

**Submission  
No 10**

**ACCESS TO TRANSPORT FOR SENIORS AND  
DISADVANTAGED PEOPLE IN RURAL AND  
REGIONAL NSW**

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**Position:** CEO  
**Date Received:** 11 July 2016



**NSW Legislative Assembly**  
**COMMITTEE ON COMMUNITY**  
**SERVICES**

**Inquiry into access to transport for  
seniors and disadvantaged people in  
rural and regional NSW**

**Submission from Alzheimer's  
Australia NSW**

Alzheimer's Australia NSW is the peak body for people with dementia and their carers in NSW. We provide advocacy, support services, education and information. Our organisational mission is to minimise the incidence and impact of dementia through leadership, innovation and partnerships - in advocacy, policy, education, services and research.

Dementia describes the symptoms of a large group of illnesses that cause a progressive decline in a person's functioning including loss of memory, intellect, rationality, social skills and physical functioning. Dementia is the single greatest cause of disability in Australians over the age of 65 years and the third leading cause of disability burden overall<sup>i</sup>.

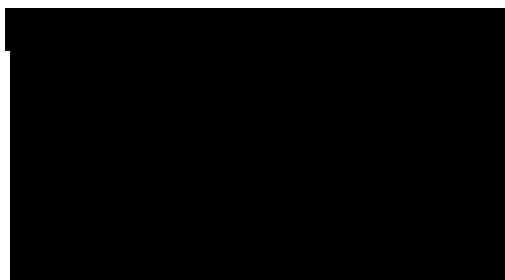
There are currently 353,000 Australians living with dementia and, without a significant medical breakthrough, it is projected that this number will rise to almost 900,000 by 2050<sup>ii</sup>. In NSW there is estimated to be almost 115,000 people living with dementia, with this number to reach 272,000 by 2050<sup>iii</sup>.

The content of our submission is primarily drawn from:

A 2014 research paper titled *Meeting the Transport Needs of People with Dementia* available at <https://nsw.fightdementia.org.au/files/NSW/documents/Meeting-the-Transport-Needs-of-People-with-Dementia-Full-Report.pdf>; and

A discussion paper *Living with Dementia in Regional NSW*, available at [https://nsw.fightdementia.org.au/files/20131113-NSW-PUB-Dementia\\_in\\_regional\\_NSW.pdf](https://nsw.fightdementia.org.au/files/20131113-NSW-PUB-Dementia_in_regional_NSW.pdf)

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Yours Sincerely,  
The Hon. John Watkins AM  
CEO, Alzheimer's Australia NSW

## Introduction

People living in regional, rural and remote NSW deserve to have equitable access to services and be supported to remain living in these areas 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 living in regional and rural areas due to geographic isolation, travel distances, and limited services and resources. 'Ageing in place' for people with dementia in regional, rural, and especially remote areas is an admirable, but not always achievable, goal because of these factors.

*"I find that carers stop looking for services, including transport. So many barriers are put up in trying to access any community service that people often throw their hands in the air and say it is all too hard and do without. They and the person with dementia become more isolated."*

These issues have been recognised by Governments and attempts have been made to address them through a range of policy initiatives. Despite these efforts, the challenges remain. Governments, regional health professionals and care service providers need to be prepared to respond to the growing number of people with dementia living in regional areas.

There are particular service access issues for regional and rural communities in the provision of social support, home care, respite, and residential aged care. Dispersed populations, distances from service centres, access to transport and travel times are also key factors.

*"It is a cumulative disadvantage because the options available within the service network are limited and distances to be travelled are longer than metropolitan people experience. In addition road conditions are generally worse and petrol more expensive in rural and regional locations." Carer*

Despite these and other limitations, our research has found that people with dementia and their carers generally do not want to move from their local

communities in order to have greater access to services. There are many benefits to country life, such as a sense of community and connection to place.

Adequate transport is regarded as key to enabling people with dementia to live at home successfully. Without mobility, quality of life can be seriously diminished. If getting out becomes more difficult, the knock on effects of reduced social interaction and activities can lead to social exclusion. 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. Furthermore, lack of access to activities and more time spent housebound often leads to reduced physical activity. Physical activity can help reduce memory loss, and improve cognitive function, which is particularly important for people with dementia.

The impact of the unmet need for transport is frustration and social isolation. 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. The Australian Institute of Health and Welfare (AIHW) estimates that 80% of people living with dementia in the community need assistance with private transport.

In a study of what people with dementia, their carers and service providers want for people with dementia, several factors were seen as key to enabling the people with dementia to live at home successfully including:

- having access to personalised activities that provide stimulation and enjoyment and are relevant to the client's interests and abilities
- enjoying the company of others instead of being isolated at home
- the maintenance of a predictable daily routine and minimising stress and anxiety
- adequate transport.

**(a) Specific issues relating to the transport needs of seniors and disadvantaged people in rural and regional NSW;**

A consistent message is that the problems of transport disadvantage and the associated flow-on effects such as, access to health care and participation in the community are most pronounced in rural and regional Australia. Transport disadvantage leads to isolation of people with dementia and carers, as well as reduced access to appropriate medical care.

*“I have had clients who have just given up trying to get anywhere, even medical appointments. If they cannot drive and community transport is not an option they give up.”*

Rural and regional areas are disadvantaged by a number of factors which have a negative impact on people with dementia and their carers, notably: distances to services and limited taxi, public and community transport options. Driving cessation can be more of an issue in rural and regional Australia because of a lack of alternative transport options and the traditional reliance on the car.

The key concerns and challenges for people with dementia, carers and service providers in regional, rural and remote Australia have been documented in previous research. These issues include:

- assessment, diagnosis and management of dementia
- education and awareness of dementia
- opportunities for social engagement and community participation for people with dementia and carers
- access to community, respite and residential aged care
- workforce issues for community, respite and residential aged care services.

Whilst these issues are also experienced in urban areas, for people in regional areas they are exacerbated by geography, distance, inadequate access to transport, limited resources and city-centric policies and service models. The most commonly cited barrier to accessing services in rural and remote Australia is the lack of available transport. The centralisation of health services has exacerbated the difficulties people in rural and regional areas experience accessing these services.

The dearth of specialist health workers has a knock on effect of imposing a transport burden on people living in regional areas. For example, people living in the Tweed, Richmond and Clarence Valleys in Northern NSW only have access to one geriatrician who is based in the Richmond Valley. Many people in regional areas are required to travel significant distances to see specialists, and, with more than one appointment needed to confirm a diagnosis of dementia, this places considerable time and financial pressures on people with dementia and their families. The issue of retiring geriatricians and psycho-geriatricians and the lack of replacements was raised in our research as a major problem.

The importance of transport access to facilitate participation and inclusion was noted.

The transport needs of people with dementia vary with the stage and type of 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. Many continue to drive and are capable of using public transport for some time. When dementia symptoms are more marked, carers tend to carry the main burden for meeting transport needs and this can be a daily stress for carers.

Over three quarters of the carers in our research met the transport needs of the person they cared for, primarily by driving them wherever they needed to go. Carers and service providers report that the toll of providing transport is high. Most carers are older, many have their own health issues, they may not drive or be confident drivers or they may care for someone who is a difficult passenger.

*“I only drive him when I have to and we don’t go far. I don’t like it and he shouts at me. He used to do all the driving and he still thinks he is a better driver than me.” Carer*

For too many, the transition to non-driver leaves the driver and carers traumatised. Driving cessation is a particular issue as there are often not alternative modes of transport, such as public transport options, available. After giving up their license many people become socially isolated and depressed. Social support programs that include linked transport are required. Anecdotal feedback, especially from service providers and community transport providers, was that people with dementia who

live outside Sydney are more resistant to addressing issues around driving and dementia.

In a study of Indigenous Australians with dementia, their carers and service providers in the Kimberley Region of Western Australia it was found that:

- Lack of public transport, access to vehicles and the high cost of fuel affect the ability of older people in remote communities to access health and community services, as well as to take part in activities and to visit family and friends.
- The large distance between remote and rural communities and the towns where the majority of health and community services providers are located affects the ability of service providers to administer quality care to people living in remote and rural regions.
- It is important to Aboriginal communities and the people with dementia that the latter can stay in the community. Community members may be reluctant to go to town based residential care because it is regarded as a place where people are sent to die

It is likely that these findings would also apply to remote areas of NSW.

#### **(b) Accessibility of current public transport services in rural and regional NSW;**

In rural communities public transport is usually minimal and often inaccessible. Lack of transport makes it harder for the people with dementia to access services and social activities and for the carer to visit the people with dementia once they are in residential care. The difficulty in accessing residential and respite care may lead to reluctance to use both services.

Having access to suitable transport is vital to enabling people with dementia and their carers to maintain a reasonable quality of life and to remain living in the community for longer. The physical and mental wellbeing of carers plays a pivotal role in whether the person with dementia can remain living in the community. Better access to alternative transport may contribute to a reduction of the number of people with dementia who continue to drive when they become unsafe drivers.



**(c) Potential strategies to improve access, including better alignment between different modes of transport, available routes and timetabling generally;**

***Public transport***

Not a great deal is known about experiences of public transport for people with dementia and relatively few of the participants in our research travelled this way. The symptoms of dementia affect a person's access to transport and they may have difficulty knowing which bus, train or ferry to catch and when to get off.

Training all transport providers in dementia and awareness is an obvious first step in making this mode of transport more dementia friendly, as is improving access to information.

Travel training and providing transport escorts are also thought to be worth investigating.

Some issues have been identified including:

- The ability of people with dementia to use public transport will vary according to the severity of their symptoms and type of dementia.
- It is difficult for some people with dementia, even in the early stages, to understand timetables, display 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 alighting, 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

*“There are no options in our area. Hardly any public transport and it is full of children, very noisy. Not many taxis come out here. I don’t think there is any option other than driving her. She certainly couldn’t travel on her own even if I could find something so someone would have to go with her and that would be me so I might as well drive her. It means we are always together which is very tiring but I don’t see any option”. Carer*

**(d) Support that can be provided to seniors and disadvantaged people to assist with the costs of private transport where public transport is either unavailable or unable to meet the needs of these groups;**

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

***Taxis***

Taxis have some advantages for people with dementia: they are flexible, available on demand and can provide door-to-door service. However, they are said to be too expensive for many people. There is low awareness of the Taxi Transport Subsidy Scheme (TTSS) program and some feedback that even with this subsidy (recently increased and very welcome), taxis are still too expensive to use as a regular form of transport, particularly in regional areas.

***Community transport***

Community transport includes the Community Transport Organisations (CTOs), funded through the Commonwealth Home Support Program and the NSW Government, and transport provided by local governments, licensed clubs and other organisations, such as schools and various not-for-profit organisations.

CTOs are major players in meeting transport needs in regional areas for the frail aged, the disabled and the transport disadvantaged. The providers have grown organically and reflect the needs and resources of the area they serve. Thus each is different from one another. Because CTOs operate differently, not all providers offer the full range of benefits but the features offered by the service can include:

1. door to door, or even door through door, service
2. service on request
3. volunteer escorts
4. rides to a variety of destinations, including shopping, medical and social outings
5. assistance for disabled passengers
6. low or little cost
7. many drivers and escorts, both volunteer and paid, are accustomed to dealing with vulnerable passengers.

Providing transport for people with dementia can be more time consuming and resource intensive for all forms of community transport. A funding system that is based on the number of trips, rather than the hours involved, will disadvantage clients with dementia.

### ***Volunteers***

Volunteers are already involved in meeting the transport needs of people with dementia. It is suggested in the literature and by people involved in transport that volunteers will play an essential role in meeting future demand for transport. On the other hand, it is also suggested that the number of volunteers will dramatically decrease. The reasons given for declining numbers in volunteering include changing demographics and changing employment patterns.

Most of the organisations consulted about their use of volunteers noted that some volunteering jobs are harder to fill and driving can be one of these. This can be due to volunteers' reluctance to use their own cars, the organisation's views on

appropriate roles for volunteers and/or licensing requirements. Despite the problems, many organisations endorse and encourage the involvement of volunteers.

The majority of participants in our research believe that having more volunteers would help to meet the transport needs of people with dementia. Ideas for extending this involvement were explored and the following ideas were widely endorsed:

- providing appropriate training, supervision and support for people who volunteer to work with people with dementia
- providing volunteer escorts for people with dementia who travel on community transport
- working with other service providers such as Neighbourhood Aid to provide support for people with dementia looking for transport
- allocating a volunteer travel buddy to make travel arrangements for a person with dementia
- using vetted volunteers who use their own cars to transport people with dementia
- targeting recruitment of particular categories of volunteers.

Many of these approaches are incorporated in not for profit transport models in the US and Australia. The US has given significant recognition to the transport challenges faced by older non-drivers. This recognition is illustrated by the memorandum of understanding between the US Administration on Aging and the Federal Transit Administration, an increase in federal and state funding for senior transportation services and increased interest by communities in organising or coordinating transportation programs for older adults. Alternative transportation options available for seniors are public and paratransit services, private and specialised transportation services and senior transportation services

### ***Alternative models***

There are many models that are geared to improving access to transport for vulnerable populations. Some of these models provide transport others provide assistance in other ways such as providing information or making transport more

effective by coordinating services, passenger schedules or modes of transport. The following are some examples of models that provide transport services.

- Transportation Vouchers Programs
- Commercial companion driver service
- Council cabs/taxis
- Targeted transport

HillsCarPal is a community initiative, which aims to reduce the social isolation of older people in the Hills district and surrounding areas by providing a flexible transport network with the help of volunteer drivers. Any senior eligible for Centrelink or DVA can access this service. Under the auspices of Hills Community Aid and with seed funding from NRMA, The Hills Shire Council, the Community Foundation of north-western Sydney and support from local businesses, HillsCarPal began operation using a Facebook page to arrange rides for seniors in August 2013. It now has 30 volunteer drivers, approximately 40 registered clients and 3 online facilitators, with 200 hundred rides provided so far. The destination for a ride can be anywhere in Sydney, and is determined by the client's particular needs. HillsCarPal's volunteer drivers are not asked to make a special trip to take clients where they want to go, rather just a detour as part of a trip they would be making anyway. It aims to be on demand, is not limited to office hours or week days and is about providing transport in a "neighbourly" way. Matching clients' requests for transport with volunteer drivers is managed using a Facebook "secret" group, but facilitator assistance is also available to clients who are not online. Such "phone clients" pay an annual fee of \$30 for phone support. Requests can be made well in advance or with as little as 2 hours' notice. There is no cost to clients until they use the service. They are billed monthly at \$7.50 per trip and an escort can also travel for no extra cost. Volunteer drivers are reimbursed monthly at \$5.00 per trip. Payments are made electronically. All drivers have their licenses and Greenslip insurance verified, a police check undertaken by Hills Community Aid (HillsCarPal) and are interviewed by the convener before they can offer rides. Once registered, they receive an ID badge, a Mobility Parking Scheme permit and flag for their car. [www.hillscarpal.org.au](http://www.hillscarpal.org.au)

UCCTT – is a community volunteer transport organisation, under the auspices of the Uniting Church that operates in the Northern Rivers region. UCCTT’s website states its mission is “to see that no person goes without the necessary transport, when it is needed” and “to allocate a volunteer with a caring and listening ear who will transport the client to their medical related appointment or treatment, then safely return them home, if needed”. Trained volunteers in their own cars provide this transport for residents of Casino, Lismore and their outlying areas to as far away as Brisbane and the Gold Coast. It is a “door through door” service. Drivers are familiar with dementia and can usually support a client with dementia on their own, but if extra help is required, a volunteer “carer” escort can be arranged. UCCTT has 38 drivers, many of whom are retired bus and taxi drivers and couriers. Last year they carried out 3510 trips and covered 275,020km. Bookings can be made by phone 7 days per week from 8am to 6pm, and whilst some notice is preferred, they will do their best to assist with “on demand” requests. Whilst UCCTT receives some funding from Department of Veterans Affairs and Cancer Council for transporting their clients, they raise the majority of funds to cover their operational costs. <http://www.ucctt.org>

Independent Transportation Network, a national privately run, not for profit system involves the use of private automobiles, 24 hours a day. Rides are provided by both volunteer and paid drivers who assist passengers door-through-door or door-to-door. Users pay an annual, minimal subscription to join and make a small contribution for each trip. Volunteer drivers earn credits that they can give to older relatives, to low income seniors, or keep for their own future use. The system is not specifically for people with dementia but is well suited to them. <http://www.itnamerica.org/what-we-do>

In Western Australia, aged pensioners living in rural and remote areas received a \$500 Country Age Pension Fuel Card to put towards fuel costs of private cars or taxis.

**(e) Any other related matters.**

Our research identified policy initiatives that have been implemented by the Australian and NSW Governments to compensate for increased travel time and the costs associated with service delivery in rural and regional areas. These include:

- remoteness funding supplements for residential and community aged care
- prioritised access to capital grants for residential aged care
- a resource allocation formula for block funded community care programs
- incentive payments for use of telehealth
- improved access to mental health services and supports
- a practice incentives program with targeted initiatives for GPs in rural areas
- the purchase of more flexible service delivery arrangements to meet local needs

While these initiatives are not all directly about transport, some decrease the need for, or the burden of transport on people with dementia and their families.

Our research highlighted that vehicles are currently under-utilised by Local Governments, ClubsNSW and other organisations. It would be valuable for the NSW Government to explore ways that this surplus capacity can be captured to meet the transport needs of people with dementia and other disadvantaged groups in regional and rural areas of the State. The models of ride sharing platforms could be an avenue to increase use of State assets, while meeting the social needs of a vulnerable population.

**References**

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<sup>i</sup> Australian Institute of Health and Welfare (2012) *Dementia in Australia*

<sup>ii</sup> *Ibid.*

<sup>iii</sup> Alzheimer's Australia NSW and Deloitte Access Economics, August 2014