# Royal Commission into Aged Care Quality and Safety

## Program Design Submission

**Dementia Australia**

January 2020

# About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 459,000 Australians living with dementia and the estimated 1.6 million Australians involved in their care.

Dementia Australia works with people of all ages impacted by dementia, all governments, and other key stakeholders to ensure that people with all forms of dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with individuals and communities means that we can advocate for those impacted by dementia and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people of all ages living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.

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# Executive Summary

The proposed redesign of the aged care system and the principles that underpin it align with the perspectives of people living with dementia, their families and carers. People with a lived experience of dementia want to ensure that their voices are heard and that there is greater inclusion, support, respect and ultimately, improved quality of life for all people living with dementia.

The current aged care system does not adequately support people living with dementia as part of core business. In order for dementia to become core business, a series of foundational shifts in leadership, culture and workforce capacity across all elements of the system is required, including access and navigation, care planning and coordination, and care delivery.

If this transitional and capacity building work does not pre-empt the design of a new aged care system, the same barriers, challenges, and at worst, breach of human rights, will continue to impact people with dementia, their families and carers in any new system.

In our submission, Dementia Australia identifies where these capacity-building elements are required. Our support for the new model posited by the Commission is predicated on the understanding that a foundational shift has occurred and that dementia is core business for the aged care sector.

Specific components of the proposed model and the regulatory, funding and operational frameworks that underpin it, require further modelling and analysis. Dementia Australia looks forward to further consultation with the Royal Commission on the aged care system of the future and discussing further the issues raised in our submission.

# Introduction

Dementia Australia welcomes the opportunity to provide a program design submission to the Royal Commission into Aged Care Quality and Safety. Our submission responds to the questions posed in the Commission's consultation paper, focusing on the needs of people living with dementia, their families and carers.

A redesign of the aged care system and fundamental reform must be underpinned by a significant shift in the culture, leadership and operations of the sector, in order to ensure that it includes and supports people living with dementia and does not replicate the barriers and challenges they face in the existing system.

## Dementia in Australia

The reason that a concerted focus on dementia in the design of a new system is so important is that dementia is one of the largest health and social challenges facing Australia and the world.

Dementia is the term used to describe the symptoms of a large group of neurocognitive diseases which cause a progressive decline in a person's functioning. Symptoms can include memory loss as well as changes in speech, reasoning, visuospatial abilities, emotional responses, social skills and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease. Dementia is a terminal condition and there is currently no cure.

It is estimated that there are more than 459,000 Australians living with dementia in 2020 and around 1.6 million people involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.[1] It is the leading cause of death of women in Australia, the second leading cause of death in this country and it is predicted to become the leading cause of death within the next five years.[2] Dementia is not a natural part of ageing. It is more common in older people but it can affect people in their 40s, 50s and even their 30s.[3]

## Dementia in the current aged care system

The policy intent and practices that have driven aged care reform over recent years have been increasingly based on the premise that supporting people impacted by dementia is part of core business for service providers. Combined with this approach has been an underpinning ideal of a consumer-focused and market-driven approach to service quality and innovation within aged care.

Both elements are predicated on the idea that consumers who have the tools and comparable information to make informed choices will 'vote with their feet' on the services that are most able to support their needs and preferences as well as contribute to the cost of

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[1] Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by The National Centre for Social and Economic Modelling [NATSEM], University of Canberra

[2] Australian Bureau of Statistics (2018) *Causes of Death, Australia, 2017* (cat. no. 3303.0)

[3] There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

their care where they are able to do so, while those providers not able to meet consumer demand will either adapt or exit the aged care market. In the case of dementia care, these mechanisms are problematic at best and flawed and/or underdeveloped at worst.

The Royal Commission's Interim Report[4] as well as many of the experiences recounted by witnesses demonstrates overwhelmingly that dementia is not yet core business across the aged care sector. There are still significant steps required for quality dementia care and support to become an intrinsic part of aged care services, as well as health and disability services. This is especially so for marginalised or disadvantaged communities (for example, Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse communities) who often experience longer delays in diagnosis, limited access to information and treatment, and lack of choice in home and residential care.

A summary of some of the most relevant issues facing the aged care sector and those impacted by dementia who interact with it include:

- A lack of understanding about dementia among formal and informal carers;
- A workforce that lacks dementia-specific training and education;
- A lack of acknowledgement of the role of carers, families and advocates as partners in care or as facilitators of supported decision making and care planning;
- A lack of meaningful activities for people living with dementia to engage with or participate in;
- Service environments that are not supportive or friendly for people living with dementia and which do not create a sense of homeliness or familiarity;
- Feedback and complaints systems that do not take people living with dementia seriously or facilitate their involvement;
- An organisational culture that does not understand dementia or respond effectively to meet the needs of a person living with dementia.

These issues, in turn, lead to reduced access to care, diminished care experiences, poor quality dementia care and increased costs for clients/residents, providers and governments.

The need for fundamental transformation is clear: there have been multiple failings in the aged care system for people living with dementia, their families and carers – both at the individual provider level and at system level.

The lack of a consistent focus on dementia within legislative, regulatory, policy, funding and service delivery contexts means that the needs and preferences of people living with dementia, their families and carers are not fully or adequately addressed in the current system and they will not be addressed in a new system that steps over the transition required to raise the foundational level of care.

We need a strong and sustained focus on dementia in the aged care sector for the hundreds of thousands of Australians living with dementia and their families and carers.

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[4] Royal Commission into Aged Care Quality and Safety (2019) *Interim Report: Neglect*

## Dementia in the proposed new system

Dementia Australia broadly supports the Commission's aged care system redesign, as it is outlined in the consultation paper, *Aged care program redesign: services for the future.* We support the Commission's view of the need to change from a system of transactions between providers, consumers and governments to one that is a relationship of care with people at the centre.

Our responses are underpinned by a key assumption that, in order for a new system to work for people impacted by dementia, a significant transitional phase is required, which builds the capacity of the sector to respond to dementia consistently as part of core business. This phase in itself requires fundamental culture and leadership changes, extensive capacity building across all components of the workforce and a committed investment in regulation, operations and funding by government and regulators.

Without this foundational shift, the challenges people with dementia, their families and carers experience in the current aged care system will remain. Dementia must become core business for a future aged care system – one in which all staff have an understanding of dementia and how to support people living with dementia, and where specialist services will respond to more complex needs.

Within this new system, then, Dementia Australia envisages two broad service streams:

1. Mainstream services that have the capacity to support people living with dementia by having staff that are trained in dementia; by having supportive physical environments; by having some operational/organisational requirements that demonstrate dementia credentials;
2. Specialist dementia pathways that support the (improved) foundational-level service delivery: e.g. dementia clinical champions, communities of practice and other pathways that mean individuals, families, carers and providers can access specialist advice or services where care needs are complex or there are multi-comorbidities.

If these recalibrations are implemented, dementia will be core business in the new system in practice as well as in principle: people with dementia will be able to access services that are tailored to them and maximise their abilities and autonomy; families and carers will receive integrated supports that empower them; staff working across a wide range of disciplines will be qualified, informed and empathetic.

# Principles

Dementia Australia is supportive of the high-level principles for a new system, as outlined in the consultation paper. The principle of putting people at the centre aligns with what people with dementia and carers identify as being particularly important.

Dementia Australia has been able to test the principles with people who have a lived experience of dementia because a key priority for Dementia Australia is focused on quality dementia care and how to define it. We consulted with people with a lived experience of dementia around Australia to find out what quality dementia care meant to them, particularly in the context of the recently introduced Aged Care Quality Standards. We asked people:

- What does quality dementia look/feel like?
- What are the key points of difference between quality dementia care and aged care more generally?

The culmination of this consultation was a Consumer Summit in June 2019, attended by a cross section of people with dementia, families and carers from across the country. Attendees of the Summit discussed the findings and ratified a communique – *Our Solution: Quality Care for people living with dementia*.[5]

What became clear through consultations with people impacted by dementia was that there are two fundamental components of quality dementia care:

1. Taking a holistic and person-centred approach, including high-quality communication, with every individual;
2. A workforce that is appropriately skilled and educated in dementia as well as person-centred practices.

People also felt that it was imperative to have strong leadership that promotes positive organisational cultures within and across the sector.

To put it simply, people with a lived experience of dementia want to ensure that their voices are heard, that quality care involves them and that their contribution leads to greater inclusion, support, respect and ultimately, improved quality of life.

> *"If you can get it right for dementia, you can get it right for everyone else" – Person living with dementia*

And although the principles in the Communique are framed within the context of the Aged Care Quality Standards, they speak to the need for sector-wide transformation.

Success of any new aged care system that puts people at the centre in practice as well as in principle is, we would argue, predicated on there being a detailed transition phase that raises the foundational level of the aged care sector to create greater consistency in:

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[5] Dementia Australia (2019) *Our Solution: Communique Care for people living with dementia* https://www.dementia.org.au/files/documents/DA-Consumer-Summit-Communique.pdf

- Person centred approaches for everyone, including people with dementia;
- A workforce that has the capacity to understand the fundamentals of dementia; knows how to engage with and communicate with someone with dementia – e.g. with basic dementia education built into qualifications and specialist knowledge to facilitate mentoring and capacity building as well as communities of practice etc.;
- A system that has specialist areas of focus and specialist dementia workers where they are required – e.g. perhaps navigation; some respite; services that support people with symptoms of the behavioural and psychological symptoms of dementia (BPSD) – these require further scoping in a new system;
- A shift in leadership and culture across the sector to ensure greater transparency and accountability (and improvement in the quality of dementia care).

As we have already made clear, unless these foundational changes are made and transition activities implemented in a comprehensive way to shift the entire sector, a new system model will simply perpetuate the issues people with dementia already experience.

It is crucial that the transitional/foundational activities are sector-wide because dementia is not yet core business for the aged care sector and it is not sustainable, equitable or in alignment with human rights principles and the right to choose to create another system which is inadequate (at best) or dangerous (at worst) for people with dementia.

Over recent years, aged care strategies and reviews have all acknowledged, to some extent, the importance of the principles outlined in the consultation paper. Yet numerous inquiries, including the Royal Commission into Aged Care Quality and Safety itself, have also highlighted that principles are not being translated into practice on a consistent basis, especially with regard to the care and support of people living with dementia, who experience even more significant barriers in accessing inclusive care.

It is therefore imperative that systemic changes occur within aged care sector culture, leadership and operations in order to lift the foundational level of dementia. Without this transformation, we will continue to see the same discrepancy between principles and practice in the new system.

Dementia Australia is currently working with a range of stakeholders on some fundamental transitional components of improving quality dementia care in the sector (especially in the regulatory and workforce spaces), but the support of Government and the sector more broadly is required to embed these principles consistently.

# System access and navigation for people living with dementia and carers

## Access to a new aged care system

Following a diagnosis of dementia, many people report feeling confused about where to go for support or they are unaware of support that is available to them – which delays their opportunity to access early intervention supports and services.

> *“How many people know about the 'My Aged Care' site, do they have access to, or the ability on a computer? Sure you can use the telephone but who has the time to wait up to 40 minutes, centralising where to find information has its downside.” Carer*

A current challenge for people living with dementia, their families and carers in accessing the aged care system is the use of My Aged Care and the gateway’s lack of ability to adequately support vulnerable populations in navigating the aged care system. The introduction of the Carer Gateway, while providing beneficial services for carers, adds to the complexity that people face because it requires carers to access and navigate yet another system (and potentially receive conflicting information) to receive much needed supports.

An inability to navigate the system effectively results in negative impacts across the care spectrum for people with dementia, families and carers. It increases stress on carers and family; puts pressure on service providers to provide care they may not be equipped to deliver; does not necessarily guarantee access to the type and level of services required; and results in people accessing acute hospital services at times of crisis. It also increases the risk of premature or inappropriate admission to residential aged care homes.

A new system for aged care must have a ‘no wrong door’ philosophy underpinning service access. While we acknowledge that there needs to be an access gateway, such as My Aged Care, people with dementia, their families and carers may need support from those around them, such as their GP or other health professional to initiate or facilitate access to the aged care system. This scenario must be accommodated for a in a new system.

Staff in an access or gateway system must have a basic education in dementia, record the condition in notes in a consistent way and understand how to escalate to dementia knowledge experts as required.

More consistent access to early interventions has been shown through the National Dementia Support Program to enhance the ability of people living with dementia, their families and carers to synthesise information about a dementia diagnosis, plan ahead and have key discussions about informed consent, medical and other powers of attorney, advance care planning and service preferences.

As such, the system must be designed to ensure that aged care services are engaged in a timely manner and, typically, a lot earlier in the dementia trajectory than currently occurs, rather than at a time of crisis for the individual or their family//carer (which is currently a far more common experience). Services should then include restorative or reablement approaches to maximise the independence of a person with dementia and delay entry to other care services.

## Provision of information

Accessible information about the aged care system and services is critical to the success of a new system. And although quality dementia care should be core business for the sector, information provided about programs and services must include comparable indicators for people to know how dementia is supported (for example, via staffing levels, staff education programs, evidence of consumer engagement that includes people with dementia etc.). The level of detail may be scaled according to the type of service required (e.g. ‘light touch’ services like gardening may have a much lower threshold for demonstrating dementia credentials compared with a home care provider or residential aged care provider, for instance). Importantly, services which say they can support people living with dementia must have to demonstrate their capacity to do so through some consistent measures or indicators, so that people can have the reassurance that a stated approach is backed by evidence (and so they can compare provider performance).

Accessible, user-friendly technology is critical. Following the introduction of the My Aged Care website, it received multiple criticisms over its design and the lack of key information on providers. Taking on board this feedback, it is important that any technology platform that is created is simplistic in design, incorporates universal design principles and contain clear and concise information. There also needs to be an easy to reach face-to-face outreach program or community hub option, which all users are able to access.

People living with dementia often value – or indeed require – access to a face-to-face service which allows them to have a conversation about their care needs and what supports are right for them, and facilitates them developing a care plan that best suits their needs. A face-to-face delivery approach should be available wherever possible and could be delivered through an outreach or community hub style approach. Face-to-face services are especially beneficial to people with dementia who have communication difficulties and cognitive impairments that impact on their ability to use and access the current systems, navigate the system or find service providers.

Indeed, for individuals with limited communication, written information and online systems are more difficult to navigate and comprehend, which subsequently limits the amount the individual can engage in discussions around their care. Alternately, face-to-face interaction enables people with dementia to engage and get across information so they can inform their own care. Therefore, to fully accommodate the needs of people with dementia, Dementia Australia recommends a flexible mode of delivery, where a range of contact methods e.g. face to face, phone, email and videoconferencing is available.

A key feature of a new aged care system must also be to consider the breadth of services and care options that would support each individual unique set of needs and preferences. This is a fundamental limitation of existing access points – service referral pathways are limited and tend to focus on reactive care needs rather than proactive approaches that maximise independence. Similarly, contact centre staff do not always have the degree of dementia knowledge, skills and experience required to adequately facilitate a proactive approach to information provision and planning.

Shifting the approach to, and provision of, information, planning and support, as well as expanding the settings in which people receive information, will fundamentally improve the system of information provision for people with dementia, their families and carers. Linking information approaches and service referral pathways to those in the Carer Gateway will also ensure the system is more user friendly and links carer needs to the individuals they care for.

## The need for a system navigator

Transitions between discrete aged care programs, as well as between aged care and primary/acute/allied healthcare settings can be complex, difficult to navigate, and the pathways can lack clarity and transparency for both consumers and providers. Roles and responsibilities are often unclear, with informal carers (where an informal carer is available) typically taking up a coordinator role, despite often also experiencing their own health challenges or multiple caring roles, and struggling to identify a cohesive way forward.

> *"I would like [the government] to consider a case manager that works with the family. So you have one holistic management process. I could then go to the person who knows me, and when I get depressed I would know what to do. I need someone to develop a relationship who knows me, the family and circumstances."*

Although pilots of system navigator supports are underway, there is an urgent need to expand this function and, given the increasing numbers of people with dementia, to provide more substantial navigation supports that specifically support people with dementia and their carers.

The delivery mode for a system navigator model must consider the geographical spread of people who need to access services, the variability in access to technologies, and the variability in comprehension of technology use. In addition, it is also important to consider the most appropriate methods to aid rapport, trust and relationship building – which is central to a person-centred approach.

A key contributor to the complexity in accessing aged care supports is the lack of public transparency around providers, including the services they deliver and their quality, especially as it relates to dementia. Progressively, those transparency issues have fostered a general lack of trust in providers by people needing to access services, and nervousness about who to select to provide their care. Concerns around the vulnerability of people living with dementia can make this navigation of the system even more fraught. A system navigator should therefore be an independent service that operates separately from aged care providers.

An independent navigator would help assure people that the advice and guidance they are given is not driven by the competitive provider market, but by the needs of that individual and the most appropriate range of supports that are available to them. As part of this approach, there also needs to be comparison criteria for aged care services that is accessible to the general public to empower consumers to make informed decisions. This requires rigour and transparency in how providers present their services, and there is a need for improved regulatory processes to ensure providers deliver on what they receive funding for. This is especially relevant to dementia, where providers are able in the current system to identify themselves as dementia specialists without necessarily providing standard comparable data on how they facilitate the provision of quality dementia care.

To ensure the inclusion of people from remote, Aboriginal and Torres Strait Islander, and Culturally and Linguistically Diverse communities, navigators should implement a partnership approach with trusted organisations. Relationship-building and information sharing between local communities and organisations would ensure the navigator is delivering culturally sensitive and appropriate services from the outset.

## Support for carers

> *"There should be only one "easy to access and navigate" aged care system. The Carers Gateway and My Aged Age means the care must learn to navigate two systems. Access to aged care services is complex." Former carer*

The pivotal role of carers in supporting people living with dementia means that access to carer supports should be considered in the development of an aged care access and navigator system. Carers need access to a range of supports to help maintain their physical and mental health, in addition to psycho-educational supports to assist them in their caring role. The existing Carer Gateway aims to provide carers access to these supports; however, to date the gateway is often underused. This may be because of carers not seeking out support, but it is also possible that carers lack awareness of the gateway and the services available to them. Linking the carer gateway with the aged care system would enable all those impacted by a diagnosis of dementia to receive the supports they need, when they need them.

## The role of GPs

GPs are often the first point of contact for people seeking a diagnosis of dementia or newly diagnosed with the disease, and it is important that they are aware of the access and navigation system so they can direct people to services and supports immediately following a diagnosis. More broadly, the access and navigation model needs to be integrated into health pathways and diagnostic pathways.

> *"Much more use of GPs, often the first point of contact for an elderly person or their family, should be used. Packages with information about the system, contacts etc., should be handed to a patient who receives a diagnosis of dementia. The same could happen with specialists such as geriatricians." Former carer*

Unlike some other health conditions (e.g. breast cancer or diabetes) there is no clearly defined referral pathway from GP to services for someone who receives a diagnosis of dementia, nor is there a consistent approach to accessing information or support.

Many people newly diagnosed with dementia are not connected to information, advice, counselling or services that focus on maintaining/supporting autonomy and independence. Too often, people with dementia and their carers report to Dementia Australia that they did not experience a comprehensive referral pathway following their diagnosis of dementia, with advice limited to 'getting their affairs in order' and waiting until they need high-level care services. There is therefore a need for a new system of access and navigation to include a structured pathway that supports post-diagnosis referral to early intervention supports.

# Entry-level support stream

Most people living with dementia would prefer to remain living at home, for as long as possible. They often have better outcomes in the longer term as a result of receiving appropriate early intervention services and basic supports at home. However, as there is not always a recognised visible or acute functional disability in the early stages of dementia, access to the aged care system in this early stage is, at times, denied within the current system. What we know from people with a lived experience of dementia, however, is that entry-level services, accessed at the right time, can not only support individuals to plan for the future but maximise their functional independence for as long as possible.

As the Royal Commission's discussion paper suggests, people maintain their homes and gardens, do laundry, cook meals, get themselves to appointments and attend social engagements across their whole adult lives; and as such, the functions that underpin these activities – whether undertaken by a service provider or the individual themselves – can be classed as 'universal' services rather than specialist aged care services. The experiences of people living with dementia, their families and carers, however, suggests that people with dementia need to be supported to access these universal entry-level support services, regardless of whether the provider is drawn from the aged care sector or the broader community.

Arguably, one of the most important roles at this entry-level stage is that of the navigator or care coordinator/case manager, who can ensure that the individual living with dementia, as well as their family and carers, is able to access the most impactful entry level services to facilitate and maintain independence.

While subsidised services may be necessary for some individuals, it is reasonable to assume that people who can contribute to the cost of their entry-level services should do so.

However, there are some early/entry-level supports for people with dementia that require increased funding and service infrastructure (including building comprehensive service pathways at the point of diagnosis) to ensure their availability and applicability. The question of whether these services, discussed further below, should be block funded, cash or debit-card enabled requires further financial analysis as to what services people living with dementia currently receive in the entry-level stages of the existing system: currently, robust data on dementia in the home care environment is absent and it is difficult to model the service trajectory of someone with dementia other than through anecdotal evidence.

## Entry-level services that maximise independence

Advance care planning, for example, which identifies potential support and care preferences as dementia progresses, should become part of entry-level service delivery pathways in a new system, even though it is not recognised as an entry-level service currently. This ability to plan for the future and make decisions at a point at which capacity to do so is still present, can be enormously important for someone with dementia and empower them – and their families and carers – to make informed decisions about their health and care trajectories.

Additionally, there needs to be a greater focus on sustaining and improving the wellbeing of people with dementia, their families and carers through increased funding for social and peer support programs, which encourage community engagement and participation. People with dementia (and often their carers too) tend to socially withdraw as their symptoms progress, or conscious or unconscious discrimination prevents them from participating or accessing services in the way that they did before developing dementia. Programs and services that facilitate the social inclusion of people living with dementia, families and carers are incredibly important, as are psycho-social supports and counselling.

In the current system, however, the majority of consumers will tend to choose home care services over counselling or social support because they do not have enough funding for both. The immediate need for, say, domestic support is prioritised over activities that have the potential to improve wellbeing in the long term.

In a new system, there needs to be more flexibility in how social support services are accessed and they should not be neglected because of the pressure to access more traditional entry-level services. The flexibility to maintain these new entry-level services should also be possible regardless of accommodation setting. Currently, the majority of social support services accessed while living at home are no longer accessible once an individual enters residential aged care. This can be particularly disorientating for a person with dementia, when they have been in a routine of attending activities and have developed trusted relationships with staff. Eligibility to access social support and community engagement activities therefore needs to be independent of care setting.

The flexibility to access a wider range of activities within the community, such as tailored fitness and exercised programs, volunteering opportunities, and programs with young people, would also make a significant difference to people impacted by dementia, especially at the entry-level stage of service access. Activities which are dementia inclusive (not just dementia specific) are important in enabling people with dementia to continue to participate and engage with their local community.

## Supporting carers

As dementia progresses, individuals will come to rely heavily on their carers and family. Supports that aim to delay entry to care must therefore also consider the needs of carers and family members.

Research demonstrates that access to supports which target the psychological, social and physical impacts of dementia and which target both the individual with dementia and their family and carers, are most effective at delaying entry to residential aged care. For people with dementia who do access social support programs, services that have the option of including carers are very popular. Yet this is currently more difficult to coordinate because of the separation of carer specific services. As such, it is imperative that entry-level service modelling and pathways in the new aged care system take into consideration the needs of people living with dementia and their families/carers.

## Continuity of support

Regardless of the type of entry-level services accessed by a person living with dementia, it is important that once they have built a trusting relationship with that service provider, they are able to continue to use their services at other stages of their care trajectory (if it is appropriate to do so). For example, in the current system, for people with dementia who access Commonwealth Home Support Program (CHSP) services and then transition to a home care package as their needs progress, the process is often complicated by the need to change organisations who are providing the support, even if the entry-level activities remain the same (e.g. domestic assistance). This means that familiar staff move on and relationships and trust need to be built with new staff. This is particularly challenging for people with dementia and can lead to behavioural responses which then result in the person being labelled as difficult and uncooperative, lead to a review and potentially result in an escalation of care needs. A new system needs to enable relationships of support and care to be maintained regardless of the program providing the service.

## A trusted workforce

As mentioned, trusted relationships with service providers can be especially important for people impacted by dementia. And while entry-level services may be drawn from the aged care sector or the community more broadly, people living with dementia, their families and carers must have access to staff (possibly navigators and/or care coordinators or case managers at a minimum) who understand dementia, can monitor the appropriateness of entry-level service delivery and, where applicable, link individuals to services and staff who understand dementia, undertake regular dementia education and have the capacity to respond to changed behaviours or cognitive abilities.

# Investment stream

A new aged care system needs to ensure that the dyad – that is, the person living with dementia, their family and cares – are individually and collectively supported throughout the trajectory of dementia. Recent reforms have introduced greater emphasis on individual needs, which is important, but this is impacting on the ability for services to respond to the collective needs of the person with dementia and their family/carer. As the Commission's paper states, the benefits from regular and planned respite, reablement and restorative approaches are well documented, but services are scarce – and even more so for people impacted by dementia.

As dementia progresses, carers and families typically experience increasing pressure and can often feel overwhelmed as symptoms become more severe. To prevent burnout or undue stress, families and carers must have access to supports which help them to maintain their own health and wellbeing, in addition to supports that assist them with their caring responsibilities.

There are a multitude of benefits of respite and reablement approaches for people living with dementia, their families and carers. Access to these services needs to be significantly increased from current levels and arguably they need to be available earlier, possibly even as entry-level services where a diagnosis of dementia is present. These respite and reablement services also need to be flexible, proactive and timely to prevent crisis situations.

## Reablement

Dementia Australia supports a reablement approach to care for people living with dementia, so that individuals are encouraged to act as independently as possible, for as long as possible.

People with dementia need more opportunities to access such services – the current assumption is that because people with dementia are experiencing a progressive decline, rather than experiencing a disease trajectory with an obvious restorative path, they are not suitable candidates for reablement. However, people with dementia should still be eligible for reablement approaches to enable them to make the most of their abilities, stay active and participate in meaningful activities. Adopting a reablement approach also reduces the sense of 'feeling helpless' – especially amongst people living with dementia, who experience a progressive loss in their abilities.

In a new system, reablement approaches/services need to be more readily available for people living with dementia. Dementia Australia suggests that reablement approaches should be made available as entry level services. By supporting the independence and participation of people living with dementia, reablement services may slow the demand for more intensive services (and this shift in approach will ensure that the effectiveness of such interventions can be more comprehensively assessed from the point of view of outcomes and economic efficiencies).

## Respite

Respite may be used to give carers a break from their caring responsibilities, for mental or physical relief, to allow carers to engage in social or recreational activities, or in response to a crisis, and enable the person with dementia to continue to remain living at home for as long as is appropriate.

> *"I would take husband to my daughter's home for a few weeks to access respite in Mudgee. There was nothing available here." Carer*

According to the 2012 Dementia in Australia Report, 39% of primary co-resident carers of people with dementia had used respite services – compared with just 11% of all primary carers.[6] The key reasons for accessing respite were: emotional stress and strain (49%); increasing needs of the care recipient (22%); carer employment issues (9%); and carer's need for time to maintain regular activities (7%). Over half of co-resident primary carers of people with dementia (52%) also reported needing additional support and 48% stated respite care was the main area in which they needed more help.

Respite, therefore, has long been shown to improve carer emotional wellbeing and physical health, provide time for carers to look after themselves, and enhance autonomy and independence.[7] Respite is essential for carers to sustain their caring duties. However, access to respite is limited in the current system, where insufficient capacity, lack of local services and, in many cases, lack of sufficient resources to meet the needs of people living with dementia, prevent access to respite. The increased supply of such services, as well as the capacity of services to support people living with dementia, must be a core component of a new aged care system.

A more flexible range of service options is also vital.

Carers may need a break from the physical demands of caring, for example, but they may not want to be separated from the person they care for. In a new aged care system, support for couples to access in home or residential respite at the same time would be provided. This would allow them to spend quality time together, with the carer receiving a break from the physical care tasks.

In 2016, the University of Wollongong conducted a literature review of the features that make up high quality respite.[8] In sum, the report concluded the need for flexible respite care, which covers five key domains (who, what, where, when and why). Taking on board these recommendations, services should take steps to incorporate the following key domains to promote flexibility:

- Who: Respite care needs to consider how it is going to benefit the individual with dementia and the carer
- What: Respite should include a range of activities, tailored to the needs of the individual

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[6] Australian Institute of Health and Welfare (2012) *Dementia in Australia*, Canberra: AIHW 2012. Cat. no. AGE 70

[7] M Hamilton, G Giuntoli, K Johnson and K Fisher. (2016) *Transitioning Australian Respite*, Social Policy Research Centre, University of New South Wales

[8] Phillipson L, Cridland E, Cappetta K. (2016) *Understanding the factors that contribute to 'flexibility' in the provision of respite for people with dementia and their carers: A Literature Review*, Dementia Australia

- Where: The setting of respite care should be chosen in response to the consumer's needs and preference, and not constrained by it. Settings include; in-home respite, host home respite, day centres, outings and residential care.
- When: Respite needs to be responsive to the situation of the individual, this requires consideration to the time, frequency and duration of respite services.

The review also discussed the need for government and services to consider how policies and programs can support the uptake and delivery of flexible respite services. Dementia Australia recommends that flexible dementia specific or inclusive respite funding is prioritised in a new aged care system to enable the delivery of respite where and when it is needed.

A new system must also provide for more emergency respite options. There are very few dementia-specific or dementia-inclusive respite options available in the current system and they require investment. Indeed, people with a lived experience of dementia often report that, currently, many respite services will not accept people with dementia with any history of behavioural and psychological symptoms. Raising the foundational level of dementia skills across the aged care workforce will go some way to address this issue, but the sector also needs to be incentivised to develop flexible and responsive respite options for people living with dementia, their families and carers, rather than excluding them from accessing services on the basis of their diagnosis.

## Dementia enabling services

Dementia enabling principles must be incorporated throughout a new aged care system, and in particular in the investment stream, to ensure greater access to home modifications and assistive technologies that support people living with dementia. Access to technologies that can support independence, facilitate social engagement and community connectedness for both the person living with dementia and their family or carer can have a significant impact on maintaining independence and wellbeing.

More information about home modifications and adaptations is available on the Dementia Australia website at https://www.dementia.org.au/files/helpsheets/Helpsheet-Environment01_AdaptingYourHome_english.pdf

# Care stream

Dementia Australia is supportive of the philosophy of the proposed care stream – that care services are provided independent of setting. An effective care stream for people living with dementia, their families and carers is predicated on:

- Mandatory workforce education in dementia across all staff regardless of care setting;
- Care models that are supportive of people living with dementia;
- Greater engagement with people with dementia and their families/carers in a true partnership approach;
- The support of rigorous quality assurance and compliance.

With regard to funding options to underpin higher levels of care, current modelling is unduly influenced by the inability of the aged care system as a whole to effectively support people living with dementia. Financial modelling should be undertaken which is predicated on systemic culture, leadership and workforce shifts in relation to dementia, because service use and the entry-point for certain services may look very different in an environment in which dementia is understood, individualised capacity-building is normal and services are engaged in a proactive, planned way.

## Eligibility for care

As a starting point, a diagnosis of dementia could be a key eligibility criterion, since a person with dementia will inevitably have an escalation of care needs (although the pathway and timeframes will vary between each individual). However, eligibility should always be based on a comprehensive assessment of current and future need and include interventions to improve quality of life. Dementia Australia would be pleased to work with the Royal Commission and Government to chart the broad trajectory of people with dementia as service users and how and when they need to enter the care system – currently and in a new system.

Whilst the NDIS system has some merit, it should be noted that it is a work in progress and highly dependent on the capabilities and knowledge of those assessing. The National Disability Insurance Scheme (NDIS) concept of ‘reasonable and necessary’ can be open to interpretation, especially for people living with younger onset dementia, so its use is only as good as the definitions and the interpretation of these by assessors. A wholesale incorporation of the NDIS risks building in or perpetuating some of the barriers people with younger onset dementia face in the disability sector, such as disconnected care, inappropriate services, and under-skilled staff who do not understand dementia.

## Models of care to support people with dementia

The care needs of people with dementia will increase because of the progressive nature of the condition, so any system design needs to have people with dementia at the heart of its design principles. Quality dementia care, when it is embedded consistently across the sector, does not simply benefit those individuals living with dementia that access aged care services but all of those accessing aged care services. Improving the foundational level of dementia care (and the education, leadership structures and culture that underpin it) also delivers corollary benefits to governments, providers and staff working in the aged care sector in terms of their capacity and effectiveness to respond to the needs of people living with dementia, their families and carers.

For a care steam to appropriately support people living with dementia, the following must be considered:

- Cognitive needs are recognised early;
- Staff are trained in dementia and know how to escalate concerns to dementia specialists if necessary;
- Non-pharmacological approaches and diversional therapies are a first line of approach instead of physical and chemical restraints;
- Timely medication reviews are conducted and reflected in quality of care indicators;
- Care planning and reviews include the person living with dementia, their family and a multidisciplinary team.

As dementia progresses, many individuals will experience a number of physical and psychological comorbidities. Some of the additional care needs arise from decreased mobility and physical function, unexpected weight loss and nutritional concerns, poor oral health and, mental health concerns. The unpredictability of dementia and how it impacts individuals means that access to additional supports such as nutritionists, dentists, physical therapists and psychologists need to be readily available to ensure emerging needs are met. Timely access to these supports, regardless of whether a person is living at home or in residential aged care, is integral to maintaining an individual’s independence, wellbeing and prevention of further illnesses.

## The need for mandatory dementia training of care staff

Regardless of where care is provided, all staff must have dementia training. Dementia Australia strongly recommends that all staff working in aged care receive a minimum level of mandated dementia education. This needs to form part of any vocational or tertiary education before being able to work in aged care.

It is critical that all aged care services have an appropriately skilled workforce that is qualified to provide safe, high quality care for people with dementia. Over the past decade and more, there has been a trend towards employing less skilled (and lower cost) staff in the delivery of direct care services. This is impacting the quality of care for people with dementia, and has the potential to worsen in future if a comprehensive workforce strategy is not implemented as a matter of urgency. The fundamental importance of the workforce is echoed in Matter of Care report as well as the Royal Commission’s Interim Report. We need a strong and sustained focus on leadership and culture as well as practical initiatives that improve the knowledge, skills and capacity of the workforce in issues relating to dementia.

Care for people with dementia must be a core responsibility of the entire aged care workforce. A first step in ensuring all providers can deliver appropriate dementia care is to have clearly defined criteria and expectations of staff, and a program of training that supports the delivery of that criteria. To support the needs of people with dementia, training must therefore include:

- knowledge of dementia including developing a real empathy for the person living with dementia (and the carer, and the role they play in supporting a person with dementia);
- the delivery of person-centred care;
- strategies for communication and engagement;
- psychosocial approaches to addressing unmet needs (including alternative methods to physical and chemical restraint use);
- pain assessment and management (particularly as people with dementia may be unable to verbalise their needs);
- appropriate end-of-life and palliative care; and
- emotional intelligence and mindfulness.

Dementia Australia's workforce submission[9] provides further details and recommendations for how to improve the quality of the aged care workforce.

## Limiting the use of physical and chemical restraint

Workforce education and training in dementia will go some way to changing the way that physical and chemical restraint are used in relation to people living with dementia. But building the capacity of the workforce must be matched by a greater regulatory focus and leadership accountability, and focusing on the human rights of people with dementia must be a cornerstone of a new system.

### Physical restraint

The use of physical restraint in aged care facilities varies, with evidence suggesting prevalence rates ranging from 12% to 49%.[10] Physical restraint can result in a range of adverse psychological and physical outcomes. Adverse physical effects include an increased risk of falls from struggling to get free; the subsequent risk of serious injury caused by falls, such as head injury and trauma, [11]decreased mobility and weakening of muscles; and the development of pressure ulcers. Psychological impacts of being restrained include feelings of humiliation; loss of freedom or feeling 'trapped'; depression; withdrawal; and increased stress and agitation.[12]

It has been reported to Dementia Australia that, often in situations where consent is provided to use physical restraint, no alternatives to restraint are offered, and the family may feel obliged to provide consent for fear that the person with dementia may otherwise be asked to leave the service.

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[9] Dementia Australia (2019) *Workforce Submission to the Royal Commission into Aged Care Quality and Safety* available at https://www.dementia.org.au/files/submissions/DA-workforce-submission-to-royal-commission.pdf

[10] Peisah C. & Skladzien E. (2014) *The use of restraints and psychotropic medications in people with dementia*, Alzheimer's Australia Paper 38

[11] Evans, D., Wood, J. & Lambert, L. (2003) Patient injury and physical restraint: a systematic review, *Journal of Advanced Nursing*, 41(3): 274-282; Barnett, R., Stirling, C. & Pandyan (2012) A review of the scientific literature related to the adverse impact of physical restraint: gaining a clearer understanding of the physiological factors involved in cases of restraint related death, *Medicine Science and the Law*, 52: 137-142

[12] Castle, N. G. (2006) Mental health outcomes and physical restraint in nursing homes, *Administration and Policy in Mental Health*, 33: 696-704

All of this information demonstrates that foundational changes in workforce capacity, leadership and culture are imperative now, so that the use of restraint is minimised in a new aged care system.

### Chemical restraint

The overuse and inappropriate use of chemical restraint on people with dementia is all too common in residential aged care, with use in the home environment uncertain. It is estimated that just over half of people living in residential aged care are receiving antipsychotic medications and about 80% of those people have dementia.[13] International data suggests that only 20% of people with dementia derive any benefit from antipsychotic medications.[14] Australian clinical guidelines recommend that antipsychotics are only prescribed after non-pharmacologic approaches have been attempted; yet we continue to see the over-prescription of these drugs.

Antipsychotic medications have a range of serious side effects and are associated with an increased risk of stroke and mortality for people living with dementia. Despite overwhelming evidence that antipsychotics are not effective or safe, they are still being routinely prescribed and administered – against the best practice advice outlined in clinical guidelines – to people living with dementia, and often as the primary (not 'last resort') 'treatment' for 'managing' people with dementia.

The evidence for avoiding or minimising the use of chemical restraint is hardly new. The 2012 (then) Department of Health and Ageing's Decision-Making Tool to support a restraint free environment in residential aged care also states "the application of restraint, for ANY reason, is an imposition on an individual's rights and dignity and, in some cases, may subject the person to an increased risk of physical and/or psychological harm. The inappropriate use of restraint may constitute assault, battery, false imprisonment or negligence."[15]

The Royal Australian and New Zealand College of Psychiatrists Professional Practice Guideline on the use of antipsychotic medications as a treatment of behavioural and psychological symptoms of dementia state: "When prescription of a medication is being considered, informed consent is essential. Therefore, it is necessary that information about the risks and benefits of prescribing a medication to a person with dementia is conveyed to the person or their substitute decision maker, and that this is understood."[16] Carers often report to Dementia Australia that, when antipsychotics are prescribed for their loved one, they are either not informed at all or they are notified in a context in which the staff of the approved provider or the GP presents the administration of medication as the only option. GPs have anecdotally reported that they can be brought into an emergency situation without having a full background history or profile of the resident on which to make informed decisions about medication administration – and that they face pressure from providers to

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[13] Peisah C. & Skladzien E. (2014) *The use of restraints and psychotropic medications in people with dementia*, Alzheimer's Australia Paper 38

[14] *Ibid.*

[15] Australian Government (2012) *Decision-Making Tool: Supporting a restraint free environment in residential aged care*, Department of Health and Ageing

[16] The Royal Australian and New Zealand College of Psychiatrists (2016) *Professional Practice Guideline 10 - Antipsychotic medications as a treatment of behavioural and psychological symptoms of dementia* https://www.ranzcp.org/files/resources/college_statements/practice_guidelines/pg10-pdf.aspx

prescribe sedating medications. Residential aged care staff, on the other hand, have reported that they are just following the prescribing instructions of the GP or specialist.

There are missed opportunities for more a collaborative and informed decision-making process that includes families and carers (and people with dementia, where possible). The role of pharmacists also needs to be clarified in terms of initiating medication reviews and refilling ongoing repeat prescriptions of aged care residents. Quality and regulatory processes that support the minimisation of restraint, as well as support for the underpinning training and other mechanisms that are required to make this possible, must be an imperative in a new system for aged care.

A new system for aged care must have a focus on limiting the use of physical and chemical restraint on people with dementia. Key to this is increasing the capacity of the aged care workforce to use non-pharmacological approaches to support people living with dementia.

# Specialist and in reach services for people living with dementia

> *"I don't believe that the aged care and health systems work very well together at this stage. They are separate government bodies and rely on motivated individuals within each of the departments, but systems need to be more formalised to make them 'play together nicely'" - Person living with dementia*

Although dementia is particularly highlighted in the Royal Commission's consultation paper in the section on specialist and in reach services, it is important to preface Dementia Australia's comments with the position that dementia needs to become core business for all levels and parts of the aged care sector; and that to achieve this requires a fundamental shift in culture, leadership and workforce capacity to understand and support quality dementia care.

If this foundational shift is made, a new system of aged care services will still require some specialist dementia services, as well as palliative and end of life expertise, but the nature of these multidisciplinary, targeted interventions will be more proactive and less likely to be sought only at a time of crisis or acuity of need.

This may, then, change the requirements of the specialist service model required from what we currently have (e.g. Dementia Behaviour Management Advisory Service, Severe Behaviour Response Teams), because managing changed behaviours or clinical complexities of dementia will be managed differently by mainstream service providers.

## Specialist or in reach services

Given dementia often occurs in people with complex comorbidities, specialist and multidisciplinary in reach services are vital where there are:

- Complex symptoms of dementia and/or chronic disease (e.g. very severe BPSD);
- The need for multiple service providers to deliver comprehensive care and support (e.g. where someone has symptoms of dementia as well as a profound disability);
- Specialised end of life care;
- Lack of access to multiple care services (e.g. for people in remote communities);
- Cultural complexities where culturally safe/trusted relationships are important (e.g. for people from CALD backgrounds and from Aboriginal communities).

To effectively and efficiently deliver these targeted services, three components need to be in place:

1. Solid data on local health profiles: it is difficult to plan effective specialist or in reach services if the prevalence of dementia (and other co-morbidities) within particular communities and therefore the demand for specific services is unknown. Moreover, the planning and delivery of specialist services needs to keep pace with the increasing proportion of the population predicted to develop dementia and the care needs they may experience most acutely;
2. A specialist workforce with clinical, psychosocial and pharmacological expertise in dementia, quality dementia practices and translational research to whom people with complex care needs can be escalated; and, closely related to this;

3. A streamlined pathway (or series of pathways) that support timely access to specialist or in reach services when they are required, including complex care and palliative care. The development of these pathways should include reference to mainstream medical, health and disability services (where appropriate) and focus on multidisciplinary approaches.

## Palliative care for people living with dementia

Quality palliative care should be available to all people, regardless of where they receive aged care services and what condition they have. Currently, there is limited access to general palliative care services for people with dementia, with dementia-specific/specialist palliative care even rarer.

Access to quality palliative care, whether that be in an individual's home or in a residential aged care setting, is critical to ensuring people with dementia die well. It is therefore imperative that there are care staff who are appropriately skilled to deliver palliative care to people with dementia and across various care settings. Service redesign that is deliberately aimed at better coordination, integration and individually tailored palliative and end of life care is required to ensure people with dementia are able to access quality palliative care services and support during their end of life across the different care settings.

Under the National Health Reform Agreement, the Australian government is responsible for funding palliative care through general practice and residential aged care; the Australian government and State and Territory governments jointly fund palliative care through public hospital funding; while State and Territory governments are responsible for the delivery of specialist public palliative care services, including community palliative care, inpatient and outpatient services, and providing support to primary health care providers. To ensure the best possible outcomes for people with dementia, their families and carers, it is imperative that all levels of government and service providers focus on delivering person-centred models of care that overcome or minimise the policy and funding complexity created by multiple federal, state and territory systems.

Currently, there is a lack of dementia-specific palliative care services and the awareness that dementia is a terminal condition is lacking from the knowledge of many staff working in aged care.

A redesign of the aged care system needs to begin by addressing this limited understanding of palliative care for people with dementia.

Dementia Australia recommends that, in a new aged care system, there needs to be:

- Dementia-specific palliative care training provided to aged care staff;
- In-service or independent clinical nurse consultants who specialise in dementia palliative care;
- Improved options for appropriate palliative care for people with dementia across all settings – community or home based care, residential care, hospice care and acute care.

Importantly, planning for palliative care and end of life should begin at the point of diagnosis and early intervention, when people with dementia are more likely to have capacity to make decisions and express their wishes. If this happens, the process of good palliative care and a good death, regardless of the setting, can be done not only well, but respectfully to the individual's wishes.

## Responding to severe behaviours of dementia

The current ability of mainstream aged care services to appropriately manage the complex and unique needs of people with dementia, and in particular, behavioural and psychological symptoms of dementia (BPSD), is worryingly inconsistent. This is despite the fact that most people with dementia will experience BPSD at some stage during the course of their disease trajectory.[17] BPSD can include depression, anxiety, apathy, agitation, hallucinations, verbal and physical aggression, screaming, sexual disinhibition and other disinhibited behaviours.[18]

> *"Train all staff in dementia and dementia care, including all levels of accessing services from the aged care and health systems. i.e. in-home care as well as residential care. Treat each person living with dementia as a unique individual with their own specific background and life experiences and likes and dislikes." Person living with dementia*

The causes of BPSD are not always clear, but changes in behaviour may be triggered by biological, psychological, social or environmental factors. BPSD is not necessarily due to the pathology of dementia, but is largely an expression of emotion or unmet need that the person with dementia cannot otherwise express (such as pain, frustration, loneliness, confusion or fear).[19] These triggers are exacerbated in many ways by the environments of residential aged care homes and staff responses across a wide range of settings, from the home to hospitals and residential aged care.

Currently, both physical and chemical restraint are inappropriately used and overused, especially in residential aged care, as 'behaviour management' strategies. In a new aged care system, in which dementia truly is core business, all aged care staff (including non-care staff) would be equipped to more appropriately support people with dementia and implement non-pharmacological approaches to de-escalate responsive behaviours.

Consequently, we would see the use of restraint as it is intended: a very last resort. Where a person with dementia experiences very severe BPSD (which equates to a very small proportion of people with dementia, based on current data) requiring a more complex and multi-disciplinary response, this could be managed by specialist and/or in reach services tailored to severe BPSD and/or comorbid psychiatric conditions.

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[17] Best Practice Advocacy Centre, New Zealand (2008) *Antipsychotics in Dementia: Best Practice Guide*, Available at http://www.bpac.org.nz/a4d/resources/docs/bpac_A4D_best_practice_guide.pdf

[18] Brodaty, H, Draper, BM, Low, L. (2003) Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery, *Medical Journal of Australia*, 178: 231-234

[19] Algase, D., et al. (1996) Need-driven dementia-compromised behaviour: An alternative view of disruptive behaviour, *American Journal of Alzheimer's Disease & Other Dementias*, 11(6): 10-19

# Designing for diversity

Dementia Australia supports the Royal Commission's position that diversity needs to be integrated into core business and not added as an afterthought in aged care program design. People living with dementia, their families and carers experience many challenges in the current aged care system; for people from diverse backgrounds, these challenges are further compounded and make access to services even more complex.

If the capacity of the sector is able at the outset to support people living with dementia (via culture, workforce and leadership improvements, the nature and importance of which has been articulated throughout this submission), individualised, person-centred approaches will already be a part of a refreshed aged care system. However, this does not mean that the system will be able to support all of the needs of people from diverse backgrounds.

Differentiated or additional funding (whether block funded or through some other model) should be considered for language and resource support, additional workforce capacity-building, the implementation of specific or specialist services in thin or hard-to-reach markets, and technology innovations to connect people with a wide range of services. Efforts must also be made to train and maintain qualified and skilled staff in regional and rural areas. Service providers who identify their ability to support the needs of diverse communities must be able to demonstrate how they can achieve quality care and their stated capacity should inform quality regulation and assessment.

## Supporting people with dementia from culturally diverse backgrounds

People from culturally and linguistically diverse (CALD) backgrounds, for example, are likely to experience difficulties in accessing and navigating the aged care system without language-specific support; and their ability to receive appropriate supports and services must not be reliant on English literacy. Instead, any new system must facilitate access to interpreters and the availability of information in other languages. In the case of people living with dementia, some cultural perspectives about the disease may create additional stigma and misunderstanding, so broader awareness campaigns tackling dementia discrimination will be vital in the uptake and availability of aged care services.

Time and again, Dementia Australia hears about the importance of culturally safe and appropriate services being paramount to ensure people with dementia from diverse backgrounds are supported and included. In addition to specific services (e.g. ethno-specific services, the demand for which needs to be supported by robust population data that not only understands diversity but the impact of diverse needs on dementia), a new aged care system needs to build the capacity of mainstream aged care services through partnerships with communities.

It is important that government, regulators and providers work with diverse communities to ensure their unique needs are identified and met, and that information is received in a way that is accessible and appropriate to them. This is particularly the case for CALD and Indigenous communities where language, imagery and storytelling can play a key role in how well information is received and absorbed.

Through our Centre for Dementia Learning, Dementia Australia has developed a specific program for Aboriginal health workers to improve their understanding of the various screening tools for cognitive impairment and we also deliver programs to Aboriginal workers in rural and remote communities. The focus on improving the understanding of dementia more broadly and quality dementia care, particularly, needs to be a key component of the education of those workers in culturally specific service provision as well as those working in regional and remote services. Of particular importance in Indigenous communities (and regional/remote communities) is the need also educate the broader community about dementia: this is especially important when access to services is limited and many people living with dementia are cared for by their community.

## Access to aged care in regional and remote areas

People living with dementia, their families and carers living in regional and rural areas currently experience difficulties in accessing appropriate aged care services due to geographic isolation, travel distances, and limited resources. Without a specific focus on building access and capacity in regional and remote locations, there is a risk that a new aged care system will perpetuate these challenges and isolation for people with a lived experience of dementia.

Although technology can play an effective role in reaching people in rural and remote areas, it is not always the ideal situation. For example, people with dementia, families and carers have reported to Dementia Australia that they have received their dementia diagnosis via telehealth but have not felt supported by the health practitioner in what occurs after the diagnosis. Technology may be an effective communication tool, therefore, but if a pathway to supports that help an individual connect to others, process their diagnosis and maintain or maximise their autonomy and independence is absent, the technological intervention is de-valued.

Access to transport that enables participation and inclusion in community aged care programs is also essential. Driving cessation due to dementia marks a considerable change for someone with dementia and if alternative modes of transport are not available, social isolation will be more acute. Social support programs that include linked transport are particularly important for people living with dementia in regional and remote Australia.

Despite these and other limitations, people with dementia, their families and carers generally do not want to move from their local communities in order to have greater access to services. The challenge, then, is to design and deliver services that are flexible, innovative, locally appropriate and culturally safe to ensure people with dementia and carers are well supported through all stages of dementia.

There is a need to build, on an ongoing basis, the capacity of the system to respond to what people with dementia, families and carers want in regional, rural and remote locations, as well as the capacity of multidisciplinary health professionals and care staff to support and care for people with dementia.

# Financing a new aged care system

Insufficient funding and resources has been a key concern in the aged care sector for many years, most recently highlighted through the Royal Commission as one of the key issues associated with the variability of the delivery of quality aged care.

> *"It is quite obvious that part of the problem with the system is the lack of funding, staff shortages in residential care, lack of packages for home care and the low level of dementia training in all areas. A serious change of attitude towards our aged care system is needed at all levels." Carer*

As the Australian population ages and the prevalence of dementia increases, greater Government investment in the aged care system is paramount. It is critical that funding models are aligned to a person-focused and holistic model of care for everyone in the aged care system that supports cognitive, clinical and functional health as well as cultural needs and living well aspirations.

Dementia Australia recommends a financing approach in which there are two funding phases by government:

1. A finite period of transition funding to build the capacity of the sector and adapt to a new system of aged care; and

2. Funding models that stimulate innovation and also subsidise care services in a new aged care system.

## Transition funding

In the first phase, funding would be targeted to support the sector to ensure transition to a new system is possible. These funding pools would focus on specific capacity-building elements, such as empowering leadership (and making leaders accountable), up-skilling the workforce (especially in foundational dementia education, person-centred care principles and communication strategies) and developing more comprehensive consumer-engagement mechanisms. Funding for the capital upgrade of aged care infrastructure is also important, especially in facilitating a transition to more dementia-friendly, inclusive design principles.

Without this initial investment in capacity-building and culture-shifting, future funding models in aged care will continue to perpetuate the inequity and lack of quality aged care services that many people living with dementia, their families and carers already face.

## Funding in the future

Funding models in a new aged care system first and foremost need to ensure equitable access to services and recognise that people who can contribute to the cost of their care and accommodation should do so. The rules that apply to this system must also be transparent and equitable across care streams.

Arguably, targeted block funding for thin markets will also be required, though further consideration of how to define thin markets and determine their applicability should be undertaken, much as the National Disability Insurance Scheme has done. If the foundational capacity of the sector to support dementia is improved through transition activities, for instance, dementia-specific services may be part of a ‘thin market’ approach but services may only need to be limited to highly specialised services addressing complex needs.

Consulting with the aged care sector to ascertain the true costs of delivering quality care should be central to developing a new aged care system, and will help ensure funding models (regardless of whether they are consumer-pays or subsidies) can sustainably allocate sufficient funding to deliver high quality care.

The sustainability of a new aged care system must also be underpinned by a focus on financial sustainability along with clearly defined fiscal roles and responsibilities. It is imperative that government, the aged care sector and consumers work together to build a cohesive, sustainable aged care system that consumers want and that is viable for providers; can maintain workforce and service quality; provides the choice that consumers are seeking; and takes into account affordability for taxpayers and consumers. Key elements to consider are:

- Equity and consistency in the approach to client/resident contributions across care settings;
- Transparency around fees and charges payable by consumers, including those living with dementia;
- The models of funding that underpin home care and residential aged care, and their appropriateness for ensuring the care needs of people with dementia are adequately addressed;
- A review of the modelling, viability and application of dementia-specific supplements across all forms of care (given that we currently do not know the impact of supplements in home care and whether they improve the quality of care provided to people living with dementia in the home setting);
- Funding to organisations to provide services that is tied to evidence of quality care and provider accountability.

## Building on what we have

The outcome of current reviews and pilots of new funding arrangements must also be considered in the development of a new aged care system as it pertains to people living with dementia. For example, the principles of the Australian National Aged Care Classification (AN-ACC) are sound but it remains to be seen how this model will improve the quality of care provided to people living with dementia. Overall, Dementia Australia has been supportive of the developing AN-ACC model, which applies a branching classification model that considers the mix of variables that reflects both general and individualised costs of care. We also welcome the separation of funding classification from service providers: independent assessment workforces should ensure funding classifications are entirely driven by the individual and their level of need.

Dementia Australia has some concerns that the AN-ACC model – which is based on current care standards and practices (which have shown not to suit a large number of people with dementia) – will not facilitate the delivery of a high quality of dementia care. It is important that the variable cost per resident is also sufficient to deliver person-centred care. For example, the added cost of offering individualised social and emotional supports to residents needs to be modelled and offset against the potential decrease in complex clinical care needs that currently stem from unrecognised pain, unmet emotional needs or clinical responses to changed behaviours.

Similarly, the current and previous reviews of the Aged Care Approvals Rounds (ACAR) will also provide useful insight into the design of a new aged care system and the funding models that underpin it. Although the current ACAR model requires residential aged care services to be operated by approved providers (which are subject to accreditation, regulatory and monitoring processes), the model does seem to enable poorer quality providers to enter the market and operate, as well as remain financially viable/operational – and market mechanisms are not strong enough to drive quality or genuine competition – especially as it relates to people with dementia.

As demonstrated through the Royal Commission, as well as numerous Government inquiries into the aged care sector over recent years, poor quality dementia care can be delivered by approved providers who are able to operate, in part, as a result of their success in the ACARs. Approved providers who state that they are able to deliver quality dementia care in their applications do not always put this into practice and people with dementia often receive inappropriate and/or substandard care from staff who do not understand the complexity of dementia, how to engage clients/residents with dementia or respond appropriately to the expression of unmet needs of clients/residents. Even service providers who claim to be dementia-specific do not necessarily provide quality dementia care on a consistent basis because there are no specific requirements around staff education, person-centred care or (where applicable) the built form.

A review of home care package arrangements is needed to ascertain what level of support people actually need to remain living in their own home for as long as possible, particularly when they are living with the symptoms of cognitive impairment. Packages currently do not deliver the breadth of supports that are required for people living with dementia and their families and carers to live at home, particularly in the later stages of dementia, and it is unclear whether this is down to provider capacity, funding capacity, or both.

To ensure equitable access aged care services for people with dementia, the following principles need to be considered:

- Equity and consistency in the approach to consumer contributions across care settings;
- Transparency around fees and charges payable by consumers;
- The link between funding and assessment, accreditation and quality performance;
- Exploration of specific funding components/requirements to determine whether they need to be tied to a diagnosis of dementia;
- Funding models that focus on building capacity as well as exploring innovation.

Funding for aged care should be contingent on providing care that is of high quality, person-centred and responsive to the clinical, social and emotional needs of all consumers, regardless of their location, background or care needs. Approved providers must be able to demonstrate how funding will be used to deliver quality care for people living with dementia, where their client/resident profile expects it (which should be all providers if dementia is core business for the sector).

> *“No amount of tinkering with the current system will result in the quality care that is required without a significant increase in government resourcing. The provisions of the current act are now very dated and along with the productivity commission findings in 2012 reflect a time gone by when folk in aged care facilities were much more capable and easier to look after. Demographics now are such that residents are considerably more frail and an increasingly large percentage have dementia. I acknowledge that acuity provisions and extra government funding for same seeks to address the situation but in reality such only tinkers around the edges. Also, it encourages ‘gaming’ by the industry…If the required significant increase in federal government funding is not provided now it will result in hugely increased amounts necessary in the future as demand escalates. The funding is there. It just requires adjustment to government priorities.” Carer*

Further modelling and investigation of how a new aged care system would operate in a fiscal context is required, and people with a lived experience of dementia should be involved in modelling and testing assumptions.

Dementia Australia welcomes further opportunities to discuss the issues raised here further and support people with dementia and carers to participate in consultations to ensure that funding arrangements and models facilitate the consistent delivery of quality dementia care.

# Quality regulation

The Royal Commission has demonstrated that there has been a system-wide failure to engage in quality improvement to the level and consistency that consumers – including people living with dementia, their families and carers – expect and to which they are entitled. A new system must ensure that regulations and quality improvement mechanisms are a priority to ensure the safety and wellbeing of older people, especially those with increased vulnerability, including people living with dementia. Greater transparency, comparability and accountability are critical to mitigating some of the issues experienced in the current system.

Dementia Australia argues that, in a system in which dementia is practically supported as part of core business, regulation and quality management will go a long way to assuring the community that the services they receive are of a high standard of quality and safety. Much of the way in which people living with dementia, their families and carers describe quality dementia care hinges on person-centred approaches and well-educated, empathetic workers: quality regulation must therefore focus on these elements, regardless of the level of service being received.

## Regulation that protects people living with dementia

The consistent realisation of person-centred care principles into all elements of aged care practice will go some way to ensuring quality regulation provides the kind of consumer protection required. It may also provide the level of consistency that means different regulatory approaches, based on the nature of the service being delivered, is appropriate.

However, it is vital that quality regulation is based on client/consumer profile rather than simply just provider capacity. While Dementia Australia does not recommend the application of separate, distinct dementia-specific standards or quality regulation for a new aged care system, we do recommend that key criteria/measures/indicators are built into quality regulation to ensure that the unique needs of people living with dementia are addressed in a systematic way.

For example, if an applicant identifies their ability to address the needs of people living with dementia in an application to become an approved provider, that applicant must demonstrate that their workforce has foundational and specialist dementia education and qualifications (and that their environment reflects dementia-inclusive design principles if it is a residential aged care application).

The approved provider's subsequent quality audits must be assessed against their ongoing ability to support people living with dementia through evidence of their ongoing management of staff skills and continuing education, their demonstrated ability to work with people living with dementia, families and carers to identify preferences, needs and wishes (irrespective of care setting), their evidence of dementia friendly environmental design (where they are delivering residential aged care), and their adherence to performance measures that are transparent, comparable and publicly available.

## Proactive and protective quality regulation

Quality regulation must be proactive and preventive. While a reactive response to the reporting of complaints has a necessary and legitimate function in any monitoring regime, systemic issues require a proactive and preventive approach from quality regulation that does not rely upon vulnerable older people to identify, articulate and progress a complaint in circumstances in which they are likely subject to a significant power imbalance.

In the case of people living with dementia, proactive quality regulation must be able to mitigate some of the challenges that someone with a cognitive impairment can face: a declining ability to make informed choices or exercise their right to complain; their ability to communicate about their care experiences; their vulnerability to poor practice. This might be achieved, for example, by regular check-ins by quality regulators whose quality assurance frameworks are influenced or scaled according to client/resident profiles; it may be addressed through 'front-end' quality regulation that gains an understanding of a person's wishes and preferences while they are able to articulate them and monitors the impact of a service to honour those wishes.

Complaints mechanisms must demonstrate evidence of the way they are able to address the needs of people living with dementia, particularly as their cognitive impairment makes it difficult or impossible for people experiencing unsatisfactory service or even abuse to report their experiences through the appropriate channels and, in many instances, to be in a position to provide irrefutable evidence in the instances of abuse.

## Consumer engagement at the heart of quality regulation

It is important to involve consumers at the organisational governance level, to drive real improvement in quality assessment and compliance processes.[20] People living with dementia, their families and carers are the experts in what is like to be impacted by dementia and receive support through the aged care system. They should be actively and consistently included in regulatory reviews and accreditation processes.

At Dementia Australia, we operate the Dementia Australia Advocates Program and the Dementia Australia Advisory Committee, which involve people with a lived experience in policy, strategy and advocacy activities and decisions within the organisation. In a new aged care system, the inclusion of people with dementia and their carers should be common practice, not an example of how things might be done.

Dementia Australia would welcome discussions with the Commissioners about how the aged care sector could consult and engage with people living with dementia and carers to develop, improve, and monitor their services. We acknowledge the work already being done by regulators like the Aged Care Quality and Safety Commission in this space.

## Transparency, comparability and accountability

An essential driver of quality improvement is transparent, comparable indicators that empower people to have informed conversations and make informed choices. People with dementia, their families and carers want to have clear information about the quality of services being offered and the impact of those services on quality of life.

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[20] Dementia Australia (2018) *Submission to the Inquiry into the Quality of Care in Residential Aged Care Facilities in Australia*, Available at https://www.dementia.org.au/files/submissions/Inquiry-quality-RAC.pdf

A new aged care system needs to be underpinned by clearly articulated information on providers, including performance indicators, policies with regards to restraints, medications and continuous improvement frameworks, and details on staff training and skills mix.

Without this information there is no meaningful way for individuals, families and carers to distinguish between providers and ultimately make informed, empowered decisions. Increasing transparency of providers not only helps individuals to find the support they need, in a more simplified and logical way, it also provides an incentive for providers to focus on the quality of their service delivery.

# Conclusion

Dementia Australia commends the Royal Commission for the aged care system redesign proposed in the consultation paper. In any new system for aged care, it is imperative that the needs of people living with dementia, their families and carers are comprehensively recognised, addressed and supported.

For any new aged care system to succeed, it must be predicated on a fundamental shift in culture, workforce and attitudes to people living with dementia. The ability of the aged care sector to deliver quality dementia care as part of core business must be improved. As we have stated, to do so requires, at a minimum:

- Mandatory dementia education and skills development for the aged care workforce;
- Professional development opportunities for staff to enable a rewarding career in dementia care;
- A quality regulation framework that enforces the delivery of quality dementia care and has clear consequences if this is not achieved;
- Transparency in care outcomes and consumer experiences of care with accessible data about aged care services publicly available.

Only once these foundational components of aged care have been improved will we see an aged care sector that is able to adequately support people living with dementia, their families and carers.

We welcome further discussions with Commissioners about our submission and how the aged care system must change to improve the accessibility and quality of care to people impacted by dementia in the future. In particular, we would welcome the opportunity to facilitate the inclusion of people with dementia and carers in these discussions to ensure the voice of those directly impacted is heard.