

South Australia Retirement Villages Amendment Bill 2023 – Community Consultation

Dementia Australia submission

16 May 2023

This page is left blank intentionally

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.

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.

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, 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.

Dementia is one of the largest health and social challenges facing Australia and the world.

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

Our response

Dementia Australia appreciates the opportunity to provide feedback to the *South Australia Retirement Villages Amendment Bill 2023* Community Consultation.

There is not enough known about the number of people living with dementia residing in South Australian retirement villages. Anecdotal evidence suggests that nationally, there is an increasing number of retirement village residents living with dementia, but little is known about their experiences.

Many people living with dementia in retirement villages will likely reach a point where their care needs cannot be appropriately met, and they transition to residential aged care. However, at any point in time there may be at least 1 in 10 retirement village residents living with dementia, and even more with a mild cognitive impairment that is not at the threshold for dementia².

Given this, regulation of the retirement village industry should consider the needs and rights of people living with dementia or who have a mild cognitive impairment, and their carers and families. Dementia Australia's research has found that many retirement village providers are uncertain about how to support residents living with dementia.

Dementia Australia supports the intentions of the *Retirement Villages Amendment Bill 2023* to provide increased clarity and transparency for consumers. We note that this means that information and communication should be provided in a way that is tailored to the needs of people living with dementia or who have a mild cognitive impairment.

Specifically, at the point of entry to a retirement village, providers should be transparent about the level of support that will be provided to people who have or develop dementia, and what the roles and responsibilities of family members are.

Information about contracts, what happens when a resident transitions to residential aged care and how disputes are managed should all be provided in a way that is dementia friendly. People living with dementia should be supported to meaningfully participate in residents' committees and be involved in decision-making.

A wide range of help sheets are available at [dementia.org.au](https://www.dementiafriendly.org.au), which provide information about the impacts of dementia and guidance on supporting people living with dementia. Information about becoming a dementia friendly organisation is available at <https://www.dementiafriendly.org.au/>.

For guidance on meaningful consultation with people living with dementia, we recommend *Half the Story: A guide to meaningful consultation with people living with dementia, families and carers*, available at <https://www.dementiafriendly.org.au/find-resources/half-story-meaningful-consultation>.

² Dementia Australia (2015) Dementia in Retirement Villages, Discussion Paper #13.
https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-OtherInformation02-RetirementVillages_english.pdf

If you would like to discuss any aspects of our advice further, the Dementia Australia Policy team can be contacted on [**policyteam@dementia.org.au**](mailto:policyteam@dementia.org.au).