



New Aged Care Act

Consultation Paper No. 1

Dementia Australia Submission

September 2023

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 2058.¹

In February, 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 women.²

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>

Summary of recommendations

Dementia Australia welcomes the opportunity to provide a submission on the foundations of the new Aged Care Act. We are the leading voice in Australia for people living with dementia and their carers, and an active participant in the aged care reform process. People living with dementia or mild cognitive impairment represent a substantial cohort of aged care recipients. Our advocacy has highlighted key themes across the aged care reforms:

- A system which prioritises high quality, person-centred care.
- Realisation of human rights, autonomy and choice.
- Recognising and supporting the needs of carers.
- Investment in workforce capability.

Dementia Australia supports the joint Consumer Submission made on behalf of a range of consumer advocacy organisations. We have prepared this additional submission to note further issues of specific relevance to people living with dementia and their carers.

We make the following recommendations:

1. Recognise people living with dementia and include provision of quality dementia care in the Objects of the Act.
2. Recognise the rights of carers to access support, throughout the Act.
3. Strengthen the Purpose Statement and the focus on outcomes of quality of life, wellbeing, independence, and self-determination.
4. Recognise and reflect the rights of people living with dementia in the Statement of Rights.
5. Outline the roles, responsibilities, obligations of different parties in enacting the Statement of Rights.
6. Outline how aged care providers in proposed registration categories 1, 2 and 3 will be required to implement the Statement of Rights.
7. Revise the Statement of Principles to better reflect the rights, identity and autonomy of older people, recognise carers, and emphasise the delivery of person-centred, multidisciplinary care and the requirement for a skilled dementia-capable workforce.
8. Ensure that the Act facilitates universal access to high-quality, person-centred care which is clearly defined and supported by a skilled and sustainable workforce.
9. Simplify and clarify the supported decision-making model and recognise the needs of people living with dementia and carers in the supported decision-making approach.
10. Work with Dementia Australia to ensure that the supported decision-making model is effective for people living with dementia and their carers.
11. Ensure that accountability and complaints mechanisms are appropriate for people with dementia and other cognitive impairment.
12. Amend the definition of care needs in the eligibility criteria to include cognitive needs and recognise the symptoms of cognitive decline and dementia.
13. Include people living with younger onset dementia in the cohorts able to access the aged care system in limited and controlled circumstances, including access to respite, in-home support and residential care.

Dementia in aged care

An estimated 67% of people with dementia live in the community.³ This will likely increase as more Australians choose to live at home in their older age.⁴ The new Act must reflect this evolving community expectation and ensure that regardless of the care setting, older people living with dementia receive quality care delivered by a skilled workforce which supports their wellbeing.

In a residential context, people living with dementia account for at least two thirds of aged care residents in Australia.⁵ The prevalence of dementia in aged care settings underpins Dementia Australia's position that dementia should be core business in aged care. The new Act must enable the delivery of quality, individualised care to older people with dementia, empowering them in their choices and advancing their quality of life.

It is also important the new Act does not lose sight of carers. The Royal Commission into Aged Care Quality and Safety recommended that the new Act should define aged care as

- support and care for people to maintain their independence as they age, including support and care to ameliorate age-related deterioration in their social, mental and physical capacities to function independently,
- supports, including respite for informal carers of people receiving aged care.⁶

The Royal Commission also recommended under Recommendation 3, Key Principles, that informal carers of older people should have the certainty that they will receive timely and high quality supports in accordance with assessed need.

We note that the proposed Objects of the Act do not recognise carers and their support needs, despite carers accessing a range of funded services from the current aged care system including respite, counselling, education and support. This needs to be rectified in the Exposure Draft of the Act, in recognition of the rights of carers to access support, and the essential role they play in the sustainability of Australia's aged care system.

Objects of the Act

As noted above, the Objects of the Act should include both the rights of the older person requiring care, and the right of carers to access funded support services. Carers are integral to the delivery of high-quality aged care, including to people living with dementia. They have a right to be recognised, valued and offered practical support.

[Carers] are without doubt the unsung heroes of the dementia world... their impact on the care economy is immeasurable. They keep patients out of expensive full-time care for as long as they possibly can. They significantly reduce the demands on short term respite care and home-care provision

³ AIHW (2023) [Dementia in Australia, Prevalence of Dementia](#).

⁴ AIHW (2023) [Dementia in Australia, Community Based Aged Care](#).

⁵ National Institute of Labour Studies (2017) The Aged Care Workforce, March 2016.

⁶ Royal Commission into Aged Care Quality and Safety (2021). [Final Report, Recommendations](#).

until matters have moved beyond the ability of anyone to care singlehandedly anymore and still retain some semblance of their own health and wellbeing.

~ Carer of a person with dementia

It is also critical that the new Act explicitly recognise people living with dementia and make the provision of quality dementia care one of its Objects.

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”.⁷

With the known high prevalence of dementia among people living in residential aged care, it is essential that the Act provides the foundation for an aged care system which can responsively deliver quality dementia care.

We recommend that point 3 of the Objects be reworded as:

Ensures universal, equitable access to funded aged care that flexibly responds to the individual needs of older people, including people living with dementia, carers, people from diverse backgrounds, and socially disadvantaged people. This care will protect and advance the rights of older people and carers.

Purpose of the Act

The proposed Purpose Statement for the Act could be strengthened by focussing on the socially desirable outcomes for quality aged care in Australia. We suggest amending the Purpose Statement to:

Support older people to have the highest attainable quality of life, wellbeing, independence and self-determination by delivering a quality, accessible, and person-centred aged care system.

Statement of Rights

Dementia Australia recommends that the following be noted in the Statement of Rights, which would strengthen their application for people living with dementia and carers:

- Assessment for aged care services needs to be suitable for people living with dementia or other cognitive impairment and include the right for timely reassessment as needs change.
- Older people have a right to high-quality, person-centred care. Services should not only be based on need, but also on the choices of the older person.

⁷ Royal Commission into Aged Care Quality and Safety (2021). A Summary of the Final Report.

- Services should assist people to maintain independence with the progression of illness or disease, including dementia.
- To be truly empowering, communication needs to be appropriate and accessible for people living with dementia and other cognitive impairment.
- People living with dementia have the right to freedom of movement, independence and autonomy while being safe and free from harm.
- People living with dementia have the right to dignity of risk with respect to care and lifestyle decisions. They have the right to access to support with decision-making.
- People have a right to have their personal property protected while living in a residential aged care facility.
- Complaints mechanisms need to be appropriate for people living with dementia, so that they and their chosen support people can easily make complaints without fear of reprisal, and have their needs met promptly.
- People living with dementia have the right to access palliative care.
- Carers have a right to health and wellbeing, and to have access to funded services to support them in their caring role.

Realisation of the Statement of Rights

It is imperative that new Act provides a clear and sound basis for government, private providers, and the non-government sector to deliver on the Statement of Rights. If the responsibilities and obligations of different parties in the aged care system are not articulated in the Act, the Statement of Rights may have little effect.

For example, for older people in regional or remote areas to have true choice in the provision of supports, services must be available in the market that are capable of providing the individualised support required to realise their right to high quality care. This means that government has a role to play in managing market spread, industry development and workforce capability to ensure that older people and carers can attain their rights. This role for government, and the roles of other parties, should be articulated in the Act.

Similarly, if an aged care provider's workforce is not dementia capable, people living with dementia and carers will not be able to realise their rights and access quality care in the service.

Dementia education in residential care settings is central to reducing the use of physical and chemical restraint and promoting psychosocial interventions to respond to changed behaviours. The design of the built environment is also critical to quality dementia care, with good design promoting dignified living, focussing on the strengths and capabilities of people living with dementia while compensating for changes in their function, and considering people's needs holistically.⁸

⁸ [The Dignity Manifesto of Design for People Living with Dementia](#) (2023).

If through a lack of dementia capability, a service is unable to offer a supportive environment, provide dementia specific care and respond appropriately to the clinical needs of a person with dementia experiencing changed behaviours, the person living with dementia will likely be unable to attain their right to freedom of movement and autonomy while remaining safe and free from harm.

As such, we recommend that the new Act stipulate the roles, responsibilities and obligations of different parties in enacting the Statement of Rights. This will assist and guide all parties in the practical, system-wide and service-specific reforms required to enact the Statement of Rights.

We further note that the current proposed regulatory model does not apply the same requirements to all providers in the aged care system. Providers classed in registration categories 1, 2 or 3 will not be required to comply with the Aged Care Quality Standards or subject to the same monitoring requirements as providers in categories 4,5 or 6.

The new Act will need to outline how providers in categories 1, 2 and 3 will be required to implement the Statement of Rights, how this will be monitored and enforced, and what recourse older people will have if their rights are breached.

Statement of Principles

The language framing the Statement of Principles needs to be strengthened to “will” instead of “should”. The Principles must be requirements which are foundational to the delivery of high-quality aged care outcomes, rather than being optional or idealistic.

We recommend that the following amendments be made to the Statement of Principles:

- Point 1 – include the autonomy and rights of the older person as primary considerations in the delivery of funded aged care services.
- Point 2 – include that the aged care system will support the older person’s identity and choices, including maintaining connection to family, chosen family, friends, community, culture and religion or spirituality.
- Point 3 – recognise carers and their right to access respite, counselling, education and other supports.
- Point 3 – change bullet point 3 to “being active and informed decision makers about the funded aged care services delivered to them and the lifestyle they choose”.
- Point 4 – include people living with dementia and carers.
- Point 5 – information will be provided in accessible formats for people living with dementia or other cognitive impairment.
- Point 7 – change to “the aged care system will work collaboratively with the health, disability and other care sectors, to provide holistic, person-centred models of care and coordinated transitions between sectors, meeting individual needs, goals and preferences”.
- Point 8 – note that people living with younger onset dementia whose needs cannot be met by the disability or other care sectors will have access to support in the funded aged care system.

- Point 9 – note that all older people will have access to the care they need, and nobody will be denied high-quality care because of their personal financial position.
- Point 10 – parties in the aged care system will work proactively and collaboratively with the health, mental health, disability and other care sectors to provide continuity of care and integrated, holistic services.
- Point 11 – An appropriately skilled and educated workforce is a shared responsibility of government and registered providers. The aged care workforce will be dementia capable.
- Point 13 – Regulation will ensure that all older people are protected from abuse and neglect, particularly those who experience additional vulnerabilities such as dementia. The regulatory model will monitor and enforce compliance with the Aged Care Act for all providers, including the realisation of the Statement of Rights.

Definition of high-quality care

Dementia Australia undertook extensive consultation with people living with dementia, families and carers to develop a consensus definition of quality dementia care in 2019. Two core components were outlined:

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

People told us that 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 in residential settings.
- Feedback and complaints being taken seriously.
- Having staff trained in dementia with ongoing mentoring.
- Leadership and culture that understands the impact of dementia.⁹

The definition of high-quality care in the new Act should be focussed on enabling person-centred care to be delivered across different environments. Care should balance innovation with a strong evidence base, move away from low value approaches, and remain responsive to consumer and community feedback and changing expectations. The requirement for high-quality care must be backed with a strong regulatory and compliance framework, and standards which include workforce education in dementia care.

People living with dementia and their carers have also told Dementia Australia that:

⁹ Dementia Australia, 2019. [Our Solution: Quality Care for people living with dementia.](#)

- Quality care means a good quality of life based on a high standard of emotional, physical, and environmental supports to enable people to live their best life.
- Quality care means dignity and interest in the client as a person.
- Care should be person-centred and holistic with a team providing appropriate, customised and necessary supports to address individual needs, while also supporting independence and choice.
- Care should be based on living well, support autonomy and the rights of the person, and offer the person what they want rather than what is thought best for them by others.
- Staff should be professional, in secure, paid employment, appropriately skilled and with adequate training.
- There need to be less complicated options to access and navigate the care and support system.
- Aged care workers should be educated in understanding the different types of dementia, communicating with people with dementia, responding appropriately to changed behaviours, and providing culturally safe care.

A person living with dementia observed that quality care means:

Someone who listens to me. Someone who understands me. Someone who can provide me with what I need or tell me what options I have. If they provide the care required, I expect them to be competent and knowledgeable about my condition and caring and respectful in providing what I need.

Dementia Australia supports a principle of universal coverage, so that all older people have access to the care they need and choose. High-quality care should be clearly defined and measurable, rather than aspirational. Components of care that are in scope in the new Act should include:

- Nursing, clinical and allied health
- Reablement and rehabilitation
- Personal care including assistance with showering, toileting and mealtimes
- Dementia support services
- Respite services
- Mental health care
- Equipment and aids for health and disability support
- Domestic services including cleaning, laundry and yard work
- Meals in residential aged care and respite services
- Social support
- Transport
- Carer support services.

Accountability

Accountability and complaints mechanisms must be appropriate for people living with dementia and other cognitive impairment. At both an individual and system level, transparency and accountability need to be dementia-friendly, including accessible

complaints mechanisms and methods of engagement. There should also be strong protections for people living with dementia, their carers and chosen support people if they make complaints or provide feedback, and for those who are whistleblowers.

Supported decision-making

We agree that supported decision-making should be enshrined in the Act, including the right of autonomy and the presumption of legal capacity. However, the proposed arrangements do not provide a clear model and are likely to cause confusion and increased administrative burden for older people, families and their carers.

We suggest that the proposed model be reconsidered and a new simplified model be developed to provide clarity, information and support for the older person and their chosen support people to realise their rights and understand their responsibilities.

The supported decision-making model in the new Act also needs to take account of the needs of people living with dementia. Such a model would recognise that decision-making ability will fluctuate, and that all possible options to support a person to make their own decisions should be explored.

However, due to the progressive nature of the disease, people with very advanced dementia will likely need a substitute decision-maker. Provisions should be made to support and guide substitute decision-makers in these circumstances, to ensure decisions align with the wills and preferences of the person living with dementia.

We recommend that the Department works with Dementia Australia to consult about how a model of supported decision-making would work best for people living with dementia and their carers, including how carers can support people as their decision-making ability is declining due to progression of dementia symptoms.

The model in the new Act also needs to include information about how all components of decision-making systems will work together in an aged care context. For example, what are the respective roles of an Enduring Power of Attorney or Guardian under State or Territory legislation, a Person Responsible, a restrictive practice decision-maker, medical decision-maker or an authorised Centrelink representative? How will conflicts between these roles be resolved?

The model also needs to build in advanced care directives, and safeguards for the prevention of elder abuse. It needs to be accompanied with workforce development so that aged care staff can understand and implement rights-based and supported decision-making practices day-to-day.

Eligibility

Dementia Australia supports the creation of a single-entry point to the funded aged care system with consistent eligibility requirements based on a streamlined assessment process. It will be important to clarify whether the single-entry point will also be accessible to carers when seeking carer support services.

To recognise and include people living with dementia, the definition of care needs should include cognitive needs, alongside physical, mental/psychological and social needs.

As well as daily living skills and independent function, the definition of care needs should also consider symptoms of cognitive decline and dementia, such as:

- memory loss
- changes in planning and problem-solving skills
- confusion about time or place
- visual and perceptive difficulties
- trouble with speech, writing or comprehension
- losing items or becoming lost
- decreased or poor judgement
- withdrawal from work or social activities, and
- changes in mood or personality.

People diagnosed with dementia should have streamlined access to support in the aged care system after diagnosis, with pathways that remove barriers and facilitate timely access to services and supports. It should also be easy for older people and carers to seek timely reassessment as needs change, and support with care navigation, for example with the progression dementia and increasing severity of symptoms.

The eligibility criteria and care needs definition should also include carers seeking access to support services including respite, education, counselling, and other services.

We note that the description of access and eligibility arrangements included in the Consultation Paper states that access to services will be considered for prioritisation, based on individual circumstances. The circumstances and criteria used to make prioritisation decisions for access to funded aged care services need to be clearly defined, publicly accessible and should also be open to community consultation.

Younger onset dementia

It is estimated that there are more than 28,650 Australians living with younger onset dementia (dementia diagnosed under the age of 65) in 2023 and this is projected to increase to 42,400 by 2058.

In general, Dementia Australia supports the Royal Commission's recommendation that younger people should not live in residential aged care facilities. However, we note that the disability service system is not always able to meet the needs of people living with younger onset dementia, and that they should not be refused access to funded aged care supports if required.

We recommend that the people living with younger onset dementia be included in the cohorts able to access the aged care system in limited and controlled circumstances, including having access to respite, in-home support and residential care.