

Tasmanian Retirement Villages Amendment Bill 2023

Dementia Australia submission

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 2058. In 2023, it is estimated that there are more than 10,300 people living with all forms of dementia in Tasmania. This figure is projected to increase to more than 16,000 by 2058.

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

¹ Dementia in Australia

² Dementia in Australia

leading cause of death of women. Dementia is one of the largest health and social challenges facing Australia and the world.

Our response

Dementia Australia appreciates the opportunity to provide feedback to the Retirement Villages Amendment Bill 2023.

There is not enough known about the number of people living with dementia residing in Tasmanian 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 dementia.³

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 strengthen protections for residents of retirement villages including increased regulation and transparency about fees setting. Information and communication about fees and charges in retirement villages should be provided in a way that is accessible to the needs of people living with dementia or who have a mild cognitive impairment.

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 and accessible to people living with a cognitive impairment. People living with dementia should be supported to meaningfully participate in residents' committees, meetings and decision-making.

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³ Dementia Australia (2015) Dementia in Retirement Villages, Discussion Paper #13. https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-OtherInformation02-RetirementVillages_english.pdf

A wide range of help sheets are available at <u>dementia.org.au</u>, 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*.

If you would like to discuss any aspects of our response further, the Dementia Australia Policy team can be contacted on policyteam@dementia.org.au.