



**Dementia
Australia®**

A new model for regulating aged care – consultation paper 2

Dementia Australia Submission

23 June 2023

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Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in Australia.

Our organisation engages with people with dementia, their families and carers in our activities, planning, policy and decision-making, ensuring we capture the diversity of the living experience of dementia across Australia.

Our advocacy amplifies the voices of people living with dementia by sharing their stories and helping inform and inspire others. As the trusted source of information, education and support services, we advocate for positive change for people living with dementia, their families and carers, and support vital research across a range of dementia-related fields.

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Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of complex neurocognitive conditions which cause progressive decline in a person's functioning.

Dementia is not just memory loss - symptoms can also include 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 one of the largest health and social challenges facing Australia and the world. In 2023, it is estimated there are more than 400,000 people living with all forms of dementia in Australia. This number will continue to grow to more than 800,000 by 2058¹.

In February this year, the Australian Institute of Health and Welfare released data showing dementia is now the leading cause of disease burden among Australians aged 65 and over. Dementia is the second leading cause of death for Australians and the leading cause of death of women².

¹ AIHW (2023) *Dementia in Australia*. <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

² AIHW (2023) *Dementia in Australia, Summary, Impact* <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

Introduction

Dementia Australia appreciates the opportunity to provide input into the development of the new model for regulation of the aged care sector. We support the strengthening of the regulatory framework for aged care with a person-centred, rights-based approach.

We note that it is important to continue to involve people with living experience of dementia in the reform process and genuinely engage them, especially those with experience of aged care systems. This also applies to future work associated with the regulatory reform, such as the definition of high-quality care in the Aged Care Act, development of a Statement of Rights and work to develop a supported decision-making model.

Dementia Australia recommends that consultation with people living with dementia aligns with [Half the Story: A guide to meaningful consultation with people living with dementia, families and carers.](#)

Rather than respond to all questions, we have chosen to focus our response on three key components of a strong regulatory system for quality aged care in Australia:

- The understanding that quality dementia care is an intrinsic, core element of quality aged care.
- A core registration condition requiring compulsory dementia education for the workforce in all parts of the aged care sector, including all services delivered in people's homes.
- Complaints mechanisms and protections that are appropriate for people with dementia, their families, carers and advocates.

Importantly, the regulatory system should be future focussed, ensuring that standards and obligations can manage quality and risks in a changing aged care system, including an increase in the proportion of older people choosing to receive care at home, and new home support models in Australia.

The final report of the Royal Commission into Aged Care Quality and Safety reinforced that:

“training about the nature and effects of dementia and how best to care for the increasing number of Australians living with dementia is essential to the provision of quality and safe care”³.

It now remains to embed dementia education into all aspects of the aged care regulatory and compliance system. Dementia must be core business in aged care. In the words of a person living with dementia: “if we can get it right for people living with dementia, we can get it right for everyone”.

³ Royal Commission into Aged Care Quality and Safety, Final Report – Care, Dignity and Respect: Volume 4A.

Response to consultation questions

Raising the quality of aged care

Questions

1. What regulatory interventions are needed to raise the quality of aged care?’
2. To raise the quality of care, what role should government and nongovernment stakeholders play? These include:
 - the Regulator and the Department
 - providers, workers, professional associations, advocacy groups,
 - unions, volunteers, and community groups
 - older people and their representatives
3. Culture change is key to raising the quality of aged care. Who can be the culture change champions, either at the local or the sector level? What support will they need to champion culture change?

Dementia Australia’s response

It is important to note that people with dementia account for at least two thirds of aged care residents in Australia⁴, and this is likely underestimated.

The prevalence of dementia in aged care underpins Dementia Australia’s position that the regulatory system must be highly attuned to achieving quality dementia care, to ensure that people living with dementia are safe, supported and empowered in all care environments.

The new regulatory system needs to contain mechanisms which ensure that quality dementia care is embedded across all aged care environments.

This applies to all parts of the aged care sector, including all services delivered in the home. Around 1 million Australians currently receive in home aged care services⁵. Most Australians prefer to remain living at home as they age, and the demand for home support services is predicted to increase as more people choose to receive care at home⁶. This is reflected in the Australian Government’s 2023 budget measures, which plan for a lower volume of residential aged care packages in forward estimates⁷.

⁴ National Institute of Labour Studies (2017) The Aged Care Workforce, March 2016.

⁵ Australian Government Department of Health January 2022 [Support at Home Program Overview](#).

⁶ Ratcliffe J. et al (2020) [Australia’s aged care system: assessing the views and preferences of the general public for quality of care and future funding](#). Caring Futures Institute, Flinders University, South Australia.

⁷ <https://www.abc.net.au/news/2023-05-11/budget-aged-care-measures-and-home-care/102328544>

Simultaneously, the number of people living with dementia in Australia is growing⁸, and there continue to be low levels of community awareness of dementia and its impacts⁹.

In the current aged care system, the quality of care provided to those living with dementia can vary significantly. The Royal Commission into Aged Care Quality and Safety found that:

“Substandard dementia care was a persistent theme in our inquiry. We are deeply concerned that so many aged care providers do not seem to have the skills and capacity required to care adequately for people living with dementia”¹⁰

Quality dementia care encompasses:

- Understanding diversity and maintaining identity through relationships.
- Involving carers and advocates as vital partners in care.
- Flexibility in provision of care, how and when services are received.
- Including people in the community, in meaningful activities and in decision-making.
- Providing a community and home-like design, look and feel.
- Feedback and complaints being taken seriously.
- Having staff trained in dementia with ongoing mentoring.
- Leadership and culture that understands the impact of dementia¹¹.

People living with dementia, their families and carers report that effective leadership underpins the delivery of high-quality dementia care and impacts their personal wellbeing and quality of life¹². Effective leadership creates a culture which enables and motivates staff to deliver high-quality, person-centred care in an environment of mentoring and continuous improvement.

Leadership and staff education should be considered a critical enabler to the delivery of high-quality dementia care. Leadership should be proactive in implementing learning plans for staff and creating clear career pathways to enable staff to specialise in key areas, such as dementia care.

At a systemic level, embedding the principles of quality dementia care into regulatory requirements can drive improvements in practice and culture.

⁸ AIHW (2023) *Dementia in Australia*. <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>.

⁹ Cations, M. et al (2018) [What does the general public understand about prevention and treatment of dementia?](#) A systematic review of population-based surveys. Plos One. April 19, 2018.

¹⁰ Royal Commission into Aged Care Quality and Safety (2021). A Summary of the Final Report, Retrieved from Final Report - Executive Summary, Royal Commission into Aged Care Quality and Safety.

¹¹ Dementia Australia, 2019. [Our Solution: Quality Care for people living with dementia](#).

¹² Dementia Australia (2021) [Leadership and Cultural Change](#).

Supporting quality care

Questions

1. What are your views on the proposed approach to supporting quality care?
2. What challenges can you identify for implementing the proposed approach to engagement and capability building? What could be the solutions?
3. How else could provider capability be improved in aged care at the individual provider and sector wide levels?
4. What types of education or engagement do you think would support providers to continuously improve?
5. How could the Regulator, the Department and providers improve the provision of information to older people and their representatives so that they have access to the right information, at the right time, in the right way?

Dementia Australia's response

Dementia Australia's view is that providers in all categories should be required to undertake compulsory dementia education as a core registration condition.

This is consistent with Recommendation 80 of the Royal Commission into Aged Care Quality and Safety, that:

By 1 July 2022, the Australian Government should implement **as a condition of approval of aged care providers**, that **all workers** engaged by providers who are involved **in direct contact** with people seeking or receiving services in the aged care system **undertake regular training about dementia care** and palliative care" (our emphasis)¹³.

It is clear that improving the quality of aged care means building genuine capability for quality dementia care in all parts of the sector. Quality dementia care requires a workforce with, at a minimum:

- Knowledge, skills and empathy.
- An understanding of dementia and its impacts.
- The ability to communicate effectively with people living with dementia.
- The capability to provide dementia-specific risk assessment.
- The capacity to safely respond to changed behaviours of dementia.

¹³ Royal Commission into Aged Care Quality and Safety. Final Report, page 262.

Home care supports

An estimated 67% of people with dementia live in the community¹⁴. This will likely increase as more Australians want to remain living in their home in their older age¹⁵. The new regulatory system needs to reflect this evolving community expectation and ensure that home care supports at all levels are high quality for people living with dementia, through registration conditions and compliance monitoring.

While a risk-proportionate regulatory model is appropriate, Dementia Australia believes that the risks associated with the delivery of any nature of supports in the home to people living with dementia are significant. This may be particularly the case where people are socially isolated, have little family support, have difficulty with communication or their needs change rapidly.

All workers providing services in a home environment need additional training to develop the knowledge and skills to support people living with dementia. As with any service, home care services for a person living with dementia should be collaboratively planned and customised to their choices. Care workers and service providers need to understand the impacts of dementia and risk factors, in order to develop appropriate person-centred supports.

Risks for people living with dementia are different to the risks for people without dementia. Additional risk factors can relate to changing behaviour, confusion, becoming lost, functional decline or design of the home environment.

The Royal Commission into Aged Care Safety and Quality noted in their Final Report that:

“It is hard to justify the lack of oversight of allegations of abuse and neglect in home settings. The need for oversight of serious incidents in home settings will increase as more people receive aged care in their homes for longer. People receiving aged care at home will also most likely have increased levels of frailty, cognitive impairment or both. Frailty is directly linked to vulnerability”¹⁶.

An appropriate strategy to address this concern is that all providers be required through core registration conditions to ensure that their staff receive appropriate dementia education specific to their role, with compliance monitored and enforced and opportunities for continuous improvement. It is critical that training is not just a ‘tick the box’ exercise, but that aged care workers and services have access to ongoing mentoring and opportunities to develop quality dementia practice.

Residential aged care

Dementia education leads to a reduction in high-risk incidents, lower rates of inappropriate use of medication, and more positive staff attitudes, which result in better care outcomes¹⁷.

¹⁴ AIHW (2023) [Dementia in Australia. Prevalence of Dementia.](#)

¹⁵ AIHW (2023) [Dementia in Australia, Community Based Aged Care.](#)

¹⁶ Royal Commission into Aged Care Quality and Safety. Final Report, page 141.

¹⁷ Anderson, K., Bird, M., MacPherson, S and Blair, A. (2016) How do staff influence the quality of long-term dementia care and the lives of residents? A systematic review of the evidence, *International Psychogeriatrics* AND Travers, C.M., Beattie, E., Martin-Khan, M. et al. A survey of the Queensland healthcare workforce: attitudes towards dementia care and training. *BMC Geriatrics* 13, 101 (2013). <https://doi.org/10.1186/1471-2318-13-101>.

Dementia education in residential care settings is central to reducing the use of chemical restraint and promoting psychosocial interventions to respond to changed behaviours.

Aged care staff want ongoing, comprehensive dementia training¹⁸. In a residential aged care context, elements of workforce training should aim to ensure that there is:

- Sufficient staffing to meet the care needs of all residents living with dementia at all times.
- Person-centred, comprehensive care planning.
- Understanding of consent, supported decision-making and substitute decision-making, including in relation to the use of medication.
- A living environment which supports cultural connection, including speaking first languages and offering cuisine preferences.
- Access to care from Registered Nurses trained in dementia care, including recognition and management of pain, and access to palliative care.
- Training for care staff in the impacts of dementia, communicating with a person living with dementia, and prevention and safe responses to the behavioural and psychological symptoms of dementia.
- Creation of physical and social environments appropriate for people with dementia and which reduce the risk of behavioural and psychological symptoms of dementia.
- Minimisation of restrictive practices (physical and chemical restraint).
- Training in falls prevention, specifically in relation to the impact of dementia.
- Strategies in place to reduce the unnecessary hospitalisation of people with dementia.
- Clear pathways for escalation of clinical support, including to dementia behaviour advisory services and specialist or acute care settings.

System wide approaches and roles

A cohesive, structured and integrated national approach to dementia education and training is needed. Dementia Australia suggests that a national framework for dementia education should be developed.

This should align with the National Dementia Standards being developed by Dementia Training Australia (to be released in 2024). This framework should be supported by learning pathways and career pathways. This would support robust and tailored training, with education differentiated and tailored to setting and care context.

A critical enabler to raise the quality of aged care, including dementia care, is the development of a national aged care worker registration scheme.

Dementia Australia strongly supports registration for all workers providing direct support and care to older people, including those living with dementia. While the Australian Health Practitioner Regulation Agency currently administers the registration of Registered and Enrolled Nurses working aged care, there is no equivalent registration process for direct care workers (personal care workers/ attendants and Assistants in Nursing).

¹⁸ Australian Nursing and Midwifery Federation (2019). ANMF National Aged Care Survey 2019 – Final Report. Australian Nursing and Midwifery Federation (Federal Office), Melbourne, Victoria.

We believe this is a necessary reform to ensure minimum qualifications are in place to enter the sector and that ongoing levels of knowledge and skill are maintained. The Regulatory model should have capacity for future iterations to include a requirement for worker registration through a national scheme.

With respect to the roles of different parties in the regulatory landscape, we note that in the current environment, the Department of Health and Aged Care will need to enable equitable access to dementia training pathways. This can be supported by the work of non-government organisations including Dementia Australia and Dementia Training Australia, in promoting leadership, culture change and practice change in the sector.

Ultimately, it will be the responsibility of aged care providers and services to ensure that their workforce is appropriately trained and supported in quality dementia care. In the meantime, the Department of Health and Aged Care will have a critical role to play.

The Regulator should be responsible for compliance monitoring and enforcement of dementia training requirements, noting that a compliance culture alone will not be sufficient to raise the quality of care.

Becoming a provider

Questions

1. What are your views on the proposed registration categories?
2. Which registration category should care management and personal care be in and why?
3. How should online platforms that connect older people to aged care services (but are not themselves Approved Providers) be regulated under the proposed new model?
4. What are your views on how the proposed model will allow other business types, such as sole traders and partnerships, to enter the sector?

Dementia Australia's response

The registration categories increase the scope for new, smaller providers such as sole traders to enter the market. While workforce expansion is necessary, it must also be underpinned by capability requirements, to avoid low quality or unsafe care.

New entrants must be capable of implementing person-centred care, communicating with people living with dementia, upholding rights and managing risks related to the impact of dementia.

All providers of care to people living with dementia should be required to provide safe, high-quality services appropriate to the environment and in accordance with the client's choices. This can be assessed and enforced through compliance monitoring with a core registration condition of dementia education.

Responsibilities of a provider

Questions

1. What are your views on the proposed approach to provider obligations?
2. What challenges can you identify for implementing the proposed approach? What could be the solutions?
3. Do you think there are any key areas of risks that are not addressed by the core conditions proposed to apply to all providers?
4. Are there any other category-specific obligations that you think should apply?
5. What are your views on the proposed application and audit of the Quality Standards to categories 4 to 6?
6. What does high quality care mean to you?

Dementia Australia's response

Providers in all registration categories should have a core condition requiring compulsory dementia education for the workforce. This should include providers in categories 1 to 3, providing services to people living with dementia at home such as meals, domestic assistance, or home modifications.

Although there may be fewer clinical risks related to delivery of services in proposed registration categories 1-3, risks still exist. These risks may relate to communication, choice and control, safety and wellbeing, or vulnerability to abuse, neglect or exploitation. The risks may be exacerbated where the person living with dementia is isolated in the community or does not have family support, and there may be specific risks in the home environment.

Providers in the proposed registration categories 4 – 6 will be required to comply with the Aged Care Quality Standards, which should ideally enable higher quality dementia care. However, no such requirement is proposed for providers in categories 1 – 3.

Similarly, while all providers will be obligated to comply with the Aged Care Code of Conduct, which provides a high expectation for safe, quality care, the Code does not include dementia specific requirements.

Compliance with the proposed core conditions alone may not be sufficient to prevent low quality care. Dementia specific education is needed for all parts of the workforce, to improve the quality of care and reduce the risk of serious incidents, particularly in relation to changed behaviours. This needs to be supported by dementia training targeted to leadership positions in aged care, to enable the cultural and organisational change that is critical to improving quality.

Dementia Australia recommends that an additional registration condition be included as a core obligation for all providers, requiring compulsory dementia education of the workforce. Compliance with dementia education should be enforced, and opportunities to engage in education and training programs made available to the aged care sector. There should be ongoing mentoring and a continuous improvement focus for the aged care workforce in quality dementia care.

Holding providers accountable

Questions

1. What are your views on the proposed features of this safeguard that seek to hold providers accountable?
2. Do you think the proposed new complaints model will help older people to raise concerns about the standard of services and have them addressed? Please include your reasons for this view.
3. Do you think the proposed enforcement mechanisms will be sufficient to address poor performance by providers where required?
4. How should restorative justice outcomes be reflected in the new Act?
5. How and when do you think access to financial compensation should be available?
6. What role should the Regulator have in seeking compensation on behalf of older people?

Dementia Australia's response

Dementia Australia supports a strengthened complaints model providing greater protections to aged care consumers including people living with dementia and their families, carers and advocates. The role of independent advocates in the complaints process should be recognised.

To be effective, complaints mechanisms and protections need to be dementia appropriate, tailored to the communication, safety and support needs of people living with dementia. Protections afforded to people living with dementia when making complaints should also apply to family members, informal carers and advocates.

All complaints, feedback and advisory structures under the regulatory system need to be dementia-friendly and provide meaningful opportunities for people living with dementia, carers, family members and advocates to safely participate. They should be culturally and psychologically safe for all members of the community.

All complaints relating to serious issues such as restraint, assault, neglect, abuse, exploitation or any criminal offences should be escalated rapidly, with systems geared for immediate response.

The Statement of Rights to be included in the Aged Care Act needs to be developed in consultation with people living with dementia, their carers and families. Once in place, consumers of aged care services who are living with dementia should be supported to understand and their rights and empowered to address issues. This will require considerable sensitivity to the communication needs of people with a cognitive impairment and memory loss, and the creation of clear pathways to elevate concerns without fear of retribution.

Dementia Australia notes that the proposed 'relational' regulation model must also orient to consumers, including people with dementia. To achieve effective engagement of people with dementia, there need to be consumer advisory structures to the new Registrar, with ongoing consultation, monitoring and review of the success of the system.

This will improve the capability of the regulatory system to better support quality dementia care outcomes, as well as promoting transparency and accountability. It will also ensure that the regulatory system keeps pace with changing community expectations.

Again, we reiterate that the assessment which informs the risk-based monitoring approach should consider the risk factors for people living with dementia and receiving any type of support in their home environment. The regulator should provide monitoring and oversight of home-based services, and opportunities for continuous improvement.

Transitioning to the new model

Questions

1. What are your views on the proposed transition arrangements?
2. What challenges can you identify for implementing the proposed transition arrangements? What could be the solutions?
3. What support do you need as a provider to help you with a smooth transition to the new model?
4. What other transitional arrangements need to be considered?

Dementia Australia's response

Dementia Australia recommends that the transition arrangements should consider the impacts on, and experiences of, aged care consumers, including people with living experience of dementia. There needs to be clear communication and information provided to aged care consumers, which is delivered in dementia-friendly ways, throughout the reform process.

Information and supportive structures for feedback should be offered, to ensure that people living with dementia are meaningfully involved in development and implementation of the new regulatory model.

Lastly, we note that that proposed Regulatory model does not clarify the relationship between the Registrar, Inspector-General of Aged Care, and the Aged Care Quality and Safety Commissioner. It would be beneficial to outline these relationships and areas of responsibility clearly in the new model.