



**Dementia
Australia®**

Aged Care Bill 2024

Dementia Australia's submission to the
Senate Community Affairs Legislation
Committee

7 October 2024

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Contents

- About Dementia Australia 3
- Dementia in Australia..... 3
- Executive summary..... 4
- Consultation and Recommendations 5
- Next steps..... 11

About Dementia Australia

Dementia Australia is the peak dementia advocacy organisation in 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.

The Dementia Australia Policy team can be contacted at policyteam@dementia.org.au.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of 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 ultimately a terminal condition.

In 2024, it is estimated there are more than 421,000 people living with all forms of dementia. This figure is projected to increase to more than 812,500 by 2054.¹

Dementia is major public health issue and a leading cause of disease burden among Australians aged 65 and over.² It is the second leading cause of death for all Australians and the leading cause of death for women.³ In 2023, there were an equivalent of 15 people with dementia per 1,000 Australians.⁴

¹ Dementia Australia (2024) [Dementia in Australia 2024-2054](#).

² Australian Institute of Health and Welfare (2024) [Dementia in Australia](#).

³ Ibid.

⁴ Ibid.

Executive summary

Dementia Australia welcomes the introduction of the Aged Care Act Bill 2024 (the Bill) to Parliament and the opportunity to comment on the Bill as it relates to the experience of people living with dementia, their families and carers.

The Bill is a crucial articulation of the aged care system in Australia and the way in which individuals experience care and support. We note that other peak consumer organisations, including Council on the Ageing (COTA) and Older Persons Advocacy Network (OPAN), are providing the Senate Committee with detailed submissions on the content of the Bill as it pertains to older people more generally, and based on our discussions with these organisations, Dementia Australia aligns with the positions they outline through their respective submissions.

In this submission, therefore, Dementia Australia focuses specifically on the issues that relate to people living with dementia, and our recommendations can be viewed in the context of access, appropriateness and availability of aged care services for this cohort of aged care service users.

We note that legislating for dementia is potentially challenging: through the new Bill service users have the right to access services that are appropriate to their individual needs (including cognitive impairment); yet there are key components of aged care that need to be articulated within the specific context of dementia (e.g. workforce capability) to ensure their effectiveness. As such, Dementia Australia's submission attempts to draw out those elements that require further consideration.

We also caveat our analysis of the Bill by expressing concern about the lack of clarity on the supporting Rules and subordinate legislation, which are yet to be finalised or published for comment. Understanding the full impact of the Bill on the experience of someone living with dementia is impossible without these details, so many of our recommendations are underpinned by requests for further information.

In summary, our **Recommendations** consist of the following:

1. Involve Dementia Australia and other consumer organisations in the development of the Rules and subordinate legislation to ensure appropriateness for people living with dementia (who constitute a significant proportion of aged care service users).
2. Legislate an early review of the Bill in the primary legislation with specific terms of reference, including evaluation of unintended consequences for people living with dementia.
3. Include in the Rules or subordinate legislation specification that 'non-clinical' independence and activities of daily living for people living with a cognitive impairment are fully funded by Government as crucial elements of supportive care for people living with dementia in both residential care and in-home support.
4. Include in the Rules or subordinate legislation a requirement that the aged care workforce must be educated in dementia care to an appropriate standard aligned with

the forthcoming National Dementia Education and Training Standards Framework, and outline in the Bill and/or Rules a process for regulatory monitoring and compliance action.

5. Ensure that Assessors for all elements of aged care, including the new Support at Home program, are qualified and trained to assess people living with dementia.
6. Strengthen security of tenure provisions in the Bill, Rules and supporting legislation to ensure security of tenure is maintained when people living with dementia need to temporarily access other care settings (e.g. acute care), with any required reassessment undertaken by trained and qualified assessors in a timely way.
7. Reintroduce criminal penalties OR increase penalty levels (including the number of incidents subject to infringement notices) and increase the capacity of the Aged Care Quality and Safety Commission to a) manage incidents proactively and b) undertake transparent public reporting.
8. In the absence of an authorisation model for restrictive practices, ensure that there is enhanced oversight and transparent reporting of the use of restrictive practices. It is also not appropriate to include a permanent liability waiver for restrictive practices in the primary legislation and this should be removed or the sunset clause revised.

Consultation and Recommendations

People living with dementia should have access to an aged care system that understands and supports the specific needs and challenges of living with declining cognitive impairment.

In consulting with people impacted by dementia, Dementia Australia has heard key concerns about:

- a) The ability of the Bill, Rules and supporting legislation to uphold their right to quality dementia care;
- b) The scope and affordability of services available under the home care and residential aged care system;
- c) The capacity of the workforce to deliver quality dementia care;
- d) Security of tenure for people living with dementia, both within home or community care, or as they need to transition between care types (including acute care);
- e) The lack of clarity on restrictive practices, supported decision making and informed consent within the Bill (and absence of further detail in the Rules and/or supporting legislation); and
- f) The potential for people living with dementia to continue to receive substandard care while having to pay more for services.

Our recommendations therefore reflect the above feedback of people living with dementia, families and carers as well as analysis by Dementia Australia staff and key external stakeholders.

1. Involve Dementia Australia and other consumer organisations in the development of the Rules and subordinate legislation to ensure appropriateness for people living with dementia (who constitute a significant proportion of aged care service users).

Dementia Australia notes and supports the impetus for the development of a new Aged Care Act and the complexity of the legislative processes that underpin its development.

However, it is imperative that Dementia Australia and other consumer organisations are involved in the development of the infrastructure within which the aged care system will operate – not least because the organisation is already hearing on an increasing basis that people with symptoms of cognitive impairment (especially changed behaviours or behaviours of unmet need) are finding it difficult to secure aged care services or maintain their security of tenure.

Consideration of how a person with dementia is assessed, enters and moves through the aged care system is vital in ensuring that the new system is appropriate for people with a cognitive impairment and that nuances between principle and implementation can be fully considered.

2. Legislate an early review of the Bill in the primary legislation with specific terms of reference, including evaluation of unintended consequences for people living with dementia.

In much the same way that the Living Longer Living Better Aged Care Bill 2013 included a review requirement with specific terms of reference, it is proposed here that the Aged Care Bill 2024 includes a review 3 years after implementation.

Dementia Australia strongly recommends that the terms of reference should include analysis of system appropriateness for people with dementia, which is particularly important given the prevalence of service users with a cognitive impairment: more than half of people in residential aged care have dementia while it is possible that at least a quarter of home care users will have experienced dementia at the time of assessment or as their care needs progress.⁵

3. Include in the Rules or subordinate legislation specification that ‘non-clinical’ independence and activities of daily living for people living with a cognitive impairment are fully funded by Government as crucial elements of supportive care for people living with dementia in both residential care and in-home support.

While Dementia Australia is reviewing and will respond to the consultation on the Rules relating to the Support at Home Service List, we urge Senators to recognise the unique needs of people living with dementia within their analysis of the Aged Care Bill.

⁵ Australian Institute of Health and Welfare (2024) [Dementia in Australia](#) and analysis by Dementia Australia.

In dementia care, there is still (and likely to be for some years) a lack of effective and widely utilised clinical treatment.

This means that ‘non-clinical’ supportive care is the only care paradigm currently available for people living with dementia. In essence, supportive care is a person-centred approach responding to the individual needs of each person living with dementia.⁶ Early access to supportive care can help to delay the progression of dementia symptoms, while lack of access to these supports could increase symptom severity and the likelihood of premature entry to residential aged care.

For people living with dementia, this means support for showering, eating, meal preparation, access to transport and support workers, and social engagement – all of which are vital to maintaining or strengthening cognitive function, but which the initial home care service list has identified as ‘non-clinical’ care and therefore potentially subject to means testing.

Further, the arrangements proposed for restorative care with a 12-week maximum are also inappropriate for people living with dementia, given that it is a degenerative disorder and there is an ongoing need for reablement and support for independence.

For people living with dementia, supportive care is essential to maintain quality of life. Dementia Australia is concerned that only clinical care will be fully funded by government and that independence functions, which are crucial to effective supportive care for people living with dementia will require a consumer contribution in both in-home and residential care.

Dementia Australia believes that the Statement of Principles and Aged Care Quality Standards cannot be fully realised for people living with dementia if activities of daily living, personal care and independence are not fully funded by government and accepted as part of a comprehensive (clinical and supportive) model of care.

- 4. Include in the Rules or subordinate legislation a requirement that the aged care workforce must be educated in dementia care to an appropriate standard aligned with the forthcoming National Dementia Education and Training Standards Framework, and outline in the Bill and/or Rules a process for regulatory monitoring and compliance action.**
- 5. Ensure that Assessors for all elements of aged care, including the new Support at Home program, are qualified and trained to assess people living with dementia.**

Dementia Australia is concerned that the aged care workforce, including assessors, currently has limited capability to implement the rights-based care that will be prescribed under the

⁶ Supportive care can be described as a framework that includes: symptom management; psychosocial support; reablement/enablement; and palliative care. Dementia supportive care also includes the prevention and management of adverse effects of dementia: not least the management of physical and psychological symptoms and side effects across the continuum of the dementia experience. See Victorian Department of Health (2024) [Supportive Cancer Care](#). Multinational Association of Supportive Care in Cancer (2024) [What is supportive care in cancer?](#)

Act. Unfortunately, people living with dementia continue to experience substandard outcomes in the aged care system, despite reform efforts to date.⁷

The Strengthened Quality Standards and Aged Care Code of Conduct do not provide adequate mechanisms to ensure that all aged care providers and staff are trained to deliver quality dementia care. These models neither establish a foundational level of dementia capability for the workforce nor provide an effective monitoring and compliance system for dementia education.

We recommend that the Rules and subordinate legislation develop further mechanisms for mandating dementia education to an appropriate standard, aligned with the forthcoming National Dementia Education and Training Standards Framework. There should also be a clear process for regulatory monitoring and compliance action.

It is also essential to ensure that Assessors across all parts of the aged care system, including for the new Support at Home program, are qualified and trained to assess people living with dementia.

It would also be appropriate to build mandatory dementia education into the proposed Worker Registration Scheme. We request that Dementia Australia be consulted in the development of the rules for the Worker Registration Scheme to provide advice about an appropriate framework for dementia education in relation to worker registration.

6. Strengthen security of tenure provisions in the Bill, Rules and supporting legislation to ensure security of tenure is maintained when people living with dementia need to temporarily access other care settings (e.g. acute care), with any required reassessment undertaken by trained and qualified assessors in a timely way.

It is critical that people living with dementia have strengthened security of tenure for both residential and in-home support, and that the new Bill enforces this in a consistent way.

Based on increasing feedback from individuals impacted by dementia, we are concerned that aged care providers are increasingly assessing people living with dementia as too expensive to support (especially when it comes to changed behaviours/behaviours of unmet need), and either not accepting them for placement or discharging them to hospital without providing security of tenure.

There is a real risk, therefore, that aged care providers will be able to ‘cherry-pick’ aged care participants within the new Act who are less expensive to support, to the detriment of people living with dementia with more complex needs in both residential and in-home settings.

We note that the Bill authorises the prescription of Rules relating to security of tenure for residential care homes and for continuity of funded aged care services. But the Bill and/or the Rules must also outline the responsibility of aged care providers not to end or amend the

⁷ Dementia Australia (2024) [Submission to 2024 Progress Report on Implementation of Aged Care Royal Commission Recommendations.](#)

security of tenure of an individual except in very limited circumstances, which should also be encapsulated in the Rules.

We also recommend that the Rules strengthen security of tenure provisions, ensuring people living with dementia cannot be discharged to hospital care or other settings without security of tenure, including within the Support at Home program. We request that Dementia Australia be consulted to outline critical issues for consideration in the operation of security of tenure policy in relation to care for people living with dementia.

7. Reintroduce criminal penalties OR increase penalty levels (including the number of incidents subject to infringement notices) and increase the capacity of the Aged Care Quality and Safety Commission to a) manage incidents proactively and b) undertake transparent public reporting.

We are disappointed that the Aged Care Bill 2024 now does not impose criminal penalties. If this exclusion is maintained, Dementia Australia recommends that the regulator has the capacity to be more responsive and to give more transparent public reporting on incidents, complaints, quality of care and financial management issues.

It is the right of every person living with dementia and their families to have clarity on the capability of aged care providers to deliver quality dementia care. Based on feedback from people impacted by dementia, the Star Ratings system and other current reporting mechanisms do not currently offer this transparency on care outcomes.

Addressing this transparency is even more vital if we build an aged care system in which participant co-contributions for aspects of care are increased.

8. In the absence of an authorisation model for restrictive practices, ensure that there is enhanced oversight and transparent reporting of the use of restrictive practices. It is also not appropriate to include a permanent liability waiver for restrictive practices in the primary legislation and this should be removed or the sunset clause revised.

We have concerns about the lack of clarity in the Bill regarding restrictive practices, supported decision-making and informed consent as these concepts pertain to people impacted by dementia.

Supported decision-making

If an authorisation model for restrictive practices is not included in the Bill, there must be enhanced oversight of provider conduct. We are unclear as to which mechanisms will provide this independent view and seek involvement in development of the legislation around restrictive practices.

Supported decision-making must apply across all components of aged care, from daily decisions to longer-term matters. People living with dementia have a right to be involved in decision-making about their lives as fully as possible. Decision-making supporters, including

those formally appointed, should be guided by advanced care directives and the known will and preferences of the person living with dementia.

A broad requirement for supported decision-making as part of daily care, and practices around advanced planning, do not appear to feature strongly in the new Act. The Rules and subordinate legislation need to provide guidance as to how supported decision-making must apply across the entirety of care practice.

State and territory legislation

In addition to the above issues, Dementia Australia remains concerned that the supported decision-making arrangements in the proposed Act are discordant with existing state and territory legislation.

We note that Subclause 18(2) will allow for the rules to authorise a hierarchy of persons or bodies to consent to the use of restrictive practices where it is not clear that State and Territory laws currently provide for this authorisation, and it is intended that this interim solution will apply until all State and Territory governments address the current legislative issues.

While we understand that the current timelines mean that changes to state and territory legislation cannot be reflected in the Bill, it is critical that these legislative reforms at state and territory level take place as soon as possible to fully implement supported decision-making. Decision-making and consent models must be simplified and empowering for people living with dementia.

Dementia Australia will continue to advocate to state and territory governments, stressing the importance of ensuring their legislative frameworks allow for supported decision-making to be enacted for restrictive practices.

Restrictive practices

In the absence of an authorisation model for restrictive practices, the Bill and Rules must ensure that there is enhanced oversight and transparent reporting of restrictive practice implementation.

There must be independent, transparent processes to ensure that the unmet needs of people living with dementia, such as expressions of pain or distress, have been assessed and properly responded to prior to use of any restrictive practices, including chemical restraint. There must be effectively implemented models for informed consent and oversight of restrictive practices implementation. These are calls that have long been made by people living with dementia, families and carers.

We request that Dementia Australia be consulted in the development of the subordinate legislation for restrictive practices and that permanent liability waivers are removed from primary legislation.

Next steps

Dementia Australia is wholly available to the Senate Committee, Department of Health and Aged Care, and Government to ensure the success of the new Aged Care Act.

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