Relating to People Living with Dementia as Equals

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A thesis submitted for the degree of *Doctor of Philosophy*

Declaration

I, Matilda Rebecca Carter, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

As populations around the globe grow older, a greater number of people are becoming susceptible to the diseases and chronic illnesses associated with age. Recent international studies concur that, of these, dementia is either the most feared by the general population, or among the most. It is no small wonder, then, that analytic philosophy in the Anglo-American tradition on dementia repeatedly invokes what Rebecca Dresser calls the "tragedy narrative."[1] So understood, arguments about dementia rely on the idea that a life lived with it represents an unfortunate and intolerable indignity.

There is, however, an alternative narrative present in the work of dementia self-advocates,[2] which suggests that dementia can be considered as what Elizabeth Barnes calls a mere difference.[3] So understood, we can think of people living with dementia as a distinct social group who experience life in just one of many of the ways human diversity offers.

Proceeding from the tragedy narrative, the notion of justice for people living with dementia might focus on compensating or insuring people against this loss of dignity. The mere difference narrative, on the other hand, invites us to consider what would be necessary for people living with dementia to be fully integrated into society and for the distinctive kind of life they experience to be treated with respect. This thesis considers the question of justice for people living with dementia on these terms.

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

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

[3] Elizabeth Barnes, "Valuing Disability, Causing Disability," *Ethics* 125, no. 1 (2014): 109-111.

Impact Statement

By invoking relational egalitarianism, my thesis offers a philosophical analysis of our social and political responses to dementia. Within the academy, it pushes the field forward by making novel connections between this area of contemporary political theory and work on cognitive disability, making significant contributions to both. In chapter 2, for instance, I offer a comprehensive analysis of the concept of moral equality and its relationship to social equality. This chapter contributes to relational egalitarianism, by further specifying its groundings and implications, and the philosophy of cognitive disability, by offering an account of moral equality that includes all those with severe cognitive impairments.

This scholarly impact has already been demonstrated through tangible research outputs. Chapter 3, which concerns the authority of advance directives over people living with advanced dementia, has been accepted for publication by the leading bioethics journal *The Hastings Center Report*. Additionally, chapter 4, which concerns the relationship between dementia care and the concept of non-domination, is under review at the internationally renowned social and political philosophy journal *Res Publica*, having been shortlisted for their 2021 postgraduate essay prize.

In a context in which it is universally acknowledged that social care must be improved, this thesis also has the potential to make a significant contribution to public policy. Some of the conclusions arrived at are uncontroversial, such as the demand for additional funding for and training by care services I set out in chapters 5 and 6. Nevertheless, my thesis strengthens these demands by placing them within a framework of social justice. So understood, these reforms would not be indicative of *exceptional* social care policy, but merely meet the baseline demands of justice for people living with dementia.

In other places, I argue against common intuitions. For instance, in chapter 5 I argue that a just society would not rely on *informal* dementia care by loved ones and, further, that when professional care services are adequate, associates of people living with dementia who *choose* to avoid them act unjustly. Alongside reinforcing common demands for improvements to social and political responses to dementia, then, the thesis seeks to challenge many of our assumptions about our relationships with people who live with the condition.

Finally, as I elaborate on in Chapter 7, my thesis aims to make an impact on the lives of people living with dementia, by contributing to destigmatising the condition. In pursuit of that aim, I unpack a number of oppressive social structures common among western societies in Chapter 1, argue for decentralising rational agency in political philosophy in Chapter 2, argue in favour of the moral weight of present-day expressions of interests by people living with dementia in Chapter 3, couch my social care proposals in terms of respecting members of this group for who they are in Chapters 4, 5 and 6, and make extensive reference to the work of self-advocates throughout the thesis.

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Introduction

As populations around the globe grow older, a greater proportion of people are becoming susceptible to the diseases and chronic illnesses associated with age. Many recent international studies indicate that, of these, dementia is either the most feared by the general population, or among the most.[4] It is no small wonder, then, that analytic philosophy in the Anglo-American tradition on dementia repeatedly invokes what Rebecca Dresser calls the "tragedy narrative."[5] So understood, arguments about dementia begin from the assumption that a life lived with it represents an unfortunate and intolerable indignity; a position represented by Norman Cantor,[6] Ronald Dworkin[7] and Dan Brock,[8] among others.

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[4] See:
Alzheimer's Research UK, *Dementia Attitudes Monitor*, (Dementia Statistics Hub: Cambridge, 2019), https://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).
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).
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)
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).
Ladislav Volicer, "Fear of Dementia," *Journal of the American Medical Directors Association* 17, no. 10 (2016).
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).
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 (July 2017).

[5] Rebecca Dresser, "Advance Directives and Discrimination Against People with Dementia," *Hastings Center Report* 48, no. 4 (2018): 27.

[6] Norman L. Cantor, "Changing the Paradigm of Advance Directives to Avoid Prolonged Dementia," *SSRN Electronic Journal*, 2017.

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

[8] Dan W. Brock, "Justice and the Severely Demented Elderly." *The Journal of Medicine and Philosophy* 13, no. 1 (1988): 73-99.

In the philosophy of disability, however, this kind of narrative has been undermined by the social model, which holds that disabled people are primarily disadvantaged by an unaccommodating society, rather than their impairments.[9] 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.[10] Considered in this light, dementia could be viewed as what Elizabeth Barnes calls a *mere difference*.[11] So constructed, people living with dementia can be thought of as a distinct social group who experience life in just one of the many ways human diversity offers: a view shared by many self-advocates.[12]

While the tragedy narrative implies the need for a just society to compensate for or insure against a misfortune, the difference narrative invites us to consider what would be necessary for people living with dementia to be fully integrated into society and for the distinctive kind of life they experience to be treated with respect. As this thesis proceeds from the latter view, the conclusions reached differ significantly from much public policy work in this area, such as that of the Nuffield Council on Bioethics, which includes the belief that dementia is inherently harmful as one of the six components of its ethical framework.[13]

I begin, in Chapter 1 – *Diagnosing the Injustices Faced by People Living With Dementia*, by providing arguments for abandoning the tragedy narrative and the purely distributive approach to justice that I argue it entails. Instead, I defend the adoption of a relational egalitarian approach, which views justice as a matter of ridding society of domination, oppression, and unjust stigma. This analysis, and the work that comes after it, is

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

[10] 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.

[11] Elizabeth Barnes, "Valuing Disability, Causing Disability," *Ethics* 125, no. 1 (2014): 109-111.

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

[13] Nuffield Council on Bioethics, "Dementia: Ethical Issues," Nuffield Council on Bioethics, last modified 2009, xviii.

focused on Western societies. It should be noted, however, that the stigma of dementia is internationally prevalent[14] so, although they may take different forms, relational injustices are likely also present in non-Western societies.

In Chapter 2 – *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 unclear that we owe this form of social equality to 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 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.

Then, in Chapter 3 – *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 decisionmakers have a duty to determine a person's authentic values before deciding treatment.

Defending the view that people living with dementia can generate contemporary authentic values, I then conclude with the first public policy recommendation of the thesis: that

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[14] World Health Organisation, *Dementia: A Public Health Priority*, (World Health Organisation, 2012), 82-87.

advance directives are necessary to avoid domination, but they must (a) be defeasible and (b) 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*.[15]

These first three chapters establish the following ethical framework: (i) justice is achieved by successfully eradicating oppression, domination and unjust stigma from society, (ii) people living with dementia (in Western societies) are a social group who are exposed to relational injustices of this kind, (iii) these relationships are unjust because they fail to respect unique subjects as equal bearers of fundamental interests related to their capacity to live authentically, (iv) people living with dementia bear such interests, (v) 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 (vi) people living with dementia are capable of changing these values, even if they are not able to rationally reflect upon them.

With this framework firmly in mind, in the next three chapters I proceed to an analysis of care. In Chapter 4 – *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, offers the best prospects for avoiding carer domination. In Chapter 5, I reject the widely held view of professional dementia care as a regrettable last resort, arguing instead that its informal counterpart carries greater risks of injustice. Though I concede that informal care may be necessary where professional services are poor, I conclude that a just society should seek to improve the quality and provision of its professional counterpart, and that family members ought only to engage in dementia care as a

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[15] Nuffield Council on Bioethics, "Dementia: Ethical Issues," Nuffield Council on Bioethics, last modified 2009, 86.

last resort. Finally, in Chapter 6 – *Can the Secure Dementia Unit Be Justified? Building Egalitarian Care Infrastructure,* I argue that, though in need of significant reform, formal dementia care institutions are both compatible with and required by a just society.

The analysis I conduct in these three chapters yields the following framework for the provision of dementia care: (i) cities and town centres must be adapted so as to be inclusive of people living with dementia, (ii) social services must assist people living with dementia in constructing *cognitive scaffolding*, reducing the need for care intervention, (iii) when needed, people living with dementia ought to be cared for, initially in their own home, by well-trained professional carers provided by well-staffed professional care services, and (iv) in a limited number of cases, people 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, which requires restricting the power of carers and challenging our cultural images of dementia. Thus, though few would disagree that Western dementia care services are in need of reform, the depth and character of the reforms I propose in this thesis differ significantly from many of those under public discussion.

My focus on the power of the carer is, in part, 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 in care services, and the heavy demands on the practical moral decision-making skills of their staff. I witnessed and collaborated in knowingly suboptimal care interventions, made because of staffing pressures, institutional inertia or management directives, making me starkly aware of the asymmetry of the care relationship. 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. Accordingly, 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 correcting mistaken and stereotypical images of those with cognitive disabilities in moral philosophy.[16] Yet, 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. Accordingly, in Chapter 7 – *Dementia and the Problem of Speaking for Others*, I use Linda Alcoff's influential framework to analyse the thesis 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. 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 any reader who shares the all-too-common belief that members of this group universally lack insight, so cannot identify their own interests.[17] In this sense, the thesis is committed to the liberation of people living with dementia from relational injustice, in both content and form.

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[16] 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, UK: John Wiley & Sons, 2010), 410.

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

Chapter 1

Diagnosing the Injustices Faced by People Living with Dementia

> "My heart is racing at the secret I've kept from the girls. I read the email quickly, as if it's sent from an illicit lover, my eyes scanning for sweet nothings, my finger ready to click it closed if anyone appears by my side. And then I find it: a dementia diagnosis would entitle me to a free bus pass. I lean in closer, read again.
>
> Footsteps in the hall make me snap the screen shut, Sarah waking up and walking in.
>
> The morning goes by and I'm still thinking of that bus pass. The first positive thing I've read. My brain in exchange for a bus pass. A ludicrous swap."[18]

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[18] Wendy Mitchell, *Somebody I Used to Know* (London: Bloomsbury Publishing, 2018), 77-78.

Introduction

During the United Kingdom’s 2017 General Election, then Prime Minister Theresa May was sharply criticised over a proposed funding mechanism for social care. What became known as the ‘dementia tax’ was charged with treating people living with dementia unfairly, by requiring them to shoulder the burden of the greater care costs they would likely accrue *through no fault of their own*.[19] It is widely agreed that dementia care services across the West are inadequate, and the extra funding provided by this policy might genuinely have helped to improve those of the UK. Nevertheless, it was rejected by many as *unjust*.

Many of us are likely to agree with the UK public, but we may differ in our reasons. Some may look at this case through what Iris Marion Young calls the distributive paradigm,[20] within which social justice is achieved through distributing some specified ‘currency’ fairly.[21] On this view, the lack of funding for dementia care services might be considered a distributive injustice, but the dementia tax would have failed to address it adequately. In this chapter, I reject this kind of analysis as, at best, incomplete. Instead, I make the case that people living with dementia are an oppressed social group, who suffer relational injustices as a result of social structures which fail to accommodate their differences.

This argument sits within a standard relational egalitarian framework, whereby social justice is achieved through eliminating intolerable inequalities of power and status. From this point of view, injustice is not simply a matter of what institutions or individuals do, but of *how they do it.* If they fail to challenge, reinforce or create paradigm social injustices such as domination, stigma and oppression, citizens remain socially unequal *whatever their distributive*

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[19] Rowena Mason and Denis Campbell, "Theresa May under pressure over 'dementia tax' social care shakeup," *The Guardian*, May 21, 2017, https://www.theguardian.com/politics/2017/may/21/theresa-may-under-pressure-over-dementia-tax-social-care-shakeup.

[20] Iris M. Young, *Justice and the Politics of Difference* (Princeton: Princeton University Press, 1990), 15.

[21] Gerald A. Cohen, "On the Currency of Egalitarian Justice," *Ethics* 99, no. 4 (1989): 906.

positions.[22] As I shall demonstrate in this chapter, the case of dementia clearly illustrates the value of this approach, as purely distributive views cannot fully capture the severity nor the character of the injustices those that live with this condition face.

The argument proceeds as follows. In section 1, I set out the ways in which people living with dementia are vulnerable to abuses of power. I then demonstrate that the injustice of this position is better understood when construed as a standard case of domination, rather than as a threat to wellbeing. In section 2, I consider two possible ways of capturing this inequality of power within the distributive paradigm: through an objective understanding of welfare and through a concern for opportunities. I contend, however, that these analyses and their implied resolutions assume and risk perpetuating an unjust stigma about a life lived with dementia. Drawing on work in the philosophy of disability, I argue that the disadvantages of living with dementia are primarily a consequence of a society that fails to properly accommodate this particular way of life. I then elaborate on this in section 3, using Young's framework to highlight examples of social norms, practices and institutions which contribute to the oppression of persons living with dementia.

1. Dementia, Wellbeing, and Domination

When dementia care services are inadequate, the people using them are exposed to several harms. They may, for instance, be at greater risk of contracting infectious diseases or lack access to timely personal care interventions. Under such circumstances, it seems intuitive to think that the subjective wellbeing of the people using these services would be threatened. Thus, one way of understanding the injustice of inadequate care is that it leads to people living

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[22] This is a view shared by prominent relational egalitarians such as Christian Schemmel and Iris Marion Young. It stands apart from the view that social equality is an ideal outside of the sphere of justice, held by David Miller and Martin O'Neill among others. For a helpful taxonomy, see: Christian Schemmel, "Social Equality - or Just Justice?" in *Social Equality: On What it Means to be Equals*, ed. Carina Fourie, Fabian Schuppert, and Ivo Wallimann-Helmer (New York: Oxford University Press, 2015), 152-164.

with dementia having less welfare than they are entitled to have. In this section, I argue that this analysis is problematic. Inadequate care services may threaten subjective wellbeing, but where this occurs it is only a downstream consequence of a deeper injustice: the exposure of people living with dementia to *domination*.

1.1 Dementia and its Relationship with Power

Though it is commonly conflated with Alzheimer's Disease,[23] dementia is a condition with numerous underlying causes, including aggregates of protein known as Lewy bodies, damage to the frontal and temporal lobes, problems in blood supply to the brain, Parkinson's disease, multiple-sclerosis, Creutzfeldt-Jacobs disease, and syphilis.[24] This heterogeneity of origin is matched by a diverse range of symptoms. Early Alzheimer's disease, for instance, is more associated with memory and spatial orientation problems.[25] Parkinson's and Lewy-Body dementia, on the other hand, are more associated with visual disturbances and hallucinations.[26]

Nevertheless, while significant, the extent of this differentiation should not be overstated. All types of dementia draw on a common pool of symptoms; the key differences are their severity and frequency in the differing patterns of progression.[27] Thus, despite their diversity, all people living with dementia share three characteristics which render them more vulnerable to abuses of power than the average member of the population.

Firstly, they have impaired cognitive functioning, which makes them more likely to be *dependent* on others to meet their basic needs. This manifests as a vulnerability to abuses of

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[23] "What is the Difference Between Dementia and Alzheimer's Disease," *Alzheimer's Society Blog*, August 2, 2018, accessed September 20, 2018, https://blog.alzheimers.org.uk/dementia-insight/dementia-alzheimers-difference/.

[24] "Types of Dementia • Dementia Care," Dementia Care, accessed September 20, 2018, http://www.dementiacare.org.uk/services/need-some-advice/what-is-dementia/types-of-dementia/.

[25] L. L. Smits et al., "Trajectories of cognitive decline in different types of dementia," *Psychological Medicine* 45, no. 5 (2014): 6.

[26] Urs P. Mosimann et al., "Characteristics of Visual Hallucinations in Parkinson Disease Dementia and Dementia With Lewy Bodies," *The American Journal of Geriatric Psychiatry* 14, no. 2 (2006): 153-160

[27] J. Cerejeira, L. Lagarto, and E. B. Mukaetova-Ladinska, "Behavioral and Psychological Symptoms of Dementia," *Frontiers in Neurology* 3 (2012).

power through refusal to meet needs or the meeting of needs in harmful or disrespectful ways. For example, by rationing incontinence products, a care home in Edmonton Canada in 2020 met the personal hygiene needs of those under its care, but only infrequently and in a way that threatened their dignity.[28]

Secondly, dementia is a progressive condition, which means the capabilities of those who live with it are *declining*. Thus, they are vulnerable to abuses of power in ways related to their increased dependency over time. For instance, rehoming of people living with dementia has a well-established deleterious effect on health and wellbeing.[29] Consequently, they are exposed to the power of others when decisions are made about facilitating and providing care. If the decisionmakers choose not to diligently research services to ensure that they can continue meeting a person's needs *throughout* the progression of the condition, they expose them to risks of neglect.

Thirdly, hallucinations, persistent misconceptions and erroneous interpretations become increasingly prevalent across this decline,[30] which means that, to varying degrees, people living with dementia experience life through *parallel subjectivities*. Where this occurs, the person's internal experience of the world is subjectively consistent but differs significantly from what others perceive as the objective world. Once this stage of decline is reached, powerful others can determine the connection between their subjective experience of the world and objective reality.

To illustrate this phenomenon, consider the following anecdote from dementia self-advocate Christine Bryden. When visiting a dementia care facility as part of her outreach work,

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[28] Erica Johnson, "Nursing Home Rationed Diapers While Residents Suffered Rashes, Infections," CBC, last modified February 21, 2020, https://www.cbc.ca/news/canada/edmonton/nursing-home-rations-senior-diapers-1.5470130.

[29] Eric A. Coleman, Joseph C. Barbaccia, and Mary S. Croughan-Minihane, "Hospitalization Rates in Nursing Home Residents with Dementia," *Journal of the American Geriatrics Society* 38, no. 2 (1990): 108-112.

[30] "A Different Reality," Social Care Institute for Excellence (SCIE), last modified 2015, https://www.scie.org.uk/dementia/living-with-dementia/difficult-situations/different-reality.asp.

she struck up a conversation with a woman living with dementia who was seeing mice running along the wall. Bryden, who was at an early stage of progression, reports that she was able to assuage this woman's anxiety by taking her on a walk to find a cat to chase them away.[31] Had Bryden ignored this woman, persistently corrected her or dismissed her experience, she might well have missed the need being expressed. Thus, as this example illustrates, people experiencing parallel subjectivities are exposed to the power of others to interpret *what their needs are*.

People living with dementia, then, are severely exposed to the power of others. When this power is abused, as has become an all-too-common phenomenon,[32] most of us would believe that they have experienced an injustice. Our ability to address and prevent these injustices, however, is dependent on being able to fully understand their character.

1.2 Power, Distribution and Subjective Wellbeing

In public discourse around dementia, abuses of power are often construed as threats to wellbeing. The discussion of abuse in the 2009 Nuffield Council on Bioethics report on dementia, for instance, characterises it as behaviour that causes "harm" and "distress."[33] This

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[31] Christine Bryden, *Dancing with Dementia: My Story of Living Positively with Dementia* (London: Jessica Kingsley Publishers, 2005), 148.

[32] See:
Andrea Grunau, "Nursing Home Abuse in Germany: 'I Can't Let My Mother Die of Thirst'," Deutsche Welle, last modified December 28, 2018, https://www.dw.com/en/nursing-home-abuse-in-germany-i-cant-let-my-mother-die-of-thirst/a-46890600.
BBC News, "Nurse Abused Care Home Residents," BBC News, last modified November 13, 2018, https://www.bbc.co.uk/news/uk-scotland-edinburgh-east-fife-46201827.
Matthew Clemenson, "Hornchurch care home closed after health inspectors find evidence of 'financial abuse' of dementia sufferers," *The Romford Recorder*, March 5, 2020, https://www.romfordrecorder.co.uk/news/health/hornchurch-care-home-alton-house-to-close-over-abuse-fears-1-6546143.
Sarah Ravani, "Contra Costa DA Alleges Elder Abuse, Sexual Assault at Troubled Orinda Nursing Home," San Francisco Chronicle, last modified July 3, 2020.
Shaun Lintern, "Care home criticised after staff recorded abusing elderly resident with dementia," *The Independent*, December 24, 2019, https://www.independent.co.uk/news/health/care-home-abuse-neglect-elderly-dementia-ombudsman-a9259566.html.

[33] Nuffield Council on Bioethics, "Dementia: Ethical Issues," Nuffield Council on Bioethics, last modified 2009, 109-110.

kind of welfarist thinking is also endemic in political theorising about justice, such that the following represents a plausible distributivist response to the vulnerabilities noted above:

> (D1) All people are entitled to their fair share of welfare, understood as their subjective level of wellbeing. People living with dementia are vulnerable to abuses of power. Abuses of power reduce a person's subjective level of wellbeing. Therefore, goods ought to be redistributed to prevent or compensate for abuses of power.

The exact pattern of this distribution will differ depending on the commitments of the particular theorist. A sufficientarian might only favour redistributing that which is necessary to ensure that people living with dementia have *enough* welfare,[34] while an outcome egalitarian might favour redistributing so that they have *as much welfare as everybody else*. It is not necessary to consider every possible iteration of this view to understand its problematic core: the assumption that the power held over people living with dementia can be best understood as a threat to welfare, and the implicit recommendation that it be addressed through purely distributive means.

No doubt, cases of egregious abuse do threaten the welfare of people living with dementia, and they could likely be much reduced or even prevented entirely by a redistribution of funds to improve the funding for and training of care staff. There are, however, some threats that may not be so easily detected or remedied on this model. For instance, the dementia studies pioneer Tom Kitwood has argued that adopting dismissive or exclusionary attitudes towards people living with dementia can lead to a drop in wellbeing so significant that it exacerbates the effects of the underlying neurodegeneration; a process he calls "the dialectics of dementia."[35]

D1 can certainly account for the intuition that this is a wrongful abuse of power, but it is unclear how purely distributive policies can resolve it. Quite apart from anything else, these

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[34] Liam Shields, "Some Questions (and Answers) for Sufficientarians," in *What Is Enough?: Sufficiency, Justice, and Health*, ed. Annette Rid and Carina Fourie (New York: Oxford University Press, 2016), 85-86.

[35] Tom Kitwood, "How Personhood is Undermined," in *Dementia Reconsidered, Revisited*, ed. Dawn Brooker (London: Open University Press, 2019), 55.

attitudes are widely shared and, as such, their expression could occur at any time from any person.[36] Tracking and predicting the outcomes of every single social interaction is likely to be arduous, if not impossible, so preventing welfare reduction by these means is unlikely to be successful. There remains, of course, the option to compensate. However, if their dementia is sufficiently advanced, a person living with dementia may not be able to recall the interaction, making it difficult to identify cases in which compensation is appropriate.

Perhaps a defender of the view could suggest redistributing the right kind of relationships or people with the right kind of attitudes towards this group, but such a policy would misunderstand the problem. As Young argues, "when metaphorically extended to nonmaterial social goods, the concept of distribution represents them as though they were static things, instead of a function of social relations and processes."[37] In other words, the problem is not just that people hold these attitudes, but that we live in a society which produces and maintains them.

Note too that accounts like these do not have the resources to address these structures fully. D1 can only identify these attitudes as wrongful if they are expressed in a way that reduces a person's welfare. It would be perfectly compatible with the account, then, for people living with dementia to be excluded from most aspects of social life, as long as they did not lose welfare from the limited number of social interactions they had. All the while, these attitudes could be maintained or even strengthened in the majority of the population.

Now, it might seem odd to suggest that a group of people could experience such extreme social exclusion and not experience welfare reduction, but it is not so far-fetched.

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[36] See:
Julian C. Hughes, *How We Think about Dementia: Personhood, Rights, Ethics, the Arts and What They Mean for Care* (London: Jessica Kingsley Publishers, 2014), 17.
Nuffield Council on Bioethics, "Dementia: Ethical Issues," Nuffield Council on Bioethics, last modified 2009, 60.
World Health Organisation, *Dementia: A Public Health Priority*, (World Health Organisation, 2012), 80.

[37] Young, *Justice and the Politics of Difference*, 16.

Some level of exclusion exists in our societies today, but evidence suggests that people living with dementia are as likely to self-assess their well-being as 'good' as the general population.[38] Indeed, among those experiencing life through parallel subjectivities, this is fairly intuitive; as long as the care they receive is good, it is quite probable that they would not even know their social world was limited in this way. Consequently, D1 not only cannot identify prevention of welfare reduction through social exclusion as wrongful, it may actually *endorse it* as the most efficient way of remedying the injustice of low well-being.

Even if there is a way around this that is consistent with D1, however, it need not be the case that an abuse of power will always lead to a reduction in welfare. Consider, for instance, a close relative who has the responsibility of managing a person living with dementia's money. Certain abuses of that power may lead to a reduction in welfare, like deliberately withholding funding necessary to meet needs. However, the relative could also abuse it by making donations to political parties or causes that the person disagrees with, or by investing the money in such a way that their estate declines in value. Should the person not be made aware of actions like these, they would be unlikely to experience a loss of welfare. Yet, they are clearly abuses of the power held over people living with dementia because of their dependency.

In addition to these issues, there is a more fundamental problem with D1: an exclusive focus on the *outcome* of power relations, to use Frank Lovett's language.[39] As it only recommends redistribution in response to *actual abuses* of power, the mere fact that the relative was in a position to do this is, on its own, of no concern to such a view of justice. Yet, just as slavery remains unjust even with lazy or benevolent masters, it seems intuitive to think that the power held over people living with dementia is too, even if it is not used.

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[38] Towako Katsuno, "Dementia from the inside: how people with early-stage dementia evaluate their quality of life," *Ageing and Society* 25, no. 2 (2005), 197-241.

[39] Frank Lovett, *A General Theory of Domination and Justice* (Oxford: Oxford University Press, 2010), 80-84.

Of course, in most jurisdictions, egregious abuse is unlawful. However, as I have demonstrated, the vulnerability of people living with dementia to abuses of power is wide-ranging and multi-faceted. Addressing this requires a change of focus to the *structure* of these power relationships. The injustice is not just that actual abuses of power over people living with dementia may reduce wellbeing, but that such abuses are possible in the first place. In this sense, powerful actors possess the ability interfere in the choices of people living with dementia, in ways that do not track their interests, without adequate safeguards or punitive measures to prevent them from doing so. Where freedom from the ability of others to act in this way cannot be robustly guaranteed, people living with dementia are subject, in the sense used by neo-republicans and (most relational egalitarians), to *domination*.[40]

2. Dementia and Stigma

In the previous section, I argued that the vulnerability of people living with dementia to abuses of power can neither be fully identified nor properly addressed through a focus on the distribution of welfare. An objection may be raised, however, to the way this analysis treats *welfare* and *subjective accounts of wellbeing* as synonymous. Were the position of this group to be, instead, appraised from an *objective* account of welfare, many of my concerns about domination may be captured. Alternatively, these concerns might be possible to account for through a focus on the way dementia affects a person's *opportunities*.

Nevertheless, while such accounts may be successful in capturing concerns about *domination*, their purportedly objective presumptions about human lives create an issue of their own: the perpetuation of unjust *stigma*. In this section, I draw on Elizabeth Barnes's 'value-neutral' account of disability to make this case. In so doing, I suggest that, because they locate the source of injustice in the condition itself, purely distributive accounts of justice do not

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[40] Rekha Nath, "Relational Egalitarianism," *Philosophy Compass* 15, no. 7 (2020), 4-6.

possess the resources to fully diagnose the social injustices faced by people living with dementia.

2.1 Dementia and Objective Approaches to Welfare

Consider the following distributive solution to the vulnerability of people living with dementia to the power of others.

> (D2) All people are entitled to a fair share of welfare. Relationships of domination objectively reduce a person's welfare. As dementia entails a vulnerability to such relationships, all people living with it are badly off. Thus, if a person develops dementia, we ought to redistribute goods to compensate them for this loss.

It is, again, unnecessary to consider every possible iteration of this distributive approach; as with D1, there will be varying proposals for the optimally just distributive pattern, and the exact composition of the bundle of goods that is thought to contribute to welfare will also vary. For present purposes, all that is necessary to understand about such an account is its core assumption: that dementia inherently reduces welfare.

As demonstrated in the last section, such analysis may conflict with subjective testimony. Nevertheless, given the wide range of international studies suggesting that dementia is the age-related condition most feared among the general population, some may think this dismissal appropriate.[41] Such a feeling may be strengthened by appealing to the core of the condition: dementia involves a loss of cognitive abilities, meaning a person living with it may be less likely to recognise threats to their welfare.

Consider, for instance, Maureen Barnett: a British woman living with advanced vascular dementia, who was reported in 2016 to be experiencing a constant, joyous state of present-focused appreciation.[42] While she would almost certainly report high levels of wellbeing if asked and would even appear, from the outside, to be thoroughly enjoying her life, there are elements of her situation which many of us would consider troubling *for her*. The fact that she lives in a society in which freedom from abuses of power is not robustly guaranteed, to take the analysis of the previous section as an example, would seem to bear on her (objective) welfare significantly.

This capacity to recognise the injustice of domination on distributive terms is a strength of D2. Note, too, that, unlike on D1, protecting people living with dementia from abuse through social exclusion can be categorically ruled out on some versions of this view. After all, social

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[41] See:
Alzheimer's Research UK, *Dementia Attitudes Monitor*, (Dementia Statistics Hub: Cambridge, 2019), https://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).
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).
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)
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).
Kyle S. Page et al., "Development of a Multidimensional Measure to Examine Fear of Dementia," *The International Journal of Aging and Human Development* 89, no. 2 (2018).
Ladislav Volicer, "Fear of Dementia," *Journal of the American Medical Directors Association* 17, no. 10 (2016).
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).
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 (July 2017).

[42] Kate Pickles, "Family of Grandmother with Alzheimer's Say Disease Has Made Her HAPPY," Mail Online, last modified September 30, 2016, https://www.dailymail.co.uk/health/article-3815418/Family-grandmother-Alzheimer-s-say-disease-remarkable-effect-HAPPY.html.

inclusion is a very intuitive candidate for the bundle of goods which contribute to a person's welfare.

It is concerning, nevertheless, that such an approach seems to render it rational to possess some problematic and dismissive attitudes towards people living with dementia. The dismissal of reports of high wellbeing, for instance, involves *invalidation* of subjective experience, while the justification for doing so involves *disparagement* of people living with dementia as incompetent. Thus, adopting D2 might risk reinforcing the "malignant social psychology" that Kitwood argues is so threatening to their wellbeing.[43]

That people hold these attitudes then, cannot be considered unjust or problematic on this account. It may, of course, justify compensating people living with dementia when these attitudes are expressed, but by failing to challenge them and, worse, reinforcing them, a society governed by D2 would be problematic in its own right. Thus, although D2 succeeds where D1 fails, it can only do so by threatening the subjective wellbeing of people living with dementia and treating them disrespectfully, in the sense that compensations would be justified on the grounds of perceived inferiority – a key criticism of distributive accounts of justice made by foundational relational egalitarian theorist Elizabeth Anderson.[44] Such treatment is plausibly understood as reflecting and reinforcing an unjust stigma: an intuition I will elaborate on in section 2.3.

2.2 Dementia and Opportunities

This issue of dismissiveness arises because D2 can only capture the injustice of domination by interpreting it as a problem of *welfare*. An alternative approach is to accept that some people living with dementia have high standards of welfare but argue that they are wronged

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[43] Kitwood, "How Personhood is Undermined",, 52-53.
[44] Elizabeth S. Anderson, "What is the Point of Equality?," *Ethics* 109, no. 2 (1999): 289.

nonetheless by the way vulnerability to abuses of power threatens their *opportunities*. Such an account might look something like this:

> (D3) All people are entitled to a fair share of opportunities. Vulnerability to the power of others threatens a person's opportunities. As dementia leads to such a vulnerability, we ought to redistribute goods to improve the opportunity sets of those who develop the condition or compensate them for the loss.

Note that D3's solution to the dismissiveness problem does not lie in dispensing with the idea of welfare entirely. Indeed, within the broad range of views about the distribution of opportunities, there are theorists such as Richard Arneson who are committed to equalising opportunity *for* welfare.[45] Rather, it lies in the implied claim that, whatever their self-reported levels of wellbeing, all people living with dementia have restricted opportunities and that people like Maureen Barnett are merely *lucky* that they have been able to navigate a narrow path. As it seems fairly intuitive that domination restricts opportunities, in the sense that dominating power can make them uncertain or out of reach, D3 also avoids the pitfalls of D1. Nevertheless, it raises further issues.

Firstly, many people living with dementia are older adults and, as such, may have been furnished with opportunities in their early lives, leaving some of them comparatively advantaged.[46] Bryden, for instance, had a successful career in public service before the onset of her dementia, including advising the then Australian Prime Minister on science and technology.[47] This suggests that the injustice of domination may differ in severity depending on the age and previous lives of the persons experiencing it. Worse a society governed by D3 might permit leaving someone like Bryden dominated, if the resources necessary to remove this dominating power would lead younger persons without dementia to have fewer opportunities than she enjoyed in her youth.

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[45] Richard J. Arneson, "Equality and Equal Opportunity for Welfare," *Philosophical Studies* 56, no. 1 (1989): 77-93.

[46] María M. Corrada et al., "Dementia Incidence Continues to Increase with Age in the Oldest Old: The 90+ study," *Annals of Neurology* 67, no. 1 (2010): 114-121.

[47] Bryden, *Dancing With Dementia,* 15.

More fundamentally, it is simply unclear that this proposed currency of social justice has the same value to people living with dementia as it does to those without the condition. After all, while welfare is something a person can *experience,* opportunities have a future-oriented, conditional character. Given the lives of people living with dementia become increasingly present-focused,[48] it may not even be appropriate to state that they have opportunities *at all*, at least not when their dementia is sufficiently advanced.

Of course, a defender of D3 might think this strengthens the account, by providing a clear reason to think that all people living with dementia are disadvantaged. However, this too seems to rely on the disparagement of people living with dementia as incompetent, as well as another dismissive attitude identified by Kitwood: *disempowerment* through devaluation of the capabilities they have.[49] After all, living with dementia features experiences that may be difficult to access without it; as Bryden argues in defence of the value of a life lived with dementia, "many of us seek earnestly for this sense of the present time, the sense of 'now', of how to live each moment and treasure it as if it were the only experience to look at and wonder at."[50]

Given D3 must frame this transformation as a *loss* rather than a *difference* to identify *all* people living with dementia as disadvantaged, a society governed by it risks perpetuating the same stigma identified in the previous section at the first stage (a concern I substantiate further in the next section). Given it must then compensate on the basis of a perceived inferiority, because it cannot justify distributing opportunities towards those for which they bear decreasing value, it risks perpetuating stigma in its response. Thus, though it avoids some of the pitfalls of D1 and D2, D3 cannot fully capture the character of nor successfully address the injustices people living with dementia face.

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[48] Hughes, *How We Think About Dementia,* 32.
[49] Kitwood, "How Personhood is Undermined," 52.
[50] Bryden, *Dancing with Dementia,* 11.

2.3 Disability, Difference, Stigma and Ways of Life

I have argued that the above views struggle to identify people living with dementia as disadvantaged, without also assuming that dementia is something that inherently involves losses. But some may be wondering why this matters. Indeed, some might strongly agree that a person living with dementia is worse off *simply because they have dementia,* and that they should be compensated for it.

While this is certainly a common belief, it is one that the advocacy group Alzheimer's Disease International (ADI) specifically identifies as stigmatising.[51] Nevertheless, some may disagree, maintaining that it is possible to recognise a health condition as bad for a person without stigmatising them. Indeed, they might think we need to do so to justify allocating time and resources to research treatments and cures.

However, this need not be the case. As argued by Barnes, in a society free of ableism, cures for impairments amount only to mechanisms a person can use to make themselves nondisabled, which any theorist who values self-determination ought to value.[52] Understood this way, it is bad that we do not have a choice over whether or not we live with dementia, but the way of life this condition entails is merely a difference, not a loss. Central to this is Barnes's observation that disability, for many disabled people, is felt as something fundamental to their identity: akin to sexuality or gender identity.[53]

There may, of course, be some who are sceptical of this *value-neutral* view of disability,[54] or at least of its application to dementia. Indeed, although she does not preclude its

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[51] Alzheimer's Disease International, *World Alzheimer Report: Attitudes to Dementia*, (London: Alzheimer's Disease International, 2019).

[52] Elizabeth Barnes, "Valuing Disability, Causing Disability," *Ethics* 125, no. 1 (2014): 109-111.

[53] Elizabeth Barnes, *The Minority Body: A Theory of Disability* (New York: Oxford University Press, 2016), 134.

[54] Ibid, 79-81.

extension, Barnes herself only applies her analysis to *physical* disability.[55] I have implied that a life lived with dementia is something akin to, following Barnes, a life lived with homosexual attraction: a merely different experience which is stigmatised when it is considered inherently bad. Some, however, may feel dementia is more like cancer: an illness which most of us, including Barnes, would think *is* inherently bad.[56]

My response to this is, simply, that dementia is like both. A life with dementia is different and, even in a world free of stigma, some people may experience it as something bad for some of the same reasons Barnes thinks people with physical disabilities may experience them as bad. First, they may regret losses reliably associated with the experience, labelled "local losses" by Barnes, such as a shortened life span.[57] Second, they might consider it a bad thing that such a significant change to their identity occurred without their consent.[58] Even in a world free of homophobia, some people may experience a life lived with homosexual attraction as something bad for several reasons. First, they might consider things related to homosexuality as bad, such as the extra complexity involved in rearing children they are genetically related to. Second, someone like Chris Birch, who claimed to have experienced a change in sexual orientation after a stroke, might consider it a bad thing that a significant change to their identity occurred without their consent.[59] Recognising these possibilities, however, does not require, for either, that these *local* losses equate to an *inherently bad way of life*.

Though it may seem counterintuitive to some, the experience of living with cancer can also be understood on these terms. Of course, it may still be true that some people, maybe even a lot of people, experience it as something bad, but we can account for this without claiming

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[55] Ibid, 2.
[56] Ibid, 80-85.
[57] Ibid, 80-84.
[58] Ibid, 146-149.
[59] Lucy Wallis, "'The Stroke Had Turned Me Gay'," BBC News, last modified April 17, 2012, https://www.bbc.co.uk/news/magazine-17703018.

that a life lived with cancer represents something inherently bad. First, they might consider things related to the cancer, such as a shorter life span and chronic pain, bad. Second, they might consider a profound change to their identity, caused by a drastically shortened life span, to be a bad thing to have happened without their consent. Just as in the cases of dementia and homosexuality, however, arguing that the overall experience of living with cancer is a loss, rather than a difference, involves perpetuating some level of stigma. Indeed, this is corroborated by literature on the experience of cancer patients, which identifies a stigma some experience related to the idea that the condition has worsened their life or demands pity as an appropriate response.[60]

This symmetry between health conditions and other differences is the essence of what it means to hold a mere-difference view of disability. Little is lost (and much gained) by expanding Barnes's account to include cognitive disabilities and chronic health conditions.[61] To the extent that people with these ways of life are disadvantaged, it is either because they live in a society which does not accommodate their difference or because they have experienced a non-consensual change to their social identity which they do not regard as authentic to them (or both).

Nevertheless, it should not be taken from this that there is as little need to search for a cure for cancer or dementia as there is for a mechanism to change sexuality. In our present societies, cancer and dementia represent dramatic identity changes that near-exclusively occur without consent, while there are only sparse, unverified anecdotes of the same thing happening

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[60] Zehao Huang et al., "Correlates of Stigma for Patients with Cancer: a Systematic Review and Meta-analysis," *Supportive Care in Cancer*, 2020.

[61] Of course, this might not require including *all* health conditions. Those that arise as a result of a hostile invading force, such as infectious diseases, may be entirely different in character: especially given the threat they represent to bodily integrity.

with homosexuality.[62] Moreover, those who advocate for conversion therapy or research into mechanisms for changing sexual orientation, often do so for reasons that have little to do with concern about non-consensual identity transformations. Such interventions have, instead, historically been forced on people and justified through quasi-moral claims about the effect of homosexuality on society, or spiritual arguments that cast it as a moral failing.[63] Thus, even though there is nothing inherently harmful about a mechanism to change sexuality, the contingent harms associated with researching one in *this* society, as Barnes notes, may be far higher.[64]

Nevertheless, the comparison is instructive in the following sense: the increased difficulty producing genetically related children would be best addressed through prioritising research into fertility treatments, rather than research for a (mostly) unwanted mechanism to change sexual orientation. Likewise, although there is greater demand for an identity shifting mechanism, research on cancer or dementia should not focus on this exclusively, given more could be done to address local losses like pain and reduced lifespan. Though many may find this counterintuitive, it parallels an argument Barnes makes about physical disability, wherein she notes the objections of people with muscular dystrophy to a relentless focus on finding a cure.[65]

In a world without homophobia, a mechanism to change sexuality would merely contribute to self-determination.[66] In a world without ableism, mechanisms to treat dementia

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[62] This may turn on whether you consider the development of identity traits you are born with ‘consensual.’ Regardless, the key point of the case of Chris Birch is that he, allegedly, transformed from having a heterosexual orientation to a homosexual orientation. A child growing up and coming to understand themselves as gay has not gone through an equivalent transformation. Perhaps we might say the child transformed from a person without an orientation to a person with one without their consent. If so, the urgency of finding a reversal mechanism would depend on how many people, in a world free of stigma, would desire it.

[63] Jack Drescher et al., "The Growing Regulation of Conversion Therapy,” Journal *of Medical Regulation* 102, no. 2 (2016): 7-12.

[64] Barnes, *The Minority Body*, 162.

[65] Ibid, 160-165.

[66] Intuitively it might seem like nobody would choose to use this mechanism at all. However, it is conceivably possible to imagine people who are curious about what it is like to have a different orientation, or who, for some reason, do not have access to sexual relationships with the sex that are attracted to.

would do the same. Although our world features homophobia and ableism, neither the impetus to develop these mechanisms nor the social effects advocating for them has are the same. Nevertheless, lives lived with dementia are no more *inherently* bad than a life-lived with homosexual attraction (or, to be resolutely clear, heterosexual attraction: a difference that features local losses associated with a lack of access to experiences valued by others).

We do not, then, need to hold that a life lived with dementia represents a loss, to justify providing and researching treatments. *We need only hold that it would be better if people could prevent or reverse radical identity shifts that occur without their consent.* Shifting the focus away from claims about what is universally good or bad for persons, to a focus on identity and authenticity, helps to illustrate why representing disability as a loss is stigmatising.

People living with dementia, from this point of view, do not just share a medical condition; they share a social identity and, as I shall elaborate further on in the next section, a particular way of life. Addressing the injustices they face requires recognising how unaccommodating social structures leave them vulnerable to domination and give rise to stigmatising beliefs. Exclusive focus on the distribution of goods, at best, obscures the social structures that produce these views and, at worst, reinforces them. While addressing this *stigma* may have distributive implications,[67] *purely* distributive accounts of justice do not suffice.

3. Dementia and Oppression

So far in this thesis, I have argued that people living with dementia are, in most if not all societies, subject to domination, which cannot be addressed through distributive accounts of

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[67] This is something widely acknowledged by relational egalitarians, see:
Carina Fourie, Fabian Schuppert, and Ivo Wallimann-Helmer, "The Nature and Distinctiveness of Social Equality: An Introduction," in *Social Equality: On what it Means to be Equals*, ed. Carina Fourie, Fabian Schuppert, and Ivo Wallimann-Helmer (New York: Oxford University Press, 2015), 9.
Christian Schemmel, "Distributive and Relational Equality," *Politics, Philosophy & Economics* 11, no. 2 (2012), 123-148.
Gideon Elford, "Survey Article: Relational Equality and Distribution," *Journal of Political Philosophy* 25, no. 4 (2017), 80-99.

justice without perpetuating *stigma*. At the core of this is a concern raised by Iris Marion Young: that focusing excessively on individual disadvantage obscures the extent to which injustices are produced by the interaction of social groups.[68] After all, it is *individual* people living with dementia who are wronged by exposure to abuses of power, but it is by their shared possession of particular traits that they become vulnerable to stigma. For Young, it is at this level of group interaction that distinctive relational injustices occur. Where social structures leave certain groups persistently disadvantaged through social norms, habits, symbols and assumptions, she argues, they are subject to *oppression.*[69]

In this section, I argue that people living with dementia, at least in the Western world, are subject to this set of injustices. Before engaging in this analysis, however, it is necessary to demonstrate that they are rightly thought of as a social group in Youngian terms, that is: "a collective of persons differentiated from at least one other group by cultural forms, practices, or way of life".[70]

As I set out in the first section of this chapter, the vulnerability of people living with dementia to power occurs because of three core features of the condition: dependency, decline and parallel subjectivity. It is not unreasonable, I would suggest, to think that these interact in a way that constitute a distinct way of life, despite overlaps with the experiences of older adults and those with cognitive disabilities. After all, though they share the experience of dependency with other people with cognitive disabilities, and the experience of *parallel subjectivity* with those with similar symptoms, their experience of *decline* differentiates them from both of these wider groups. Indeed, dementia is both statistically and culturally associated with older adults, who share the experience of decline, to the extent that there remains a persistent myth that

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[68] Young, *Justice and the Politics of Difference,* 45-49.
[69] Ibid*,* 40-44.
[70] Ibid, 43.

dementia is a natural consequence of ageing,[71] and even those with young-onset dementia come to be treated as if they are aged.[72]

People living with dementia can, then, be understood as lying at the *intersection* of age and cognitive disability. This is to say that people living with dementia are both cognitively disabled and (at least treated as if they are) aged, and thus exposed to the injustices levelled at those with both of these group markers. Moreover, just as a lesbian is not only exposed to misogyny and homophobia, but distinctive injustices caused by the way these group markers overlap, many of the group-based injustices experienced by people living with dementia have a specific character.[73]

These injustices, as I have argued thus far, originate in social structures that fail to accommodate their differences, not an inherent loss involved in developing the condition. In this section, I will use examples to demonstrate that these problematic beliefs, practices and institutions are pervasive in Western societies, and create a barrier to the accommodation of the differences members of this group possess. In fact, as I shall demonstrate, the oppression they are subject to is particularly stark, given that they are subject to all five 'faces' that make up Young's definition of oppression.

3.1 Exploitation

Exploitation, in everyday language, is usually thought of as a matter of unfair transactions. As a face of oppression, however, Young argues that exploitation involves unjust structures which lead to processes which "transfer energies" from a subordinated group to a dominant group.[74]

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[71] Hughes, *How We Think About Dementia,* 39-42.
[72] Tom Kitwood, "On Being a Person," in *Dementia Reconsidered, Revisited*, ed. Dawn Brooker (London: Open University Press, 2019), 11.
[73] For more detail on the concept of intersectionality, see:
Brittney Cooper,"Intersectionality", in *The Oxford Handbook of Feminist Theory*, ed. Lisa Disch and Mary Hawkesworth (New York: Oxford University Press, 2015), 387-388.
[74] Young, *Justice and the Politics of Difference,* 50.

Understood this way, persistent, structural exploitation maintains unjust, inegalitarian relationships and is, thus, a form of oppression. People living with dementia are exposed to the exploitation, in this structural sense, of aged and cognitively disabled people.

Given the relative wealth of older adults, it might seem strange to argue that they are exploited by younger people. Aged people, as a group, require a greater degree of health and social care intervention than other demographics, so receive a significant proportion of public funds in most societies.[75] They are also, as a social group, relatively wealthy compared to others. For example, although those aged 71-90 are worse off compared to those aged 51-70, older people in the UK remain substantially better off as a group than those under 50.[76] Thus, some may reasonably hold that; even if health and social care come at an increased cost,[77] they ought to be able to cushion themselves from the drawbacks of greater demand for care.

In many societies, exploitation persists, however, through a warped manifestation of the concept of intergenerational responsibility. A 2019 study of older adults in England, for instance, identified family pressure over inheritance as a common limiting factor when choosing care services.[78] Perhaps unsurprisingly, then, there are an increasing number of "forced transfer" cases being brought to court, in which a younger relative coerces an older person with care needs into transferring assets.[79]

Likewise, a report on elder abuse in Northern Ireland and the Republic of Ireland found that the belief that younger relatives were entitled to assets was widely shared, and that

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[75] Age UK, *Briefing: Health and Care of Older People in England 2019*, (Age UK, 2019), https://www.ageuk.org.uk/globalassets/age-uk/documents/reports-and-publications/reports-and-briefings/health--wellbeing/age_uk_briefing_state_of_health_and_care_of_older_people_july2019.pdf.

[76] The Resolution Foundation, *The Generation of Wealth*, (Asset Accumulation Across and Within Cohorts, 2017), https://www.resolutionfoundation.org/app/uploads/2017/06/Wealth.pdf.

[77] "Paying for Permanent Residential Care | Paying for a Care Home | Age UK," Age UK | The UK's Largest Charity Working with Older People, last modified August 20, 2018, https://www.ageuk.org.uk/information-advice/care/paying-for-care/paying-for-a-care-home/.

[78] K. Baxter, E. Heavey, and Y. Birks, "Choice and Control in Social Care: Experiences of Older Self-funders in England," *Social Policy & Administration* 54, no. 3 (2019).

[79] Misa Izuhara and Stephan Köppe, "Inheritance and Family Conflicts: Exploring Asset Transfers Shaping Intergenerational Relations," *Families, Relationships and Societies* 8, no. 1 (2019): 63-65.

inheritance considerations were often used to justify neglect of care needs.[80] Similar findings have also been found in Australia[81] and the United States.[82] Although the view that older people have duties towards their younger relatives is not automatically exploitative, these studies highlight a warped form: a belief that older people should leave as many of their assets as possible behind for their younger relatives, and that any money spent for their own benefit, even if it is to meet basic needs, is to be treated with suspicion.

This belief is so pervasive that it can also influence debates on public policy. For instance, former UK Prime Minister Gordon Brown's proposal to fund social care via a levy on estates after death was the subject of outrage during the 2010 General Election campaign, precisely because it would reduce the assets available for inheritance. Worse still, the proposal was not even intended to *improve* social care, which is widely recognised to be underfunded and suboptimal,[83] but to stabilise the system as the ageing population creates increased demand.[84]

Labelling this phenomenon exploitation might be thought to be needlessly provocative. Nevertheless, it falls well within Young's definition, given the status gap between the two social groups it helps to maintain.[85] Any structural account of justice must recognise that, whatever their relative wealth gap, a belief that younger people are automatically entitled to the resources of their older relatives, even if this is at the expense of their own care needs, relies

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[80] Age Action Ireland, "*A Total Indifference to our Dignity" Older People's Understandings of Elder Abuse*, (Centre for Ageing Research and Development in Ireland, 2011), https://pure.ulster.ac.uk/ws/portalfiles/portal/11257581/A_Total_Indifference_to_our_Dignity_-_Older_People%27s_Understandings_of_Elder_Abuse.pdf

[81] Dale Bagshaw et al., "Financial Abuse of Older People by Family Members: Views and Experiences of Older Australians and their Family Members," *Australian Social Work* 66, no. 1 (2013): 86-93.

[82] Donna J. Rabiner, Janet O'Keeffe, and David Brown, "A Conceptual Framework of Financial Exploitation of Older Persons," *Journal of Elder Abuse & Neglect* 16, no. 2 (2005): 60.

[83] In the following study, for instance, 91 out of 92 care homes reported some abuse or neglect: Claudia Cooper et al., "Do Care Homes Deliver Person-centred Care? A Cross-sectional Survey of Staff-reported Abusive and Positive Behaviours Towards Residents from the MARQUE (Managing Agitation and Raising Quality of Life) English National Care Home Survey," PLOS ONE 13, no. 3 (2018).

[84] Patrick Wintour and Randeep Ramesh, "Inheritance Levy to Fund Social Care Being Considered by Ministers," *The Guardian*, February 8, 2010.

[85] Young, *Justice and the Politics of Difference,* 50.

on and reinforces the idea that the lives of older adults are less worthy of consideration than the young.

This is not intended as a broadside against the concept of inheritance; not every transfer between the old and young is exploitative. However, when the expectation of inheritance takes a perverse form and leads to a devaluing of the immediate care needs of older adults, an exploitative structure is formed. Moreover, given the way the lives of people with cognitive disabilities are devalued and stigmatised,[86] alongside the cultural association of age with dementia, it is not unreasonable to suggest that cognitive ableism plays a motivating role in the maintenance of this structure. In other words, it is likely that our cultural subordination of the needs of older people to those of their young relatives is, in part, motivated by a dismissal of the value of cognitively disabled lives. For those who do have cognitive disabilities, like people living with dementia, this motivating factor becomes clearer and may be experienced more sharply.

3.2 Marginalisation

Young herself identifies aged people as a group oppressed by marginalisation.[87] Where such a structure exists, she argues, the marginalised are expelled from useful participation in social life and stripped of opportunities for social recognition.[88] Although some older people are able to maintain public profiles, such as the main candidates for the 2020 US Presidential Election, in many societies Young's insight still rings true. While total expulsion may be less usual, there still remains a pervasive cultural norm that older people have little that is *relevant* to contribute to mainstream social life.

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[86] Licia Carlson, "Philosophers of Intellectual Disability: A Taxonomy," in *Cognitive Disability and its Challenge to Moral Philosophy*, ed. Eva F. Kittay and Licia Carlson (Chichester, UK: John Wiley & Sons, 2010), 317.

[87] Young, *Justice and the Politics of Difference,* 39.

[88] Ibid, 53.

As cathartic and amusing as it may be for frustrated millennials and members of Generation Z, the propagation of the 'ok boomer' meme in recent years illustrates this bias. Although the baby boomers are not the oldest generation and many younger people claim to be acting in solidarity with the oldest old by castigating their children, the meme follows a familiar ageist pattern; younger people dismiss their elders apparently simply *because* they are elders. That this is usually adopted as a response to political, social and cultural contributions, however frustrating or ill-informed they may appear, illustrates the continued marginalisation of older adults.[89]

It ought also to be noted that, in many cases the mechanism of this exclusion is cognitive; it proceeds from a belief that older people are out of touch and unable to process or appreciate the modern world. This marginalisation of older people thus, again, seems to draw on the erroneous belief that serious cognitive decline is a normal part of ageing, and operates by subjecting older people to the marginalisation that people with cognitive disabilities already face.[90] Where these structures exist, then, people living with dementia face marginalisation on two fronts; they are automatically excluded from social life because they are cognitively disabled and if they try to contribute there is a deep suspicion and likelihood of dismissal because they are aged (or, at least, are treated as if they are).

3.3 Powerlessness

While it overlaps with the domination I have already argued that people living with dementia are exposed to, Young's concept of oppression by powerlessness differs in significant ways. To be structurally powerless is not just to be exposed to the power of others, but to occupy a

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[89] Taylor Lorenz, "'OK Boomer' Marks the End of Friendly Generational Relations," The New York Times - Breaking News, World News & Multimedia, last modified October 29, 2019, https://www.nytimes.com/2019/10/29/style/ok-boomer.html.

[90] For a detailed exploration of this, see:
Licia Carlson, *The Faces of Intellectual Disability: Philosophical Reflections* (Bloomington: Indiana University Press, 2010).

status which prevents the exercise of agency and control in the work environment, while carrying less authority and respect in social settings,[91] While people living with dementia, generally speaking, are less likely to work and so, are not captured by this definition, this merely suggests a need to expand it. In inadequate care settings, after all, they may have little control over how that care is provided, and the status of being a beneficiary of care is often met with disrespect.[92] The conditions in which people living with dementia act, thus, are determined by others, and this status carries less authority and respect: an archetypal state of powerlessness.

The primary thrust of this powerlessness may arise from the way cognitively disabled people are often regarded as *morally inferior* and, thus, unsuited to any degree of authority or control.[93] It may also be influenced by age, however, as, in many cultures, older people are expected to become less technically adept, less suited to authority, and their words are expected to carry less weight.[94] That people living with dementia *are* cognitively disabled and, thus, may seem to conform to this expectation, would seem to make this powerless status particularly acute.

3.4 Cultural Imperialism

Young argues that, "to experience cultural imperialism is to experience how the dominant meanings of a society render the particular perspective of one's own group invisible at the same time as they stereotype one's group and mark it out as the other."[95] That aged people are victims

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[91] Young, *Justice and the Politics of Difference*, 56.

[92] Tom Shakespeare, "The Social Relations of Care," in *Rethinking Social Policy*, ed. Gail Lewis, Sharon Gewirtz, and John Clarke (Thousand Oaks: SAGE, 2000),

[93] Licia Carlson, "Cognitive Ableism and Disability Studies: Feminist Reflections on the History of Mental Retardation," *Hypatia* 16, no. 4 (2001): 131-142.

[94] Bill Bytheway, "Ageism," in *The Cambridge Handbook of Age and Ageing*, ed. Malcolm L. Johnson (New York: Cambridge University Press, 2005), 338-339.

[95] Young, *Justice and the Politics of Difference,* 55.

of this phenomenon can clearly be demonstrated through modern cultural representations, in characters like Abe Simpson, in the US animated comedy *The Simpsons.*

Abe is presented as cantankerous, pitiful and hopelessly out of touch with modern society. He also, predominantly, appears only for short gags at his expense, with few of the more touching, sympathetic moments the rest of the family can experience. Granted, characters in sitcoms are all stereotypes to some degree, but older characters like Abe Simpson are unique in the sense that the things targeted for mockery more than anything else are their attempts to fight against the idea that their lives have no value.

These stereotypes are of course not unique to Grampa Simpson. Martha Nussbaum has written about similar issues in modern productions of King Lear,[96] and much has been published on the pervasiveness of these stereotypes in advertising and daytime television.[97] Indeed, what is particularly striking about this stereotype is how ubiquitous it is, given the comparative absence of media which explores issues of age from the perspective of older people.[98] This is particularly problematic given that in Britain, for example, people over-65 are the largest consumers of television.[99]

Note too that these tropes rely, in part, on the view that serious cognitive decline is a normal part of ageing. In fact, there is some data which suggests older people experience temporary cognitive dampening after being exposed to these stereotypes: such is the strength and influence of this link.[100] Unsurprisingly, then, cognitively disabled people are subject to

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[96] Martha Nussbaum, "Aging and Control in King Lear," in *Aging Thoughtfully*, ed. Martha C. Nussbaum and Saul Levmore (New York: Oxford University Press, 2017), 9-23.

[97] Virpi Ylänni, "Representations of Ageing in the Media," in *Routledge Handbook of Cultural Gerontology*, ed. Julia Twigg and Wendy Martin (London, England: Routledge, 2015), 369-376

[98] Aside from the fantastic Netflix series Grace & Frankie, which challenges many of the tropes highlighted here, this is particularly true for older women.
See: Dafna Lemish and Varda Muhlbauer, "'Can't Have it All': Representations of Older Women in Popular Culture," *Women & Therapy* 35, no. 3-4 (2012): 165-180

[99] Ofcom, *Communications Market Report*, (United Kingdom, 2017), https://www.ofcom.org.uk/research-and-data/multi-sector-research/cmr/cmr-2017/uk.

[100] Gerben J. Westerhof et al., "Filling a Missing Link: The Influence of Portrayals of Older Characters in Television Commercials on the Memory Performance of Older Adults," *Ageing & Society* 30, no. 5 (July 2010): 897-912.

similarly demeaning stereotypes. Stevenson and his coauthors, for instance, describe how fiction concerning people with cognitive disabilities tends to represent them either as children or child-like, feeding into a cultural image of eternal innocence and vulnerability.[101]

These two sets of stereotypes intersect for people living with dementia in an almost paradoxical way, through the common stereotype of dementia as a 'second-childhood'.[102] Thus they come to be treated in a patronising and dismissive manner, which can clearly be traced back to the reductive cultural stereotypes of both age and cognitive disability. Indeed, Bryden recounts how these stereotypes led to her needing to begin her advocacy presentations by showing the audience her latest brain scans, otherwise the legitimacy of her diagnosis would be questioned.[103]

3.5 Violence

Social groups are oppressed by violence, according to Young, when they are both subject to instances of violence and live under the constant threat of it.[104] This can certainly be true of both aged people and those with cognitive disabilities; for instance, crimes against older people and disabled people form a significant chunk of reported hate crimes in the UK.[105] Indeed, this is particularly noticeable in the provision of care, where violence is widely acknowledged to be pervasive, both between carers and the cared for, and between care home residents.[106]

Although instances of violence against older people and those with cognitive disabilities may be met with outrage, their persistence indicates a tangible effect of reductive

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[101] Jennifer L. Stevenson, Bev Harp, and Morton A. Gernsbacher, "Infantilizing Autism," *Disability Studies Quarterly* 31, no. 3 (2011).

[102] Karin Jongsma and Mark Schweda, "Return to Childhood? Against the Infantilization of People with Dementia," *Bioethics* 32, no. 7 (2018): 414-420.

[103] Bryden, *Dancing With Dementia,* 47-50.

[104] Young, *Justice and the Politics of Difference,* 61.

[105] Crown Prosecution Service, "Hate Crime and Crimes Against Older People Report," The Crown Prosecution Service, last modified 2012, https://www.cps.gov.uk/sites/default/files/documents/publications/cps_hate_crime_report_2012.pdf.

[106] Emma Forde, "Care Homes Assaults Reported Daily," BBC News, last modified May 23, 2017, https://www.bbc.co.uk/news/uk-39962700).

stereotypes and cultural stigma. Of course, both these groups are less able to protect themselves from violence, but when this is treated as a failure of kindness, rather than a failure of social accommodation, we fail to acknowledge the way social structures enable it. There are, thus, good reasons to think our dismissiveness and devaluing of both of these groups, as well as their marginalisation from culture contributes to the violence they face.

In sum, there are many social structures and practices which oppress people living with dementia and pervade Western societies. Those that I have raised here are intended to be illustrative, not exhaustive. There may, thus, be further examples at the general level, or specific examples that only pertain to a particular country. All I have sought to demonstrate here is that, however they may manifest, the injustices people living with dementia face originate in societal structures, not in the condition itself.

Conclusion

In this chapter, I have sought to diagnose and map the injustices faced by people living with dementia. I have argued that these cannot be fully understood on, and indeed may be worsened by, purely distributive accounts of justice. Instead, I have made the case that people living with dementia are an oppressed social group, who are exposed to domination and stigma through a lack of accommodation for their way of life. To attain social justice for them, then, we must set aside the idea that dementia makes a person inherently worse off and engage in radical reform of our social and political structures.

While this may be burdensome, it is not unique among the demands of egalitarian justice. In recent years, new social movements have begun to influence public dialogue, by popularising terms like structural racism, structural misogyny and group-based oppression. At this point in the history of political challenges to structural injustice, it would be a profound error and, indeed, an injustice, to overlook people living with dementia as a group who are in need of liberation too.

Chapter 2

Severe Cognitive Disability and the Relationship Between Moral and Social Equality

“I believe there is a sense of what Martin Luther King described as ‘the degenerating sense of nobodiness’ among many disabled people, especially those who are struggling with mental, terminal or chronic illness, old age and dementia.”[107]

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[107] Kate Swaffer, *What the Hell Happened to My Brain?: Living Beyond Dementia* (London: Jessica Kingsley Publishers, 2016), 190.

Introduction

In the previous chapter, I argued that people living with dementia are an oppressed social group, and that they face injustices when societies fail to accommodate their differences. This argument relies on the assumption that members of this group are owed *social equality*: that they are wronged when exposed to paradigm inequalities of power and status, such as domination, oppression and stigma. There may be some, however, who object to this assumption.

To use Ronald Dworkin's well-known phrase, *moral equality* is usually taken to be the "egalitarian plateau" on which theories of social justice (including theories of social equality) are built.[108] If this is right, then people living with dementia must be our *moral equals,* in the sense of possessing the same basic moral standing, if we are to have duties of social justice towards them. Yet, there are a number of influential moral philosophers who hold that severe cognitive disability, including advanced dementia, can strip a person of this status.[109] If *they* are right, then at least some members of this group would fall off of the egalitarian plateau and, consequently, would not be entitled to social justice.

Defending my assumption that people living with dementia are owed social equality, then, requires a disruption of this picture. This could be achieved by arguing that, either (i) moral equality is *not* a prerequisite for social equality, or (ii) *all* people living with dementia, however advanced their condition, *are* our moral equals. In section 1 of this chapter, I draw on work in care ethics to set out an argument for claim (i) but raise three problems that cannot be resolved without an account of moral equality: the inclusion, exclusion and justification problems. In section 2, I consider various accounts of moral equality, and demonstrate that

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[108] Ronald Dworkin, "Comment on Narveson: in Defense of Equality," *Social Philosophy and Policy* 1, no. 1 (1983): 25.

[109] See:
Jeff McMahan, "Challenges to Human Equality," *The Journal of Ethics* 12, no. 1 (2007): 93.
Peter Singer, "Speciesism and Moral Status," in *Cognitive Disability and its Challenge to Moral Philosophy*, ed. Eva F. Kittay and Licia Carlson (Chichester, UK: John Wiley & Sons, 2010), 330-332.

none can resolve the justification problem. Finally, in section 3, I adapt work from George Sher to set out an alternative view of moral equality which can solve all three problems *and* underpin claim (ii). I conclude that *all* people living with dementia are our moral equals because they possess a unique subjectivity, and that they are entitled to social equality when situated within a matrix of relationships that forms an *ethical community.*

1. Egalitarianism Without the Plateau

Even if moral equality were a prerequisite for social equality, few scholars would think it *the only* prerequisite. After all, the social contract tradition, which, broadly speaking, assigns duties of justice to all those covered by a hypothetical agreement on the terms of mutually advantageous co-operation, remains influential in contemporary political philosophy.[110] One way of defending the assumption that *all* people living with dementia are entitled to social equality, then, would be to *remove* moral equality from the list of prerequisites, while maintaining social requirements of this kind.

The social contract tradition itself, however, may be unsuited to this purpose. Indeed, both Eva Feder Kittay[111]and Martha Nussbaum[112] have criticised it for being incapable of treating people with severe cognitive disabilities as full members of society. In this section then, I will offer an alternative view on the origins of justice. Drawing on feminist care ethics, I outline the idea of the non-voluntary, pre-political, *ethical community*: a matrix of overlapping, affective, obligatory relationships within which *all* members are entitled to social

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[110] By this I mean both that John Rawls's version of this approach [see: John Rawls*, A Theory of Justice: Revised Edition* (Oxford: Oxford University Press, 1999)] remains widely supported, and that there are modern scholars defending or expanding upon contractarianism in general [for examples, see: Johanna Thoma, "Bargaining and the Impartiality of the Social Contract," *Philosophical Studies* 172, no. 12 (2015): 3333-3355, Nicholas Southwood, *Contractualism and the Foundations of Morality* (New York: Oxford University Press, 2010), and Ryan Muldoon, *Social Contract Theory for a Diverse World: Beyond Tolerance* (New York: Routledge, 2017)].

[111] Eva F. Kittay, *Love's Labor: Essays on Women, Equality and Dependency* (London: Routledge, 1999), 83-113.

[112] Martha C. Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* (Cambridge: Harvard University Press, 2006), 107-127.

equality. Though I defend the value of this approach, I identify three problems it faces which cannot be resolved without an underpinning account of moral equality: the inclusion, exclusion and justification problems. Thus, I conclude that the egalitarian plateau cannot be abandoned.

1.1 The Ethical Community

Kittay argues that the conception of the person implied by the social contract tradition is profoundly misleading; we are not born as individuals who seek social relationships voluntarily, but as dependent beings in social relationships with our primary caregivers, which must be maintained if we are to survive at all.[113] In feminist care ethics, these deep, affective, meaning-making bonds are thoughts to generate moral obligations through their intrinsic value, which precedes and would exist in the absence of institutional structures.[114] The caregivers of a person with a severe cognitive disability, on this view, have moral obligations towards that person because they are situated in such a relationship.

That these obligatory relationships can underpin duties of social justice, however, requires more argument. McMahan has challenged Kittay on this point, arguing that it is unclear how the existence of these obligations on primary caregivers can entail that others also owe duties to the recipient of care.[115] Of course, caregivers have duties to those who depend on them, but these cannot be generalised so that all members of society owe them justice: at least not without a further argument. Indeed, some care ethicists, such as Nel Noddings, who view care and justice as separate, often contradictory moral frameworks, might be inclined to agree with this.[116]

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[113] Kittay, *Love's Labor,* 60-64.

[114] Virginia Held, *The Ethics of Care: Personal, Political, and Global* (Oxford: Oxford University Press, 2006), 10-16.

[115] 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, UK: John Wiley & Sons, 2010), 410.

[116] Nel Noddings, *Caring: A Feminine Approach to Ethics & Moral Education* (Oakland: University of California Press, 2003), 1-6.

Yet, as Kittay responds, if duties of justice are owed to a caregiver, these may well involve just treatment of the people they care for.[117] The way their charge is treated, after all, may bear significantly on the social status of the caregiver and their ability to meet their needs. The affective bond between a dependent and their caregiver is, on this view, *embedded* within a wider matrix of obligatory relationships, which can be understood as something akin to a family.[118]

To understand this, consider three children raised by the same caregivers. They have affective, meaning-making, obligation-generating bonds with their caregivers, but it also seems quite natural to think they have these bonds with each other. If those siblings then become parents, their special obligations will come to include supporting one another (or, at least, refraining from obstructing one another) in meeting the needs of their dependents. These siblings might then form friendships from shared experiences which carry a similar, mutually affective character, or they may, as Kittay notes, develop practices with others so that they can transfer their caring duties when they cannot meet them.[119]

What this demonstrates is that non-voluntary, obligatory relationships are usually overlapping and interconnected. If we accept the idea that such relationships, through which needs are met that are necessary for survival, generate moral obligations, then this sprawling web of interrelated duties begins to resemble a pre-political form of society. On this view, even in the absence of institutions, there are special obligations that people embedded within it owe to one another, that have their basis in the duties of care owed to dependents.

These obligations, which entail a sense of togetherness and common endeavour, play an important role in David Miller's defence of liberal nationalism.[120] Political institutions, on this view, do not create duties of justice. Rather, members of the pre-political society, which,

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[117] Kittay, "The Personal is Philosophical is Political", 411.
[118] Kittay, "At the Margins of Moral Personhood," 111.
[119] Ibid.
[120] David Miller, "In Defence of Nationality," *Journal of Applied Philosophy* 10, no. 1 (1993), 7-9.

to paraphrase Miller, we can term the *ethical community*, create and uphold political institutions so that they can better meet the associative obligations they owe to one another.[121]

Although Miller envisages this community as coextensive with the nation, it need not necessarily be so; the reach of affective bonds across borders is a perceptible feature of our globalised world. Regardless, however large this community is, it provides us with clear conditions for an inclusive account of the origins of justice. From this perspective, justice demands that all members of the ethical community are treated as social equals, and that our political and social institutions be organised to better achieve that aim.[122] As the severity of a person's cognitive disability has no bearing on this status, all people living with dementia, within a given ethical community, have a claim to social justice.

1.2 The Inclusion Problem

The idea of the ethical community tells us that we have pre-political obligations of justice that extend from our duties towards dependents with whom we share affective relationships. What qualifies a relationship as such, however, is not immediately clear. The plants in a green house, for instance, are dependent on a gardener to create the conditions in which they can grow. Without temperature control, watering and attentiveness to removing pests from a particular other, these plants will not survive. If the gardener feels a strong sense of affection towards these plants, he might believe others owe them duties of justice on the ethical community account.

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[121] David Miller, *On Nationality* (Oxford: Clarendon Press, 1995), 41-43.

[122] Other scholars, such as Seth Lazar [see: Seth Lazar, "A Liberal Defence of (Some) Duties to Compatriots," Journal of Applied Philosophy 27, no. 3 (2010): 246-257] and Andrew Mason [see: Andrew Mason, "Special Obligations to Compatriots," Ethics 107, no. 3 (1997): 427-447], have defended similar accounts of the status of associative obligations. Such a view tracks common sense morality, but there may be some who are doubtful that this intuition can be justified. As I have implied here, I consider the focus on universal dependency and the need for care in feminist care ethics the most persuasive justification of this approach. Nevertheless, even this relies on an implicit axiological claim about the *value* of the survival of the human species. Consequently, those unpersuaded that there is anything valuable about our continued existence (or the value of care relationships to ensuring it), are likely to remain unconvinced.

The idea of plant dependency might seem glib, but this ambiguity also creates a problem for the resolution of real-world disputes. Consider, for instance, these slogans from the anti-abortion organisation Students for Life: “Women’s Rights Begin in the Womb”, “Black Preborn Lives Matter,” “A Person is a Person, No Matter How Small.”[123] It would be a mistake to view these merely as claims about the moral status of a foetus. These slogans explicitly invoke other social movements, so it is highly likely that some anti-abortion activists would think that relationships with foetuses, at any stage of development, generate the kind of special obligations that typify the ethical community.

Consider, also, the status of non-human animals. While the ethical community likely excludes the vast majority of animals who live in the wild and cannot be said to be part of our society, some share the social world with us. Indeed, Sue Donaldson and Will Kymlicka argue that domesticated animals ought to be treated as our co-citizens, due to the way they are integrated into our societies through labour, companionship and other social practices.[124] Consequently, it is also highly likely that pet owners, vegetarians or others with similar concerns would argue that non-human animals qualify as members of the ethical community.

These are fierce disputes that exist within our societies today; there are people who think it is obvious that foetuses are owed duties of justice, while it is absurd to think we owe them to animals (and vice-versa). These conflicts can only be resolved by specifying the relevant kind of affective dependency relationship further, which requires us to consider the kind of attributes a being must have to be able to be situated in it—i.e., to be a *bona fide* member of the ethical community. As this implicitly creates a division between those beings who matter equally and those who do not, adjudicating over these claims requires an account of moral equality.

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[123] Students for Life, "Good Pro-Life Sign Slogans," Students for Life, last modified May 5, 2020, https://studentsforlife.org/good-pro-life-sign-slogans/.

[124] Sue Donaldson and Will Kymlicka, *Zoopolis: A Political Theory of Animal Rights* (New York: Oxford University Press, 2011), 8-15.

1.3 The Exclusion Problem

As well as being potentially too inclusive, the ethical community account *sans moral equality* may also be too exclusionary, because it cannot tell us how we should treat outsiders. Indeed, it may imply that we have no moral obligations to those outside at all. The dangers of this are pretty clear if we think the ethical community is coextensive with the nation. After all, if we have no concept of moral equality, then we have no reason to believe that the lives of those outside of our nation are valuable or worth moral consideration. This opens up the possibility that one could claim to be a relational egalitarian while also believing that it is acceptable to kill, dominate or otherwise harm those outside of the nation-state—a kind of virulent, imperialist nationalism that Miller rightly argues is indefensible.[125]

Note too that the dangers remain present in a more cosmopolitan approach. Consider, for instance, the significant number of 'uncontacted peoples' who live without sustained contact with any other groups of humans.[126] Due to their isolation, members of these groups are highly unlikely to share the relevant bonds with anybody in the rest of the world. Consequently, they cannot be said to be embedded within the ethical community, which leads to the uncomfortable conclusion that, even if we adopt an internationalist approach, we have no stringent moral obligations towards them at all.

Without an account of moral equality, there are no resources within the ethical community account to specify duties to outsiders. Thus, they are at best uncertain and, at worst, non-existent. This bullet could, of course, be bitten, but it may lead to some distressing implications. For instance, it implies a retrospective justification for imperialism, in the sense that citizens of European nations, who were not embedded in a matrix of affective relationships with the peoples of the rest of the world, would have had no moral obligations to refrain from

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[125] David Miller, *On Nationality,* 15.

[126] Libby Gerstner, "The Right to Be Left Alone? Protecting "Uncontacted" Tribes of India and Brazil," *Tulane Journal of International and Comparative Law* 28, no. 1 (2019): 80-85.

colonisation. To avoid such implications, the account must solve the exclusion problem. It can only do so by appeal to some morally pertinent property which insiders share with outsiders: an account of moral equality.

1.4 The Justification Problem

Any conception of justice derived from the ethical community, if unmoored from moral equality, faces the same problems of inclusion and exclusion. In addition, there is a third problem which changes depending on the account of justice. The relational egalitarian version of this problem is as follows. The idea that we have obligations which arise from embeddedness in affective relationships is plausible – attractive even – but there is nothing inherent in the idea that suggests that these are obligations of *equality*. Indeed, if the smallest unit of the ethical community is the relationship between a dependent and a caregiver, then this account might just as easily entail a strongly hierarchical, paternalistic view of justice.

Note that it is not enough to say each person is an *equal member* of the community. Certainly, equal membership tells us that we are all equally entitled to justice, but this could easily be interpreted in a way that is incompatible with relational egalitarianism. For instance, a strongly hierarchical society based on prescriptive ideas about the role members of particular classes ought to play could claim to be treating them all as equal members, in the sense that they are all equally important to maintaining the social structure and, thus, are equally able to find fulfilment and purpose.

Of course, most relational egalitarians would think that such a structure is exploitative, domineering and marginalising, but there is no obvious way to reach that conclusion solely from the idea of equal membership. In part, this is because it is entirely possible that beings could be equal members of the community while possessing a different moral worth. More significantly, though, because the relationships cannot be specified further without an account of moral equality, it is unclear that they can generate specifically egalitarian duties of justice. There must be something substantive that is violated, mistreated or disrespected when inegalitarian relationships are established to label them unjust. Without an account of moral equality, however, this case cannot be made within the ethical community account of the origins of justice.

In sum, the ethical community approach faces intractable problems of inclusion, exclusion, and justification without a corresponding account of moral equality. Nevertheless, its inclusiveness of people with severe cognitive disabilities, in comparison to the social contract account, is valuable. That it cannot justify abandoning the egalitarian plateau, then, is no reason to jettison it. Thus, the remainder of this chapter is dedicated to identifying an inclusive account of moral equality, which can underpin the ethical community approach to the origins of relational egalitarian justice.

2. Prominent Accounts of Moral Equality and the Justification Problem

In this section, I will consider several prominent accounts of moral equality. While all provide clear enough answers to the inclusion and exclusion problems, they all fail to support a relational egalitarian approach to justice. I will, thus, argue that relational egalitarians must abandon them. By identifying their failures, however, I will ascertain desiderata for an inclusive account of moral equality which can solve all three problems.

2.1 Rational Agents

Moral equality by rational agency offers very clear answers to the inclusion and exclusion problems. Regarding inclusion, the ethical community would exclude all those who do not possess rational agency from the scope of justice. Regarding the exclusion problem, all rational agents would be viewed as morally equal, which means that those outside of the ethical community would be entitled to basic moral consideration.

Evidently, the rational agency account of moral equality excludes people with severe cognitive disabilities. Nevertheless, it is a widely held view among relational egalitarians. Fabian Schuppert, for example, argues that a relational egalitarian theory of justice should "refer to a set, or rather various sets, of social relations which allow each and every person to exercise their capacity for rational agency freely and autonomously."[127] Likewise, Stefan Gosepath argues that respecting the moral equality of rational agents[128] rules out arbitrary treatment, condemning all forms of oppression to which relational egalitarians are opposed.[129]

Rational agency seems to give a particularly useful and comprehensive answer to the justification problem. It is fairly straightforward, after all, to ground the claim that relationships of domination and oppression wrong rational agents: by, as Iris Marion Young holds, restraining the development and exercise of a person's capacities,[130] and, as Christian Schemmel argues, damaging their sense of themselves as a "free and effective agent."[131] As all rational agents have the requisite cognitive capacities to understand their relationships and the effects they have on each other's agency, it is fairly intuitive to think that they generate duties of non-domination and non-oppression.

However, while this account is adequately substantive, it falls at the hurdle of the justification problem, because it is far from clear that those who are rational agents are *equally*

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[127] Fabian Schuppert, *Freedom, Recognition and Non-Domination: A Republican Theory of (Global) Justice* (Berlin: Springer, 2013), 8.

[128] Stefan Gosepath, "On the (Re)Construction and Basic concepts of the Morality of Equal Respect," in *Do All Persons Have Equal Moral Worth?: On 'Basic Equality' and Equal Respect and Concern*, ed. Uwe Steinhoff (New York: Oxford University Press, USA, 2015), 131.

[129] Stefan Gosepath, "The Principles and the Presumption of Equality," in Social Equality: On What it had to be Equals, ed. Carina Fourie, Fabian Schuppert, and Ivo Wallimann-Helmer (New York: Oxford University Press, 2015), 172.

[130] Iris M. Young, *Justice and the Politics of Difference* (Princeton: Princeton University Press, 1990), 37.

[131] Christian Schemmel, "Why Relational Egalitarians Should Care About Distributions," *Social Theory and Practice* 37, no. 3 (2011): 366.

so.[132] Consider, for instance, how we might compare goal-oriented, successful scientists with reactive, impulsive artists and musicians. While not necessarily more *intelligent*, the former group are likely to exhibit traits associated with rationality such as reflectiveness, cautiousness or objectivity at a higher level. The latter, while not *incapable* of exhibiting these traits, are likely to do so to a lesser degree and, instead, exhibit traits like creativity or emotional intuitiveness.

To reach the conclusion that members of both groups are *equally* rational agents, as noted by Sher, a particular threshold must be placed upon the scale of rational agency, after which differences between people in this property are morally irrelevant.[133] The problem for these kinds of views, which has been identified by Richard Arneson, is that it seems entirely arbitrary that large variances *above* the threshold are irrelevant to moral status, while small variances *across* the threshold matter a great deal.[134] After all, P1, who has the lowest possible capacity for rational agency *over* the threshold, would share the same moral status with P2, who has the highest measurable capacity for rational agency. In contrast, P3, who has the highest possible capacity for rational agency *under* the threshold, would have a lower moral status than both P1 and P2 even though the difference between P2 and P3 is *much smaller* than the difference between P1 and P2.[135]

Despite this seemingly devastating objection to the idea that moral equality ought to be based on our rational agency, there have been a few attempts to salvage it. John Rawls's concept of a range-property is one such attempt. On this view, as long as the level at which people hold this scalar property lies within a particular range, they are moral equals, as they

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[132] Here I follow George Sher's helpful reconstruction of how the debate over rational agency and moral equality has unfolded; see: George Sher, "Why We are Moral Equals," in *Do All Persons Have Equal Moral Worth?: On 'Basic Equality' and Equal Respect and Concern*, ed. Uwe Steinhoff (New York: Oxford University Press, USA, 2015), 17-129.

[133] Sher, "Why We are Moral Equals", 19.

[134] Richard Arneson, "What, if Anything, Renders all Humans Morally Equal?," in *Singer and His Critics*, ed. Dale Jamieson (Hoboken: Wiley-Blackwell, 1999), 110

[135] Sher, "Why We are Moral Equals", 17-19.

are all equally within it.[136] As Ian Carter notes, however, there is no reason offered by Rawls for ignoring variation within the range nor for focusing on this range property over the scalar property it supervenes on.[137] Absent an independent argument, appealing to this range property appears like a convenient way to include all the people we like to think of as valuable in our notion of moral equality.

Carter himself tries to provide such an argument, contending that it is a requirement of human dignity that we take no account of empirical differences above a certain threshold: a concept he calls *opacity respect*.[138] However, as argued by George Sher, this is more plausibly read as an approach to social or political equality than as an approach to moral equality. Carter is telling us how we should relate to people once they reach a relevant threshold at which opacity respect is required to respect their human dignity. Presumably, however, not all beings are owed human dignity, which makes this property the real basis of moral equality in Carter's approach. Consequently, opacity respect offers no defence for the rational agency account of moral equality.[139]

Aside from being counter-intuitive to those of us who believe people with severe cognitive disabilities ought to be treated as social equals, then, moral equality by rational agency fails to solve the justification problem: because it is based on a property that is not equally shared. Consequently, even those unmoved by the claim that people with severe cognitive disabilities ought to be treated as social equals must concede that moral equality by rational agency is unsuitable for grounding the relational egalitarian conception of justice.

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[136] John Rawls, *A Theory of Justice* (Cambridge: Harvard University Press, 1999), 444.
[137] Ian Carter, "Respect and the Basis of Equality," *Ethics* 121, no. 3 (2011): 550-554.
[138] Ibid.
[139] Sher, "Why We are Moral Equals," 21.

2.2 Human Beings

Carter's appeal to human dignity prompts consideration of another widely held view: that humanity itself is the right grounding of our moral equality. Such a view certainly does well at solving the exclusion problem. From this point of view, any human outside of the ethical community is a moral equal and due moral consideration. Further, at first blush, it seems to offer a clear answer to the inclusion problem: only humans can share the kind of relationships that generate obligations of justice, because these relationships are distinctly human. And it also seems to answer the justification problem: the type of relationships humans have with one another bear on the capacity to live a live worthy of human dignity.

Yet, this resolution is less clear than it appears, given that the category 'human being' and the concept of 'human dignity' are subjects of dispute. To illustrate this, consider Nussbaum's capabilities approach. She argues that all humans require effective access to a list of central capabilities, derived from a conception of human dignity grounded on an Aristotelian emphasis on social relationships and a Marxian emphasis on needs.[140] However intuitive this may be, it is notable that she has conceded in co-authorship with Rosalind Dixon that human foetuses are included on this account.[141]

Now, as Nussbaum and Dixon argue, a rights-balancing argument could nevertheless justify abortion even with these claims in place.[142] However, while rights-balancing may be able to ensure that no specific person is morally required to carry *any* foetus in *all* circumstances, it cannot remove the equal moral status of the foetus, at any stage of development, if our moral equality is grounded on our humanity. Thus, in a near-future in

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[140] Martha C Nussbaum, *Frontiers of Justice*, 74-81.

[141] Rosalind Dixon and Martha C. Nussbaum, "Abortion, Dignity, and a Capabilities Approach," in *Feminist Constitutionalism: Global Perspectives*, ed. Beverley Baines, Daphne Barak-Erez, and Tsvi Kahana (Cambridge: Cambridge University Press, 2012), 70-74.

[142] Ibid.

which ectogenesis is possible, abortion would likely need to be banned, because justice would demand all foetuses a right to develop in artificial wombs.[143]

One way around this is to argue, as Elselijn Kingma does, that a foetus ought not to be considered a being in its own right but, rather, a part of the parent hosting it.[144] So understood, a foetus would not be a moral equal, because a foetus is simply a body part and will not be a human being in its own right unless it is born. Such an approach may be able to exclude the foetus from the ethical community in a large number of cases,[145] but this raises another question about the moral status of the huge number of embryos discarded in the process of in-vitro fertilisation (IVF).[146] These, after all, carry human DNA, can be said to be alive and are not a part of any other being. While full ectogenesis is not currently possible, if these embryos are human beings and, as such, moral equals with, when embedded in the relevant relationships, a claim to social equality, then justice might demand some kind of social structure which connects those intending to have children with them. An argument might even be made that producing new embryos rather than implanting those leftover from IVF represents some kind of systematic oppression or marginalisation.

Of course, a counter-intuitive answer to the inclusion problem is not a failure to answer it. Nevertheless, many relational egalitarians would be uncomfortable with this conclusion, and seek to dispute the inclusion of foetuses and especially embryos within the definition of 'human being.' This, however, is precisely the point; either to be a human being merely means to exist in a body comprised of human DNA or it means something more specific which is the subject of dispute. If the former, the equal moral status of foetuses and embryos (perhaps even

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[143] In fact, arguments of this kind are already being made; see: Bruce P. Blackshaw and Daniel Rodger, "Ectogenesis and the Case Against the Right to the Death of the Foetus," *Bioethics* 33, no. 1 (2019): 76-81.
[144] Elselijn Kingma, "Were You a Part of Your Mother?," *Mind* 128, no. 511 (2019), 609-646.
[145] There is an exceptionally tiny percentage of abortions that deliver an intact and partially viable foetus, which would have to be considered moral equals entitled to relational equality on this approach – which might create complications for this technique. See: Michael L. Gross, "Abortion and Neonaticide: Ethics, Practice and Policy in Four Nations," *Bioethics* 16, no. 3 (2002).
[146] M. Simopoulou et al., "Discarding IVF Embryos: Reporting on Global Practices," *Journal of Assisted Reproduction and Genetics* 36, no. 12 (2019): 2447-2457.

gametes!) must be accepted, if the latter, the account does not have the resources to adjudicate over this dispute.

Even were a resolution to be found, however, this account of moral equality falls at the hurdle of justification. Admittedly, Nussbaum's particular view on human dignity does have some of the resources to uphold a relational egalitarian account of justice. All humans are equal and are equally entitled to effective access to the central capabilities. Inegalitarian relationships that restrain this access are unjust. Indeed, Elizabeth Anderson makes use of Amartya Sen's version of the capabilities approach in her foundational contribution to this view.[147] A key problem, however, is that it is far from clear that the properties of sociability and deep need that underpin this list are defining features of human beings.

To illustrate this, consider once more the rational agency view of moral equality. Some might take the Kantian view that rational agency is the defining feature of humanity but, as the case of severe cognitive disabilities shows, not all humans possess it. Moreover, it is conceivably possible that intelligent aliens or genetically modified non-human animals could come to possess it. Therefore, moral equality by rational agency is not coextensive with moral equality by humanity, because not all humans are rational agents and not all rational agents (that could ever exist) are humans.[148]

Likewise, Nussbaum's account of human dignity is vulnerable to a similar objection: humans are not the only beings with deep needs, nor the only beings that form societies. Deep need and social relationships, then, also cannot be the defining feature of human beings. In fact, as Donaldson and Kymlicka note, our 'human' society contains several needy domesticated animals with whom we share relationships.[149] Consequently, just as the rational agency view, in principle, ought to consider highly cognitively developed non-human animals as moral

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[147] Elizabeth S. Anderson, "What is the Point of Equality?," *Ethics* 109, no. 2 (1999): 316-318.

[148] For a representative argument of this kind, see Jeff McMahan, *The Ethics of Killing: Problems at the Margins of Life* (New York: Oxford University Press, 2002), 189-215.

[149] Donaldson and Kymlicka, *Zoopolis*, 8-15.

equals, so too ought the Nussbaumian conception to include all beings which have such needs and build such relationships. If not, it is vulnerable to the charge of arbitrariness, as there is no principled reason offered for thinking of human needs and sociability as morally distinctive.

How might Nussbaum reply? Perhaps the capabilities approach could, instead, be understood as specifying what is necessary for human beings to fulfil their needs and socialise in a distinctively *human* way.[150] However, this would not justify treating humans as morally superior to non-human animals on its own, because there is no clear reason for thinking human ways of meeting needs and socialising are morally superior. Besides, what constitutes a distinctly human way of life is hugely debatable. A strongly hierarchical society, for instance, could justify its structure by arguing that fulfilling a place in a status hierarchy is a distinctively human way of living and, therefore, constitutive of human dignity. They might even appeal to the fact that most human societies in history appear to have been hierarchical to justify this.

The substantive criteria that underpin our moral equality must be able to rule out such a structure, but the resources necessary to do so are not present in the idea of moral equality by human dignity. Given this, it cannot solve the justification problem and, as such, is unsuitable for grounding the relational egalitarian approach to justice.

2.3 Needs and Being Some Mother's Child

Although the characteristics underpinning Nussbaum's conception of the person cannot be arbitrarily limited to human beings, they may not need to be abandoned. Perhaps, in a parallel move to the rational agency approach, moral equality could be grounded on the possession of deep needs that require social relationships to be met, regardless of our species. Such a conception would certainly offer clear answers to the inclusion and exclusion problems, although they would likely seem highly unintuitive to many.

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[150] Indeed, she does claim that the capabilities list is species-specific; Nussbaum, *Frontiers of Justice,* 325-333.

On the inclusion front, this conception would still struggle to justify excluding foetuses and IVF-curated embryos from the scope of relational equality. On the exclusion front, it would seem to require us to extend moral consideration beyond human beings outside of the ethical community, to encompass a large number of wild, non-human animals, all of whom are social and have deep needs. Again, an unintuitive answer is not a failure to answer, so a relational egalitarian might adopt it despite its revolutionary implications. Even if accepted, however, this account would fall at the hurdle of justification.

To see why, recall that the special class of human beings (and their hypothetical alien companions) who possess rational agency do not possess it equally; for this reason, moral equality by rational agency is implausible. Likewise, the much wider class of beings who require social relationships to meet deep needs also do not possess this property equally. People with severe cognitive disabilities, evidently, possess far greater needs than nondisabled humans and they are evidently far more dependent on social relationships to meet them. Outside of humanity (as this conception must go), the needs of solitary hunting mammals like domesticated cats are far fewer and they are far less dependent on others to meet them. Thus, just like rational agency, the possession of deep needs which must be met through social relationships is a scalar property and, therefore, unsuitable for grounding our moral equality.

Many, of course, would not even make it to the justification problem before rejecting this view; the inclusion of a vast number of nonhuman animals, alongside foetuses and discarded embryos, would be enough to render it entirely unattractive. There is, however, a more nuanced needs-based account of moral equality which has more intuitive boundaries and avoids the problems that plague scalar properties. On this account, we may all be differently needy, but no human can survive to adulthood without having been cared for by other humans.

This account, offered by Kittay, holds that we are all moral equals because we are all “some mother’s child.”[151]

This conception fares very well at the exclusion problem; all humans, whether a part of the ethical community or not, are equally some mother’s child and, thus, worthy of basic moral consideration. Wild animals, however, can survive without ever having been cared for by humans, so they are not automatically part of *our* ethical community.[152] On the inclusion front, all humans and, potentially, domesticated animals are our moral equals. Whether or not foetuses count as some mother’s child may be slightly more complicated, but it could be argued that the ability of embryos to survive is dependent on biological processes, rather than care and nurturing. Regarding domesticated animals, there may be room for debate, because they, by definition, are dependent on humans to survive. Wherever the boundaries land, however, some mother’s child is certainly less expansive than moral equality by relationship-dependent needs in isolation.

Nevertheless, this account still fails at justifying the relational egalitarian approach to justice: not because it is a scalar property but because it is far from clear how relationships of domination and oppression disrespect this equally shared status. Perhaps, one could argue that such treatment disrespects the time and effort parents dedicate to raising their child but, of course, not all parents expend equal amounts of energy, so it is unclear how this can ground a claim to egalitarian treatment. Alternatively, one might argue that such relationships *endanger* the relationship between mother and child, but this might raise the uncomfortable prospect of the moral permissibility of dominating persons whose mothers are deceased.

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[151] Eva F. Kittay, *Love's Labor: Essays on Women, Equality, and Dependency* (London: Routledge Press, 1999), 23-33.

[152] Of course, many wild animals cannot survive without being care for by *their* mothers, but this is only relevant to us if the relationship is embedded within our ethical community – if, for instance, these animals are housed in our zoos.

This claim should not be misunderstood; it is certainly possible that some conception of justice could be grounded on moral equality by being some mother's child. Social structures which actively degrade and treat particular people with contempt could be said to be disrespecting the fact that we all, equally, are beings who were once, or currently are, dependent on care and nurturing to develop. It is unlikely, however, that this can be extended to a prohibition on all relationships of oppression and domination.

Consider, for instance, a society in which all women have internalised patriarchal views on the appropriate roles they should play in society. Women are not only discouraged from earning independent incomes and being involved in decision-making but are legally prohibited from doing so. Despite this, they are treated lovingly and attentively by the men that dominate them and the social order is justified via a warped (but widely accepted) view of how best women flourish. Such treatment would be perfectly compatible with respect for the fact that we are all some mother's child, but it appears dominating and oppressive on a standard relational egalitarian analysis.

Thus, while moral equality by the status of being some mother's child can justify claims that certain kinds of harmful treatment are wrongful, it is not suitable for underpinning the relational egalitarian conception of justice as usually understood. After all, this is a distinctive view about how the quality of societal relationships, and the mere requirement that these relationships be caring or respectful of care fails to rule out social structures with these kinds of fixed, widely-held views of flourishing

In sum, rational agency, human dignity and being some mother's child are unsuitable candidates for accompanying an ethical community approach to relational egalitarian justice. Although all can offer clear answers to the inclusion and exclusion problems, all fail to solve the justification problem. Nevertheless, two key desiderata can be derived from the preceding discussion. Firstly, the property by which we are to be thought of as moral equals cannot be scalar. In other words, it must be a property which, when possessed, is possessed equally. Secondly, it must be substantive, in the sense that respect for it straightforwardly entails a prohibition on paradigmatic inegalitarian relationships

3. Unique Subjects in Affective Bonds

In this chapter thus far, I have defended an ethical community account of the origins of justice, but have argued that a corresponding account of moral equality is required to determine its membership. Having rejected several prominent accounts of moral equality, in this final section I will set out an alternative. This view, which holds that we are moral equals in virtue of our unique subjectivities, is adapted from work by George Sher. However, following criticism from Stan Husi, I reject certain criteria that underpin Sher's view, arguing instead that *all* subjects are moral equals, not just those that pursue aims. I then demonstrate how this account can effectively underpin the relational egalitarian approach to justice.

3.1 Subjectivity and the Justification Problem

Sher also rejects the theory of moral equality by rational agency. In its place, he seeks to defend his own account, inspired by Bernard Williams's claim that it is morally significant that different beings occupy their own epistemic viewpoints.[153] Our experiences of the world are unique, in the sense that no other being views and interacts with the world exactly as we do. They are also epistemically isolated, in the sense that we can never fully explain to others what it is like to be us.[154] This property is perhaps best explained by Thomas Nagel; a being has it if there is something it is like to be that being.[155]

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[153] Bernard Williams, "The Idea of Equality," in *Philosophy, Politics, and Society: Second Series*, ed. Peter Laslett and Walter G. Runciman (New York: Barnes and Noble, 1962), 117.
[154] Sher, *Why We are Moral Equals*, 20-25.
[155] Thomas Nagel, "What Is It Like to Be a Bat?," *The Philosophical Review* 83, no. 4 (1974): 437-438.

To be clear, though it is a necessary condition of subjectivity, this is quite distinct from the idea of moral equality by consciousness. There are those, for instance, that believe plants are conscious (at least in a very limited sense of the term), because they appear to exhibit intelligent behaviour like learning and processing complex information.[156] It is highly unlikely that plants are subjects, however, because their internal structures are too decentralised to possess an internal centre of phenomenological experience.[157] Unlike consciousness, which we can arguably have more or less of, subjectivity is binary; a being either has a unique viewpoint on the world arising from a flow of consciousness, or it does not. Thus, it meets the first desideratum for solving the justification problem: all who possess it, possess it equally.

Without further specification, however, it may not be substantive enough to meet the second desideratum: that it be the kind of property that triggers relational-egalitarian concern for its possessors. Now, respecting our possession of unique subjectivities might be able to ground some claims about justice – that we should have democratic decision-making structures that take account of each of our viewpoints, for instance. Nevertheless, because it is unclear how relationships like these can wrong a person in their capacity as a bearer of a unique viewpoint, it is less clear that it can ground an approach to justice that prohibits domination and oppression.

This concern can be met, however, with the following observation: we, as subjects, are not mere observers of the world, but actors within it. Thus, Sher argues that respecting our moral equality requires respecting our *pursuit of aims* that are derived from our unique viewpoints. These aims, he elaborates, entail four fundamental interests: in staying alive long enough to realise aims (the interest in life), in being free to form and revise them (the interest

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[156] Monica Gagliano, "The Mind of Plants: Thinking the Unthinkable," *Communicative & Integrative Biology* 10, no. 2 (2017).
[157] Michael Marder, "Plant Intentionality and the Phenomenological Framework of Plant Intelligence," *Plant Signaling & Behavior* 7, no. 11 (2012): 1371.

in freedom), in having what is needed to fulfil them (the interest in sufficiency) and in actually being successful in achieving them (the interest in success).[158]

If respecting a person as an equal in their capacity as a subject requires respecting these interests, the rationale for a relational egalitarian approach to justice becomes clearer. Domination of subjects is wrong, at least in part, because it frustrates their interest in freely forming and revising aims and, potentially, their interest in being successful in achieving them. Cultural imperialism and group-based stigma are also wrong on this account, because they denigrate the self-conceptions of minority groups in ways that arbitrarily restrain and limit the kind of aims they can form, while oppression by violence, self-evidently, disrespects their aim-related interests in life. Finally, relationships of exploitation and powerlessness are wrong because they restrain their victim's capacities to form and revise aims, deprive them of the social standing which is required to achieve many of them and, to paraphrase Young, put them in social-positions where their aim-related interests are structurally suppressed in order to fulfil those of powerful others.[159]

Relationships between aim-pursuing subjects can be said to generate obligations of this kind, because neither party to the relationship has any greater claim to pursue their aims than the other, given both are equally unique subjects. Thus, moral equality by aim-pursuing subjectivity, at first blush, seems to have the resources to ground the claim that members of the ethical community have obligations of relational egalitarian justice towards each other. Nevertheless, the account as offered by Sher faces two serious objections which undermine its plausibility.

Firstly, plants can turn towards light sources, attract beneficial insects and spread seeds in order to reproduce. When displaying this behaviour, some may argue that they aim without

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[158] Sher, "Why We are Moral Equals," 21.
[159] Iris M. Young, *Justice and the Politics of Difference* (Princeton: Princeton University Press, 1990), 50.

having the necessary experience of the world to be subjects.[160] If so, just as I argued that it would be arbitrary to separate humans from others by deep need or rational agency, because they are not exclusively human properties, so too would it be arbitrary to separate subjects from non-subjects when both can be said to pursue aims. This objection, perhaps, could be dealt with by further specifying what counts as an aim – though it should be noted that any such criterion risks excluding some people with severe cognitive disabilities.

The second objection, regardless, is not so easily dealt with. Sher specifies the following consciousness criteria a being must meet to be an aim-pursuing subject:

1. An understanding that the world is temporally as well as spatially ordered
2. A recognition that the being is an embodied subject who existed in the past and will exist in the future
3. An understanding that various forms of actions are possible
4. An understanding that the world gives reasons to do some things and not others
5. The ability to find out why they should do some things and not others.[161]

Even though these criteria can be held to differing degrees, Sher argues that this morally salient form of subjectivity (which would likely exclude many people with severe cognitive disabilities) is a binary matter: a being either has it or it does not. He runs into trouble, however, by admitting that these features are only *necessary* conditions of morally pertinent subjectivity, and that the list is inexhaustive.[162] As Husi argues, there may be many other features which affect our subjectivities, such as the capacity for empathy. Most people have this feature of subjectivity, but true sociopaths do not. Therefore, it is unclear why the true sociopath should share the same status as everyone else, while a person missing one of Sher's criteria would not.[163]

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[160] Lincoln Taiz et al., "Plants Neither Possess nor Require Consciousness," *Trends in Plant Science* 24, no. 8 (2019).
[161] Sher, "Why We are Moral Equals," 22-23.
[162] Ibid.
[163] Husi, "Why We (Almost Certainly) are Not Moral Equals," 399.

Husi thus contends that Sher is passing off a scalar property as binary.[164] Admittedly, Sher's view is that the possession of this kind of consciousness is binary because, without said cognitive features, it cannot exist.[165] However, Husi's criticism is not that the *level* of consciousness is scalar, but that there is a scale of *types of subjectivity* positioned more closely or further away from that which Sher specifies. This account, then, is vulnerable to the same criticism as all threshold accounts; it cannot explain why variations across the threshold matter while variations above the threshold do not.[166]

In response to Husi, Sher's account could be amended by jettisoning the consciousness criteria. On this view, *all* aim-pursuing subjects, no matter their differences in the ability to understand, defend and execute them, are moral equals. Such a view would be attractive, in the sense that it would be friendlier to the notion that people with severe cognitive disabilities are our moral equals. Yet Husi's criticisms may still hold. After all, it could be objected that not all subjects necessarily pursue aims. If we could conceive of a being which had such a window on the world, but did not experience intention, want, desire or investment, then even aim-pursuing subjectivity without the consciousness criteria rests on a scale.

This concern can be resolved, however, while remaining true to Williams's insight. While aim-pursuit may vary in its centrality to the lives of subjects, experience does not; all subjects are equally subjects because they all, equally, have a unique experience of the world.[167] It is uniqueness which is at the heart of this claim, not consciousness or the pursuit of aims. As the possession of subjectivity, regardless of the cognitive structures that underpin it or the

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[164] Stan Husi, "Why We (Almost Certainly) are Not Moral Equals," *The Journal of Ethics* 21, no. 4 (2017), 396.
[165] Sher, "Why We are Moral Equals." 22-23.
[166] Husi, "Why We (Almost Certainly) are Not Moral Equals," 400.
[167] Perhaps it could be objected that not all experiences are equally unique; some people's experiences are very similar, while some people face circumstances which make their experience far less comprehensible to the average person. This objection, however, confuses uniqueness with difference. While experiences can be more or less different from the average, they cannot be more or less unique. After all, something is unique if there is nothing else exactly like it. By analogy, live performances of jazz standards are unique in the sense that no two musicians play exactly alike. While they maybe more similar to each other than they are to, say, a live performance of Metallica's thrash metal song Master of Puppets, this does not bear on their uniqueness.

extent to which it influences aims, is a binary property, it is a plausible candidate for grounding moral equality *on its own*.

A concern may be raised that, by jettisoning both consciousness and the pursuit of aims, this account of moral equality loses justificatory power. After all, because the thought is that it is through a failure to respect them that inegalitarian relationships wrong subjects, Sher's aim-related interests are central to its ability to resolve the justification problem. Consider again, however, the proposed relationship between subjectivity and these interests; subjects use their unique experience of the world to produce aims, which entail interests in life, freedom, sufficiency and success. Even if we accept this picture, there is no clear reason to believe that their aims ought to be respected equally. After all, subjects' aims, on their own, are not always unique; consider the number of teenagers who aim to become pop musicians or frustrated millennials who aim to own property.

To ground relational egalitarian justice in these interests, a link between them and the *moral equality conferring uniqueness* of subjectivity is necessary. I propose they are linked by the concept of *authenticity*, understood broadly as the quality of being true to one's self.[168] As subjects possess unique experiences, they also possess unique ways of existing in the world. So understood, all subjects have the capacity to exist in accordance with the values, desires and other mental elements they derive from this unique epistemic viewpoint. Likewise, all subjects are vulnerable to being restrained, manipulated or otherwise prevented from exercising this capacity.

Accordingly, to the extent that their aims are to be respected, it is in virtue of the role they play in enabling these subjects to be true to themselves. Likewise, aims that subjects pursue through fear, manipulation or some other malign influence, may not be worthy of respect. In this sense, the interests in life, freedom, sufficiency and success are not

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[168] Charles Taylor, *The Ethics of Authenticity* (Cambridge: Harvard University Press, 1992), 14.

fundamentally aim-related, but authenticity-related; subjects have an interest in living authentically, in being free to develop and revise their authentic way of living, in having what is needed to live authentically and in being successful in doing so.

Understood this way, moral equality by unique subjectivity can ground relational egalitarian claims of justice as easily as its aim-pursuing cousin, if not more convincingly. Domination is wrong because it restrains a subject's interest in life and freedom by binding them to the will of another and allowing them to interfere in ways that disrespect their authentic wants and desires. Cultural imperialism and group-based stigma are wrong when they denigrate authentic experiences and ways of life, because they frustrate the interests of the individual members of this group in life, sufficiency and success. Finally, relationships of exploitation and powerlessness are wrong because they violate the interests in life and freedom, while depriving them of the social standing they require to live authentically.

There is considerable debate on what it means for a life to be authentic, and some versions of it may exclude people with severe cognitive disabilities.[169] In the next chapter, I will defend an account of authenticity as *non-alienation*, modified from John Christman, that offers clear criteria for determining when interests, aims and other mental elements are authentic. For now, however, it suffices to say that an appeal to authenticity, however cashed out, helps moral equality by unique subjectivity in solving the justification problem, because it identifies exactly what is at stake when the interests a being derives from its epistemic viewpoint are threatened. As this property is also binary and genuinely equally-shared, it is an ideal account of moral equality to undergird the relational egalitarian approach to justice.

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[169] This is particularly true of those that require some level of rational reflection. This seems to be implied by view of Soren Kierkegaard, [see: Soren Kierkegaard, *The Present Age,* trans. A. Dru (New York: Harper Torchbooks, 1962), 125-145], Martin Heidegger [see: Martin Heidegger, *Being and Time*, trans. J. Macquarrie and E. Robinson (Hoboken: Blackwell Publishing, 1967), 12-51] and, notably, Ronald Dworkin [see: Ronald Dworkin, *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* (London: Vintage Books, 1994), 201-130], whose view I will contend with in the next chapter.

3.2 Inclusion and Exclusion

Having demonstrated that moral equality by unique subjectivity can underpin the relational egalitarian approach to justice, all that remains is to cash out its solutions to the inclusion and exclusion problems. No doubt, many people will find its conclusions counterintuitive but, as I have argued, this does not mean it cannot answer the questions at all. Such controversy is inherent to the problems themselves; since each solution generates different counterintuitive results, no answer can be given which leaves everyone's initial intuitions undisturbed. Nevertheless, as this account is able to solve the justification problem where others have failed, I argue that relational egalitarians ought to endorse it as the most plausible option currently available.

Regarding inclusion, this account holds that all unique subjects deeply embedded in the matrix of mutual, affective and obligatory relationships that define the ethical community ought to be treated as social equals. This account includes all human adults and children, including those with severe cognitive disabilities. It does not, however, include embryos or early-stage foetuses, because humans do not possess the underlying neurological structures necessary to generate subjective experience until at least the twenty-fourth week of development.[170]

It *might* include late-term foetuses, especially if Kingma's argument does not hold, but the emergence of the relevant structures of consciousness tracks the legal term limit on abortions in most jurisdictions.[171] Besides, even if late-term foetuses are to be regarded as social equals, this does not preclude the kind of rights-balancing argument for the right to an abortion offered by Judith Jarvis Thomson; the fact that I am morally prohibited from dominating or oppressing someone does not strip me of my right to self-defence if they are seriously threatening my health or directly threatening my life.[172]

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[170] Hugo Lagercrantz, "The Emergence of Consciousness: Science and Ethics," *Seminars in Fetal and Neonatal Medicine* 19, no. 5 (2014): 300.

[171] Ibid.

[172] Judith J. Thomson, "A Defense of Abortion," *Philosophy and Public Affairs* 1, no. 1 (1971): 57-72.

The account also entails that, roughly in line with Donaldson and Kymlicka’s view, (at least some) domesticated animals could be situated in the kind of relationships that entail obligations of egalitarian justice. Although I will not take a stand here on the animals that could be in such a relationship, I emphasise that the ethical community account of justice ascribes moral obligations to *relationships*, not *interactions.* Humans do not have obligations of justice to wild animals who show no interest in human companionship. It is only when there is an affective bond, of the kind I specified in the first section, that the relationship generates special obligations. The bonds that dogs have with humans may, for instance, be of this kind, but wild rats who make their homes in human settlements would likely be excluded.

Within societies, this might require us to tighten up laws on animal abuse and, perhaps, cease to intensively farm livestock, but this should not be mistaken for a claim that animals need to be treated like humans. After all, it is intuitive to think that the species we belong to bears on what it means for us to live authentically.[173] To be educated, as far as possible, to use and develop tools or to wear clothing is not part of an authentically canine life. Systematically denying these things to humans would be oppressive and leave them vulnerable to domination, but it is not so for dogs. Even walking a dog with a leash, which would be utterly objectionable for a human, is not necessarily unjust, as long as it is not used in a way which violates their authenticity related interests. Given this, even for those sceptical of the idea that we can owe duties to animals, the way unique subjectivity solves the inclusion problem might not be so radical in practice.

Its answer to the exclusion problem, however, may be more controversial. While only those unique subjects who *can* form affective relationships with humans are ever candidates to be treated as equals by them, the account seems to imply that all outside of the ethical

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[173] For a full articulation of a similar view, see: Elizabeth Anderson, "Animal Rights and the Values of Nonhuman Life," in *Animal Rights: Current Debates and New Directions*, ed. Cass R. Sunstein and Martha C. Nussbaum (New York: Oxford University Press, 2004), 281-292.

community are owed basic moral consideration. This, of course, includes human adults and children, but it also includes wild animals who could never form such bonds with us.

Now, the idea that we owe some kind of moral consideration to these subjects is not necessarily the radical part. If basic moral consideration is taken to mean something like a restraint from interference, unless necessary for self-defence or survival, and a general prohibition on cruelty, then this would seem to track common intuitions; many people are aghast at those who hunt for sport, for example. The controversial idea is that they are owed the *same* moral consideration as humans outside of our ethical community. Even if we take the most cosmopolitan interpretation of the boundaries of our society, it seems to imply that the uncontacted peoples are only owed the same consideration as wild animals.

However, there are two reasons why we might afford a greater degree of moral consideration to some unique subjects outside of the ethical community, even if they are technically morally equal to the others. First, we might think of it as *constitutive* of our duties towards those inside our ethical community to treat beings like them with a greater degree of respect. The thought here would be that, if we treat human outsiders as equivalent to wild animals, this might perpetrate psychological harms on those within it: perhaps because it would suggest that, if society were to break down, others could just as easily kill them for survival, or because it might perpetuate the idea that it is acceptable to create moral divisions between humans in societies in which racism, sexism, ableism and other identity-based hierarchies already exist.[174]

Secondly, we might think we have special obligations towards those unique subjects with whom we *could* form the relevant affective bonds, even if we are not actually in them. They may not be as strenuous as those we owe to others within the ethical community, but they

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[174] This kind of argument is already present in the literature on immigration, see: Christopher H. Wellman, "Immigration and Freedom of Association," *Ethics* 119, no. 1 (October 2008): 137-141.

would be more demanding than those of basic moral consideration. Although this approach could be criticised as a case of making ‘some animals more equal than others’, the extra obligations may be independently justifiable. We might, for instance, think that we have an obligation to refrain from action which would prevent candidate beings from forming affective bonds with members of our ethical community.

Regardless, even if counterintuitive for some, moral equality by unique subjectivity succeeds in answering the inclusion, exclusion and justification problems. It is also fully inclusive of people with severe cognitive disabilities. It is, therefore, suitable for grounding an inclusive, ethical community based relational egalitarian approach to justice.

Conclusion

In this chapter, I have sought to justify the claim that people with severe cognitive disabilities, including those with advanced dementia, are entitled to be treated as social equals. Drawing on work in care ethics, I have argued that obligations of justice arise in the ethical community, made up of a matrix of obligatory, affective bonds. I noted, however, that an account of moral equality is necessary to adjudicate conflicting claims about the generation of these obligations. After testing candidate accounts, I defended the view of moral equality by unique subjectivity, adapted from Sher, which is substantive enough to justify a prohibition on paradigm inegalitarian relationships. People living with dementia then, no matter how severe, are wronged when they are dominated, oppressed or stigmatised, because such relationships fail to respect them in their capacity as *unique subjects capable of living authentically.*

Chapter 3

Determining the Authentic Interests of People Living with Dementia: The Case of Advance Directives

> "After they have spent years dealing with the impact of end-stage Alzheimer's on their loved ones, I have heard caregivers say out loud, 'it would be best for him if he died in his sleep. Mercifully, it should happen sooner rather than later.'
>
> Wait a minute here! Can we talk about this before you increase my pain medication? Pull the plug? Withdraw drugs, food, or water? What happened to me and the disease being separate entities? Am I now less human? Is my existence diminishing in lockstep and because of the progression of the disease? Is my existence less and less important because my shrinking brain is filled with the tangled plaques and dead cells caused by Alzheimer's disease?"[175]

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[175] Richard Taylor, *Alzheimer's from the Inside Out* (Baltimore, Maryland: Health Professions Press, 2007), 117.

Introduction

While studying at medical school, neurosurgeon Andrew Firlik met Margo, a woman living with advanced Alzheimer's disease. Though she painted the same picture every day, read through her mystery novels in a seemingly random order, and did not appear to be able to remember people's names, Firlik observed that she was "undeniably one of the happiest people [he had] ever known."[176]

Given her contentment, it might seem obvious that Margo ought to be provided with life-saving treatment, should she come to need it. The right course of action might seem less clear, however, had she signed an advance directive instructing medical practitioners to withhold such treatment, prior to the onset of dementia. In this scenario, set out by Ronald Dworkin,[177] there is an apparent conflict between Margo's past and present selves that makes substitute decision-making difficult. Unsurprisingly, then, it has been the subject of much dispute in medical ethics.

What is underappreciated, however, is the *political* nature of this case. After all, because Margo lacks the capacity to make medical decisions for herself, she is vulnerable to the power of others. If those others are not *restrained* from exercising that power in ways that do not *track her interests*, she is subject to *domination,* under Phillip Pettit's influential framework.[178] Thus, this case is not merely about what is *good* for Margo, but about *what justice demands.*

In the previous chapter, I argued that inegalitarian relationships wrong unique subjects in their capacity as *beings capable of living authentically*. On this view, interventions must track a person's *authentic* interests in order to be non-dominating: that is, those related to their claim, as moral equals, to be allowed to live in ways that are true to their unique viewpoint

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[176] Andrew D. Firlik, "Margo's Logo," *JAMA: The Journal of the American Medical Association* 265, no. 2 (1991): 201.

[177] Ronald Dworkin, *Life's Dominion: An Argument About Abortion, Euthanasia, and Individual Freedom* (London: Vintage Books, 1994), 226.

[178] Philip Pettit, "The Determinacy of Republican Policy: A Reply to McMahon," *Philosophy & Public Affairs* 34, no. 3 (2006): 275-276.

of the world.[179] Given this, a relational egalitarian response to this case must offer a framework for determining what constitutes living authentically for Margo. Thus this case is useful for elaborating on authenticity and the role it plays in my account of relational egalitarian justice.

As I demonstrate in section 1 of this chapter, Dworkin himself invokes authenticity in his response to the case. However, in section 2, I argue that Dworkin's integrity-oriented account of authenticity is undesirable, affirming instead a time-specific view. With this in place, I conclude that Margo's present contentment justifies overruling her advance directive. I then set out, in section 3, a number of recommendations for ensuring decisionmakers can arrive at interest-tracking decisions, even in complex cases.

1. Margo, Medical Ethics and Dworkin's Appeal to Authenticity

Two candidate principles are invoked in medico-legal contexts to determine the best course of action when a patient is deemed unable to make a decision for themselves: the *principle of respect for autonomy* and the *principle of beneficence towards patients*.[180] The former favours a *substituted judgment standard*, wherein the subjective viewpoint of the patient is reconstructed, with the aid of an advance directive where possible, to enact a decision they would have made for themselves. For patients who are temporarily incapacitated, this is thought to be the appropriate principle.[181] The latter principle favours a *best interests standard* which takes a more general view of interests and is thought to be more appropriate for patients who have never been rationally autonomous.[182]

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[179] This line of argument bears a resemblance to Pettit's emphasis on the need for interventions to track interests that are avowed or avowal-ready: that is, those constructed from a person's own perspective, rather than an objective view on their welfare. See: Philip Pettit, "The Determinacy of Republican Policy: A Reply to McMahon," *Philosophy & Public Affairs* 34, no. 3 (2006): 275-276.

[180] David C. Thomasma and Edmund D. Pellegrino, "The Role of the Family and Physicians in Decisions for Incompetent Patients," *Theoretical Medicine* 8, no. 3 (1987): 283-286.

[181] Karen B. Hirschman, Jennifer M. Kapo, and Jason H. Karlawish, "Why Doesn't a Family Member of a Person With Advanced Dementia Use a Substituted Judgment When Making a Decision for That Person?," *The American Journal of Geriatric Psychiatry* 14, no. 8 (2006): 659-661.

[182] Norman L. Cantor, "The Bane of Surrogate Decision-Making Defining The Best Interests of Never-Competent Persons," *Journal of Legal Medicine* 26, no. 2 (2005): 155-205.

Which principle to invoke in cases like Margo's, however, is the subject of dispute, because she used to possess rational competence, but her capacities have permanently declined. Dan Brock, for instance, argues that we should follow the principle of respecting autonomy and uphold advance directives in all such cases, as they represent autonomous choices made before such choices were no longer possible.[183] Rebecca Dresser, on the other hand, argues that Margo may no longer be the same being who signed the directive, so the principle of beneficence applies.[184]

Dworkin's own response is particularly interesting, however, because it effectively bypasses this debate; rather than arguing for either principle, he argues that both recommend upholding Margo's advance directive.[185] In this section, I set out both of Dworkin's arguments, and expose their reliance on an implicit appeal to the moral weight of authenticity. I then highlight the failure of his critics to fully engage with this implication, demonstrating the need to reject his view of authenticity before his conclusion can be rejected.

1.1 Dworkin's Argument from Autonomy

Overruling a person's apparent present wishes in favour of those expressed in the past might strike many as a strange way of respecting autonomy. Though Dworkin concedes this, he argues that this intuition is misguided, because it is based on a defective understanding of the grounds for respecting autonomy.[186] Those who hold *the evidentiary view* of autonomy, as he terms it, believe that we should respect autonomous decisions because people, in general, know what is in their best interests better than anyone else.[187] So understood, there is no conflict

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[183] Dan W. Brock, "Death and Dying: Euthanasia and Sustaining Life: Ethical Issues," in *Encyclopedia of Bioethics*, ed. Warren T. Reich (New York: Simon and Schuster, 1995), 563-572

[184] Rebecca Dresser, "Dworkin on Dementia: Elegant Theory, Questionable Policy," *The Hastings Center Report* 25, no. 6 (1995): 34-36.

[185] Ibid, 232.

[186] Ibid*,* 226.

[187] Ibid*,* 223.

between beneficence and autonomy; if people know what is in their best interests, then respecting their autonomy will always promote them.

The problem with this view, as Dworkin notes, is that it seems obviously counterfactual. The need for substitute decision-making in the case of Margo only arises, after all, because people living with advance dementia are often incapable of weighing decisions to come to a view of their best interests. Moreover, even cognitively non-disabled people make autonomous choices that clash with their stated best interests, such as those who claim to care about their health yet continue to smoke heavily. Thus, given its implausibility, he rejects the evidentiary view.[188]

Instead, he asks us to consider "people's general capacity to lead their lives out of a distinctive sense of their own character." Though many may never fully achieve it, he argues a person can use this capacity to reach a life that displays "*overall integrity*." This capacity, he claims, is at the core of what it means to be autonomous. Thus, on his *integrity view*, we must respect autonomous decisions, even if they are not wise, to protect every person's capacity to reach this goal.[189]

Though it is not explicitly spelled out in the text, this argument relies heavily on an implicit appeal to the importance of authenticity. After all, we are told that the capacity we have to live in a way that is true to ourselves, to live *authentically,* is of paramount importance and must be protected. Indeed, it is so important that it needs to be protected even if we do not exercise it to its full potential. In other words, Dworkin's argument is not that we should respect autonomy because all autonomous people *will* achieve a life of integrity or even that they *want* to; if it were, he would be making a similarly implausible claim to the one that undergirds the

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[188] Dworkin, *Life's Dominion,* 223.
[189] Ibid*,* 224.

evidentiary view. Rather it is because all autonomous people *can live authentically*, meaning they *may* achieve this goal if they are left to make their own choices.

In this sense, Dworkin does not just have an integrity-view of autonomy, but an *integrity-oriented view of authenticity*, upon which a person only has this capacity if they can make decisions motivated by determining the *overall character of their lives*. Margo, because she has advanced dementia, is unable to do this. She was, however, able to do this when she made the advance directive, so Dworkin concludes that respecting her autonomy requires upholding it.[190] Though he does not state it in these terms, the clear implication here is that we should reject any expressions of values and interests from Margo in the present-day, because they are *inauthentic*.

1.2 Dworkin's Argument from Beneficence

Even if we accept Dworkin's arguments about the basis of autonomy, the idea that we should not try to save the life of someone who is plainly content is intuitively troubling. Dworkin acknowledges this and suggests that some people may see a tension between what the principle of beneficence and the principle of respecting autonomy require.[191] He dismisses this perceived conflict however, arguing that it arises from a misguided view of what it means to act in someone's *best* interests.[192]

People, according to Dworkin, have two kinds of interests. On the one hand, they have *experiential interests*; things we do "because we like the experience of doing them."[193] On the other, they have *critical interests*: "interests that it does make their [lives] genuinely better to satisfy."[194] While both are important, Dworkin argues that acting in someone's *best* interests

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[190] Dworkin, *Life's Dominion,* 226.
[191] Ibid, 229.
[192] Ibid.
[193] Ibid, 201.
[194] Ibid.

means acting in light of the latter, as the latter represent choices that are "not only good at the moment but in character for them."[195]

Once again, though not stated explicitly, this argument appeals to the central importance of authenticity. After all, we are told that the primacy of critical interests is grounded in their relationship with a person's *character*. In other words, critical interests are more important than experiential interests, because only the former are derived from the same capacity Dworkin invokes in his argument from autonomy: the ability to live authentically, in pursuit of integrity.

As Margo lacks this capacity, Dworkin argues that she has "no contemporary opinion about [her] critical interests."[196] Nevertheless, he claims she still has them, because the way she lives now may affect the character of her life as a whole.[197] Thus, acting in her best interests, according to Dworkin, is acting in accordance with the advance directive, because it is the last expression of her opinion on her critical interests.[198] Again, though he does not state it in these terms, the clear implication here is that any present-day expression of interests from Margo is to be rejected as *inauthentic*.

1.3 Authenticity and Dworkin's Critics

These arguments from Dworkin are influential, but controversial. Two prominent critics of his approach are Agnieszka Jaworska and Rebecca Dresser, both of whom favour overruling the advance directive in the case of Margo. As compelling as these arguments are, however, both miss the mark, because they fail to respond to the appeal to authenticity underlying Dworkin's work.

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[195] Dworkin, *Life's Dominion*, 202.
[196] Ibid, 230.
[197] Ibid.
[198] Ibid*,* 235.

Consider, first, Jaworska's critiques. Drawing on empirical accounts of people living with Alzheimer's disease, she argues that even those with advanced dementia maintain a capacity to value, in the sense of being capable of holding something to be important to them. Mental elements created through this process are rightly called values, rather than desires, she argues, because the people that hold them (i) think they are correct in doing so, (ii) act in ways that suggest they are intimately connected to their self-worth and (iii) act in ways that suggest the importance of realising them is independent of their experiences.[199]

Thus, she argues that Margo may be capable of generating a contemporaneous opinion on these values, reflecting a *time-specific* sense of her character. If so, the principle of beneficence, on Dworkinian terms, may recommend overruling the directive.[200] Moreover, because Dworkin ties autonomy to our capacity to express our character, she argues that Margo may even be autonomous on his terms: even if she needs assistance to put these values into practice.[201] Thus, if she were right, the principle of respecting autonomy, on Dworkinian terms, would also recommend overruling the directive.

The problem with both of these approaches, however, is that they fail to fully engage with Dworkin's argument. Of course, he must concede that some people living with advanced dementia are capable of valuing, and he may need to concede that this allows them to generate a time-specific sense of character. Doing so, nevertheless, does not undermine his conclusion.

Crucially, Jaworska does not dispute the inability of those with advanced dementia to reflect on the way their decisions affect their lives as a whole. Accordingly, because these mental elements do not arise from the capacity to live authentically in pursuit of integrity, they are, on Dworkin's view, *inauthentic.* To overrule the directive, on Dworkinian terms, Jaworska would need to establish the *authenticity* of these present-day expressions of value. In order to

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[199] Agniezska Jaworska, "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value," *Philosophy & Public Affairs* 28, no. 2 (1999): 109.

[200] Ibid, 113-119.

[201] Ibid, 119-126.

do so, Dworkin's integrity-oriented view of authenticity would need to be rejected and replaced.

More promisingly, Dresser attempts to critique Dworkin on the grounds that few live their lives in pursuit of the kind of narrative coherence integrity requires. Instead, she suggests, many of us live our lives one day at a time, meaning experiential interests may be equally as or more important to us than critical interests.[202] Yet, this too fails to undermine Dworkin's conclusion. Whether or not people *exercise* their capacity to live authentically in pursuit of integrity has no obvious bearing on whether or not it is vital to protect it. Again, on Dworkin's view, experiential interests that are disconnected from this sense of narrative coherence are *inauthentic* and thus, not a person's *best* interests. Even if people genuinely value experiential interests over critical interests, then, Margo's advance directive, on Dworkinian terms, still ought to be respected.

Both Dresser and Jaworska could, of course, reject the claim that the authenticity of Margo's present-day values and interests matters, but this would lead to counterintuitive conclusions. After all, if I were to express a set of values while under the influence of a powerful hallucinogenic drug, which conflicted sharply with my sense of character before my state of mind was altered, it would be quite strange to think of them as authentic. Certainly, I would not want a medical practitioner to make health decisions on my behalf in the light of them. Appealing to authenticity helps to make sense of the idea that, if they were to do so, they would be acting unjustly.

Given this, alongside the parsimony that would be achieved by dismissing the autonomy-beneficence paradigm, it would be preferable to give compelling reasons for rejecting Dworkin's integrity-oriented view of authenticity and offer a coherent alternative. By doing so, contrary to the implications of Dworkin's arguments I have set out in this section, the

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[202] Dresser, *Dworkin on Dementia*, 36.

present-day expressions of interests and values from Margo and other people living with dementia could be rendered authentic and, thus, important enough to justify overruling advance directives.

2. Integrity, Authenticity and Non-Alienation

While neither Jaworska nor Dresser fully disarms Dworkin's response to the case of Margo, both offer useful resources for doing so. The fact that, as Dresser notes, many of us do not live our lives seeking narrative coherence, suggests there may be convincing reasons for rejecting it as the determining factor for authenticity. Likewise, Jaworska's thought that people living with advanced dementia can value in a way that reflects a time-specific sense of self suggests there may be an alternative way of viewing authenticity, which can capture the importance of these present-day values.

In this section I offer reasons for rejecting Dworkin's response to the case of Margo by building on these insights. First, I argue that it may not be possible for most of us to live a life of overall integrity, and that its pursuit is, in fact, undesirable. Second, I argue in favour of John Christman's view of authenticity as non-alienation, amending it to allow for external judgment. Thus, I conclude that Margo's present-day values, including her contentment with her life, *can* be authentic, even if they clash with those set out in her advance directive. This means that, in this case, the directive can be overruled.

2.1 Problematising the Integrity-Oriented Account of Authenticity

Dresser rightly notes that Dworkin's argument rests on a number of undefended empirical claims, yet her criticism fails because it is mistargeted; whether or not people *do* pursue integrity has little bearing on whether or not protecting *their capacity to reach it* is of moral importance.[203] What is relevant, however, is whether or not people *genuinely have this capacity*.

One reason to doubt that this capacity exists, at least in any widespread way, is that life resists narrative coherence. Events like severe illnesses, family tragedies and global conflicts can change the character of our lives dramatically and, because the future is unpredictable, few if any of us can plan for them in advance. The overwhelming majority of us, who cannot get through life without experiencing disruption to our plans, will consequently be highly unlikely to achieve the kind of narrative coherence implied by the notion of overall integrity. Most of us who are living through the Covid-19 pandemic, for example, are currently living in ways that would be alien to our past selves, and the character of our lives will be forever changed because of it.[204]

Even in the absence of dramatic events, moreover, sometimes things we once considered valuable or integral to our characters simply lose their appeal. For instance, when I was 18, I was the singer and main songwriter for a band, and I was certain that my life would be incomplete if I never had a chance to pursue music as a career. Many years later, having not achieved this success, it is no longer a part of my value set.

Now, a Dworkinian might say that I have simply *failed* to exercise my capacity to its fullest, because I spent my young adulthood pursuing something that was not genuinely valuable to me. Yet if that is the case, it seems unlikely that any of us can succeed in achieving a life of overall integrity. After all, it would seem that most of us *need* to make mistakes or pursue things that we lose interest in quickly—spending time in ways that threaten the narrative coherence of our lives—in order to discover things that we value more deeply.

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[203] Dresser, *Dworkin on Dementia*, 36.

[204] Indeed, as R. L. Berghmans argues, this uncertainty is a key problem with drawing up strict advance directives, as we are also unable to fully anticipate how events may change the character of our lives before they happen. See: R. L. Berghmans, "Advance Directives for Non-therapeutic Dementia Research: Some Ethical and Policy Considerations," *Journal of Medical Ethics* 24, no. 1 (1998): 36.

Alternatively, a Dworkinian could respond that changes in values through reflection are part of what it means to reach overall integrity. On this view, I can make sense of my desire to grace the front cover of rock magazines retrospectively, by tracing the evolution of the values and preferences I hold over time. The problem with this much looser notion of narrative consistency, however, is that it is difficult to see how anyone could fail to meet this goal. Even Margo, who does not have the capacity to do this retrospective reflection herself, will not jeopardise her overall narrative coherence by acting in ways contrary to her values before onset, because her dementia is merely a further chapter in the story.

This distinction between strong and weak narrative coherence speaks to the kernel of the dispute between Jaworska and Dworkin: whether or not the values that people living with dementia hold reflect their authentic characters. If narrative coherence refers only to being able to trace the evolution of character, values and preferences over time, then there is nothing problematic about a person's character changing due to the development of dementia. To deny the authenticity of the values Jaworska argues people living with dementia are capable of possessing, Dworkin must appeal to the stronger account. Yet, given the unpredictability of life and the way our values change over time, this goal would be very difficult for most of us to achieve.

A Dworkinian could respond to this by noting that difficulty is not incapacity; we could respond to life-changing events by digging into our values, even if this means having lower wellbeing because of our failure to adapt, and we could adhere to values we develop early in adulthood, even if they have begun to lose their appeal now. This response, however, highlights another flaw in this account of authenticity; the pursuit of overall integrity might be genuinely *undesirable*, for at least two reasons.

Firstly, there is growing recognition in therapeutic practice that many mental health issues are exacerbated by an overidentification with life narratives and an essentialising of character.[205] For example, the process of repeatedly telling themselves the same story about their lives and their character has been found to exacerbate suicidal ideation in people with symptoms of borderline personality disorder.[206]

A Dworkinian might respond by arguing that the integrity-oriented view does not exalt a life that is rigidly consistent in character. But this misses the point; the psychological evidence suggests that using overarching narratives to evaluate our lives and making categorical statements about who we are *actually inhibits our capacity for growth*. In this sense, the pursuit of overall integrity through narrative coherence can take on a *corrosively narcissistic quality.*

Moreover, it may also inhibit our ability to recover from trauma, given the fact that therapeutic professionals sometimes use a form of narrative therapy to help survivors of sexual abuse and violence to construct a new sense of themselves.[207] Adherence to an integrity-oriented account of authenticity requires us to view such techniques as a process of creating inauthentic mental elements, which seems wildly implausible.

Secondly, it is quite plausible to think that there are circumstances in which our preferences, values and commitments *should* change. We would be unlikely to think, for instance, that a white supremacist would be losing something worth protecting if they jettisoned their ideological commitments in the wake of an epiphany. Yet, if we were to follow the strong form of the integrity-oriented view of authenticity, we would be forced to conclude that such a person, were they to do so, would have failed in exercising a capacity that is of *central* moral importance, which seems equally implausible.

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[205] See: Gerben J. Westerhof, "Life Stories and Mental Health: The Role of Identification Processes in Theory and Interventions," *Narrative Works* 2, no. 1 (August 2012). https://journals.lib.unb.ca/index.php/NW/article/view/19501.
Matti Hyvärinen et al., eds., *Beyond Narrative Coherence* (Amsterdam: John Benjamins Publishing, 2010),

[206] J. Mark G. Williams, "Capture and Rumination, Functional Avoidance, and Executive Control (CaRFAX): Three Processes that Underlie Overgeneral Memory," *Cognition and Emotion* 20, no. 3-4 (January 2007): 548-568.

[207] Peggy Penn, "Rape Flashbacks: Constructing a New Narrative," *Family Process* 37, no. 3 (1998): 299-310.

There are both empirical and normative reasons, then, for doubting Dworkin's integrity-oriented account of authenticity; it is unclear that many people hold the capacity that underpins it, and it seems like that capacity might not be worth protecting. There is, thus, ample motivation to appeal to an alternative account.

2.2 Authenticity as Non-Alienation

Quite apart from its implausibility and undesirability, there seems to be a bias towards the cognitive in the integrity-oriented view, which renders authenticity primarily a matter of our thoughts. On this view, we have a life narrative arrived at through rational reflection, and the authenticity of our mental elements depends on their compatibility with this imagined life, however they may *feel* in the moment. Yet, much of how we talk about authenticity in everyday contexts revolves around how it *feels*; we might, for instance, feel energised, complete, understood or validated when we engage in activities that feel authentic to us.

Once this emotional component of authenticity is highlighted, it seems utterly bizarre to automatically discount the present-day values of Margo and others like her. After all, most if not all people living with dementia continue to experience and display a full range of emotions.[208] Thus, though they may not be able to *reflect* on what is important to them or generate an *opinion* about it, they may still be able to generate contemporary *feelings* of significance, including those related to authenticity.

To determine this in particular cases, however, an emotionally-informed account of authenticity is needed. One promising account is offered by Christman, who describes

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[208] See:
Alaine E. Reschke-Hernández et al., "Hooked on a Feeling: Influence of Brief Exposure to Familiar Music on Feelings of Emotion in Individuals with Alzheimer's Disease," *Journal of Alzheimer's Disease* 78, no. 3 (2020): 1019-1031.
Edmarie Guzmán-Vélez, Justin S. Feinstein, and Daniel Tranel, "Feelings Without Memory in Alzheimer Disease," *Cognitive And Behavioral Neurology* 27, no. 3 (2014): 117-129.
Stephanie Wong et al., "Should I Trust You? Learning and Memory of Social Interactions in Dementia," *Neuropsychologia* 104 (2017): 157-167.

authenticity as a state of non-alienation. On this view, a mental element, such as a value or belief, is inauthentic to a person if they would, upon reflection over a variety of circumstances, feel a deep need to repudiate it. All those they would not be alienated from in this way are authentic, given they form the person's settled disposition.[209]

Vitally, because Christman wants to allow for the authenticity of mental elements we have not chosen, he does not require a person to actually reflect in this way.[210] The gender identity of a cisgender man, for instance, is not inauthentic on this account just because he did not choose it and has never reflected on it. Rather, the reflection is *hypothetical*, concerning how a person *would* feel if they were to reflect, under the right conditions, whether or not they can or choose to do so.[211]

Alongside the need for the hypothetical reflection to be iterated across a variety of circumstances, Christman stipulates that it must take place "without constriction, pathology, or manipulation."[212] This is important to distinguishing unchosen, but potentially authentic mental elements—such as an aversion to smoking instilled by a skilled hypnotist—from covertly instilled *adaptive preferences*, which a person may not be able to identify as inauthentic while still exposed to the malign influences that produced them.[213] It creates a problem for the view that Margo can generate authentic mental elements, however, as dementia is commonly understood as such a pathology.

No doubt, Margo cannot be autonomous in Christman's terms, as she lacks the rational capacities necessary to reflect on her mental elements and the actions she can take in light of them.[214] However, given he does not require the reflection to actually take place, only a small

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[209] John Christman, *The Politics of Persons: Individual Autonomy and Socio-historical Selves* (Cambridge: Cambridge University Press, 2009)
152-153.

[210] Ibid*,* 145.

[211] Ibid, 147.

[212] Ibid.

[213] Ben Colburn, "Autonomy and Adaptive Preferences," *Utilitas* 23, no.1 (2011): 64-68.

[214] Christman, *The Politics of Persons*, 154.

modification to Christman’s view is needed to render some of her contemporary values and desires authentic. Through *external reflection*, decisionmakers could use evidence of her dispositions, behaviours and stated preferences, across a variety of circumstances, to determine how she would feel about these mental elements *if she were capable of reflecting upon them*. Where there is obvious evidence that they would be alienating, they can be considered inauthentic, where no such evidence exists, they can be considered authentic.

Of course, there are two the different counterfactuals implied by this ‘if’. The first concerns how Margo’s past self, before the onset of dementia, would feel about these mental elements. In this case Margo would be extremely likely to repudiate her present preferences, as she signed the advance directive in the first place. However—and this is the crucial insight—*this Margo is missing information which is central to the decision being made.*

As Dresser notes, before onset, Margo would not have been aware of the experience of living with dementia nor of the therapeutic options that would be available to her once it developed.[215] Moreover, as Emily Walsh argues, dementia is a cognitive transformation, which changes the way a person views themselves.[216] Given this, Margo before the onset of dementia is not a reliable benchmark for what is authentic to her now, as there was no way she could have known what living with dementia would feel like.

The relevant counterfactual for present-day Margo, then, *is present-day Margo*—with the added capacity to reflect on the advance directive and the preferences she now holds. When deciding whether or not to execute the advance directive, determining whether or not Margo would be alienated requires engaging in this reflection *for her*. Given what we know of her, that she is the happiest person Firlik has ever met and that this contentment was apparent to him on multiple occasions, it seems as if Margo would be highly unlikely to repudiate her clear

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[215] Dresser, *Dworkin on Dementia,* 35.

[216] Emily Walsh, "Cognitive Transformation, Dementia, and the Moral Weight of Advance Directives," *The American Journal of Bioethics* 20, no. 8 (2020): 59.

contentment with her living situation and would be much more likely to be alienated from the preferences implied by the advance directive. So it goes, I argue, for all similarly situated persons with dementia.

A sceptic might respond that the variety of imagined points of reflection must include circumstances in which she does not have dementia. Such a claim, however, would profoundly misunderstand both the nature of dementia and the point of this reflective process. This is a condition that is typified by progressive cognitive decline for which there is currently no cure; in every possible circumstance in which we imagine Margo reflecting on her desire to live, she would have dementia. There is little point in considering how Margo would feel in near-impossible counterfactuals, because there is nothing at stake; this deep sense of alienation that accompanies an inauthentic desire would never come to pass.

A more nuanced critique would be to suggest that the very addition of the capacity to reflect might change Margo's preference set. So understood, we are taking Margo out of one of the effects of her dementia and asking her to decide whether she wants to carry on living with it once the reflective process is over. Here Margo might become influenced by the kind of narrative concerns that underline Dworkin's argument from integrity, and although we have no evidence that she would be deeply alienated from her experiential pleasure, she might suddenly decide she is concerned about how living with dementia will affect the character of her life.

This may be conceivable but, from the evidence we have, it does not seem relevant. Inevitably, there is some epistemic uncertainty involved in engaging in a reflective process from the outside, and decisionmakers will need to avoid becoming too drawn into a discussion about how added capacities might affect preference sets. As Margo will never cease to have dementia, any conceivable concern about narrative coherence that she does not currently possess but might arise from the hypothetical granting of reflective prowess is moot.

The outside party is only seeking to determine which actually existing mental elements represent a stable disposition; they need not consider any hypothetical preferences which are not currently evident. Where there are conflicting behaviours or indicators of angst, decisionmakers must take seriously the possibility of alienation. However, in a case like Margo, where a preference to continue living is stable and unchallenged, there is little reason to suspect these elements are inauthentic, even if they clash with her advance directive.[217]

In sum, Dworkin's account of authenticity as orientation toward integrity is implausible, undesirable and, crucially, neglectful of the emotional component of authenticity. I have argued, instead, in favour of an adapted version of Christman's account of authenticity as non-alienation. On this account, because there is no evidence to suggest Margo would be deeply alienated from her present values, preferences and ways of living upon reflection across a variety of circumstances, they can be considered authentic.

3. Advance Directives and Non-Dominating Substitute Decision-Making

At the outset of the chapter, I argued that substitute decisionmakers must track the authentic interests of the patients they are deciding for to avoid domination. I then rejected Dworkin's integrity-oriented view of authenticity in favour of Christman's non-alienation account, concluding that, on the latter, the present-day mental elements of people living with dementia can be authentic. By implication, then, a policy of blanket adherence to advance directives enables domination. After all, because they may clash with the authentic, present-day values

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[217] This feature of the view is important in differentiating it from cases of addiction or cases of temporary states from which a person would recover. For instance, if an alcoholic gives the key to his wine cooler to his partner and asks her not to give it back to him, even if he asks, a craving may not be an authentic mental element because it is one that we have good reason to believe he will repudiate with that craving removed. Of course, it might be the case that the alcoholic would deeply repudiate his intention to quit drinking while he is experiencing a craving but, if this is the case – if he is truly alienated – then we have no choice but to conclude that his intention to quit is not yet a settled part of his character.

of their bearers, decisions adhering to them may be interfering in a way that no longer tracks a person's authentic interests.

In Margo's case, then, the advance directive ought to be overruled; Firlik describes her contentment with her life as consistent and unyielding, and the rationale for her hypothetical advance directive, at least as laid out by Dworkin, consists only of a desire to not live with dementia that no longer seems present or authentic. Thus, it is reasonable to infer an authentic interest in continuing to live, that any decision over her medical treatment must track.

Equally, however, were Margo to express consistent and unyielding discontent with her life, it seems fairly clear that adhering to the advance directive would track her authentic interests. After all, Margo's advance directive tells us that, before its onset, she believed that living with dementia would be incompatible with her authentic values. If there is no evidence that this belief has changed, then there is no reason to believe that she would be alienated from that value statement upon hypothetical reflection. Thus, a blanket policy of disregarding or prohibiting advance directives in cases of dementia would also be dominating.

It should be noted that Dresser would likely object to this view, given her scepticism towards the idea that present and past Margo are the same person.[218] The notion that dementia causes a loss of identity, however, is specifically highlighted by Christine Bryden as a contributor to stigma, which fails to take account of the continuity of the person's ability to distinguish themselves from others and "develop a sense of identity in the present moment."[219] As relational egalitarian societies should avoid promoting unjust stigma, there are good reasons to reject this identity-altering view on the validity of advance directives.

Indeed, to those friendly to relational egalitarianism, the need to maintain advance directives should be clear. Decisionmakers wield considerable power over the lives of patients

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[218] Dresser, "Dworkin on Dementia", 35.

[219] Christine Bryden, *Will I Still Be Me?: Finding a Continuing Sense of Self in the Lived Experience of Dementia* (London: Jessica Kingsley Publishers, 2018), 10-14.

who lack the capacity to make medical decisions, and advance directives can act as a highly effective way of constraining it. My stipulation that they must be defeasible to avoid domination, however, might raise some concerns.

After all, many if not most real-life scenarios will be more complex than the case of Margo, leading to at least two types of difficulty. First, the settled disposition of the patient may not be readily apparent, so there may be conflicting views on its content among relevant parties. Second, it may not be easy to determine whether a medical decision is in a person's authentic *interests*, even if their authentic *value-set* has been determined. Freedom from non-interest tracking interventions may be hard to guarantee, then, unless decisionmakers have clear guidance to cope with these difficulties.

Fortunately, there are two crucial aspects of the case of Margo that may help to shape such guidance. Firstly, Firlik met her in a variety of circumstances and interacted with her over a significant period of time, lending credence to his claims about her contentment. Secondly, Dworkin's imagined advance directive is fairly specific; it states that Margo does not want *any* life-saving treatment in the event that she develops dementia, because living with dementia is incompatible with her values. Consequently, a decisionmaker can confidently justify overruling the advance directive, because her authentic contentment with her life stands as evidence that *she no longer holds the values underpinning it.*

It stands to reason, then, that a non-dominating, relational egalitarian society ought to make every effort to replicate these conditions in all such cases. For example, if decisionmakers were required to seek testimony from a number of the patient's associates or interact with them in a number of scenarios, then they would attain a clearer picture of their present-day values. Moreover, if a person living with dementia's carers were required to document apparent changes in behaviour or other expressions of value, then the decisionmaker would have access to a wealth of relevant information, even in time-sensitive, emergency scenarios.

For these practices to operate successfully, however, it is crucial for the status and content of advance directives to be as clear as possible. In my analysis of the case of Margo, I have assumed that the values represented by the advance directive are to be assumed authentic *unless proven otherwise*, and there are good reasons for a relational egalitarian society to formally imbue them with this status. After all, doing so narrows the scope of relevant considerations; rather than searching for evidence of a potentially infinite list of values a patient might have, the decisionmaker need only determine whether the values underpinning the advance directive *are still present*.

Nevertheless, an advance directive cannot effectively play this role if it is vaguely worded. If, for instance, it is merely a formulaic checklist of interventions the patient consents to, with no underlying reasoning provided, then the decisionmaker will not know what the relevant values are. Moreover, it cannot play this role if it does not exist; where people living with dementia do not have advance directives, a decisionmaker will struggle both to focus their investigations and to determine how their authentic values, should they be able to determine them, interact with particular medical decisions.

Therefore, it would be advisable for a relational egalitarian society to make advance directives, with stringent requirements on the amount of detail they should contain, mandatory. For instance, all citizens could be required to maintain a regularly updated list of interventions they do not wish to receive in the event that they are unable to make a decision, with an accompanying note on the values informing their reasoning. Were they to do so, it would both be easier to determine a person living with dementia's authentic value-set and come to a decision that tracks their authentic interests, even in complex scenarios.

Consider, for example, a person living with dementia who has signed an advance directive rejecting a number of treatments that risk causing permanent incontinence, because they believe this to be an intolerable indignity. If that person has experienced sporadic episodes of incontinence without seeming bothered by it, then a decisionmaker can reasonably assume that the values underpinning this decision are no longer present. Thus, they can authorise a medical practitioner to proceed with one of these treatments, should it be necessary, because it is in no-one's authentic interests to be forced to abide by values they no longer hold. On the other hand, if they have displayed obvious distress during episodes of incontinence or, even if they have not experienced them, shown no evidence of having changed their mind, then the decisionmaker can confidently uphold the directive.

Of course, in clinical practice, there are decisions that must be made whose outcomes are not easy to predict: intensive cancer interventions which put the body under extreme stress but offer chances of recovery that vary from case to case, for instance. Nevertheless, were these mandatory, detailed advanced directives to contain information on the person's attitude towards risks, decisionmakers could assess whether this attitude is still present and recommend decisions accordingly.

These suggestions: that decisionmakers should be required to seek information from a wide range of sources and that advance directives should be mandatory, detailed, and treated as authentic until proven otherwise, are tentative. It may be that concerns I have not mentioned here problematise these procedures or require others to be produced. Nevertheless, they illustrate that it is *possible* for a relational egalitarian society to robustly guarantee freedom from non-interest tracking medical interventions, even in cases of uncertainty or complexity.

Conclusion

In this chapter, I have used the case of advance directives to specify the content of and role played by authenticity in my account of relational egalitarianism. I have argued that substitute medical decision-making risks domination, unless decisionmakers are forced to track the *authentic* interests of their patients. I have rejected Dworkin's integrity-oriented view of authenticity in favour of (a modified version of) Christman's non-alienation view, and I have argued that, on the latter, people living with dementia's present-day preferences can be authentic. Further, I have set out a series of suggestions for determining these value-sets in complex cases and robustly guaranteeing that medical decisions track the interests that arise from them.

The arguments of this chapter cohere with a growing acceptance of the moral weight of present-day preferences in the decisionally-impaired[220] and of the importance of authenticity in surrogate decision-making.[221] They are novel, however, because they suggest a methodological framework for coming to decisions in cases of dementia. Achieving non-dominating substitute decision-making may not be entirely within the gift of practitioners, but these arguments suggest a pathway for doing so through structural, political change.

In the context of this thesis, these arguments underlie much of the analysis to come. People living with dementia can generate a present-day set of values that are authentic, in the sense of being non-alienating. When decisions are made for them, they must track the authentic interests derived from them. To avoid subjecting them to domination, societal change is necessary to robustly guarantee those interests will be tracked. This is true for medical care and, as I will demonstrate in the coming chapters, so too is it true for social care.

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[220] See:
Nancy Berlinger, "You Can't Always Get (or Give) What You Want: Preferences and Their Limits," *Hastings Center Report* 48, no. 3 (2018).
Jason A. Wasserman and Mark C. Navin, "Capacity for Preferences: Respecting Patients with Compromised Decision-Making," *Hastings Center Report* 48, no. 3 (2018).

[221] Daniel Brudney, "Choosing for Another: Beyond Autonomy and Best Interests," *Hastings Center Report* 39, no. 2 (2009).
Daniel Brudney and John Lantos, "Agency and Authenticity: Which Value Grounds Patient Choice?," *Theoretical Medicine and Bioethics* 32, no. 4 (2011).

Chapter 4

The Indirect-First Approach: Towards Non-Dominating Dementia Care

> "If you take over our lives, then it is so easy for us to withdraw into helplessness. Life is so hard anyway, and you can make it so much easier for us. But in so doing, because we need constant repeating of actions and thoughts to keep remembering, we will lose functions daily. It would of course be easier to give up and withdraw and be helped in every way. I wouldn't have to struggle. But then I fear I would lose so much function, as each day I have to try harder to remember what skills I still have."[222]

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[222] Christine Bryden, *Dancing with Dementia: My Story of Living Positively with Dementia* (London: Jessica Kingsley Publishers, 2005), 103.

Introduction

In a hospital in Hull in 2015, a man living with dementia died after mistakenly drinking a large amount of hand sanitizer.[223] Cases like these exemplify the vulnerability to harm engendered by the development of dementia, prompting the common intuition that some level of interference is required to keep those who live with it safe. After all, had someone been present and capable of preventing this tragic accident, most of us would have expected them to do so.

Inevitable as it is, interference of this kind need not be dominating in the sense used by neo-republicans and (most) relational egalitarians.[224] As set out in the last chapter, decisionmakers can wield power over people living with dementia justly as long as the interventions track their authentic interests, and it seems highly intuitive to think that swiping a bottle of hand sanitizer out of the hands of someone trying to drink it, whether they have dementia or not, meets this standard.

Rather than improving their ability to react in this way, however, the hospital elected to redesign their dementia ward so that hand sanitizer was inaccessible to its patients.[225] Though this might not initially seem troubling, many people would have strong objections if they were exposed to *indirect* interventions of this kind, which seek to promote good choices by exercising control over the environment in which they are made. After all, few if any of us would think that having our choice-set severely restricted or altered by others tracks our interests, especially if it were justified on the grounds that we could not be trusted to choose well for ourselves without the change.[226]

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[223] Tanveer Mann, "NHS Staff Warned After Dementia Patient Died from Drinking Hand Sanitiser," Metro, last modified December 12, 2019, https://metro.co.uk/2017/06/03/dementia-patient-76-died-after-drinking-hand-sanitiser-at-hospital-6682056/.

[224] Rekha Nath, "Relational Egalitarianism," *Philosophy Compass* 15, no. 7 (2020).

[225] Tanveer Mann, "NHS Staff Warned After Dementia Patient Died from Drinking Hand Sanitiser," Metro, last modified December 12, 2019, https://metro.co.uk/2017/06/03/dementia-patient-76-died-after-drinking-hand-sanitiser-at-hospital-6682056/.

[226] Of course, we may be more receptive if they are justified on the grounds of preventing harm to others; many people supported interventions like lockdowns and mask mandates during the Covid-19 pandemic, for instance.

Nevertheless, in this chapter I argue that indirect intervention of this kind offers the best prospects for establishing a non-dominating system of social care for people living with dementia. In section 1, I lay out a working definition of dementia care. In section 2, I make the case against direct intervention, and elaborate on my proposed 'indirect-first' approach using examples. Finally, in section 3, I consider and reject two objections to the indirect-first approach: (i) that it is objectionably paternalistic, and (ii) that the amount of monitoring necessary to robustly ensure its use would unfairly expose carers to relational injustices.

1. What is Dementia Care?

Before considering different approaches to it, it is necessary to gain some clarity on what dementia care actually is. Care, after all, is a notoriously slippery concept; Virginia Held highlights its polysemous nature by observing that, among many other senses: we tell people to take care when they leave, we sometimes talk about caring for particular kinds of music, and we often speak of caring about political issues.[227]

Of course, it is possible to care for someone living with dementia in many of these senses, but they may not always accompany the provision of *dementia care*. After all, it seems unlikely that abusive or neglectful carers *care about* the people living with dementia they work with, but it still seems more accurate to say they are providing care *badly* than that they are not providing it *at all*. There is, thus, a distinction between care *as an activity* and care as a value, practice or feeling. The indirect-first approach, as I defend it here, concerns only the former.

Even when specified in this way, however, the boundaries of care are fuzzy and difficult to define. Indeed, many definitions are overly broad or otherwise implausible. Joan Tronto, for instance, defines caring as, "everything we do to maintain, continue and develop our world so

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[227] Virginia Held, *The Ethics of Care: Personal, Political, and Global* (Oxford: Oxford University Press, 2006), 30.

that we can live in it as well as possible."[228] Admittedly, this covers most if not all of the activities involved in dementia care, but it also includes activities that have little to do with it.

The atomic bombs dropped by the US military on Japan, at least on one common reading of history, hastened the end of the Second World War, helping to *maintain and continue the world* by rescuing it from a state of war between powerful states, and helping to *develop* it by ensuring the defeat of fascism, ensuring that *we would live in it as well as possible*. Yet, it seems absurd to think that devastatingly violent acts of warfare are caring activities, as Tronto's definition seems to imply.

Diemut Bubeck offers a more precise definition, where caring refers to "the meeting of the needs of one person by another person, where face-to-face interaction between carer and cared-for is a crucial element of the overall activity and where the need is of such a nature that it cannot possibly be met by the person in need herself."[229] However, while these conditions are specific enough to avoid pulling in activities that obviously have little to do with care, the definition is still too expansive. Rescuing a drowning person who cannot swim involves *meeting a need* for survival, via *face-to-face interaction*, which the person *cannot meet for themselves*. Likewise, killing the captor of a hostage may *meet their need* to be rescued that they cannot *meet themselves*, via *face-to-face interaction*. Of course, both of these acts may be motivated by a desire to care, but neither has much to do with care as an activity.

Now, it may be objected that face-to-face interaction is not a *crucial* element of these activities, on a more stringent definition of that term, so the definition does not include them. However, this only serves to highlight that the conditions are problematically restrictive too. After all, a parent does not need to interact with their child face-to-face to prepare them a packed lunch, clean their clothes or keep their environment safe. Excluding these acts from the

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[228] Joan C. Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (London: Psychology Press, 1993), 103.

[229] Diemut E. Bubeck, *Care, Gender, and Justice* (Oxford: Oxford University Press on Demand, 1995), 129.

definition of care as an activity seems highly counterintuitive, but this is precisely what Bubeck's conditions do.

A more promising attempt at defining care as an activity comes from Eva Feder Kittay, who uses the term "dependency work" to describe activities engaged in by workers who direct their "energies and attention" towards a "charge" who, without a dependency worker "would be bereft of life-sustaining resources".[230] As this definition focuses on the *roles* involved in care as an activity, rather than the nature of the acts themselves, many of the above examples fall on the right side of the line. After all, there is no dependency worker in the dropping of atomic bombs, but there is in the making of packed lunches.

However, by not specifying the type of acts which are included, the definition may render anything a dependency worker does with the charge in mind an act of care. This might include buying a bus ticket to get to work, setting an alarm to make sure they get up on time or giving themselves time to recoup to ensure they can carry out their duties well. To be clear, all of these acts may be *caring,* in the sense that they help the dependency worker to carry out *care as an activity* well, but it would be counterintuitive to think of them as acts of care in themselves.

Perhaps this is an uncharitable interpretation, and Kittay should be read only as referring to those activities which directly ensure the charge is not bereft of life-sustaining resources. If we read her this way, however, the definition becomes too exclusionary. Activities like playing a game with a person living with dementia or accompanying them for a walk can contribute to emotional and physical wellbeing, but they do not directly ensure access to life-sustaining resources. Yet, especially in the context of high levels of dependency, it is surely intuitive to count them as caring activities.

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[230] Eva F. Kittay, *Love's Labor: Essays on Women, Equality, and Dependency* (London: Routledge Press, 1999), 30-31.

Each of these definitions of care is problematic, yet all contain vital insights that can be used to build a working definition of care as an activity. Firstly, as Kittay rightly notes, these activities are performed by specified agents in service of others, taking place in the context of a *caring relationship*. As well as excluding the problematic examples noted above, requiring a designated carer and charge also helps to exclude social practices like welfare payments or policing from the definition of care as an activity.

Secondly, these activities need to be directed towards the charge, rather than being tangentially related to them. This helps to separate activities that may bear on whether or not the dependency worker will perform care *well*, from the activity itself. Kittay's implied "life-sustaining resources" condition, however, is too narrow, so it ought to be replaced with a more general condition that these activities are provided because, without them, a number of vital needs, including nutrition, emotional well-being and health, would not be met.

Thirdly, contra both Kittay and Bubeck, it need not be the case that a person would be entirely bereft of the necessary resources to meet their needs or is incapable of meeting them themselves. Though this helpfully excludes services provided for other reasons, such as Bubeck's example of a person cooking a meal for their non-disabled spouse,[231] it also excludes several activities involved in paradigm care relationships.

Consider, for instance, a disabled person who can meet their own needs by themselves, but only with the most extraordinary effort. If that person chooses to hire a carer so that they can reduce the strain on their energy, it seems obvious that the activities that worker provides ought to be understood as care. Likewise, a person may be capable of meeting each of their vital needs individually but may struggle to meet all of them, whether due to limited energy or a difficulty co-ordinating their actions. Given this, it would be better to invoke Tronto's

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[231] Bubeck, *Care, Gender and Justice*, 130.

language; the charge may either be unable to meet the need on their own or can only do so in a way that severely threatens their ability to live in the world *as well as possible*.[232]

These three conditions provide a clear, working definition of care as an activity, which can be used to clarify the bounds of *dementia care*. Where a person living with dementia is situated as a charge in a relationship with a dependency worker, who directs their energies towards them to meet vital needs they either cannot meet alone or can only do so with extraordinary effort, they are in receipt of dementia care. Given the asymmetry of this relationship, they are vulnerable to domination in the meeting of their needs. The indirect-first approach, as I will set out below, is intended to prevent this relationship from taking on this inegalitarian character.

2. The Indirect-First Approach

A non-dominating dementia care relationship is one in which a carer's interventions robustly track the interests of the person they are caring for. No doubt, this will often be tailored to the specific lives of individuals; bringing your dog to work with you might track the interests of one person you are caring for, but if another is allergic to or petrified of dogs, it will clearly not. Nevertheless, given the common symptoms of dementia, it ought to be possible to establish a general picture of the *kind* of interventions which reliably track their interests.

In this section, I argue that direct interventions to meet vital needs ought to be avoided, where possible, because they decrease a person living with dementia's ability to develop and express their wider interests, hasten the decline of their capacities, and decrease the control they have over their care relationship. No doubt, some will eventually require extensive direct intervention to meet their vital needs but, this does not negate the argument I will make here;

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[232] I say 'severely' here to differentiate between carers and workers like butlers or housekeepers. While the latter certainly improve their client's chances of living in the world as well as possible, they are not in place to prevent a serious threat and are, thus, not care workers. Though I will not specify a threshold of severity here, it suffices to say that anybody who can only meet their needs in ways that threaten their *dignity* is in need of care.

all people living with dementia, in so far as they are capable of it, have an interest in being allowed or assisted to meet their own needs, so care which frustrates this does not track their interests.

2.1 The Case Against Direct Intervention

Consider the following scenario:

> During a visit to his brother Barry's house, Luke notices that he has not shaved, is wearing dirty clothes and that there is expired food in his fridge. Most alarmingly, he also appears to have left his gas stove on. While trying to discuss this with him, Barry is uncharacteristically evasive and defensive. After some persistence, Barry relays to Luke that he is fine, and he is just struggling to keep on top of the housework as his job has become very tiresome recently. Luke becomes very concerned at this, as Barry has been retired from his teaching job for a number of years.

In this case, which ought to be familiar to anyone who has cared for a person living with dementia, there are a number of unmet vital needs. First, Barry does not seem to be maintaining his personal hygiene, risking his skin integrity and leaving him vulnerable to infection.[233] Second, he does not seem to be managing his nutritional intake, leaving him vulnerable to foodborne illnesses. Third, he does not seem to be maintaining a safe environment, leaving him at severe risk of being harmed in a fire or by exposure to noxious gas. Fourth, he does not display emotional wellbeing, suggesting that he is struggling to self-soothe or otherwise manage his emotions.

Though only a doctor can diagnose Barry, there is more than adequate evidence here to suspect he is living with dementia. If so, there are a number of reasons why Luke might believe his brother needs care. First, the condition impairs memory, coordination, spatial orientation, muscle memory, and capacities related to cognitive processing and judgment, meaning he is

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[233] M.V. Baldelli et al., "Dementia and Occupational therapy," *Archives of Gerontology and Geriatrics* 44 (2007): 45.

unlikely to be able to tend to these unmet needs on his own.[234] Second, dementia is a progressive condition, meaning this impairment is likely to increase over time. Worse, many common symptoms of having unmet needs of this kind, such as dehydration and depression, may exacerbate this decline.[235] Finally, because Barry's subjective experience of the world seems to contain persistent misconceptions, he may not be able to recognise, interpret or express his needs to others.

As I argued in Chapter 1, these three features of dementia – dependency, decline and parallel subjectivity – are vital to understanding why people who live with it are vulnerable to domination by malicious actors. Avoiding this, however, is not merely a matter of ensuring that their needs are met. On the contrary, if Luke were to hire carers who intervened *directly* in Barry's choices, they may expose him to power that does not track his interests, regardless of whether or not his vital needs are met.

To illustrate this, consider the following set of direct interventions. First, to ensure that Barry maintains adequate hygiene, his carer washes him and changes his clothes every morning. Second, to ensure that he maintains adequate nutrition, his carer takes over his shopping, cooking and monitoring his food supplies. Third, to ensure he maintains a safe environment, Barry's carer takes over the cleaning and organisation of his home. Fourth, to improve his emotional wellbeing, Barry's carer takes over any other task perceived to be causing him stress.

At first blush, such interventions might seem interest-tracking: especially if they were successful in attending to the unmet needs. After all, Barry almost certainly has an interest in being safe, well-fed and secure, all of which are likely to be fulfilled. However, there are a number of drawbacks to direct interventions of this kind, that may frustrate other interests.

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[234] World Health Organization, *Dementia: A Public Health Priority*, (2012), 7.

[235] Sophia Bennett and Alan J. Thomas, "Depression and Dementia: Cause, Consequence or Coincidence?," *Maturitas* 79, no. 2 (2014): 184-189.

Firstly, such interventions may make it harder for a person living with dementia to make their wider interests known. If a carer were to provide Barry with personal care in a fast-paced way, for instance, his impaired evaluative capacities might be outpaced. Consequently, he may be unable to voice objections to the way he is being washed or suggest alternatives that better track his values and authentic way of living.

Further, if a carer were to make interventions in Barry's absence, such as shopping and cooking for him, he may not even have the opportunity to raise a concern. After all, because dementia impairs a person's memory and ability to weigh information, Barry may forget his objections or be unable to voice them without being prompted. Thus, he may end up eating meals that are cooked in ways he is not fond of or at times that do not suit him, frustrating his interest in living according to his own authentic values.

Secondly, because maintaining cognitive and physical activity has been shown to preserve functioning in people living with dementia, direct interventions may hasten the decline of their capacities.[236] Of course, cognitive decline itself is not, all things being equal, an unjust constraint on or frustration of this core interest. Indeed, it is widely thought that natural constraints which interfere with our interests are of a different kind than those imposed by others.[237] However, if his decline were hastened by the actions of another who could have chosen otherwise, there would be a clear violation of Barry's interest in being free to live authentically. After all, he would not have *chosen* to become more dependent on others, yet he would have become so because of the actions of a powerful other.

Finally, because this unnecessary decline involves further impairment of their evaluative capacities, direct interventions may reduce a person's ability to evaluate their carer and the care relationship itself *over time*. After all, if his decline is hastened, Barry will have

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[236] Sheung-Tak Cheng et al., "Mental and Physical Activities Delay Cognitive Decline in Older Persons with Dementia," *The American Journal of Geriatric Psychiatry* 22, no. 1 (2014): 63-74.
[237] Christian List and Laura Valentini, "Freedom as Independence," *Ethics* 126, no. 4 (2016): 1070.

fewer opportunities to raise objections to non-interest tracking interventions and be less able to connect them to a broader understanding of how he relates to his carer. Thus, because he may forget the number of non-interest tracking interventions he has received from a particular carer, he may be less able to raise concerns to a third party or request a change in staffing.

Given these problems, a blanket policy allowing or requiring carers to make direct interventions without considering other options would be problematic. Of course, sometimes direct interventions may be the only option carers have to meet a person's needs. However, the risks involved suggest that people living with dementia have an interest in being empowered to meet their own needs, *insofar as they can*. Thus, where there are options that improve a person's ability to do so, direct intervention should not be a carer's first choice.

2.2 Intervening Indirectly to Provide Cognitive Scaffolding

In his current living situation, Barry appears unable to meet his own needs. That this is the case, however, does not necessarily entail that he needs *care*. After all, philosophers of disability have long disputed the excessive focus placed on a person's impairments as a cause of their disadvantage. Indeed, rather than through care, adherents to the social model of disability argue that unmet needs or disadvantages can be better addressed through societal reorganisation.[238] On this view, a lack of mobility, for example, might be addressed by changing the way public buildings are built or by making wheelchairs widely available.[239]

Though there have been some concerns about expanding the social model of disability to include cognitive disabilities,[240] there are valuable insights here for an analysis of dementia

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

[239] Tom Shakespeare and Nicholas Watson, "Defending the Social Model," *Disability & Society* 12, no. 2 (1997):
296.

[240] Jonathan Wolff, "Cognitive Disability in a Society of Equals," in *Cognitive Disability and its Challenge to Moral Philosophy,* ed. Eva F. Kittay and Licia Carlson (Chichester, UK: John Wiley & Sons, 2010), 151.

care. In fact, one need not even fully agree with the social model of disability, let alone expanding it to include cognitive disability, to recognise that there are a number of ways in which social reorganisation and improved access to assistive technology might prevent people like Barry from needing carers *per se*.

Regarding technology, there is profound potential to empower people living with dementia to meet their own needs. Christine Bryden, for instance, has utilised assistive technology to write books, organise and give speeches at conferences, and produce a PhD thesis in theology.[241] Analogously, it is easy to imagine new artificial intelligence tools or internet-enabled appliances being offered to Barry to help him to keep his fridges stocked, his gas turned off and his home clean. Were this technology to be made readily available, Barry and others like him may be prevented from needing an asymmetric care relationship.

Of course, some forms of this technology may be similarly disenabling; a smart fridge ordering Barry's food for him seems as direct an intervention as a carer buying it for him. However, if the purpose of the technology were to act as a prosthesis, responding to Barry's will rather than supplanting it, it would not carry this risk. What I am suggesting here, in other words, is that technology can sometimes be used as a form of what Andy Clark calls *cognitive scaffolding*: a term he coined to describe the notes, labels and schedules he witnessed people living with dementia using to successfully maintain their independence, despite scoring poorly on cognitive tests.[242] Playing this role, it can hold information, be used to set reminders or otherwise externalise some of the cognitive functions Barry is losing, supporting his agency without the need for the care relationship.

Admittedly, such technology might be baffling or beyond Barry's control, which suggests that it may not always be appropriate. However, he may still be able to meet his needs

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[241] Christine Bryden, *Will I Still Be Me?: Finding a Continuing Sense of Self in the Lived Experience of Dementia* (London: Jessica Kingsley Publishers, 2018), 27-41.

[242] Andy Clark, *Natural-born Cyborgs: Minds, Technologies, and the Future of Human Intelligence* (Oxford: Oxford University Press, 2003), 139-140.

with the assistance of non-technological forms of cognitive scaffolding to facilitate, maintain or improve his agency. For instance, his home environment could be reorganised such that he can see his clean clothes more easily or notes and signs could be used that prompt him to go shopping or check the gas switch on his oven. If this kind of environment shaping were enacted as an aim of public policy, perhaps pursued by outreach programmes, then it is likely that fewer people living with dementia would require asymmetric care relationships to meet their own needs.

It must be conceded, however, that social reorganisation of this kind is limited in scope. Indeed, while it may be relatively straightforward to reorganise a person living with dementia's own home, extending cognitive scaffolding into the shops, churches, parks and other public spaces in the wider community would be much more challenging. After all, what works as cognitive scaffolding for some might not work for others and, given roughly 7.1% of people over 65 live with dementia, there are likely to be a large number of people with conflicting demands, even in a very small town.[243]

This point should not be overstated; there are many changes that can be made in community centres to make them more accessible to people living with dementia. Indeed, through the dissemination of training programs on how to deal with customers with dementia, the changes made to Purley high street in the UK led to it being named a dementia-friendly community,[244] and similar movements exist in Japan[245] and Belgium.[246] Nevertheless, insofar as they require access to the wider community to meet their needs, environmental organisation

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[243] Alzheimer's Society, "Dementia UK Report," Alzheimer's Society, accessed August 6, 2020, https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-uk-report.

[244] Peter Watts, "Forget-me-nots in Purley: How the Town Became 'Dementia Friendly'," The Guardian, last modified February 2, 2017, https://www.theguardian.com/cities/2017/feb/02/purley-uk-latest-dementia-friendly-community.

[245] Alzheimer's Disease International, "Japan - Dementia Friendly Communities," Alzheimer's Disease International, accessed August 6, 2020, https://www.alz.co.uk/dementia-friendly-communities/japan.

[246] Ross Davies, "Is Bruges the Most Dementia-friendly City?," The Guardian, last modified April 21, 2015, https://www.theguardian.com/society/2015/apr/21/bruges-most-dementia-friendly-city.

and assistive technology may only be able to prevent Barry and those like him from needing a care relationship in the early stages of the condition.

Regardless, the notion of cognitive scaffolding suggests that there are ways in which people living with dementia can be assisted to meet their own needs. While indirect interventions of this kind may not remove the need for carers in all or even most cases, they may greatly reduce their power while greatly improving the ability of those like Barry to live according to their own authentic values. Where such scaffolding is available, carers may only be necessary to maintain it or to assist those living in appropriately designed homes to access the wider community. Thus, ensuring readily available technology and access to environmental reorganisation is vital to a non-dominating practice of dementia care.

2.3 Indirect Intervention Through Interpretation

Cognitive scaffolding may put people like Barry in the position to meet needs that are going unmet because of impairments to memory, spatial orientation or judgment. What is critical to the case of Barry, however, is his mistaken belief that he is still working. As I have previously noted, all people living with dementia eventually experience life through a parallel subjectivity and, thus, may find it difficult to identify and express their own needs in a way that is comprehensible to the rest of us. Spatial reorganisation and technology may ameliorate some of this, but meeting the needs of someone with persistent misaligned beliefs will, inevitably, involve some level of *interpretation*.

As I highlighted in Chapter 1, Tom Kitwood makes a persuasive case that statements grounded in such misconceptions are attempts to communicate real needs.[247] For instance, Barry's claim about his non-existent working life might reflect a feeling of being overwhelmed

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[247] Tom Kitwood, "Personhood Maintained," in *Dementia Reconsidered, Revisited: The Person Still Comes First*, ed. Dawn Brooker (London: Open University Press, 2019), 69-71.

or a lack of control. Where people living with dementia are experiencing hallucinations and delusions in this way, vital needs may go unmet if others fail to investigate the reasons why they are making these claims. Moreover, even where the need is identified, it may go unmet if the carer cannot address it in a way that is explicable from the person living with dementia's point of view.

On the other hand, as Kitwood notes, the apparent delusion or hallucination itself might reflect a misunderstanding the person living with dementia has about what we require from them, which arises from their need to interact with their environment in a meaningful way.[248] Barry might believe he is still required to work because he has misinterpreted an aspect of his environment, and it has acted as a trigger for earlier memories of his working life. Thus, one way in which his 'job' may have become 'tiresome' is that the objective world does not match his interpretation of how he ought to interact with it. For example, he might be trying to teach children on the television who do not appear to him to be listening, or he might be trying to mark books or newspapers that he interprets as homework.

A final consideration that ought to be noted is that Barry may not actually think he is still at work. Bryden encourages us to recognise the degeneration of language capacities that accompanies dementia, which may lead to people expressing themselves awkwardly or in a way that indicates a delusion that is not actually present.[249] Understood this way, Barry's claim that his 'job' has become tiresome, may just be an awkwardly phrased way of explaining that his day-to-day routine has become difficult to manage.

To put Barry in a position to meet his own needs, then, a carer must be able to identify what is being expressed and interpret the world for him in a way that is comprehensible. In this

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[248] Tom Kitwood, "The Experience of Dementia," in *Dementia Reconsidered, Revisited: The Person Still Comes First*, ed. Dawn Brooker (London: Open University Press, 2019), 88-91.
[249] Bryden, *Dancing with Dementia*, 138-139.

way, the carer can act as an interpretive bridge between Barry's parallel subjectivity and the objective world, using this to inform their interventions.

For instance, if his belief that he is still working is a true delusion or hallucination, then a carer attending to that need may be able to organise his environment in a way that coheres with it; for instance, they might install a bell to signal the end of class and the beginning of a mealtime. Alternatively, if this is about a misunderstanding of what is needed of him, the carer may be able to direct him towards the tasks that are necessary to meet his own needs. For instance, the carer might say that they need to cook a meal or go shopping for food together to make sure he is well enough to teach properly. If it is a communication impairment, on the other hand, the carer can indicate to Barry that they understand what he is trying to say and discuss with him how to ensure his needs are met.

No doubt, indirect intervention through providing cognitive scaffolding and interpreting parallel subjectivities may not be enough to meet all of a person living with dementia's vital needs. However, because it avoids the pitfalls of reducing opportunities for objection, hastening the decline of capacities, and reducing the ability of people living with dementia to evaluate their care relationships over time, it is better placed to track their interests.

3. Deception, Paternalism and the Domination of Carers

Given the risks involved in direct intervention, I have argued that people living with dementia have an interest in being empowered to meet their own needs, wherever possible. In order to track this interest, carers should adopt an *indirect-first* approach to dementia care, wherein they refrain from direct intervention unless the person they are caring for cannot be empowered to meet their own needs through cognitive scaffolding or interpretation of their parallel subjectivity. Note, however, that this is not *sufficient* to liberate people living with dementia from domination, because they may still do so with impunity. In other words, it is not enough that carers choose to refrain from interventions that do not track the interests of those they care for; they must be prevented from doing so by being subject to oversight and robust laws.[250]

The requirement to establish such an oversight regime, however, raises two concerns about the egalitarian credibility of the approach it is intended to support. Firstly, state endorsement of an approach that enables carers to deceive and restrict the choice sets of people living with dementia might be thought to be objectionably paternalistic, in a way that is stigmatising. Secondly, some might be concerned that the level of oversight necessary to prevent carer domination might be intolerable and even perpetuate other relational injustices. In this section, I consider and reject both of these objections.

3.1 Choice Restriction and Deception Without Stigma

Returning to the tragic case this chapter opened with, it is clear to see how some may find the indirect-first approach objectionably paternalistic. After all, because it could have empowered patients to meet their own need for hydration without risking serious injury or death, the Hull hospital's policy of removing hand sanitizer from its dementia ward might be thought of as the kind of environment-shaping intervention encouraged by the indirect-first approach. Yet, were these patients cognitively non-disabled, many would find the idea that they cannot be trusted to pursue their own good around dangerous substances insulting.

In a similar vein, some may be concerned that the indirect approach implies people living with dementia are not capable or not worthy of being told the truth. After all, where interpretive intervention requires colluding with a mistaken belief, such as my example of installing a school bell in Barry's home, some level of deception is involved. This deception is not recommended for nefarious reasons, nor with license to engage in it for self-interested

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[250] Phillip Pettit, "Republican Freedom: Three Axioms, Four Theorems," in *Republicanism and Political Theory*, ed. Cécile Laborde and John Maynor (Oxford: Blackwells, 2008), 120-124.

purposes. Nevertheless, it might be thought that there is something insultingly infantilising about it anyway. As noted by Christine Koorsgaard, many of us object to others deciding what information we should or should not be made aware of, whether they do so with benevolent intentions or not.[251]

Worse still, the adoption of such a policy by the state might be thought to reify and communicate these insults further, raising egalitarian concerns about forcing people to identify with perceived deficiencies in order to access resources. Thus, a relational egalitarian may be concerned that this policy would perpetuate stigma about particular groups, of the same kind that Elizabeth Anderson identifies as a consequence of purely distributive policies.[252]

This concern loses force, however, when contrasted with the impact of alternative policies. After all, enforcement of a direct-first strategy would not only be dominating, it might communicate a stigmatising image of people living with dementia as being incapable of or unworthy of being empowered to meet their own needs. Likewise, the *absence* of an enforced care strategy might communicate an insulting image of this group as unworthy of robust protection from powerful others.

Of course, the state could outlaw dementia care in an attempt to free people living with the condition from exposure to powerful others. However, not only would this leave them vulnerable to being exploited or manipulated by nefarious actors, it likely would also communicate something insulting. After all, the very justification for dementia care, as I have set out here, is that people living with dementia who need it are unable to meet their vital needs on their own. Thus, a state outlawing something that is necessary to meeting them would seem to express attitudes of negligence or contempt, highlighted by Schemmel as key examples of relational injustices.[253]

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[251] Christine Korsgaard, "Two Arguments Against Lying," *Argumentation* 2 (February 1988): 29.
[252] Elizabeth S. Anderson, "What is the Point of Equality?," *Ethics* 109, no. 2 (1999): 289.
[253] Christian Schemmel, "Distributive and Relational Equality," *Politics, Philosophy & Economics* 11, no. 2 (2012): 134.

Admittedly, that the indirect-first approach is not *uniquely* stigmatising is not to say that it is unproblematic. Nor is it sufficient to defend its use as the least unjust option, even it is the only one that is non-dominating. However, though superficially plausible, the argument from stigma against the indirect-first approach might, itself, be built on some problematic assumptions.

Consider, first, the environment-shaping argument. Certainly, for a person who is able to easily tell the difference between hand sanitizer and drinkable liquid, it would be insulting to remove the former from their environment. The point in the Hull hospital case, however, is that many of their patients *genuinely could not*, so the policy could just as easily be interpreted as respectful of the capacities they have. Analogously, though a sighted person might feel a government campaign to declutter streets insults their ability to navigate obstacles, it is a key demand of the UK's Royal National Institute of Blind People, because a large majority of its members genuinely struggle to do so.[254]

Indeed, given the intended purpose of environment-shaping is to empower people living with dementia to meet their own needs by facilitating their agency, failing to engage in this practice could reinforce some of the oppressive structures I set out in Chapter 1. After all, disempowering a person living with dementia and diminishing their agency would likely increase the decision-making power of their carer, in the sense that they would be dependent on them to meet more of their needs. Thus, a system of care which refrained from indirect, environment-shaping intervention would risk reinforcing a strict hierarchy in dementia care, in which the cared-for are rendered powerless by, on Young's terms, being exposed to decision-making power without exercising it.[255]

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[254] RNIB, "Blind and Partially Sighted Campaigners to Meet with Lothians MSP Jeremy Balfour to Discuss Street Obstacles," RNIB - See Differently, last modified April 29, 2019, https://www.rnib.org.uk/scotland/news-and-media/blind-partially-sighted-campaigners-meet-msp-street-obstacles.

[255] Iris M. Young, *Justice and the Politics of Difference* (Princeton: Princeton University Press, 1990), 58.

Likewise, though a person who is capable of remembering and weighing new information might feel insulted if their mistaken beliefs are validated by others, a strong case could be made that this can be respectful of the capacities people living with dementia have. Indeed, as Bryden notes, persistent correction can often discourage people living with dementia from expressing themselves, pushing them to the margins of social interaction.[256] Given this, carers refusing to embrace the parallel subjectivities of people living with dementia risk contributing to or reinforcing their marginalisation, in the sense that, in Young's terms, this would further restrict their opportunities "to exercise capacities in socially defined and recognised ways."[257]

Besides, the indirect-first approach does not require or empower carers to make *blanket* judgments about the capacities of the people they care for. If a person could be capable of fully preparing and cooking a meal with only a few adjustments, then a non-dominating carer ought to make them, despite the dangers the kitchen can pose to all of us. Likewise, if a person is capable of weighing some new information, can be assisted to meet their own needs in another way or is asking to be corrected if they are wrong about something, then a non-dominating carer need not *fully* embrace their parallel subjectivity to meet their needs. Indeed, if collusion of this kind *restricts* a person's agency, in the sense that it needlessly frustrates capacities they still possess while their needs could be met in other ways, the indirect-first approach would *not* recommend it.

Certainly, if the state were to communicate the inaccurate belief that people living with dementia are *universally* incapable of doing risky things or being told the truth, they could contribute to oppression. After all, doing so might reinforce the kind of culturally imperialistic images of people living with dementia I noted in Chapter 1. The indirect-first approach,

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[256] Bryden, *Dancing with Dementia*, 139-141.
[257] Young, *Justice and the Politics of Difference,* 54.

however, does not require the state to do this, because it only recommends environment-shaping and subjectivity-interpreting when doing so facilitates, preserves or improves agency. In this sense, it requires the state to communicate an understanding of people living with dementia as *capable* under the right circumstances, and *worthy* of being empowered to meet their own needs.

Once this is understood, a problematic assumption at the heart of this objection can be highlighted. Certainly, it is disrespectful to be treated as if one does not have capacities that one actually has, merely because of one's group membership: this insight is at the heart of many egalitarian objections to social practices like mansplaining or infantilising autistic adults. However, this should not be understood as unjust treatment because it is *always* insulting to be treated as if one lacks those capacities. After all, such a justification would imply that those who *do* lack those capacities are of such a low status that it is insulting to be compared to them.

Rather, it should be understood as such because it is always insulting to be treated in accordance with a reductive or inaccurate image of the capacities members of one's social group have, rather than those one actually possesses. This is so, not because those who lack certain capacities are of lesser value or live lives that are less worthy, but because our entitlement, as social equals, to live authentically, entails an entitlement to a social order that respects us for *who we are* and the *capacities we have*. The indirect-first approach, as I have set it out, is of this character and, therefore, is not stigmatising.[258]

3.2 Making Robust Legislation Without Unjustly Burdening Carers

While it may not be stigmatising for people living with dementia, however, some may be concerned about the impact on carers. The idea that domination requires only a capacity for

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[258] Kantians who favour a strong prohibition on deception *in all circumstances* will be unpersuaded by this. It should be noted, however, that some scholars hold that benevolent deception *is* compatible with a Kantian moral framework [see: David Sussman, "On the Supposed Duty of Truthfulness," in *The Philosophy of Deception*, ed. Clancy Martin (New York: Oxford University Press, 2009), 225-243].

unjustified interference has caused significant concern among care ethicists. Marilyn Friedman, for instance, argues that this conception unacceptably renders the relationship between mother and child an archetypal relationship of domination.[259] After all, a mother, like any carer, has a significant degree of authority over the person they care for, and makes a multitude of decisions which can frustrate their interests. Instead, she suggests, domination ought only to focus on actual attempts to interfere arbitrarily,[260] a thought which is echoed by Kittay.[261]

While this may be attractive for those who would never dream of harming the people they care for, it brings with it disadvantages outside of the context of care. On a general level, it seems to suggest that there is nothing troubling, whether we call it domination or not, about relationships in which a person maintains an unexercised capacity to make non-interest tracking interventions. For example, M. Victoria Costa notes that failing to take into account this capacity, even when not exercised, makes an account of domination incapable of accounting for the injustices faced by women who "preempt attempts at interference by seduction, ingratiation, avoidance, or other such strategies."[262]

Nevertheless, there is something compelling at the core of Friedman's argument. Given the power carers have over their charges, she argues that if its definition includes mere capacity, domination is ubiquitous and the only laws that could restrain it would be those that produce a police state. Much care, after all, goes on in private and, so, cannot easily be regulated from the outside. Given this, she argues, attempting to solve the domination of mothers over children would involve such a great expansion of state power, that all carers would come to be dominated by state agents.[263] Thus, the implication here is that the conception of domination used by neo-republicans and most relational egalitarians presents an irresolvable problem;

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[259] Marilyn Friedman, "Pettit's Civic Republicanism and Male Domination," in *Republicanism and Political Theory*, ed. Cecile Laborde and John Maynor (Malden, MA: Blackwell Publishing, 2008), 254.
[260] Friedman, "Pettit's Civic Republicanism and Male Domination," 250-252.
[261] Kittay, *Love's Labor*, 33-34.
[262] M. Victoria Costa, "Is Neo-Republicanism Bad for Women?," *Hypatia* 28, no. 4 (2013): 926.
[263] Friedman, "Pettit's Civic Republicanism and Male Domination", 252.

either care users are subjected to this power by their carers or their carers are subjected to this power by the state.

Though striking, however, there are good reasons to doubt Friedman's analysis. For one, the idea that laws can and should restrain the power of carers to intervene with those they care for is intuitive; it is fairly standard for a country to have legal standards on child abuse, elder abuse and gross misconduct in professional caring roles. Admittedly, preventing carer domination would likely involve strengthening, further regulating and increasing oversight to ensure compliance with these laws, but it is not clear how this amounts to state domination. After all, presumably any society concerned enough about arbitrary power to monitor care relationships for non-interest tracking interventions would also *monitor the monitors*.

Perhaps from the perspective of the carer who would never dream of harming the person they care for, this is an unacceptable breach of their privacy and represents a demeaning judgment of their character but, given *all* carers would be subject to the same level of monitoring, it is unclear that this feeling arises from injustice. Perhaps, because a lot of care in the Western world is provided by women and members of ethnic minorities, there may be a concern of stigma but, again, the justification for this monitoring is grounded in the dangers of the *relationship*, rather than a judgement about those commonly occupying the more powerful position. Thus, though a carer may feel like they are being treated as if they would harm someone they care for, they would be being treated as such because of an *accurate* assessment of the professional or family position they occupy, not the social group of which they are a member.

Analogously, in many Western societies the majority of teachers of young children are women. Nevertheless, it is widely accepted that a just society should subject all prospective schoolteachers to extensive criminal records checks and monitoring by safeguarding teams, even those who would never dream of harming children. Thus, it is unclear how teachers and carers differ in this regard; if the personal is the political, as one of the key tenets of feminist theory states, then this surely applies to the relationship between carer and charge as much as it does the relationships between men and women in heterosexual couples.

Further, it is unclear that oversight requires *constant* monitoring of the activities of carers. Children have various contact points through which abuse can be detected and reported, such as play-groups, schools and outside clubs. Similar contact points might be established for other dependents, such that they too can be protected from interventions which do not track their interests. It might be the case that preventing domination requires rendering some care choices, such as home-schooling or eschewing professional contact with elderly relatives unjust, but it is unclear that this requires a state that is much more interventionist than that which is familiar to us.

Admittedly, as Anca Gheaus argues, parents are capable of arbitrarily intervening with their children's interests in numerous, seemingly trivial ways,[264] and the same might be true of other carers of dependents. Accordingly, we might think that it is highly inappropriate or disproportionate to level heavy sanctions when this occurs. Indeed, we might think a regime that is this punitive genuinely does dominate carers.

However, sanctions for such interference need not be heavy to be effective. If a carer frustrates their charges interest in a trivial way, then a well-known, relatively trivial sanction may be appropriate. For example, we might establish a norm that a parent must offer an explanation for their actions, admit wrongdoing and reaffirm their love for their child if they lose their temper or react unfairly to their children. Likewise, in the case of dementia, we might establish a social norm that carers must attend additional training or give an account of their actions to a superior if they needlessly disrupt the agency of those for whom they are caring.

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[264] Anca Gheaus, "Child-rearing With Minimal Domination: A Republican Account," *Political Studies*, 2020, xx, doi:10.1177/0032321720906768

Of course, such norms cannot be rigorously enforced on every occasion but, through the contact points I mentioned above, it should become apparent to external actors when carers are not fulfilling their duties. As long as those bodies are empowered to intervene, either by reaffirming the duties a carer has or by offering support to ensure those duties can be met, there is a sufficient level of oversight to ensure they do not make non-interest tracking interventions with impunity.[265]

In sum, the indirect-first approach can be enforced through the state without perpetuating further relational injustices. This is so because it is not unjust to treat a person in accordance with the capacities they have and because, where care services are subject to regulation and oversight, with effect sanctions in place for non-compliance, the capacity for interference without interest tracking can be restrained.

Conclusion

In this chapter, I have argued that an indirect-first approach to dementia care offers the best prospects of avoiding domination. Needless to say, in most jurisdictions the infrastructure, training and laws necessary to achieve this are not in place. Indeed, establishing such an effective regime will require significant social reform, with implications for all institutions which deal with people living with dementia. Nevertheless, to achieve just care relationships for members of this group, reforms with this goal in mind must be pursued. Accordingly, in the next two chapters, I will suggest a number of such reforms.

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[265] Perhaps Friedman may be concerned about this, but it is worth noting that child welfare organisations such as the NSPCC already consider persistent shouting at or punishing a child without explanation a form of child abuse.
See: NSPCC, "Emotional Abuse," NSPCC, accessed December 22, 2020, https://www.nspcc.org.uk/what-is-child-abuse/types-of-abuse/emotional-abuse/.

Chapter 5

The Imperative of Professional Dementia Care

> "I don't want sympathy. What I want is empathy. I don't want people to feel sorry for me, I want people to help care for me, and to understand better what it is that I'm living with."[266]

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[266] Keith Oliver, *Dear Alzheimer's: A Diary of Living with Dementia* (London: Jessica Kingsley Publishers, 2019), 154-155.

Introduction

Estimates by Alzheimer's Disease International suggest that 84% of those living with dementia globally do so at home, supported by *informal care* from friends and relatives.[267] Despite negative effects on their health and social lives, many informal carers claim to be acting in accordance with a *moral obligation*. Indeed, feelings of failure and shame are commonly reported by those who later give up their caring responsibilities, suggesting a widespread belief that *professional care*, whether delivered in the person's own home or in an institutional setting, ought always to be a last resort.[268]

From the point of view of relational egalitarian justice, however, this belief is dangerously misguided. As I argued in the previous chapter, the kind of oversight necessary to prevent carers dominating their charges need neither be stigmatising nor intolerably intrusive. Nevertheless, as I shall argue here, informal *dementia* care is far more resistant to the kind of structural reforms needed to establish such a regime. Consequently, rather than *requiring them* to provide it, a just society would sometimes *prohibit* informal care from the relatives of people living with dementia.

In section 1, I use the UK as a case study, setting out a number of reforms that could prevent professional carers from dominating their charges. In section 2, I suggest that it may not be possible to reform informal care, which features near-identical problems, in the same

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[267] Alzheimer's Disease International, *Global Estimates of Informal Care*, (Alzheimer's Disease International, 2018), https://www.alzint.org/u/global-estimates-of-informal-care.pdf.

[268] See:
Benedicte Carlsen and Kjetil Lundberg, "'If it Weren't for Me…': Perspectives of Family Carers of Older People Receiving Professional Care," *Scandinavian Journal of Caring Sciences* 32, no. 1 (2017).
Eve Brank and Lindsey Wylie, "Assuming Elder Care Responsibility: Am I a Caregiver?," *SSRN Electronic Journal*, 2008.
Janelle Jacobson et al., "Carers' Experiences When the Person for Whom They Have Been Caring Enters a Residential Aged Care Facility Permanently: a Systematic Review," *JBI Database of Systematic Reviews and Implementation Reports* 13, no. 7 (2015).
Mike Nolan and Cheryl Dellasega, "'I Really Feel I've Let Him Down': Supporting Family Carers During Long-Term Care Placement for Elders," *Journal of Advanced Nursing* 31, no. 4 (2000).

way. I then consider and reject a rejoinder from the view that the more personal, loving nature of informal care renders it superior, arguing instead that this quality creates additional, distinctive issues not present in professional care. Finally, in section 3, I consider and reject the view that loved ones have a filial duty to provide informal care, arguing instead that, even when it is very poor (as in many contemporary societies), *supplementation* of inadequate professional care ought to be preferred to informal care.

1. Barriers to Non-Dominating Care: Understaffing and Undertraining in the UK

In this section, I set out two key problems with dementia care services in the UK, which allow or even encourage carers to make non-interest tracking interventions with impunity. I then set out a series of potential reforms that could be sufficient to ensure non-dominating dementia care. As I go on to emphasise, these are not radically different from those already under consideration by relevant stakeholders. Although the feasibility of such reforms has no direct bearing on the duties of policymakers to implement them, the relative ease with which they could be implemented does helpfully highlight the *contingent* nature of the injustices committed by care services in the UK

Of course, because each individual jurisdiction has its own hurdles to overcome, the suggestions I make here may not be appropriate in every case. However, this discussion is intended to be illustrative, not definitive. Rather than offering firm public policy prescriptions, my goal is to demonstrate that many of the problems with care services have very little to do with them being *professional*. In fact, as I will go on to argue, this quality may be an *asset* to the goal of achieving social equality for people living with dementia.

1.1 Lack of Training

In the UK, there are at least three training-related issues with professional services that stand as barriers to achieving just care. These are of concern, both because they make it less likely that carers will pursue interest-tracking interventions and because they give them an unacceptable amount of leeway to do so with impunity. As I suggest here, however, these problems could be easily remedied through reforms.

The first problem is that recruitment standards across the sector are low and, consequently, staff are usually not required to have undertaken training before they are employed.[269] Of course, there are other workers such as nurses and physiotherapists who are required to work while they are being trained, but there are usually clear distinctions between the role of a trainee and that of a fully qualified member of staff. By contrast, many professional carers spend some time working as full members of staff, before receiving any formal training.[270] Indeed, a report by the trade union UNISON found in 2015 that 27% of carers working with people living with dementia had received no training on the condition at all.[271]

In the UK, professional healthcare roles like 'registered nurse' and 'physiotherapist' are protected titles, which means they can only be used by people who are fully qualified and maintain registration with the relevant professional body.[272] Although the Government created the 'Care Certificate' in response to the Francis Inquiry into the failings of Mid Staffordshire

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[269] Claudia M. Groot Kormelinck et al., "Systematic Review on Barriers and Facilitators of Complex Interventions for Residents with Dementia in Long-term Care," *International Psychogeriatrics*, 2020, 13-16.

[270] All-Party Parliamentary Group on Social Care, *Elevation, Registration & Standardisation: The Professionalisation of Social Care Workers*, (London: All-Party Parliamentary Group on Social Care, 2019), https://img1.wsimg.com/blobby/go/c6219939-c33a-4460-a71e-4df262903498/downloads/SC%20Inquiry%20Final%20%20.pdf?ver=1567432735387%C2%A0, 27-28.

[271] UNISON, *Homecare Training Survey Report*, (UNISON, 2015), https://www.unison.org.uk/content/uploads/2015/04/TowebUNISONs-Homecare-Training-Survey-Report.pdf.

[272] The Chartered Society of Physiotherapy, "Regulation of Physiotherapy," The Chartered Society of Physiotherapy, last modified November 3, 2016, https://www.csp.org.uk/professional-clinical/professional-guidance/regulation-physiotherapy.

"Our Order and Rules," The Nursing & Midwifery Council, last modified 3, 2020, https://www.nmc.org.uk/about-us/governance/our-legal-framework/our-order-and-rules/.

Hospital, this is not dementia-specific and, moreover, is not a statutory requirement for recruitment.[273] Thus, no equivalent set of professional standards exists for dementia care.

Without the need to be trained and registered, staff who are not competent, or have a track record of acting in ways that do not track their charges' interests, are able to apply for jobs across the sector, even if they are fired from their particular service. In my experience of working in care, it was common to hear that staff who had been fired for gross misconduct had been hired by another service. Although it is difficult to find data on how common this experience is, the fact that it is possible at all means that freedom from interest-violating interventions cannot be robustly guaranteed. To avoid professional carers dominating their charges, then, this kind of professional registration ought to be mandatory.

Promisingly, there is already progress in this direction. For instance, the All-Party Parliamentary Group on Social Care has recommended a registration body for social care in England, alongside statutory enforcement of the Care Certificate.[274] This is intended to bring England in line with the rest of the UK, in which schemes of general social care registration do exist.[275] Of course, none of these regimes are *dementia-specific*, which could allow non-specialist carers to work with people living with dementia without the requisite specialised training. Nevertheless, a registration scheme that recognized the specific requirements of a dementia carer would not require much change to those that are active or proposed today. Indeed, there is already a similar distinction in the process of registering as a mental health nurse, as opposed to a general nurse.[276]

The second problem is that, while the Care Quality Commission (CQC) has recently increased the number of mandatory training programmes that must be refreshed on a yearly

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[273] UNISON, *Introducing the Care Certificate*, (UNISON, 2015).

[274] All-Party Parliamentary Group on Social Care, *Elevation, Registration & Standardisation*, 25-26.

[275] Ibid, 12.

[276] Nursing and Midwifery Council, *Standards for competence for registered nurses*, (London: Nursing and Midwifery Council, 2010), https://www.nmc.org.uk/globalassets/sitedocuments/standards/nmc-standards-for-competence-for-registered-nurses.pdf.

basis,[277] there remains no statutory obligation for care providers to deliver specific ongoing training on dementia. Tom Kitwood, whose theory of person-centred care undergirds many training programmes, argues that without ongoing training, staff would not complete their learning cycle and would be unlikely to improve their practice. To that end he proposed monthly training sessions centred around the current practice within each facility.[278] Yet UNISON found that, of those that had received some training, less than half of carers working with people living with dementia had received anything on an ongoing basis.[279]

Care services in the UK, then, are able to present staff that have not received training for a significant amount of time as dementia-trained. Consequently, family and friends who are tasked with choosing a care service for their loved ones are unable to reliably distinguish between carers who have received ongoing training and those that have only received initial training. Moreover, given the idiosyncrasies of particular people and their particular experience with dementia, a lack of ongoing training makes it less likely that carers will be able to identify wider interests, effectively shape their environment or interpret their parallel subjectivities.

Yet again, the appropriate solution to this is clear. Bodies such as the forementioned APPG[280] and the Nuffield Council on Bioethics[281] have long called for changes to the frequency of dementia care training. Now, neither specifically recommends mandatory training for carers centred around the *specific people they care for*, which is key to Kitwood's proposal and likely important to ensure the indirect-first approach can be carried out well.[282] However,

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[277] Skills for Care, "Core and Mandatory Training," Skills for Care, accessed May 29, 2020, https://www.skillsforcare.org.uk/Learning-development/Guide-to-developing-your-staff/Core-and-mandatory-training.aspx.

[278] Tom Kitwood, "The Caring Organisation," in *Dementia Reconsidered, Revisited: The Person Still Comes First*, ed. Dawn Brooker (London: Open University Press, 2019), 130.

[279] UNISON, *Homecare Training Survey Report*, (UNISON, 2015), https://www.unison.org.uk/content/uploads/2015/04/TowebUNISONs-Homecare-Training-Survey-Report.pdf.

[280] All-Party Parliamentary Group on Social Care, *Elevation, Registration & Standardisation*, 42.

[281] Nuffield Council on Bioethics, "Dementia: Ethical Issues," Nuffield Council on Bioethics, last modified 2009, 42-57.

[282] Kitwood, "The Caring Organisation", 130.

this is a very minor addition to these recommendations, which ought to be easy for relevant stakeholders to embrace.

Finally, there is a problem with the quality and content of training. While there are some exceptions, such as the University of Bradford's postgraduate Dementia Studies degree,[283] a 2019 audit of training programmes for carers found that the majority were unassessed and relatively superficial: both because of insufficient content and duration.[284] This means many staff can present themselves as trained despite having no proof that they fully engaged with their training and a lack of depth in what was presented to them. Any care system with this little rigour, evidently, cannot robustly guarantee freedom from abuse or other interventions that do not track interests.

Now, while the need for greater training is likely to be as common-sensical a recommendation as the others I have made here, there are some specific requirements entailed by the indirect-first approach that require greater defence. For instance, few would disagree that dementia carers need to be trained on the symptoms of the various types of dementia, which would make it easier for carers to assess and discover wider interests. Nor would there be widespread objections to improving training on recognising abuse, which would help carers to play an effective role in the kind of oversight needed to robustly guarantee just care.

However, policymakers might require more convincing to, for example, establish training in the kind of therapeutic questioning skills counsellors and psychotherapists possess. Yet these will likely be necessary to effectively interpret parallel subjectivities and avoid non-interest tracking intervention. After all, as Christine Bryden argues, many people living with dementia only appear violent or threatening because their expressions of needs are not being

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[283] University of Bradford, "Advanced Dementia Studies," University of Bradford, accessed May 27, 2020, https://www.bradford.ac.uk/courses/pg/advanced-dementia-studies/.

[284] S. J. Smith et al., "An Audit of Dementia Education and Training in UK Health and Social care: a Comparison with National Benchmark Standards," *BMC Health Services Research* 19, no. 1 (2019): 1-9.

heard.[285] Unsurprisingly, then, a 2019 study found that restraint was being overused on people living with dementia in hospital wards, in part because of inadequate training.[286]

Nevertheless, given many health and social care workers, such as paramedics, nurses and physiotherapists are now educated to undergraduate degree level in the UK, it does not seem unreasonable to argue that similar standards are required in the initial training of dementia carers. Thus, although the level of training required to pursue the indirect-first approach effectively is far beyond current policy, there are several precedents for it. If policymakers can be convinced of the value of the indirect-first approach, then, it should not be impossible to establish the kind of training necessary to support it.

1.2 Staffing Levels

In addition to being poorly trained, many carers are allowed or even encouraged to perform non-interest tracking interventions, because they operate within services that are understaffed. In the UK, the Care Quality Commission requires care providers to have an adequate level of staff to meet the needs of its users but does not recommend a specific ratio.[287] Of course, as service users have different needs which require differing numbers of staff, what might be adequate staffing for one service may be over or understaffing for another, so perhaps it is wise to avoid being too numerically stipulative. Nevertheless, it is striking that a 2018 study found neglect present in 99% of care homes, with staff shortages among the most common contributing factors.[288]

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[285] Christine Bryden, *Nothing About Us, Without Us!: 20 Years of Dementia Advocacy* (London: Jessica Kingsley Publishers, 2015), 196.

[286] Ramith Gunawardena and David G. Smithard, "The Attitudes Towards the Use of Restraint and Restrictive Intervention Amongst Healthcare Staff on Acute Medical and Frailty Wards—A Brief Literature Review," *Geriatrics* 4, no. 3 (2019): 50.

[287] CQC, "Regulation 18: Staffing," Care Quality Commission, last modified July 18, 2019, https://www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-18-staffing.

[288] Claudia Cooper et al., "Do Care Homes Deliver Person-centred Care? A Cross-sectional Survey of Staff-Reported Abusive and Positive Behaviours Towards Residents from the MARQUE (Managing Agitation and Raising Quality of Life) English National Care Home Survey," *PLOS ONE* 13, no. 3 (2018).

Evidently, where carers face staffing pressures, they will face difficulties in following the indirect-first approach. After all, because environment shaping and parallel subjectivity interpretation take time, carers may not be able to meet the vital needs of their charges without unnecessary direct intervention that, for the reasons set out in the previous chapter, is rarely in their interests. It ought to be unsurprising, then, that a 2013 study found that the overall level of resident activity in care homes remains low, despite a renewed emphasis on meaningful activity in government policy.[289]

I would be hard pressed to find an expert on this topic who did not agree that care services tend to be understaffed. It might be more difficult, however, to convince relevant stakeholders of the *degree* of that understaffing. After all, the indirect-first approach demands a sufficient number of staff to work at the person living with dementia's pace, interpret their parallel subjectivity, and maintain a specially tailored environment within which they can exercise their agential capacities as best they can. Though the dedicated empirical research necessary to establish the right staffing ratio has yet to be carried out, it seems very likely that this will require more carers than would be needed to meet everyone's needs through direct intervention.

Nevertheless, because there is a broad consensus that staffing levels need to be improved, it is not impossible to imagine the CQC tightening its recommendations and sanctioning those services that do not deploy sufficient staff. Again, because the solution to this problem is implied by the indirect-first approach, and already partially accepted, it is not implausible to think that policymakers can be convinced of the need to remove this barrier to just care.

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[289] Jennifer Wenborn et al., "Providing Activity for People with Dementia in Care Homes: A Cluster Randomised Controlled Trial," *International Journal of Geriatric Psychiatry* 28, no. 12 (2013): 1296-1304.

No doubt, there are resource challenges in particular jurisdictions and structural problems I have not considered. What I have sought to illustrate here, however, is that a significant number of present-day problems with *professional* dementia care can be resolved through effective public policy. Were policies of this kind to be implemented, people living with dementia could have their freedom from non-interest tracking interventions robustly guaranteed. Consequently, the aversion of some to professional care would become much harder to justify.

2. The Case Against Informal Care

Public policy, if the arguments above are generalisable, can and should reform private dementia care services to make them non-dominating. Even so, there may be some who would still view them as a last resort. After all, that such services need not be dominating, does not automatically entail that they are optimally good or just for their users. Indeed, some may feel that informal care *maximises* a person's interests, rather than merely refraining from violating them, so anyone who can provide it, ought to.

In this section, I reject this view. First, I consider informal care in light of the previous section, demonstrating that it faces similar problems which are much harder to resolve. Second, I demonstrate that an oft purported advantage of informal care – its intimate, personal and loving nature – actually risks a number of relational injustices that are also difficult to resolve through public policy. Thus, I conclude that informal dementia care is riskier*,* from the point of view of relational egalitarian justice, than its professional counterpart.

2.1 The Difficulty of Regulating Informal Care

Informal carers, by definition, are not employees. In that sense, the issues of poor training and understaffing, which I identified as root causes of dementia carer domination in the UK, are not directly translatable to them. However, albeit in a different form, problems of this kind are still present in non-professional dementia care contexts.

To understand this, consider how people come to take on the role. Though it would be odd to refer to them as ‘recruitment standards’, the requirements for adopting this role are fairly loose, by definition. After all, were a friend or family member required to maintain official registration, attend a rigorous job interview or demonstrate extensive prior experience, we would no longer be talking about informal care.

Rather, informal carers come to occupy their roles because of the relationships they already have with the person being cared for, not the skills or demonstrated competence they have. Accordingly, due to the nature of the role, informal carers are less likely to be adequately trained, less likely to receive ongoing training, and need not necessarily meet any particular standards before taking on their duties. All three training-related issues that are present in the UK’s professional care services, then, are likely to be present in informal care relationships.

Moreover, because family and friendship group numbers are limited, informal carers may not always have enough people to provide adequate care to their loved ones. No doubt, informal carers often operate on a 1-1 ratio with the person being care for, which is better than many care homes can offer. Problems in staffing may still occur, however, if the person living with dementia needs access to care throughout the day. After all, professional care services can split days into shifts so that the person in receipt of care has access to a carer who is awake and alert *at any time of day*. In a limited group of informal carers, however, this may be impossible without subjecting them to an intolerable strain on their time and energy; indeed, over a third of informal carers in the UK report working over 100 hours a week providing care for their loved ones.[290] The risks of understaffing that are present in today's professional care services are therefore likely to be present in many informal care relationships.

To be clear, this is not to say that all informal carers are incompetent, nor that families and friendship groups do not engage in serious deliberation over who among them should provide care. The point, rather, is that, without specified standards of experience and training, competence cannot be *robustly guaranteed* for all people living with dementia who receive care informally. As a result, they are at great risk of being subjected to interventions that do not track their interests, without adequate sanctions or restraints on their carers.

Perhaps, similar to proposals that have been made about parenting,[291] governments could issue dementia care licenses on the receipt of training, which could be removed in instances of abuse. Provided there is adequate financial and social support to enable informal carers to receive these licenses, this might go some way towards ameliorating these risks. Nevertheless, there are a number of problems with invigilating care, which might make such a regime difficult to uphold.

Consider first, the lack of institutional support inherent to informal care. While a professional care service can make use of supervisions, spot-checks and peer evaluation to moderate standards and tackle issues, none of these is fully compatible with the provision of informal care. Thus, because carers do not have superiors to report to or formal channels through which they can ask for assistance or be disciplined, they may intervene in their charges' choices without tracking their interests without anybody knowing.

Of course, egregious abuse may be apparent to other family or friends, but whistle-blowing cannot be robustly guaranteed in every case. After all, different families and friendship groups involve different social dynamics, are of different sizes and are spread out over

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[290] Dementia Statistics Hub, "Impact on Carers," Dementia Statistics Hub, last modified August 14, 2018, https://www.dementiastatistics.org/statistics/impact-on-carers/.
[291] Hugh LaFollete, "Licensing Parents Revisited," *Journal of Applied Philosophy* 27, no. 4 (2010): 327-343.

differently sized geographical areas. Thus, the ability to invigilate one another's work may vary depending on each group's particular situation.

Likewise, though well-funded social workers may be able to invigilate the provision of informal care to some degree, their ability to discover and sanction abuse may be limited. After all, while a professional care service can increase staff numbers, replace carers who are not performing well or remove those struggling from particular service users until they are better trained, social workers can do little of this without professionalising the role of the informal carer. Thus, if its informal nature is to be maintained, social workers may only be able to react to problems by mandating professional care or threatening to do so – something they may be reluctant to do outside of cases of egregious abuse.

All this is to say that, though it is often romanticised, informal dementia care is fraught with the same problems as its professional counterpart. Moreover, because its practitioners are not employees, regulating and applying sanctions to their activities may be much more difficult. The upshot of these reflections, then, is that a preference for informal care cannot be defended on the grounds that it is *optimally just* in comparison with professional care. On the contrary, it carries the same risks of domination alongside a greater difficulty in restraining carer power.

2.2 The Problem with "the Personal Touch"

Alongside those risks of domination shared with professional care, there are distinctive issues that arise from one of informal care's purported goods. It is common to hear people expressing concerns about professional care as *impersonal* or *transactional*, such that it strips away important emotional components of the care relationship. Indeed, disparaging them as operating on a "warehouse model", many of Tom Kitwood's critiques of professional dementia care services in the 1990s were of this character.[292]

No doubt, overpopulated care homes with tiny, clinical bedrooms and dreary lounges with dozens of armchairs packed tightly together are terribly undignified and oppressive. So too are brusque, impersonal community carers, who can only attend to each of their long list of clients for fifteen minutes before rushing on to the next home. Both are, likewise, antithetical to the indirect-first approach, which emphasises the importance of attending to the unique needs and communicative patterns of each individual.

Where services of this kind are all that are available, the aversion of many towards professional care is perfectly understandable. Due to their personal relationship, an informal carer may be kinder, more knowledgeable and more loving towards the person receiving care, than an employee of an unjust professional care organisation. A lack of professional distance, such as that which exists between informal carers and their charges, however, may also carry risks of indignity and oppression—risks that are more difficult to mitigate through policy than their professional counterparts.

Consider first the embeddedness of informal carers within particular family or friendship systems. The fact that these carers have close relationships with other loved ones of the person they are caring for might lead to a number of issues with the ability to invigilate their care. Non-interest tracking interventions may be tolerated, for instance, because the person living with dementia fears the withdrawal of familial affection or because there is no effective conflict resolution practice within the group they are embedded in.

Even where an incompetent or malicious informal carer is relieved of duties, moreover, they may not be totally removed from the social or familial circle. Thus, unlike in properly

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[292] Tom Kitwood, "Improving Care: The Next Step Forward", in *Dementia Reconsidered Revisited: The Person Still Comes First*, ed. Dawn Brooker (New York: Open University Press, 2019), 105.

regulated professional care settings, a victim of abuse or neglect may be required to continue sharing social space with the perpetrator, in the sense that they may be cared for by or socialise with people who maintain contact with them. In this sense, the lack of professional distance both makes sanctioning bad behaviour more emotionally taxing and makes it harder to fully remove threats to dignity and vital needs.

Key to understanding these difficulties is recognising that informal care is provided over *transformed* relationships, rather than new ones. People living with dementia are the elderly relatives, spouses or friends of their informal carers. These are either relationships in which they could have sought social recognition by providing care themselves or peer relationships in which they could share in a common life on equal terms. However, as care relationships are unavoidably asymmetric in power, informal care transforms these ties such that the person becomes dependent on and vulnerable to those they are close to.

For many, this transformation may be accompanied by a risk to their sense of dignity. Indeed, as noted by Maria Stuifbergen and Johannes Delden, many people are uncomfortable with the idea of being cared for by their children, spouses or friends, because it involves activities, such as being assisted to wash or eat by them, that they consider inappropriate for the relationship.[293] Even for those that can tolerate it, however, this transformation may carry an oppressive, marginalising character, because it erodes their ability to gain recognition as a useful participant in the most intimate circle of their social lives.

Note that it is not the mere fact of their dependency that causes this marginalisation; as Young herself states, dependency need not be oppressive.[294] Rather, it is that the barrier between their social circle, and the people on whom they directly depend to meet their vital needs, has broken down. Thus, the asymmetry of the care relationship risks overshadowing

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[293] Maria C. Stuifbergen and Johannes J. Van Delden, "Filial Obligations to Elderly parents: a Duty to Care?," *Medicine, Health Care and Philosophy* 14, no. 1 (2010): 68.

[294] Young, *Justice and the Politics of Difference*, 55.

their intimate, familial and social relationships in a way that disrupts their ability to be an equal participant in their social life.

By way of illustration, consider an informal care relationship between two friends. Sam, who lives with dementia, used to think of herself as an equal participant in her friendship with Nina. They would help each other with personal problems, provide assistance when one of them was in need and take part in leisure activities they both enjoyed together. As Nina now cares for her, however, Sam is now dependent on her friend's assistance in a way she knows she can never repay. She also has little privacy in their interactions, while Nina has an entire life outside of this care relationship. Worse, when she is upset with Nina or feels like she is making a mistake, Sam cannot be frank and honest with her the way she used to for fear of losing support. Where Sam once enjoyed social recognition from a peer then, she now experiences a marginalising, asymmetrical dependency, of the kind Young herself highlights, in which she has no private life, little individual choice and lacks the social standing necessary to demand respectful treatment.[295]

Of course, exceptional carers will do their best not to highlight this asymmetry, instead seeking to enable their charges to take part in social life with people outside of the circle who are not involved in their care. While these practices may reduce the severity of this risk of marginalisation, however, they cannot remove it from *their relationship with the charge*. After all, no matter how professionally a son seeks to care for his father, there is a history of intimacy between them that cannot be easily discarded. Thus, even exceptional informal carers remain a part of their charge's social circle, such that the capacity for social recognition and equal participation between them is eroded.

Some may doubt that a barrier between one's carers and one's social circle is necessary to avoid marginalisation. Indeed, many care ethicists might think the solution to

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[295] Young, *Justice and the Politics of Difference*, 54.

marginalisation through asymmetric dependency is to *normalise* our interdependence, such that we are all conscious and appreciative of the way we care for *each other*.[296] As noted by Tom Shakespeare, however, this approach ignores the extent to which disabled people are *socially* constructed as dependent, such that they needlessly have less control over their own lives and fewer opportunities for social recognition than others. Without minimising the areas in which disabled people are dependent through social support schemes and professional care, he argues, they will be further marginalised by a social structure that does not take their needs for social recognition and independence seriously. Maintaining the barrier between one's personal care and one's social circle is then, in Shakespeare's terms, a necessary component of the "level-playing field" upon which the social order that recognises our interdependence must be built.[297]

Far from being straightforwardly good for people living with dementia, then, the personal nature of informal care carries many risks of injustice. This example serves to illustrate the threats to dignity and social equality inherent to delivering dementia care through extant, intimate relationships. Accordingly, just as a preference for informal dementia care cannot be justified on the grounds that it is less prone to domination, it also cannot be justified on the grounds that it is more personal than its professional counterpart, due to the risks of marginalisation.

3. Choosing Dementia Care for a Loved One, as an Egalitarian

From the point of view of egalitarian justice, informal care is at least as prone to domination as its professional counterpart, while carrying unique risks of marginalisation. It stands to reason, then, that an ideally just society would not *rely* on family and friends of people living

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[296] Virginia Held, *The Ethics of Care: Personal, Political, and Global* (Oxford: Oxford University Press on Demand, 2006), 11-14.

[297] Tom Shakespeare, "The Social Relations of Care," in *Rethinking Social Policy*, ed. Gail Lewis, Sharon Gewirtz, and John Clarke (Thousand Oaks: SAGE, 2000), 59-63.

with dementia in the provision of care. Instead, well- regulated, trained, and staffed professional care services would be accessible to all those who needed them.

That family and friends in an egalitarian society would not have an *obligation* to provide informal care, however, does not settle the *permissibility* of doing so. Nor does it clarify the duties of the loved ones of people living with dementia in our present-day, non-ideal circumstances. In this final section, then, I address these two issues in turn, concluding by inverting the common intuition I began by considering: informal, not professional care, should always be considered a *last resort* for people living with dementia.

3.1 Informal Care in Ideal Circumstances

In ideal circumstances, public policy initiatives would be used to restrain the power of professional dementia care workers, using training, regulation and staffing to prevent them from making non-interest tracking interventions with impunity. In other words, in ideal circumstances, professional care services would not be dominating. It is for this reason that, in such a society, informal care would not be relied upon.

As I indicated in the previous section, some restraint on the power of informal dementia carers could be exercised through such initiatives. Yet even if legislation were able to prevent informal care domination entirely, the risks of marginalisation inherent in the transformation of intimate social bonds into asymmetric dependency relationships may not be resolvable. Consequently, anyone choosing to provide informal dementia care, in ideal circumstances, would appear to be committing a grave harm, by exposing their loved ones to unnecessary risks of injustice.

This, however, may be too quick for some. After all, such an argument implies that a relational egalitarian society ought to *prohibit* the provision of informal care, which would strike many as a demeaning intrusion into family life. Moreover, there may be some people living with dementia who consistently communicate that they *want* to be cared for by their close family and friends, such that a preference for informal dementia care forms part of their authentic value-set.

The former objection, though perhaps emotionally compelling, does not carry much weight. As I argued in the previous chapter, there is nothing demeaning or insulting about making policy that applies to *all* carers, highlighting the risks *inherent in the relationship*. Of course, there might be bad versions of a prohibition on informal care, involving injustices such as disproportionate sanctions or over-monitoring of minority groups. None of these, however, is *inherently* risked by such a prohibition.

The latter, however, might appear thornier. After all, the prevention of people living with dementia from receiving the type of care that they authentically want, could be construed as a non-interest tracking intervention. Thus, though they would not be dominated by the *professional care services*, such a prohibition might entail that they would be dominated *by the state*.

Nevertheless, there are a number of ways in which this policy could be defended from this objection. That a person has a preference for informal care, first of all, does not necessarily mean that a prohibition on it would fail to track their interests overall. After all, however strongly they may hold it, this is not the only interest they have. Consequently, given the risks of marginalisation inherent in informal dementia care, alongside risks of harm attributable to incompetence, banning it could be justified on an *all things considered* basis.

Secondly, though people living with dementia can generate contemporary authentic value-sets, they can be mistaken, like any of us, about the interests that arise from them. For instance, as per the discussion in Chapter 3, a person might value their health but believe it is in their interests to continue smoking. Of course, this might not justify a ban on personal smoking but, because informal care involves another person, banning it is more analogous to attempts to limit second-hand smoke; people are entitled to harm themselves in pursuit of a mistaken view of their interests, but the state does not necessarily dominate them by taking steps to prevent persons subjecting one another to harm.

Finally, banning *exclusively informal* dementia care, in which those who receive it are *only* cared for by non-professional loved ones, need not violate a person living with dementia's authentic preference to be cared for by friends and family. After all, there are many ways in which people can contribute to the care of their loved ones without *becoming their carers*, such as engaging in meaningful activities with them, helping professional carers to shape their environments or providing them with emotional support. Given that the risks of marginalisation I specified in the previous section emerge, primarily, through the designation of carers and dependents in intimate social circles, such an arrangement would be less troubling from the point of view of relational egalitarian justice.

Understood this way, there is nothing objectionable about friends and family members *helping* people living with dementia, which may occur throughout the progression of the condition. An ideally just society, however, would *prohibit* loved ones from taking on *the role of carer in an asymmetric dependency relationship*, given that non-dominating professional dementia care would be widely available. Thus, though a loved one might prepare some of a person living with dementia's meals, wash their clothes, manage their diary or make suggestions to a professional carer, an ideally just society would prohibit them from bearing the *primary* responsibility for meeting a person living with dementia's needs.

Note that this need not require any one with a diagnosis of dementia to move to a care home or be cared for by a permanent, live-in carer. In the early stages of the condition, it may be sufficient to have an advisor who helps to build cognitive scaffolding so that they may live at home independently. In later stages, they may need to be visited several times a day by a carer but, if there are no immediate dangers that require constant monitoring, they may be helped by their loved ones, without risks of injustice in between visits. When continuous access to care is needed, however, relational egalitarian justice demands that this is provided by a well-trained, properly regulated professional service: either in the person's own home or in an institutional setting.

Concerns about privacy and family life may, of course, be raised at the prospect of a state-mandated live-in carer. While I have little sympathy with the view that carers should be free from state scrutiny, for the reasons I set out in Chapter 3, in the next chapter I will address concerns about the optimally just type of care service for people living with advanced dementia. For now, it suffices to say that, in an ideally just society, concerns for privacy on the part of a person living with dementia's loved ones *cannot* outweigh the greater risks of injustice involved in informal care.

3.2 Avoiding Informal Care in Non-Ideal Circumstances

Absent such a just society, however, many would likely default to the position of viewing professional care services as a last resort. On this view, even though informal dementia care carries greater risks of injustice, the known injustices of professional services are too severe to countenance subjecting their loved ones to them. In this sense, many believe they have a *duty* to care for their older relatives and friends living with dementia.

Many versions of this view rest on the idea of reciprocity.[298] So understood, children who have been cared for by older adults who then, themselves, require care have incurred a debt that ought to be repaid. Yet, while there is something poetically pleasing about such a view, it is highly problematic. Not only does it exclude persons who have not cared for children (either because they do not have them or were not able to) from its scope, it also suggests that

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[298] R. Bliezner and R. R. Hamon, "Filial Responsibility: Attitudes, Motivators, and Behaviors," in *Gender, Families, and Elder Care*, ed. Jeffrey W. Dwyer and Raymond Coward (Thousand Oaks: SAGE Publications, 1992) 105-119.

such duties vary in strength depending on the kind of relationship a person has with their parent. This is particularly problematic, as those who are likely to have received extensive care, perhaps due to disability or other particular needs, may experience the duty to care for their carers as much more challenging.

Another version of this view rests on *hypothetical reciprocity*. So understood, the relationship between the informal carer and the person living with dementia rests on mutual acknowledgement that informal care would be provided were the roles reversed.[299] This duty may be plausible for many caring acts, but it is less clear that it can cover highly specialised dementia care. Such a duty, after all, must surely be limited by what it is possible for a person to do, and in particular limited by what costs it is reasonable to demand they bear.

By analogy, a friend who lives next door to me may have a care duty, grounded on hypothetical reciprocity, to bring me a bowl of soup or some paracetamol when I am struck with influenza. It would be unreasonable, however, for me to demand the same of a friend living on another continent. Indeed, it would still be unreasonable even if both of us mistakenly thought that we would be able to bring one another soup when the other is ill. Given the level of skill and knowledge I have argued is necessary for effective dementia care, there can, similarly, be no reasonable duty derived from hypothetical reciprocity to provide it: at least not in all circumstances.

That this is an uncomfortable conclusion for many likely rests on the fact that, in our present-day societies, injustices that arise in professional care settings are much more familiar. In a sense, this ought to be unsurprising, as professional dementia care services, in many jurisdictions, are inadequate. That some may feel they have a duty to provide informal care in such circumstances, *despite its costs,* does seem to suggest that there is some duty of care they are drawing on.

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[299] Bliezner and Hamon "Filial Responsibility: Attitudes, Motivators, and Behaviors", 105-119.

This duty, however, is not best characterised as a duty to provide care. On the contrary, as argued by Stuifbergen and Delden, what is being invoked here is a duty to care *about* our loved ones.[300] Naturally, this duty requires us to care about our loved one's vital needs and to do what we can to ensure they are met, but it is also requires us to care about their social status and their claims to just treatment. Where care services are ideally just, as I have argued above, this duty requires the loved ones of a person living with dementia in need of care to ensure those needs are met by professionals. Where professional care services are imperfect but are likely to bear fewer risks than informal care, this duty also points towards them. After all, *how* a person's needs are met is just as important, on the relational egalitarian view, as whether or not they are met at all.

Note, however, that where professional care services cannot meet a person's needs at all (or can only do so in a demeaning, disempowering way), the duty to care about our love ones would require their loves ones to provide informal care. In many of our societies, professional care services are of this nature, which might account for our common, intuitive aversion to professional carers and, in particular, care homes. It should be understood, nevertheless, that the validity of this intuition is *contingent*: the duty to care about our loved ones, given all I have said above, only requires informal care where professional care services are *utterly inadequate*.

Moreover, it ought to be noted that, if the inadequate professional care can be made good enough by informal *supplementation,*[301] the duty to care *about* our loved ones with dementia is best served that way, given the particular risks that arise from the private nature of informal care. For example, if a care home is generally pleasant and caring, but too understaffed to attend to all residents who need assistance with eating, their loved ones could supplement

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[300] Maria C. Stuifbergen and Johannes J. Van Delden, "Filial Obligations to Elderly Parents: a Duty to Care?," *Medicine, Health Care and Philosophy* 14, no. 1 (2010): 69-71.

[301] This is a practice which some contemporary informal carers engage in, see: B. J. Bowers, "Family Perceptions of Care in a Nursing Home," *The Gerontologist* 28, no. 3 (1988): 361-368.

that care by visiting daily to sit with them at mealtimes. Likewise, if community care services are adequately staffed, such that they can help their clients out of bed at times of their choosing, but are only able to offer 15-minute appointments, loved ones could supplement that care by laying out fresh clothes, preparing the bathroom or offering to help with the final stages of getting them dressed – e.g. putting on their socks or tying their shoes.

All this is to say that there is exists no general duty for a person to provide informal dementia care to their relatives as such. No doubt, there are many circumstances in which a person has no choice but to provide such care; and it seems plausible that there is a special obligation to do so (though the obligation may be unenforceable). No doubt, there are many others in which the duty to care about their loved ones requires them to supplement the professional care that is available. In all such cases however, this obligation exists because of the inadequacy of professional care, not because of the superiority of informal care. Thus it is informal, not professional care, that should be considered a last resort.

Conclusion

In this chapter, I have argued that professional dementia care carries fewer risks of injustice than informal care and, therefore, a just society would not rely on the latter. I have also argued that there exists no general moral duty to provide dementia care within close, personal relationships, though there may be when professional services are inadequate.[302] There are,

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[302] This argument bears a family resemblance to Adam Swift's work on school choice [see: Adam Swift, "The Morality of School Choice," *Theory and Research in Education* 2, no. 1 (2004): 7-21], though it differs in important aspects. For Swift, parents act unjustly by sending their children to private schools, in ideal circumstances, because it makes *everyone else* worse off. As I have argued here, loved ones act unjustly by providing informal care, in ideal circumstances, because it makes the person *in receipt* of that care worse off. Thus, while both arguments use institutional inadequacy as a justification for doing something that would, in ideal circumstances, not be morally permissible, the consequences of doing so differ greatly. On Swift's view, a child sent to a private school when state schools are inadequate would not be exposed to an injustice: in fact, they would be better off than they would have been had they attended a state school in ideal circumstances. A person living with dementia, on my view, would be exposed to a number of injustices if provided with informal care and would be much worse off than they would have been if they had received professional care in ideal circumstances.

thus, two pressing moral upshots of this analysis. First, there is an imperative for policymakers to improve professional care services so that people living with dementia can be free from injustice. Second, decision-makers ought to view informal dementia care as a *last resort*: only to be considered if their loved one’s needs cannot be met through the professional care system.

Chapter 6

Can the Secure Dementia Unit Be Justified? Building Egalitarian Care Infrastructure

> "I have visited quite a few nursing homes now over the years, here and overseas. Entering the foyer and the main areas, at first the impression is bright and airy, cheerful and homely. This delight changes to despair as I enter the secure area. Clearly this is hidden away and not showcased by the nursing home.
>
> I am terrified by what I see. People sit without dignity in chairs at tables, or in lounges. Staff speak loudly to each other, with scant regard for this area being the residents' living room.
>
> The occupational therapist comes in once or twice a week, larger than life in her cheery determination to make residents do activities that seem meaningless.
>
> TV and radio compete with staff chatter.
>
> After an hour or so of visiting, I feel exhausted, needing to sit like the others in the room, staring into space."[303]

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[303] Christine Bryden, *Nothing About Us, Without Us!: 20 Years of Dementia Advocacy* (London: Jessica Kingsley Publishers, 2015), 188.

Introduction

Described provocatively by Christine Bryden as ‘dementia prison’,[304] the secure dementia unit (SDU) is a staple element of social care infrastructure in many Western countries.[305] These institutions, which use keypad locked doors, secure windows, high fencing and other barriers to keep their residents from leaving without authorisation, can take many forms.[306] Hotel-style care homes, in which each resident occupies a single room in a large building with shared communal areas, are most familiar in the UK.[307] In the Netherlands, on the other hand, ‘dementia villages’, in which residents live in small households situated in a larger complex of homes, shops, hairdressers, restaurants and other amenities, are increasingly commonplace.[308]

Despite their differences in implementation, both of these SDU models rely on a degree of coercive control which is intuitively troubling. At first blush, it may even seem like they are inherently unjust. Yet, despite her chilling description, Bryden views them as an inevitability in need of reform, rather than abolition.[309] In this chapter, I will provide a normative defence of this position, arguing that, though their role is currently outsized, suitably reformed SDUs are integral to the social care infrastructure of a just society.

In section 1, I set out the limits of community care, making an egalitarian case for retaining the SDU. In section 2, I consider the type of reforms necessary to prevent SDUs from perpetuating serious injustice. I do so by identifying problematic features of both hotel and village-style SDUs, concluding that the demands of egalitarian justice are best met by a hybrid

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[304] Bryden, *Nothing About Us, Without Us!,* 185.
[305] World Health Organisation, *Dementia: A Public Health Priority*, (World Health Organisation, 2012), 25.
[306] SCIE, "Deprivation of Liberty Safeguards at a Glance," Social Care Institute for Excellence ( ), last modified June 2017, https://www.scie.org.uk/mca/dols/at-a-glance.
[307] Amy Horton, "Liquid home? Financialisation of the Built Environment in the UK’s “Hotel‐style” Care Homes," *Transactions of the Institute of British Geographers*, 00 (2020): 1-3.
[308] William J. Van der Eerden and Gemma M. Jones, "Dutch Large-scale Dementia-care Environments: A Village Within the Community," *Journal of Care Services Management* 5, no. 3 (2011): 137-139.
[309] Bryden, *Nothing About Us, Without Us!,* 200-201.

model. Finally, in section 3, I discuss the funding of social care, arguing that all care services risk perpetuating oppression unless they are state-funded and free at the point of use.

1. The Limits of Community Care and the Place of the SDU

In the UK, the restrictions on liberty necessary to house someone in an SDU require legal authorisation through the Adults with Incapacity Act 2000 (Scotland), the Mental Capacity Act 2005 (England & Wales) or the Mental Capacity Act 2016 (Northern Ireland). In each jurisdiction, moreover, these restrictions are subject to monitoring and review.[310] Nevertheless, authorisations are commonplace for those with advance dementia and,[311] perhaps concerningly, the number of applications has increased by an average of 15% each year since 2014.[312]

In Chapter 4 I noted that, because of their vulnerability to the power of others, people living with dementia require access to care. On its own, however, this does not justify the level of coercive control involved in housing people living with dementia in SDUs. After all, in our present-day societies, such housing arrangements are involuntary, if only because the resident has lost the capacities necessary to evaluate the decision. Moreover, because people living with dementia are increasingly reliant on their home environment to compensate for reduced cognitive function, such moves can be incredibly disorienting. It is unsurprising, then, that demands to be taken home are levelled so frequently at SDU staff.[313]

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[310] Julian C. Hughes, *How We Think About Dementia: Personhood, Rights, Ethics, the Arts and What They Mean for Care* (London: Jessica Kingsley Publishers, 2014), 120-125.

[311] Alzheimer's Society, "The Deprivation of Liberty Safeguards Assessment," Alzheimer's Society, accessed June 12, 2020, https://www.alzheimers.org.uk/get-support/legal-financial/deprivation-liberty-safeguards-dols-assessment.

[312] NHS Digital, *Mental Capacity Act 2005, Deprivation of Liberty Safeguards England, 2018-19*, (2019), https://digital.nhs.uk/data-and-information/publications/statistical/mental-capacity-act-2005-deprivation-of-liberty-safeguards-assessments/england-2018-19.

[313] Michelle S. Bourgeois, "“Where Is My Wife and When Am I Going Home?” The Challenge of Communicating with Persons with Dementia," *Alzheimer's Care Quarterly* 3, no. 2 (April 2002): 132-133.

Yet, many family members and friends feel as if they have no other options for their loved ones. From the empirical literature, there appear to be two reasons used to justify moving a relative or friend into an SDU: a feeling that the decisionmakers can no longer meet their needs and a concern for the person's safety if left alone.[314] Although these motivations are interrelated, there is an important conceptual distinction between them. While both could be good reasons for transferring people living with dementia to SDUs in present-day, imperfect conditions, only the latter represents a concern that would be present even with reform.

Consider first the feeling that family members and friends can no longer meet their relative's needs. While the degree of the deficit varies depending on the country, it is generally accepted that governments throughout the world do not provide enough public assistance for those with dementia.[315] Consequently, affordability is one of the main considerations of friends and family members when deciding on social care options. For many people who lack the assets to sustain long-term care, public assistance alone will be insufficient. A move to an SDU, then, is sometimes the only financially viable option.

These financial considerations do represent good reasons to move relatives to SDUs in unreformed societies which remain hostile to people living with dementia, but they cannot justify the society which offers this unenviable choice. With better funded homecare, technology, and outreach programmes to develop cognitive scaffolding, people living with dementia could have their care needs met in their own homes, by professionals, for much longer than they presently do. No doubt, we can imagine desperately poor societies who would not have the necessary funds to do so, but these non-ideal circumstances do not detract from the

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[314] See:
G. Livingston et al., "Making Decisions for People with Dementia who Lack Capacity: Qualitative Study of Family Carers in UK," *BMJ* 341, no. 7771 (August 2010): c4184.
Gillian F. Reuss, Sherry L. Dupuis, and Kyle Whitfield, "Understanding the Experience of Moving a Loved One to a Long-Term Care Facility," *Journal of Gerontological Social Work* 46, no. 1 (2005): 25.
Philippe Thomas et al., "Reasons of Informal Caregivers for Institutionalising Dementia Patients Previously Living at Home: the Pixel Study," *International Journal of Geriatric Psychiatry* 19, no. 2 (2004): 127.

[315] J.E. Carter, J.R. Oyebode, and R.T.C.M. Koopmans, "Young-onset Dementia and the Need for Specialist Care: A National and International Perspective," *Aging & Mental Health* 22, no. 4 (2017): 468-470.

general point: where there is no resource impediment to providing universal homecare, there is no moral justification for unnecessary SDU transfers.

Concerns for safety, on the other hand, present a conceptually distinct problem. Some safety concerns, of course, arise from the lack of finances available to provide constant care for people in their own homes, but others arise because of threats posed by external actors. Where people living with dementia are not provided with care, as I argued in Chapter 1, they become at risk of abuse, exploitation, violence and other forms of inegalitarian treatment. This risk is particularly acute in centres of community activity as, even with large-scale dementia training programmes, there may still be malicious actors willing to take advantage of a person living with dementia's vulnerability.

Effective homecare can, of course, ameliorate this risk significantly, in the sense that carers can protect their charges from the malicious actions of others or bear witness to them so that effective sanctions can be applied. The level of monitoring necessary to do so, however, comes at a cost that is likely to be intolerable. After all, some of those with advanced dementia might need to be monitored closely across their social life, subjecting their entire experience of communication and socialisation to rigorous scrutiny. Consequently, their opportunities to engage in spontaneous, social activity with other persons would be greatly diminished.

An SDU, on the other hand, can afford to monitor their residents less closely, because staff can control who enters the home, greatly reducing the risk of spontaneous interaction leading to injustice. Moreover, within the SDU the residents are able to engage in social interactions with each other without the kind of close monitoring that would be necessary outside it. Thus, though the SDU inevitably involves constraints on liberty, some people living with advanced dementia may be better able to act as agents because of them: at least within the institution itself.

Of course, it may be objected that greater freedom in social interaction cannot outweigh the fundamental violation of liberty that the SDU must make to exist; the residents are not free to leave the home. Such an objection, however, involves a fundamental misapprehension; while present-day SDUs do need to decline requests to leave the majority of the time, this is a feature of circumstances, not the institution itself. Even a fully reformed SDU would need to prevent their residents from leaving *alone*, but so too would fully reformed home-carers in the case of advanced dementia. The SDU might restrict a person's liberties more than declining to make any care interventions but, in this sense, it is no more inherently restrictive than homecare.

Admittedly, there is a distinction between these cases, as home-carers are preventing people from leaving their own homes alone, rather than an institution they may not have consented to moving to. However, as a person begins to rely more and more on their environment to scaffold cognition, they may become overwhelmed by spaces outside of the home, reducing their ability to appear and interact with others in public space and putting them at greater risk of marginalisation. In the controlled environment of the SDU, on the other hand, a capacity for social interaction might be retained longer. Thus, it is far from clear that restrictions in a person's own home are *always* better or more justifiable than restrictions in an institution. Indeed, in some cases they may be worse.

Consider, for instance, a person with advanced dementia who lives alone, has no living family or friends and is usually too overwhelmed to access public spaces. This person has no opportunities to interact spontaneously with others and has been pushed to the margins of society — neither of which need be the case if they lived in an SDU. Thus, they are exposed to greater injustice by being cared for in their own homes than by being moved.

Some may still be squeamish about the interference involved, especially if a person resists being moved. It must be remembered, however, that mere interference does not necessarily constitute an injustice on this framework. For relational egalitarians, freedom is best conceived of as a state of non-domination: where all interference is forced to track a person's interests. For some, a move into an SDU with all its restrictions would not constitute a violation of liberty, because they have an interest in social interaction and recognition that cannot be satisfied in their own home. For others, this may not be the case. Though this may seem like a perverse interpretation of liberty to some, particularly those with libertarian leanings, it should be recognized that many people living with dementia are *de facto* confined to their own homes and unable to exercise agency; in cases like these, a move to a suitably-reformed SDU could be genuinely liberating.

Even a fully reformed SDU may not always be the right choice, but it should be acknowledged that, in a significant number of cases, it will be the intervention that best tracks a person's interests. Thus, if it only houses those whose spontaneous opportunities for social recognition are better retained through its controlled environment, there is an egalitarian case for retaining the SDU.

2. Reforming the SDU: Hotels vs Model Villages

While focus on improving their treatment of people living with dementia has increased in recent years,[316] there are well known problems with the UK's hotel-style SDUs. While many of these could be resolved through reforms to staffing and training, some are attributable to this model's design and the culture that arises from it. In this section, I set out a number of these problems, demonstrating their risks of relational injustice. It would be a mistake, however, to assume that nothing can be salvaged from this model. Accordingly, in what follows I also critique the Dutch dementia village, concluding that a hybrid model would better track the demands of egalitarian justice.

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[316] Corrine Greasly-Adams et al., *Good Practice in the Design of homes and Living Spaces for People with Dementia and Sight Loss*, (London: Pocklington Trust, 2014).

2.1 Overstimulation

Various studies suggest that environmental factors increase the prevalence of violence and agitation in people living with dementia.[317] It is well-known, for instance, that such incidents are more likely in overstimulating environments.[318] Yet, many SDUs are overcrowded, with several residents cramped into noisy shared areas.[319] Likewise, many of these institutions broadcast a constant stream of television or music into their lounges, despite research suggesting this is one of the key factors in overstimulation[320] and clear guidance from the Social Care Institute for Excellence (SCIE) against doing so.[321] In addition, despite studies suggesting that people living with dementia become overstimulated and restless when they do not have access to outdoor areas,[322] many SDUs have spaces that are inaccessible to many of their residents.[323]

Residents in these environments evidently experience domination, as it can hardly be said that such circumstances constitute interest-tracking interventions. However, it is not simply an interest in avoiding harm that is being transgressed here. Such environments can reduce cognitive function in people living with dementia and increase confusion, making direct

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[317] See:
Ann Kolanowski and Mark Litaker, "Social Interaction, Premorbid Personality, and Agitation in Nursing Home Residents With Dementia," *Archives of Psychiatric Nursing* 20, no. 1 (2006).
Federico Tartarini et al., "Indoor Air Temperature and Agitation of Nursing Home Residents With Dementia," *American Journal of Alzheimer's Disease & Other Dementias* 32, no. 5 (2017).
Marieke Van Vracem et al., "Agitation in Dementia and the Role of Spatial and Sensory Interventions: Experiences of Professional and Family Caregivers," *Scandinavian Journal of Caring Sciences* 30, no. 2 (2015).

[318] Richard Fleming and Nitin Purandare, "Long-term Care for People with Dementia: Environmental Design Guidelines," *International Psychogeriatrics* 22, no. 7 (2010): 1086.

[319] Sook Y. Lee, Habib Chaudhury, and Lillian Hung, "Exploring Staff Perceptions on the Role of Physical Environment in Dementia Care Setting," *Dementia* 15, no. 4 (2014): 743.

[320] J. Van Hoof et al., "The Indoor Environment and the Integrated Design of Homes for Older People with Dementia," *Building and Environment* 45, no. 5 (2010): 1258.

[321] SCIE, "Noise Levels - Dementia-friendly Environments - SCIE," Social Care Institute for Excellence (SCIE), last modified May 2015, https://www.scie.org.uk/dementia/supporting-people-with-dementia/dementia-friendly-environments/noise.asp.

[322] Habib Chaudhury and Heather Cooke, "Design Matters in Dementia Care: the Role of the Physical Environment in Dementia Care Settings," in *Excellence in Dementia Care*, ed. Murna Downs and Barbara Bowers (London: Open University Press, 2014), 153.

[323] Fiona Kelly, Anthea Innes, and Ozlem Dincarslan, "Improving Care Home Design for People with Dementia," *Journal of Care Services Management* 5, no. 3 (2011): 147-149.

interventions more likely.[324] To this point, Christine Bryden notes that "in such a disabling environment, much of [her] time will be spent gazing blankly into space as [her] brain shuts down and [she feels] weariness rise within [her]."[325]

Moreover, this reduction in cognitive function contributes to oppression, as people living with dementia will become less able to partake in activities that ensure social recognition. For example, a person living with dementia who is facing this kind of cognitive dampening may struggle to engage in conversation or be unable, even with assistance, to prepare food and drink. In addition, as overstimulation increases the prevalence of violence and agitation, and a lack of outside areas leads to restlessness, both other residents and staff might become vulnerable to environmentally induced aggression. Thus, they may be met with unnecessary restraint and forceful separation, reinforcing the oppression of people living with dementia by violence.

Among these contributors to injustice, noisiness is perhaps the easiest one of these issues to deal with, as care staff can be instructed to use television and radio sparingly. Note, however, that they should be used strategically, not ruled out entirely; recent research suggests that the targeted use of broadcasts can be beneficial for people living with dementia by helping them to feel connected to the wider community and providing meaningful stimulation,[326] which will assist carers in providing opportunities for social recognition. What it does imply, however, is an obligation to be vigilant and ensure that broadcasts do not become too loud, overstimulating or disruptive. Moreover, they ought to be conscious of where the noise is broadcasting into and at what time. Energetic music might be suitable in the main living area in the morning but is perhaps less suitable for the dining area at night, for instance.

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[324] Melanie Burgstaller et al., "Experiences and Needs of Relatives of People with Dementia in Acute Hospitals-A Meta-synthesis of Qualitative Studies," *Journal of Clinical Nursing* 27, no. 3-4 (2018): 503.

[325] Bryden, *Nothing About Us, Without Us!,* 194.

[326] June Andrews and Mark Butler, *Telly On: Older People, Dementia and the Potential of Television*, (Stirling, UK: Dementia Services Development Centre, 2016), http://juneandrews.net/perch/resources/tellyonfinalpdf.pdf.

Overcrowding is an issue of noise too, but it also pertains to personal space and visual clutter.[327] While I cannot recommend a precise resident-to-square kilometre ratio here, because it will require empirical research, it is possible to specify what an SDU that lacks overstimulation through overcrowding would feature. For instance, an SDU in which the level of noise from all of the residents talking at a normal volume becomes loud enough to be overstimulating is evidently overcrowded. It also ought not to be cluttered with the personal belongings of its residents and there ought to be enough space for residents to walk freely without the risk that they will bump into each other accidentally.

Regarding outside space, it plainly ought to be large enough to prevent overcrowding, must not be too noisy and ought not to be cluttered with garden ornaments or furniture. In addition to this, it must be accessible with doors to the outside unlocked and adaptive mechanisms like ramps in place and, importantly, it ought to be functionally accessible for all residents. If, for instance, an SDU is multiple storeys high but only has outdoor space on the ground floor, placing the bedrooms of people living with dementia with mobility issues on the upper floors could make outside space inaccessible without dedicated assistance.

Where SDUs are designed and operated in the ways I suggest here, carers can prevent overstimulation and, in so doing, reduce the confusion and agitation in their residents which lead to carers dominating and becoming agents of oppression.

2.2 Recipient-Positioning

Residents in SDUs are too often positioned as mere recipients of care.[328] This is to say that the design and culture of the care home is oriented around the assumption that essential tasks of daily living are to be completed by staff and that people living with dementia are to relax and

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[327] Kristen Day and Margaret P. Calkins, "Design and Dementia," in *Handbook of Environmental Psychology*, ed. Robert B. Bechtel and Arza Churchman (Hoboken: John Wiley & Sons, 2003), 376.

[328] Nicky Britten et al., "Elaboration of the Gothenburg Model of Person-centred Care," *Health Expectations* 20, no. 3 (2016): 408.

receive them passively. This positioning also extends to the provision of activities in the home which, rather than playing a meaningful role in the maintenance of the surroundings or relationships with the community, are often designed to be immediately pleasurable.[329] Bryden bemoans this, when she implores to managers of care homes to understand that she wants "to do meaningful activities, such as going on outings, making useful things, and being included in the main nursing home activities."[330]

Positioning people living with dementia as mere recipients in this way also directly violates the indirect-first approach to care. Consider, for instance, the fact that food and drink in SDUs is universally prepared and served by staff without involvement from the people living there.[331] No doubt, there are many people living with dementia who would not be able to cook or prepare drinks for themselves even with the environment-shaping techniques that can be used to intervene indirectly. Where an SDU falters, however, is when it positions all of their residents as mere recipients of care by preventing any from meeting their own nutritional needs or, indeed, the needs of others, leading to domination, by violating their interest in living authentically, and marginalisation, by reducing their opportunities for social recognition.

Additionally, the combination of recipient-positioning in the activities of daily living and the meaninglessness of many scheduled activities creates a marginalising environment. This is to say that the activities that the residents are encouraged to engage in, which include arts and crafts, conversations and singing,[332] while being pleasurable and contributing to some sense of community, do not tend to offer people living with dementia opportunities to contribute in a way that is socially recognised. Such activities ought not to be ruled out, but

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[329] Samuel R. Nyman and Paulina Szymczynska, "Meaningful Activities for Improving the Wellbeing of People with Dementia: Beyond Mere Pleasure to Meeting Fundamental Psychological Needs," *Perspectives in Public Health* 136, no. 2 (March 2016): 103.

[330] Bryden, *Nothing About Us, Without Us!,* 200.

[331] Jane L. Murphy, Joanne Holmes, and Cindy Brooks, "Nutrition and Dementia Care: Developing an Evidence-based Model for Nutritional Care in Nursing Homes," *BMC Geriatrics* 17, no. 55 (2017): 4.

[332] NICE, "Mental Wellbeing of Older People in Care Homes," NICE | The National Institute for Health and Care Excellence, last modified December 12, 2013, https://www.nice.org.uk/guidance/qs50/chapter/Quality-statement-1-Participation-in-meaningful-activity.

exclusive focus on immediate pleasure obscures the extent to which these residents lack access to social recognition. Too often, the activities that do offer opportunities for social recognition, such as preparing and serving meals, laundry, cleaning and gardening are engaged in exclusively by staff which, by removing these opportunities from them, contributes to the oppression of people living with dementia.

In the UK, the grip of the recipient-positioning model has begun to be loosened a little. For instance, the SCIE now actively encourages SDUs to assist their residents in gardening.[333] Nevertheless, it remains the case that people living with dementia contributing to the maintenance of their environment in a way that is socially recognised by other residents seems to only take place on an ad-hoc basis. Moreover, there is little appreciation of the fact that such activities are required for people living with dementia to be treated justly, not just to improve their wellbeing. Understanding that people living with dementia are entitled to these activities as a matter of justice, helps us to understand the urgency with which these changes must be implemented.

In other countries, this practice is further developed. For instance, some people living with dementia in the early stages in the Netherlands are housed in group-living units, which emphasise opportunities for residents to take part in housework and meal preparation.[334] Of course, in the later stages of the condition more assistance will likely be needed, but it would be a mistake to think that activities like these would be entirely inaccessible. Even where residents cannot be assisted in engaging in more complex activities of daily living, they could be encouraged to take part in simple activities like pouring pre-prepared drinks from a jug or folding and handing out napkins. Inevitably, this will not be possible in all cases, especially

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[333] SCIE, "Gardens - Dementia-friendly Environments - SCIE," Social Care Institute for Excellence (SCIE), last modified May 2015, https://www.scie.org.uk/dementia/supporting-people-with-dementia/dementia-friendly-environments/gardens.asp.

[334] Ezra Van Zadelhoff et al., "Good Care in Group Home Living for People with Dementia. Experiences of Residents, Family and Nursing Staff," *Journal of Clinical Nursing* 20, no. 17-18 (2011): 2494.

where people living with dementia are close to the end of life, but this does not negate the fact that far more can be done to avoid *automatic* recipient-positioning.

In an environment which is neither overstimulating and nor overcrowded, SDU staff can use environment shaping techniques to assist their residents in meeting their own nutritional needs and in taking part in the socially recognised work required to meet activities of daily living. The social recognition that these activities offer is best thought of as *internal* social recognition. In other words, they contribute to the fostering of a community in which people living with dementia find social recognition in each other and in other staff members of the home. Where this is achieved, staff can avoid dominating and marginalising their residents.

2.3 Connection to the Wider Community

SDUs keep residents within their walls by coercion. Although this chapter is aimed at justifying this coercion, there are troubling parallels between this kind of living arrangement and other forced living arrangements (hence Bryden's term "dementia prison"). Even if an SDU is able to provide opportunities for internal social recognition, it remains the case that the people living with dementia who are resident in it are at risk of marginalisation.

Social exclusion is at the heart of Young's definition of marginalisation, which she describes as "the most dangerous form of oppression."[335] This is echoed by later social egalitarian theorists, such as Elizabeth Anderson who describes it as "the lynchpin of categorial inequality"[336] and Jonathan Wolff, who argues that social exclusion is a significant barrier to achieving a society of equals.[337]

SDUs, at first blush, are archetypal tools of social exclusion, since they take people from a single social group and house them together, cutting them off from the outside. Internal

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[335] Iris M. Young, *Justice and the Politics of Difference* (Princeton: Princeton University Press, 1990), 53.
[336] Elizabeth Anderson, *The Imperative of Integration* (Princeton: Princeton University Press, 2010), 16.
[337] Jonathan Wolff, "Forms of Differential Social Inclusion," *Social Philosophy and Policy* 34, no. 1 (2017): 166.

social recognition goes some-way towards ameliorating this, but it does not solve the problem entirely. Liberating people living with dementia from marginalisation, rather, requires furnishing them with opportunities for *external* social recognition: that is, recognition by people who do not live or work in the SDU.

Though such opportunities are sparse, there have been some positive steps taken in the UK. For instance, there has been a movement among local authorities to link schools and nurseries with care homes, including SDUs, giving the residents the chance to provide some socially recognised care to children.[338] Likewise, there is a long-running trend of bringing people from the community into the home through, among other things, musical performances, tailored exercise classes and opportunities to interact with non-human animals.[339]

While both provide some connection to the wider community, however, they carry a recipient-oriented character which positions people living with dementia as people otherwise excluded from society who wait to be visited, rather than active members of their own community. When Bryden appeals to the idea that people living with dementia should be encouraged to do useful things, we cannot simply answer by giving them the ability to do useful things for each other. I cannot give an exhaustive list of activities oriented towards external social recognition here, but such a list might include staff-assisted services for members of the community, like pet-sitting, Christmas card delivery or stands giving away hot tea to locals on cold nights.

Establishing and maintaining this connection to the wider community requires having enough well-trained staff to allow residents to leave the SDU at times of their choosing, which has implications for where they can be situated. If an SDU, for instance, is so far outside of a town centre as to require a long car journey to reach it, there is a practical impediment to this

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[338] Andrew Cole, "Children in Care Homes: 'It Makes Residents Feel More Human'," *The Guardian*, November 12, 2018.

[339] SCIE, "Care Home in the Community - SCIE," Social Care Institute for Excellence (SCIE), last modified June 2017, https://www.scie.org.uk/person-centred-care/older-people-care-homes/in-the-community.

kind of social recognition. Moreover, there is also an expressive quality of marginalisation in this kind of SDU design; it seems to represent an unjust attitude that people living with dementia need to be kept out of sight.

2.4 The Dementia Village

Given all of the issues with hotel-style SDUs that I have identified here, it might be thought natural to replace them with dementia village-style SDUs, such as De Hogeweyk in the Netherlands. In these innovative institutions, residents can roam relatively freely across model town centres into shops, cafes and hairdressers, perhaps helping to avoid overstimulation. They also, in many cases, live in small households in which they assist with preparing food and cleaning to the extent that they can, which may avoid recipient-positioning.[340] On this specific issue of exclusion from the wider community, however, these institutions may do worse.

As residents do not need to leave to access amenities (and, indeed, cannot without accompaniment), wholesale adoption of dementia villages may lead to a reduced level of interaction and recognition from the wider community. While internal amenities may be preferable where dementia-friendly town centres are lacking, implementing them in a context of social oppression could lead to stigmatising attitudes. It is not hard to imagine, for instance, some people objecting to projects to make town centres dementia-friendly on the grounds that 'they have their own places to go to.'

None of this is to say that villages are further from the ideal SDU than the dementia hotel; in fact, in most respects they are significantly closer. The point is, rather, that they can wrong people living with dementia if they are entirely self-contained and disconnected from the wider community. The optimal solution then, is likely a mixed-model, which makes use of

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[340] Suraj Patel, "'Alternative Reality' in Dementia Village," BBC News, last modified December 16, 2012, https://www.bbc.co.uk/news/av/health-20727157.

the smaller housing units and protected social spaces typical of the dementia village, but on the smaller scale of the hotel model, with a secure but soft boundary between it and the dementia-friendly neighbourhood it is situated in. We can imagine, for instance, gated, private roads lined with small homes and facilities, branching off of a clearly visible high street which residents can walk out to, with accompaniment.

In sum, SDUs can and ought to be redesigned so as not to be overstimulating, and the culture of recipient-positioning ought to be abandoned in favour of an approach that gives residents opportunities for both internal and external social recognition. Reforms of this kind are necessary, because the design and culture of present-day SDUs makes it difficult for carers to avoid dominating and oppressing their residents.

3. Funding Social Care

The cost of staying in an SDU, in the UK, is substantial, with most paying between £600 and £1200 a week.[341] The reforms I have proposed, inevitably, would increase that cost significantly. It is evident then, when considered alongside the other changes I have argued for in this thesis, that just treatment of people living with dementia requires a substantial investment of resources. How that increased bill is paid is a question of egalitarian justice. In this final section, I make the case that SDUs, alongside the social care system they operate within, ought to be free at the point of use.

In Chapter 1, I noted that demands for inheritance can take an exploitative form, leading to people living with dementia receiving substandard care. It is not unreasonable to suggest that large upfront payments for care services have some causal link with the prevalence of this norm in the UK. After all, though there are some local authority funding provisions, these are

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[341] Alzheimer's Society, "Dementia Tax," Alzheimer's Society, last modified 2017, https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/dementia-tax#:~:text=The%20cost%20of%20a%20care,for%20a%20number%20of%20years.

only accessible once a person's assets and savings have been depleted to below £23,250 (at time of writing).[342] Consequently, there is a direct link between how long the individual spends in care and how much they can leave behind for their younger relatives. Where the exploitative form of the social norm that people living with dementia should pass as much on to their children as possible persists, this direct link may reinforce and contribute to it.

Indeed, it is notable that in the UK, where healthcare is funded by general taxation, the receipt of essential healthcare by older adults does not contribute to this exploitative social norm in the same way. To be sure, some policymakers bemoan the increasing cost of providing healthcare to an aged population, but it does not carry with it the connotation of a failure of individual responsibility. If social care were, like the National Health Service, funded by taxation and free at the point of use, the social meaning of the money the person would spend on care would differ. Even if the people living with dementia were particularly wealthy beforehand and, as such, would spend more on taxation than they would if they were paying upfront, the direct connection between the cost of care and their payments would be severed. Instead, they would be paying into a common fund from which all those who need care can draw.

Beyond reinforcing this exploitative norm, the upfront model of care has a further problem. Earlier in this thesis I mentioned the furore that arose during the 2017 General Election campaign about Theresa May's proposed funding model for social care. Dubbed the "dementia tax", this model was widely condemned, because it required those that lived with chronic, progressive conditions like dementia to pay more into the social care budget than those who died of illnesses that only require a comparatively short time in care, like terminal cancer. While I am reluctant to defend this proposal, it was not so much a new injustice, but a

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[342] NHS, "When the Council Might Pay for Your Social Care," Nhs.uk, last modified August 30, 2018, https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/when-the-council-might-pay-for-your-care/.

reinforcing of an existing injustice. After all, care services generally charge the same fees for beds, regardless of the person's illness, which means people living with dementia already pay more than those with terminal cancer (at least on average).[343]

Questions about the distribution of health funding are not merely questions of fairness. The way our social systems distribute goods and costs has an expressive character, which can stigmatise or disrespect particular groups. A social structure that distributes care based on ability to pay, in which those with dementia will inevitably pay more than those with other illnesses, expresses an attitude of neglect. This is so, because it relegates the funding necessary to ensure that people living with dementia are not unjustly treated through inegalitarian relationships to the status of an optional extra, and a burden for which persons living with dementia are themselves responsible. This attitude of neglect, when expressed by institutions, represents a fundamental inegalitarian injustice because, as Schemmel argues, it shows disregard and disrespect for moral equality.[344]

These two relational injustices – the reinforcement of an exploitative cultural norm and the expression of neglect by social institutions, can be ameliorated through care services, including SDUs, that are free at the point of use and funded by general taxation.[345] To achieve full social equality for people living with dementia, such services must meet all of the other criteria that I have set out here. Note, however, that this aim does not require care providers be identical in their design and working practices; there may be many different ways in which they can ensure access to social recognition, for instance. Rather, justice merely demands that

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[343] Alzheimer's Society, "Dementia Tax," Alzheimer's Society, last modified 2017, https://www.alzheimers.org.uk/about-us/policy-and-influencing/what-we-think/dementia-tax#:~:text=The%20cost%20of%20a%20care,for%20a%20number%20of%20years.

[344] Christian Schemmel, "Distributive and Relational Equality," *Politics, Philosophy & Economics* 11, no. 2 (2011), 134.

[345] Whether these tax funds should be paid for by increases in personal taxation or redistributions from other parts of the state budget is a further question. As it is deeply contextual, depending on the specifics of a jurisdiction's budget in a given spending year, I set it aside.

their care is genuinely non-dominating, does not perpetuate stigma and does not reinforce oppression.

Likewise, private companies that charge a premium for access to luxury goods or designs need not be ruled out. The relational egalitarian view, at least as I have interpreted it, rejects the idea that there is something intrinsically wrong about unequal distributions of resources. Rather, such inequalities are instrumentally unjust if they lead to paradigm inegalitarian relationships. In this sense, these differences need only be problematic if they are connected to wider inequalities of status or restrictions on the ability of certain groups to live authentically: if only the wealthy have access to institutions that are built near areas of natural beauty, for instance. If, on the other hand, the differences between private and state services consist merely in the provision of goods or design choices that are generally considered to be frivolous and eccentric, such as gourmet foods like caviar and lobster, then they are unlikely to contribute to or reinforce any relational injustices.[346]

In both cases, variation between services is morally insignificant because the demands of egalitarian care are *so high*. In a society which robustly guaranteed the social equality of people living with dementia, it would not be possible for either state- or private-funded to provide a *better standard* of dementia care than one another, because *all* care services would operate on the terms I have set out in this thesis and, thus, be free from relational injustices. While a just society would not prohibit variation, then, the spheres in which care providers could differ would be severely limited.

Setting up this high threshold, however, is likely to be extremely expensive. It is possible to imagine a rejoinder from those sceptical about the idea that older people are disadvantaged, holding that the sheer volume of resources necessary to ensure that all people

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[346] I leave the question of whether we ought to use state-funding to support private providers or move to a wholly state-operated system open.

living with dementia are related to as equals represents an unfair burden on the young. There are, however, two reasons for questioning this concern.

The first, is to note how the force of this claim is dependent on how younger cohorts are treated within a society. If those younger cohorts are free from paradigm inegalitarian relationships like domination and oppression, then it becomes harder to see, from a relational egalitarian point of view, why this would represent a grave injustice.

Perhaps those attracted to this criticism have in mind our present-day societies, in which younger people lack the financial assets of their parents and, subsequently, are more vulnerable to unjust treatment. I have no quarrel with this interpretation of the generational dynamics of present-day societies but it does not, and cannot entail that the upfront system for funding care is just. What it might tell us, as we move from an unjust to a just society, is that we should not necessarily expend all of our energy improving the lot of people living with dementia while other groups continue to suffer domination and oppression, but this is a practical question about how to achieve justice – not a devastating blow to the idea that the system is unjust.

Secondly, that care services should be free at the point of use does not entail that they should be funded in an unfair way. Raising this money through general taxation might activate some of these worries about younger people having to self-abnegate to benefit the old but, even if this criticism lands, it is not the only way to ensure this public funding is available.

Gordon Brown's proposal for an increased levy on estates, for instance, targeted inheritance rather than income and, in so doing, focused squarely on the assets of the age cohort who make the most use of the system. In recent years, the idea of a hypothecated tax, kicking in at middle-age, has been floated to combat similar concerns.[347] Which funding mechanism adequately balances the just treatment of both young and older age groups is a question beyond

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[347] CJ Marshall, "A Hypothecated Tax for the NHS and Adult Social Care?," Future Care Capital, last modified February 13, 2018, https://futurecarecapital.org.uk/latest/hypothecated-tax-for-the-nhs-and-adult-social-care/.

this thesis, requiring further empirical research and, in any case, belonging to a full account of intergenerational justice. Regardless of the outcome of such an inquiry, it seems fairly likely that funding mechanisms which do not represent unjust treatment can be determined.

In sum, the system of upfront funding for social care cannot be maintained, because it reinforces exploitative social norms about the role of older people and expresses an attitude of neglect towards people living with dementia. Instead, justice demands care that is provided based on need, which is free at the point of use. Ensuring that state-funded care providers meet the demands of egalitarian care is likely to be expensive, and few if any contemporary societies are close to that goal. Nevertheless, at this stage it is vital to recognise that we cannot go on with institutions that express the idea that dementia care is an optional extra, which is not the duty of the state to ensure.

Conclusion

There are many reasons to think that housing some people living with dementia in secure units can be beneficial for them, but the degree of coercion involved requires justification. In this chapter I have explored unjust features of the present-day SDU and defended a series of reforms. These include ensuring SDUs are state funded, that they position their residents as active participants in their care, that they are properly staffed, and that they maintain connections with the wider community. Some of these proposed reforms are underway, but there are too few, and those that exist tend not to go far enough. In general, SDUs, alongside other care services, continue to fail to treat people living with dementia as equals.

Chapter 7

Dementia and the Problem of Speaking for Others

"Es gibt ja sonst keinen, der das versteht.

Mit wem soll man sich sonst besprechen? Es gibt eben Dinge, die nur ein Betroffener verstehen kann, nicht mal ein Angehöriger kann das. Und das Verstehen ist ja das Wichtigste."

[There is nobody else who understands this.

Who else should you speak to? There are many things that no-one other than someone affected can understand: not even a relative. And understanding is the most important thing.] [348]

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[348] Helen Merlin, "Ich Will Integriert Werden! [I Want to be Integrated]," in *"Ich spreche für mich selbst": Menschen mit Demenz Melden Sich zu Wort ["I speak for myself." People with Dementia Have Their Say]*, ed. Demenz Zupport Stuttgart (Frankfurt am Main: Mabuse-Verlag, 2010), 16. (my translation).

Introduction

In the light of the arguments I have made in this thesis, many philosophical depictions of dementia appear highly problematic. Norman Cantor's self-described "strong aversion to being *mired* in dementia" due to the way it would "*soil* the lifetime image or memories to be left with [his] survivors", for instance, might express something legitimate about his interest in living authentically, but does so in horrifically stigmatising terms.[349] Likewise, Jeff McMahan's claim that "dementia gnaws unrelentingly at the core of the self, eventually stripping it to the vanishing point",[350] might speak to the kind of radical changes in behaviour and interests that some people living with dementia experience, but does so through the 'loss of self' narrative emphatically rejected as inaccurate and stigmatising by dementia self-advocate Christine Bryden.[351]

Beyond merely being misguided or insulting, these kinds of depictions can have concrete, negative consequences. As argued by Peter Byrne,[352] Licia Carlson[353] and Eva Feder Kittay,[354] philosophical arguments about cognitive disability frequently make their way into clinical practice and public policy through the discipline of bioethics. Consider, for instance, the fact that Peter Singer's views on the justifiability of ability-selective abortion,[355] are seemingly, at least partially, shared by the British Prime Minister's former senior advisor.[356] Whether arrived at independently or not, the congruence of these views ought to be troubling

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[349] Norman L. Cantor, "On Avoiding Deep Dementia," *Hastings Center Report* 48, no. 4 (2018): 15-16.

[350] Jeff McMahan, *The Ethics of Killing: Problems at the Margins of Life* (New York: Oxford University Press, 2002), 494.

[351] Christine Bryden, *Will I Still Be Me?: Finding a Continuing Sense of Self in the Lived Experience of Dementia* (London: Jessica Kingsley Publishers, 2018), 10-14.

[352] Byrne, Peter. *Philosophical and Ethical Problems in Mental Handicap*. Basingstoke: Springer, 2000, 13.

[353] Carlson, "Philosophers of Intellectual Disability: A Taxonomy," 319.

[354] Kittay, *The Personal is Philosophical is Political*, 409.

[355] Peter Singer, *Practical Ethics* (Cambridge: Cambridge University Press, 1993), 181-192.

[356] Dominic Cummings, "On the Referendum #30: Genetics, Genomics, Predictions & 'the Gretzky Game' — a Chance for Britain to Help the World," *Dominic Cummings's Blog*, February 27, 2019, https://dominiccummings.com/2019/02/21/on-the-referendum-29-genetics-genomics-predictions-the-gretzky-game-a-chance-for-britain-to-help-the-world/.

for any scholar committed to social justice, as their expression by academics risks legitimising and reinforcing common prejudices.

The arguments of my thesis, by contrast, are intended to tackle such prejudices, along with the oppression, domination, and stigma they accompany. Rather than speaking *about* others, in a way that may be misguided or demeaning, I have sought to speak *for* people living with dementia, making claims on their behalf. Nevertheless, as Linda Alcoff argues, this may be a distinction without a difference, as many instances of speaking for others also involve speaking about them by "engaging in the act of representing the others' needs, goals, situation and in fact, *who they are*."[357] Thus, even if well-intentioned, claims on behalf of others, such as those I have offered in my thesis, carry the same risks of contributing to or reinforcing injustices.

This concern, known as *the problem of speaking for others*, has led some critical theorists to decry the practice as "arrogant, vain and politically illegitimate,"[358] with more radical thinkers, such as Joyce Trebilcot[359] and Giles Deleuze renouncing the idea that we can speak for anyone but ourselves.[360] Though few adopt this extreme response, the view that we should not speak for groups of which we are not a member –influenced by adherents to standpoint epistemology like Charles Mills, who hold that we cannot fully understand their experiences, especially if they are oppressed–[361] is more common. Much contemporary criticism of popular culture, for instance, is informed by this view, with increasing scrutiny

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[357] Linda Alcoff, "The Problem of Speaking for Others," *Cultural Critique*, no. 20 (Winter 1991): 9.

[358] Ibid, 6

[359] Joyce Trebilcot, "Dyke Methods," *Hypatia* 3, no. 2 (Summer 1988): 1-13

[360] Gilles Deleuze, "Intellectuals and Power," in *Language, Counter-memory, Practice: Selected Essays and Interviews*, ed. Donald Bouchard, translated by Donald Bouchard (Ithaca: Cornell University Press, 1977), 209

[361] Charles Mills, "White Ignorance," in *Race and Epistemologies of Ignorance*, ed. Shannon Sullivan and Nancy Tuana (Albany: SUNY Press, 2007), 11-38.

being paid to the way male fiction authors write women,[362] the portrayal of LGBTQ characters by cis heterosexual actors[363] and the practice of 'whitewashing' in film and television.[364]

Alcoff argues, however, that a blanket 'retreat' response, in many circumstances, is likely to undermine political effectiveness. In such cases, *refusing* to speak for others also risks contributing to or reinforcing injustices.[365] Given this, she rejects a general retreat, in favour of the view that "anyone who speaks for others should only do so out of a concrete analysis of the particular power relations and discursive effects involved." To aid in this, she suggests four "interrogatory practices", which any person intending to speak for another ought to engage in.[366] In this chapter, I apply each of these, in turn, to the thesis.

This methodological contribution has been highly influential in feminist philosophy and critical thought more generally.[367] While it is not beyond critique, it does offer a clear framework for reflecting on instances of speaking for others and their likely effects. Thus, though I offer particular interpretations of and elaborations on Alcoff's view, its validity is not my main area of focus. The purpose of this chapter, rather, is to engage in a concrete analysis of the power relations and discursive effects involved in this thesis, and to demonstrate the steps I have taken to mitigate risks of injustice.

In section 1, I consider the *necessity* and *proportionality* of speaking for people living with dementia, concluding that the urgency of the injustices they are exposed to, their inadequate representation in philosophy, and the impediments to self-advocacy they face make

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[362] John Bonazzo, "Twitter Challenge Proves Male Authors Don't Know How to Write About Women," Observer, last modified April 2, 2018, https://observer.com/2018/04/male-authors-write-about-women-twitter/.
[363] Alexandra Pollard, "Should Straight Actors Play Queer Characters on Screen?," The Independent, last modified January 16, 2019, https://www.independent.co.uk/arts-entertainment/films/straight-actors-playing-gay-roles-characters-ben-whishaw-darren-criss-cate-blanchett-rachel-weisz-a8723421.html.
[364] Steve Rose, "'The Idea That It's Good Business is a Myth' Why Hollywood Whitewashing Has Become Toxic," The Guardian, last modified November 24, 2017, https://www.theguardian.com/film/2017/aug/29/the-idea-that-its-good-business-is-a-myth-why-hollywood-whitewashing-has-become-toxic.
[365] Alcoff, "The Problem of Speaking for Others", 17-22.
[366] Ibid, 24.
[367] Jennifer K. Fenton, "Storied Social Change: Recovering Jane Addams's Early Model of Constituent Storytelling to Navigate the Practical Challenges of Speaking for Others," *Hypatia* 36, no. 2 (2021): 391-409.

a retreat response irresponsible. In section 2, I consider the influence of my status as a cognitively non-disabled, former carer writing in academic philosophy on the meaning of my work. I then set out the ways in which I have tried to avoid any negative effects: by writing from a position of epistemic humility, critiquing stigmatising depictions of people living with dementia, and emphasising the *social* origins of the problems people living with dementia face. In section 3, I consider the difficulty of remaining accountable to people living with dementia, given the significant impediments to self-advocacy they face. I conclude, nevertheless, that it is to members of this group *themselves* that my work must be accountable, rather than their families or friends. Finally, in section 4, I consider the probable effects of my thesis on the social position of people living with dementia to speak for themselves. While I accept its limitations, I argue that my extensive reference to the work of self-advocates and my arguments in favour of the authenticity of their present-day mental states may improve the ability of members of this group to be heard, if only marginally.

1. The Need to Speak for People Living with Dementia

Alcoff notes that some people, by virtue of social markers like class, gender or race, are more likely to be able to speak publicly, and more likely to be heard when they do. In such cases, members of oppressed groups may not be able to effectively self-advocate, implying a duty of justice upon members of relatively privileged groups to speak for them. Yet, in other cases, this same phenomenon might mean that speaking for members of oppressed groups effectively silences them or, at least, reinforces the very social hierarchy that impeded their ability to speak in the first place. Thus, as her first interrogatory practice, Alcoff emphasises the need for the *impetus to speak* to be "carefully analysed and, in many cases, fought against."[368]

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[368] Alcoff, *The Problem of Speaking for Others*, 24.

Alcoff is not explicit about the method or goals of this analysis. The practice can be reasonably interpreted, however, through the familiar concepts of necessity and proportionality. Speaking for others, Alcoff tells us, can draw attention to oppression, but it also carries risks of perpetuating or reinforcing it. It is reasonable to infer then, that the purpose of this analysis is to determine whether or not choosing to speak for others, given its risks, is a *necessary* and *proportionate* response to injustice. If it is, it is *all things considered* justified, so the speaker *should* speak. If it is not, then it is not justified, and the speaker should retreat or move over, to allow the oppressed to advocate for themselves.

Consider Alcoff's example of Rigoberta Menchu: a native South American who learned Spanish in order to travel to other countries and spread awareness of the exploitation of the native communities of Guatemala.[369] The nature of the oppression was severe and urgent, involving exploitation at the hands of landowners, and mass death by malnutrition and insecticide poisoning.[370] Alongside this, Alcoff argues that in not knowing Spanish and not having access to the outside world, members of these native communities, including those of which she was not a member, would likely not have been able to alert the world to their condition on their own.[371]

Her decision, as Alcoff notes, carried risks associated with conflating 34 distinct communities in the eyes of others, including misrepresenting particular community difficulties and reinforcing an imperialist view of native Americans as a generalised other.[372] However, given the severity and urgency of the injustices in this case, alongside the significant impediments to self-advocacy, it would seem absurd to argue that Menchu's decision to speak was not a necessary and proportionate response. Accordingly, it seems reasonable to suggest that in any case in which a group (i) is unable to successfully self-advocate and (ii) faces

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[369] Alcoff, "The Problem of Speaking for Others," 18.

[370] Ibid, 19.

[371] Ibid.

[372] Ibid, 18.

injustices severe and urgent enough to outweigh the risks of speaking for them, choosing to do so is both a necessary and proportionate response. In what follows, I seek to justify my decision to speak for people living with dementia in these terms.

At first glance, it may seem like people living with dementia are even less likely to be able to draw attention to their oppression than the native Guatemalan communities in the case of Menchu. After all, dementia is characterised by a decline in cognitive abilities, which creates internal barriers to self-organisation and advocacy. However, depicting this group as uniformly incapable of speaking for themselves is, at best, reductive, and at worst, oppressive. Christine Bryden, who has lived with dementia since 1995, argues that:

> The myths and fears about dementia – the stereotype of someone in the later stages of the diseases that cause dementia – give rise to stigma which isolates us. You say we do not remember, so we cannot understand. We do not know, so it is OK to distance yourself from us. And you treat us with fear and dread. We cannot work, we cannot drive, we cannot contribute to society. I am watched carefully for signs of odd words or behaviour, my opinion is no longer sought, and I am thought to lack insight, so it does not matter that I am excluded.[373]

The idea that people living with dementia are universally incapable of representing their own interests, then, is not only inaccurate but is also a key component in their oppression. In reality, dementia self-advocacy is an increasingly common phenomenon, with organisations such as the Dementia Engagement and Empowerment Project[374] and Dementia Alliance International[375] providing resources and training to help people living with dementia to represent their own interests. To produce work in ignorance or in disregard of the growing phenomenon of self-advocacy would not just be an ineffective counter to the very stigma Bryden highlights above; it would contribute to it.

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

[374] "What is DEEP?," DEEP, accessed January 28, 2020, https://www.dementiavoices.org.uk/about-deep/.

[375] Dementia Alliance International, "About DAI," Dementia Alliance International, last modified January 3, 2014, https://www.dementiaallianceinternational.org/about-dai/.

Nevertheless, it is necessary to highlight both the significance of the progressive nature of dementia and the fact that, after establishing the claim that people living with dementia are oppressed, I have predominantly focused on how that oppression manifests in dependent relationships. That many people living with dementia can and do self-advocate is indisputable. That most in its later stages cannot and do not is equally indisputable. As their condition is typified by the decline of cognitive prowess and a gradual increase in the need for care, people living with dementia become more vulnerable to injustices (and may experience different kinds) at the same time as they become less able to recognise and describe them as such– something that Bryden herself acknowledges.[376] While the testimony of dementia self-advocates is vital to dismantling the oppression of people living with the condition, there are phenomena that most have not yet experienced and will struggle to draw attention to when they experience them.

Admittedly, it does not seem credible to argue that these experiences are so distinct as to demarcate entirely separate social groups. It is, after all, doubtful that there is a fixed point at which the experience of dementia suddenly transforms from one discrete way of living to another. Dementia is, as Bryden describes, "a journey, from diagnosis to death" with "many steps along the way."[377] Consequently, while the subjective experience of advanced dementia requires some imagination to be understood by others, it is probably better understood by those who already have some epistemic authority on the lived experience of the condition. Indeed, Bryden dedicates much of her self-advocacy work to using her insights to analyse the experience of care by people living with dementia in the advanced stages.[378]

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[376] Bryden, *Dancing with Dementia,* 97.

[377] Ibid, 40.

[378] See:

Bryden, Christine. *Nothing About Us, Without Us!: 20 Years of Dementia Advocacy*. London: Jessica Kingsley Publishers, 2015.

Nevertheless, while Bryden is far from the only dementia self-advocate, the support necessary for people living with dementia to organise politically has only begun to emerge in recent years.[379] As I have argued throughout this thesis, the oppression faced by people living with dementia is severe and urgent. Problematic cultural narratives, the dominant care relationship model and the provision of inadequate services to this group contribute to an environment in which they are not related to as equals and, because most people living with dementia are older adults, they have little time to wait for liberation. Thus, it seems irresponsible to refuse to engage in the task of detailing and undermining these injustices until the necessary communicative infrastructure is in place for the group to speak for themselves. Indeed, failing to speak for people living with dementia in this context is likely to contribute to them, because it is unclear how they can be analysed and drawn attention to without assistance.

This is not to say that the decision to write this thesis is without risk. On the contrary, as a cognitively non-disabled former carer, speaking from my social position carries far greater risks than present in the case of Menchu, who was much more closely positioned to the social groups she was speaking for. However, as I will demonstrate in the next section, I have made a number of decisions in putting this work together that significantly ameliorate these risks. That I was able to do so, suggests that they are not so great as to outweigh the risks involved in failing to speak at all. My initial decision to write this thesis, then, can be justified as a necessary and proportionate response to the injustices people living with dementia face.

2. Location and Context

Once the impetus to speak has been critically examined, Alcoff then instructs a would-be speaker to "interrogate the bearing of [their] location and context on what it is [they] are

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[379] Keith Oliver and Reinhard Guss, "The Experience of Dementia: Commentary," in *Dementia Reconsidered Revisited: The Person Still Comes First*, ed. Dawn Brooker (New York: Open University Press, 2019), 101

saying."[380] The need to engage in this interrogatory practice can be illustrated through Alcoff's example of a lecturer from the United States speaking for the Global South in an academic context. While, as she concedes, "the speaker may be trying to materially improve the situation of some lesser-privileged group", this speech carries the risk of reinforcing the 'hierarchy of civilizations' view, deeply embedded in the academy (among other public institutions), that affords greater legitimacy to speakers from Western countries.[381]

Similar objections have been raised about the activism of Irish musician Bono, with critics arguing that his representation serves to depict Africans as universally poor, helpless and in need of saving by the West.[382] To this point, writer Teju Cole argues that this representation feeds a "White Saviour Industrial Complex" in which simplistic, charitable solutions are presented as the answer to problems caused by oppressive, colonial structures.[383]

Likewise, the neurotypical-led organisation Autism Speaks, has been criticised for promoting the view that autism is a disease that causes maladaptation, rather than a cognitive difference which is poorly accommodated in society (as many autistic self-advocates prefer).[384] Part of the problem in such a case is that Autism Speaks do not hold epistemic authority on the experience of autism, yet neurotypical people tend to carry an assumed authority due to their position in their status hierarchy, meaning their misrepresentation is likely to be believed. Indeed, the very name of the organisation implies that their work represents the standpoint of the oppressed group, yet it is staffed by members of the privileged group who do not have epistemic access to that experience.

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[380] Alcoff, "The Problem of Speaking for Others." 25.

[381] Ibid, 26.

[382] Barry Malone, "'We Got This, Bob Geldof, So Back Off'," Al Jazeera, last modified November 13, 2014, https://www.aljazeera.com/news/africa/2014/11/bob-geldof-ebola-africa-band-aid-bono-one-direction-famin-20141113833733496.html.

[383] Teju Cole, "The White-Savior Industrial Complex," *The Atlantic*, March 21, 2012, accessed July 15, 2020, The White-Savior Industrial Complex.

[384] Autistic Self Advocacy Network, "ASAN Has Ended Partnership With Sesame Street," Autistic Self Advocacy Network, last modified August 5, 2019, https://autisticadvocacy.org/2019/08/asan-has-ended-partnership-with-sesame-street/.

In each of these cases, the speaker interprets the experience of the spoken-for party from an outside perspective. This is problematic in itself, at least to adherents to standpoint epistemology, because such speech could be oversimplified, erroneous or misinterpreted due to the biases and knowledge gaps of the speaker.[385] The kernel of Alcoff's concern, however, pertains to the *privileged* position of these speakers and the oppressive social structures underlying the context in which they speak. As illustrated in each case, these factors can change the full meaning of what is said, in ways that can contribute to, perpetuate or reinforce injustice. Applying Alcoff's second interrogatory practice to my thesis, then, requires analysing my social location and the context from which I speak in these terms, while taking steps to mitigate any risks associated with it.

Regarding my social location, as in each of the above examples, my thesis involves interpretation from an outside perspective. Being young and cognitively non-disabled, I am also privileged in relation to the group I have spoken for, meaning my speech is more likely to be heard and may reinforce existing injustices of the kind I have highlighted throughout the thesis, such as the persistent, stigmatising belief that a life lived with dementia is inherently undesirable.

Yet, while I do not live with dementia, I have substantial experience of working with people who do in care settings. I would argue that this has attuned my understanding of the extent of the power carers have and the ease of unwittingly abusing it, particularly within institutional constraints. In the context of political philosophy, in which the majority of people do not have this experience, it does seem like writing from this perspective may have benefits.

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[385] Phyllis Rooney, "Rationality and Objectivity in Feminist Philosophy," in The Routledge Companion to Feminist Philosophy, ed. Ann Garry, Serene J. Khader, and Alison Stone (New York: Taylor & Francis, 2017), 247.

Indeed, this potential for providing a unique perspective on liberation is part of Kittay's justification for writing about her cognitively disabled daughter in a similar manner.[386]

Nevertheless, the extent of the epistemic privilege gained by my career ought not to be overstated. Epistemic authority on the care relationship from the carer's point of view is authority on trying (and sometimes failing) to treat people living with dementia justly. It is not authority on the experience of living with dementia, nor the experience of receiving care. Consequently, this is authority on operating as a potential agent of oppression, not on suffering it.[387]

Though dementia studies pioneer Tom Kitwood encouraged researchers and practitioners to use "poetic" imagination to try to understand the experience of advanced dementia and the receipt of care,[388] this has been rejected by dementia self-advocate Keith Oliver, who highlights the wealth of first-hand accounts which are available.[389] To avoid misrepresentation, then, I have made extensive reference to the accounts of dementia self-advocates such as Christine Bryden, while only referring to my experience when discussing the experience of providing care.

While this has ameliorated some of the risks, however, it also carries its own. After all, despite defending the importance of it in Chapter 5, I have repeatedly noted that professional care, in the present-day, is inadequate and unjust. Thus, having acknowledged that carers, perhaps unwittingly, act as the direct agents of their oppression in many circumstances, I must also acknowledge that this means that I have likely contributed to the oppression of people living with dementia already.

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[386] 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, UK: John Wiley & Sons, 2010), 400-402

[387] Indeed, because our present-day care services are so unjust, the *professional* nature of this experience further emphasises this potentially oppressive character.

[388] Tom Kitwood, "The Experience of Dementia," in *Dementia Reconsidered Revisited: The Person Still Comes First*, ed. Dawn Brooker (New York: Open University Press, 2019), 95-96.

[389] Oliver and Guss, "The Experience of Dementia: Commentary," 100.

Over ten years, I worked in a series of unjust care services in which the relationships between people living with dementia and their carers seemed inegalitarian by design. While my first-hand knowledge of working within these systems is part of what makes analysing from the perspective of a carer valuable (in a way that is distinct from family members or volunteers), it carries a risk of transmitting this problematic ethos into my depictions of dementia and dementia care.

I had a duty, thus, to be highly judicious with my language and the way I framed my arguments. For instance, were I to have framed each chapter as a problem with *dementia*, rather than a problem with *power* and *inequality,* I would have risked reinforcing oppression. After all, positioning the recipient of care as a problem to be solved is a common feature of stigmatising depictions of the care relationship.[390] It for this reason that, at the outset of Chapter 1, I repeatedly emphasised that the problems I identify in the thesis are created by *social structures*, not the condition itself.

Regarding context, it must be noted that academic philosophy has a history of engaging in what Licia Carlson calls the *conceptual exploitation* of people with severe cognitive disabilities. Consequently, any work written about this group risks legitimising this practice, in which members of this group are used as ‘edge cases’ to gain clarity on concepts “without any benefit in return.”[391] The work of McMahan and Singer on animal rights is, according to Carlson, a particularly egregious case, because it is unnecessary to downgrade the moral status of people with severe cognitive disabilities to challenge speciesism.[392]

Producing work that seeks to speak for people living with dementia when they have been spoken about so unjustly in the academic context carries risk. Without understanding the

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[390] Tom Shakespeare, "The Social Relations of Care," in *Rethinking Social Policy*, ed. Gail Lewis, Sharon Gewirtz, and John Clarke (Thousand Oaks: SAGE, 2000), 53.

[391] Licia Carlson, "Philosophers of Intellectual Disability: A Taxonomy," in *Cognitive Disability and its Challenge to Moral Philosophy*, ed. Eva F. Kittay and Licia Carlson (Chichester, UK: John Wiley & Sons, 2010), 318

[392] Ibid.

extent to which "the assumption that persons with intellectual disabilities cannot lead meaningful lives [underlies] our philosophical discussions,"[393] there is a risk that this work will reflect this bias and reinforce the damage of conceptually exploitative arguments. I took at as vital, therefore, vital to engage directly with them, as I have done in Chapters 2 and 3. Failing to do so, after all, could have led to tacit complicity in the maintenance of injustice.

By making reference to self-advocates, emphasising the *social* nature of the injustices people living with dementia face, and engaging directly with the conceptually exploitative arguments of other theorists, I hope to have minimised the risks associated with my social location and the context in which this thesis is presented. No doubt, I may have made mistakes and there may be risks I have not considered here. This inability to fully understand the perspective of the oppressed is, after all, at the core of the problem of speaking for others. Thus, though I have taken these risks seriously, I must remain accountable. In the next section, I will explore what this entails in the context of dementia.

3. Accountability

However well-intentioned and carefully constructed it may be, any instance of speaking for others, particularly from a privileged social position, carries risks of misrepresentation and perpetuating injustice. This is so because, in accordance with standpoint epistemology, none of us can fully understand what it is like to be a member of another group. Thus, though it may sometimes be a necessary and proportionate response to injustice, Alcoff argues that any person speaking for others must remain accountable to members of that group.[394]

Her suggestion for what this entails in practice is uncontroversial: "a serious and sincere commitment to remain open to criticism and to attempt actively, attentively, and sensitively to

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[393] Carlson, "Philosophers of Intellectual Disability: A Taxonomy," 320

[394] Alcoff, "The Problem of Speaking for Others", 25.

‘hear’ (understand) the criticism.”[395] In any of the examples I have mentioned, to whom this accountability is owed is self-evident: Menchu needed to be accountable to the native American peoples she spoke for, Bono needs to be accountable to the African communities he claims to speak for, and the leaders of Autism Speaks need to hear the criticism levelled at them by autistic self-advocates. Identifying a group to be accountable to in the case of my thesis, however, is more complex.

As I have mentioned, there are dementia self-advocates, but these first-hand accounts, by their nature can only be written in the earlier stages of dementia. As I have demonstrated throughout the thesis, however, a significant proportion of the injustices this group face are experienced by those in the advanced stages. It may be the case, then, that *the experience of oppression within the dependent care relationship is something of an inaccessible epistemic phenomenon*. If so, then some might object to the idea that members of this group *can* hold me accountable for what I write in this thesis.

This difficulty, however, does not absolve me of the need to be open to criticism. As Alcoff notes, to whom a speaker is accountable is both an epistemological and a political *choice*.[396] It is epistemological, in the sense that it requires us to identify a group who are best positioned to understand the experience of the group being spoken for. In most cases, this will be members of the group themselves, but this is not a necessity.

The concern is not just that those with advanced dementia might not be *capable* of holding me to account, but that, regrettably, they might not have the requisite capacities to *understand* their own experience of oppression. Thus, though this may seem counterintuitive, people living with advanced dementia are *not* optimally positioned to hold me to account. In

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[395] Alcoff, “The Problem of Speaking for Others”, 26.
[396] Ibid.

this case, it is not those suffering the injustices themselves who are optimally epistemically positioned, but the *outsider group closest to their experience*.

Kittay invokes this kind of reasoning when defending her decision to speak for her cognitively-disabled daughter, noting that "because [she has] a deep and intimate relationship with her, [she is] able to see what is hidden from those who are not privileged enough to see her when she opens up to another."[397] Understood in Alcoff's terms, Kittay is appealing to her status as the mother of someone with a severe cognitive disability to claim that she is a member of the group best positioned to understand that experience. Thus, as she argues, others who write about cognitive disability have a duty to maintain both epistemic responsibility and epistemic modesty, while remaining open to criticism from her and similarly positioned carers.[398]

If Kittay is correct in her analysis, then it might seem natural to identify the carers of people living with dementia, both professional and informal, as the group of people to whom those who speak for people living with dementia should be accountable. In the context of this thesis, this would be a pleasingly straightforward solution because, as a former carer, I could consider myself a member of that group. The *political* nature of this choice, however, militates against this simple solution.

As I have argued throughout this thesis, carers often act as the agents of oppression, domination and stigma. This unjust dynamic of asymmetric social power, which exists in both professional and informal care relationships, must be taken into account. If I were to identify carers as the group to whom I must remain accountable, rather than self-advocates in the early stages of the condition, I would risk reinforcing those injustices by legitimating the unjust power that carers wield and creating a new hierarchy between people living with dementia and

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[397] Kittay, "The Personal is Philosophical is Political", 407.
[398] Ibid, 400-412.

the cognitively non-disabled. This is so, because it would perpetuate what Miranda Fricker calls a "testimonial injustice", in the sense that it would devalue and degrade the testimonies of those who live with the condition, in a way that disrespects them as "knowers".[399]

This is not to say that family and professional carers have nothing of value to say about the social position of people living with dementia; if that were the case, there would not be anything especially valuable about this thesis! Rather it is to say that, because dementia self-advocates are well-positioned to understand the injustices that *all* people living with dementia face, and because I am writing in an inegalitarian social context in which their testimonies are often dismissed, identifying them as the *primary* group to whom I must be accountable is the right epistemological and political decision.

4. Analysing the Probable Effects of Speech

Alcoff considers her fourth interrogatory practice the "central point". Though it is important to evaluate the initial decision to speak, reflect on one's own social location and the context in which one intends to speak, and identify a group to whom one must remain accountable, none of these three practices can render speaking for others morally legitimate *on its own*. Rather, she argues, we must "look at where the speech goes and what it does there."[400]

To understand this point, consider again the case of Bono. As noted by democratic theorist Laura Montanaro, Africans affected by HIV, debt, and trade policy had no representation in relevant decision-making bodies when Bono first began his activism,[401] meaning his initial decision could easily be justified as a necessary and proportionate response to an urgent and severe injustice. He has also engaged in some rudimentary reflection on his

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[399] Miranda Fricker, *Epistemic Injustice: Power and the Ethics of Knowing* (New York: Oxford University Press, 2007), 9-18.

[400] Alcoff, "The Problem of Speaking for Others", 26.

[401] Laura Montanaro, "The Democratic Legitimacy of Self-Appointed Representatives," *The Journal of Politics* 74, no. 4 (2012): 1099.

social position and the context of his speech, as well as identifying the group he must remain accountable to, telling a journalist in 2005: “they haven’t asked me to represent them. It’s cheeky but I hope they’re glad I do.”[402] However, while at one stage these representations produced positive effects and were not widely protested against by the people he claimed to represent, it is increasingly argued that his activism does more harm than good.[403]

Alcoff’s fourth interrogatory practice, to evaluate instances of speaking for others by their effects, helps us to understand why earlier instances of Bono’s activism could have been justified while latter instances must be rejected as morally illegitimate. Africans affected by HIV, international trade and debt *still* lack adequate representation in formal decision-making bodies, and little has changed about Bono’s social location and the context of speech. The relevant difference consists in the *effects* of his speech; where once he successfully lobbied wealthy governments to increase aid and cancel debt, his speech now, it is argued, has the effect of stifling self-advocacy and drawing attention away from the injustices these people face.[404] In this sense, using Alcoff’s terms, evaluations of the legitimacy of speaking for others are “indexed”: obtaining for specific instances, rather than universally.[405]

Evidently, I cannot know the effects of writing this thesis in advance, so any defence of its content is, of necessity, contingent; were it to have unforeseen, highly negative consequences, it ought rightly to be considered a morally illegitimate instance of speaking for others. However, Alcoff also encourages speakers to consider the *probable* effects of their speech on the “discursive and material context” when engaging in speaking for others.[406] This implies that, if there are any *reasonably predictable* negative effects that the speech may have

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[402] Chrissy Iley, "Why Africa Needs U2," *London Evening Standard*, June 8, 2005.
[403] Sally Hayden, "Bono Gets a Nod as ‘White Saviours’ Called out in Uganda," The Irish Times, last modified August 22, 2019.
[404] Teju Cole, "The White-Savior Industrial Complex," *The Atlantic*, March 21, 2012, accessed July 15, 2020, The White-Savior Industrial Complex.
[405] Alcoff, “The Problem of Speaking for Others”, 26.
[406] Ibid.

on (i) the ability of the group in question to speak and be heard, and (ii) their wider social position, the speaker should refrain from speaking, or modify the content so as to avert them.

Now, it seems a little presumptuous to think that my work can have any material impact at all, given the relatively limited audience most doctoral theses have. Nevertheless, by submitting and eventually seeking to publish this thesis, I am publicly communicating a number of claims about the interests of people living with dementia. This is not a private diary, and I must be mindful of the possibility, whatever its size, that my arguments will be read by others and may eventually exert influence on public policymakers (as I hope they someday will). It is, therefore, important to engage in this kind of analysis, to increase the likelihood that its impact, however modest, will be positive rather than negative. In what remains of this section, then, I consider probable effects of this thesis on the discursive and material context, respectively, that people living with dementia face.

As I first noted in Chapter 1, people living with dementia face significant hurdles to self-advocacy, because of a tendency to disregard or discount their testimony. By opening each chapter with a quote from a self-advocate, as well as making reference to them throughout the thesis, I intended to challenge this norm, while introducing this work to a wider audience. Doing so, as I argued above, mitigates the risk that, given my social location, the thesis could reinforce this unjust testimonial hierarchy. Nevertheless, there remains a risk that readers will fail to take these testimonies seriously, viewing my use of them as merely superficial or rhetorical.

The content of Chapter 3, in which I defended the authenticity of people living with dementia's present-day expressions of value and Chapter 4, in which I emphasises the way in which social and institutional factors can dampen their cognition, is vital to avoid this problem. By setting out these arguments in the middle of the thesis, I aimed to persuade readers to reflect on the weight they had given to these testimonies in the first half of the thesis, and to take those in the second half more seriously. If successful, it seems reasonable to hope that this reflection will stay with readers after finishing the thesis and cause them to change the way they engage with people living with dementia. Not only have these arguments reduced the risk of the thesis reinforcing the testimonial injustices this group face then, they may, if only in a modest way, challenge them.

Regarding the material context, much turns on the success of the arguments. The broad goal of this project is to contribute to describing and challenging a series of injustices faced by people living with dementia. I have done so by analysing and critiquing the cultural biases that contribute to their oppression (Chapter 1), providing an account of moral and social equality that is free from bias towards rational agency (Chapter 2), arguing that the authentic present-day values of people living with dementia should determine the validity of advance directives (Chapter 3), uncovering the normative demands on carers to ensure care relationships are egalitarian (Chapter 4), arguing for the importance of, suitably reformed, professional care (Chapter 5) and advocating radical reforms to the secure dementia unit (Chapter 6).

If these arguments are sound and persuasive, the risk of contributing to injustice is likely to be reduced. I should note, nevertheless, that every chapter featured pitfalls that could have led to it being counterproductive. In Chapter 1, for instance, I made reference to cultural representations of dementia in order to justify the claim that people living with it are oppressed. To guard against the potential for this chapter to further promote these stereotypes, I sought to critique and undermine them in the same place as they were introduced. In addition to using secondary empirical research, I also drew on the work of self-advocates during this analysis. In so doing, I sought to use my platform to amplify the voices of the oppressed to combat the social structures that maintain this oppression.

In Chapter 2, I engaged with the question of the basis of our moral equality on the terms of the current debate: with all people with severe cognitive disabilities presented alongside animals and human foetuses as marginal cases. My goal in this chapter was to provide a firmer basis upon which to argue that people with severe cognitive disabilities are morally equal to cognitively-able people and, in so doing, disarm the argument from marginal cases.

Nevertheless, there is a legitimate worry that engaging with the debate on these terms may reinforce the idea that questions about the status of people with severe cognitive disabilities and the status of nonhuman animals are of the same kind, contributing to an oppressive denial of human dignity on the part of people living with dementia.[407] This is especially pressing as, in the course of my argument, I affirmed the claim that species membership is a category that is arbitrary regarding moral status, which could have the effect of further marginalising people living with dementia and contributing to their conceptual exploitation.

In order to guard against this possibility, I have emphasised that species membership is only arbitrary regarding basic moral status, not entirely morally arbitrary. I have also made it clear that there are particular kinds of species dignities,[408] and that people with severe cognitive disabilities ought, of course, to be treated with human dignity. In addition, I have explicitly framed the chapter as a process of validating the intuition that severe cognitive disabilities do not change a person's moral status, in order to guard against the potential for the paper to reinforce this oppressive denial of moral equality.

In Chapter 3, I engaged with Dworkin's view that both autonomy and beneficence should push us towards honouring advance directives made by people living with dementia, even if their present-day selves unambiguously express happiness and contentment.[409] The

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[407] 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, UK: John Wiley & Sons, 2010)

[408] For more on this, see: Elizabeth Anderson, "Animal Rights and the Values of Nonhuman Life," in *Animal Rights: Current Debates and New Directions*, ed. Cass R. Sunstein and Martha C. Nussbaum (New York: Oxford University Press, 2004)

[409] Ronald Dworkin, *Life's Dominion: An Argument About Abortion and Euthanasia* (London: Vintage Books, 1994), 190-200

case, as interpreted by Dworkin, relies on some of the stigmatising cultural images I critique in Chapter 1, so I have sought to undermine the assumptions of the case while making my own argument.

In addition, in order to combat the view that cognitively-able philosophers know what is best for people living with dementia, I reframed the debate on advance directives as a debate about what is permissible in a social relationship. Rather than presenting people living with dementia as problems to be solved, then, I presented the decisionmaker as an agent whose power needs regulating. This shift in focus undermines the view that the person living with dementia is themselves the problem.

Chapters 4, 5, and 6 feature the same potential to produce negative effects. In all, I have made extensive use of my own experience of working in care homes and facing moral quandaries. As discussed in sections 2 and 4, I have tried to ensure that I describe this experience in such a way that the people living with dementia are not presented as problems to be solved. However, there is a deeper concern about the aims of these chapters.

Throughout all, I have relied on the idea that people living with dementia require the assistance of others to function in order to defend coercive care and a form of the secure dementia unit. In an environment in which autonomy is prized and dependency stigmatised, this could reinforce oppression. Indeed, Bryden has railed against the way people living with dementia are constructed as defective autonomous individuals, rather than people to be included in society as equals.[410] In order to ensure my work does not reinforce this, I have explicitly and repeatedly rejected rational autonomy as a foundational attribute for an equal society. Further, I have repeatedly emphasised the common interdependency among humans, drawing on work in care ethics.[411]

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[410] Christine Bryden, *Will I Still Be Me?: Finding a Continuing Sense of Self in the Lived Experience of Dementia* (London: Jessica Kingsley Publishers, 2018), 13

[411] Virginia Held, *The Ethics of Care: Personal, Political, and Global* (Oxford: Oxford University Press on Demand, 2006), 53

In sum, while I cannot know the actual effects of writing this thesis in advance, there were a number of risks involved in writing it that I have taken steps to ameliorate. It is possible that I have not addressed every concern I should have to prevent this thesis from being counterproductive. Part of the problem of speaking for others is that, in lacking membership of the oppressed group, the speaker may not notice biases, patterns or concerns that a member of the oppressed group would have.[412] Nevertheless, as I have demonstrated above, I have paid serious attention to the potential pitfalls of this project in order to avoid reinforcing oppression.

Conclusion

In this chapter, I have applied Alcoff's four interrogatory practices for tackling the problem of speaking for others in the context of this thesis. I have defended my decision to speak as a necessary and proportionate response to urgent and severe injustice, I have considered the effects of my social location and the context in which this thesis is written on the meaning of its content, I have identified people living with dementia as the group to whom I must remain accountable, and I have demonstrated a number of steps I have taken to avoid the thesis having negative effects. Some may be unconvinced by the need to engage in such analysis, so are likely be unpersuaded by what I have said here. For those who believe speaking for others must always be justified, however, I hope this chapter demonstrates my sincere commitment to reflecting on my speech and its effects on people living with dementia.

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[412] See: Janet A. Kourany, "Philosophy of Science and the Feminist Legacy", in The *Routledge Companion to Feminist Philosophy*, ed. Ann Garry, Serene J. Khader, and Alison Stone (New York: Taylor & Francis, 2017)

Conclusion

The Covid-19 pandemic has exposed the frailties of privatised, underfunded social care infrastructure. In the UK, for instance, nearly 30000 excess deaths were recorded in care homes during the initial outbreak:[413] a tragic outcome which has been tentatively attributed to, among other factors, a chronic shortage of personal protective equipment,[414] the decision to allow care home residents to be discharged from hospital without testing them for the virus[415] and, crucially, a lack of coordination among care services.[416]

Although some countries have had better outcomes, similar problems have been exposed across the West. The World Health Organisation reports, for instance, that over half of coronavirus deaths in Europe have occurred in care homes, attributing this to long-term

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[413] BBC News, "Almost 30,000 More Care Home Deaths Than Last Year," BBC News, last modified July 3, 2020, https://www.bbc.co.uk/news/uk-53280011.

[414] Gareth Iacobucci, "Covid-19: Lack of PPE in Care Homes is Risking Spread of Virus, Leaders Warn," *BMJ*, 2020.

[415] Laura Bundock, "Coronavirus: More Than 4,000 Hospital Patients Discharged into Care Homes Without Test," Sky News, last modified July 16, 2020, https://news.sky.com/story/coronavirus-more-than-4-000-hospital-patients-discharged-into-care-homes-without-test-12030165.

[416] David Rowland, "To Protect Older People from COVID-19, State Coordination of the Social Care Sector is Urgently Needed," British Politics and Policy at LSE, last modified April 29, 2020, https://blogs.lse.ac.uk/politicsandpolicy/covid19-social-care-sector/.

neglect from government.[417] Meanwhile, in the United States, during the first wave of the pandemic, nearly 40% occurred in nursing homes, with 1 in 5 reporting at least one death.[418]

This may be the moment that Western political leaders finally take decisive action to reform the sector and make it fit for purpose. If and when they do so, special attention must be paid to improving our treatment of people living with dementia which, as I have demonstrated in this thesis, entails specific and widespread reforms to our social norms, practices and care infrastructure. This begins with recognizing that, as I argued in Chapter 1, viewing dementia as a threat to wellbeing or opportunities perpetuates an unjust stigma about the condition, fails to fully capture the injustice of their exposure to powerful others, and conceals the extent of their oppression.

To tackle these *relational* injustices, we must first tackle the bias against cognitively disabled people at the root of political thought. As I have argued in Chapter 2, we can do so by centring moral equality around our unique subjectivities and the capacity to live a life that is truly ours they entail. This appeal to authenticity, which I argue in Chapter 3 should be understood as a state of non-alienation, supports the moral weight of people living with dementia's present-day expressions of values and the interests that are derived from them, even where they conflict with past statements, such as those contained in an advance directive.

With justice understood in these terms — as a matter of liberating all subjects with whom we share a society from relationships that fail to respect them as bearers of authentic interests — the demands on carers and care institutions become clearer. As I argued in Chapter 4, carers act unjustly when they fail to empower people living with dementia to meet their own

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[417] Hans H P. Kluge, "Statement – Invest in the Overlooked and Unsung: Build Sustainable People-centred Long-term Care in the Wake of COVID-19," WHO/Europe, last modified August 26, 2020, https://www.euro.who.int/en/media-centre/sections/statements/2020/statement-invest-in-the-overlooked-and-unsung-build-sustainable-people-centred-long-term-care-in-the-wake-of-covid-19.

[418] Olga Khazan, "The U.S. Is Repeating Its Deadliest Pandemic Mistake," The Atlantic, last modified July 6, 2020, https://www.theatlantic.com/health/archive/2020/07/us-repeating-deadliest-pandemic-mistake-nursing-home-deaths/613855/.

vital needs, insofar as they can, through *indirect* intervention. As I argued in Chapter 5, the skills needed to provide this kind of care, as well as the regulation needed to robustly guarantee it to people living with dementia, renders informal dementia care *suboptimal*. As such, a just society would not rely on family members or other loved ones to provide it and, all such persons would be acting unjustly if they chose to do so. Moreover, even in our present-day societies, in which care is far from just, *supplementing* professional care with its informal counterpart is likely to preferable, at least in a significant range of cases. Finally, as I have argued in Chapter 6, secure dementia units must be radically reformed and severely limited in their use. Where people living with dementia could meet their own needs, in their own homes, with indirect support from community carers, sending them to formal institutions needlessly exposes them to injustice. Where they are needed, they should be oriented around the principles of indirect-first care and connected to the wider community.

I hope, as I stated in Chapter 7, these arguments will have a positive impact on the desperately unjust social position of people living with dementia. Yet, while this thesis has answered many pressing moral and political questions about the status of people living with dementia in our society, it has not covered all such concerns. Indeed, there are a number of further questions that arise from establishing people living with dementia as social equals which need urgent philosophical attention. For instance, we might wonder if treating people living with dementia as social equals is compatible with the intuitive idea that they are not to be blamed for wrongful or harmful actions they may make. On the other hand, we might wonder if the many people who maintain romantic and sexual relationships with their partners throughout the course of the progression of dementia are committing grave injustices and, if so, what the appropriate, egalitarian policy response ought to be.

Naturally, it would be impossible to address all such questions in one thesis. What I hope to have contributed here, however, is the basic conceptual groundwork for an analysis of dementia from the point of view that those who live with it share a way of life, which ought to be respected, rather than feared. Dementia has been neglected by relational egalitarians and, as I have repeatedly emphasised, this is a serious mistake. This thesis, I hope, goes some way towards remedying that and establishing people living with this condition as moral equals who, too, are entitled to be related to as such.

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