

## Tasmanian Disability Health Strategy

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.<sup>1</sup>

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<sup>2</sup>.

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

<sup>2</sup> AIHW (2023) *Dementia in Australia, Summary, Impact* <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

In 2023, it is estimated 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.<sup>3</sup> In Tasmania, there are an estimated 680 people living with younger onset dementia, which is dementia diagnosed before the age of 65.<sup>4</sup>

## Dementia Australia's response

Dementia Australia appreciates the opportunity to provide feedback on the Tasmanian Disability Health Strategy. We have also circulated the consultation opportunity to our network of Dementia Advocates in Tasmania, who are people living with dementia, carers and former carers.

Dementia Australia advocates for improvements in policy, resources and service delivery to ensure equity of access to quality health services that are responsive to the needs of people living with dementia, their families and carers in all communities, including rural and remote areas.

It is essential that the voices of people living with dementia are heard in any health consumer consultation. People living with a dementia and their carers:

- are experts in the lived experience
- can identify shortfalls, gaps or unmet needs
- bring new ideas and perspectives
- can help you reach your target market, and
- come from a broad range of professional backgrounds.

Dementia Australia has developed a comprehensive guide to meaningful engagement with people living with dementia, families and carers in consultation, called **Half the Story**. Meaningful engagement means seeking out, affirming and ratifying the voices of people living with dementia, families and carers. It is necessary to understand the full story.

Meaningful engagement requires us to remove or reduce the barriers that prevent people from participating. It requires us to work differently. Meaningful engagement respects people's dignity and human rights, recognises their knowledge and skills, amplifies their voices, and involves people in decisions that will affect their lives. We recommend continued engagement with people living with dementia and carers in Tasmania in the development and implementation of the Tasmanian Disability Health Strategy.

## Dementia is a disability

Dementia is a progressive cognitive disability which affects people of all ages, causing difficulties with thinking, memory and behaviour. Dementia describes a collection of symptoms caused by disorders affecting the brain. It is not one specific disease. Dementia affects people

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<sup>3</sup> **Dementia in Australia**

<sup>4</sup> **Younger Onset Dementia in Australia**.

of all ages including in childhood - there are approximately 2,300 Australian children living with dementia.<sup>5</sup>

Community awareness of dementia as a disability is limited. The cognitive and other changes that are associated with the condition are often 'invisible' or under-recognised. People living with dementia relate the common experience of being told that they 'can't possibly have dementia' because they don't appear, speak or act in a way that corresponds with community expectations or understanding of the disabling nature of dementia.<sup>6</sup>

Cognitive disability is an umbrella term that can broadly be conceptualised as difficulties with memory and thinking that arise from intellectual disability, dementia, brain injury, autism, neurological disorders, fetal alcohol spectrum disorder, learning disorders or mild cognitive impairment. People with cognitive disability may have challenges with remembering, learning, concentrating, decision-making, attention, communication and problem-solving, among other difficulties<sup>7</sup>.

Dementia Australia suggests that the Tasmanian Disability Health Strategy make specific reference to dementia and cognitive disability and include strategies relevant to the outcomes and experiences of people with dementia in the Tasmanian health system, including those living in rural and remote areas.

The challenge is to design and deliver services that are accessible, dementia-capable and culturally safe to ensure people with dementia, their families and carers are well supported in the Tasmanian health system.

## Quality health services

Dementia affects people across all parts of the community and of all ages. 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 quality health care services delivered by a dementia capable workforce. Specifically, it means being able to access early diagnosis, being referred to accessible specialist care and having ongoing clinical management of symptoms and psychosocial health throughout disease progression.

Health outcomes for people living with dementia and their carers in Tasmania could be significantly improved by ensuring better availability and spread of dementia educated primary care, allied health, palliative care, ambulance services and specialists across the state. Government action is required to grow the capacity of the health system to respond effectively for people living with dementia and improve health and wellbeing outcomes.

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<sup>5</sup> [Childhood Dementia](#)

<sup>6</sup> [Dismantling Dementia Discrimination](#).

<sup>7</sup> [Cognitive Impairment, Identifying and managing cognitive impairment, Indefinite detention of people with cognitive and psychiatric impairment in Australia, Issues Paper: Health Care for People with Cognitive Disability, Cognitive Impairment and the NDIS](#).

## Regional and rural areas

There is currently a great deal of inequity in the health system for people living with dementia in Tasmania. Outside of Hobart and Launceston, access to services, including primary and specialist care, is very difficult to access. These services are crucial to maintaining a good quality of life for people in rural and remote areas. The lack of access to health and support services for people living with dementia has a flow-on effect for carers, impacting negatively on their mental health.

Restricted access to health care can have numerous impacts on people living with dementia, their families and carers, including delayed diagnosis, poorer access to information regarding dementia, and limited access to a range of quality dementia supports and services. People living in rural and remote areas deserve to have equitable access to services and be supported to remain living in their local community throughout their experience with dementia.

Living with dementia brings challenges for all people with a diagnosis and those who care for them. These challenges are compounded if a person lives in rural and remote areas due to geographic isolation, travel distances, and limited services and resources. Key concerns in accessing health care services in rural and remote areas include:

- assessment, diagnosis and management of dementia
- education and awareness of dementia
- access to specialist support services
- cost of transport for specialist services and travel time
- availability of culturally appropriate services and supports
- workforce capability and capacity.

People living with dementia, families and carers in rural and remote areas of Tasmania have outlined their concerns that:

- There is a lack of GPs who remain in the community over time and know their patients. This is especially difficult for people living with dementia to have to retell their experiences and relate to changing doctors.
- Rural GPs are under time pressure in consultations. People living with dementia need time to think and speak, and they feel that the lack of time is challenging and impacts on care.
- People living with dementia and family carers value bulk billing services. The choice of which GP to consult is often made according to whether the practice bulk bills. This means that people living with dementia are going to GPs who bulk bill even if they feel the GP is time pressured and does not have time to listen to them.

People living in rural and remote areas are less likely to receive a timely diagnosis due to the limited availability of local specialists, with people required to travel significant distances to see specialists. With more than one appointment often needed to confirm a diagnosis of dementia,

this places considerable time and financial pressures on people with dementia, their families and carers.

Attending specialist medical appointments in Hobart is a significant issue for rural Tasmanians living with dementia and their carers. Carers often have to take time off work to take the person living with dementia to appointments as they are no longer able to drive themselves. The journey to Hobart often leaves people living with dementia tired and stressed.

## Hospital and ambulance services

There are also concerns about the capacity of the health system, including ambulance services, to respond effectively to the needs of people living with dementia. Where ambulance services are unavailable in crisis situations, police may be first responders. Police may not have sufficient training or understanding of dementia.

Generally, hospital stays are not positive experiences for people living with dementia. The confusion and distress associated with hospitalisation, regardless of whether it is planned or unplanned, can exacerbate symptoms of dementia as well as cause considerable stress for families and carers.

People living with dementia are twice as likely to be admitted to hospital, and 2-3 times more likely to have an adverse event in hospital (for example falls, delirium and sepsis) than people of the same age who do not have dementia.<sup>8</sup>

When in hospital, people with dementia are at greater risk of adverse events and preventable complications such as falls, pressure injuries, accelerated functional decline, longer lengths of stay, premature entry to residential care and death than others. People with dementia are two times more likely to experience falls, pressure injuries or infections in hospital.<sup>9</sup>

Analysis of AIHW hospital data indicates that people with dementia have longer hospital stays than people without dementia. This additional length of stay can exacerbate or worsen symptoms of dementia, potentially leading to a decline in cognition and physical functioning.

It also creates additional complexities related to ongoing care planning, medication management and psychosocial support, and puts pressure on residential aged care facilities to support residents who may be admitted with additional complexities because of extended hospitalisation.

Despite being a common condition among hospital patients, cognitive impairment is often misdiagnosed or undetected in hospital.<sup>10</sup> Dementia training for hospital staff is inconsistent

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<sup>8</sup> Panayiotou, A (2018) **Preventing Avoidable Hospital Admissions for People with Dementia, Final Report**, Melbourne Ageing Research Collaboration.

<sup>9</sup> Australian Commission on Safety and Quality in Health Care (2016) **Caring for Cognitive Impairment – A National Campaign**

<sup>10</sup> Australian Commission on Safety and Quality in Health Care (2016) **Caring for Cognitive Impairment – A National Campaign**.

and there is still low awareness of how to support someone with dementia or how to create enabling environments, despite the introduction of cognition and delirium standards through the Australian Commission on Safety and Quality in Health Care.

Admission processes, emergency protocols (including security arrangements and management of code 'red' situations involving people with dementia) and day-to-day care are typically not supportive of people with dementia (or cognitive impairment as a result of delirium).<sup>11</sup>

People with dementia as well as families and carers often report a change or decline in physical or cognitive health during or following a hospitalisation. Hospital stays are also stressful for carers and families of people with dementia because it can significantly increase their caring responsibilities as they must negotiate the hospital system as well as provide assistance and reassurance to the person they support. There are additional issues for people living with dementia in rural and remote Tasmania when they are hospitalised far from family and their support network.

Dementia Australia notes that the Royal Hobart Hospital used to have a special room for people living with dementia who presented to the Emergency Department. This room had a less clinical feel, presented as an ordinary bedroom with armchair. It included accessibility features like a bathroom with coloured toilet seat. This room no longer exists, to the detriment of people living with dementia who need to attend the Emergency Department.

Another current issue for people living with dementia accessing hospital care at the Royal Hobart Hospital is inflexibility of visiting rules. Limitations on the number of visitors, and time that visitors can see the person living with dementia, are having negative impacts on the quality of care received. It may often be helpful to have multiple family members supporting a person living with dementia during their hospital stay to assist with communication, reduce distress and education staff about the person's individual needs.

Dementia Australia's Client Services staff are aware of several issues related to the lack of supervision of people living with dementia in hospital, particularly with the provision of food and drink. People living with dementia may often be unable to access or open food and drink packaging which is delivered to them in the ward. Dehydration and malnutrition are significant concerns.

These are systemic issues which need to be addressed through mandatory education of nurses and other staff in supporting patients with dementia in hospital, including strategies to support nutrition and hydration.

## **Palliative Care**

Issues for people living with dementia in accessing palliative care in Tasmania include a lack of continuity of care and reduced access to palliative care in the community. Workforce

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<sup>11</sup> Dementia Australia (2019) **Dementia and Delirium Q&A sheet**

shortages are also having an impact on access to appropriate palliative care for people with dementia.

Dementia is a terminal condition, and a person living with dementia has the right to appropriate, compassionate and timely palliative care. This includes pain relief and symptom management, and the prevention and relief of suffering. This should be accessible in the setting which the person living with dementia chooses.

For further information please refer to Dementia Australia and Palliative Care Australia's **Joint Policy Statement: Palliative Care and Dementia.**

## Building our workforce

A skilled, dementia-capable health workforce will make a tangible difference to the lives of people living with dementia in the Tasmania.

### Diagnosis and primary care

Diagnosing dementia is not a straightforward process and people with dementia, their families and carers often report experiencing a lengthy and distressing diagnosis process. A lack of understanding of dementia among health care professionals presents a barrier to a timely diagnosis. GPs, who are most often the first point of contact for people who are worried about their cognition, lack a consistent understanding of dementia.

It is not known how many GPs have a thorough understanding of dementia, given dementia is only a small component of GP training and there is no mandatory professional development in dementia. Given the increasing number of Tasmanians with dementia, greater consistency in the training of GP and primary care professionals will improve the quality of care and support provided to people at risk of dementia and people living with dementia, as well as their families and carers.

In cases where GPs have an awareness and understanding of dementia, individuals receive a quicker diagnosis, and consequently can access supports earlier. GP knowledge of dementia and a referral process to appropriate supports is important for ensuring that people with dementia, their carers and families receive a timelier diagnosis and access to support.

Dementia Australia understands that GPs are time-poor and have limited capacity for longer consultations. As well as partnerships to promote GP education, we recommend that supportive approaches be implemented in GP clinics to improve capacity for dementia care. These could include practice managers or practice nurses being educated in dementia assessment and referral pathways, to support people to connect to services and navigate care systems.

### Hospital workforce

Similarly in the hospital environment, health professionals need access to dementia education to improve knowledge of dementia, reduce stigma and support referral for appropriate

supports for people living with dementia and their carers, particularly when transitioning out of hospital.

To ensure hospital staff are equipped to support patients with dementia, Dementia Australia recommends mandatory dementia education of all hospital staff. Education must include identification of dementia, management of dementia without inappropriate use of physical or chemical restraints, supported decision-making and communication approaches, nutrition and hydration, palliative care and pain management and an understanding of dementia enabling environments.

## Improving the accessibility of our infrastructure

Health infrastructure design should include the creation of dementia-friendly environments. People living with dementia can experience their surroundings as confusing, disorienting, disabling and even dangerous. Good design should provide essential prompts for wayfinding, maximise accessibility and reduce risks.

The physical environment of hospital settings is a key contributor to the confusion and distress experienced by people with dementia. They are busy, hectic, noisy and bright. Signage is often unclear and long, unmarked corridors may look the same.

Very few medical facilities have given any consideration to the 'dementia-friendly' design principles. Indeed, much of the classical 'hospital design' is the reverse. Simple things like visible and readable signage would be a big step forward.

~ Person living with dementia

The physical environment of Tasmanian hospitals needs to be dementia enabling. We recommend consulting with the following documents for additional information:

- [How to design dementia-friendly care environments](#)
- [The Dignity Manifesto of Design for People Living with Dementia](#)
- <https://dta.com.au/dementia-friendly-environments/>

## Empowering decision-making

It should be assumed that people living with dementia have the ability to make their own decisions about their health and care options. Supported decision-making enables people with dementia and other cognitive disabilities to make decisions about their own lives, with appropriate assistance. The supported decision-making model recognises that for someone living with dementia, decision-making capacity can change day to day.

A variety of psychological, physical and environmental factors can influence someone's capacity to engage in decision-making. Both supported and substitute decision-making can be appropriate in different contexts. More information can be found in Dementia Australia's position statement: [Supported Decision Making](#).

The health workforce needs capacity to implement appropriate decision-making models, working closely with the person living with dementia and their families and carers. It is important that health professionals can understand a person's decision-making capacity at different times, and work inclusively with the person living with dementia.

This relies on the health workforce having good knowledge of the types and presentations of dementia and well-developed skills in communicating with people with cognitive disability. It means implementing a truly person-centred approach where the individual is empowered, and their personal choices realised.

Thank you for considering these issues in the development of the Tasmanian Disability Health Strategy. We would be happy to provide any further information that may be useful to assist in improving health outcomes for people living with dementia in Tasmania and their families and carers.