



**dementia
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The new voice of Alzheimer's Australia

Transport for NSW Older Persons Transport and Mobility Plan 2018-2022

A response from Dementia Australia

January 2019

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people of all ages, living with all forms of dementia, their families and carers. We represent the more than 436,000 Australians living with dementia and the estimated 1.5 million Australians involved in their care.

Dementia Australia works with individuals, families, communities, all levels of government, and other key stakeholders to ensure that people with dementia, their families and carers are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with people who have a lived experience of dementia means that we are an important advocate for those impacted by the condition and we are also well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people living with all types of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.



What is Dementia?

Dementia remains one of the largest health and social challenges facing Australia and the world. It is not a natural part of ageing. It is the leading cause of death of women in Australia, the second leading cause of death in this country and is predicted to become the leading cause of death within the next five years.¹ Dementia is not a natural part of ageing. It is more common in older people but it can affect people in their 40s, 50s and even their 30s.

In essence, the term describes a disease process that results in progressive cognitive degeneration. It is a terminal condition that affects people's abilities and memories and it has a profound impact on the individual and their loved ones.² The condition can lead to discrimination and misunderstanding,³ it isolates people, their families and carers from social networks,⁴ and it continues to carry significant social and economic consequences.⁵

People living with dementia constitute one of the most vulnerable groups in our society. A wide range of evidence comprehensively demonstrates that the care provided to people living with dementia is worse than the care delivered to any other vulnerable group.

It is estimated that there are more than 436,000 Australians living with dementia and 1.5 million people involved in their care; by 2058 it is estimated there will be almost 1.1 million people living with dementia. These numbers include the more than 27,000 people with younger onset dementia, that is, dementia that develops before the age of 65.⁶

There is currently an estimated 146,000 people living with dementia in NSW. This is expected to increase to 193,200 by 2028 and 345,300 by 2058 without a significant medical breakthrough.⁷

The Need for Dementia-Friendly Transport

A dementia-friendly community is a place in which people living with dementia are engaged, valued and empowered to remain active in their local area. Although Australia is already taking its first steps in creating dementia friendly communities, it is clear that local communities require on-the-ground support to engage with people impacted by dementia, determine what steps to take and be empowered to make positive changes. The World Health Organisation's *Global Action Plan on the Public Health Response to Dementia*⁸ echoes the need to build community capacity, with the importance of dementia-friendly communities highlighted in its priority areas.

¹ Australian Bureau of Statistics (2018). *Causes of Death, Australia, 2017* (cat. no. 3303.0).

² Mitchell, S. et al. (2009) The clinical course of advanced dementia, *The New England Journal of Medicine*, 361: 1529-38

³ George, D. (2010) Overcoming the 'Social Death' of dementia through language, *The Lancet*, 376: 586-87

⁴ Blay, S. & Peluso, E. (2010) Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2): 163-7

⁵ Access Economics (2003) *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Report for Alzheimer's Australia, Available at: www.fightdementia.org.au/research-publications/access-economics-reports.aspx

⁶ Dementia Australia (2018). Dementia Prevalence Data 2018-2058, commissioned research undertaken by The National Centre for Social and Economic Modelling [NATSEM], University of Canberra.

⁷ The National Centre for Social and Economic Modelling NATSEM (2018) *Economic Cost of Dementia in Australia 2018-2058*

⁸ World Health Organisation (2017) *Global action plan on the public health response to dementia 2017 - 2025*

Dementia Australia welcomes the opportunity to review the *Draft Older Persons Transport and Mobility Plan 2018-2022* (the Draft Plan). When disability access to transport is considered, it is generally based on the needs of people with physical disabilities. Little, if any, provision is made for people with cognitive disabilities such as dementia. Dementia Australia commends you for making specific reference to people living with dementia and acknowledging that there are specific requirements needed to ensure people living with dementia, their families and carers enjoy safe and effective public transport.

We are pleased to note that the Draft Plan acknowledges dementia as a priority moving into the future and that consideration has been given on the need to plan, design and operate public transport infrastructure to meet the needs of people with living with dementia. Transport for NSW's understanding of the importance of social connectivity for people living with dementia and the role transport plays in facilitating this also aligns with Dementia Australia's findings. We support the action of providing dementia awareness training to frontline customer service staff and are happy to discuss how it can be most effectively implemented.

Dementia-friendly transport options are vital to ensuring that people of all ages, living with all forms of dementia, are able to remain engaged and connected with their local community. As such, our response to the Draft Plan is focused on how Transport for NSW can provide and/or support dementia-friendly transport initiatives and strengthen its support for people living with dementia, their families and carers.

The diagnosis of dementia does not necessarily mean that an individual needs to stop travelling; however travel will require increased and careful planning to ensure their safety and comfort. The transport needs of people with dementia vary with the stage and type of the dementia, individual responses and co-morbidities. Individuals diagnosed in the early stages of dementia are generally capable of maintaining their regular activities. Many continue to drive while they are cognitively capable of doing so and are capable of using public transport even as their cognitive abilities change.

There will come a point when a person with dementia will need to cease driving. Two major consequences of driving cessation are a loss of the sense of independence and autonomy, and social isolation as a result of a reduction in mobility. Without independent means of mobility, quality of life can be seriously diminished. Reduced ability to access services, visit friends and go to social events means relying more on others, which impacts on the sense of control and independence that mobility gives.⁹

The ability of people with dementia to use public transport depends on their existing familiarity with using transport. If they lose their drivers licence and start to rely on public transport for the first time, this can be harder to adjust to than for someone who has dementia but has a history of using public transport.

⁹ Alzheimer's Australia NSW (2014) *Meeting the Transport Needs of People with Dementia Final Report*

What people living with dementia and carers have told us¹⁰

My husband was used to public transport and kept using it for a long time after the diagnosis but then he got off at the wrong stop and was totally disorientated and got into a panic. So now he doesn't use it. Carer

I love the buses. I never used to use them. But I can only use them if someone helps me and reminds me when I have to get off. Person living with dementia

Dad cannot walk far so even if public transport was available we wouldn't try to use it because we don't know how far he would have to walk or whether there are steps. Carer

My daughters won't let me use the train on my own. I reckon I would be alright but they worry that someone will take advantage of me. The train does go through some rough places. Person living with dementia

Mum has problems with her eyesight and often the signs are not clear enough. That is yet another barrier. Carer

It is difficult for some people with dementia, even in the early stages, to understand timetables. Some people with dementia may have difficulty making payments for transport trips. People with dementia may find it difficult to know which bus or train to board. Even people with mild dementia can have difficulty knowing which stop to get off and can become lost and disorientated when alighting, particularly if it is the wrong stop. It can be difficult for many people with dementia to follow directions.¹¹

Access to dementia-friendly public transport options therefore becomes even more important as dementia progresses. People in different stages of dementia are likely to have different transport issues; however, the following impacts of dementia need to be considered when developing transport solutions for people with dementia:

- memory loss, for instance forgetting that a transport arrangement has been made or where they are going
- difficulty performing tasks such as organising transport, understanding timetables
- problems with language which may, for instance, make it difficult to communicate with a driver or an escort
- disorientation to time/place which may mean they get lost after transit drop off
- poor or decreased judgment
- loss of financial skills which could lead to difficulties in paying transport fares
- changes in abstract thinking, e.g. they may not be able to navigate route changes or interpret timetable signs and information
- misplacing things changes in mood or behaviour which could lead to the person being agitated or behaving inappropriately
- difficulty in coping with changes in transport arrangements.¹²

¹⁰ Quotes from Alzheimer's Australia NSW (2014) *Meeting the Transport Needs of People with Dementia Final Report*

¹¹ Alzheimer's Australia NSW (2014) *Meeting the Transport Needs of People with Dementia Final Report*

¹² Alzheimer's Australia NSW (2014) *Meeting the Transport Needs of People with Dementia Final Report*

As a result of these impacts, it is proposed that transport for people with dementia needs to:

- be flexible
- be available at short notice
- provide door through door service, rather than curb to curb
- involve no waiting
- provide escorts
- involve people trained in dementia awareness and management – whether they are paid or volunteers.¹³

It is important to recognise that the ability of people with dementia to use public transport will vary according to the severity of their symptoms and type of dementia.

Recommendations

To ensure that transport options provided by Transport for NSW are dementia-friendly, Dementia Australia recommends the following:

- Provide travel training¹⁴ opportunities to assist people with dementia.
- Provide bus service routes using small vehicles that pick-up and drop-off passengers close to their journey origins and destinations. These smaller vehicles should coordinate with regular public transport.
- Provide volunteer transport escorts who are trained in supporting people with dementia.
- Allow time in the transport timetables and schedules for passengers to board and alight without feeling rushed and provide assistance when required.
- Build pedestrian infrastructure that facilitates clear and safe access to transport services.
- Provide clear signage and directions at stops and on transport.
- Provide voice over announcements on Sydney buses to alert passengers to the current and upcoming stops (similar to those provided on train services).
- Ensure that information on routes and timetables is easy to access, read and understand.
- Work collaboratively with the Australian, NSW and other Local Governments as well as private companies as required.

¹³ The Beverly Foundation (2008) *Dementia Friendliness Calculator - The Road to Dementia Friendliness*, Beverly Foundation Fact Sheet Series, Vol 1, No.6 cited in Alzheimer's Australia NSW (2014) *Meeting the Transport Needs of People with Dementia Final Report*

¹⁴ Travel Training is a service that teaches people to travel independently on public transport. It is quite widespread in the US. Travel training may be suitable for people in early stages of dementia, or for older people who may develop dementia or become carers of people with dementia.

- Facilitate access to dementia education for transport providers and staff – not just customer service staff. People who are involved in transport should be trained to recognise dementia and be provided with the skills required to assist and support people with dementia in an appropriate manner.
- Support the development of an “I have memory concerns” card for people with dementia who regularly use public transport, especially buses. The cards could be registered and passengers could show it when they get on the bus and/or if they need help or assistance.
- Support the development of a transport app that empowers people living with dementia to maintain their independence. For example, users could input their start location and desired finish location and the app then provides voice instructions and shows them which bus/train to catch, at what time, and tells them how long they need to wait. Being GPS linked, it could recognise if the user gets off at the wrong stop and provide instructions on what to do/where to go next.
- Implement a telephone support service for people to call if they need assistance that is immediately answered by a real person not a computerised answering service.
- Have more staff at train platforms who are easily identifiable to help people living with dementia as well as other people living with disabilities.
- Implement designated ‘quiet’ waiting areas to minimise disruptions and overwhelm for people living with dementia.

Conclusion

Dementia Australia thanks Transport for NSW for the opportunity to review and provide comment on the Draft Older Persons Transport and Mobility Plan 2018-2022. We hope that you will implement the dementia-friendly transport ideas outlined in our submission and look forward to seeing improved transport options for people living with dementia in NSW.

Dementia Australia is committed to working with all levels of Governments. We can work with Transport for NSW to consult with people impacted by dementia to ensure that transport is accessible to people of all ages living with all forms of dementia, and have education consultants available to provide dementia training to staff.