

Email to: DisabilitiesTransportAccessSecretariat@infrastructure.gov.au

Review of Disability Standards for Accessible Public Transport – Draft Report

Comment from Alzheimer's Australia NSW

Alzheimer's Australia NSW is the peak body for people with dementia and their families and carers in NSW. There are more than 332,000 Australians living with dementia and, without a significant medical breakthrough, that number is expected to increase to almost 900,000 by 2050.

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in functioning, including the loss of memory, intellect, rationality, social skills and physical functioning. There are many types of dementia including Alzheimer's disease (which is the most common form of dementia), vascular dementia, fronto temporal dementia and dementia with Lewy Bodies.

Dementia is a disabling condition. It is the single greatest cause of disability in older Australians (age 65 years and over) and the third leading cause of disability burden overall.

Alzheimer's Australia NSW is currently conducting research into the transport needs of people with dementia. We will send a summary of findings from the final research report to the Department when it is published later this year.

The research is being undertaken because little is known about how people with dementia meet their transport needs. We do know that these needs 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 for a limited period of time. Many are capable of using public transport for some time.

Although little is known about the use and experience of public transport by people with dementia, some issues have been identified including:

- It is difficult for some people with dementia, even in the early stages, to understand timetables, displays or verbally communicated warnings at stations and bus bays
- Many people with dementia have difficulty dealing with scheduled timing and routes
- It can be difficult for people with dementia to wait at public places
- It can be difficult for people with dementia 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 getting off, particularly if it is the wrong stop

- Some people with dementia may behave inappropriately on public transport (either with or without a carer)
- It is difficult for many people with dementia to follow directions
- Some people with dementia may have difficulty making payments for trips.

The research has found that people with dementia have particular needs to facilitate their use of public transport yet these needs are not necessarily covered by actions taken to address access issues for people with physical disabilities. For example, the introduction of information apps on smart phones will not meet the information needs of people with dementia as the progressive nature of the condition limits the ability of people with dementia to learn new skills and adapt to changes in technology.

There are some issues that are particularly relevant to people with dementia. In particular, training transport providers in the most appropriate and supportive way to treat people with disabilities and improving access to information. However both training and the provision of information need to address the specific needs of people with dementia.

While meeting the transport needs of people with dementia is obviously not cost free, transport and other costs involved in enabling and encouraging people with dementia to live in the community are considerably less than the costs involved in caring for them in residential care facilities. The longer people with dementia live in the community the less it costs Governments to care for them in other settings such as residential aged care or hospitals.

Accessible transport is an essential factor in supporting people with dementia to live in the community. Transport enables people with dementia and their carers to access the services they need and maintain their social connections. Accessible transport for people with dementia forms part of a dementia-friendly community.

Alzheimer's Australia NSW thanks the Department of Infrastructure and Regional Development for the opportunity to review the Draft Report and hope that the needs of people with dementia will be considered in the design of accessible public transport.

Yours sincerely,



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