinations on senile dementia], *Zeitschrift für die gesamte Neurologie und Psychiatrie* 111 (1927): 774.
 - 80 Johannes Schottky, 'Über präsenile Verblödungen' [On cases of presenile stultification], *Zeitschrift für die gesamte Neurologie und Psychiatrie* 140 (1932): 342, 361.
 - 81 The photographs were shown at the conference of the Society of German Neurologists and Psychiatrists in 1936; Maurer and Maurer, *Alzheimer*, 276–9; see p. 277 for representative images (of course, their selection in 1998 from the archived slides could also be discourse influenced).
 - 82 Ernst Grünthal, 'Über die Alzheimersche Krankheit: Eine histopathologisch-klinische Studie' [On Alzheimer's disease: A histopathological-clinical study], *Zeitschrift für die gesamte Neurologie und Psychiatrie* 101 (1926): 128–57; references incorporated in the text.

- 83 Schottky, 'Über präsenile Verblödungen,' 396.
- 84 A full-text search of the *Asylum Journal* (later the *Journal of Mental Science* and today the *British Journal of Psychiatry*) and *Brain: A Journal of Neurology* (today *Brain*) suggests that British and French interest in Alzheimer's disease surged only after the publication of Alzheimer's second case in 1911 and Kraepelin's publicity, with discussion focused on histopathological phenomena and their use for differential diagnosis; consider, for example, Samuel T. Orton, 'A Study of the Satellite Cells in Fifty Selected Cases of Mental Disease,' *Brain* 36 (1914): 525–42; G. Mingazzini, 'On Aphasia due to Atrophy of the Cerebral Convolutions,' *Brain* 36 (1914): 493–524; L. Bouman, 'Senile Plaques,' *Brain* 57 (1934): 128–42; A. A. W. Petrie, 'Differential Diagnosis of Organic and Functional Nervous Disorders,' *British Medical Journal* 2 (1934): 503–6.
- 85 W. H. McMenemey (also McMenemy), 'Alzheimer's Disease: A Report of Six Cases,' *Journal of Neurology and Psychiatry* 3 (1940): 211–40.
- 86 M. A. Green et al., 'Cerebral Biopsy in Patients with Presenile Dementia,' *Diseases of the Nervous System* 13 (1952): 303–7; Myre Sim and W. Thomas Smith, 'Alzheimer's Disease Confirmed by Cerebral Biopsy: A Therapeutic Trial with Cortisone and ACTH,' *Journal of Mental Science* 101 (1955): 604–9.
- 87 Consider, for example, the following two connected papers: Myre Sim, Eric Turner and W. Thomas Smith, 'Cerebral Biopsy in the Investigation of Presenile Dementia: I. Clinical Aspects,' *British Journal of Psychiatry* 112 (1966): 119–25; and W. Thomas Smith, Eric Turner and Myre Sim, 'Cerebral Biopsy in the Investigation of Presenile Dementia: II. Pathological Aspects,' *British Journal of Psychiatry* 112 (1966): 127–33.
- 88 Smith, Turner and Sim, 'Cerebral Biopsy,' 129.
- 89 A further conference on 'Alzheimer's Disease and Related Conditions' was held in London in 1969, inter alia, drawing attention to familial cases of Alzheimer's disease.
- 90 Ch. Müller and L. Ciompi, eds, *Senile Dementia: Clinical and Therapeutic Aspects* (Bern: Hans Huber, 1968), quoted from the sleeve text of the conference book.
- 91 J. A. N. Corsellis and P. H. Evans, 'The Relation of Stenosis of the Extracranial Cerebral Arteries to Mental Disorder and Cerebral Degeneration in Old Age,' *Proceedings of the 5th International Congress of Neuropathology* (1965): 546; B. E. Tomlinson, G. Blessed and M. Roth, 'Observations on the Brains of Demented Old People,' *Journal of the Neurological Sciences* 11 (1970): 205–42; V. C. Hachinski, N. A. Lassen and J. Marshall, 'Multi-infarct Dementia: A Cause of Mental Deterioration in the Elderly,' *The Lancet* 2 (1974): 207–10.
- 92 Ballenger, *Self, Senility, and Alzheimer's Disease*, 109; Furst, *Between Doctors and Patients*, 6.
- 93 G. Stanley Hall, *Senescence: The Last Half of Life* (New York: D. Appleton, 1922), 199, 201, 366–438.

- 94 Consider also Schottky, 'Über präsenile Verblödungen', and note that McMenemey's publication discusses female cases only.
- 95 Jeanette King, *Discourses of Ageing in Fiction and Feminism: The Invisible Woman* (Basingstoke: Palgrave Macmillan, 2013), 39–42.
- 96 Norah Hoult, *There Were No Windows* (London: Persephone Books, 2005); references incorporated in the text.
- 97 Lisa Appignanesi, *Mad, Bad and Sad: A History of Women and the Mind Doctors from 1800 to the Present* (2008; London: Virago, 2009).
- 98 Julia Briggs, afterword to Hoult, *There Were No Windows*, 329. According to Briggs, the writer Violet Hunt (1862–1942) was Claire Temple's real-life model.
- 99 Nick Hubble and Philip Tew, *Ageing, Narrative and Identity: New Qualitative Social Research* (Basingstoke: Palgrave Macmillan, 2013), 185.
- 100 McDonagh, *Idiocy*, 102–28.
- 101 Suzanne Nalbantian, *Memory in Literature: From Rousseau to Neuroscience* (Basingstoke: Palgrave Macmillan, 2003), 93.
- 102 Briggs, afterword, 333.
- 103 Greenslade, *Degeneration, Culture and the Novel*, 38–40; Hoult makes Claire Temple particularly aware of the slum courts in London's East End.
- 104 Jesse F. Ballenger, 'Disappearing in Plain Sight: Public Roles of People with Dementia in the Meaning and Politics of Alzheimer's Disease', in *The Neurological Patient in History*, ed. L. Stephen Jacyna and Stephen T. Casper (Rochester: University of Rochester Press, 2012), 109–28.
- 105 Shuttleworth, *The Mind of the Child*, 33.
- 106 Joanna Moncrieff, 'The Politics of a New Mental Health Act', *British Journal of Psychiatry* 183 (2003): 8.
- 107 Joan Lane, *A Social History of Medicine: Health, Healing and Disease in England, 1750–1950* (London: Routledge, 2001), 96–119.
- 108 This was the case also outside Britain. For the asylum situation in the United States, consult Ballenger, *Self, Senility, and Alzheimer's Disease*; on the relationship between criminalization and madness in France, see Robert A. Nye, *Crime, Madness, and Politics in Modern France: The Medical Concept of National Decline* (Princeton, NJ: Princeton University Press, 1984); and for the German context, consider Paul Weindling, *Health, Race and German Politics between National Unification and Nazism, 1870–1945* (1989; Cambridge: Cambridge University Press, 1993).
- 109 Michel Foucault, *Psychiatric Power: Lectures at the Collège de France, 1973–1974*, trans. Graham Burchell (2006; Basingstoke: Palgrave Macmillan, 2008), 108; Shuttleworth, *The Mind of the Child*, 183.
- 110 Berrios and Freeman, 'Dementia before the Twentieth Century', 26.
- 111 Greenslade agrees on this with Nye, who scrutinizes the period of the French Third Republic (1870–1940); however, Pick brings the period's end forward to

1918; Weindling considers 1945 to be its end point in the German context of his cultural enquiry.

- 112 Bynum, *Science and the Practice of Medicine*, 194.
- 113 Emil Kraepelin, 'Altersblödsinn' [senile dementia], in *Einführung in die psychiatrische Klinik: Dreissig Vorlesungen* [Introduction into clinical psychiatry: Thirty lectures] (Leipzig: Johann Ambrosius Barth, 1901), 237, <https://archive.org/details/einfhrungindiep01kraegoog/page/n249>.
- 114 Thane, *Old Age in English History*, 436–8.
- 115 Chase, *The Victorians and Old Age*, 61.
- 116 Also the passing appearance of an elderly woman, who suffers from memory loss, in *Lady Audley's Secret* seems to me to be a clear manifestation of this phenomenon; Mary E. Braddon, *Lady Audley's Secret* (London: Penguin, 2012), 456.
- 117 Lodge, *Consciousness and the Novel*, 58.
- 118 Stiles, introduction, 1.
- 119 Thomas G. Pavel, *The Lives of the Novel: A History* (Princeton, NJ: Princeton University Press, 2013), 267.
- 120 I borrow this term from Cary Smith Henderson, *Partial View: An Alzheimer's Journal* (Dallas, TX: Southern Methodist University Press, 1998).
- 121 Kennedy, *Revising the Clinic*, 200.
- 122 Lodge, *Consciousness and the Novel*, 17.

3 Culture shapes politics shapes science

- 1 Robert N. Butler, *Why Survive? Being Old in America* (Baltimore: Johns Hopkins University Press, 2002), xi.
- 2 Emma Brown, 'Robert N. Butler Dies, "Father of Modern Gerontology" Was 83', *Washington Post*, 7 July 2010.
- 3 Stephen Katz, *Disciplining Old Age: The Formation of Gerontological Knowledge* (Charlottesville: University Press of Virginia, 1996), 41.
- 4 Elie Metchnikoff, 'Old Age', in *Annual Report of the Smithsonian Institution for the Year Ending June 30, 1904* (Washington, DC: Smithsonian Institution, 1903–4), 537, 541, 548. Metchnikoff's definition signalled the epidemiologic transition from infectious to degenerative diseases around the turn of the century, as he appreciated the role of infectious diseases on health in ageing, but did not yet clearly separate infectious from chronic diseases; Abdel R. Omran, 'The Epidemiologic Transition: A Theory of the Epidemiology of Population Change', *Milbank Quarterly* 83 (2005): 731–57; reissue of 49 (1971): 509–38; cf. ch. 2, 29; Achenbaum, *Crossing Frontiers*, 30 (for a fuller account of Metchnikoff's scientific research on ageing, see pp. 23–33).

- 5 Achenbaum, *Crossing Frontiers*, 37.
- 6 Pat Thane, 'Geriatrics', in *Companion Encyclopedia of the History of Medicine*, ed. W. F. Bynum and Roy Porter (Abingdon: Routledge, 1993), 1103–4.
- 7 Georges Canguilhem, *The Normal and the Pathological*, trans. Carolyn R. Fawcett (1978; New York: Zone Books, 1991), 160. For a concise account of the medicalization of the aged body, see Katz, *Disciplining Old Age*, 40–8.
- 8 Achenbaum, *Crossing Frontiers*, 86. Conferences on geriatrics and gerontology became more frequent, and pioneering textbooks emerging from these conferences marked a growing collaboration among researchers from different disciplines – a collaboration that promoted new professional organizations; Ballenger, *Self, Senility, and Alzheimer's Disease*, 57; see also Achenbaum, *Crossing Frontiers*, chs 2 and 3, on the role of Edmund Cowdry, Edward Sieglitz and Oscar Kaplan for discipline building in relation to gerontology and geriatrics.
- 9 The International Association of Gerontology formed in Liège in 1950, and medical journals devoted to geriatrics were being established across Europe, including *Giornale di Gerontologia* (Italy, 1958), *The Gerontologist* (United Kingdom, 1961) and, slightly later, *Age and Aging* (United Kingdom, 1972), *Gerontology* (Switzerland, 1976) and *Age* (Netherlands, 1978). The first journal to carry 'Alzheimer's' in its title was the US journal *Alzheimer Disease and Associated Disorders*, launched in 1987.
- 10 Thane, *Old Age in English History*, 437; see ch. 22 on the rise of geriatric medicine in Britain.
- 11 Marjorie Warren, 'Care of the Chronic Aged Sick', *The Lancet* 1 (1946): 841.
- 12 Thane, *Old Age in English History*, 385.
- 13 Joseph H. Sheldon, *The Social Medicine of Old Age: Report of an Inquiry in Wolverhampton* (London: Nuffield Foundation, 1948), references incorporated in the text. On Peter Townsend's (1928–2009) socio-medical work in London around mid-century, see Charlotte Greenhalgh, *Aging in Twentieth-Century Britain* (Oakland: University of California Press, 2018), ch. 2.
- 14 Kenneth Hazell, *Social and Medical Problems of the Elderly* (London: Hutchinson, 1973), 19 (preface to 1960 edition); all further references incorporated in the text with each edition's year of publication.
- 15 Thane, *Old Age in English History*, 385.
- 16 Trevor H. Howell, *Our Advancing Years: An Essay on Modern Problems of Old Age* (London: Phoenix House, 1976), 13.
- 17 Butler, *Why Survive?*, 12.
- 18 Barbara Pym, *Quartet in Autumn* (London: Bello, 2013), 92, 103; all further references incorporated in the text.
- 19 H. L. Freeman, 'Social Aspects of Alzheimer's Disease', in Berrios and Freeman, *Alzheimer and the Dementias*, 60; Ngatcha-Ribert, *Alzheimer*, 128–49.

- 20 J. De Ajuriaguerra and R. Tissot, 'Some Aspects of Psycho-neurologic Disintegration in Senile Dementia'; and R. Tissot, 'Discussion Remarks on Senile Disintegration'; both in Müller and Ciompi, *Senile Dementia*, 69 and 83, respectively.
- 21 De Ajuriaguerra and Tissot, 'Some Aspects', 74.
- 22 Ibid., 76, 77.
- 23 Ch. Müller, foreword to Müller and Ciompi, *Senile Dementia*, 12.
- 24 Ballenger, *Self, Senility, and Alzheimer's Disease*, 56.
- 25 Robert Katzman, 'Editorial. The Prevalence and Malignancy of Alzheimer Disease: A Major Killer', *Archives of Neurology* 33 (1976): 217.
- 26 Martin S. Brander, 'The Scientist and the News Media', *New England Journal of Medicine* 308 (1983): 1170–3; Van Dijck, *Imagination*, 72.
- 27 Ballenger, *Self, Senility, and Alzheimer's Disease*, 115.
- 28 Constance Rooke lists thirty-nine works, fifteen and sixteen of which were published in the 1970s and 1980s, respectively; Constance Rooke, 'Old Age in Contemporary Fiction: A New Paradigm of Hope', in *Handbook of the Humanities and Aging*, ed. Thomas R. Cole, David D. Van Tassel and Robert Kastenbaum (New York: Springer, 1992), 256–7.
- 29 Sally A. Gadow, 'Part Two. Subjectivity: Literature, Imagination, and Frailty. Introduction', in Cole and Gadow, *What Does It Mean to Grow Old?*, 132.
- 30 The epigraph is from the 1973 edition, pp. 23–4.
- 31 Paul Bailey, *At The Jerusalem* (London: Penguin, 1982); all references incorporated in the text.
- 32 Thane, *Old Age in English History*, 385.
- 33 Personal conversation with the author subsequent to: Paul Bailey, 'Contemporary Narrative and the Coming of Ageing' (Literary dialogue with Courttia Newland, Senate House, University of London, 30 October 2013).
- 34 Mike Hepworth, *Stories of Ageing* (Buckingham: Open University Press, 2000), 77.
- 35 Robert N. Butler, 'The Life Review: An Interpretation of Reminiscence in the Aged', in *New Thoughts on Old Age*, ed. Robert Kastenbaum (New York: Springer, 1964), 266.
- 36 Thane, *Old Age in English History*, 452.
- 37 Charles L. Rose, 'Social Correlates of Longevity', in Kastenbaum, *New Thoughts on Old Age*, 87; see also in the same volume: M. Elaine Cumming, 'New Thoughts on the Theory of Disengagement', 3–18. Compare this with Barbara Pym's poignant vignette of the theme of social disengagement in *Quartet in Autumn*. Both Letty and Marcia retire at the same time, but only Letty keeps 'making an effort with her clothes' (7) and going to 'the library for her own pleasure and possible edification' (3). Marcia, in contrast, does 'not bother[] to touch up the roots of her hair' (102)

- and spends most of her time doing 'a good deal of classifying and sorting' of tinned foods in her cupboard (54).
- 38 Small, *The Long Life*, 21.
- 39 Sidney Levin, 'Depression in the Aged: The Importance of External Factors', in Kastenbaum, *New Thoughts on Old Age*, 179–85.
- 40 It is perhaps only rhetorically correct to suggest that workhouses were 'not intended for the very aged and frail' because almost all the aged poor were destitute since unable to work; F. B. Smith, 'Old Age', in *The People's Health, 1830–1910* (1979; London: Weidenfeld and Nicolson, 1990).
- 41 Erving Goffman, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates* (1961; London: Penguin, 1991), 43, 25; Michel Foucault, *Madness and Civilization: A History of Insanity in the Age of Reason*, trans. Richard Howard (1965; London: Vintage, 1988).
- 42 On grooming in old age in Britain between the 1940s and 1970s, see Greenhalgh, *Aging in Twentieth-Century Britain*, ch. 4.
- 43 Hepworth, *Stories of Ageing*, 77.
- 44 Kathleen Woodward, *Aging and Its Discontents: Freud and Other Fictions* (Bloomington: Indiana University Press, 1991), 70.
- 45 Butler, *Why Survive?*, 188, 189.
- 46 Bailey, 'Contemporary Narrative'; R. D. Laing, *The Politics of Experience and The Bird of Paradise* (1967; Harmondsworth: Penguin, 1987), 110.
- 47 R. D. Laing, *The Divided Self: An Existential Study in Sanity and Madness* (1960; London: Penguin, 2010), 25–6 *et passim*; see also Sander L. Gilman, *Disease and Representation: Images of Illness from Madness to AIDS* (1988; Ithaca, NY: Cornell University Press, 1991), 98–111.
- 48 Irving Wardle, 'A Worthy Guest', *Times*, 12 June 1974.
- 49 Herrman L. Blumgart, 'Caring for the Patient', *New England Journal of Medicine* 270 (1964): 452.
- 50 Small, *The Long Life*, 28.
- 51 J. L. Villa and L. Ciompi, 'Therapeutic Problems of Senile Dementia', in Müller and Ciompi, *Senile Dementia*, 135.
- 52 Helen Dunmore, introduction to *Ending Up*, by Kingsley Amis (London: Penguin, 2011), ix, xi; all references from this edition are incorporated in the text.
- 53 Paul Bailey, 'Author, Author: Paul Bailey', *Guardian*, 15 January 2011, <https://www.theguardian.com/books/2011/jan/15/paul-bailey-author-author>.
- 54 John Updike, *The Poorhouse Fair* (London: Penguin, 2006), 5.
- 55 Robert H. Binstock, Stephen G. Post and Peter J. Whitehouse, 'The Challenges of Dementia', in *Dementia and Aging: Ethics, Values, and Policy Choices*, ed. Robert H. Binstock, Stephen G. Post and Peter J. Whitehouse (Baltimore: Johns Hopkins University Press, 1992), 1.

4 The loss of self in healthcare and cultural discourse

- 1 Nancy L. Mace and Peter V. Rabins, *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life* (Baltimore: Johns Hopkins University Press, 1981), 139; all further references incorporated in the text are from this first of (to date) six editions, unless noted otherwise.
- 2 Rosalie Walsh Honel, *Journey with Grandpa: Our Family's Struggle with Alzheimer's Disease* (Baltimore: Johns Hopkins University Press, 1988); all references incorporated in the text. Yasushi Inoue, *Chronicle of My Mother* (New York: Kodansha International, 1985), originally published in 1975, was translated from Japanese in 1982, but had not received the same endorsement.
- 3 Jane Lewis and Barbara Meredith, *Daughters Who Care: Daughters Caring for Mothers at Home* (London: Routledge, 1988), 10.
- 4 May, 'The Virtues and Vices', 46.
- 5 Margaret Forster, *Have the Men Had Enough?* (London: Vintage, 2004), 94–114, 177.
- 6 Elaine M. Brody, "'Women in the Middle" and Family Help to Older People', *The Gerontologist* 21 (1981): 471–80.
- 7 Peter V. Rabins, foreword to Honel, *Journey with Grandpa*, ix.
- 8 Thane, *Old Age in English History*, 430.
- 9 This motif reflects the impact of population changes in Italy, where since the 1980s, demographic figures have caused serious concern; Rita C. Caviglioli, *Women of a Certain Age: Contemporary Italian Fictions of Female Aging* (Madison, NJ: Fairleigh Dickinson University Press, 2005), 50.
- 10 Sawako Ariyoshi, *The Twilight Years*, trans. Mildred Tahara (London: Peter Owen, 1984).
- 11 The first time I encountered this term was in Richard C. Adelman's questioning of the NIA's political strategies in 'The Alzheimerization of Aging', *The Gerontologist* 35 (1995): 526–32.
- 12 Binstock, Post and Whitehouse, 'The Challenges of Dementia', 5. Honel became active in response to Ronald Reagan's 1982 call for November to be the National Alzheimer's Disease Awareness Month. She provided the local newspaper with factual information (166), participated in a Chicago television news show (173) and made 'a documentary film on the problems of aging' (193). She also published a poem about her experience in a prominent medical journal. This, by itself, I take as a first and significant step that forged a way for caregivers as members of the general public to feed back into, and thus contribute to shaping, how the medical profession thought about the condition; *My Mother, My Father*, directed by James Vanden Bosch (1984; Concord Media, n.d.), DVD; Rosalie Walsh Honel, 'Alzheimer's Disease', *New England Journal of Medicine* 309 (1983): 1524. On

- the popularizing effect of Alzheimer's Awareness Week, consider, for example, Nadine Brozan, 'Coping with Travail of Alzheimer's Disease', *New York Times*, 29 November 1982. On the central role of the Alzheimer's Disease and Related Disorders Association (ADRD) in the Alzheimer's movement, see Patrick Fox, 'From Senility to Alzheimer's Disease: The Rise of the Alzheimer's Disease Movement', *Milbank Quarterly* 67 (1989): 58–102. In a chapter developed around oral narratives, Marlene Goldman beautifully illustrates the personal involvement of caregivers which led to the creation of the Alzheimer's Society of Canada; Goldman, *Forgotten*, 193–215.
- 13 Honel's use of the term 'Grandpa' could be seen as perpetuating the image of the individual with memory loss as elderly, but her choice might be inspired by Ariyoshi's Akiko referring to *Ojii-chan* (Grandpa), a term the Japanese use endearingly for a male elderly; also Inoue writes about his mother as *Obā-chan* (Granny).
 - 14 Fox, 'From Senility to Alzheimer's Disease', 73–4.
 - 15 Cohen, *No Aging in India*, 58, 54.
 - 16 Richard J. Martin and Stephen G. Post, 'Human Dignity, Dementia, and the Moral Basis of Caregiving', in Binstock, Post and Whitehouse, *Dementia and Aging*, 66.
 - 17 Andrea Fontana and Ronald W. Smith, 'Alzheimer's Disease Victims: The "Unbecoming" of Self and the Normalization of Competence', *Sociological Perspectives* 32 (1989): 35, 36.
 - 18 Susan M. Behuniak, 'The Living Dead? The Construction of People with Alzheimer's Disease as Zombies', *Ageing and Society* 31 (2011): 70–92.
 - 19 Ballenger, *Self, Senility, and Alzheimer's Disease*, 113.
 - 20 Rabins, foreword, ix; Shenk, *The Forgetting*, 137.
 - 21 Anne Davis Basting, *Forget Memory: Creating Better Lives for People with Dementia* (Baltimore: Johns Hopkins University Press, 2009), 35–45; Peter J. Whitehouse with Daniel George, *The Myth of Alzheimer's: What You Aren't Being Told about Today's Most Dreaded Diagnosis* (New York: St. Martin's Griffin, 2008), 97–102.
 - 22 A feature article of the period, for example, opened with accounts of famous stars such as Rita Hayworth turned *Schreckbild* (image of horror); 'Das Hirn wird brüchig wie ein alter Stiefel' [The brain turns crumbly like an old boot], *Der Spiegel*, 19 June 1989.
 - 23 Lawrence Meyer, 'A Cure Is Sought for Disease of Aged', *Washington Post*, 8 January 1982; Katzman, 'Editorial'.
 - 24 M. Clark, M. Gosnell and D. Witherspoon, 'A Slow Death of the Mind', *Newsweek*, 3 December 1984.
 - 25 Donna Cohen and Carl Eisdorfer, *The Loss of Self: A Family Resource for the Care of Alzheimer's Disease and Related Disorders* (New York: W. W. Norton, 1986), 64; all further references incorporated in the text.

- 26 King's Fund, *Living Well into Old Age: Applying Principles of Good Practice to Services for People with Dementia* (London: King's Fund, 1986); references incorporated in the text.
- 27 Philip M. Boffey, 'Alzheimer's Disease: Families Are Bitter', *New York Times*, 7 May 1985.
- 28 Note that objectifying terms such as the 'impaired person' have been replaced in later editions of *The 36-Hour Day*. The 1999 edition changed it to 'person with dementia', and the 2011 edition wrote about 'the person who has dementia'. Consider also the focus of Jaber F. Gubrium, 'Structuring and Deconstructing the Course of Illness: The Alzheimer's Disease Experience', *Sociology of Health and Illness* 9 (1987): 1–24.
- 29 Larry Rose, *Show Me the Way to Go Home* (Forest Knolls, CA: Elder Books, 1996), 26 (manual title *sic*).
- 30 Jill Manthorpe, 'A Child's Eye View: Dementia in Children's Literature', *British Journal of Social Work* 35 (2005): 316; Stuart Murray, *Representing Autism: Culture, Narrative, Fascination* (Liverpool: Liverpool University Press, 2008), 68–70.
- 31 Martina Zimmermann, '"Journeys" in the Life-Writing of Adult-Child Dementia Caregivers', *Journal of Medical Humanities* 34 (2013): 385–97.
- 32 Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988), 183.
- 33 Compare to this Kleinman's later call for 'practical and emotional support' for caregivers; Arthur Kleinman, 'Caregiving: The Odyssey of Becoming More Human', *The Lancet* 373 (2009): 293.
- 34 Samuel Beckett, 'Company', in *Company, Ill Seen Ill Said, Worstward Ho, Stirrings Still* (London: Faber and Faber, 2009), 4; all further references from this edition are incorporated in the text.
- 35 Hartung, *Ageing, Gender and Illness*, 180.
- 36 Ballenger, *Self, Senility, and Alzheimer's Disease*, 153, 173, 179.
- 37 Anthony Elliott highlights 'fragmentation, dislocation and decomposition of identity and everyday working life' as central to postmodern theory; Anthony Elliott, *Concepts of the Self*, 2nd edn (Cambridge: Polity, 2008), 141.
- 38 Peter Tinniswood, '"Company" by Samuel Beckett', *Times*, 26 June 1980. I could not find any reference to Alzheimer's disease in connection with Beckett's *Company* in the *Times*.
- 39 Joseph M. Foley, 'The Experience of Being Demented', in Binstock, Post and Whitehouse, *Dementia and Aging*, 30.
- 40 J. Bernlef [Hendrik Jan Marsman], *Out of Mind*, trans. Adrienne Dixon (London: Faber and Faber, 1988); references incorporated in the text.
- 41 Alexander Zweers, 'The Narrator's Position in Selected Novels by J. Bernlef', *Canadian Journal of Netherlandic Studies* 19 (1998): 35; Hartung, *Ageing, Gender and Illness*, 187.

- 42 Steven Connor, *Postmodernist Culture: An Introduction to Theories of the Contemporary*, 2nd edn (Oxford: Blackwell, 1997), 127.
- 43 Ellipses are very important in this novel; to distinguish them from editorial omissions, original suspension points are reported without space on either side of the ellipsis.
- 44 Hannah Zeilig, 'Gaps and Spaces: Representations of Dementia in Contemporary British Poetry', *Dementia* 13 (2014): 167.
- 45 Luce Irigaray, *Le Langage des Déments* [The manner of speaking of the demented] (The Hague: Mouton, 1973).
- 46 Barry Reisberg, 'Clinical Presentation, Diagnosis, and Symptomatology of Age-Associated Cognitive Decline and Alzheimer's Disease', in Reisberg, *Alzheimer's Disease*, 174–5.
- 47 W. G. Sebald, *Austerlitz* (Frankfurt am Main: Fischer, 2013), 173, 269.
- 48 Andreas Huyssen, *Present Pasts: Urban Palimpsests and the Politics of Memory* (Stanford, CA: Stanford University Press, 2003), 4.
- 49 Rick Crownshaw, 'Theoretical Anticipations: Memory and Photography in W. G. Sebald's *Austerlitz*', in *The Politics of Cultural Memory*, ed. Lucy Burke, Simon Faulkner and Jim Aulich (Newcastle upon Tyne: Cambridge Scholars, 2010), 60.
- 50 Saul Bellow, *Mr. Sammler's Planet* (1969; London: Penguin, 1995), 73.
- 51 Harry Mulisch, *The Assault*, trans. Claire N. White (New York: Pantheon, 1985), originally published in Dutch in 1982; references incorporated in the text.
- 52 Thomas DeBaggio, *Losing My Mind: An Intimate Look at Life with Alzheimer's* (2002; New York: Free Press, 2003), 1, 184; Zimmermann, 'Alzheimer's Disease Metaphors', 82–3.
- 53 Barbara Ehrenreich, *Smile or Die: How Positive Thinking Fooled America and the World* (2009; London: Granta Books, 2010); Zimmermann, *The Poetics and Politics*, ch. 4.
- 54 Stuart Taberner, *Aging and Old-Age Style in Günter Grass, Ruth Klüger, Christa Wolf, and Martin Walser: The Mannerism of a Late Period* (Rochester: Camden House, 2013), 40. Helen Small makes a similar observation on Bellow's writing, considering it 'a hyper-self-reflexive prose, forever revising its own claims, refining, sharpening, justifying, retracting, softening, debunking'; Small, *The Long Life*, 108.
- 55 Barlow, 'Senile Dementia', 359.
- 56 Woodward, *Aging and Its Discontents*, 89; emphasis original.
- 57 Hartung, *Ageing, Gender and Illness*, 86.
- 58 Zimmermann, *The Poetics and Politics*, ch. 5.
- 59 Consider, for example, Lawrence Meyer, 'A Family Stranger', *Washington Post*, 9 January 1982.
- 60 J. Wuest, P. K. Ericson and P. N. Stern, 'Becoming Strangers: The Changing Family Caregiving Relationship in Alzheimer's Disease', *Journal of Advanced Nursing* 20 (1994): 437.

- 61 Anita Desai, 'The Narrator Has Alzheimer's', *New York Times*, 17 September 1989.
- 62 Eakin, *How Our Lives Become Stories*, 46.
- 63 Ruth M. Tappen, 'Awareness of Alzheimer Patients', *American Journal of Public Health* 78 (1988): 987–8.
- 64 Zweers, 'The Narrator's Position', 40.
- 65 Desai, 'The Narrator Has Alzheimer's'.
- 66 Foley, 'The Experience of Being Demented', 40, 42.
- 67 Basting, *Forget Memory*, 39.
- 68 *Black Daisies for the Bride*, directed by Peter Symes, aired 30 June 1993, on BBC Two, <https://www.youtube.com/watch?v=c8YxHk7yMo8> and <https://www.youtube.com/watch?v=6Z2r1brCBrY>; Tony Harrison, *Black Daisies for the Bride* (London: Faber and Faber, 1993), 1, 10, 14, 9.
- 69 Lucy Burke, 'The Poetry of Dementia: Art, Ethics and Alzheimer's Disease in Tony Harrison's *Black Daisies for the Bride*', *Journal of Literary and Cultural Disability Studies* 1 (2007): 70.
- 70 Basting, 'Looking Back from Loss'; Ballenger, *Self, Senility, and Alzheimer's Disease*, ch. 6; Burke, 'Alzheimer's Disease'; and, slightly later, Ryan, Bannister and Anas, 'The Dementia Narrative'.
- 71 Ann Robertson, 'The Politics of Alzheimer's Disease: A Case Study in Apocalyptic Demography', *International Journal of Health Services* 20 (1990): 439; Jeroen Spijker and John MacInnes, 'Population Ageing: The Timebomb That Isn't?', *Biomedical Journal* 347 (2013): f6598.
- 72 David Callahan, 'Dementia and Appropriate Care: Allocating Scarce Resources', in Binstock, Post and Whitehouse, *Dementia and Aging*, 141–52.
- 73 On efforts of the 'gray lobby' in the United States, see Achenbaum, *Crossing Frontiers*, chs 4 and 6.
- 74 Estes and Binney, 'The Biomedicalization of Aging', 593.
- 75 Ronald Sahyouni, Aradhana Verma and Jefferson Chen, *Alzheimer's Disease Decoded: The History, Present, and Future of Alzheimer's Disease and Dementia* (New Jersey: World Scientific, 2017), 236.

5 The narrative of loss in a growing biomedical and literary marketplace of Alzheimer's disease

- 1 Bick, Amaducci and Pepeu, *The Early Story of Alzheimer's Disease*; consider also Alzheimer et al., 'An English Translation'.
- 2 A 'topic' Web of ScienceTM (<http://wok.mimas.ac.uk/>) search indicates that the number of studies naming 'Alzheimer' rose from twenty-eight in the 1940s to forty-six and ninety per decade in the 1950s and 1960s, respectively. From the 1980s to

- the 1990s, publication numbers on 'Alzheimer' increased 5-fold, while those on 'dementia' (though much larger in absolute terms) increased by only 2.7 times.
- 3 Ballenger, *Self, Senility, and Alzheimer's Disease*, 87.
 - 4 Arne Brun, 'An Overview of Light and Electron Microscopic Changes', in Reisberg, *Alzheimer's Disease*, 37, 38, 40, 43.
 - 5 Rose and Abi-Rached, *Neuro*, 43.
 - 6 Robert N. Butler and Marian Emr, 'An American Perspective', in Reisberg, *Alzheimer's Disease*, 464.
 - 7 David B. Morris, *Illness and Culture in the Postmodern Age* (Berkeley: University of California Press, 1998), 2.
 - 8 Otis, *Networking*, 3.
 - 9 Reynolds, *The Third Lens*, 115–17.
 - 10 P. Davies and A. J. F. Maloney, 'Selective Loss of Central Cholinergic Neurons in Alzheimer's Disease', *The Lancet* 2 (1976): 1403. Similar discoveries were made contemporaneously in two other British laboratories: David M. Bowen et al., 'Neurotransmitter-Related Enzymes and Indices of Hypoxia in Senile Dementia and Other Abiotrophies', *Brain* 99 (1976): 459–96; and E. K. Perry et al., 'Correlation of Cholinergic Abnormalities with Senile Plaques and Mental Test Scores in Senile Dementia', *British Medical Journal* 2 (1978): 1457–9.
 - 11 Peter J. Whitehouse et al., 'Alzheimer's Disease and Senile Dementia: Loss of Neurons in the Basal Forebrain', *Science* 215 (1982): 1237–9; references incorporated in the text.
 - 12 Otis, *Networking*, 80.
 - 13 Ibid., 220.
 - 14 David A. Drachman, 'The Pharmacological Basis for Cholinergic Investigations of Alzheimer's Disease: Evidence and Implications', in Reisberg, *Alzheimer's Disease*, 342; emphasis original.
 - 15 Michael Ignatieff, *Scar Tissue* (London: Vintage, 1994); references incorporated in the text.
 - 16 Dementia occurs in the final stages of ALS, but goes largely unnoticed due to the rapid progression of the condition; Majid Fotuhi, Vladimir Hachinski and Peter J. Whitehouse, 'Changing Perspectives Regarding Late-Life Dementia', *Nature Reviews Neurology* 5 (2009): 649–58.
 - 17 Also Otis underlines the conceptual link between connectedness and the ability to convey intelligence and identity when referring to the late astrophysicist and ALS patient Stephen Hawking as 'an extreme case of merged organo-technical communications systems'; Otis, *Networking*, 221.
 - 18 Michelle Wildgen, *You're Not You* (New York: Picador, 2007), 117, 228.
 - 19 Joel Havemann, *A Life Shaken: My Encounter with Parkinson's Disease* (Baltimore: Johns Hopkins University Press, 2002); references incorporated in the text.

- 20 The neuromolecular model of Parkinson's disease ascribes loss of movement control to a loss of the neurotransmitter dopamine in the brain region named substantia nigra.
- 21 Sandi Gordon, *Parkinson's: A Personal Story of Acceptance* (Boston: Branden, 1992), 21.
- 22 Jonathan Franzen, *The Corrections* (London: Fourth Estate, 2010), 642.
- 23 C. G. Rasool, C. N. Svendsen and Dennis J. Selkoe, 'Neurofibrillary Degeneration of Cholinergic and Noncholinergic Neurons of the Basal Forebrain in Alzheimer's Disease', *Annals of Neurology* 20 (1986): 482–8.
- 24 Michael Kidd, 'Paired Helical Filaments in Electron Microscopy of Alzheimer's Disease', *Nature* 197 (1963): 192–3.
- 25 I. Grundke-Iqbal et al., 'Microtubule-Associated Protein Tau: A Component of Alzheimer Paired Helical Filaments', *Journal of Biological Chemistry* 261 (1986): 6084.
- 26 Kenneth S. Kosik, Catherine L. Joachim and Dennis J. Selkoe, 'Microtubule Associated Protein Tau (τ) Is a Major Antigenic Component of Paired Helical Filaments in Alzheimer Disease', *Proceedings of the National Academy of Sciences* 83 (1986): 4044; Heiko Braak and Eva Braak, 'Neuropathological Stageing of Alzheimer-Related Changes', *Acta Neuropathologica* 82 (1991): 239–59.
- 27 Rudolph E. Tanzi and Ann B. Parson, *Decoding Darkness: The Search for the Genetic Causes of Alzheimer's Disease* (Cambridge, MA: Perseus, 2000), 103; all further references incorporated in the text.
- 28 David A. Snowdon, *Aging with Grace: The Nun Study and the Science of Old Age: How We Can All Live Longer, Healthier and More Vital Lives* (2001; London: Fourth Estate, 2002), 92; all further references incorporated in the text.
- 29 Henryk M. Wisniewski, 'Neuritic (Senile) and Amyloid Plaques', in Reisberg, *Alzheimer's Disease*, 57.
- 30 Dennis J. Selkoe, 'The Deposition of Amyloid Proteins in the Aging Mammalian Brain: Implications for Alzheimer's Disease', *Annals of Medicine* 21 (1989): 73–6.
- 31 George G. Glenner and Caine W. Wong, 'Alzheimer's Disease: Initial Report of the Purification and Characterization of a Novel Cerebrovascular Amyloid Protein', *Biochemical and Biophysical Research Communications* 120 (1984): 885–90; Jie Kang et al., 'The Precursor of Alzheimer's Disease Amyloid A4 Protein Resembles a Cell-Surface Receptor', *Nature* 325 (1987): 733–6.
- 32 Lock, *The Alzheimer Conundrum*, 155.
- 33 Peter H. St. George-Hyslop et al., 'The Genetic Defect Causing Familial Alzheimer's Disease Maps on Chromosome 21', *Science* 235 (1987): 885–90.
- 34 Alison Goate et al., 'Segregation of a Missense Mutation in the Amyloid Precursor Protein Gene with Familial Alzheimer's Disease', *Nature* 349 (1991): 704–6.
- 35 John A. Hardy and Gerald A. Higgins, 'Alzheimer's Disease: The Amyloid Cascade Hypothesis', *Science* 256 (1992): 184.

- 36 Gina Kolata, 'Alzheimer's Researchers Close In on Causes', *New York Times*, 26 February 1991.
- 37 Ronald Kotulak, 'Stalking "Demons of the Mind"', *Chicago Tribune*, 4 June 1980.
- 38 Van Dijck, *Imagination*, 37. The exaggerated importance ascribed to genetic research became ironically manifest in the genotyping of Auguste D's condition in 1998. The general public's belief in the importance of genetics, in turn, was conveyed in the related newspaper report which conceded that 'Alois Alzheimer had not erred'; M. B. Graeber et al., 'Histopathology and APOE Genotype of the First Alzheimer Disease Patient, Auguste D', *Neurogenetics* 1 (1998): 223–8; 'Alois Alzheimer hat sich nicht geirrt', *Frankfurter Allgemeine Zeitung*, 15 April 1998.
- 39 Dennis J. Selkoe, 'Missense on the Membrane', *Nature* 375 (1995): 734. The presenilin 1 and 2 genes were identified on chromosomes 14 and 1, respectively.
- 40 Van Dijck, *Imagination*, 39.
- 41 Daniel A. Pollen, *Hannah's Heirs: The Quest for the Genetic Origins of Alzheimer's Disease*, exp. edn (New York: Oxford University Press, 1996); all references incorporated in the text.
- 42 Van Dijck, *Imagination*, 122.
- 43 Latour, *Science in Action*, 164.
- 44 Foucault, *The Birth of the Clinic*, 166–7; as also cited in Nikolas Rose, *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century* (Princeton, NJ: Princeton University Press, 2007), 193.
- 45 Rose, *The Politics of Life Itself*, 93.
- 46 Charles P. Pierce, *Hard to Forget: An Alzheimer's Story* (New York: Random House, 2000); references incorporated in the text.
- 47 Lucy Burke, "'The Country of My Disease": Genes and Genealogy in Alzheimer's Life-Writing', *Journal of Literary and Cultural Disability Studies* 2 (2008): 63, 66. Pierce's book remains, to my knowledge, the only Alzheimer's narrative that explicitly centres around genetic testing. But consider Lisa Snyder's account of 33-year-old Consuelo, who underwent (positive) genetic testing; Lisa Snyder, *Speaking Our Minds: What It's Like to Have Alzheimer's*, rev. edn (Baltimore: Health Professions, 2009), 133–50. Tracy Mobley tells of disease onset at age 38 in *Young Hope: The Broken Road* (2007); however, genetic testing does not play a major role in her narration.
- 48 Burke, "'The Country of My Disease"', 71.
- 49 Hacking, *Rewriting the Soul*, 111.
- 50 On a powerful exploration of how genes function 'within culture and within the body in culture as condensed arguments and contests', see Valerie Hartouni, *Cultural Conceptions: On Reproductive Technologies and the Remaking of Life* (Minneapolis: University of Minnesota Press, 1997), 128–9. Consider also Ana M. Soto and Carlos Sonnenschein, 'Reductionism, Organicism, and Causality

- in the Biomedical Sciences. A Critique', *Perspectives in Biology and Medicine* 61 (2018): 493–4.
- 51 Jean Baréma, *The Test: Living in the Shadow of Huntington's Disease* (New York: Franklin Square, 2005); references incorporated in the text.
- 52 Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography*, 2nd edn (West Lafayette: Purdue University Press, 1999), 5.
- 53 Franziska Draeger, 'Da war ich tot' [Then I was dead], *Die Zeit*, 27 March 2013. Also Sandy Sulaiman's *Learning to Live with Huntington's Disease: One Family's Story* (2007) evolves around each family member's risk and testing dilemma. It remains to be demonstrated whether the recent gene silencing success in Huntington's disease research can slow or prevent the disease before symptoms develop; James Gallagher, 'Huntington's Breakthrough May Stop Disease', *BBC News*, 11 December 2017, <http://www.bbc.co.uk/news/health-42308341>. The pharmaceutical company Roche launched a Phase 3 clinical trial in December 2018 and started enrolling patients in early 2019.
- 54 E. H. Corder et al., 'Gene Dose of Apolipoprotein E Type 4 Allele and the Risk of Alzheimer's Disease in Late Onset Families', *Science* 261 (1993): 921–3.
- 55 David A. Snowdon et al., 'Linguistic Ability in Early Life and Cognitive Function and Alzheimer's Disease in Late Life: Findings from the Nun Study', *Journal of the American Medical Association* 275 (1996): 528–32; references incorporated in the text.
- 56 Ann E. Vandenberg, 'What We Can Say about Cognition in Aging: Arguments for and against Cognitive Health Promotion' (PhD thesis, Emory University, 2012), 66, 174, 210.
- 57 Whitehouse, *The Myth of Alzheimer's*, xix, 244–9; Vandenberg, 'What We Can Say', 136. For a more recent contribution that closes on a chapter on 'where you live, what you eat', consider Jay Ingram, *The End of Memory: A Natural History of Aging and Alzheimer's* (2014; London: Rider Books, 2016), 241–52.
- 58 John A. Hardy, 'ApoE, Amyloid, and Alzheimer's Disease', *Science* 263 (1994): 454.
- 59 Whitehouse, *The Myth of Alzheimer's*, xvii.
- 60 Gayatri Devi, *The Spectrum of Hope: An Optimistic and New Approach to Alzheimer's Disease and Other Dementias* (New York: Workman, 2017), viii, ix.
- 61 Daniel R. George and Peter J. Whitehouse, 'Marketplace of Memory: What the Brain Fitness Technology Industry Says about Us and How We Can Do Better', *The Gerontologist* 51 (2011): 595.
- 62 Stephen Katz and Barbara L. Marshall, 'Tracked and Fit: FitBits, Brain Games, and the Quantified Aging Body', *Journal of Aging Studies* 45 (2018): 63, 66.
- 63 Huyssen, *Present Pasts*, 16.
- 64 Annie Ernaux, *Une femme* [A woman] (1987; Paris: Éditions Gallimard, 2002), 42; Mary Gordon, *The Shadow Man: A Daughter's Search for Her Father* (1996;

- New York: Vintage, 1997), 56; Lillian B. Rubin, *Tangled Lives: Daughters, Mothers, and the Crucible of Aging* (Boston: Beacon, 2000), viii. I am not aware of a similar body of work in the Spanish or Italian culture.
- 65 Lisa Appignanesi, *Losing the Dead: A Family Memoir* (London: Chatto and Windus, 1999), 167.
- 66 Linda Grant, *Remind Me Who I Am, Again* (London: Granta Books, 1999), 31; all further references incorporated in the text.
- 67 Nicola King, *Memory, Narrative, Identity: Remembering the Self* (Edinburgh: Edinburgh University Press, 2000), 2–3, 40; emphasis original.
- 68 Huyssen, *Present Pasts*, 8.
- 69 Eleanor Cooney, *Death in Slow Motion: A Memoir of a Daughter, Her Mother, and the Beast Called Alzheimer's* (New York: Harper Perennial, 2004), 210; all further references incorporated in the text.
- 70 Michael Bury, 'Chronic Illness as Biographical Disruption', *Sociology of Health and Illness* 4 (1982): 167–82; Gay Becker, *Disrupted Lives: How People Create Meaning in a Chaotic World* (Berkeley: University of California Press, 1997).
- 71 Rooke, 'Old Age in Contemporary Fiction', 255.
- 72 Ehrenreich, *Smile or Die*, 59.
- 73 Kathlyn Conway, *Illness and the Limits of Expression* (Ann Arbor: University of Michigan Press, 2007), 1.
- 74 G. Thomas Couser, *Recovering Bodies: Illness, Disability, and Life Writing* (Madison: University of Wisconsin Press, 1997), 5.
- 75 Appignanesi, *Losing the Dead*, 81.
- 76 Margarita Retuerto Buades, *Mi vida junto a un enfermo de Alzheimer* (Madrid: La Esfera de los Libros, 2003); references incorporated in the text.
- 77 Booth, *The Art of Growing Older*, 40.
- 78 Flora Sáez, 'Mi marido tiene Alzheimer' [My husband has Alzheimer's], *El Mundo*, 22 September 2002, <https://www.elmundo.es/cronica/2002/362/1032772217.html>.
- 79 Ann Burack-Weiss, *The Caregiver's Tale: Loss and Renewal in Memoirs of Family Life* (New York: Columbia University Press, 2006), 69.
- 80 Bradley T. Hyman, 'Alzheimer's Disease or Alzheimer's Diseases? Clues from Molecular Epidemiology', *Annals of Neurology* 40 (1996): 136.
- 81 John Bayley, *The Iris Trilogy: A Memoir of Iris Murdoch* (London: Abacus, 2003); all references from this edition are incorporated in the text.
- 82 Among the narratives referring to Bayley's account are Gillies's *Keeper*, Tilman Jens's *Demenz: Abschied von meinem Vater* (Dementia: Farewell to my father; 2009), Nucci A. Rota's *La bimbamamma: Cosa vuol dire convivere con l'Alzheimer. Il diario di una figlia* (The mommy girl: What it means to share your life with Alzheimer's. A daughter's diary; 2009), and David Sieveking's *Vergiss mein nicht: Wie meine Mutter ihr Gedächtnis verlor und ich meine Eltern neu entdeckte* (Forget me

- not: How my mother lost her memory and I discovered my parents anew; 2012); Zimmermann, *The Poetics and Politics*, 51.
- 83 *Iris*, directed by Richard Eyre (2001; Miramax Home Entertainment, 2002), DVD.
- 84 Sally Chivers, *The Silvering Screen: Old Age and Disability in Cinema* (Toronto: University of Toronto Press, 2011), 82.
- 85 For a broader discussion, see David M. R. Orr and Yugin Teo, 'Carers' Responses to Shifting Identity in Dementia in *Iris* and *Away from Her*: Cultivating Stability or Embracing Change?', *Medical Humanities* 41 (2015): 81–5.
- 86 Consider, for example, Vassilas, 'Dementia and Literature'; Yahnke, 'Old Age and Loss'.

6 Neurotechnologies and narrative examine the failing mind

- 1 G. E. Berrios and H. L. Freeman, introduction to Berrios and Freeman, *Alzheimer and the Dementias*, 5–6.
- 2 'Project on the Decade of the Brain', Library of Congress, last modified 1 March 2000, <http://www.loc.gov/loc/brain/>.
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- 4 Kelly A. Joyce, *Magnetic Appeal: MRI and the Myth of Transparency* (Ithaca, NY: Cornell University Press, 2008), 2; emphasis original.
- 5 J. P. Seab et al., 'Quantitative NMR Measurements of Hippocampal Atrophy in Alzheimer's Disease', *Magnetic Resonance in Medicine* 8 (1988): 200–8.
- 6 William Bondareff et al., 'Magnetic Resonance Imaging and the Severity of Dementia in Older Adults', *Archives of General Psychiatry* 47 (1990): 47; all further references incorporated in the text.
- 7 Barry F. Saunders, *CT Suite: The Work of Diagnosis in the Age of Noninvasive Cutting* (Durham, NC: Duke University Press, 2008), 5.
- 8 Bruno Latour and Steve Woolgar, *Laboratory Life: The Construction of Scientific Facts* (1979; Princeton, NJ: Princeton University Press, 1986), 51.
- 9 Hacking, *Rewriting the Soul*, ch. 7.
- 10 G. Blessed, B. E. Tomlinson and M. Roth, 'The Association between Quantitative Measures of Dementia and of Senile Changes in the Cerebral Grey Matter of Elderly Subjects', *British Journal of Psychiatry* 114 (1968): 799; Marshal F. Folstein, Susan E. Folstein and Paul R. McHugh, 'Mini-Mental State: A Practical Method for Grading the Cognitive State of Patients for the Clinician', *Journal of Psychiatric Research* 12 (1975): 189–98.

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- 12 The Diagnostic and Statistical Manual DSM-III-R of Mental Disorders was published in 1987; and the Clinical Dementia Rating (CDR) was introduced in 1982.
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- 14 Joseph Dumit, *Picturing Personhood: Brain Scans and Biomedical Identity* (Princeton, NJ: Princeton University Press, 2004), 92, 93.
- 15 Ibid., 95–100.
- 16 Lisa Cartwright, *Screening the Body: Tracing Medicine's Visual Culture* (Minneapolis: University of Minnesota Press, 1995), xvii; consider also José Van Dijck, *The Transparent Body: A Cultural Analysis of Medical Imaging* (Seattle: University of Washington Press, 2005), 9–14.
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- 19 Lennard J. Davis, *Obsession: A History* (Chicago: University of Chicago Press, 2008), 23.
- 20 H. Shinotoh et al., 'Progressive Loss of Cortical Acetylcholinesterase Activity in Association with Cognitive Decline in Alzheimer's Disease: A Positron Emission Tomography Study', *Annals of Neurology* 48 (2000): 194, 199.
- 21 F. Nobili et al., 'Brain Perfusion Follow-Up in Alzheimer's Patients during Treatment with Acetylcholinesterase Inhibitors', *Journal of Nuclear Medicine* 43 (2002): 983.
- 22 Ian Hacking, *The Social Construction of What?* (1999; Cambridge, MA: Harvard University Press, 2003), 237 n. 1.
- 23 Van Dijck, *The Transparent Body*, 6–7.
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- 27 Vandenberg, 'What We Can Say', ch. 4.
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- 33 Foley, 'The Experience of Being Demented', 37.
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- 43 George Grella, 'The Formal Detective Novel', in Winks, *Detective Fiction*, 86.
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- 45 Alan Palmer, 'Ontologies of Consciousness', in Herman, *The Emergence of Mind*, 278.
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- 53 Vai Ramanathan, *Alzheimer Discourse: Some Sociolinguistic Dimensions* (Mahwah, NJ: Lawrence Erlbaum Associates, 1997), ch. 1.
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- 55 Steven R. Sabat, *The Experience of Alzheimer's Disease: Life through a Tangled Veil* (Oxford: Blackwell, 2001), vii.
- 56 Martin Suter, *Small World* (Zurich: Diogenes, 1999); references incorporated in the text.
- 57 Miriam Seidler, 'Zwischen Demenz und Freiheit: Überlegungen zum Verhältnis von Altern und Geschlecht in der Gegenwartsliteratur' [Between dementia and freedom: Considerations regarding the relationship between ageing and gender in current literature], in *Graue Theorie: Die Kategorien Alter und Geschlecht im kulturellen Diskurs* [Grey theory: Categories of age and gender in cultural discourse], ed. Heike Hartung et al. (Cologne: Böhlau Verlag, 2007), 208.
- 58 Consider, for example, M. Hofmann et al., 'Individualisiertes, computergestütztes Gedächtnistraining bei Alzheimer-Patienten' [Computer-assisted individualized memory training in Alzheimer's patients], *Nervenarzt* 66 (1995): 703–7.
- 59 Brooks, *Reading for the Plot*, 168.
- 60 Carmelo Aquilina and Julian C. Hughes, 'The Return of the Living Dead: Agency Lost and Found?', in Hughes, Louw and Sabat, *Dementia*, 143–61.
- 61 Christine Boden, *Who Will I Be When I Die?* (Sydney: HarperCollins, 1998), 54; all further references from this edition are incorporated in the text. Boden's narrative

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 - 69 Christine Bryden, *Dancing with Dementia: My Story of Living Positively with Dementia* (London: Jessica Kingsley, 2005), 141–2.
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 - 72 'Welcome to the Trebus Project', Trebus Project, accessed 25 October 2019, <http://www.trebusprojects.org/>; Rick Noack, 'A German Nursing Home Tries a Novel Form of Dementia Therapy: Re-creating a Vanished Era for Its Patients', *Washington Post*, 26 December 2017, <https://www.washingtonpost.com/news/worldviews/wp/2017/12/26/a-german-nursing-home-tries-a-novel-form-of-dementia-therapy-re-creating-a-vanished-era-for-its-patients/>.
 - 73 Julian C. Hughes, Stephen J. Louw and Steven R. Sabat, 'Seeing Whole', in Hughes, Louw and Sabat, *Dementia*, 4.
 - 74 Arthur Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: University of Chicago Press, 1995), ch. 5, 97–9.
 - 75 Hawkins, *Reconstructing Illness*, ch. 3; Zimmermann, 'Alzheimer's Disease Metaphors', 74–8.
 - 76 Couturier, *Puzzle*, 72; Zimmermann, *The Poetics and Politics*, 107.
 - 77 Literary scholarship has described a similar, though much earlier, shift in breast cancer life-writing; Couser, *Recovering Bodies*, 63; Lisa Diedrich, *Treatments: Language, Politics, and the Culture of Illness* (Minneapolis: University of Minnesota Press, 2007), 26.
 - 78 Bryden's Alzheimer's disease diagnosis had been amended to that of less aggressively advancing fronto-temporal dementia in 1998.

- 79 Wendy Mitchell with Anna Wharton, *Somebody I Used to Know* (London: Bloomsbury, 2018), 63, 94; consider also Mitchell's recent 'Alzheimer's in the Workplace', *New York Times*, 12 September 2018; and her presence on Twitter active since March 2015; 'Sharing My Journey', Twitter, accessed 25 October 2019, www.twitter.com/wendypmitchell.
- 80 Ulrike Draesner, 'Ichs Heimweg macht alles alleine' [It's journey home does everything by itself], in *Es schneit in meinem Kopf: Erzählungen über Alzheimer und Demenz* [It snows in my head: Narratives about Alzheimer's and dementia], ed. Klara Obermüller (Munich: Nagel and Kimche, 2006), 59–81.
- 81 Kim Howes Zabbia, *Painted Diaries: A Mother and Daughter's Experience through Alzheimer's* (Minneapolis: Fairview, 1996); references incorporated in the text.
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- 83 Jeannette Montgomery Barron, *My Mother's Clothes: An Album of Memories* (New York: Welcome Books, 2009), 94.
- 84 Consider, for example, Cathy Stein Greenblat, *Alive with Alzheimer's* (Chicago: University of Chicago Press, 2004); Peter Granser, *Alzheimer* (Heidelberg: Kehrler Verlag, 2008); Carlos H. Espinel, 'De Kooning's Late Colours and Forms: Dementia, Creativity, and the Healing Power of Art', *The Lancet* 347 (1996): 1096–8.
- 85 John Berger, *Ways of Seeing* (1972; London: Penguin, 2008), 8.
- 86 Woodward, *Aging and Its Discontents*, 196; Simon Biggs, 'Toward Critical Narrativity: Stories of Aging in Contemporary Social Policy', *Journal of Aging Studies* 15 (2001): 303–16.

7 The dichotomy of Alzheimer's disease

- 1 *Honig im Kopf*, directed by Til Schweiger (2014; Warner Home Video, 2015), DVD; time points indicated in the text.
- 2 The audience would also remember Hallervorden having received awards for his previous performance as former Olympic medallist Paul Auerhoff who, now resident in a nursing home, rebels against the monotony and belittling nature of unsuitable group therapy; *Sein letztes Rennen* [His final race], directed by Kilian Riedhof (2013; Universum Film, 2014), DVD.
- 3 Medina, 'Alzheimer's Disease', 364.
- 4 Chivers, *The Silvering Screen*, 60.

- 5 Among all films starting to show in Germany in 2014, *Honig im Kopf* had attracted most viewers by June 2015; 'Top 100 Deutschland 2014', Inside Kino, accessed 25 October 2019, <http://www.insidekino.de/DJahr/D2014.htm>. By mid-August 2015, over seventy cinemas across Germany continued to show the movie; 'Honig im Kopf', Kino.de, accessed 20 August 2015, <http://www.kino.de/kinofilm/honig-im-kopf/imkino/152963>. On 2 February 2015, during peak viewing time, German public television channel ARD broadcasted a talk show, in the *Hart aber fair* (Tough but fair) programme, which asked: 'Alzheimer als Komödie – hilft Lachen gegen die Angst?' (Alzheimer's as comedy – does laughing help against fear?).
- 6 Joachim Kurz, 'Die vergebliche Gnade des Vergessens' [The futile grace of forgetting], *Kino-Zeit*, 14 January 2015, <http://www.kino-zeit.de/blog/b-roll/die-vergebliche-gnade-des-vergessens-die-kino-zeit-de-kolumne>.
- 7 One of the final scenes of *Honig im Kopf* – Amandus dying in the hospital bed in the centre of the Rosenbachs' living room (2:04:18) – I read as alluding to Sieveking's depiction of his own mother's end. The documentary was much less popular than Schweiger's comedy, reaching number 142 in the viewer hit list; 'Top 100 Deutschland 2013', Inside Kino, accessed 25 October 2019, <http://www.insidekino.de/DJahr/D2013.htm>. I offer a detailed analysis of this documentary in *The Poetics and Politics*, 123–7.
- 8 Chivers, *The Silvering Screen*.
- 9 Emily Martin, *Flexible Bodies: Tracking Immunity in American Culture – from the Days of Polio to the Age of AIDS* (Boston: Beacon, 1994), 184–5.
- 10 Kolata, 'Alzheimer's Researchers Close In on Causes'; cf. ch. 5, 94.
- 11 Francesco Panza et al., 'Is There Still Any Hope for Amyloid-Based Immunotherapy for Alzheimer's Disease?', *Current Opinion in Psychiatry* 27 (2014): 129.
- 12 Dale Schenk et al., 'Immunization with Amyloid- β Attenuates Alzheimer-Disease-Like Pathology in the PDAPP Mouse', *Nature* 400 (1999): 173–7; references incorporated in the text.
- 13 Martin, *Flexible Bodies*, 96, 99, 92, 95.
- 14 Morris, *Illness and Culture*, 7.
- 15 Frank, *The Wounded Storyteller*, 6, 7.
- 16 Basting, 'Looking Back from Loss'.
- 17 Ballenger, *Self, Senility, and Alzheimer's Disease*, 173, 174.
- 18 Martina Zimmermann, 'Terry Pratchett's *Living with Alzheimer's* as a Case Study of Late-Life Creativity', in *Creativity in Later Life: Beyond Late Style*, ed. David Amigoni and Gordon McMullan (Abingdon: Routledge, 2019), 198–207.
- 19 Richard Taylor, *Alzheimer's from the Inside Out* (Baltimore: Health Professions, 2008), 49, 118, 130.
- 20 Martin, *Flexible Bodies*, 70.

- 21 Redefinition would not, I believe, have changed the sociocultural perception of Alzheimer's disease, as the representation of multiple sclerosis, a neurodegenerative condition actually defined in immunological terms, suggests. The writer Nancy Mairs openly speaks about 'relentless physical losses'. But it is – as with Parkinson's disease – the maintaining of an intellectually performing self that makes the conceptual difference. In Mairs's words: 'Myelin dissolves, nerves short out, muscle atrophies, but the old brain, riddled now with sclerotic patches, goes on wailing, "I can do it myself!"'; Nancy Mairs, *Waist-High in the World: A Life among the Nondisabled* (Boston: Beacon, 1996), 7, 70.
- 22 Lawrence M. Fisher, 'Vaccine in Mice Offers Hope in Fight against Alzheimer's', *New York Times*, 8 July 1999.
- 23 Latour, *Science in Action*, 164.
- 24 A. J. Bayer et al., 'Evaluation of the Safety and Immunogenicity of Synthetic Abeta42 (AN1792) in Patients with AD', *Neurology* 64 (2005): 94, 99. A further clinical trial was suspended, because several participants developed an unexpected and severe reaction.
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- 26 Lisa Genova, *Still Alice* (New York: Pocket Books, 2009); references incorporated in the text.
- 27 Sarah Falcus, 'Storying Alzheimer's Disease in Lisa Genova's *Still Alice*', *Entertext* 12 (2014): 92.
- 28 Rebecca A. Bitenc, 'Representations of Dementia in Narrative Fiction', in *Knowledge and Pain*, ed. Esther Cohen et al. (Amsterdam: Rodopi, 2012), 320, 318.
- 29 Block, 'A Place beyond Words'.
- 30 S. Salloway et al., 'A Phase 2 Multiple Ascending Dose Trial of Bapineuzumab in Mild to Moderate Alzheimer Disease', *Neurology* 73 (2009): 2061.
- 31 Latour, *Science in Action*, 113–21. Ian Dowbiggin convincingly illustrates the power of the pharmaceutical industry to dictate patient destiny in *The Quest for Mental Health*. On how dementia research teamed up with pharmaceutical companies, see also Shenk, *The Forgetting*, 178–89; Whitehouse, *The Myth of Alzheimer's*, 168–70; Basting, *Forget Memory*, 38; Cornelia Stolze, *Vergiss Alzheimer! Die Wahrheit über eine Krankheit, die keine ist* [Forget Alzheimer's! The truth about a condition that does not exist] (2011; Freiburg im Breisgau: Herder, 2013), 155–206.
- 32 'Newly Reported Research Advances from the Alzheimers Association International Conference 2012', Canada Newswire, 18 July 2012, <http://www.newswire.ca/news-releases/newly-reported-research-advances-from-the-alzheimers-association-international-conference-2012-510488911.html>.

- 33 Panza et al., 'Is There Still Any Hope?', 131.
- 34 *Still Alice*, directed by Richard Glatzer and Wash Westmoreland (2014; Curzon Artificial Eye, 2015), DVD; time points indicated in the text.
- 35 Riley II, *Disability and the Media*, 70.
- 36 'Julianne Moore Winning "Best Actress"', Youtube, 6 March 2015, <https://www.youtube.com/watch?v=TzR3CUU51IU>; 'Julianne Moore's Oscars 2015 Acceptance Speech in Full: "I'm Thrilled We Were Able to Shine a Light on Alzheimer's Disease"', *Independent*, 23 February 2015, <https://www.independent.co.uk/arts-entertainment/films/oscars/julianne-moore-oscars-2015-acceptance-speech-in-full-im-thrilled-we-were-able-to-shine-a-light-on-10064112.html>.
- 37 Chris Smyth, 'Dementia Clinics Are Swamped by Worried Well', *Times*, 11 March 2015; see also John Sutherland, 'Art Is Shining a Light on Dementia at Last', *Times*, 21 February 2015.
- 38 Lucy Bolton, '"The Art of Losing"', *Times Higher Education*, 5 March 2015.
- 39 Baker, *The Politics of Neurodiversity*, 164.
- 40 John Abraham, *Science, Politics and the Pharmaceutical Industry: Controversy and Bias in Drug Regulation* (London: University College London Press, 1995). This perspective also applies to the fact that pharmacological dementia research continues to appear reluctant to challenge the hypotheses underlying its investigations; Karl Herrup, 'The Case for Rejecting the Amyloid Cascade Hypothesis', *Nature Neuroscience* 18 (2015): 794; [John Hardy and John Mayer for the Models of Dementia: The Good, the Bad and the Future Meeting Attendees], 'The Amyloid Cascade Hypothesis Has Misled the Pharmaceutical Industry', *Biochemical Society Transactions* 39 (2011): 920–3.
- 41 Eric R. Siemers et al., 'Phase 3 Solanezumab Trials: Secondary Outcomes in Mild Alzheimer's Disease Patients', *Alzheimer's and Dementia* 12 (2016): 110.
- 42 Consider, for example, James Gallagher, 'The Drug to Slow Alzheimer's?' *BBC News*, 22 July 2015, <http://www.bbc.co.uk/news/health-33621109>; Panza et al., 'Is There Still Any Hope?' As I am finalizing this manuscript, the press once again gets excited about outcomes related to a further passive immunization compound, aducanumab. It remains to be seen whether the drug can slow or halt the progression of the condition; Tom Whipple, 'Doctors Hail First Drug to "Slow Down" Alzheimer's', *Times*, 22 October 2019, <https://www.thetimes.co.uk/article/biogen-new-drug-offers-hope-for-alzheimer-s-sufferers-sh90z3q9h>.
- 43 Latour, *Science in Action*, 114, 115.
- 44 Claire Hilton, 'Sauerkraut and African Violets: The Art of Old Age Psychiatry' (paper, Medical Humanities and Ageing Workshop, King's College London, 29 June 2015).
- 45 Bryden, *Dancing with Dementia*, 174.
- 46 Baker, *The Politics of Neurodiversity*, 35.

- 47 Consider, for example, Denis Campbell, 'NHS Dementia Plan to Give GPs Cash for Diagnoses Criticised as "Ethical Travesty"', *Guardian*, 22 October 2014, <https://www.theguardian.com/society/2014/oct/22/nhs-dementia-diagnoses-gps-patients-criticised>.
- 48 Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (1963; London: Penguin, 1990), 31.
- 49 David Hugendick, 'Ich vergisst sich' [I forgets itself], *Die Zeit*, 25 February 2015.
- 50 For bibliographies, see Hanna Kappus, *Das Leben ist ein großes: Alzheimer – ein langer Abschied* [Life is a big one: Alzheimer's – a long farewell] (Gütersloh: Gütersloher Verlagshaus, 2012), 159–60; and Erin Y. Sakai, Brian D. Carpenter and Rebecca E. Rieger, "'What's Wrong with Grandma?': Depictions of Alzheimer's Disease in Children's Storybooks", *American Journal of Alzheimer's Disease and Other Dementias* 27 (2012): 589; consider also Falcus and Sako, *Contemporary Narratives of Dementia*, ch. 5.
- 51 Linda Scacco and Nicole Wong, *Always My Grandpa: A Story for Children about Alzheimer's Disease* (Washington, DC: Magination, 2006), 46, 29.
- 52 Barbara Schnurbush and Cary Pillo, *Striped Shirts and Flowered Pants: A Story about Alzheimer's Disease for Young Children* (Washington, DC: Magination, 2007), 29 (my counting, beginning with title page).
- 53 Diedrich, *Treatments*, ch. 3.
- 54 Mareike Hachemer, *Alzheimer im problemorientierten Bilderbuch: Inhaltliche, künstlerische und sprachliche Aspekte* [Alzheimer's in the problem focused picture book: Contextual, artistic and linguistic aspects] (Norderstedt: Grin Verlag, 2009), 41.
- 55 Ibid., 19.
- 56 Frank P. Riga, 'Religion in Children's Literature: Introduction', *Children's Literature Association Quarterly* 14 (1989): 5.
- 57 Alessandro Borio, *La guardiana di Ulisse: Una malata di Alzheimer, un angelo e una domanda* (Arrone: Edizioni Thyrsus, 2006); references incorporated in the text.
- 58 Cynthia Marshall, 'Reading "The Golden Key": Narrative Strategies of Parable', *Children's Literature Association Quarterly* 14 (1989): 22–5.
- 59 Atul Gawande, *Being Mortal: Illness, Medicine and What Matters in the End* (2014; London: Profile Books, 2015), 22, 9.
- 60 Lisa Zunshine, 'Theory of Mind, Social Hierarchy, and the Emergence of Narrative Subjectivity', in Herman, *The Emergence of Mind*, 179, 171.
- 61 Simon Kemp and Christopher D. B. Burt, 'Memories of Uncertain Origin: Dreamt or Real?', *Memory* 14 (2006): 87–93.
- 62 Frank P. Riga, 'Mortals Call Their History Fable: Narnia and the Use of Fairy Tale', *Children's Literature Association Quarterly* 14 (1989): 27.
- 63 Luigi Berzano, preface to Borio, *La guardiana di Ulisse*, 7.

- 64 A text featuring an angel who peers into the psyche of an ageing woman goes against the grain of the critical reader, but in suspending realistic modes of thinking we may be able 'to apprehend what eludes our conscious grasp'; Teresa Casal, 'Experiential Reading of Jennifer Johnson's *Two Moons*' (paper, Mellon Seminar on Ageing, King's College London, 23 November 2015).
- 65 Jens Brockmeier, *Beyond the Archive: Memory, Narrative, and the Autobiographical Process* (New York: Oxford University Press, 2015), 258.
- 66 Douwe Draaisma, *Forgetting: Myths, Perils and Compensations*, trans. Liz Waters (New Haven, CT: Yale University Press, 2015), 175–8; originally published in Dutch in 2010; consider also Basting, *Forget Memory*, 18–19.
- 67 Brockmeier, *Beyond the Archive*, 20, 17, 21.
- 68 Andrew O'Hagan, *The Illuminations* (London: Faber and Faber, 2015); references incorporated in the text.
- 69 Debra Dean, *The Madonnas of Leningrad* (2006; London: Harper Perennial, 2007), 206; Samantha Harvey, *The Wilderness* (2009; London: Vintage, 2010), 276; Emma Healey, *Elizabeth Is Missing* (2014; London: Penguin Books, 2015), 236.
- 70 Dean, *The Madonnas of Leningrad*, 225. But consider Lucy Burke's perspective on the continued abilities to narrate of Healey's Maud, and the argument made by Falcus and Sako that Healey rather 'draw[s] attention to the social environment which judges and isolates those with dementia'; Lucy Burke, 'Missing Pieces: Trauma, Dementia and the Ethics of Reading in *Elizabeth Is Missing*', in *Dementia and Literature: Interdisciplinary Perspectives*, ed. Tess Maginnes (Abingdon: Routledge, 2018), 88; Falcus and Sako, *Contemporary Narratives of Dementia*, 130.
- 71 Nicci Gerrard, 'Words Fail Us: Dementia and the Arts', *Guardian*, 19 July 2015, <https://www.theguardian.com/culture/2015/jul/19/dementia-and-the-arts-fiction-films-drama-poetry-painting>.
- 72 Salisbury, 'Narration and Neurology', 897.
- 73 Ian McEwan, *Atonement* (London: Vintage, 2002), 354. Further novels that remove dementia from principally negative notions of memory loss include: Andrea Gerster, *Dazwischen Lili* (Lili inbetween, 2008), Pupi Avati, *Una sconfinata giovinezza* (A boundless youthfulness, 2010), Katharina Hacker, *Die Erdbeeren von Antons Mutter* (The strawberries of Anton's mother, 2010), and Alice Lichtenstein, *Lost* (2010).
- 74 Janice Turner, 'I Dreamt of Greek Olives as I Fumed in Munich', *Times*, 13 August 2015.
- 75 Sally Magnusson, *Where Memories Go: Why Dementia Changes Everything* (London: Two Roads, 2014); references incorporated in the text.

- 76 Elena De Dionigi, *Prima di volare via: Quello che l'Alzheimer non ci può rubare* [Before flying away: What Alzheimer's cannot steal from us] (Magenta: La Memoria del Mondo Libreria Editrice, 2012), 61.
- 77 Giovanna Venturino, *Il tuo mare di nulla: La mia mamma e l'Alzheimer* [Your sea of nothingness: My mother and Alzheimer's] (Rome: A&B Editrice, 2012), 73; Donatella Di Pietrantonio, *Mia madre è un fiume* [My mother is a river] (Rome: Elliot Edizioni, 2010), 74.
- 78 Baker, *The Politics of Neurodiversity*, 167–89.
- 79 Gawande, *Being Mortal*, 193.
- 80 Callahan, 'Dementia and Appropriate Care', 151.
- 81 Cécile Huguenin, *Alzheimer mon amour* (Paris: Éditions Héloïse d'Ormesson, 2011); references incorporated in the text. Huguenin's text has been translated into Spanish and Italian in 2013, and into Dutch in 2017.
- 82 Ngatcha-Ribert, *Alzheimer*, 34–7.
- 83 'Alzheimer mon amour', Mollat, 30 September 2011, <http://www.mollat.com/livres/cecile-huguenin-alzheimer-mon-amour-9782350871707.html>.
- 84 Charlotte L. Clarke et al., *Risk Assessment and Management for Living Well with Dementia* (London: Jessica Kingsley, 2011), 25; all further references incorporated in the text. Also Magnusson refers to *Alice's Adventures* to depict nonsensical experiences regarding the organization of caregiving (287); and Walrath maps her narrative onto Carroll's story to depict the condition itself.
- 85 Cohen, *No Aging in India*, 233, 267, 292; Sivaramakrishnan, *As the World Ages*, 197; consider also W. Ladson Hinton and Sue Levkoff, 'Constructing Alzheimer's: Narratives of Lost Identities, Confusion and Loneliness in Old Age', *Culture, Medicine and Psychiatry* 23 (1999): 453–75.
- 86 Jane Wilkinson, 'Remembering Forgetting', *Status Quaestionis* 6 (2014): 111–12. Wilkinson takes the term from Elie Wiesel's 1989 *L'oublié*, translated as *The Forgotten* in 1992, which belongs to the body of memory literature explored in Chapter 4.
- 87 'Alzheimer: L'éthique en question. Recommendations' [Alzheimer's: Ethics in question. Recommendations], Association Francophone des Droits de l'Homme Agé, 25 April 2007, http://www.sante.gouv.fr/IMG/pdf/ethique_en_questions.pdf; Department of Health, *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care* (2007) and *Living Well with Dementia: A National Dementia Strategy* (2009). Also note the recent guidelines published by the Department of Health and Social Care, *After a Diagnosis of Dementia: What to Expect from Health and Care Services* (2018).
- 88 'Philosophie', Demenz Support Stuttgart, last modified 1 January 2019, <http://www.demenz-support.de/portraet/philosophie>; compare to this the recent agenda

- Gemeinsam für Menschen mit Demenz* [Together for people with dementia] (Berlin: Bundesministerium für Gesundheit, 2014).
- 89 Schrauf and Müller, *Dialogue and Dementia*, i.
 - 90 Personal conversation with Kathleen Woodward, Dartmouth College, NH, 13 July 2015; Kathleen Woodward, 'A Public Secret: Assisted Living, Caregivers, Globalization', *International Journal of Ageing and Later Life* 7 (2012): 17–51.
 - 91 De Dionigi, *Prima di volare via*, 22–5, 69; Diane Keaton, *Then Again* (2011; London: Fourth Estate, 2012), 274.
 - 92 Julia Neuberger, *Not Dead Yet: A Manifesto for Old Age* (London: HarperCollins, 2008), 193; also consider Janette Davies, *Living before Dying: Imagining and Remembering Home* (New York: Berghahn, 2017), and my review thereof, Martina Zimmermann, 'Book Review: Living before Dying. Imagining and Remembering Home by Janette Davies', *Times Higher Education*, 8 February 2018.
 - 93 Susan H. McFadden and John T. McFadden, *Aging Together: Dementia, Friendship, and Flourishing Communities* (2011; Baltimore: Johns Hopkins University Press, 2014), 164.
 - 94 'Oral History Meets Dementia: A Staged Reading of the Play Timothy and Mary', Columbia University, 3 September 2014, <http://oralhistory.columbia.edu/upcoming-and-past-events/People/oral-history-meets-dementia-a-staged-reading-of-the-play-timothy-and-mary>; C. F. Vinci, C. Pontesilli and D. Fo, 'Telling about the Stolen Mind', *Neurological Sciences* 26 (2005): 185–7; Hannah Zeilig, 'The Critical Use of Narrative and Literature in Gerontology', *International Journal of Ageing and Later Life* 6 (2011): 7–37; Hannah J. Roberts and James M. Noble, 'Education Research: Changing Medical Student Perceptions of Dementia. An Arts-Centered Experience', *Neurology* 85 (2015): 739–41.
 - 95 June Andrews, *Dementia: The One-Stop Guide. Practical Advice for Families, Professionals and People Living with Dementia and Alzheimer's Disease* (London: Profile Books, 2015); Peter J. S. Ashley, 'This Is My Life', in *The Law and Ethics of Dementia*, ed. Charles Foster, Jonathan Herring and Israel Doron (Oxford: Hart, 2014), 497–503.
 - 96 Cole and Gadow, *What Does It Mean to Grow Old?*; Gary M. Kenyon, James E. Birren and Johannes J. F. Schroots, eds, *Metaphors of Aging in Science and the Humanities* (New York: Springer, 1991).
 - 97 Eva-Marie Kessler and Clemens Schwender, 'Giving Dementia a Face? The Portrayal of Older People with Dementia in German Weekly News Magazines between the Years 2000 and 2009', *Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 67 (2012): 261–70. But see in contrast: Allison M. Kirkman, 'Dementia in the News: The Media Coverage of Alzheimer's Disease', *Australasian Journal on Ageing* 25 (2006): 74–9.

- 98 Consider, for example, Hannah Zeilig, 'Late-Life Creativity and the "New Old Age"', archived by King's Digital Lab, October 2018, www.latelifecreativity.org; 'Creative Dementia Arts Network', Creative Dementia Arts Network, last modified 1 January 2019, www.creativedementia.org; Aagje Swinnen, 'Book Club as Intersubjective Space with Transformative Potential' (paper, Dementia and Cultural Narrative Symposium, Aston University, 9 December 2017); and projects described in Basting, *Forget Memory*.
- 99 Mary Mothersill, 'Old Age', *Proceedings and Addresses of the American Philosophical Association* 73 (1999): 21.
- 100 Lucy Burke, 'Imagining a Future without Dementia: Fictions of Regeneration and the Crises of Work and Sustainability', *Palgrave Communications* 3 (2018): article 52, p. 7.
- 101 For a very thoughtful and measured account of the role of new capitalism in the rise of mental health diagnoses made, see Nikolas Rose, *Our Psychiatric Future* (Cambridge: Polity, 2019). Recent evidence suggests that specific lifestyle choices can intensify cognitive decline: stress-related chronic lack of sleep as well as emotional loneliness appears to heighten cognitive deterioration, while robust social networks can enhance cognitive function; Andrew R. Mendelsohn and James W. Larrick, 'Sleep Facilitates Clearance of Metabolites from the Brain: Glymphatic Function in Aging and Neurodegenerative Diseases', *Rejuvenation Research* 16 (2013): 518–23; Jae-Eun Kang et al., 'Amyloid- β Dynamics Are Regulated by Orexin and the Sleep-Wake Cycle', *Science* 326 (2009): 1005–7; Kristin R. Krueger et al., 'Social Engagement and Cognitive Function in Old Age', *Experimental Aging Research* 35 (2009): 45–60.
- 102 Matthew Thomas, *We Are Not Ourselves* (London: Fourth Estate, 2014); references incorporated in the text.
- 103 Gerrard, 'Words Fail Us.'
- 104 Block, 'A Place beyond Words.'
- 105 Ru, *The Family Novel*, 2.
- 106 Franzen, *The Corrections*, 630, 641.
- 107 Block, 'A Place beyond Words.'
- 108 Woodward, *Aging and Its Discontents*, 32.
- 109 Michel Foucault, *The Birth of Biopolitics: Lectures at the Collège de France, 1978–1979*, trans. Graham Burchell (2008; Basingstoke: Palgrave Macmillan, 2010), 224.
- 110 Ru, *The Family Novel*, 119–20.
- 111 Consider, for example, Cohen, *No Aging in India*, 15; Magnusson, *Where Memories Go*, 305; and Simon Russell Beale's interpretation of Lear's part for the National Theatre in 2014, as referred to in Bate, "'The Infirmary of His Age"'. It is not clear that Lear's madness results from ageing rather than repeated mental trauma and the devastation of his understanding of his position in the world. Performance could readily draw out either interpretation.

- 112 Elliott, *Concepts of the Self*, 140; Arno Gruen, 'War or Peace? We Cannot Survive with Real-Politik' (acceptance speech, Award Ceremony for the Loviisa Peace Prize, Loviisa, 7 August 2010), accessed 27 October 2015, <http://www.arnogruen.net/war-or-peace.pdf>.
- 113 For Heike Hartung, the 'dementia narrative' is one of the directions the bildungsroman has taken after its classical period, as it 'define[s] the limits of development by narrating the end of memory and consciousness'; in this she is joined by Rita C. Caviglioli, who places the discussion of senility in Italian family narratives in the context of bildungs- and reifungsroman theories; Hartung, *Ageing, Gender and Illness*, 171, 172; Caviglioli, *Women of a Certain Age*, ch. 5.
- 114 Foucault, *The Birth of Biopolitics*, lectures 9 and 10, 241, 245.
- 115 It is tempting to compare Eileen to the 'Man of Property' Soames Forsyte, especially because, like a Forsyte, she has 'pride, dignity, firmness, and persistence'; Ru, *The Family Novel*, 21.
- 116 Ibid., 32 (apostrophes *sic*).
- 117 Ibid., 81.
- 118 Zeilig, 'Dementia as a Cultural Metaphor', 266; Helen Dunmore, 'We Are Not Ourselves by Matthew Thomas Review – an Extraordinary Portrait of Alzheimer's Disease', *Guardian*, 27 August 2014, <https://www.theguardian.com/books/2014/aug/27/we-are-not-ourselves-matthew-thomas-review-novel>.
- 119 Foucault, *The Birth of Biopolitics*, 230.
- 120 Gerontologist Jan Baars identifies ageing with dementia as 'anti-entrepreneurial ageing'; Jan Baars, 'A Good Life in "Old Age": A Privilege for the Rich?' (paper, Living a Good Life in Older Age Symposium, University of Warwick, 5 July 2018).
- 121 Morris, *Illness and Culture*, 220–1; Lennard J. Davis, *The End of Normal: Identity in a Biocultural Era* (Ann Arbor: University of Michigan Press, 2013), ch. 1.
- 122 Gruen, 'War or Peace?', 5.
- 123 Ibid., 1.
- 124 Sally Chivers, 'Seeing the Apricot: A Disability Perspective on Alzheimer's in Lee Chang-dong's Poetry', in *Different Bodies: Essays on Disability in Film and Television*, ed. Marja E. Mogk (Jefferson, NC: McFarland, 2013), 72.
- 125 Similar observations have been made regarding Günter Grass's last novel; Taberner, *Aging and Old-Age Style*, 72.
- 126 Cathy Caruth, *Unclaimed Experience: Trauma, Narrative, and History* (Baltimore: Johns Hopkins University Press, 1996), 49, 52.
- 127 McFadden and McFadden, *Aging Together*, 14.
- 128 James Gallagher, 'Dementia Levels "Are Stabilising"', *BBC News*, 21 August 2015, <http://www.bbc.co.uk/news/health-34001144>; Steve Illiffe, 'Evidence-Based Medicine and Dementia', *British Journal of General Practice* 65 (2015): 511–12.
- 129 Woodward, 'A Public Secret', 23, 41.

- 130 Neuberger, *Not Dead Yet*, 191–214; Davies, *Living before Dying*, 81–104.
- 131 *Head Full of Honey*, directed by Til Schweiger (Barefoot Films, 2018), released in several European countries including the United Kingdom in spring 2019.

8 Conclusion

- 1 David Herman, 'Re-minding Modernism', in Herman, *The Emergence of Mind*, 254.
- 2 Pavel, *The Lives of the Novel*, 279.
- 3 I borrow the notion of 'cure narrative' from Lennard J. Davis, *Bending over Backwards: Disability, Dismodernism, and Other Difficult Positions* (New York: New York University Press, 2002), 99.
- 4 Hacking, *Rewriting the Soul*, 239.
- 5 Brockmeier, *Beyond the Archive*, 20–1.