

Tasmania's Wellbeing Framework

Dementia Australia response

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.

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

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, 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.

Dementia Australia's response

Dementia Australia appreciates the opportunity to provide feedback on the consultation questions for Tasmania's Wellbeing Framework. We have also circulated the survey website to our network of Dementia Advocates in Tasmania, who are people living with dementia, their carers and family members.

What does wellbeing mean to you?

Dementia affects people across all parts of the community and of all ages. In 2023, there are estimated to be 10,300 people in Tasmania living with all forms of dementia. This figure is projected to increase to more than 16,000 by 2058³. There are an estimated 680 people living with younger onset dementia in Tasmania, who are those diagnosed before the age of 65⁴.

People living with dementia can experience a range of changes, including:

- memory loss
- · problems with thinking and planning
- difficulties communicating
- · difficulties carrying out daily activities like cooking, banking and driving
- · confusion about time or place
- sight and visual difficulties
- apathy and withdrawal.

¹ AIHW (2023) Dementia in Australia, Summary, Impact.

www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary

² AIHW (2023) Dementia in Australia.

www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary

³ Dementia Australia (2023) Dementia in Australia 2023-2058 Dementia Prevalence Data Estimates and Projections - All forms of dementia.

 $[\]underline{www.dementia.org.au/sites/default/files/2023-03/Prevalence-Data-2023-Updates.pdf}$

Dementia Australia (2022) Younger onset dementia in Australia - Prevalence Estimates 2022-2058. https://www.dementia.org.au/sites/default/files/2021-03/2021-DA-Prev-Data-YOD-in-Aus.pdf

Living as well as possible with dementia can mean adjusting to these changes when they affect quality of life. This may include:

- Continuing to exercise and maintain a healthy diet
- · Learning and engaging a variety of activities
- · Reducing stress
- · Maintaining hobbies and pastimes
- · Continuing with household tasks
- Accessing support services
- · Maintaining positive relationships
- Staying social and connected to the community
- · Planning ahead.

People living with dementia require high quality care and support to live well in the community, and carers of people living with dementia also need support for their wellbeing. This means having access to support services in the home, as well as respite options for carers. It also means that communities need to be inclusive, understanding and dementia friendly.

Living well with dementia means having access to health care from dementia trained professionals, supporting early diagnosis and referral for specialist care.

Within residential aged care facilities, wellbeing for people living with dementia relies on the delivery of person-centred care which upholds rights and autonomy. Quality care and support delivered by a dementia educated workforce is essential.

What does an ideal Tasmania look like for future generations?

An ideal Tasmania for future generations would have inclusive and supportive communities. People living with dementia would be able to take part in the activities they enjoy and maintain connections that matter. Carers would be supported and have a good quality of life. There would be no stigma or discrimination against people living with dementia, enabling people to access health and care services, and be understood by their communities.

There are some positive initiatives for people living with dementia in Tasmania already in place, and these could be built on to strengthen dementia friendly communities and reduce stigma. There are dementia-friendly cafes in several locations, and a Dementia Friendly Alliance in Tasmania.

Neighbourhood houses and clubs are showing an interest in becoming dementia friendly. Several local councils are also interested in including people living with dementia in their access and diversity strategies.

Dementia Australia supports individuals, organisations and communities to become dementia friendly through the Dementia Friendly Communities program, which is funded by the Australian Government. This program aims to build understanding, awareness and acceptance of dementia in the community.

Stigma continues to be an issue experienced by people living with dementia in Tasmania, and people in more rural and remote parts of the state are more disadvantaged than those nearer to Hobart or Launceston. The lack of GPs in rural and remote Tasmania, especially on the west coast, is a barrier to wellbeing for people living with dementia. Similarly, people in rural areas need to travel to Hobart and Launceston to access specialists, with very little support available locally.

Availability of support workers for home care services is also a barrier to a good quality of life. Because of workforce shortages, it can be difficult to access home care and respite outside of Hobart and Launceston.

Wellbeing for people living with dementia and their carers in Tasmania could be improved by ensuring better availability of primary and specialist health care services, respite, and home care. The work to build dementia friendly communities and reduce stigma is also essential, empowering communities to take action, learn and support each other.