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Introduction

As average life expectancy increases, ever more people around the globe are becoming susceptible to the serious health conditions associated with old age. Recent international studies indicate that, of these, dementia is among the most – if not *the* most – feared by the general population.[1] It should be of no surprise, then, that analytic philosophy in the Anglo-American tradition has repeatedly invoked what Rebecca Dresser calls the 'tragedy narrative' when addressing dementia,[2] with any such discussions beginning from the assumption that it is an unfortunate and intolerable indignity to develop this condition – a

[1] See: Alzheimer's Research UK, *Dementia Attitudes Monitor* (Dementia Statistics Hub: Cambridge, 2019), www.dementiastatistics.org/statistics/perceptions-of-dementia/; André Hajek and Hans-Helmut König, 'Fear of Dementia in the General Population: Findings from the German Socio-Economic Panel (GSOEP)', *Journal of Alzheimer's Disease* 75, no. 4 (2020), 1135–1140; Bo R. Kim and Hee K. Chang, 'Factors Influencing Fear of Dementia among Middle-Aged and Older Adults', *Journal of Korean Academy of Community Health Nursing* 31, no. 2 (2020), https://doi.org/10.12799/jkachn.2020.31.2.156; Inge Cantegreil-Kallen and Stéphanie Pin, 'Fear of Alzheimer's Disease in the French Population: Impact of Age and Proximity to the Disease', *International Psychogeriatrics* 24, no. 1 (2011), 108–116; Karen Johnston et al., 'Understandings of Dementia in Low and Middle Income Countries and amongst Indigenous Peoples: A Systematic Review and Qualitative Meta-synthesis', *Aging & Mental Health* 24, no. 8 (2019), 1183–1195; Ladislav Volicer, 'Fear of Dementia', *Journal of the American Medical Directors Association* 17, no. 10 (2016), 875–878; Sarang Kim, Kerry A. Sargent-Cox, and Kaarin J. Anstey, 'A Qualitative Study of Older and Middle-Aged Adults' Perception and Attitudes Towards Dementia and Dementia Risk Reduction', *Journal of Advanced Nursing* 71, no. 7 (2015), 1694–1703; Weizhou Tang et al., 'Concern about Developing Alzheimer's Disease or Dementia and Intention to be Screened: An Analysis of National Survey Data', *Archives of Gerontology and Geriatrics* 71 (2017), 43–49.

[2] Rebecca Dresser, 'Advance Directives and Discrimination against People with Dementia', *Hastings Center Report* 48, no. 4 (2018), 27.

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position represented, among others, by Norman Cantor,[3] Ronald Dworkin,[4] and Dan Brock.[5]

Tragedy narratives about disabilities more broadly have been undermined by the development of the social model, which holds that disabled people are primarily disadvantaged by an unaccommodating society, rather than their underlying impairments.[6] Though this approach has come under sustained criticism from disability theorists in recent years, the insight that disability need not be *inherently bad* remains influential.[7] Considered in this light, dementia could be viewed as what Elizabeth Barnes calls a 'mere difference',[8] such that those that live with it are conceived of as members of a diverse and heterogenous social group united by overlapping experiences, rather than victims of a tragedy through which they have, in the words of self-advocate Christine Bryden, 'become overwhelmed by and subsumed within [their] condition'.[9]

While the tragedy narrative implies the need to compensate for or insure against dementia as if it is a misfortune, adopting a mere difference narrative invites us to consider what would be necessary for people living with dementia to be fully integrated into society and for the sorts of lives they lead to be treated as worthy of respect. Proceeding from the latter view, in this book I mount arguments about how medical and social care practitioners, as well as other members of society more broadly, ought to relate to people living with dementia. Though there is some considerable overlap, the view I take in this book differs from much public policy work in this area, including that of the

[3] Norman L. Cantor, 'Changing the Paradigm of Advance Directives to Avoid Prolonged Dementia', *SSRN Electronic Journal*, 2017, https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2955975.

[4] Ronald Dworkin, *Life's Dominion: An Argument about Abortion and Euthanasia* (London: Vintage Books, 1994), 232.

[5] Dan W. Brock, 'Justice and the Severely Demented Elderly', *The Journal of Medicine and Philosophy* 13, no. 1 (1988), 73–99.

[6] Tom Shakespeare, 'The Social Model of Disability', in *The Disability Studies Reader*, ed. Lennard J. Davis (Oxford: Taylor & Francis, 2006), 197.

[7] Jonas-Sébastien Beaudry, 'Theoretical Strategies to Define Disability', in *The Oxford Handbook of Philosophy and Disability*, ed. Adam Cureton and David Wasserman (New York: Oxford University Press, 2020), 8–12.

[8] Elizabeth Barnes, 'Valuing Disability, Causing Disability', *Ethics* 125, no. 1 (2014), 109–111.

[9] Christine Bryden, 'Foreword', in *Dementia Reconsidered, Revisited: The Person Still Comes First*, ed. Dawn Brooker (New York: Open University Press, 2019), xi–xiii.

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Nuffield Council on Bioethics, which incorporates the belief that dementia is inherently harmful as one of the six components of its ethical framework.[10] Instead, it is much more closely aligned with work in the emerging field of critical dementia studies,[11] alongside other works in the social sciences that have paved the way for thinking of dementia in social and political terms.[12]

In Chapter 2 – 'Diagnosing the Injustices Faced by People Living with Dementia' – I provide arguments for abandoning the tragedy narrative and the purely distributive approach to justice it entails. Instead, I defend the adoption of a relational egalitarian approach, which views justice as a matter of ridding society of intolerable inegalitarian relationships such as oppression, domination, and stigma. This analysis, and the work it undergirds, is focused primarily on the UK, with some references made to other Western societies. It should be noted, however, that the stigma of dementia is internationally prevalent,[13] so, although they may take different forms, the relational injustices I explore here will likely be present in other contexts.

In Chapter 3 – 'Severe Cognitive Disability and the Relationship between Moral and Social Equality' – I consider a conceptual difficulty. The argument from marginal cases, which presents people living with *advanced* dementia as necessarily below the threshold of moral equality, threatens to derail a relational egalitarian analysis, as it is not immediately clear why we should treat as *social equals* those who are not our *moral equals*. Indeed, as I demonstrate, many prominent relational egalitarians are either tacitly or explicitly committed to a Kantian view of moral equality, which excludes those without some specified level of rational agency from its scope. Considering and rejecting a number of

[10] Nuffield Council on Bioethics, *Dementia: Ethical Issues* (London: Nuffield Council on Bioethics, 2009), xviii.

[11] Richard Ward and Linn J. Sandberg, 'Introduction: Why Critical Dementia Studies and Why Now?', in *Critical Dementia Studies: An Introduction*, ed. Richard Ward and Linn J. Sandberg (Oxfordshire: Taylor & Francis, 2023), 1–12.

[12] See especially: Charles Foster, Jonathan Herring, and Israel Doron, *The Law and Ethics of Dementia* (London: Bloomsbury Publishing, 2014); Ruth Bartlett and Deborah O'Connor, *Broadening the Dementia Debate: Towards Social Citizenship* (Bristol: Policy Press, 2010); Steven R. Sabat, *The Experience of Alzheimer's Disease: Life through a Tangled Veil* (Hoboken: Wiley-Blackwell, 2001); Suzanne Cahill, *Dementia and Human Rights* (Bristol: Policy Press, 2018).

[13] World Health Organization, *Dementia: A Public Health Priority* (Geneva: World Health Organization, 2012), 82–87.

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justificatory strategies, I conclude by defending the view that people living with dementia, as *unique subjects capable of living authentically*, are owed social equality from all those embedded in the same *matrix of mutually affective bonds* as them.

In Chapter 4 – 'Determining the Authentic Interests of People Living with Dementia: The Case of Advance Directives' – I elaborate on the concept of authenticity with reference to the question about dementia which has received the most attention in philosophy: whether or not it is acceptable to execute an advance directive to withhold treatment when a person living with dementia is clearly content with their life. Identifying substitute decision-making as a process in which people living with dementia are at risk of domination, I argue that decision-makers have a duty to determine a person's authentic interests before deciding on a treatment path.

Defending the view that people living with dementia remain capable of generating authentic values and authentically discarding those they held before the onset of the condition, I then conclude with the first public policy recommendation of the book: that advance directives, as a potentially useful tool for preventing domination, ought to be more widely promoted, but they must (1) be defeasible and (2) contain detailed information on the values underpinning the decisions made. This coheres with similar recommendations made by the Nuffield Council on Bioethics, but I differ by firmly stipulating that it should be possible to override such directives *even when a person has lost the legal capacity to make the decision in question*.[14]

These first three chapters establish the following conceptual framework: (1) justice is achieved by successfully eradicating relational injustices such as oppression, domination, and stigma from society; (2) people living with dementia (in Western societies) are a social group who are exposed to relational injustices of this kind; (3) these relationships are unjust because they fail to respect unique subjects as equal bearers of fundamental interests related to their capacity to live authentically; (4) people living with dementia bear such interests; (5) to live authentically is to live in accordance with values one would not be alienated from upon hypothetical reflection across a variety of circumstances; and (6) people living with dementia are capable of changing these values, even in the absence of the capacity to rationally reflect upon them.

[14] Nuffield Council on Bioethics, 'Dementia', 86.

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With this framework firmly in mind, in the next three chapters I conduct an analysis of dementia care. In Chapter 5 – 'The Indirect-First Approach: Towards Non-dominating Dementia Care' – I argue that the use of environment-shaping and interpretive techniques to empower people living with dementia to meet *their own* vital needs, wherever possible, offers the best prospects of avoiding domination by carers. In Chapter 6 – 'The Imperative of Professional Dementia Care' – I reject the widely held view that professional dementia care ought always to be a last resort, arguing instead that its informal counterpart carries greater inherent risks of relational injustice. Though I concede that informal care may be preferable where professional services are poor, I conclude that the just state ought to focus on improving these services, rather than encouraging loved ones to fill gaps in provision by taking on primary caring responsibilities for people living with dementia. Finally, in Chapter 7 – 'Can the Secure Dementia Unit Be Justified? Building Egalitarian Dementia Care Infrastructure' – I argue that formal dementia care institutions, though in need of significant reform, are not just compatible with a relationally just society but would be actively required to build it.

The analysis I conduct in these three chapters yields the following picture of a relationally just dementia care settlement: (1) centres of community life must be adapted so as to be inclusive of people living with dementia; (2) social services must assist people living with dementia in constructing cognitive scaffolding, reducing the need for direct care intervention; (3) when needed, people living with dementia ought to be cared for, initially in their own homes, by well-trained professional carers provided by well-staffed professional care services; and (4) in a limited range of cases, people living with advanced dementia should be housed in (radically reformed) secure dementia units.

This framework reconceptualises the problem of dementia care as a problem of power and social exclusion. At every stage, the goal should be to empower recipients of care to meet their own needs and participate fully in social life as equals, necessitating restrictions on the power of carers and radical changes to our cultural assumptions about and depictions of dementia. Though few would disagree that Western dementia care services are in need of reform, my emphasis on social equality means that the depth and character of the reforms I propose differ significantly from many of those under public discussion. Indeed, as I demonstrate in Chapter 8 – 'Dementia, Equality, and the Law of the United Kingdom' – significant changes would be needed to the way my home country treats

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people living with dementia under the law in order to support the reforms I have recommended.

My focus on the power of the carer is inspired by my decade-long career in care for the elderly and those living with dementia. As a professional carer, I gained valuable insights about the injustices present in care services and the heavy demands placed on the practical moral decision-making skills of their staff. I witnessed and even collaborated in suboptimal care interventions, necessitated by problems such as understaffing, unsuitable facilities, and wider budget constraints. This experience made me starkly aware of the asymmetry of power in the dementia care relationship and the wider structural issues that incentivise poor care. Yet I also witnessed and collaborated in innovative solutions to suboptimal care, making the value of interpretive and environment-shaping skills equally clear to me. When I illustrate arguments by way of examples or constructing descriptive hypotheticals, I do so by drawing on this experience.

In the philosophy of disability, practices of this kind are not uncommon. Eva Feder Kittay, for instance, has written extensively about cognitive disability with reference to the insights she has gained through caring for her daughter. This methodological choice is motivated, in part, by the need to correct mistaken and stereotypical images of those with cognitive disabilities in moral philosophy.[15] Though I am similarly motivated, I would be remiss if I did not reflect on my social position, as both a former carer and person living without dementia, and the effect it may have had on the work I have produced. With this in mind, in Chapter 9 – 'Dementia and the Problem of Speaking for Others' – I use Linda Alcoff's influential framework to analyse this book as an instance of *discursive representation*, highlighting areas in which it may have risked reinforcing injustice and demonstrating the steps I have taken to prevent it from doing so.

Chief among these steps is my decision to promote the work of dementia self-advocates throughout the book. It is no mere rhetorical or aesthetic choice that the first voice heard at the start of each chapter is that of a person living with dementia. My intention, rather, is to challenge the reader who shares the all-too-common belief that members of

[15] Eva F. Kittay, 'The Personal Is Philosophical Is Political: A Philosopher and Mother of a Cognitively Disabled Person Sends Notes from the Battlefield', in *Cognitive Disability and Its Challenge to Moral Philosophy*, ed. Licia Carlson and Eva F. Kittay (Chichester: John Wiley & Sons, 2010), 410.

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this group universally lack insight, so cannot identify their own interests.[16] In this sense, this book is both in form and content committed to the liberation of people living with dementia from injustice through relating to them as equals.

[16] Christine Bryden, *Dancing with Dementia: My Story of Living Positively with Dementia* (London: Jessica Kingsley Publishers, 2005), 46.

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