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Can the Secure Dementia Unit Be Justified?

Building Egalitarian Dementia 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.

Christine Bryden, *Nothing About Us, Without Us!*

Introduction

Labelled provocatively by Christine Bryden, in light of the experience she conveys in the epigraph, as 'dementia prison',¹ the secure dementia unit (SDU) is a staple element of social care infrastructure in most Western countries.² These institutions, which use barriers such as keypad locked doors, secure windows, and high fencing to keep their residents from leaving without authorisation, can take many forms.³ Hotel-style care homes, in which each resident occupies a single room in a large building

¹ Bryden, *Nothing About Us, Without Us!*, 185.

² World Health Organization, *Dementia*, 25.

³ SCIE, 'Deprivation of Liberty Safeguards at a Glance', Social Care Institute for Excellence (SCIE), last modified June 2017, www.scie.org.uk/mca/dols/at-a-glance.

with shared communal areas, are most familiar in the UK.⁴ In the Netherlands, by contrast, ‘dementia villages’, in which residents live in small households situated within a larger complex of homes, shops, hair-dressers, restaurants, and other amenities, are increasingly commonplace.⁵

Though there are significant differences in the way each model operates, all forms of the SDU involve a degree of coercive control that stands in need of justification. Remove dementia from the equation and it seems obvious that a relational egalitarian society could not accept the existence of institutions that prevented those they house from freely leaving – especially not if those institutions claimed to be doing so for those residents’ own good. Put dementia back in, and there is an egalitarian worry about group-based subordination and exclusion that needs to be dealt with; in most other cases, the fact that all residents of a coercive institution share a social group identity would not ameliorate concern about that coercion but further fuel it.

Though she describes these institutions in chilling terms, however, Bryden favours reform over abolition.⁶ In this chapter, I provide a relational egalitarian 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 7.1, I set out the limits of community care, making an egalitarian case for retaining SDUs. In Section 7.2, I consider the type of reforms that would be needed to prevent SDUs from perpetuating injustice. I do so by identifying problematic features of both hotel- and village-style SDUs, concluding that the demands of justice would be best met by a hybrid model. Finally, in Section 7.3, I discuss the funding of dementia care, arguing that all care services risk perpetuating oppression unless they are state funded and free at the point of use.

7.1 The Limits of Community Care and the Place of the SDU

In Chapter 5 I noted that, because of the way their vulnerability to the power of others increases as their condition progresses, all people living

⁴ Amy Horton, ‘Liquid Home? Financialisation of the Built Environment in the UK’s “Hotel-Style” Care Homes’, *Transactions of the Institute of British Geographers* 47, no. 1 (2020), 179–192.

⁵ 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.

⁶ Bryden, *Nothing About Us, Without Us!*, 200–201.

with dementia will eventually require access to care. This fact alone, however, cannot justify the level of coercive control involved in SDU placements, especially where they are involuntary and consistently met with objections. To force a person living with dementia to relocate, even if well intentioned, is both to restrict their liberty and potentially to subject them to increased risks of functional decline, emotional dysregulation, physical ill-health, and death – a phenomenon that is sometimes termed ‘transfer trauma’.⁷ To then prevent them from leaving the place to which they have been moved without their consent, especially in the face of the commonly issued request to be taken home,⁸ is to interfere in their choices in a manner that, unless it tracks their interests, would represent a clear-cut case of domination.

It is notable, nevertheless, that many family members and friends of people living with dementia feel as if they have no other option than to make use of SDUs. Two main justifications for this attitude arise from social scientific research into this question: a feeling that the decision-makers can no longer meet their loved ones’ needs and a concern for their safety if left alone.⁹ 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.

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.¹⁰ Consequently, it can be reasonably assumed that most friends and family members

⁷ Ana Montoya et al., ‘Transfer Trauma among Nursing Home Residents: Development of a Composite Measure’, *The Gerontologist* 64, no. 2 (2023), 1–2.

⁸ 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 (2002), 132–133.

⁹ 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 (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.

¹⁰ 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.

deciding on social care options for their loved ones will be concerned about financial costs. For those who lack the assets to fund long-term care placements, public assistance alone will be insufficient to keep them in their own home with adequate community care support, leaving a move to an SDU as the only financially viable option.

These financial considerations do represent good reasons to move relatives to SDUs in unreformed societies that remain hostile to people living with dementia, but this fact does not absolve, in terms of justice, the society which offers this unenviable choice. With better funded homecare, assistive 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, the resource constraints most world governments are operating under make it very difficult to achieve these kinds of reforms, but these non-ideal circumstances do not detract from the 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. Certainly, some safety concerns arise from the lack of finances available to provide community care for people in their own homes, but others arise because of threats posed by external actors. Where people living with sufficiently advanced dementia are not provided with caring support, as I argued in Chapter 2, they become at risk of abuse, exploitation, violence, and other forms of inequalitarian treatment. This risk is particularly acute in centres of community activity as, even with large-scale dementia training programmes, there will inevitably be malicious actors willing to take advantage of a person living with dementia's vulnerability.

Effective homecare can ameliorate risks of abuses of power 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 establish such a regime of oversight, however, comes at a cost that is likely to be intolerable in most circumstances. If a person living with advanced dementia were to be monitored closely across their social life, subjecting their entire experience of communication and socialisation to intense scrutiny, their opportunities to engage in spontaneous social activity with other persons would be greatly diminished.

An SDU, by contrast, can afford to monitor residents most at risk of abuses of power less closely than community care services, because staff can control who enters the home, greatly reducing the risk of spontaneous interaction leading to injustice. Moreover, within the SDU residents can be empowered to freely engage in social interactions with *each other* without the kind of close monitoring necessary outside of it. Though a transfer to an SDU in these circumstances will still involve constraints on liberty, the persons living with advanced dementia are likely to be better able to make use of their agency because of it, at least within the institution itself.

It may be objected that greater freedom in social interaction cannot outweigh the fundamental violation of liberty inherent to the SDU; 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 this institution itself. Even a fully reformed SDU would need to prevent its residents from leaving *alone*, but so too would fully reformed home care services when dealing with clients living with advanced dementia wishing to leave their own homes. The SDU might restrict a person's liberties more than declining to make any care interventions but, at least in this respect, it is no more inherently restrictive than homecare.

There is an important distinction between these cases, as home carers are preventing people from leaving their own homes alone, rather than an institution to which they may not have consented to moving. However, as a person begins to rely more and more on their environment to scaffold cognition, they are likely to 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 can be retained for longer. It is far from clear, therefore, 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 living with advanced dementia alone, having no living family or friends and being 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 a (suitably reformed) SDU. They would be, in this sense, exposed to greater injustice by being cared for in their own homes than by being moved.

Naturally, many readers will still be uncomfortable with the level of interference involved in housing a person living with dementia in an SDU. This is a good thing, because interference in choices always stands in need of justification. Some interference, nevertheless, can be justified under relational egalitarianism, as long as it occurs within relationships in which the interfering party is forced to track the interests of the person interfered with – where it is, in other words, non-dominating. For some, a move into an SDU with all its restrictions would not constitute a relational injustice, because they have an interest in social interaction and recognition that cannot be satisfied in their own home. For others, this will not be the case. Though this may seem like a perverse interpretation of justice to some – particularly those with libertarian leanings – it should be recognised 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 model of care that best tracks a person's interests. Thus, if they only house those whose spontaneous opportunities for social recognition are better retained through its controlled environment, there is an egalitarian case for retaining SDUs in some form.

7.2 Reforming the SDU: Examining Dementia Hotels and Model Villages

While the focus on improving their treatment of people living with dementia has increased in recent years,¹¹ there are well-known problems with the UK's hotel-style SDUs. Many could be resolved through the kind of reforms to staffing and training that I set out in Chapter 6. Others, however, are directly attributable to the way this model is designed and the resulting culture. In this section, I discuss the ways in which these issues expose people living with dementia to relational injustices but stop short of writing the model off altogether. Setting out unique issues that are apparent in the model village approach, I conclude by proposing a hybrid model as offering the best prospects of meeting the demands of justice.

¹¹ Corrine Greasley-Adams et al., *Good Practice in the Design of Homes and Living Spaces for People with Dementia and Sight Loss* (London: Pocklington Trust, 2014).

7.2.1 Overstimulation

It is well known within the empirical literature that environmental factors increase the prevalence of violence and agitation in people living with dementia,¹² with overstimulation being a common issue.¹³ Despite this, many SDUs are overcrowded, with several residents cramped into noisy shared areas.¹⁴ 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,¹⁵ and notwithstanding clear guidance from the Social Care Institute for Excellence (SCIE) against doing so.¹⁶ In addition, despite studies suggesting that people living with dementia become overstimulated and restless when they do not have access to outdoor areas,¹⁷ many SDUs have spaces that are inaccessible to some of their residents.¹⁸

Residents in these environments evidently experience domination, as it can hardly be said that such circumstances constitute interest-tracking interventions. 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 it more likely that carers will need to resort to direct intervention.¹⁹ To this

¹² 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), 12–20; 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), 272–281; 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), 281–289.

¹³ Richard Fleming and Nitin Purandare, 'Long-Term Care for People with Dementia: Environmental Design Guidelines', *International Psychogeriatrics* 22, no. 7 (2010), 1086.

¹⁴ 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.

¹⁵ 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.

¹⁶ SCIE, 'Noise Levels – Dementia-friendly Environments – SCIE', Social Care Institute for Excellence (SCIE), last modified May 2015, www.scie.org.uk/dementia/supporting-people-with-dementia/dementia-friendly-environments/noise.asp.

¹⁷ 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.

¹⁸ 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.

¹⁹ 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, nos. 3–4 (2018), 503.

point, 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]’.²⁰

Environmentally induced reduction in cognitive function, in turn, contributes to oppression by marginalisation, as it artificially inhibits the ability of people living with dementia to participate in activities from which they can receive 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. This may then 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 televisions and radios 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,²¹ which could assist carers in providing opportunities for social recognition. There is, however, an obligation to be vigilant and ensure that broadcasts do not become too loud, overstimulating, or disruptive. Carers ought also 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.

Overcrowding, as well as being a contributor to noisiness, threatens personal space and leads to visual clutter.²² Determining the maximum number of people who can be justly housed together will require context-sensitive empirical research that goes beyond the aims of this book. I can, nevertheless, offer some guidance on how that threshold should be set.

²⁰ Bryden, *Nothing About Us, Without Us!*, 194.

²¹ June Andrews and Mark Butler, *Telly On: Older People, Dementia and the Potential of Television* (Stirling: Dementia Services Development Centre, 2016), <http://juneandrews.net/perch/resources/tellyonfinalpdf.pdf>.

²² 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.

If the level of noise from all of the residents talking at a normal volume becomes loud enough to be overstimulating for at least one of them, a care home is clearly overcrowded. Likewise, if communal areas are so cluttered with furniture and personal belongings that there is not enough space to walk freely, there are too many people using that space.

Reducing noisiness, overcrowding, and visual clutter is key to developing the type of outdoor space to which people living with dementia are entitled. It also must be functionally accessible, with connecting doors unlocked, ramps in place for wheelchair users, and, importantly, all residents' rooms set in close enough proximity to encourage use. Questions of proximity are sometimes overlooked in discussions of accessibility but addressing them is vital to ensuring egalitarian relationships over space. 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 risks of carers dominating and becoming agents of oppression.

7.2.2 Recipient Positioning

Residents in SDUs are too often positioned as mere recipients of care.²³ 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 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.²⁴ Bryden bemoans this when she implores 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'.²⁵

²³ Nicky Britten et al., 'Elaboration of the Gothenburg Model of Person-Centred Care', *Health Expectations* 20, no. 3 (2016), 408.

²⁴ Samuel R. Nyman and Paulina Szymczyńska, '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 (2016), 103.

²⁵ Bryden, *Nothing About Us, Without Us!*, 200.

Positioning people living with dementia as mere recipients in this way 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.²⁶ 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 I have been discussing in this book. Where an SDU falters, however, is when it positions *all* of their residents as mere recipients of care, preventing any from meeting their own nutritional needs or, indeed, the needs of others. As this frustrates the interests of some of those residents in living authentically, this kind of recipient positioning is dominating.

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 may include arts and crafts, conversations, and singing,²⁷ can certainly be pleasurable and contribute to some sense of community but 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 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 offer their residents opportunities to take part in gardening.²⁸ Nevertheless, it remains the case that people living with dementia contributing to the maintenance of their environment in a way that is

²⁶ 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.

²⁷ NICE, 'Mental Wellbeing of Older People in Care Homes', NICE, last modified 12 December 2013, www.nice.org.uk/guidance/qs50/chapter/Quality-statement-1-Participation-in-meaningful-activity.

²⁸ SCIE, 'Gardens – Dementia-friendly Environments – SCIE', Social Care Institute for Excellence (SCIE), last modified May 2015, www.scie.org.uk/dementia/supporting-people-with-dementia/dementia-friendly-environments/gardens.asp.

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 well-being. Understanding that people living with dementia are entitled to be able to take part in 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.²⁹ 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 such as pouring pre-prepared drinks from a jug or folding and handing out napkins. Inevitably, this will not be possible in all cases, especially where the person living with dementia is 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 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 involved in activities of daily living. The social recognition that these activities offer is best thought of as *internal* social recognition. In other words, these activities 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.

7.2.3 Connection to the Wider Community

SDUs keep residents within their walls by coercion. Although this chapter is aimed at justifying this kind of control in limited circumstances, there are troubling parallels with other forced living arrangements (hence Bryden's term 'dementia prison'). Even if an SDU is able to provide

²⁹ 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, nos. 17–18 (2011), 2494.

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'.³⁰ This is echoed by later social egalitarian theorists, such as Elizabeth Anderson, who describes it as 'the linchpin of categorical inequality',³¹ and Jonathan Wolff, who argues that social exclusion is a significant barrier to achieving a society of equals.³²

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 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.³³ 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.³⁴

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

³⁰ Young, *Justice and the Politics of Difference*, 53.

³¹ Elizabeth Anderson, *The Imperative of Integration* (Princeton: Princeton University Press, 2010), 16.

³² Jonathan Wolff, 'Forms of Differential Social Inclusion', *Social Philosophy and Policy* 34, no. 1 (2017), 166.

³³ Andrew Cole, 'Children in Care Homes: "It Makes Residents Feel More Human"', *The Guardian*, 12 November 2018.

³⁴ SCIE, 'Care Home in the Community – SCIE', Social Care Institute for Excellence (SCIE), last modified June 2017, www.scie.org.uk/person-centred-care/older-people-care-homes/in-the-community.

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, such as 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 kind of social recognition. Moreover, there is also an expressive quality of marginalisation in this kind of SDU design; it seems to embody an oppressive attitude that people living with dementia need to be kept out of sight.

7.2.4 *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, perhaps the most well-known example of which is De Hogeweyk in the city of Weesp, 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.³⁵ On the issue of exclusion from the wider community, however, there are reasons to think that model villages fare worse than hotel models.

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 with 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’.

³⁵ Suraj Patel, “‘Alternative Reality’ in Dementia Village”, *BBC News*, last modified 16 December 2012, www.bbc.co.uk/news/av/health-20727157.

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, would be a mixed model, which made use of the 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 in which it is situated. We can imagine, for instance, gated, private roads lined with small homes and facilities, branching off of a clearly visible high street to which residents can walk out 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 contributing to the oppression of their residents.

7.3 Funding Social Care

Staying in an SDU, in the UK, is expensive, with one recent estimate putting the average cost per person at £1,174 per week.³⁶ 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 book, that just treatment of people living with dementia requires a substantial investment of resources, and how that bill is paid is itself a matter of 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 2, I noted that demands for inheritance can take an exploitative form, leading to people living with dementia receiving sub-standard 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. Though there are some local authority funding

³⁶ Heather Walford, 'How Much Does Dementia Care Cost?', TrustedCare, last modified 31 March 2023, www.trustedcare.co.uk/help-and-advice/how-much-does-dementia-care-cost.

provisions, these are only accessible once a person's assets and savings have been depleted to below a certain threshold – at time of writing, £23,250 in England³⁷ and Northern Ireland,³⁸ £32,750 in Scotland,³⁹ and £50,000 in Wales.⁴⁰ 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 is likely to reinforce and contribute to it.

Indeed, it is notable that in the UK, where it 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 lose more in tax than they would spend if they paid for their care 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 exploitative norms, there is a further problem with the upfront payment model of care. Earlier in this book 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 relatively longer-term, progressive conditions such as dementia to pay more into the social care budget than those who died of illnesses that only require a comparatively short time in care, such as terminal cancer. While I am reluctant to defend this proposal, it did not

³⁷ Ibid.

³⁸ Nidirect, 'Paying Your Residential Care or Nursing Home Fees', Nidirect, last modified 8 February 2023, www.nidirect.gov.uk/articles/paying-your-residential-care-or-nursing-home-fees.

³⁹ Care Information Scotland, 'Capital Limits', Care Information Scotland, last modified 6 April 2023, www.careinfoscotland.scot/topics/care-homes/paying-care-home-fees/capital-limits/.

⁴⁰ GOV.WALES, 'Charging for Social Care', GOV.WALES, accessed September 29, 2023, www.gov.wales/charging-social-care.

so much represent a new injustice but a reinforcing of one already in existence; it is already the case that people living with dementia in the UK pay more on average than those with other conditions, because a far greater proportion of the costs associated with it fall under the category of social care, for which little public funding is available, rather than healthcare, which is free at the point of use.⁴¹

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 inequalitarian 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 inequalitarian injustice because, as Schemmel argues, it shows disregard and disrespect for our moral equality.⁴²

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.⁴³ 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 does not require care providers to 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 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

⁴¹ Alzheimer's Society, 'How Much Does Dementia Care Cost?', Alzheimer's Society, last modified 22 July 2020, www.alzheimers.org.uk/blog/how-much-does-dementia-care-cost.

⁴² Schemmel, 'Distributive and Relational Equality', 134.

⁴³ Whether this 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.

intrinsically wrong about unequal distributions of resources. Rather, such inequalities are derivatively unjust if they lead to, reflect, or reinforce paradigm inequalitarian relationships. In this sense, these differences need only be problematic if they are connected to wider inequalities of power and 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, for example gourmet foods such as caviar and lobster, then they are unlikely to contribute to or reinforce any relational injustices.⁴⁴

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 privately funded services to provide a *better standard* of dementia care than one another, because all would operate on the terms I have set out in this book 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 living with dementia are related to as equals represents an unfair burden on the young. There are, however, two reasons for questioning this concern.

First, it should be noted that the force of this claim is dependent on how younger cohorts are treated within a society. If those younger cohorts are free from paradigm inequalitarian relationships such as domination and oppression, then it becomes harder to see, from a relational egalitarian point of view, why substantially increased funding for social care would represent a grave injustice. Perhaps those attracted to this criticism have in mind our present-day societies, in which younger people tend to lack the financial assets of their parents and, subsequently, are more vulnerable to unjust treatment. I have no quarrel with this interpretation of contemporary intergenerational dynamics, but it does not entail that the upfront system for funding care is just. What it might

⁴⁴ 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.

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 situation 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.

Second, 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 these were sound, it is not the only way to ensure this public funding is available. Former UK Prime Minister Gordon Brown's 2010 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 address similar concerns.⁴⁵ Which funding mechanism adequately balances the just treatment of both young and older age groups is a question beyond this book, requiring further empirical research and, in any case, that cannot be answered without 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 developed.

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, free at the point of use. Ensuring that state-funded care providers meet the demands of justice 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 the urgency of ridding ourselves of institutions that express the idea that the provision of dementia care is an optional extra, rather than a basic duty of the just society.

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

⁴⁵ C. J. Marshall, 'A Hypothecated Tax for the NHS and Adult Social Care?', *Future Care Capital*, last modified 13 February 2018, <https://futurecarecapital.org.uk/latest/hypothecated-tax-for-the-nhs-and-adult-social-care/>.

coercion involved stands in need of 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 free at the point of use, 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 much more could be done; in general, SDUs in the UK, alongside other care services, continue to fail to treat people living with dementia as equals.