



# A Relational Care Framework for Dementia

Person-centred care post  
the Royal Commission

**PLUNKETT CENTRE FOR ETHICS**

A joint centre of Australian Catholic University,  
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# Executive Summary

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## INTRODUCTION

Australia's Royal Commission into Aged Care Quality and Safety has established an agenda for moral reform of the aged care system. It has also urged that dementia care be regarded as core business for aged care providers, due to several interlocking issues. These are the rate of dementia incidence in later years of life and its potential impacts on health and well-being, and the unacceptable rates of substandard dementia care that were uncovered during the Royal Commission's hearings.

This paper will propose that to realise the Royal Commission's agenda for moral reform—with a proper emphasis on quality dementia care—it is essential for aged care providers and regulatory agencies to identify and enact what is fully at stake in dementia care that is person-centred.

We argue in this paper that person-centred dementia care must be delivered with a strong sense of moral purpose, both in the ways that individuals and aged care providers care for people living with dementia, and as articulated and enacted in the policies and accountability processes of aged care providers and of regulatory agencies. This paper sets out a framework for understanding person-centred dementia care with a strong sense of moral purpose.

In this Executive Summary, we briefly outline the agenda for moral reform the Royal Commission has provided, our proposed framework for person-centred dementia care with moral purpose, and two policy proposals, one for aged care providers and one for regulatory agencies.

## THE ROYAL COMMISSION'S AGENDA FOR MORAL REFORM

The recommendations in the Royal Commission's Final Report (2021) have established an agenda for moral reform of the aged care system. This reform seeks to establish:

- a right to high quality needs-based care
- the delivery of care that is skilful, respectful, and responds to individual differences in needs and capacity, and
- an aged care system that is socially inclusive.

In addition to identifiable pathways into care, the Royal Commission has also stated that the purpose of the aged care system must be easily understood by all stakeholders. Primarily, that it is a system with the intent and the capacity to *care for* older Australians in ways that enable them to live well. This, we believe, is the moral purpose of the aged care system.

We argue in this paper that in order to realise the Royal Commission's agenda for moral reform in ways that include older Australians who live with dementia, dementia care requires moral specification—or its own sense of moral purpose—over and above that specified in the Royal Commission's Final Report for the aged care system, considered as a whole.

## REFORMING DEMENTIA CARE

Person-centred dementia care with moral purpose has three key elements which must be embedded within all dimensions of care. These are:

- egalitarian care relationships
- moral self-orientation
- social agency.

These three elements provide an enriched vocabulary of person-centred dementia care that is premised on relationships between caregivers and those who receive care. These relationships are founded on respect and recognition of the retained moral self-orientation of people who live with dementia. In brief, moral self-orientation includes having a sense of pride and a susceptibility to moral injury, which is something we all share. Egalitarian care relationships are also founded on respect and recognition of the retained social agency of people who live with dementia. In brief, social agency is the capacity to find purpose in social relationships and social activities. And likewise, we all share this too. Respect and recognition of this kind situates people in care as moral equals. Our paper will describe, in detail, these elements of an enriched conception of person-centred dementia care. Care that incorporates this richer notion we refer to as the *relational care framework*.

## OUR POLICY PROPOSALS

Where it is dependably and reliably implemented, the relational care framework we describe should be evident to families of a person with dementia. It should be evident to them that their loved one is cared for, not only with good intent and capability, but also as a moral equal. There must also be regulatory processes that can reliably identify the difference between dementia care that is person-centred in the way our paper describes and care that lacks the essential characteristics of this care. In addition, and crucially, the governance processes within aged care providers must be designed to ensure such care is consistently and reliably delivered; that not only is there the intent to offer such care, but this intent is matched by organisational capacity as well as staff capability and attitude, across all staffing levels, with an evidential framework to ensure delivery accountability.

We offer two policy proposals. One is for executive leadership of aged care providers. This policy describes a set of steps that are needed to ensure the delivery of the person-centred dementia care we describe in our paper. These steps are derived from a mission statement, to be developed by each aged care provider, which gives clear expression to the provider's moral purpose in caring for people living with dementia. This statement then provides the rationale for—and the necessity of—actions to be undertaken in the care of people living with dementia.

Our second policy proposal is for regulatory agencies. It includes three suggested initiatives: (i) that each aged care provider describe their own intended purpose for the delivery of person-centred dementia care, outlining how this is implemented across all dimensions of care; (ii) that the new quality standards the Royal Commission recommends, as a matter of urgency, clearly orient aged care provider performance around the experience and valuing of persons in their care, rather than a set of actions to be done; and, (iii) that failures to meet quality standards are assigned to an aged care provider's identified Governing Body, which should be the point of accountability for that failure.

Our policy proposals are set forth as examples of how person-centred dementia care, which is care with moral purpose, can be directly implemented within the practices of a reformed aged care system, post the Royal Commission.

# A Relational Care Framework for Dementia

## Person-centred care post the Royal Commission

### Introduction

Australia's Royal Commission into Aged Care Quality and Safety commenced on October 8<sup>th</sup>, 2018 and released a comprehensive three volume Final Report on February 26<sup>th</sup>, 2021 which included 148 recommendations to the Australian Government. The Australian Government reviewed these recommendations and released its response on May 11, 2021. While it has not accepted every recommendation, the Australian Government has endorsed the Royal Commission's view that an urgent and ambitious reform of the aged care system is needed. Specifically, the Prime Minister made this announcement:

The Royal Commission's interim report is clear – as a country, the Government, the Aged Care Sector and the entire Australian community, we can and must do better in providing improved support for our older Australians.<sup>1</sup>

Despite examples of high quality aged care, the Royal Commission has found that there are unacceptable levels of substandard care across the Australian aged care system and it has identified three areas of complex care that require immediate attention.<sup>2</sup> These are dementia care, palliative care, and the mental health of older people. Our focus in this paper is dementia care.

We note that the Royal Commission found that “many aged care providers do not seem to have the skills and capacity required to adequately care for people living with dementia.” (RC, Vol 1, p.69), and in response have

recommended system-wide initiatives. Included among these is the proposal to embed dementia education as part of mandatory training for all client-facing roles, as well as a legal requirement to implement Behaviour Support Plans for responsive behaviours in dementia, commonly referred to as the behavioural and psychological symptoms of dementia (BPSD), or ‘change behaviours’.<sup>3</sup>

We argue that the Royal Commission's reform agenda requires focussed attention on the part of individual aged care providers *to fully include people who live with dementia* within upcoming reforms of the Australian aged care system aimed at lifting the quality of care that older Australians receive. A key part of what we propose is that *dementia care needs do have a moral purpose*, and this purpose is characterised best through an understanding of what we call an *enriched vocabulary of person-centred care*, which provides the basis for a *relational care framework*. This enriched notion of person-centred care identifies three key aspects of *personhood* focussed on a *social understanding* of personhood. These are egalitarian care relationships, moral self-orientation and social agency. We describe these elements in detail below.

We believe that a reformed aged care system must embed the richer conception of person-centred care if it is serious about achieving the moral agenda for reform set out by the Royal Commission.<sup>4</sup> Accordingly, to maintain this level of care going forward such practices of care must be accompanied by an evidence-based process of governance, monitoring, and flexibility – especially, but not exclusively, at the aged care provider level.

# The Royal Commission's agenda for moral reform

## THE MORAL PURPOSES OF CARE

We advocate here for changes in aged care that would pursue a direction sketched by the Royal Commission, which is that along with palliative care, aged care providers must view dementia care as *core business* (RC, Vol 1, p.92). We believe that new system-wide initiatives and quality standards must be developed, as the Royal Commission has recommended, but these alone do not crystallise the moral purpose of quality care for people living with dementia.<sup>5</sup> This is a matter where there is considerable variation across aged care providers in Australia. Going forward, a clearly articulated moral purpose for dementia care should be an essential indicator of a provider's commitment to this distinctive and large cohort of older Australians who require aged care services.<sup>6</sup>

Our claim is that if dementia care is to be regarded as core business for aged care providers then each aged care provider must develop and articulate a core moral purpose for dementia care that would form the basis, and provide the inspiration for, the provider's commitment to people who live with dementia and to their loved ones and advocates. This commitment needs to include how aged care staff will be enabled, by their provider organisations, to enact the richer notion of dementia care required if the moral purpose of the Royal Commission recommendations is to be given effect.

Moral purpose must be core business, across all organisational levels and functions of individual aged care providers and provide the rationale and justification for the large and small-scale decisions and actions that providers and their staff take in structuring and delivering high quality dementia care. Decisions and actions taken in the delivery of care to people living with dementia must be informed as part of providers' mission and values which would express a clear sense of *why dementia care matters*, and a clear sense of *what high quality dementia care aims to achieve*. This is essential to what we mean by the term 'moral purpose'.

Effectively what the Royal Commission has put forward is a *moral agenda for reform of the aged care system* in their description of the characteristics of high quality care, along with corresponding duties on approved providers, that are to be enshrined within the new Commonwealth Aged Care Act. We advocate for a renewed focus on a proper and clear understanding of *person-centred care* which could provide a common and shared framework for reform across the aged care system.

We acknowledge the challenge of reforming practices in line with the defining conditions we set out for dementia care can't be imposed on aged care providers without allowing for local flexibility. In general, change works best when guidelines contain "elbow room" for interpretation and are taken on by individual providers against a backdrop of legislation which can then be enacted by providers as part of daily core business. To this end, individual providers of aged care are in the best position to judge how reform can be initiated within their organisation given local contexts and contingencies, and especially in recognition of factors arising in culturally and linguistically diverse communities. In this way, a local provider's sense of having a stake in the new approach is respected and preserved. By suggesting change within a *framework*, as opposed to an

inflexible set of non-negotiable and specific rules, we hope to communicate general threshold requirements that are readily operationalisable within differing local settings.

## ROYAL COMMISSION RECOMMENDATIONS: KEY ELEMENTS RELEVANT TO MORAL REFORM

We now briefly review key elements of the Royal Commission's recommendations that define aspects of the Royal Commission's moral agenda for reform, and which frame our own proposal for person-centred dementia care.

**Recommendation 1** of the Royal Commission is that the current Commonwealth Aged Care Act (1997) be replaced with a new act that enshrines the right of older Australians to "*high quality care*" that "*ameliorates age-related deterioration in their social, mental and physical capacities to function independently*" (Rec 1, 2.a.) within "*a safe and caring environment for dignified living*" (Rec 1, 3.a.ii.). In addition, older Australians who receive aged care services will have a right to "*be free from mistreatment and neglect, and harm from poor quality or unsafe care, and ... continue to enjoy rights of social participation accessible to members of society generally*" (Rec 1, 3.b.).

**Recommendation 3** sets out principles for the new act. Of particular note, the act must place "*older people first so that their preferences and needs drive the delivery of care*" (Rec 3, a.ii.), that older people "*be treated as individuals*" (Rec 3, b.iv.) who are supported to be "*active and engaged members of the community, regardless of their age or level of physical or cognitive capability*" (Rec 3, b.v.), and, as far as possible, the "*care and support [of older people] should ... emphasise restoration and rehabilitation, with the aim of maintaining or improving ... physical and cognitive capabilities*" (Rec 3, b.xi). The principles set out in **Recommendation 3** also state that "*aged care should be transparent and provide public access to meaningful and readily understood information about aged care*" (Rec 3, b.xiv.), that "*best practice*" be promoted (Rec 3, b.xvi), and that "*rights and freedoms*" of older people must only be limited by the need to respect the rights and freedoms of others (Rec 3, b.xviii). And crucially, that the Australian Government fund the aged care system so that it is enabled "*to deliver high quality and safe aged care*" (Rec 3, b.xix.).

We summarise the Royal Commission's recommendations for establishing an Australian aged care system as having the following characteristics:

- I. The Australian aged care system will be a rights-based system that offers high quality care based on need.
- II. Aged care services will be skilful and respectful of older people, and they will be individualised or *person-centred*, focussed on enablement, and socially inclusive, irrespective of an older person's level of frailty or impairment, be that physical and/or cognitive. These aged care services will be well integrated with the full range of health services available to all Australians.
- III. The nature, purpose and range of high quality aged care services and the access pathways to these care services will be inclusive and readily understood by the Australian public.

These characteristics provide a moral agenda for reform of aged care that genuinely understands what is at stake for persons living with dementia who receive care either at home or in residential care facilities and properly responds to the problems identified by the Royal Commission.

## PLACING THE PERSON AT THE CENTRE OF CARE

In this section, we set out the Royal Commission's view of the characteristics of high quality care and discuss a problem that besets the delivery of aged care services, which is that care is often task-focussed, rather than individualised or person-centred.

Recommendation 13 of the Royal Commission is that a new commission for setting Aged Care Quality Standards must "give effect" to "high quality care." Recommendation 19 is that the current Aged Care Quality Standards be "urgently reviewed" and a new set of quality standards be developed that reflect the characteristics of care that are described in Recommendation 13.

Our perspective is that the current Aged Care Quality Standards, which came into effect on July 1, 2019, are a distinct improvement on the previous standards. Of note is the emphasis within the current standards that the *intent* of each standard be *evident* in the care that aged care 'consumers' experience.<sup>7</sup> What this means is that improvements in care must acknowledge the experience of care from the perspective of a person who receives that care. We think this is, and should remain, an important overarching principle of high quality aged care, as we describe in more detail in the next section.<sup>8</sup>

The Royal Commission's criticism of the current Aged Care Quality Standards is that the current standards,

... do not define quality, or high quality, aged care. By their nature, they set out the minimum acceptable standards for accreditation (Vol 1, p.94).

The Royal Commission is proposing that the bar for acceptable aged care needs to be lifted *from* meeting accreditation standards *to* the delivery of high quality care, and the problem with the current standards is that they do not include a clear statement of what high quality care entails. Having such clarity is what is at stake in a morally informed agenda for person-centred care.

We understand the proposal to move beyond mere accreditation standards and instead – as a direction to renew the focus of aged care service delivery – shift attention to the *care of the individual person*, according to a commonly shared understanding of what this kind of care involves. The current Aged Care Quality Standards emphasise consumer or client choice, as does the Royal Commission, who propose that the ways in which older people choose to live must be prioritised in upcoming reforms. Such operationalised client autonomy is of course welcome, but for it to be meaningful it requires something else. We reason that the Commissioners are also proposing that enabling individual choice *requires a reliable foundation*. This foundation consists in an aged care system that consistently delivers morally purposed high quality care, because the *value* of client autonomy depends on having the *morally best* choices available, and properly understood as such by all stakeholders. (For comparison: patient autonomy in high quality medical care requires patients to consent to procedures only when they have the best information; that is, informed consent protocols are not worthwhile unless the patient has all and only the correct information to make decisions.) The deleterious social conditions in care that prompted investigation by the Royal Commission in the first place, evidently, were such as to disable the capacity for people living with dementia to make choices that were meaningful, and so choices that would lead to individualised care and support thereby promoting well-being in later years.

The Royal Commission states that high quality care has certain *characteristics* which they set out in Recommendation 13. These more fully inform, and add to, a definition of high quality care, and we set these out in full below.

1. The *Aged Care Act 1997* (Cth) should be amended to provide that the Australian Commission on Safety and Quality in Health and Aged Care, in setting and amending safety and quality Standards for aged care (under the functions referred to in Recommendation 18), give effect to the following characteristics of high quality aged care:
  - a. diligent and skilful care
  - b. safe and insightful care
  - c. caring and compassionate relationships
  - d. empowering care
  - e. timely care.
2. 'High quality' care puts older people first. It means a standard of care designed to meet the particular needs and aspirations of the people receiving aged care. High quality care shall:
  - a. be delivered with compassion and respect for the individuality and dignity of the person receiving care
  - b. be personal and designed to respond to the person's expressed personal needs, aspirations, and their preferences regarding the manner by which their care is delivered
  - c. be provided on the basis of a clinical assessment, and regular clinical review, of the person's health and wellbeing, and that the clinical assessment will specify care designed to meet the individual needs of the person receiving care, such as risk of falls, pressure injuries, nutrition, mental health, cognitive impairment and end-of-life care
  - d. enhance to the highest degree reasonably possible the physical and cognitive capacities and the mental health of the person
  - e. support the person to participate in recreational activity and social activities and engagement.

This recommendation is followed by the statement in Recommendation 14 that under the new act (as per Recommendation 1), approved aged care providers have a "general, positive and non-delegable statutory duty" to provide care that is "of high quality and safe."

We note that care with the characteristics described in Recommendation 13 is demanding, and that in general, aged care staff in client-facing roles, in both clinical and personal care domains, are already subject to considerable time pressure.<sup>9</sup> This is implicitly recognised by the Royal Commission in Recommendation 16 that relates to specialist dementia care services:

3. By 1 July 2023, the Australian Government should review and publicly report on:
  - a. whether the number of Specialist Dementia Care Units established or planned to be established is sufficient to address need within the areas and populations they are designed to cover
  - b. the capacity of those Units to address the needs of people exhibiting extreme changed behaviour and whether any further resources are required, and
  - c. the suitability of the Units for shorter-stay respite for people living with moderate to extreme changed behaviour.

A key issue in this connection is funding that relates directly to the capacity for providers and staff to effectively deliver person-centred care with limited resources. Without proper support, staff are reduced to 'box-ticking', or the hasty fulfilment of essential tasks. In this scenario, specification of minimum time, in minutes per day per resident for both clinical and personal forms of care, largely eliminates the possibility of the development of staff-to-client relationships that meet the moral purpose of person-centred care. A system that adheres to the moral purposes of care would *properly* take account of new and more demanding requirements as reform of the aged care system unfolds, and the fact that currently, care is often task-focussed rather than person-centred. We emphasise that the Royal Commission itself explicitly and repeatedly mentions this issue in their Final Report.<sup>10</sup>

Even when task-focussed care does meet acceptable levels of clinical and daily personal care needs, it does not meet a standard of care that is individualised, focussed on enablement, and socially inclusive.<sup>11</sup> Person-centred care is care of the individual person, given the full range of what human personhood involves including its distinctive vulnerabilities. In the next section we describe the different elements of this type of care that we proffer as achieving the moral purpose of care as indicated by the Royal Commission's Final Report.

We propose that by defining and articulating the moral purpose of dementia care within the framework of the Royal Commission's reform agenda, we will at least do so by meeting a threshold of what a common understanding of high quality care involves, viz., that Australian citizens in aged care have their individual rights respected, and in particular that they be protected from sub-standard care. They should be *free from* such sub-standard care. Yet, we submit, this should, indeed, must go further. Rights to high quality care must specify not just what persons are to be free from, but also specify in positive terms what contributes to the flourishing of vulnerable persons within such social environments. In other words, this more sophisticated moral purpose must include a clear sense of the ways in which care of the individual person who lives with dementia responds to and supports their human personhood within the social environments that aged care providers establish. A proper understanding of personhood (as deployed within the concept of 'person-centred care') thus not only specifies the rights individual persons have but says something about the social nature of persons as they relate to the environments they occupy, and the carers who support them. Quality of care cannot be specified for persons unless it sees them as integrated within the social worlds they must negotiate.

In the next section we provide a detailed snapshot of how best to conceptualise personhood, given the moral purposes of care we have outlined so far.<sup>12</sup> Our goal here is to set out an understanding of person-centred care that would properly support the moral aims embedded in the Royal Commission recommendations, and can be taken up in direct practical ways by aged care providers. In this way, we see a role for this paper as making a concrete contribution to the ways that individual aged care providers may already, or hopefully will, define and articulate the moral purpose of dementia care, i.e., why dementia care matters and what providers of dementia care aim to achieve in the care they provide to people living with dementia.

## An enriched vocabulary of person-centred care

We have so far discerned the need to regard dementia care as a core business item for aged care providers, with due attention to quality and safety. And we have also identified the need for reform that sees care as a right, focussed on addressing an individualised set of needs for those in care; needs that are registered against an acknowledgement of existing capacities. Care that registers these moral purposes must be cognisant of what different qualities persons in care *retain* including, for example, their history, personality, clinical condition, religion, culture, language, preferences, tastes, interests, and values. In other words, it must achieve its moral purpose by means of person-centred care.<sup>13</sup>

The concept of person-centred care (or PCC) as applied to dementia care began to take shape with work done by social psychologist Tom Kitwood in the late 1980s through to the mid 1990s. Kitwood put PCC forward as an "enriched model of dementia care", based on a conception of personhood that he defined as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust" (Kitwood, 1997, p.8). Dementia in this view is not conceived as a biological or neurological condition to the exclusion of other factors but includes the psychological effects of care and the social conditions of care environments. So-called 'change behaviours' result from structural failures wrought by the pathology underlying dementia but also from the physical health, biography, personality, and social situation of the agent, and how these affect their lived experience and quality of life. Kitwood rejected the medical model of care in favour of a new culture of care directed towards the well-being of individual people. This, he said,

... brings into focus the uniqueness of each person, respectful of what they have accomplished and compassionate to what they have endured. It reinstates the emotions as the well-spring of human life, and enjoys the fact that we are embodied beings. It emphasises the fact that our existence is essentially social. (Kitwood, 1997, p.135)

Kitwood emphasised positive social interactions, authentic communication, and genuine relationships, and he warned against what he called the "malignant social psychologies" that emerged under managerial-style warehousing. These included various forms of invalidation, infantilisation, intimidation, mockery, and disparagement.

Kitwood's work represented a paradigm shift in approaches to dementia care, and in aged care more broadly. His person-centred approach is now a standard feature within many aged-care settings, and a variety of models are now in use in different care jurisdictions.<sup>14</sup> The shift to person-centred care was (and still is) regarded as a significant step forward; however, there has been an unfortunate tendency to pay lip service to the radical change in care that PCC represents and to lose sight of Kitwood's original ideas and proposal.<sup>15</sup> Our central claim is that person-centred care must spring from, and enact, a clear sense of moral purpose. The Royal Commission's findings plainly indicate that a clear moral purpose is not uniformly evident across all aged care providers, and/or all aged care service delivery settings, and, indeed, has been lacking in egregious instances.<sup>16</sup> This indicates that policymakers and aged care providers may have lost sight of the moral purpose of care. Consequently,

their sense of what person-centred care is, and how it contributes morally to good outcomes, has been deficient. Some approaches to PCC think of persons in “market terms” as autonomous individuals who can make decisions independently. Those who adopt this superficial conception might in some cases mean well – because it aims at respect for the person in care – but unfortunately it presupposes a concept of personhood that Kitwood rejected. Persons in care are not independent *homo “economici”* consumers of products in a care market. They are, mostly, people who depend on others for how they live, while at the same time retaining a range of capacities sufficient for morally sensitive engagement with others, and a modicum of agency. This demands attention; it demands understanding; and, it demands respect. We think that now is the right time to renew our understanding of what is really at stake in person-centred care, and to do so by identifying a more complete, more nuanced conceptualisation of personhood, and one that, especially, is cognisant of, Kitwood’s legacy. In the remainder of this section, we identify and describe three aspects of Kitwoodian-style person-centred care. We suggest these as constituting what we call an *enriched vocabulary of moral purpose* in care.

The elements of personhood we now describe are interlocking aspects of a single overarching concept, taking our cue here from Kitwood’s position. These aspects primarily serve as a pragmatic guiding model for policy and practice, but we emphasise that the overarching concept has firm foundations in, and are supported by, a significant range of well-known models and definitions from cognitive psychology, social psychology, and philosophy.<sup>17</sup> The overarching concept regards the term ‘person’ as having both an empirical and a normative dimension. Empirically, it sees persons as essentially embodied, with a past and a future and as environmentally situated. Normatively, it sees them as having a value (and not a price, to echo Enlightenment philosopher, Immanuel Kant), as having a standing as both a moral-cum-legal agent, and with the full complement of rights – to be free *from* harms and injustices, and free *to* participate in a range of public goods, including especially the right to live well in the later years of life. When a person living with dementia comes into residential care, they must be understood in these terms, with physical needs, and abilities, with memories of a life, and plans (or preferences) for what’s to come, and as someone who now must fit in to a new social milieu. And these empirical realities have normative complements: *rights* to physical well-being, *respect* for the life so far lived and for what’s to come, and an *understanding of who this person is* so that they can best fit in with their new social counterparts.

We now spell out the three elements in detail:

### EGALITARIAN CARE RELATIONSHIPS

Earlier we claimed that a rights framework is necessary but insufficient for understanding person-centred care. Nevertheless, it does provide an important starting point because it presupposes a view about the *moral standing* of persons living with dementia that is comparable to work done in critical disability studies in which an *egalitarian care model* applies. A danger in the care of older people arises when those in direct care-giving roles, aged care provider organisations and policymakers assume – implicitly or explicitly – a view that is cognitively ableist. Such a view, as Matilda Carter has recently written “...exhibits a bias towards people with particular capacities (that is, the

capacity to retain and act on accurate information) against those who do not have them.”<sup>18</sup> An egalitarian framework is one based on justice, something [Recommendation 3](#) of the Royal Commission explicitly alludes to in the claim that care recipients be afforded *the same citizenship status and rights* of other Australians. Eliminating ableist injustice is designed to head off a range of practices in which corrupted relationships of domination, oppression and stigma have arisen. These, as Carter suggests, should be eradicated in favour of relationships of “parallel subjectivity”. By this notion is meant a relationship in which a carer acknowledges, and respects as equal, a subjectivity that apprehends the world differently, based on, and derived through, the person’s remaining capacities. Importantly, we would argue, egalitarian care relationships, if properly instantiated, would inoculate against the malignant social psychologies that Tom Kitwood identified.

### MORAL SELF-ORIENTATION

There is a myth that once diagnosed with a dementia it won’t be long before a person “loses their mind”. Many studies show this to be a gross misunderstanding.<sup>19</sup> People living with dementia retain their sense of self and are very sensitive to how others respond to them. They retain, if you like, a *moral self-orientation*.<sup>20</sup> People with Alzheimer’s disease, for example, continue for a long period to have regard for their moral standing especially from the feedback they receive from others in relation to such things as pride in their work, retaining a valued role, or acting out of a sense of purpose.<sup>21</sup> This continuing self-regard is based on a self-image which often persists through memory loss.

Psychologists point out that the self-image contains evaluations of self, including of special interest here, moral evaluations.<sup>22</sup> These evaluations are modulated by interpersonal exchanges, and so this persisting self-image continues to be, in social settings, sensitive to reward and to injury. For example, those with profound episodic memory loss often do not lose their selves understood as the objects of pride and purpose, and as a source of meaningfulness. Their ongoing responsiveness to others’ treatment of them frames their sense morally of who they are. A lack of respect or recognition is hurtful and isolating; acknowledgment of a valued role, or appreciation of a good deed done is a source of happiness and meaningfulness. This ongoing responsiveness is supported by those retained cognitive-affective capacities that situate the moral self in social space.

People with dementia, even through to the late middle stages of it, possess a range of emotions and attitudes that enable them to engage in the process of moral self-orientation. There are several key features of these emotions and attitudes. First, they involve a reflexive attitude, one that takes as their object a self, so for example, feeling pride in oneself. Second, their occurrence is psychologically rich, especially in so far as it may provide meaning and significance. Many people in residential care settings continue to think of themselves still as the people (or professionals) they once were. And of course: they are; and they can continue to bring to their social situations the knowledge and experience they once had. A retired English teacher may have great facility with words, beating everyone they play at Scrabble for example.

A third element of moral self-orientation is the retention of moral insight. That is, older people in care retain the belief that they matter as persons, that they have dignity, or that they can help out with others’ needs,<sup>23</sup> and that their efforts in this regard deserve recognition as morally laudable. Again,



a past role may continue to be occupied (as teacher, janitor, artist, scientist, etc.) and there is every reason it should be recognised, encouraged, and respected.<sup>24</sup>

Finally, and importantly for understanding the moral purposes of dementia care, the moral self-orienting emotions and attitudes are grounded in social relationships. That is, for attitudes like pride or self-affirmation to obtain requires a social framework in which close others, or those on whom they depend for care and social support, regularly provide validation.

### SOCIAL AGENCY

As the philosopher Christine Korsgaard (1989, p.101) has observed, “A person is both active and passive, both an agent and a subject of experiences”. As a subject of experiences, a person in care should be treated well and with respect in order that their lives be made as comfortable as possible. But as we noted above, on our overarching conception, persons are agents – they are active beings, with the capacity to value activities such as artistic pursuits, games, cooking, gardening, and so on. A person living with dementia, even relatively advanced dementia, is no exception. Agency is an important part of being a person. In addition, many, perhaps, most of our activities are in the company of others, and indeed certain activities – e.g., games, or choir singing, or certain types of dancing – require the company of others essentially. Moreover, these collective actions activate many different areas of the brain, thus having therapeutic benefits, in addition to making us feel connected.<sup>25</sup> This aspect of person-centred care – our social agency – is an important part of the moral purpose of care.

Good examples of activities in care that contribute to social agency are the various art therapies that have become well known – such as music therapy.<sup>26</sup> In addition to exercising a person’s mind and body, they have the effect of bringing people together into a dialogical space, social engagement with others, or one-on-one participation with a music therapist or choir group. In music therapy for example, singing old songs with others breaks down barriers and opens the possibility for social interaction and reminiscence about times past when such songs were contemporary. People who enter residential care are at risk of loneliness and social isolation, which has a negative impact on well-being and may exacerbate the effects of dementia.<sup>27</sup> With music therapy, or indeed any activity that rekindles social agency (music therapy is posited here illustratively), the person in care may re-enter the social world, and in doing so become responsive to others, to participate, and to converse. In short, such activities provide the means to restore social recognition. In addition, not only do such therapies enhance the well-being of people living with dementia, they also provide carers with an effective non-pharmaceutical cost-effective tool for providing meaningful care. Carers involved in such delivery of care enjoy a more meaningful participation in professional life. Indeed, some studies have shown that therapies that contribute to social agency in this way have a positive effect on workplace satisfaction.

### A RELATIONAL CARE FRAMEWORK

The enriched conceptualisation we offer above recognises a fundamental truth about dementia care: those in care who are living with dementia are ourselves, or as we noted above, our moral equals. The only difference is that the neurological damage done by the pathologies of dementia has made people in a variety of ways vulnerable. They are still able to

do many of the things they once did, and justice demands we treat them as moral equals on this basis. They are still sensitive to morally good and bad treatment, just as anyone would be, and should be treated respectfully and mindfully on that basis. They are still agents, with individual interests and valued pursuits, and should be treated the way we treat others in any social setting. The themes we have touched on synchronise with those identified by the Royal Commission. As they point out (Vol 1, p.78):

Over the course of our inquiry, we have identified clear common themes in what the community expects from the aged care system: dignity and respect, control and choice, the importance of relationships and connections to communities, and the desire for a good quality of life ...

Fundamentally, our care must acknowledge the relational dimension to continuing personhood, *as such*. Who we are, and how we are treated, depends constitutively on the quality of our relationships, and that presupposition should be front and centre of any model of care we deem worthy of support. Those in care living with dementia are persons with moral standing and sensitivity, and they deserve equal treatment, including especially the opportunity to be active social agents; high quality person-centred care must embed this understanding in protocols governing its provision. We will regard models of care that are based on this enriched notion of personhood, as falling within what we call the *relational care framework*.

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## Evidence of moral purpose

The Royal Commission report sets out the foundations for a significant reform of the aged care system, including its purpose and the principles that should govern. To quote at length (Vol 1, p.78):

Much has been said during our inquiry about the need to ‘place people at the centre’ of aged care. To achieve this, we are convinced that a new Act is needed as a foundation of a new aged care system. The new Act must focus on the safety, health and wellbeing of older people and put their needs and preferences first. It should provide an entitlement to the support and care each individual needs to prevent and delay the impairment of their capacity to live independently.

Framing the reform agenda as one based on entitlement is essential. Approaching reform in this way will focus on the interests of people who need or receive aged care being embedded in all key aspects of the new system. It will guide policy development and program administration; it will govern regulatory approaches and workforce development; and it will inform the approaches taken by approved providers to their internal governance, organisational culture and care delivery.

As we have argued, we think the Commissioners have presupposed a *moral* purpose for their reform agenda, and this is evident in both the language and intent of their report. To provide one further example (Vol 1, p.80):

The purpose of the aged care system must be to ensure that older people have an entitlement to high quality aged

care and support and that they must receive it. Such care and support must be safe and timely and must assist older people to live an active, self-determined and meaningful life in a safe and caring environment that allows for dignified living in old age.

Our proposal for the reformed aged care system is that this moral purpose will be achieved only if person-centred dementia care is delivered within the relational care framework. Such an ambitious new program of care, however, must be instituted against an evidence base, which we now discuss.

Systems of care must of course be regulated properly. The tendency of systems to lose sight of their moral foundations and goals is unfortunately all too common. A model of care that formally operationalizes a clear moral purpose can deteriorate for any number of reasons, including lack of funding and failures in up-to-date training of staff, and due attention to the social cultures that develop in care-giving settings. It is important, therefore, for there to be oversight measures, and that these measures be built into statutory provisions and proper governance. Critically, there must be scientifically oriented mechanisms or instruments that are designed to measure outcomes that are then compared against the purposes of care. In cases where it is not, there must then be preparedness, in the form of funding and resourcing, on the part of statutory bodies, to review and reform care practices in a way that achieves the moral ends set out at the start. In a nutshell: the moral purpose of care must be aligned with evidentiary practices.

The Royal Commission's Final Report is of course aware of the need to establish new governance arrangements:

Commissioner Pagone recommends an Independent Commission model that involves greater independence from the Australian Government of the institutions to govern the system. He recommends establishing a new independent Commission—the Australian Aged Care Commission. This newly created body should perform the roles of System Governor, Quality Regulator and Prudential Regulator. (Vol 1. p.83)

To ensure the maintenance of standards of care in line with a reformed aged care system, not only should there be mechanisms of regulation, but there must also be improvements and guarantees of their preservation through data, research and technology, and last but not least, the governance processes of aged care provider organisations. The Royal Commission report (pp.136-143) identifies a range of maintenance mechanisms including approval and accreditation for providers, the monitoring of quality and safety, complaints handling systems, serious incident reporting, enforcement, and advocacy. And on the question of aligning care with evidence, they also identify what is needed in terms of data, research, and technology (pp.144-149). They list, *inter alia*, streamlined methods of data collection, a national data base, upgraded standards for the collection and retention of data, investment in aged care research, and improvements in information technology for both clinical and business operations.<sup>28</sup>

Recommendation 108 of the Royal Commission states that by July 2022 new functions will be accorded to the Australian Institute of Health and Welfare Act 1987 (Cth). Among these will be the development of data sharing agreements with accredited users and data service providers to ensure open access to the use of aged care-related information. This will be in accordance with the commencement of a

proposed Data Availability and Transparency Act (Cth). This recommendation sees to it that not only should evidence be gleaned to determine whether the new practices accord with the goals set out by the reformed Aged Care system, but that such evidence should be openly available to relevant stakeholders whose responsibility it is to make authoritative adjustments to it.

Our proposal for an “enriched vocabulary”, as embedded within high quality person-centred care would require further research into ways of measuring its effectiveness, both in terms of quantifying outcomes, and identifying through ethically low risk qualitative studies, how, and to what degree, the new ways of caring are succeeding (or not). Once again, it must be recognised that in order to facilitate all of this, funding and resourcing is essential. The Royal Commissioners agree. As they state in the report (Vol 1, p.149):

Public funding is critical to the aged care system. The Australian Government spent \$19.9 billion on aged care payments in 2018–19, and \$21.2 billion on aged care payments in 2019–20. Despite these large expenditures, the current system delivers services that are all too often substandard, and sometimes unsafe. In many instances, the current system fails to deliver services simply because there is not enough funding to meet the assessed need.

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## Our policy proposals

It is clear from the work of the Royal Commission that a wide range of policy development and disciplined implementation is required in order to realise improvements in the lives of those living with dementia. In this spirit, and, based on the discussion developed in our paper, two distinct directions for policy open up. The first applies to the providers of aged care, and the second to the regulatory agencies responsible for the oversight of the sector. We offer an outline of a policy option for each of these below, which develops our discussion and points to a set of required actions on the part of both executive leadership of providers, and regulatory oversight bodies.

### A POLICY PROPOSAL FOR EXECUTIVE LEADERSHIP OF AGED CARE PROVIDERS

For an aged care provider serving residents who live with dementia, ongoing accreditation will require that the provider demonstrate compelling evidence that high quality dementia care is core business. This evidence must derive from the actual delivery of high quality dementia care outcomes, not evidence of having undertaken and delivered any specific action, or any set of actions, no matter how comprehensive. This will necessitate a shift in mindset, from a focus on providing ‘evidence of actions’, to ‘evidence of achievement of the purpose of actions’. This purpose will derive from a *mission statement* which provides the rationale – and the necessity – of actions to be undertaken in the care of people living with dementia. This will require that the designated Governing Body (or ‘Board’), in conjunction with Executive Management:

- Give clear expression to the organisation’s moral purpose in caring for people living with dementia by developing a dementia care ‘mission statement’ specific to that

organisation to be shared with current and prospective residents and their advocates and loved ones, which describes:

- The organisation's understanding of the meaning and value of a person in its care living with dementia
  - The dimensions of care that the organisation commits to providing to each person in its care living with dementia
  - The kind of experiences that the organisation commits to providing to each person in its care living with dementia
- Ensure a rigorous description and implementation of the work practices, accountability structures, management processes, organisational systems, staffing capability and capacity, and budget allocation required to deliver the full care experience outlined in the dementia care mission statement, on a regular and dependable basis
  - Ensure the organisation architecture outlined above is implemented in every residential facility within the provider operation, and that key staff at facility level are ready, willing and able to operate the organisation's mission statement for the care of people living with dementia
  - Establish robust evidence for the achievement of the resident experience outlined in the dementia care mission statement, and ensure regular reporting to the Governing Body and to the Executive Management on the level of achievement
  - Ensure that evidence regarding achievement of the dementia care mission statement is understood by the executive leadership and aged care staff and drives the Governing Body's and Executive Management's decision making
  - Ensure that achieving the purposes set out in the dementia care mission statement feeds into facility 'star ratings', and is publicly available to residents, prospective residents and their advocates, and to regulatory agencies.

### A POLICY PROPOSAL FOR REGULATORY AGENCIES

The Royal Commission recommends a review of the 2019 Aged Care Quality Standards, noting those standards leave the vital matter of what exactly constitutes 'high quality aged care' undefined. We suggest three productive policy initiatives for regulatory agencies, in the context of a much broader policy environment refresh. These are:

- Ensure that the revised quality standards have a unique standard that matches and spells out evidence for the Royal Commission's statement that 'dementia care become core business of providers'. This would require each provider to clearly describe the intended purpose of 'high quality' care for those living with dementia, to outline the various dimensions of that care (such as nutrition, pastoral and clinical care, day-to-day living experience, sociality, activities, amenity, communication with loved ones and advocates) and to implement an evidentiary framework that ensures accountability.
- Ensure that the revised quality standards clearly orient provider performance around the experience and valuing of persons in their care living with dementia, rather than a set of actions that can be undertaken and 'ticked off' by the provider and their staff. The evidence in question needs to be framed not around actions having been performed, but rather on the success of the action in achieving its

intended purpose. That purpose must derive from respect for, and needs of, the person living with dementia, not just actions that the provider determines to be 'practically possible';

- From a governance perspective, ensure that failure to meet these requirements is specifically and formally assigned to the organisation's identified Governing Body (its 'Board') and its members in the first instance, rather than the organisation's management.

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## Conclusion

This paper contains five strands which constitute a blueprint for meaningful action in relation to person-centred dementia care in a reformed Aged Care system. First, the Royal Commission report states (p.92) that "[a]ll mainstream aged care services should have the capacity to deliver high quality aged care for most people living with dementia—dementia care should be *core business*." Second, the Royal Commission findings and recommendations can be seen as setting forth a moral agenda for change, or in our terms, providing for a *moral purpose* that underpins aged care practices. Third, these practices put the person at the centre of care, and we have argued that for this purpose to be achieved a more sophisticated understanding of person-centred care must be in place, one that uses an enriched vocabulary as identified by the three elements of egalitarian care relationships, moral self-orientation, and social agency; this, we describe as the *relational care framework*. Fourth, for this to be operationalised and maintained, the different models that operate within it (given the diverse contexts that pertain and the nuanced differences that external providers no doubt bring) must be regulated, and periodically refreshed, to ensure that the moral purpose of dementia care *aligns with evidentiary practices*. And fifth, as a corollary to this, all such changes must be transparent and the information freely and openly available. This *openness and transparency* should apply to all relevant stakeholders including, and especially, the consumers and clients of services, the people living with dementia and their families and loved ones.

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## FOOTNOTES

1. Media release from the Office of Prime Minister, 25 Nov 2019. Response to Aged Care Royal Commission Interim Report | Prime Minister of Australia ([pm.gov.au](http://pm.gov.au)).
2. In referring to the aged care 'system', we mean aged care providers and government agencies, particularly regulatory agencies. When we refer to aged care providers, we intend to include all who work in, or for them, i.e., board members, management, clinical and personal care team members and services staff.

3. An example of a swiftly implemented measure is that from September 1, 2021, Behaviour Support Plans are a legal requirement in residential aged care. These have been introduced to limit the use, and what has been the overuse, of chemical and other forms of restraint. The Royal Commission found that the use of restraint in dementia care is unacceptably high and, in many instances, harmful.
4. The discussion in our paper has a focus on aged care providers and regulatory agencies. We focus on aged care providers, as opposed to segments of the workforce within provider organisations, as we employ the assumption that it is at the provider-level that cultures of care, care practices and care standards are established and maintained. We also employ the assumption that it will be in partnership with regulatory agencies, that aged care providers will implement the improvements in care that the Royal Commission envisages.
5. We note that our focus is squarely on the moral features of person-centred dementia care. We do not overlook the range of skills that are required in aged care management, quality clinical and personal care, and other areas of service delivery. In this paper, we employ the assumption that the moral features of person-centred dementia care that we describe can be incorporated across all aspects of aged care management and aged care delivery.
6. See the Appendix to this paper for an overview of dementia prevalence and expenditure in Australia.
7. The term 'consumer' is employed in the current Aged Care Quality Standards, whereas the Royal Commission use the terms 'older person' or 'client.'
8. We acknowledge that there are examples of quality dementia care. We would argue that even if the language that is used to describe that care differs from our own, existing quality dementia care embeds the elements of the relational care framework we describe below.
9. We note that the Covid-19 pandemic has placed even more pressure on aged care providers and their staff.
10. See Royal Commission Final Report Vol 1, p.71, and p.76, where it laments the tendency towards a 'task-based focus', or 'task-based approach' to so-called care.
11. We note that for the purposes of this paper, social inclusiveness refers primarily to the social inclusion of older people who live with dementia. We note that social inclusion also means inclusion of differing cultural, gender and sexual identities, orientations, needs and preferences.
12. This understanding reflects the results of four years research supported by an ARC Discovery Project, DP180103262, Dementia, Moral Agency, and Identity: Respecting the Vulnerable.
13. We note that our focus is squarely on the moral features of person-centred dementia care. We do not overlook the range of skills that are required in aged care management, quality clinical and personal care, and other areas of service delivery. In this paper, we employ the assumption that the moral features of person-centred dementia care that we describe can be incorporated within all aspects of aged care management and care delivery.
14. For example, Dawn Brooker's VIPS approach to care. See Brooker & Latham (2006); Rosvik et al (2011).
15. See Tieu & Matthews (in press).
16. For example, see Groves et al (2017).
17. For a comprehensive review and discussion, see Tieu & Matthews (in press).
18. See Carter (2021).
19. See Berenbaum et al (2017); Fazio & Mitchell (2009); Norberg (2019); Tappen et al (1999); Tippett (2018).
20. See Matthews (2020).
21. See Sabat (2018).
22. To expand this point, we quote from psychologist Mitchell (2009, p.247): The self-concept [or self-image] refers to a person's understanding of what she "is like" as a person, that is, what personality characteristics she manifests, what idiosyncratic abilities and proclivities define her as an individual, and *to what extent she regards herself positively (i.e. has high or low self-esteem)*. [emphasis added]
23. The Montessori approach incorporates the principle that having a sense of purpose and contributing to others is key to the well-being for all residents, including those who live with dementia. See <http://www.massa.org.au>.
24. See Sacks (2019). Sack's article also raises the ethical issue of truth-telling in dementia. For an overview of this ethical issue see Byers, Matthews & Kennett (2021).
25. For discussion of the neuro-protective effects, see Wollen (2010).
26. See Matthews (2015). See also Anne Basting's work on creative expression in dementia (2018; 2020).
27. See Victor (2012).
28. See also Chapters 15 and 16 of the Royal Commission Final Report, Vol 3B.

# Appendix

## DEMENTIA IN AUSTRALIA: PREVALENCE AND EXPENDITURE

From the Australian Government's Institute of Health and Welfare site; their latest dementia report, July 2020 (Dementia - Australian Institute of Health and Welfare (aihw.gov.au))

### PREVALENCE, PREDICTIONS, AND RISKS

- 2020: estimated diagnosable cases of dementia is between 400,000 and 459,000. Alzheimer's disease accounts for up to 70% of diagnosed cases
- By 2030, the estimation ranges between 550,000 and 590,000
- Main "fixed" risk factors include age, genetics, and family history
- Prevalence rates are 2–5 times higher among Aboriginal and Torres Strait Islander people
- Modifiable risk factors include: (1) education levels, physical fitness and social engagement, which are protective, and (2) smoking, hearing loss, depression, diabetes, hypertension, and obesity, which pose developmental exacerbations to risk

### IMPACT

#### Deaths

- 2018: second leading cause accounting for almost 14,000 deaths (ABS 2019) Females: dementia was the leading cause of death (9,000); males: third leading cause (nearly 5,000)

#### Burden of disease

- 2015: fourth leading cause of disease and injury; 3.8% of the total burden of disease and injury, equal to 179,804 disability-adjusted life years (DALY)
- Females (who live longer) account for higher proportion of total burden, comprising 52% of dementia hospitalisations and 58% of people dispensed anti-dementia medicines in 2017–18
- Dementia burden higher among people aged 65 and over, for whom it was the second leading cause of total burden of disease and injury (7.7% of total DALY)

## EXPENDITURE (2015-16)

- \$428 million in health expenditure (excluding aged care expenditure) was attributable to dementia in Australia in 2015–16
- More than \$324 million spent on hospital-related services for people with dementia—public and private sectors, admitted and non-admitted care
- \$90 million spent on public hospital outpatient services
- \$17 million on private hospital services
- \$5.1 million was spent on public hospital emergency department services
- More than \$40 million spent on medicines for people with dementia
- Specialist Services \$16 million; general practitioner services: \$23 million; \$3.1 million spent on allied health and other services

## AGED CARE SERVICES (2019)

- 107,000 people utilised home care (community, or home support care to those living at home). 9% of these received the dementia and cognition supplement, a payment for people with moderate to severe levels of cognitive impairment associated with dementia or other conditions
- 183,000 people in permanent residential aged care, and just over half (53%) had been diagnosed with dementia
- Measures of care needs domains: activities of daily living, cognition and behaviour, and complex health care. Although complex health care needs were invariant between dementia and non-dementia, both other domains showed higher care requirements, especially cognition and behaviour. Overall, 80% of those with dementia had high care needs compared to those without (46%)



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