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## **Royal Commission into Aged Care Quality and Safety**

### **Aged care system governance, market management, and roles and responsibilities**

**Dementia Australia**

**July 2020**

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## 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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## Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Royal Commission into Aged Care Quality and Safety (the Royal Commission) on system governance, market management, and roles and responsibilities in the Australian aged care system.

As we have argued in our previous submissions to the Royal Commission, a series of foundational shifts in leadership, culture and workforce capacity in the aged care sector are required to guarantee that people living with dementia receive quality care in a system that understands dementia as its core business. This capacity building work must underpin the design of a new aged care system – a system designed for people living with dementia, who are some of the most vulnerable people in our society, will benefit everyone.

Our submission focuses on the systemic arrangements necessary to ensure that quality care is provided to the growing number of people living with dementia, as well as the ways in which the aged care sector needs to adapt and mature for the rhetoric of dementia as core business to be realised.

## Market management and governance

While Dementia Australia does not have a specific recommendation around whether current or modified governance structures ought to be responsible for mandating and monitoring aged care, it is clear that the sector is not sufficiently developed for market forces to drive quality and innovation (or even compliance, in some cases).

Indeed, Dementia Australia's position is that market forces should not be relied upon for an industry that is still as compliance driven and immature as aged care, and especially not for dementia services. There is neither the transparency and comparability, nor the expertise in dementia care to ensure a true, market-driven system would work for people impacted by dementia.

In this context, strengthened compliance processes, especially around the dementia 'credentials' of a service, need to be considered – and we acknowledge that this goes hand in glove with financing and funding models to ensure that consumers, service providers and the sector more broadly understand what is being funded and by whom.

The quality systems put in place by the Aged Care Quality and Safety Commission should not be undervalued, but unless there are some key compliance changes around workforce education, physical environment (where applicable) and systemic leadership (including board accountability), the impact on people living with dementia, their families and carers may be minimal.

## Regional, rural and remote services

People living with dementia in regional, rural and remote areas deserve to have equitable access to services and be supported to remain living in these areas as dementia progresses. 'Ageing in place' for people with dementia in regional, rural, and especially remote areas is an admirable, but not always achievable, goal within the current system. We too often hear reports of people living with dementia having to move from their community to receive the aged care services that they need.

*"I find that carers stop looking for services. So many barriers are put up in trying to access any community service that people often throw their hands in the air and say it is all too hard and do without. They and the person with dementia become more isolated." Carer*

There are many communities that do not have quality services with appropriately trained staff to meet their care needs within the local area, making long distance travel unavoidable to access quality care. A major issue is the lack of choice – there is often only one provider, which in small remote communities, delivers all disability and aged care services. The ability of such services to support someone with advanced symptoms of dementia can be limited, resulting in people with more complex manifestations of cognitive decline being accommodated in hospital settings for lengthy – or even indefinite – periods.

In a designing a new aged care system, consideration must be given more flexible funding and service delivery arrangements for people living with dementia, their families and carers in regional, rural and remote communities. The workforce capacity must also be increased, and collaboration between the aged care sector, Primary Health Networks (PHNs), local health services and people who are impacted by dementia is required to understand and respond to the needs of people living with dementia, their families and carers.

## Building workforce capacity in dementia

Dementia Australia argues that the capacity of the aged care workforce to appropriately support people living with dementia, their families and carers is so intrinsic to aged care service provision – and so inadequate at a systemic level currently – that it deserves specific and strong attention. Care for people with dementia must be a core responsibility of the entire aged care workforce.

A first step to ensure 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. 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.

*"Consistent and knowledgeable staff improves my wellbeing and makes me feel safe." Person living with dementia*

Our submission to the Royal Commission on workforce and our response to Counsel Assisting's submissions on workforce provide further detail on how to build the dementia capacity of the aged care workforce.

## Interaction with other service systems

People with dementia are required to navigate their way through multiple care systems as their dementia progresses. This is especially so for people living with younger onset dementia. Although people living with younger onset dementia are generally eligible to access the National Disability Insurance Scheme (NDIS), due to the progressive nature of their condition and need for increasing supports – which may not be available in the disability system – many people with younger onset dementia also require support from aged care services. As such, people with younger onset dementia are typically required to straddle both the aged care and disability systems – neither of which is fully equipped to respond to the needs of people with younger onset dementia.

In addition to the NDIS and aged care systems, the interface with the health system can be challenging for people with dementia, their families and carers. Broadly, the health system has a limited understanding of dementia and it is critical that acute, primary and allied health staff are trained to respond appropriately to patients living with dementia.

*“The emergency department environment has to change. You have bright lights, noise, lots of people shoving things onto and into your arms...My dad went in with a psychosis so he had security guards sitting on top of him.” Carer*

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.

Navigating three separate complex and confusing systems (disability, aged care and health care) compounds the stress and overwhelm experienced by people living with dementia, their families and carers. Greater collaboration, communication and information sharing is vital to create streamlined processes and pathways for people with dementia to access the services they need, in systems that understand their condition. Ultimately, Dementia Australia advocates for more comprehensive and coordinated support for people with dementia, their families and carers to ensure that they receive the most appropriate support and care, regardless of which system/s provides it. In developing a new aged care system, how the system interfaces with other human services systems must be considered.

## Supporting quality improvement and innovation

The Royal Commission has demonstrated that there has been a system-wide failure to effectively engage in quality improvement. A new system must ensure that regulations and quality improvement mechanisms are a priority to ensure the safety and wellbeing of older people, especially people living with dementia.

To ensure the provision of quality dementia care, regulation of aged care providers must include providing funding contingent upon demonstrated capacity in dementia care, staff qualifications and ongoing professional development.

*“If you can get it right for dementia, you can get it right for everyone else.”* Person living with dementia

Although 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 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.

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.

Another 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.

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.

Much of the criticism directed at current regulation and monitoring of the aged care sector, is that the system encourages providers to focus on compliance to the detriment of innovation. Some of the move away from compliance to innovation and choice is dependent on system transparency and the ability for consumers to compare like for like. However, the aged care sector needs to address the systemic cultural barriers to innovation including:

- poor leadership amongst aged care providers;
- poor/limited application of research knowledge into dementia care practice;
- prescriptive funding opportunities that do not stimulate innovation;
- a focus on outputs rather than outcomes; and
- risk averse cultures that limit opportunities for growth and change.

Support for innovation in delivering quality dementia care is imperative. Funding should be contingent on enabling people living with dementia, rather than the current perverse incentives whereby funding increases with increasing frailty, incapacity and dependency.

*“In my experience, leaders often lack understanding of what it means to deliver high quality aged care...Leaders need to show empathy and understand what the needs are for people living with dementia.” Carer*

Finally, and importantly, 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 governance processes such as regulatory reviews and accreditation processes. In a new aged care system, the inclusion of people with dementia and their carers should be common practice.

## Conclusion

Dementia Australia agrees with Royal Commission's view that establishing clear roles and capabilities of those responsible for the aged care system is essential to ensuring quality and safe aged care. This is especially so for ensuring quality dementia care and realising dementia as core business of the aged care sector.

Dementia Australia believes that in order for quality dementia care to become core business of the aged care sector, specific governance mechanisms are required to drive this change, including:

- Market management processes and flexible funding arrangements to ensure people living with dementia, their families and carers are able to access services when and where they need them;
- Increased dementia capability of the aged care workforce (including mandatory dementia training for all aged care staff);
- Streamlined interactions between aged care and other service systems such as disability and health;
- Sector transparency and publicly available dementia credentials of providers to enable consumers to compare and make informed choices about their care;
- Systemic leadership and regulation that supports innovation; and
- Meaningful consumer engagement and inclusion of people living with dementia in governance processes.

Dementia Australia would welcome discussions with the Royal Commission on these important issues to ensure that systemic governance arrangements enable quality aged care and support for people impacted by dementia.