Dementia Australia®

Victorian State Disability Plan 2027 – 2031

Dementia Australia Policy Position Summary
July 2026

What needs to change?

- The Victorian Disability Plan should recognise dementia as a disability, including the specific needs of people living with young onset dementia.
- People living with dementia need accessible and inclusive communities that consider cognitive disability, not only physical disability.
- Carers need improved access to respite, counselling and peer support.
- Workforce knowledge of dementia must increase and be consistent across health, disability, primary and aged care, justice and emergency services, with improved coordination between systems.

What is Dementia Australia recommending?

- Improve access to dementia friendly health, housing and support services, including culturally safe and inclusive supports for diverse communities.
- Introduce dementia-specific workforce education and training across relevant sectors, including the use of Dementia Australia's Dementia Language Guidelines
- Embed supported decision-making as a core principle across government services.

If actioned, what impact could these recommendations have?

- Greater inclusion, participation and independence for people living with dementia.
- Reduced stigma and improved community understanding of dementia.
- Improved wellbeing and quality of life for people living with dementia and their carers.
- A more skilled workforce that can better support people living with dementia.

How has Dementia Australia advocated for this position?

- Dementia Australia provided a submission to the Victorian Government consultation on the Victorian State Disability Plan 2027-2031, informed by feedback from Dementia Australia Advocates, including people living with dementia, carers and family members.

What's next?

- The Victorian Government will consider feedback received through consultation before finalising the Victorian State Disability Plan 2027-2031; Dementia Australia will continue advocating for stronger recognition of dementia and cognitive disability in the final Plan.

Victorian State Disability Plan 2027 - 2031

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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 and inclusion in Victoria

Dementia Australia welcomes the opportunity to provide a submission to the consultation on the Victorian State Disability Plan.

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 a progressive and life limiting illness that is now the leading cause of death in Australia.[1] In 2026, it is estimated there are 446,500 people living with all forms of dementia in Australia. Without a significant intervention, this figure is projected to increase to over one million by 2065.[2] In 2026 there are an estimated 29,000 people living with young onset dementia (a diagnosis of any kind of dementia between the ages of 18-65), expected to increase to an estimated 41,000 people by 2054. [3] An estimated 1,500 children live with

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childhood dementia in Australia. [4] There are an estimated 1.7 million Australians involved in the care of people with dementia. [5]

In 2026 there are an estimated 113,900 people living with all forms of dementia in Victoria. This figure is projected to increase to an estimated 216,400 by 2054. There are an estimated 7,400 people living with young onset dementia in Victoria in 2026, which refers to any dementia diagnosed in adults aged 18-65. This figure is projected to increase to an estimated 11,550 by 2054.

Community awareness of dementia as a disability remains limited, and people living with dementia commonly report stigma, stereotyping and exclusion. People living with young onset dementia often have different needs and challenges compared with their older counterparts and community awareness and understanding about this younger cohort is poor. Acknowledging and understanding that dementia is a disability is critical to supporting the human rights and full inclusion of people living with dementia at any age.

“I think the biggest barrier is people …when you take your person living with dementia out into the community, that's the biggest barrier - how people view them, um, how people treat them, how people look at them…. you know that they're living with dementia, but you also don't want to scream it at everybody when you're out in public.” Carer of person living with dementia.

The current Victorian State Disability Plan

Dementia Australia is committed to inclusion planning that is transparent and accessible and works across the systems and services people living with dementia interact with. We note the current Inclusive Victoria: State Disability Plan 2021 – 2026, contains only seven references to cognitive disability. Of those references, four relate to people with cognitive disability interacting with the justice system.

More significantly, the current Plan focuses on acknowledgement and support for people living with a range of physical disabilities but lacks an equivalent recognition of and focus on the needs of people living with cognitive disabilities, including dementia. This is consistent across the four pillars and priority areas and is reflected in the emphasis on physical barriers to accessibility in public spaces and public transport, safety and the design of accessible housing. Conversely, when discussing co-design with people with disability (p. 26), the current Plan states that collaboration in relation to government policies, programs and services will include ‘identifying opportunities to increase knowledge and application of best practice co-design principles with people with disability across government, including people with cognitive disability.’ Singling out people with cognitive disability for inclusion in this context appears to imply special provisions or circumstances, rather than an expectation and assumption that they would be always involved in any co-design process.

Our submission is informed by feedback from **Dementia Australia Dementia Advocates** - people living with dementia, and those caring for them and supports the development of a Plan for 2027 – 2031 that is fundamentally underpinned by and cognisant of the needs, concerns and contribution of people living with dementia.

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Recommendations

Plan Accessibility

- multiple accessible formats (including cognitive accessibility), released at the same time as standard formats;
- monitoring/reporting on web accessibility and accessible ICT procurement;
- user testing with people with different disabilities to confirm accessibility works in practice.

Dementia as a disability:

- Dementia-friendly approaches within universal design which include the built environment, signage, quiet spaces, and communications;
- Specific acknowledgement of employment-inclusive actions to support people living with young onset dementia.

Housing, health and wellbeing

- Consideration of the constraints on timely access to health and housing services and supports and the associated impacts on wellbeing for people living with dementia and carers
- The importance of access to information, services, and support in relation to health and housing tailored to the specific cultural, linguistic, and other needs of diverse communities
- The importance of support for carers including respite care, counselling and peer support
- The need for dementia-specific home environment assessments to ensure they are tailored for the individual and changing needs of a person living with dementia and their carers

Restrictive Practices

- The Plan must clearly specify how restrictive practices oversight will interface with health, disability and aged care regulatory systems and complaints pathways;
- Actions to build workforce capability to minimise restrictive practices and reduce inappropriate restraint for people living with dementia across health, aged care, and disability settings.

Dementia education and workforce capability

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- Adoption of the Dementia Language Guidelines across Victorian government agencies and services, to promote inclusive and non-stigmatising language.
- Dementia-specific education for the workforce across disability, health, aged care, justice, and emergency services;
- Training that builds understanding of cognitive disability, communication, supported decision-making and changed behaviours; and
- Alignment of workforce development for health and disability services with the Plan's objectives to reduce restrictive practices, improve decision-making support and promote dignity and autonomy.

Supported decision-making and meaningful engagement

- The Plan should endorse supported decision-making as an appropriate approach to ensure that people living with disability are supported to make decisions about all aspects of their lives
- Embed meaningful engagement with people living with dementia in the Plan, supported by appropriate resources including Dementia Australia's **Half the Story**

Cross system coordination

- The Plan must outline how disability, health, primary care, and aged care systems will work together to deliver on the Plan's objectives.

Inclusive communities

Language

Communities play a critical role in enabling inclusion, reducing discrimination, and supporting access to services, activities, and spaces that all Victorians have a right to. For people living with dementia, inclusion is shaped by physical accessibility, community understanding, attitudes, and the design of everyday environments.

A dementia-friendly and inclusive community is one in which people living with dementia are supported to live with meaning, purpose, and value, and to continue participating in community life for as long as possible. Dementia-friendly and inclusive approaches respond to both the visible and invisible impacts of disability, addressing stigma and misunderstanding alongside environmental barriers.

Dementia Australia notes and supports the acknowledgement of language 'as a powerful tool for changing community attitudes' in the current Plan. We also endorse the current Plan's emphasis on the evolving nature of language and the need to respect individual preferences for how a person identifies and describes their disability. Language that describes dementia and the experience of people living with the condition, and those caring for them, also evolves over time and is equally shaped by individual preferences.

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The words used to talk or write about dementia can have a significant impact on how people living with dementia are viewed and treated in our community. Talking about dementia in a negative manner or using incorrect terminology or inaccurate facts can reinforce stereotypes and further exacerbate stigma and misinformation about condition.

Dementia Australia recommends our **Dementia Language Guidelines** are used in the development of the new Plan, as an important resource and inclusion strategy promoting the consistent use of appropriate, inclusive and non-stigmatising language in relation to dementia..

Dementia Australia Advocates consistently identified the need for the meaningful inclusion of individuals and groups from CALD, Aboriginal and Torres Strait Island communities, and other minority populations.

‘Dementia support materials, assessments, and services need to genuinely reach families from culturally and linguistically diverse backgrounds, not as an afterthought or a translated PDF, but as services delivered by people who understand the cultural context a family is coming from.’ Carer of person living with dementia

Dementia Australia recommends the new Plan incorporates:

- multiple accessible formats (including cognitive accessibility),tailored to diverse communities, released at the same time as standard formats;
- monitoring/reporting on web accessibility and accessible ICT procurement;
- user testing with people with different disabilities to confirm accessibility works in practice.
- Adoption of the Dementia Language Guidelinesto promote inclusive and non-stigmatising language

The physical environment

People living with dementia can experience their physical surroundings as confusing, disorienting or disabling, particularly when the environment is unfamiliar. For someone living with dementia, the impacts of increased noise, harsh light, visual and physical clutter, unclear wayfinding, confusing signage, and other environmental features can cause anxiety, make a space feel intimidating and interfere with their ability to feel safe and confident to navigate in public spaces, use public transport and participate in community life.

‘Physically, there might be, in certain areas, physical enablers like ramps, or even toilets that are catered for someone who might be experiencing dementia. But even though they are available, a lot of people with dementia might need the support of people to actually get to these public spaces.' Carer of a person living with dementia.

Features of the physical environment that can enhance the inclusivity, safety, comfort and participation of people living with dementia in public spaces and community life include:

- Wide, level footpaths where possible, free of obstructions and well maintained
- Accessible elevators, ramps, railings and stairs, and non-slip and non-glare floors and surfaces

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- Level changes are clearly marked and well lit, with handrails
- Building entrances clearly visible and well-signed externally and internally
- Signs with large graphics and symbols in clear colour contrast to the background, preferably dark lettering on a light background
- Signs with non-glare lighting and non-reflective coverings
- Colour contrasts for other key interior features to enhance navigation (for example doorways, toilet doors, and toilet seats)

The Dementia Australia resource **Making it Dementia-Friendly**, is written by Dennis Frost, who lives with dementia. Dennis notes that 'People Living with Dementia are often thwarted from achieving their potential by Social Stigma and difficulties in interacting in the built environment. Often some simple changes to signage for example can reduce the difficulties People Living with Dementia may have.' The resource offers a comprehensive guide to making venues and public spaces accessible and supportive for people living with dementia.

Dementia Australia's Dementia-Friendly Communities program has developed two resources outlining how state and local government, statutory authorities and providers of essential services can support inclusive communities. The Toolkit for Councils outlines the way in which local governments can make changes to transform their governance, consultation practices, and physical environments and ensure councils are more inclusive and dementia-friendly. The First Steps to Building a Dementia-Friendly Future is a community guide setting out practical tips for individuals and groups seeking to make their community more dementia-friendly. The information in these two documents offer insights into how to implement strategies to ensure people living with dementia, and their family members and carers, feel included, empowered and enabled to participate in their communities.

In promoting inclusive communities in the new Plan, it is important to highlight that people living with young onset dementia often face unique challenges. These can include providing care for children, pressures on relationships, managing work or early retirement from work and associated financial consequences, and other social, emotional, and financial challenges. Dementia Australia's **Younger Onset Dementia Guide** outlines issues and challenges for this group, and strategies, services and supports required to ensure people remain included and engaged in their communities.

Dementia Australia recommends that under the pillar of Inclusive Communities, the new Plan acknowledges:

- Dementia-friendly approaches within universal design which include the built environment, signage, quiet spaces, and communications
- Consider the suite of Dementia Australia resources cited above in developing strategies to promote communities that are dementia-friendly and inclusive

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Health, housing and wellbeing

Dementia Australia Advocates highlighted concerns in relation to accessing health and housing services with the following identified as the key issues:

- General difficulties accessing appropriate and timely health, disability and aged care services, particularly in rural and regional areas

‘We have a wonderful cognition nurse, but there's only one for all of the region. So I think she said when she was last here, she looks after 25,000 residents in the region. Not all of them have dementia, but that's her catchment area.' Carer of person living with young onset dementia.

- Lack of access to information, services, and support in relation to health and housing tailored to the specific cultural, linguistic, and other needs of diverse communities

‘Coming from an immigrant background, it was really hard to navigate Dad's diagnosis…there's really no education in our community about what it (dementia) means.’ Carer of person living with dementia

- Lack of access to specialist services, compounding delays in receiving a diagnosis, and accessing appropriate treatment and support services

‘I spent 10 years trying to get a diagnosis for my husband when I could have been preparing for our future, giving him a better life, learning more about how to take care of him - as opposed to trying to find a diagnosis – to enjoy the time that we had when he could physically do things he can't do now. We didn't have that.’ Carer of a person living with young onset dementia

- The need for dementia-specific assessment of home environments to ensure they are tailored for the individual and changing needs of a person living with dementia and their carers

‘So, we have asked for funding for home modifications to the bathroom. All we want is a shower, and toilet and basin, we don't want anything fancy, I don't care how it looks, I just need it to be functional. They're not looking at people - they're looking at the stats on the paper or, you know, the report from the doctor, but they need to speak to the carers themselves, they need to come and look at the house. There needs to be more understanding, and there needs to be more people looking at homes, helping us keep our loved ones at home.' Carer for person with young onset dementia

‘Funding and guidelines should support a comprehensive, personalised home environment planning, not a one-off device or modification. We need to identify specific risks in a home (trip hazards, confusing lighting and shadows, unclear sightlines, and pathways) and control them before they cause harm, rather than waiting for harm to occur and then reacting.' Carer for a person living with dementia

- The urgent need for carer support including respite in all forms and other options including counselling and peer support

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'Caring for a person with dementia is exhausting in a way that can quietly erode a carer's motivation to keep seeking out support, attend appointments, or stay engaged with services over time — particularly for carers who are also isolated or unsupported themselves. The next plans should consider how services are designed to actively encourage and sustain engagement over the long term, rather than assuming families will keep coming back on their own initiative once initial support is offered. 'Carer of person living with dementia

- Lack of providers to service NDIS Plans or Home Care Packages, sometimes resulting in premature admission to residential care

‘NDIS deals with generally visible disabilities. Finding staff that can identify and understand and build rapport with someone with dementia has been a five-year journey for me.’ Carer of person living with dementia

- Limited specialist disability accommodation and supported independent living options, resulting in hospital admission or premature admission to residential aged care.
- The NDIS review process creates unnecessary hardship and anxiety for carers.

‘I don't know why health systems are siloed across a chronological lifespan. I would like to see everybody of any age be granted the support they need.' Carer of person living with young onset dementia

Under the pillar of Health, Housing and Wellbeing, Dementia Australia recommends that the new Plan:

- Acknowledges and considers the current constraints on timely access to health and housing services and supports and the associated impacts on wellbeing for people living with dementia and carers
- The importance of access to information, services, and support in relation to health and housing tailored to the specific cultural, linguistic, and other needs of diverse communities
- Considers the importance of support for carers including respite care, counselling and peer support
- The need for dementia-specific home environment assessments to ensure they are tailored for the individual and changing needs of a person living with dementia and their carers

Fairness and safety

Safeguarding and restrictive practices

Dementia Australia welcomes the acknowledgement in the Engagement paper that restrictive practices raise safeguarding concerns across multiple service systems, and that existing workforce capability gaps contribute to the continued inappropriate use of restrictive practices, including the use of psychotropic medications.

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Many people living with dementia experience changed behaviours as their dementia progresses. Changed behaviour needs to be understood as a response to the person's environment and a form of communication about an unmet need. This unmet need might be physical, psychological, or emotional. Responses to changed behaviour should target the causes of the behaviour, rather than the resultant behaviour itself.

Despite consistent evidence of their limited efficacy and a high associated risk of adverse effects, psychotropic medications are still widely and inappropriately prescribed for people living with dementia.

Dementia Australia strongly supports minimising the use of psychotropic medications and the inappropriate use of other restrictive practices for people living with dementia. As outlined in detail in our position paper on the **use of restrictive practices in residential aged care,** people living with dementia have the right to freedom of movement, independence and autonomy while being safe and free from harm.

Dementia Australia recommends the final Plan clearly specify:

- How restrictive practices oversight will interface with health, disability and aged care regulatory systems and complaints pathways;
- Actions to build workforce capability to minimise restrictive practices and reduce inappropriate restraint for people living with dementia across health, aged care, and disability settings.

Dementia education and workforce capability

Inadequate levels of dementia knowledge and education in the disability, health and aged care nursing and carer workforce was a consistent theme in feedback from Dementia Australia Advocates. Dementia education for doctors, allied health workers and other health care professionals engaging with people living with dementia was also seen as often poor or inadequate, resulting in missed or delayed diagnosis, lack of information and/ or appropriate referrals to specialists, supports, and services.

'I think even doctors need mandatory dementia training updates …we were fobbed off and told they were age-related changes.' Carer of a person living with dementia

To support inclusion, safeguarding and supported decision-making in practice, Dementia Australia recommends the Plan include a focus on improving dementia capability across the public service, including:

- Adoption of the Dementia Language Guidelines across Victorian government agencies and services, to promote inclusive and non-stigmatising language.
- Dementia-specific education for the workforce across disability, health, aged care, justice, and emergency services;

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- Training that builds understanding of cognitive disability, communication, supported decision-making and changed behaviours; and
- Alignment of workforce development for health and disability services with the Plan's objectives to reduce restrictive practices, improve decision-making support and promote dignity and autonomy.

Opportunity and disability pride

Supported decision-making

The 2008 UN-CRPD represents an important recognition of the rights of people with a cognitive disability to make decisions about all aspects of their lives. Dementia Australia strongly supports the principles of supported decision-making for people living with dementia as this approach places the person with dementia at the centre of the decision-making process. As outlined in detail in our position paper on the importance of **supported decision-making**, the provision of different types of support at different stages of dementia, tailored specifically for each individual, offers an appropriate model to guide supported decision-making for people living with dementia. Dementia is a progressive condition, and there will be situations where substitute decision-making is an appropriate approach.

Dementia Australia recommends the Plan explicitly embed supported decision-making as a core inclusion principle across systems. This should include an expectation that supported decision-making is the default approach in interactions with people with disability, including in health, disability and aged care settings, and that substitute decision-making is used only where necessary and in a manner that prioritises the person's will and preferences.

'It's respecting agency and the right to make decisions that you may not agree with, but that are important to the person with dementia.' Carer of person living with dementia

Meaningful engagement

Dementia Australia recommends the Plan embed expectations for meaningful engagement with people living with cognitive disability including dementia. As emphasised earlier in this submission, this must include people from diverse backgrounds living with dementia or caring for someone with the condition.

There are a range of Dementia Australia resources available, many developed collaboratively with people living with dementia, which can assist in promoting meaningful engagement with people living with dementia. Dementia Australia's **Half the Story**, developed in close consultation with people living with dementia, is a detailed guide to conducting meaningful consultation with people with dementia, their family members, and carers.

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Systemic reforms – making government services and programs better

Dementia Australia Advocates identified the following key themes and issues in relation to system reforms required to improve the lives of people impacted by dementia:

- People living with dementia are subject to disparities and inequities in service provision depending on the age at which they were diagnosed with the condition i.e. the comprehensive level of NDIS support and services compared with aged care services
- The lack of connection and integration in existing systems providing services and supports for people living with dementia, with resultant inefficiencies including lengthy wait times for assessment and service provision and poorly managed transitions in care

'Well, I think the efficiency from the provider themselves is not there, which consequently cost us again.' Carer of person living with dementia

- Difficulties navigating and negotiating the NDIS and aged care systems, particularly for individuals who identify from diverse communities and have linguistic differences, experience digital exclusion, do not have the support of a carer or experience other challenges
- The cumulative health, social and financial inequities experienced by people living with dementia who are reliant on public health, housing, and other services.

'The systems that are there are struggling. When you present acutely, they can't deal with you.' Carer of person living with dementia

Cross system coordination

There is a strong need for clarification and integration of cross-system responsibilities across the health, aged care, primary care, and disability sectors. The new Plan should outline how disability, health, primary care, and aged care systems will work together to deliver on the Plan's objectives.

'I think it could be done if you look at health through a commonsense lens. These silos are just duplicating limited resources and causing stress, whereas they could collaborate and people would get better care.' Carer of person living with dementia

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Outcomes

The data collection and outcome reporting measures across the six systemic reform commitments outlined in the current Plan (p. 31) are appropriate and Dementia Australia supports the continuation of these measures in the new Plan. We note and strongly support the need to improve data collection in relation to Aboriginal and Torres Strait Islander communities, given the historical lack of accurate data and the corresponding limitations in planning culturally appropriate services for this community. We also strongly support the emphasis on the incorporation of Aboriginal defined evidence and measures of success.

Dementia Australia also supports disaggregated reporting that ensures the representation of all disability types in monitoring and evaluation, including cognitive and progressive neurodegenerative disabilities.

Conclusion

Thank you for the opportunity to participate in the Victorian Disability Plan consultation process. Dementia Australia supports the need for a new Victorian Disability Plan and welcomes the opportunity to discuss any of the issues raised and recommendations made in this submission in more detail.

The Dementia Australia Policy Team can be contacted at **policy@dementia.org.au**

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