MEETING THE TRANSPORT NEEDS OF PEOPLE WITH DEMENTIA

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Prepared by Alzheimer’s Australia NSW

NSW Government
Family & Community Services
Ageing, Disability & Home Care

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Meeting the transport needs of people with dementia

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Acronyms used in this paper

ACAT  Aged Care Assessment Teams
ADHC  Ageing, Disability and Home Care in the NSW Department of Family and Community Services
AIHW  Australian Institute of Health and Welfare
AlzNSW  Alzheimer’s Australia New South Wales
AlzVic  Alzheimer’s Australia Victoria
CALD  Culturally and Linguistically Diverse
CDC  Consumer Directed Care
CTOs  Community Transport Operators
CTP  Community Transport Program
DVA  Department of Veterans Affairs
GLBTI  Gay, Lesbian, Bisexual, Transgender and Intersex
GP  General Practitioner
HACC  Home and Community Care
NCST  National Center for Senior Transportation
NSW  New South Wales
STP  Supplemental Transport Programs
RACV  Royal Automobile Club Victoria
RMS  Roads and Maritime Services
TRIP  Transportation Reimbursement & Information Program
TTSS  Taxi Transport Subsidy Scheme
US  United States
UCCTT  Uniting Care Casino Transport Team
VA  Vision Australia
WA  Western Australia
EXECUTIVE SUMMARY

Introduction
Ageing, Disability and Home Care (ADHC) in the New South Wales (NSW) Department of Family and Community Services, provided funding to Alzheimer’s Australia NSW (AlzNSW) to undertake a project investigating the transport needs of people with dementia and what can be done to meet these needs.

The Project involved an overview of the literature and fieldwork. Five surveys were conducted in NSW involving: 96 people with dementia and carers, 51 service providers, 31 community transport operators, 55 local governments and 16 licensed clubs. In addition nearly 100 interviews were conducted with a mixture of stakeholders, people with dementia, carers and service providers and six focus groups were run with AlzNSW Consumer Advisory Groups.

The feedback from all sources involved in the Project was remarkably consistent.

Why transport is important for people with dementia
There is a lack of focus on the mobility needs of people with dementia. This appears short sighted for a number of reasons:

- The number of people with dementia is large and growing rapidly.
- Providing care for the increasing numbers of people with dementia is very expensive for Australia, particularly residential care; the longer people with dementia live in the community the less strain will be placed on the health and aged care sectors and government budgets.
- 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.1 2 3

Adequate transport is regarded as key to enabling people with dementia to live at home successfully4. The Australian Institute of Health and Welfare (AIHW) estimates that 80% of people living with dementia in the community need assistance with private transport5. The impact of the unmet need for transport is frustration and social isolation.

The lack of attention to transport is inconsistent with the State and Australian governments ageing policies, which focus on the importance of maintaining participation in community activities and with keeping people in the community rather than in residential care6 7. In order for the Australian and NSW governments’ person centred approaches to funding to be successful, the person needs to have appropriate options, including transport options. Governments have acknowledged the importance of providing transport for vulnerable populations and have invested in the provision of these services, but the transport needs of this group are a long way from being met.

The impact of dementia on access to transport
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, this can be a daily stress for carers.

Over three quarters of the carers in this Project 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. Carers may be working and have other responsibilities.

Almost all participants agreed that meeting the transport needs of people with dementia is difficult. Over half of community transport operators (CTOs) report that there is an unmet demand for transport from this vulnerable group of clients. Service providers rank transport as one of the three most important types of assistance they provide in helping people live in the community.

The symptoms of dementia which may make it difficult for people to access suitable transport include:

- memory loss
- difficulty performing tasks such as organising transport
- problems with language
- disorientation to time/place
- poor or decreased judgment
- reduced capacity for abstract thinking
- misplacing things
- changes in mood or behaviour which may involve behaving inappropriately while travelling
- difficulty in coping with changes to arrangements

In response to considerations of these characteristics the literature and the fieldwork suggests that transport for people with dementia needs to:

- involve people trained in dementia awareness and management – whether they are paid or volunteers
- provide escorts, especially for people who do not travel with a carer
- provide door to door or door through door service, rather than curb to curb
- involve no waiting
- be flexible
- be available at short notice.

In addition to the difficulties noted above, there is a widespread need for information on available transport. People find it difficult to find and interpret the various sources of transport information. It is widely acknowledged that people need this information: it assists with the smooth transition to becoming a non driver and enables people to access the services and activities they need in order to live well in the community. The preferred answer to this need is to have a case worker or mobility manager who can provide individual assistance, however this is seen as an ideal solution and difficult to implement.

Other preferred sources of information are printed material. There is limited support for websites among people with dementia and carers and even less for apps.

In addition to the common concerns noted above, there are particular issues associated with different modes of transport. Challenges arising from driving cessation are reported to have an enormous emotional impact and this is the area most comprehensively covered by existing research.

**Driving with dementia**

Given the predicted increase in the number of people in Australia with dementia, the issue of driving is going to become even more pronounced. It is widely accepted that some people with dementia are competent drivers, however all people with dementia have to stop driving eventually. For too many, the transition to non driver leaves the driver and carers traumatised. After giving up their license many people become socially isolated and depressed; both conditions can exacerbate the symptoms of dementia.
People involved in moving a driver with dementia to driving retirement have not been well served by existing resources. Action has been slow, even though the need has been identified for quite some time. In the last two years some resources have been made available in NSW and Victoria, developed from funding from those states’ motoring bodies. However, these are state based resources and do not address all the issues that make driving cessation difficult. Many other countries have central sites on dementia and driving that cover all jurisdictions with appropriate links. Issues concerning dementia and driving do not vary greatly across Australia and the regulations and the driving assessment process established by Austroads are uniform across the country.

In keeping with previous research, the Project found that the awareness of the legal requirements for a driver with dementia is too low; nearly half of the people with dementia and carers surveyed did not know dementia is a condition that a driver is required to report to Roads and Maritime Services (RMS). Just over one third were aware that a driver with dementia cannot hold an unconditional license. There is also confusion around the assessment process; the Austroads prescribed procedure appears to be somewhat haphazardly implemented. This may be partly due to the high cost of the on-road driving assessment, a cost which is almost always borne by the driver. The lack of knowledge was also found in discussions with service providers and is reported to be common among health professionals.

In addition to knowing the legal requirements, people dealing with dementia and driving need resources on:

- tips on travelling safely with a passenger with dementia
- how to have the conversations about retiring from driving
- the role of doctors, service providers and others in helping someone give up driving
- strategies for when someone will not give up driving when they should, and
- how the retiring driver with dementia can stay mobile and not become isolated.

When addressing driving cessation it is better to start the discussion in the early stages of dementia when it may be easier to involve the person in the decision and to develop and practise alternative transport arrangements. It can also be helpful to involve others, such as a health professional, in the discussion.

Despite the research that is available and the consensus about many strategies that should be pursued, inaction around the issue means that many people will find driving cessation traumatic and many will drive when they are a risk to themselves and others.

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, taxis are still too expensive to use as a regular form of transport.

Apart from the cost, there is some perception that taxi drivers may not have appropriate levels of dementia awareness. Wider and more extensive training for the taxi industry would be welcomed and may help drivers and clients to build trusting relationships.

Public transport

Not a great deal is known about people with dementia’s experiences of public transport and relatively few of the participants in this Project travelled this way. However, it is clear that the general points outlined earlier on how the symptoms of dementia affect a person’s access to transport are relevant in this context. In addition, people with dementia 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.

**Community transport**

Community transport includes the CTOs, largely funded through HACC, and transport provided by local governments, licensed clubs and other organisations, such as schools and various not-for-profit organisations.

The CTOs are the major players. They provide transport 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:

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

While the nature of the CTOs vary, they are facing some common challenges. In particular, the move of HACC funding to the federal government in 2015 and the ongoing and ever increasing demand for health transport. The focus on health transport helps people with dementia to meet this particular need but they have more frequent transport needs which are largely social. The CTOs can meet some of these needs, especially providing transport to day care centres, but overall the providers struggle to meet the transport needs of people with dementia.

The particular challenges that CTOs raised in providing transport for this group included dealing with people who exhibited dementia symptoms but were not diagnosed, providing transport for people living alone with dementia who may have particular difficulties organising and travelling without a carer and the funding arrangements.

Training for paid CTO staff and volunteers in dementia awareness and management is seen as one of the major requirements for meeting challenges posed by providing transport for some people with dementia. Another key strategy is for a carer or escort to travel with the person. CTOs are also looking for ways they can help people who may not have a diagnosis and who therefore do not receive services that may assist them.

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.

CTOs have varying levels of volunteer involvement. Some have few or none, while others have an extensive volunteer program. In total there are 3,500 volunteers supporting CTOs in NSW. Volunteers also tend to be a feature of alternative models of transport that have grown in the US and Australia. While many of these models involve clients with dementia, none of them specifically targets this group. However, given the appropriate awareness and management training most of the models may be suited to meeting some of the transport needs of people with dementia.
Role of 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 hand, it is also suggested that the role of volunteers will dramatically decrease. The reasons given for a declining role 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 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.

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

In the US there are more than 1000 transport organisations that aim to reach a population of older adults with special mobility needs. These organisations have been labelled Supplementary Transport Programs (STPs). Most appear to have grown organically to meet a local need, some have grown to cover large areas and provide a huge number of trips for little or no cost to the passengers.

In NSW, there are a considerable number of organisations dedicated to providing transport to medical appointments. Again these models do not necessarily provide transport for people with dementia but they may be useful in thinking about how the transport needs of this group could be met, particularly their health transport needs.

Other suggested models that may develop to help meet the transport needs of people with dementia include:

- facilitating a Facebook application linking volunteer drivers and escorts and people with dementia who require transport
• creating virtual communities using an app/portal such as ‘lotsahelping hands.com’
• creating a time banking arrangement for volunteer transport.

Special needs groups
Some groups of people with dementia face particular challenges in getting their transport needs met.

People with dementia who live alone
There are growing numbers of people with dementia living alone; research indicates that up to one third of people with dementia who live in the community live alone\(^\text{12,13}\). Participants often noted that people with dementia who live alone are more at risk of becoming socially isolated partly because they can find it too difficult to organise transport.

Meeting the transport needs of these people can be especially challenging for a number of reasons. Community transport operators noted in discussions that they often notice symptoms of dementia developing in people who live alone and are unsure how to handle this.

Aboriginal people with dementia
Research indicates that the prevalence of dementia is substantially higher among Aboriginal Australians than among non-Indigenous Australians but Aboriginal Australians are much less likely to access appropriate services.\(^\text{14}\) Many Aboriginal people in NSW live in areas that are characterised by a lack of transport options especially for those without access to a car. The transport problems of these areas compound other issues of disadvantage faced by Aboriginal communities, including health issues.\(^\text{15}\)

Providing culturally appropriate transport for all Aboriginal people, including those affected by dementia, involves recognising and being sympathetic to both cultural factors and the multiple disadvantages many face.

People with younger onset dementia
The support and service needs for younger people, their family and carers can be different from people who develop dementia at an older age. Often people with younger onset dementia do not fit into mainstream dementia services as they are not age appropriate\(^\text{16}\).

People with younger onset dementia are likely to: miss out on subsidised transport because they do not meet criteria, may have less support available from a carer to assist with travel, be uncomfortable if they are younger than other people on community transport, or want to go to different locations than older people with dementia\(^\text{17}\).

People with dementia from CALD backgrounds
The cultures, experience and needs of older people from culturally and linguistically diverse (CALD) backgrounds are very diverse. Given this, a single model of service delivery, including transport, may be inappropriate to meet the needs of CALD people with dementia\(^\text{18}\).

People from CALD backgrounds are most likely to face particular difficulties in accessing transport because:
• it is difficult to find culturally appropriate support to explain options or to accompany people with dementia
• information on transport in languages other than English is usually difficult to find
• people with dementia may miss out on services as they are unaware that they exist or how to access them.
Older women from some CALD backgrounds are said to be less likely to drive than older Anglo Australian women. There were several reports of older CALD female carers who had returned to driving but who were not confident in doing so.

**People with dementia from regional, rural and remote areas of Australia**

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 and on the metropolitan fringe\(^\text{19,20}\). Transport disadvantage leads to isolation of caregivers and people with dementia, as well as reduced access to appropriate medical care.

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. Lack of alternative transport options and the traditional reliance on the car, means that driving cessation can be more of an issue for people in non-metropolitan areas.

**Gay, lesbian, bisexual, transgender & intersex (GLBTI) people with dementia**

No figures were found on the number of GLBTI people who have dementia. Based on related data it is estimated that there are approximately 26,000 people with dementia in Australia\(^\text{21}\).

As for all services for GLBTI people, transport services need to recognise the sexual and gender diversity needs of people. Literature on GLBTI people recommends that community service providers should be trained in GLBTI appropriate and competent care. Those supporting GLBTI people with dementia need to be aware of their legal responsibilities regarding discrimination\(^\text{22}\).
**SUGGESTED STRATEGIES TO ADDRESS KEY AREAS OF NEED**

While this report was prepared with funding assistance from ADHC in the Department of Family and Community Services, the suggested strategies outlined below do not necessarily reflect the views held by ADHC, the NSW Government or the Minister for Ageing, Minister for Disability Services.

No one organisation or sector can be responsible for meeting the transport needs of people with dementia; it will require many organisations to take action. We need a shift in the mindset that labels the problem as something to be addressed by others to an approach that is inclusive.

This section of the report suggests strategies that can help meet needs identified in this Project. The strategies are grouped into key areas of need: training, information, travel escorts, provision of transport, retiring from driving, paying appropriate attention to the issue and knowledge gaps.

**Training**

There is a clear and recognised need for all transport workers and volunteers to be trained in dementia awareness and how to support clients who may have dementia.

- Training resources for transport workers and volunteers who work with people with dementia need to be developed and implemented. These resources could build on existing resources such as *Is It Dementia*. Resources need to be tailored to the needs of each transport sector, provide a range of material and include an evaluation component. Ideally the training resources will be appropriate for national use; the issues and knowledge involved do not vary greatly by jurisdiction.

**Information**

Accessing relevant information on travel options is difficult for many people with dementia, carers and service providers. This information is essential to enable people to access transport that will enable them live in the community. Access to information on travel options may also make the transition to driving retirement timelier and less traumatic for many.

- Investigate how information on transport available to people with dementia can be coordinated in such a way that it is accessible to potential users and service providers.
- Ensure that transport issues are addressed when clients are allocating resources they receive in packages.
- Ideally there should be one information source for all local transport options.
- People with dementia and carers need to be consulted when information resources are developed.
- Information on transport options for people with dementia and carers should be available all community languages.
- Information on transport options should be available at physical and electronic locations that people with dementia and carers are likely to visit. For example, where possible relevant NSW websites should include links to CTOs, the NRMA driving cessation resource, application forms for mobility stickers, the TTSS, the Companion Card and any other programs that may assist people to stay mobile.

**Escorts for people with dementia when they travel**

The symptoms of dementia can mean that people need an escort when travelling; some transport providers require a person with a diagnosis of dementia to travel with a carer. However, many people with dementia do not have carers to accompany them on transport.
Meeting the transport needs of people with dementia

- If travel escort programs are established for vulnerable populations, ensure that the particular needs of people with dementia are incorporated into the planning and execution of the program.
- Transport providers should work with organisations that can provide volunteer escorts.
- Transport providers should be encouraged to provide escorts for some people with dementia.

Provision of appropriate transport services
There is an existing unmet need for transport for people with dementia; this need will increase as the numbers of people with dementia increase and as the demand for appropriate transport grows with the ageing population. The following suggestions may help people with dementia to access transport services that meet their needs.

- Make allowances for the extra time and resources required to transport many people who have dementia; particularly on community transport.
- Ensure that people with dementia can access transport to meet their social needs, as well as attending medical appointments.
- Increase the TTSS and make it easier for people with dementia to apply.
- Encourage recognition, recruitment and retention of suitable volunteers. This will require addressing issues such as training, insurance needs and reimbursement for incurred costs.
- Investigate how vehicles currently under utilised by Local Governments, ClubsNSW and other organisations can be involved in meeting the transport needs of people with dementia.
- Investigate some of the alternative models of transport to establish if they have the capacity and desire to include transport for people with dementia. Provide the appropriate training and support for interested and suitable organisations.
- Implement measures that may help people in regional and rural areas meet their transport challenges. Measures that could be considered include a fuel subsidy and extending the TTSS for those areas.
- Support travel-training programs in NSW and investigate whether travel training can be tailored to the needs of people with dementia.

Assisting people with dementia to retire from driving and to remain mobile
Retiring from driving is a major issue for many people with dementia. They, their carers and service providers need resources and guidance to make the transition to non driver and to remain mobile.

- Develop a resource for GPs and other health professionals that includes basic information on the regulations on driving and dementia as well as some suggestions on how to help people move to driving cessation.
- Ensure that GPs and specialists such as gerontologists and neurologists have an information pack on driving and dementia to issue to patients with dementia at the time of diagnosis. This material should include the need for dementia patients to prepare to cease driving, the need to check their insurance liabilities and to disclose a diagnosis of dementia to their licensing authority. This material should also be available for ACATs, Dementia Advisors and other health professionals.
- People with dementia should be advised by service providers, educators and health professionals of their legal obligation to notify their licensing authority if they wish to continue to drive.
- Develop driver testing regimes that more accurately assess a person’s cognitive capacity to drive. Testing regimes are being developed overseas that may be appropriate for use in Australia.
Meeting the transport needs of people with dementia

- Address the issue of cost and accessibility of on road driving assessments so that the service is timely and affordable.
- Assess the supply of occupational therapist who can conduct on road driving assessments for people with dementia, particularly in regional areas.
- Ensure national uniformity in regulations and testing of drivers with dementia.
- Ensure that information on driving with dementia is accurate, easily accessible and widely distributed.
- Promote programs that better enable early diagnosis of dementia so those diagnosed have the opportunity to participate in planning and decision-making regarding the transition from driver to non-driver.
- Insurance companies should provide consistent, clear advice to policyholders about the implications of driving with dementia and the need to disclose the diagnosis to the licensing authority.

There are some issues around driving and dementia that are specific to the licencing authority. Suggestions concerning the RMS are below. These points were previously raised in AlzNSW’s 2010 paper on Driving and Dementia.

- Update the RMS website so that a person’s responsibilities after a diagnosis of dementia are clear. Include further helpful information such as how the assessment process works and the availability of an ID card in lieu of a driver license.
- Reissue A guide for older driver licensing with a specific section on dementia and driving that stress the legal duty of a driver to report a diagnosis of dementia
- Work with NSW Police to develop a robust tracking mechanism to report the actual number of dementia related traffic accidents.
- Improve the recording of information collected from medical professionals with regard to drivers with dementia.
- Provide dementia awareness training for relevant RMS staff.

Further suggestions are made below in response to issues that have been identified in this Project.

- Streamline the communication channels between doctors, the RMS and occupational therapists who undertake on road assessments and drivers with dementia.
- Ensure that all relevant RMS staff are aware of the licensing requirements and assessment process for a driver with dementia.

Keeping the issue on the agenda
The mobility needs of people with dementia are often overlooked. Attention needs to be focused on these needs, which are often different from the transport needs of other vulnerable populations.

- Organisations that provide direct support to people with dementia need to work in cooperation to keep the transport needs of people with dementia uppermost in the minds of policy makers.
- Driving and dementia and many other transport issues can be addressed on a national basis. Australia needs national resources in line with those produced for Canada, the UK, the US and New Zealand.
- Avoid the tendency to do more research when action is needed and supported by existing work. Focus on getting identified changes implemented.
- Be mindful of the transport needs of people with dementia when organising any type of function that involves people with dementia or carers.
Undertaking research to fill knowledge gaps
Some of the actions noted above will fill knowledge gaps and help us to better address this area, such as tracking the number of accidents that involve drivers with dementia. In addition to the above suggestions further research is required to understand the transport needs of special needs groups.

- In particular, further knowledge is needed of the driving and mobility experiences of people living alone with dementia, people with dementia from CALD backgrounds and Aboriginal and Torres Strait Islander people with dementia.
INTRODUCTION AND RESEARCH OBJECTIVES

ADHC in the NSW Department of Family and Community Services provided funding to AlzNSW to undertake a project investigating the transport needs of people with dementia and what can be done to meet these needs.

The research objectives of the Project were to:

- Understand the transport needs of people with dementia, including the needs of five specific special needs groups with dementia
  - people living alone
  - people in rural and regional Australia
  - Aboriginal people
  - people from CALD backgrounds
  - GLBTI people
  - people with younger onset dementia.
- Identify existing barriers to having these transport needs meet.
- Report on work that has been done in Australia and internationally on developing appropriate transport for people with dementia.
- Address the issue of transport affordability for people with dementia.
- Make recommendations addressing the issues of transport for people with dementia from a person centred perspective.

After discussion with ADHC, these objectives were slightly revised to reflect some of the findings of the Literature Overview; in particular the focus on the specified special needs groups was modified.

Research Methodology

The Project commenced in late 2012 and was conducted over a two-year period; it involved six phases:

Phase 1  Informing and designing the Project - the output from this phase was a Project Plan which was approved by ADHC.

Phase 2  Conducting the Literature Overview - the overview guided and informed the remaining phases of the Project.

Phase 3  Developing a detailed fieldwork plan and obtaining ethics approval.

Phase 4  Conducting the fieldwork - qualitative and quantitative fieldwork was conducted with: people with dementia and carers, service providers, transport providers, relevant peak bodies, local governments, licensed clubs, peak bodies and other stakeholders.

Phase 5  Initial analysis and testing of findings – findings were tested in discussions with a mixture of service providers, 6 Alzheimer’s Australia NSW Consumer Advisory groups made up of 60 people with dementia and carers, and other stakeholders.

Phase 6  Detailed analysis and report writing.

Modifications to the Project Plan

After discussing the themes that emerged in Phase 2 with ADHC, it was decided to place less emphasis in the fieldwork on two of the five special needs groups: GLBTI and Aboriginal Australians with dementia. It was agreed that researching the transport needs of Aboriginal Australians with dementia would not be valid as the scope of the Project could not allow for the wider issues affecting Aboriginal health and access to services. It was decided not to pursue the transport needs of GLBTI people with dementia, partly because it would be difficult to obtain a reasonable sample of
the people included in this description, but also because of feedback from initial stakeholder interviews and from literature on GLBTI transport needs.

The Literature Overview also illustrated difficulties in covering the transport needs of people from CALD backgrounds. There are many CALD groups in Australia and their issues are often different from each other. For instance, some groups consist primarily of recent arrivals while others have been in Australia for several generations. However, it was decided to include the views of people with dementia from CALD backgrounds, their carers and service providers where possible as there are some issues, such as language barriers, which tend to be common across most CALD groups.

This report brings together the learning from all phases of the Project.
OVERVIEW OF ISSUES IN THE LITERATURE

Introduction
The literature search for the paper drew on a variety of data-bases covering transport, psychology, gerontology, social work, occupational therapy, as well as more general data bases such as Pubmed, Medline, Google Scholar and Google. A number of search terms were used including ‘dementia’, ‘transport’, ‘mobility’, ‘public transport’, community transport’, ‘living alone’, ‘rural and regional’, ‘driving’ as well as various combinations of terms.

The searches were extensive but not exhaustive. The aim was not to track down every article but to obtain an overview of the issues from the various sectors that have provided information about transport for people with dementia and to identify models that may be applicable in Australia.

Why does it matter if people with dementia have access to transport?
A review of the literature could lead to the conclusion that dementia friendly transport is not an important issue. While there is widespread concern about the driving abilities of people with dementia, there is very little focus on access to appropriate transport. The lack of focus on the mobility needs of people with dementia appears to be short-sighted for a number of reasons:
- The number of people with dementia is large and growing rapidly.
- Providing care for the increasing numbers of people with dementia is very expensive for Australia, particularly residential care; the longer people with dementia live in the community the less strain will be placed on the health and aged care sectors and government budgets.
- Having access to suitable transport is vital to enable people with dementia and their carers to maintain a reasonable quality of life and to remain living in the community for longer.
- 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.

The number of people affected and the cost of caring for people with dementia

The numbers
While dementia is not an outcome of ageing, the incidence rises markedly with age. Australia, like many developed countries, has an ageing population.

There were 3.08 million people aged 65 years and over in Australia at June 2011, an increase of 26% since June 2001. In 2007, people aged 65 years and over made up 13% of Australia’s population. This proportion is projected to increase to between 23% and 25% in 205624.

Over the past two decades, the number of people aged 85 or more increased by 170.6%, compared with a total population growth of 30.9% over the same period25. There were 344,100 people aged 85 years and over in Australia at 30 June 2007, making up 1.6% of the population. This group is projected to continue to grow rapidly to between 4.9% and 7.3% of the total population by 205626.
In the year ended June 2010, the per cent of people aged over 85 in New South Wales increased by 6.3%27. Three in ten people over the age of 85 have dementia28.

In terms of numbers – there are currently approximately 332,000 Australians living with dementia. In less than 10 years that number is expected to increase to 400,000. Without a major medical breakthrough, by 2050 the number of people with dementia is expected to grow to almost 900,000. Approximately 860,000 of these people will be aged 65 or more29.

In 2011 in NSW there were approximately 102,000 people with dementia30. By 2050 the NSW Dementia Framework estimates there will be approximately 341,000 people with dementia in the
Meeting the transport needs of people with dementia

State. It is estimated that younger onset dementia affects 24,700 people in Australia. Approximately one third of these people live in New South Wales. Among people with dementia living in the community, 80% are likely to need help with private transport.

**The cost**
Dementia is the single greatest cause of disability in Australians aged 65 or older. By 2030 spending on dementia will become the third greatest source of health and residential aged care spending.

AIHW estimated that of the approximately 298,000 people with dementia in 2011, 30% lived in care accommodation while 70% lived in the community. Of the 15% of people with severe dementia, 9.5% lived in care accommodation, and 5.5% lived in the community. Of the 30% with moderate dementia, 18.9% lived in care accommodation and 11.1% in the community. Of the 55% with mild dementia, 1.8% lived in care accommodation and 53.2% lived in the community.

Allowing for higher costs of caring for the higher percentage of people with severe dementia who are in care accommodation; it appears that the costs of providing care for people with dementia in care facilities far outweighs the costs of providing support services that enable people with dementia to be cared for in the community.

The costs of transport solutions to meet the needs of people with dementia and their carers should therefore be considered in relation to the cost of care accommodation. While meeting these transport needs 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.

**The carers**
An estimated 200,000 Australians provide unpaid care to people with dementia. The loss of cognitive function means that a person with dementia gradually loses insight into their level of functioning and, over time, becomes unable to seek assistance when assistance is needed. This is likely to reach a point where constant supervision and guidance is required. It is only with the assistance provided by informal caregivers that most of these people can continue to live at home. The physical and mental wellbeing of carers therefore plays a pivotal role in whether the person with dementia can remain living in the community.

The commitment to care for someone with dementia involves major and ongoing commitment on the part of the carer – the time involved, the disruption of normal routines and lifestyle, the physical demands of caring on a 24-hour basis, the constant vigilance, and the restrictions on contacts with friends and wider family are just a part of what caregiving entails.

The shift in Government policy emphasis towards community based care for older Australians, including people with dementia, has considerable benefits for the individuals and the community but is often provided at a considerable personal cost to the family members who become principal carers. It has been established that caring for people with dementia can lead to physical and psychological problems, social isolation and financial difficulties. Given that governments, service providers, carers and people with dementia all wish to support people with dementia being cared for in the community for as long as it is practicable, it is important that carers are supported emotionally and practically in their role.
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

Difficulties in accessing social services for both rural and urban carers can in turn act as barriers to accessing paid work. The findings of a study of the competing pressures of work and care suggest that the way in which services are provided – for example, short day care hours or service provision without any accompanying transport facilities – does not suit the needs of working carers and makes it less likely they will be in paid work. The future supply of carers is likely to depend increasingly upon people’s ability to combine work and caregiving responsibilities. The NSW Dementia Framework notes that it is likely that the numbers of carers will not increase as fast as the numbers of those needing care and that there is likely to be a higher percentage of working carers.

For many carers and service providers providing safe transportation for the person with dementia is an everyday or every journey challenge. Lack of transport options increases the reliance on carers to provide transport for every trip. Expanded affordable transport options would contribute to an increased quality of life through participation and mobility and would lessen stress for carers.

The role of transport in maintaining a reasonable quality of life

Traditionally transport policy has been guided by an economic paradigm focused on connecting people with employment. Increasingly it is also being seen as a vital link between people and health services, social interactions and education as well as supporting a person’s ongoing engagement with society. Safe mobility for all people is vital to ongoing engagement in social, civic and community life and to the human interactions necessary for health, well-being and quality of life.

Having a cognitive disability such as dementia does not necessarily mean that you stop travelling, but rather that travel requires careful planning to ensure safety and comfort for all involved.

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 for a limited time. Many continue to drive and are capable of using public transport for some time.

While more research is needed to get a better understanding of the impact of a lack of transport on the lives of people with dementia, two major consequences of driving cessation are reported in the literature:

- a loss of the sense of independence and autonomy, and
- social isolation as a result of a reduction in mobility.

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 dementia sufferers. These potential negative health impacts represent a cost to governments, in terms of both health treatment and need of public support, the faster the more extreme symptoms of dementia develop the sooner the person with dementia is likely to need residential care.
The lack of attention to transport is inconsistent with the State and Commonwealth ageing policies, which focus on the importance of maintaining participation in community activities and with keeping people in the community rather than in residential care. Providing person centred transport options for people with dementia fits with numerous government policy commitments such as Living Longer Living Better\textsuperscript{50, 51}.

In order for the federal and NSW governments’ person centred approaches to be successful the person needs to have appropriate options, including transport options.

**Do some groups of people with dementia face particular challenges?**

That some groups of people with dementia face particular challenges is widely recognised. The groups that this overview paid particular attention to were:

- people with dementia who live alone
- Aboriginal people with dementia
- people with younger onset dementia
- people with dementia from CALD backgrounds
- people with dementia living in regional, rural and remote areas
- GLBTI people with dementia

**People with dementia who live alone**

Growing numbers of people living alone, coupled with the increasing prevalence of dementia in Australia, suggest the number of people with dementia who live alone is set to rise. Research indicates that up to one third of people with dementia who live in the community live alone\textsuperscript{52, 53}.

There is an underlying assumption in policy and service provision that people with dementia live with or have the support of a carer. For example, health professionals tend to assume that someone will make transport arrangements for the person with dementia.

While no Australian literature was found on the transport needs of this group, there is some evidence that older people living alone are particularly likely to need help with transport. In Canada in 2009, 14% of senior (aged 65 or over) women and 6% of senior men living alone required assistance with transportation. For seniors living in a couple, the comparable figures are 9% for senior women and 4% for senior men\textsuperscript{54}.

**Aboriginal people with dementia**

Limited data on both the prevalence of dementia and the use of dementia services by Aboriginal Australians means we do not have an accurate picture of Aboriginal people with dementia. However, research indicates that the prevalence of dementia is substantially higher among Aboriginal Australians than among non-Indigenous Australians but the former are much less likely to access appropriate services.\textsuperscript{55}

Many Aboriginal Australians in urban, regional, rural and remote areas cannot access needed services due to transport difficulties and the unavailability of staff and services capable of delivering care that is adapted to local languages, culture and circumstances.\textsuperscript{56, 57}

Although Aboriginal people in NSW predominately reside in urban and regional areas of the State, there are also many Aboriginal communities located in fringe metropolitan areas and in regional or remote areas. These areas are characterised by a lack of transport options especially for those without access to a car. The transport problems of these areas compound other issues of disadvantage faced by Aboriginal communities, including health issues.\textsuperscript{58}

Providing culturally appropriate transport for all Aboriginal people, including those affected by dementia, involves recognising and being sympathetic to both cultural factors and the multiple
disadvantages many face. In a study of the public transport needs of Indigenous Australians in the Northern Territory the following five issues were identified:

- need for door to door travel
- preference for group travel, including children
- need for low fares
- a low understanding of how transport systems work, how to use services and what the rules are
- need for demand responsive, not scheduled services

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.

In No Transport No Treatment the authors found that Aboriginal people, particularly those who live in rural and remote areas, appear to be the most disadvantaged Australians in terms of access to suitable transport services to health services. This is related to:

- the low number of people in some Aboriginal communities with driving licenses or cars
- issues of distance and lack of public transport
- low socioeconomic status and a reduced ability to purchase transport services
- the poor health status of many Indigenous people
- culturally inappropriate transport services.

The report notes that many Aboriginal people rely on family and friends for transport to health services, or on community services that do not normally provide transport. In some cases Indigenous people must walk long distances or hitchhike to access services.

Other barriers to transport for Indigenous people that are noted in No Transport No Treatment include the:

- complexity of the form and administration process – for instance in accessing the Isolated Patients’ Travel and Assistance Scheme
- requirement to make upfront payment
- need to book ahead, often Aboriginal people do not plan the trips in advance
- cost of overnight accommodation
- lack of involvement of Aboriginal and Torres Strait Islander people in planning and delivery of transport.

In approaching health and service issues affecting Aboriginal Australians it is necessary to approach issues holistically. For example, staying in one’s own language group is extremely important to many older Indigenous Australians who do not want to be separated from country and family.

**People with younger onset dementia**

People with younger onset dementia are usually more physically and socially active than older people with dementia. They are also more likely to have younger families and significant financial and work commitments. Thus the support and service needs for younger people, their family and
Carers can be different from people who develop dementia at an older age. Often people with younger onset dementia do not fit into mainstream dementia services as they are not age appropriate. The younger people have different needs, energy levels and interests from the older people with dementia. Some services have recently been developed to specifically meet the needs of this group.

The 2007 Alt Beatty Report, which looked at Home and Community Care (HACC) service models for people with younger onset dementia, recommended that services be flexible and responsive, involve physical activity, provide transport, give clients choice and use a social support and day club model of care.

A report prepared for ADHC in 2012 on people with younger onset dementia emphasised their need to remain engaged in the community for as long as possible and to keep up relationships with family and friends. Participants in the study identified lack of transport to social activities as a barrier to remaining engaged. Like all people with dementia, those with younger onset dementia eventually lose the capacity to drive safely and many have their driver’s license revoked soon after diagnosis. People with younger onset dementia want to remain mobile; many rely on carers and family members to meet their transport needs.

However, carers of people with younger onset dementia can face particular challenges that make it difficult to meet these transport needs. These carers often have to combine caring with keeping the household together, earning a living and raising children. They need services to assist them to juggle their various roles and the available services are often not tailored to their particular needs. For example, in a study of the needs of people with younger onset dementia and their carers, the carers in paid employment commented upon the unreliability of the transport to take their relative to day care. Community transport is generally more focused on older, less mobile people with dementia and commercial taxi services are not always available or affordable.

People with dementia from CALD backgrounds

Assuming that the prevalence of dementia is similar for Australians who speak English at home, the estimated number of Australians with dementia who spoke a language other than English at home was 35,000 in 2009. This is expected to increase 3.4 fold to around 120,000 in 2050. No breakdown on the rates of dementia by people from different CALD backgrounds was found. Literature on the needs of people with dementia in CALD communities is not extensive and very limited when it comes to specific CALD communities. One of the key issues identified is lower levels of access to dementia services by people from CALD communities. This is partly seen as an outcome of the information available to people from CALD backgrounds, language barriers, lack of available bilingual staff, poor referral procedures, cultural factors, and the cultural appropriateness of services.

Improving access to services for people with dementia from CALD backgrounds involves improving access to information that is easily comprehensible and available through channels that will reach potential users. Improved access to services will also require an increase in ethno-specific services as well as greater flexibility and cultural responsiveness from mainstream services and health professionals.

Research has established that there is a desire for access to improved and affordable transport services among people from CALD backgrounds caring for people with dementia. Identified transport needs include getting to hospital, visiting doctors, shopping and attending day care.

The cultures, experience and needs of older people from CALD backgrounds are very diverse. Given this, a single model of service delivery, including transport, may be inappropriate to meet the needs of CALD people with dementia. The issues and sometimes the solutions, vary between groups of people from CALD background, although a mix of ethno-specific, multicultural and mainstream services can provide better outcomes.
services seem to be appropriate for most groups. All services should also provide accredited interpreters and bilingual staff.

**People with dementia from regional, rural and remote areas of Australia**

Data from the ABS Survey of Disability Ageing & Carers in 2009 shows that: 69% of people with dementia in Australia live in major cities, 22% live in inner regional areas and 9% live in other areas. Only approximately half of one per cent of the NSW population lives in areas classified as remote or very remote.

The consistent message from the literature 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 and on the metropolitan fringe. Transport disadvantage leads to isolation of caregivers and people with dementia as well as reduced access to appropriate medical care.

It is widely recognised that rural and remote communities face additional difficulties associated with population ageing and associated health problems when compared with their urban counterparts. They tend to have fewer health care resources to service their aged populations, which are usually widely dispersed. Studies of dementia in rural and remote communities have also found there is reluctance to access the limited services available because of stigma associated with dementia.

Access to health care in rural and regional NSW is a major concern. The distance to key services and the cost, particularly of fuel and transport, limits access to specialist and community services and impacts on the level of health care available. 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.

In a study investigating the barriers to care services for people with dementia and their carers in a rural community, access to expertise came up as a major concern. People with dementia and their carers had only limited access to Aged Care Assessment Teams (ACAT), geriatricians and psycho-geriatricians. To visit a specialist or to consult with different general practitioners (GPs), a person with dementia and their carer had to travel for at least 90 minutes. This type of travel was often difficult, especially for older people. Members of the ACAT only visited the areas approximately once every six weeks to perform aged care assessments and to recommend care options for a person with dementia. This meant they often based their recommendations on one home visit. In contrast, in urban areas it is not unusual for ACAT to make several visits.

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.

**GLBTI people with dementia**

The best estimates of the number of GLBTI people with dementia are based on estimates on the proportion of the Australian population who are GLBTI and the prevalence of dementia in the total Australian population. A commonly accepted estimate of the proportion of Australians who are GLBTI is 8%.

While figures on dementia in this community have not been collected, we do know that HIV is more prevalent than in the wider Australian community. Therapies introduced in the late 1990s have meant a decline in the incidence of brain disorders such as AIDS dementia complex for people living with HIV. However some people with HIV do develop AIDS related dementia, often at an earlier age than people in the general population develop dementia.
Older GLBTI people have lived through a time where GLBTI people commonly endured stigma, discrimination, family rejection and social isolation. The Productivity Commission inquiry, *Caring for Older Australians*, recognised that people from the GLBTI community require particular attention due to their experience of discrimination and the limited recognition of their needs and preferences by service providers.84

A paper produced for Alzheimer’s Australia in 2008 suggests that 46% of GLBTI people in Australia live alone, compared to 23% of the general population. Living alone is especially difficult for a person with dementia. While some people living alone may be well connected to family and their community, others may not have children or a supporting family which can also make living with dementia more difficult as it often means fewer people to assist with the daily challenges, including the daily challenge of accessing transport if the person is no longer driving.85

As with all services for GLBTI people with dementia, transport services need to recognise the sexual and gender diversity needs of people. Literature on GLBTI people recommends that community service providers should be trained in GLBTI appropriate and competent care. Those supporting GLBTI people with dementia need to be aware of their legal responsibilities regarding discrimination, protecting people with dementia from discrimination by co-clients and ensuring that GLBTI people with dementia are treated in an understanding and empathetic way.86

**What transport characteristics are best suited to people with dementia?**

Apart from the work on driving and dementia, there are few studies in the literature that discuss the transport experiences of people with dementia. People in different stages of dementia are likely to have different transport issues. The effects of the stages of dementia and the absence of studies of people with dementia using transport make it difficult to identify the issues that affect their transport use. 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 which could lead to difficulties in paying the fare
- abstract thinking, they may not be able to navigate route changes or interpret 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 to arrangements.87 88

In response to considerations of these characteristics it has been suggested 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.89
Meeting the transport needs of people with dementia

The following sections report on the main issues identified in the literature for different modes of transport. Driving is the area that is the focus of much of the literature.

Driving and dementia

The main issues identified in the national and international literature on dementia and driving concern:

- the number of people with dementia who drive
- the way dementia affects driving, including crash rates
- licensing restrictions for drivers with dementia
- assessment techniques for assessing the driving abilities of people with dementia
- the reporting responsibilities of a person diagnosed with dementia who intends to continue driving
- the role of health professionals, carers and service providers in persuading a person with dementia to cease driving
- the impact of driving cessation on the person with dementia and their carers
- tools and approaches that make driving cessation easier for the person with dementia and their carers
- alternate transport options for people with dementia.

There is also some literature on aspects of how driving and dementia affects special needs groups such as people with dementia who live in regional and rural areas.

How many people with dementia are driving?

Estimates of the time that people with dementia continue to drive vary from about three years following diagnosis to over five years. In the United States (US) it is estimated that about 50% of drivers with dementia continue to drive more than three years after the onset of symptoms\(^90\). In 2009 in Canada more than one-quarter (28%) of people aged 65 and over with Alzheimer’s disease or another form of dementia had a license. Approximately three quarters of these seniors had driven in the month preceding a survey conducted in 2012\(^91\). We do not have figures on the number of people with dementia who drive in Australia but we do have some figures that can give us an idea of the numbers.

In 2014 approximately 910,000 license holders in NSW were aged 65 or over; approximately 142,000 were aged 80 or more\(^92\). As the population ages the number of older license holders is expected to increase significantly. We do not know how many of these older drivers have dementia but, as detailed earlier in this overview, we do know that the incidence of dementia increases significantly with age. Approximately 30% of Australians aged 85 or older have dementia\(^93\).

There is some evidence that dementia in older drivers is under diagnosed. A study of 100 older drivers found only 21 had a formal diagnosis of dementia prior to referral to the ACAT however 34 had significant impairment indicated by a mini-mental score examination. Of these 34 drivers, 19 were also disoriented to time or place and had an abnormal clock drawing test; only 10 of these drivers had a diagnosis of dementia\(^94\).

Given the predicted increase in the number of people in Australia with dementia, the issue of people addressing the issue, action on the driving with dementia has been slow. In 2010, the AlzNSW paper, Driving and Dementia, examined the context of driving with dementia in NSW\(^95\). The findings from this paper remain current and relevant; most of the recommendations that were made on the basis of the research are still valid. Few of the recommendations were implemented.

The findings of the paper are consistent with literature that has been published since 2010, including a paper from Alzheimer’s Australia Victoria in 2013 and another study of driving and dementia in Victoria commissioned by the Royal Automobile Club of Victoria (RACV)\(^96\)\(^97\).
Meeting the transport needs of people with dementia

Despite the research that is available and the consensus about many strategies that should be pursued, inaction around the issue means that many people will find driving cessation traumatic and many will drive when they are a risk to themselves and others.

**How does dementia affect driving?**

It is widely accepted that not all people with dementia are incompetent drivers, particularly in the early stages of the condition. However all people with dementia have to stop driving eventually. The ability to drive safely relies on decision-making, reactions, visuo-spatial perception and other sensory processing, memory, judgement attention and planning. All these attributes are affected by dementia at some stage.

The effects of dementia on driving may be seen in the following behaviours:

- errors with navigation
- limited concentration or gaps in attention
- errors in judgment including misjudging the distance between cars and the speed of other cars
- confusion when making choices
- poor decision making or problem solving
- poor insight and denial of deficits
- slowed reaction time
- poor hand-eye coordination
- memory loss (impaired ability to recognise places and recall things)
- elevated aggression, anger or irritability
- problems with vision.

The impact of dementia on a person’s driving can be difficult to assess because of the many relevant variables, including medication, type of dementia, rate of progress, the person’s previous driving style and skill level and any coexisting medical conditions the driver may have.

Crash data in NSW does not capture the percentage of crashes that involve drivers with dementia. However, drivers with dementia are thought to be at higher risk for unsafe driving. The Monash University Accident Research Centre study of the evidence associating chronic illness with crash risk included dementia in the top eight conditions that demonstrated significant road safety risks. Studies relating the yearly crash rates of older Americans with dementia to those of healthy older Americans generally show an inflated crash rate for those with dementia, although these studies have limited generalizability. In the absence of official data on NSW crash rates involving drivers with dementia, claims can be made that may not reflect the true situation.

Overall the number of older drivers involved in casualty crashes is small relative to drivers in other age groups. However the likelihood of a casualty crash resulting in driver fatality increases with the age of the older drivers with particularly high rates for those aged 85 and over. While we do not know how many of these drivers have dementia, we do know that dementia is much more prevalent in older people.

**What are the licensing requirements for people with dementia?**

In March 2012, Austroads and the National Transport Commission released a revised version of the Assessing Fitness to Drive Guidelines. The guidelines contain nationally agreed medical standards for the purposes of driver licensing.

The revised guidelines require all people with a diagnosis of dementia to have a conditional rather than unconditional license. The conditional license is subject to medical opinion and a practical assessment as required; it offers a driver an alternative to withdrawal of license and it means licensing can be considered on a case by case basis. Prior to the release of the revised guidelines,
people with dementia in NSW were able to hold an unconditional license until concern about their driving was formally raised or they were medically assessed because of their age. (In NSW drivers over the age of 75 are required to have annual medical reviews to ensure they are medically fit and able to drive safely. From the age of 85 older drivers can opt to have a modified license or to undertake an on road driving assessment every two years to hold an unrestricted license.)

The information on the NSW Roads and Maritime Services (RMS) website does not make the reporting requirements clear. Entering ‘dementia’ into the search engine on the page ‘Fit to Drive’ generates the following text:

**Conditions which affect safe driving**

Various medical conditions can affect your ability to drive safely, for example:

- Blackouts, fainting or other sudden periods of unconsciousness
- Vision problems
- Heart disease or stroke
- Epilepsy
- Sleep disorders
- Diabetes
- Psychiatric disorders
- Neurological disorders
- Age-related decline.

Usually, this doesn’t mean that you can’t drive at all, but you may need to provide a satisfactory medical report before you can apply for, or renew your license. In some cases you may also be required to pass a driving test.

**Decisions about your ability to drive safely**

Your doctor can provide advice about how your particular medical condition might affect your ability to drive safely, and how it might be managed.

Roads and Maritime makes the final decision about your license. We take into consideration the advice of your doctor, as well as other factors, such as your accident history (if any) and the type of vehicle you drive. For example, truck, bus and taxi drivers need to meet a higher standard, due to the nature of their driving. See Commercial and passenger vehicle drivers for more information.

**Dementia**

The progressive and irreversible loss of mental functioning caused by dementia creates issues for driver safety. All drivers with dementia will likely face a situation where their condition deteriorates, to the point that they are no longer medically fit to drive.

If you’re a driver with dementia, it’s important that you regularly talk to your doctor about how your ability to drive is being affected.

By talking to doctors, family, friends and carers about driving issues as soon as possible after a diagnosis of dementia, you can make the difficult transition away from driving an easier process. It’s important to talk about any problems you have while driving, and what your transport needs might be, to work out when it’s the right time to stop driving.\(^{108}\)

**How are driving abilities of people with dementia assessed?**

The conditional license requires a minimum annual review by a medical practitioner and on occasion the application of specific restrictions such as a fixed driving radius from home. However, the revised Austroads guidelines do not specify how such decisions are to be made, nor are there any recommendations as about the screening tools that may be used to measure change in cognitive performance that would trigger the addition of license restrictions or a recommendation to cease driving.
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The RMS medical assessment form was updated in 2012 following the release of the Austroads guidelines. The form includes a number of sections for completion by the treating doctor, including a section on neurological conditions. The NSW Older Driver Taskforce noted that the current form and process may not enable doctors to “provide sufficient detail about their patient’s medical condition to enable RMS to make an informed licensing decision, particularly in relation to dementia and vision”\(^{109}\). The Taskforce and the Australian Medical Association suggest the RMS medical assessment form should be revised to highlight the need to provide more information for certain conditions; a better way to assess and monitor dementia by doctors needs to be developed\(^{110}\).

At this stage there is no universally accepted test or standard a doctor can use which defines when driving should stop\(^{111}\). The Mini-Mental State Examination is often used as part of a doctor’s assessment of whether a person is fit to drive but this test alone does not predict motor vehicle accident rates\(^{112}\). The consensus is that, until a reliable office based test is developed to identify unsafe drivers with dementia, the most likely role of cognitive office based testing is to identify those in need of more detailed evaluation\(^{113}\).

However, there is also concern about practical driving assessments. There is little consensus about the most effective forms of assessment, there is no internationally accepted standard and considerable variation exists in term of vehicles, routes and tasks\(^{114}\). There are, however, a variety of assessments that are supported by some researchers including the DriveABLE Program and driving simulators that score safety errors. In Australia, driving trained occupational therapists conduct on road driving assessments for drivers with dementia in a vehicle with dual controls and with a driving instructor. These assessments can be costly and difficult to access.

A 2011 Cochrane Review found the impact of formal assessment of the driving abilities of people with dementia is unknown in terms of either mobility or safety. The review found that the available literature fails to demonstrate the benefit of driver assessment for either preserving transport mobility or reducing motor vehicle accidents. The authors advocate caution in applying the literature on driving assessment as the benefit of any assessment has yet to be conclusively demonstrated. The review notes that the findings also indicate the need for prospective evaluation of new and existing models of driver assessment to best preserve transport mobility and minimise road traffic accidents among people with dementia\(^{115}\). Other studies question the usefulness of existing assessment techniques; there is widespread agreement in the international literature that developing and validating screening procedures for drivers with dementia should be a high priority. Driver liability and motor vehicle insurance can also potentially pose considerable problems for drivers with dementia. In the 2010 AlzNSW paper a number of discrepancies around driver liability and disclosure of a diagnosis of dementia to the insurer were noted. This is indicative that insurers would benefit from clearer guidelines with regard to the rights and responsibilities of customers living with dementia\(^{116}\).

**Who decides when a person with dementia should stop driving?**

Many people with dementia will decide to stop driving when they are diagnosed or before their driving becomes unsafe, however we do not know what proportion of people choose to give up their licenses before their driving becomes a concern.

Many people with dementia, especially those with more advanced symptoms, do not understand how dementia impacts on their ability to drive safely. Thus it is not always possible for people with dementia to successfully regulate their own driving and it is left to others, usually carers and medical professionals, to negotiate the move to driving cessation\(^{117}^{118}\).

If people with dementia, their carers or their doctors are aware of the Austroads guidelines described above they may have discussions about driving with their doctors. However, studies in both NSW and Victoria by Alzheimer’s Australia suggest that a significant percentage of people with
dementia, their doctors and their carers are unaware or unsure of the requirement for a person with dementia to report their medical condition to a licensing authority or to their insurer.\textsuperscript{119,120} Poor awareness of the decision making process in the driver licensing system is an issue for all older drivers, not just people with dementia. In 2013, the NSW Older Driver Taskforce recommended that a communication strategy be developed for older drivers and medical practitioners dealing with older driver issues. Similar recommendations have been made in other studies.\textsuperscript{121,122,123} It is widely recognised that medical practitioners and carers are the main people who work with drivers with dementia to make the transition to not driving. Ideally the driving decision is a responsibility shared between carers and health professionals.\textsuperscript{124} This role can be difficult for both groups.

Medical practitioners can find addressing the issue of whether a person with dementia should continue driving. Medical practitioners can find this role difficult for a number of reasons such as: the changing nature of the symptoms of dementia in an individual, lack of validated assessment techniques, lack of awareness of the need to address the driving issue and a reluctance to cause friction with their patient by recommending that they cease driving.\textsuperscript{125} Some physicians do not wish to be the ‘licensing gatekeepers’. Unfortunately it is not uncommon for doctors to be called on to facilitate driving retirement during a crisis, in some instances at the same time as the driver is diagnosed with dementia. This can create a difficult dynamic between the doctor and the patient.\textsuperscript{126} Addressing fitness to drive has been said to be the most difficult and emotional task a health professional faces in providing primary health care for people with dementia.\textsuperscript{127}

It is often carers who address the issue of driving cessation with drivers with dementia. Carers are able to observe drivers with dementia and are therefore well placed to identify risky driving behaviours. The behaviours carers report noticing include: memory difficulties, becoming lost in familiar areas, and exhibiting inadequate driving performance including minor traffic events, misjudging distances, driving too fast for conditions, having difficulty with lane keeping, becoming distracted and having low levels of insight to issues that trigger responses from the carers and other drivers.\textsuperscript{128}

In an Austrian study of 240 former or current drivers with dementia, 94% of the drivers who had ceased driving did so because of ‘unacceptable risk’ according to a carer’s judgement. The decision was unaffected by caregiver characteristics such as age, sex, relationship to the patient, employment status or strain of care. The authors of the study note that they are not aware of anything in the literature concerning the number of times car accidents and revocation of the driving license are given as reasons leading to driving cessation in demented patients. They conclude that the risk-estimate of caregivers determines if, and when, a person with dementia ceases to drive.\textsuperscript{129}

The role of carers in managing drivers with dementia can be stressful. They tend to feel unsupported in addressing the issue and it can cause considerable tension in the relationships with the person with dementia.\textsuperscript{130} Carers often have little background knowledge and few resources. In 2010, VicRoads commissioned a systematic review to examine the evidence for the role of carers and the support provided to them in managing drivers with cognitive decline. The review found a small body of evidence that highlighted the important role of carers. The literature detailing carer interventions noted that carer strategies could be described as either imposed on the driver or involving the driver. The later required the driver to be an active participant in complying with suggestions led by a doctor or the family.\textsuperscript{131}

While there is very limited literature on how carers fulfil this role, it appears that despite the lack of readily available tools and resources carers develop helpful strategies: many ask for and receive assistance from other family members and doctors. Other strategies include accompanying the person with dementia to appointments, offering more transport, arranging for more home visits and hiding the keys.\textsuperscript{132}
What do we know about the impact of driving cessation process?
Losing the ability to drive is said to be easier for people who are not depended on to provide transport for others and who are mostly supported by caregivers who provide for their transport needs\textsuperscript{133}. Transport is identified in several studies as one of the main types of assistance provided by carers. As noted earlier in this paper, among people with dementia living in the community 80\% are likely to need help with private transport\textsuperscript{134 135}.

While some people with dementia are not heavily impacted by driving cessation, feelings of autonomy and independence are often associated with driving and driving cessation may prompt depressive symptoms and a decrease in activity level. These feelings are not necessarily mitigated by having a carer who drives. It appears for many, it is the actual loss of the ability to drive that is associated with depressive symptoms. These feelings, combined with concerns about social isolation and an inability to recognise a decline in their driving skills, may underpin some of the resistance a driver with dementia may have to driving cessation\textsuperscript{136}.

A US study of how former drivers access necessary destinations once they can no longer drive found that people with dementia who did not live with at least once licensed driver and those who were younger and healthier reported the greatest mismatch between their need and desire to travel and the availability of transport\textsuperscript{137}.

Driving cessation by the person with dementia can also have a negative impact on carers. It can have an impact on the carer’s work life and often means that they become the driver for the person with dementia\textsuperscript{138}.

Driving cessation among elderly drivers without dementia is reported to have similar impacts. Older people who do not drive face challenges in maintaining mobility, many report that lack of transport alternatives mean foregoing social events and opportunities to visit family and friends\textsuperscript{139 140 141 142}.

What makes driving cessation easier?
While no evidence was found of validated driving assessment tools, there is consensus about approaches that make the process of driving cessation easier for all involved. Strategies and tools are available that can assist everyone in their respective roles. However, there is low awareness of these. Indeed the whole area of driving cessation including: the medical assessment process, the licensing requirements, the role of carers and health professionals as well as the needs of the driver with dementia, appears to be very badly served by communication that alerts people to information and strategies that could provide guidance and assistance.

There is some progress in meeting the information needs around driving cessation. In 2013 the RACV and AlzVic produced a guide for health professionals, carers, families, friends and people with dementia called Dementia, Driving and Mobility. A similar guide has been produced by the NRMA and AlzNSW for NSW and the ACT called Staying on the Move with Dementia. These guides provide summaries of some key issues surrounding driving and dementia and describe some mobility options for people who can no longer drive. While not meeting the broader need for a central resource of materials for tools and strategies that deal with driving cessation, the guides provides useful, easily accessible information. Demand for the guides has been high\textsuperscript{143 144}.

RACV and AlzVic have also developed a resource for use in Victoria called Changing Conditions Ahead. The resource will be used in community information sessions in Victoria on dementia and driving for family and friends of a person diagnosed with dementia\textsuperscript{145}.

AlzNSW on the North Coast has worked with partners to develop Life After Licenses to assist people with dementia and their carers to access support during the driving cessation process\textsuperscript{146}.

The University of Wollongong are piloting Dementia and driving: a decision aid. When should I stop driving? The aim of the booklet is to assist a person with dementia in deciding when to stop driving.
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after receiving a diagnosis of dementia. However, at the time of writing the authors were finding it difficult to attract sufficient drivers with early dementia to validate the resource.

In addition to having ready access to information, the approaches reported to make the transition from driving to non-driving easier include:

- Addressing the driving concern in the early stages of dementia. This can be difficult particularly when the diagnosis is made at the same time it is recommended the person stops driving. However feedback from carers, people with dementia and service providers indicates discussing driving cessation before they need to stop makes the transition easier. Most of the approaches and tools are most effective if used in the early stages of the disease147.

- Dealing with the decision to give up driving as a process rather than as a single directive or event. Ideally the issue is discussed with carers, health professionals such as occupational therapists and social workers over a period of a year or more. Ideally the decision that a person with dementia stops driving is not made in a crisis situation but driving fitness is integrated in routine medical assessments and planned for148.

- Adopting a unified approach – ideally driving cessation is not a decision made by one party, but is the outcome of a shared approach to driving decisions between health professionals, the carers and, when practicable, the driver with dementia149.

- Identifying and discussing alternative transport options for the person with dementia and the carers in the early stages of the disease when the driver with dementia is able to process the information and understand that they will be able to remain mobile after they stop driving.

- Using various tools such as tip sheets, telephone help lines and webpages. Resources to assist with the transition to non-driving are often not known to the people who need them. There is a need for a central source of information on available services and resources150.

- An easy to understand cost benefit analysis comparing private car usage to other forms of transport for people with dementia and their carers. Information on the real cost of running a car compared with using alternative forms of transport may help people move towards alternative forms of transport, including taxis151.

- A case management approach, which involves assisting a driver with dementia over time in a staged process. The driver could be assisted to identify and try non-driving options and to work out how they will continue to engage in social activities and other aspects of their lives that have involved driving once they have made the transition to non-driver152.

A reported barrier to driving cessation is the inadequacy of appropriate alternative transport, particularly for those with physical and/or cognitive impairment153 154. Alternative transport options for people with dementia who stop driving are discussed later in this paper.

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 services155.
Do some groups of drivers with dementia have particular issues?

Aboriginal and Torres Strait Islander drivers with dementia
Existing resources, including cars and services in remote Aboriginal communities are heavily used. The average car in a remote Aboriginal community has an extremely short lifespan. The vehicles are often second hand, not always well maintained and operate over long distances in harsh conditions. However, cars in Aboriginal communities are heavily used and relied on where they can be accessed. The ABS 2002 National Aboriginal and Torres Strait Islander Social Survey stated that only 47.5% of Aboriginal people in remote populations have access to a motor vehicle. Some researchers consider this figure to be high, but whatever the access figure is, it is much lower than the access rate of non-Aboriginal people. The pattern is also evident in non-remote regions.156

Regional and rural drivers with dementia
Accessing medical and social support in regional and rural areas often involves driving long distances. The distances involved can mean:

- trips are time consuming and tiring for both the person with dementia and their carer
- there is high wear and tear on cars
- fuel costs are significant.

It is also possible that driving longer distances increases the accident rate of drivers with dementia, however statistics on the number of people with dementia who are involved in accidents are not collected in Australia.

Driving in regional, rural and remote areas of Australia is further complicated by the relative lack of transport alternatives. This may contribute to drivers with dementia being resistant to driving cessation or the carer encouraging the person with dementia to continue to drive.157

The cost of on road assessments is usually much higher in rural and regional areas than in the city. In addition to paying for the assessment the client may have to pay for the assessor’s travel time.158

Public transport and people with dementia
This section focuses on public transport and people with dementia. Due to the paucity of information on how people with dementia use public transport, some of the issues involved in older people’s use of public transport are included here. Transport issues for older people and people with dementia are definitely not the same but there is some cross over.

What do we know about how people with dementia use public transport?
The main focus of public transport is on commuters; high volume traffic on specific routes at specific times of the day. However, the purpose of public transport is to meet the wider needs of society for transport and the particular needs of groups of people, such as people with disabilities, with dementia, schoolchildren and older people.

Where consideration is made for the needs of people with disabilities it usually refers to physical disability. Little, if any, provision is made for people with cognitive disabilities such as dementia. Indeed, little is known about the transport needs of this group and how to encourage greater, easier use.

While little is known about people with dementia’s experience of public transport, 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.
Meeting the transport needs of people with dementia

- 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.

**What can be done in order that people with dementia can use public transport?**

There is little evidence on the public transport experience of people with dementia and on how to improve access. The main focus of the recommendations that do exist are on:

- training providers in dementia awareness
- providing transport escorts (probably volunteer) who can provide door to door, door through door or even chair to chair service
- adapting the concepts of travel training and mobility management similar to the services for people with physical disability. This could be particularly for people in the early stages of dementia.

Travel training for the elderly may help people with dementia access the public transport system: the individual who has short term memory impairment and cannot follow directions for an unfamiliar route may be able to continue to access a fixed route they have used routinely for years.

As noted above, changes to public transport that make it more accessible and easier to navigate for people with disabilities and older people may also make it easier for people in the early stages of dementia to use the system.

**Improving access to public transport**

The following suggestions aim to make public transport more accessible to people who are less agile and who may have difficulty in navigating the system. The suggestions are included here as they may help people in the early stages of dementia, the large majority of whom are over 65 and suffering the typical ailments of ageing as well as the symptoms of dementia. Changes which make public transport easier to access for older people (and indeed for people with a physical disability such as vision impairment) may help people with dementia because the changes aim to make the system simpler to navigate.

- Travel training, this may also assist people with dementia, as most people who develop dementia are aged 65 or more. If elderly people are trained to be familiar with using public transport, those who do develop dementia (and their carers) may be able to continue to use it post diagnosis.
- Bus service routes using small vehicles that pick-up and discharge passengers close to journey origins and destinations. These smaller vehicles should coordinate with regular public transport.
- Easily accessible vehicles such as low-floor buses and buses that kneel.
- Provide volunteer transport escorts.
- Allow time in the schedule for passengers to board and alight without feeling rushed and providing assistance when required.
- Pedestrian infrastructure that facilitates access to transport services.
- Provide clear signage and directions at stops and on transport.
- Ensure that information on routes and timetables is easy to access, read and understand.
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- Provide supportive pedestrian infrastructure that facilitate access to transport services and allow people to make journeys on foot, wheelchair or scooter.
- Adopt the five principles of senior friendly transportation developed by The Beverly Foundation.\textsuperscript{165,166}

**Community transport and people with dementia**

‘Community Transport’ encompasses a range of not for profit services usually provided for specific groups of people with particular needs. The services include buses attached to local governments, aged care residential centres, day centres, clubs, schools and shopping centres as well as approximately 120 Community Transport Operators (CTOs) and other government funded services.

The majority of funding for community transport comes from HACC. In addition, most community transport providers charge at least some passengers a fee and some receive other funding and sponsorship from local organisations. For example, the Commonwealth Home Care Packages program providers purchase services from CTOs.

The largest providers of community transport in NSW are the CTOs.

**Community transport operators and the Community Transport Program**

CTOs provide transport for the frail aged, the disabled and their carers and the transport disadvantaged. HACC funding for the CTO is currently administered by Transport for NSW. Funding is also available to these groups under the Community Transport Program (CTP) and other programs.\textsuperscript{167} In addition, the NSW Government funds transport used by vulnerable populations such as the Health Transport Units and the Isolated Patients Travel and Accommodation Assistance Scheme. As responsibility for managing the funding of HACC and other packages for people aged over 65 moves to the federal government, funding arrangements for CTOs are expected to change in June 2015.

The services CTO and CTP provide need to be sufficiently flexible to address the more dependent needs of many in the client groups. Another significant difference between community transport and public passenger services is the involvement of volunteers. The involvement of volunteers in community transport is discussed later in this paper.

CTO and CTP services are not only different from public passenger services; they are different from each other. Each service has developed in response to the needs of the local population, the available resources and the style of the operator.

**Other community transport providers**

There are various other types of providers of community transport such as: schools that have their own buses, clubs and shopping centres that collect and deliver customers in small buses, aged care facilities that use vehicles for outings or taking residents to appointments and day care centres that provide transport for clients. No literature was found on these types of community transport – it remains an area that should be investigated to see if these resources can be used to meet some of the transport needs of people with dementia.

**Community transport provided by local governments**

There is very little literature on local governments’ provision of community transport. One report \textit{A Snapshot of NSW Council Activities and Services}, does not give information on any specific transport services other than mobility or pedestrian access maps for people with a disability and access and mobility improvements for older people.\textsuperscript{168}

A survey of councils in Adelaide found widely divergent transport programs for the ratepayers of the nineteen councils surveyed. Wide variability was apparent in:

- eligibility
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- type of service available
- funding sources
- user costs.

The three councils which gave most assistance to people with dementia, provided access to shopping and medical appointments, either by the community bus or by volunteer car. The three least supportive councils refused to take people with dementia on the community transport or would only take them with a carer\textsuperscript{169}.

Some local councils provide HACC funded transport.

As CTOs are the main form of community transport available to people with dementia the following section looks at this service in more detail.

**Community transport operators**

**What are the benefits of community transport?**

Most of the literature located on community transport in NSW relates to the CTO services. There are many characteristics of transport offered by CTOs that are beneficial to the clientele. As noted, CTOs operate differently so not all providers offer the full range of benefits but the advantages of the system can include:

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

**What are the challenges facing CTOs?**

Challenges facing CTOs are well documented in the literature. Three of the most significant challenges are: the demand for health related transport, lack of coordination within the sector and significant increase in demand\textsuperscript{170 171 172 173 174 175}.

Other challenges that affect the effectiveness of CTOs include:

- restricted hours of operation
- poor utilisation rates for some vehicles and transport services
- difficulties in obtaining appropriately qualified volunteer drivers
- investing in vehicles rather than transport which may mean that issues such as accreditation, insurance and other organisational matters are not adequately funded
- poor information provision
- issues around eligibility
- poor coordination between providers and between agencies served by CTO
- poor coordination of users’ appointments, especially by health organisations\textsuperscript{176 177}.

As noted, the CTOs are further challenged by the transfer of responsibility of HACC Program funding and management for people aged over 65 to the federal government. The sector is currently operating in a climate of great uncertainty, which affects all aspects of planning and investment.

The NSW government recognised the importance of community transport services to vulnerable people in the state. The 2012 *NSW Long Term Transport Master Plan* includes statements of intent regarding the improvement of community transport services such as:
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- Updating the eligibility for using community transport to ensure people do not fall into the service gaps that occur when people are unable to access public transport services, but do not qualify for community transport.
- Overcoming historical and organisational issues that limit the sharing of the community transport fleet, leading to inefficiencies in the use of resources and infrastructure. The plan notes that legislative impediments to community transport providers make fleet and staff arrangements less efficient.
- Finding ways to respond to the increasing demand that will be generated by an ageing population demanding public and community transport connections between towns and larger regional centres.
- The need to provide convenient and safe access to health and other services for the increasing percentage of people aged over 65 in regional NSW.

Additional funding of $12 million has been provided to CTOs by the NSW government over the past four years and CTOs have been recognised in the State’s Passenger Transport Act.

Taxis

Using taxis has advantages for some people with dementia, especially if the person has mild dementia or is travelling with a carer. Taxis are flexible, often available on demand and can provide door-to-door service.

The Taxi Transport Subsidy Scheme (TTSS) provides taxi transport for the severely impaired and disabled in New South Wales. The TTSS began in 1981 and continues to operate. The Scheme uses a taxi docket system where the Government funds half of a taxi journey up to a maximum value of $30. The TTSS places no limits on the number of journeys a participant takes, nor is a financial cap placed on an individual participant.

The TTSS is useful to some people with dementia, however the literature identifies several issues that can affect their access to the program and to taxis generally. These concerns include:

- A widespread perception that taxis are expensive, especially compared to using a car or other government subsidised transport (public or community transport).
- Many taxi subsidy programs cannot keep pace with demand so only the most needy applications are funded.
- Some older adults do not like using taxis because they often feel threatened by the manner of some taxi drivers and are concerned for their personal safety.
- Many people with dementia need door to door or door through door, not kerb to kerb service.
- People with dementia can forget where they are going or ask to go to another address such as a place they remember living in.
- People with dementia may have trouble handling payment.
- Getting taxis to do very short trips can be difficult.
- Only a small proportion of taxi drivers have training in dealing with people with dementia.

Suggestions in the literature that could make taxis more suitable for people with dementia include:

- Providing a card to the taxi driver conveying important information about the person and clear instructions regarding the destination.
- Establishing a universal taxi booking system that identifies and categorises passengers who are at risk and/or who require special assistance. Such a system could be used by residential care centres, respite centres and other care providers when arranging taxi transport for people with dementia.
- Extending the subsidised taxi schemes so that cheaper taxis are more widely available.
Ensuring that all persons who lose or relinquish their license after a diagnosis of dementia, regardless of their age, are entitled to access the NSW TTSS (and NSW travel concessions).

Reducing the subsidised fare, especially in regional and rural areas where it is of little help with longer trips.

Reducing the subsidised fare for all people with dementia as many cannot afford it on a regular basis.

Training taxi drivers to recognise the symptoms of dementia.

Developing strong relationships with particular taxi drivers who are trained in managing passengers with dementia.

Booked Car Scheme
The Booked Car Scheme is available to eligible DVA clients when they attend a health provider for approved medical treatment. Under this scheme local taxi and hire car providers are contracted to DVA to arrange suitable vehicles to transport DVA clients to their medical appointments on time. Health providers can arrange transport under the Booked Car Scheme on behalf of the DVA client by contacting DVA directly or through accessing the online transport booking system. DVA clients with dementia are among those eligible for the service.

Ambulance and transfers between health settings
People with more advanced dementia can have difficulties when being transferred from one health setting to another. One case in the literature details how a patient with dementia was sent unaccompanied in a taxi to a medical appointment from a secure dementia unit in a nursing home. The patient insisted that he was taken ‘home’, a place that he had not lived for many years and which was now abandoned.

A British study of the impact of the National Health Service patient transportation on older people with dementia found that the behaviours and moods of dementia patients travelling in non-emergency patient transport systems with trained staff as escorts was considerably less agitated than dementia patients travelling without trained escorts.

Walking
The association between normal age-related cognitive decline and pedestrian safety seems to be fairly moderate. In contrast, evidence from a review undertaken by Monash suggests that cognitive and executive impairment associated with moderate to severe dementia may greatly affect pedestrian performance as dementia affects the skills necessary for safe negotiation of traffic and road-crossing decisions.

The Monash report points out that further research is needed to understand the relationships between cognitive impairment and pedestrian performance and crash risk. Without that knowledge countermeasures cannot be developed. However, there is some awareness of how the built environment affects people with dementia moving around public spaces.

In a 2011 report on building dementia and age friendly neighbourhoods, AlzNSW found that having safe and easy to navigate streets with wide, even footpaths dedicated to pedestrian traffic and safe crossings between amenities are all critical for ensuring that people with dementia can navigate their communities safely.

Transport models that may be suitable for people with dementia
There are a variety of models in the literature suggesting how to help people with dementia with transport issues. The models address different groups with dementia. For example those with early symptoms may find tools such as tip sheets for using public transport relevant, while those in the later stages, are more likely to need door through door transport assistance. Some of the models
Meeting the transport needs of people with dementia

described here address specific issues for people with dementia, such as the number who go missing. Others are more general, for instance providing training for public transport workers who may encounter a person with dementia.

The models cited below sometimes are aimed at meeting the needs of older people without dementia, or are focused on people with disabilities. These models are included because in addressing the transport needs of people with dementia we may be able to learn from the way the transport needs of less able people in general are being met.

There is considerable crossover in the models described here, for instance many use volunteers. A somewhat arbitrary division has been made into:

- training
- information
- direct assistance with transport.

Training

Travel training
Travel Training is a service that teaches people to travel independently on public transport. It is quite widespread in the US where it has been championed by the Easter Seals Action Project (described later in this paper)\(^\text{191}\). Two Travel Training services were established in Sydney; one these closed in 2014 when funding was not renewed \(^\text{192}\).

As noted earlier, 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.

Training for transport providers
There is consensus that 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. Examples of this training include:

- Alzheimer’s Australia, in conjunction with the South Australian and Northern Territory Dementia Training Study Centre, developed a resource aimed at raising awareness of dementia among service providers, including taxi drivers and public transport workers. The resource, Is it dementia is available on the Internet\(^\text{193}\).
- Thousands of bus drivers in the UK are being trained in awareness of the impacts of dementia and how to behave appropriately towards passengers with dementia.

Information
People with dementia, carers and health professionals have difficulty accessing information and resources on many aspects of transport; particularly in dealing with driving and dementia and in finding details of available alternative transport.

The following models have been developed in response to these needs.

Material to assist with managing the transition to non driving
There is considerable material available to assist carers, people with dementia and service providers in relation to managing driving cessation. Much of this material comes from the United States. It includes:

- videos depicting families having the conversation about driving and driving cessation
- links to alternate driving resources
- tips on recognising when driving is no longer safe
- tips on how to persuade the person with dementia to cease driving
- how to obtain a driving evaluation
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- how to involve others such as the family doctor in the decision.\(^{194,195,196,197,198}\)

Australia has resources available to assist with the transition to non-driving, but in the past most of these resources have been difficult to find. Recently developed resources have almost exclusively been state based so although the issues are similar across the country, access to information and resources varies considerably by location.\(^{199,200}\)

It is not only people with dementia and their carers who need information and resources, but also service providers. For example, health professionals, especially doctors, need information on driving and dementia. However most of the resources discovered were for Canadian health professionals:

- The Driving and Dementia Toolkit for Health Professionals. The e-toolkit provides background information for Canadian health professionals on driving and dementia, how to navigate the process of assessment of fitness-to-drive, how to effectively communicate verbally (and in writing) the findings of an assessment to the patient, the caregivers and to the legal authorities. An interdisciplinary team of health professionals developed the toolkit and a companion one for people with dementia and their carers.
  
  [Link](http://www.rgpeo.com/media/30695/dementia%20toolkit.pdf)

- Not if but when: helping drivers with dementia hang up the keys [Link](http://nibw.ca/physicians)

- Driving & Dementia. An e-Learning Module for physicians [Link](http://www.akeresourcecentre.org/DrivingModule)

In the absence of other resources, it is perhaps not surprising that a YouTube video developed by a doctor with an interest in the issue has received over 3,000 hits.\(^{201}\)

Central sources of information

**Websites**

Some models centralise information on transport options. Examples of websites that act as gateways to information on available transport services include:

- Safe and Mobile Senior – a Florida site described as the virtual front door for information about senior transportation. The site includes information and links on dementia. [www.SafeandMobileSeniors.org](http://www.SafeandMobileSeniors.org)

- Commission for Transportation Disadvantaged in Florida established a website and toll-free telephone system. Seniors call the toll-free number and are connected to the Community Transportation Coordinator in the county where they live.\(^{202}\)

**Mobility Managers**

The foundation concept of mobility management is to establish a clearing-house for transport information in a given area. The service should mean that ‘one-call-does-it-all’ as the mobility managers will know the community-wide transportation service network in the area and understand how it operates. Their main focus is to assist consumers in choosing the best options to meet their individual travel needs.

- An example of a version of this model is the Gold Coast mobility office in Queensland. The office acts as a budget holder for transport funding for older people and people with disabilities. Community care agencies join a consortium, organised by the office, to access funding or resources such as buses, driver hours, volunteer driver subsidies or taxi vouchers. In turn, the community care agencies engage in transport planning for the region and make their vehicles available for use in a vehicle brokerage scheme.\(^{203}\)

Other models incorporate knowledge about available transport options, without the commitment of transport bodies to anything other than providing information on their service.
Meeting the transport needs of people with dementia

Organisations focused on providing transport resources for seniors/people with dementia
These US sites are largely championed by organisations that have a focus on transport for seniors or people with dementia. The sites generally have clear pathways to information.

- The Dementia and Driving Resource Center – is designed to provide information and support to people with dementia and their families about the issue of driving. Among the resources offered are: four different videos depicting families having the conversation about driving cessation, links to alternative driving resources, tips on recognising when driving is no longer safe, how to obtain a driving evaluation and much more. The Dementia and Driving Resource Center is located at: [www.alz.org/safetycenter/we_can_help_safety_driving.asp](http://www.alz.org/safetycenter/we_can_help_safety_driving.asp)

- The Beverly Foundation – A wide range of resources for transport users and providers is provided by the Foundation including fact sheets, educational presentations and reports on relevant issues. The resources and the Foundation’s involvement with other organisations, such as the Easter Seals Action Project and Supplemental Transport Programs for Seniors (both described below), make it a significant source of resources and information on transport options for people with dementia, their carers and service providers.
  - [http://beverlyfoundationlegacy.org](http://beverlyfoundationlegacy.org)
  - Easter Seals Action Project (ESAP) was established to promote universal access to transportation for people with disabilities by partnering transportation providers, the disability community and others through the provision of training, technical assistance, applied research, outreach and communication. Programs and activities include: training online or in-person, outreach resources such as publications, assistance to individuals and communities and research. [www.projectaction.org](http://www.projectaction.org)

- The National Center for Senior Transportation (NCST) is administered by Easter Seals, Inc. in partnership with the National Association of Area Agencies on Aging. The NCST addresses the spectrum of transportation needs that allow older Americans to stay connected in their communities. Among many other resources the site offers a *Transportation Solutions for Caregivers* brochure for caregivers of older adults with disabilities, including people with dementia [http://www.seniortransportation.net/](http://www.seniortransportation.net/)

- AAA Foundation for Traffic Safety, in partnership with the Beverly Foundation, offers a database of more than 400 supplemental transportation programs (described below) for seniors in the United States, listed by state and city. [www.aaafoundation.org/multimedia/index.cfm?button=STPII](http://www.aaafoundation.org/multimedia/index.cfm?button=STPII)

- Dementia Care Central is an online resource centre that contains information on safety and driving, lists the tasks required of drivers and identifies the warning signs that carers can look for as markers of their friend’s or relative’s declining ability to drive safely and responsibly. Suggestions to assist caregivers are offered, as well as strategies for bringing in more support if the person with dementia resists intervention. [http://www.dementiacarecentral.com](http://www.dementiacarecentral.com)

In addition Alzheimer’s Associations in various countries have accessible dedicated pages for dementia and driving, for example:
Meeting the transport needs of people with dementia

**Tip sheets for providing transport**

The Florida Dementia Friendly Transportation Research Project found that professional and volunteer drivers and family members found the use of tip sheets useful when transporting people with dementia. Examples of tip sheets include:

- *Tips for Drivers of People with Dementia*, such as engaging safety locks, and how to deal with transportation challenges such as the person with dementia being unable to remember the time of appointment for the ride.
- Tips for helping with travel situations such as exploring options of pre paying travel costs to avoid the need for cash, packing a travel bag and having a written travel plan that can be given to others, such as a taxi driver[^204][^205].

**Silver Alert**

This program began in Florida and was rolled out to seventeen states by 2010. Each state has a slightly different program but essentially the Silver Alert allows for law enforcement agencies, sometimes in cooperation with the media, to alert the public that a person with dementia has gone missing while driving. Highway road signs are used to make the public aware that the person is missing[^206].

**Direct assistance with transport**

**Volunteer involvement with transport**

The literature details many ways that volunteers assist people with transport, including people with dementia. There is quite a widespread perception, particularly in the US, that these programs are increasingly viewed as a legitimate and appropriate means of providing transport to disadvantaged people. Other commentators maintain that it is increasingly difficult to involve volunteers to provide transport and in other areas.

Over the past 10 years there has been a growth in the number and rate of people who volunteer in Australia. Most who volunteer report that they are satisfied with the experience but people are asking for a wider range of ways to volunteer. People want more meaningful roles and greater flexibility in how and when they volunteer. While the ageing population may provide a wider pool of volunteers, sustaining a large volunteer force in Australia requires investment to provide the necessary infrastructure to support them[^207].

Most of the NSW models cited in the following sections involve volunteers as drivers. They are not specifically targeted at meeting the transport needs of people with dementia, but are examples of models that may be useful in meeting these needs.

- 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

- Vision Australia (VA) – Volunteer coordinators endeavour to match volunteers with clients in order to meet specific needs or interests expressed by clients. The interaction between volunteers and clients is not necessary between 9 and 5 and may include lifestyle-orientated activities such as going to the movies, sporting events or out for dinner and require a volunteer to transport them and partner with them in their chosen activity. One to one visits by matched volunteers are becoming a more popular form of support sought by VA clients and are particularly beneficial for those who live alone. As well as providing social support, the volunteer is also monitoring the health and safety of the person.

- Whilst the client and volunteer interact directly to make arrangements regarding their activities, the case worker, volunteer and client are also in regular contact to promote good communication and ensure the arrangement is working well. It is intended that this one to one relationship will last for some time, to allow the client to build trust and confidence in their volunteer. In order to facilitate this, VA staff provide support to volunteers in order to maintain boundaries to avoid burn out.

- All VA volunteers undergo a police check. Those who drive require a gold license, and, if they drive their own car, comprehensive insurance for their vehicle. Drivers over 75 undergo a NRMA safe driving test, funded by VA. Volunteers receive one full day of induction training as well as more specific client-related training with the caseworker involved.

- VA raises around 70% of its own funds, with the remainder provided by state and federal government block program and individual funding. https://www.visionaustralia.org/

- Mudgee Community Transport is a non-profit organisation providing transport for the frail aged and disabled and their carers, as well as those in the community at a disadvantage because of limited public transport services. Where possible, carers can be arranged to travel with clients to and from medical appointments where special attention and assistance is required. All vehicles in the Mudgee Community Transport fleet are driven by volunteers. Mudgee Community Transport is part of the Mid-Western Regional Council’s Community Services Department auspiced by Council and funded by ADHC together with Greater Western Area Health Service and Transport for New South Wales. The service has approximately 20 volunteer drivers covering local, regional and Sydney trips daily and on weekends (in special circumstances only). In an average year Mudgee Community Transport makes approximately 12,000 trips taking almost 2,000 clients to medical appointments, shopping trips, social, recreational and other outings.

- Fees associated with Mudgee Community Transport are based on the distance travelled. When more than one client travels in the same vehicle the client charge is reduced. In the event a client has difficulty paying a fee for travel, the service may be able to make arrangements to assist them. http://www.midwestern.nsw.gov.au/Community-Services/CommunityTransport/

In the US there are several volunteer friend transport programs, which involve passengers identifying drivers who may or may not be paid.

- Partnership to Preserve Independent Living for Seniors and Persons with Disabilities — Transportation Reimbursement and Information Program (TRIP). TRIP provides information to seniors and persons with disabilities on the availability of transport, including brochures
Meeting the transport needs of people with dementia

and schedules for all specialized transit services. TRIP provides mileage reimbursements to volunteer drivers who transport senior and disabled residents who are unable to use other transportation services. Clients are typically coached to recruit their own volunteers among family, friends, neighbours, and others. The client receives the reimbursements from the county, and then distributes the funds to his or her volunteer driver/s. The program has a service area of 7,200 square miles and has 1.5 million users, of whom more than 200,000 persons are age 65 and older.  

- PasRide sponsored by the Beverly Foundation which organised driver screening along with insurance and reimbursement. Program partners identify and refer clients who nominate volunteer drivers. The PasRide project created materials not only for its own operation but also for use by other groups that want to adapt the PasRide model to their own community. http://beverlyfoundationlegacy.org or the AAA Foundation for Traffic Safety https://www.aaafoundation.org/  

- Peninsula Shepherd Senior Center - San Diego, The Center offers an “Out and About Senior Transportation Program” as part of a menu of services. Its major sources of funding include sponsoring churches, grants, and rider donations. The Centre has two paid drivers and thirty volunteer ones, all of whom use their own vehicles to provide rides to seniors, people with disabilities, and adults in general. It provides curb-to-curb and door-to-door as well as escort services in a suburban service area. In 2005, Peninsula Shepherd Senior Center provided 2,500 rides to 100 passengers. (No website available)  

Medical transport using volunteers

There are a considerable number of organisations dedicated to providing transport to medical appointments. Again these models do not necessarily provide transport for people with dementia but they may be useful in thinking about how the transport needs of people with dementia could be met, particularly their health transport needs. 

Existing health models in NSW that use volunteers to provide medical transport include: The Leukaemia Foundation, Cancer Council NSW, Sisters of Charity Outreach Country Care Link, Sir Rodin and Lady Cutler Foundation, the "Shirley Shuttle" on the Central Coast (in conjunction with the Cancer Council) and Uniting Care Casino Transport Team (UCCTT). Most of these organisations offer a door to door service and require passengers to be mobile, independent and able to find their own way to and from the drop off / pick up point. If there are any concerns about their ability to do this, a carer needs to accompany the person. They often have a “no lift” policy, which can include wheelchairs.  

Services are generally offered Monday to Friday and can start quite early and finish late to accommodate appointment times. At least one day’s notice is required for most services, but generally longer notice is preferable to ensure a volunteer is available. Some organisations offer locality-based services, such as the “Shirley Shuttle”, which transports Central Coast cancer patients to treatment, whilst others operate across the metropolitan area, like the Country Care Link service, that provides transport for country people between Central train station or the domestic airport and medically-related accommodation or medical appointments. Pick-ups and drop offs to transport points can be accommodated on the weekend by this service. Other organisations have services across the state, such as The Leukaemia Foundation. These services are usually free or a donation is requested, as most of these organisations rely on donations and receive little or no government funding.  

The Uniting Care Casino Transport Team (UCCTT) operates in a slightly different way from others providing medically related transport because it specifically includes transport for people with dementia.
• 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](http://www.ucctt.org)

**HACC funded services involving volunteers**

Volunteers are integral to some groups of HACC service provision. Many Neighbour and Community Aids, CTOs, local government and other not for profits throughout NSW engage volunteer drivers or escorts for their HACC funded social support and transport programs. These programs provide services such as shopping buses and individual shopping trips, transport to appointments of all kinds, although medical appointments are often given a higher priority, transport to and from day centres, and social outings. When medical or other appointment-related transport is provided, volunteers may provide either a door to door service, or a door through door service. It may also include waiting with the client. With a door to door service, a carer escort would be required if there are concerns about the client’s ability to get from the vehicle to the location of their appointment.

These HACC funded transport and social support services are usually offered Monday to Friday, during business hours. These restrictions are often due to the organisation’s insurance cover and the hours worked by paid staff, who provide support and supervision to volunteers. Due to the demand for transport services, clients need to book well in advance and often confirm their attendance prior to the day the service is to be provided. Last minute decisions to attend an outing or join a shopping trip, or late notice transport needs cannot usually be easily accommodated.

As a HACC funding requirement, all organisations must provide their staff and volunteers with regular training around workplace health and safety. Additional specific training is also provided for volunteers, which covers areas such as boundaries, communication, manual handling, privacy and, in some cases, general dementia training. Whilst HACC services at this level are not dementia specific, service providers recognise that a number of their clients may have dementia. Moderate dementia and/or difficult behaviours can be challenging and may be more than many volunteers can cope with. It is important that clients are safe and volunteers are comfortable with the role with which they are tasked.

**Supplemental Transportation Programs**

Many of the US programs previously noted fall under the category of Supplemental Transportation Programs (STPs) for seniors. STP is a category developed by the Beverly Foundation which undertook a research project examining volunteer driver programs in the US. There are more than 1,000 STPs across America, most of those described in the literature appear to have grown organically to meet a local need, some have grown to cover large areas.

There is a wide range of models within the STPs. The Beverly Foundation notes that what sets them apart from most other transportation programs is that they reach a hidden population of older adults who have special mobility needs. STPs are organised to meet those needs through trip
training, transportation escorts, door-through-door service, and numerous other means of personal support. It is not clear from the literature, which of the services are used by people with dementia. Detailed descriptions of a selection of the services can be found in the reference and some of the services are described in other parts of this section on models.

**Escorted transport services**

Transport escort services often, but not always, provide door through door services. The escort can be paid or a volunteer and may be the driver or an extra passenger in a car or on public or community transport. The following are examples of some of the various ways that transport escort services are provided to people with dementia in the US:

- **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](http://www.itnamerica.org/what-we-do)

- **Mountain Empire Older Citizens Inc.** is a program located in Virginia that tailors transport services to an individual’s needs. A caseworker assesses clients and those who are eligible receive a one-on-one service to appointments, the pharmacy or shopping.

- **Ride Connection**, some Ride Connection services mobilise volunteers specifically to be escorts for frail riders. Some Ride Connection partners have volunteer couples, one of whom drives while the other acts as an escort – this is said to assist with recruitment.

In NSW, the Neighbourhood Aid program provides support for an individual which includes: one to one support to attend a social activity, shopping and banking where the person is accompanied and assisted by a volunteer or paid worker and individual transport to appointments where transport is part of the provision of social support.

Some other Australian transport escort services are described in the section above on volunteer roles in transport.

**Council cabs/taxis**

While not a model designed specifically for people with dementia, Council Cabs may be a useful model for consideration. First introduced in Queensland, Council Cabs are maxi taxis operated by a taxi company and the cost is subsidised by local councils. Passengers register with the cab company and, in some cases, book on the day they wish to travel. They are matched with other passengers who live in the same area and a maxi taxi is dispatched to take them together to their destination. The cost to the passenger is subsidised, in some locations there is a standard fee of $5.00 per trip.

**Transportation vouchers programs**

In the US, area agencies on aging and disability and other social service organisations often provide fare assistance programs that enable qualified persons (usually economically disadvantaged older adults or persons with disabilities) to purchase vouchers for transportation services at a reduced rate. The vouchers are then used to pay for services from a participating transport provider that can include public transport, volunteer programs, or taxis and other private companies. Applications for these programs are required. Participants are responsible for reserving and securing the services they need.

**Commercial companion driver service**

Commercial Companion services are for-profit businesses that do not involve volunteers. An example is a franchise business called Driving Miss Daisy, which started in Canada and now has extensive franchises throughout Canada and New Zealand.
Meeting the transport needs of people with dementia

- Driving Miss Daisy states that their point of difference over other transportation providers is the assistance offered. For example, if required, they will attend doctors’ appointments with the client and transmit relevant information back to family members. They can also assist with shopping or ensure children safely attend sports practices or music lessons, along with several other services.
- Each business sets its own rates, which are generally lower than the cost of a taxi for the equivalent trip. Charges are usually based time-based. [http://www.drivingmissdaisy.co.nz](http://www.drivingmissdaisy.co.nz)

Coordinating different modes of transport
In order to avoid a fragmented approach to transport there has been some effort to coordinate the services offered by different modes of transport, for instance coordinating school transport with public transport.
- Ride Connection in Portland created by TriMet, the public transit system serving Portland metropolitan area to meet the needs of seniors and people with disabilities, by coordinating the transport services provided by local social service agencies and volunteer programs. In 2007 with a budget of $6.5 million, it provided 374,000 rides to more than 10,500 enrolled riders through the services of more than 600 volunteer drivers. Ride Connection serves an area of 3,699 square miles (9,580 square kilometres). [www.rideconnection.org](http://www.rideconnection.org)

Coordinating passenger schedules and available transport
As noted above, demand on community transport, especially for health appointments, accounts for a large, and growing percentage of community transport trips in NSW. If the timing and location of appointments is organised so that one trip can meet the needs of several passengers, then better use is being made of the available transport. Furthermore if the booking system can take account of the type of transport available and the needs of the passengers, then more appropriate and more efficient use of available vehicles can be made.
- NCOSS reports on a trial that was conducted by Great Community Transport and south-west Area Health Services testing a coordinated approach to non-emergency transport for health trips. The simulation found that significant savings could be made through a more coordinated approach to the provision of non-emergency transport.\(^1\)
- To overcome transport difficulties for people with dementia in rural Scotland, service providers used a combination of local transport schemes, volunteer drivers, taxis, ambulances and staff member’s cars.\(^2\)

Transport options for special needs groups
The transport challenges faced by special needs groups have been recognised in establishment of various models including:
- A flexible funding initiative that funds a free community bus for older people to attend medical appointments. In rural Western Australia (WA) the local casino funded the purchase of the bus, staff and service costs, while the government houses the bus and funds its maintenance.\(^3\)
- In WA 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.\(^4\)
- Engaging the special needs groups in developing and delivering the required transportation. For example, by engaging Aboriginal people in planning and delivery of transport through the Aboriginal Transport Network, several community transport organisations have seen clear improvements in Aboriginal access to services.\(^5\)
Making it easier and safer to drop and collect passengers with dementia
Establishment of transit lounges at major health facilities and reserved short-term parking areas for community transport near to hospital entrances makes it easier to transport people with dementia to these facilities, and to collect them.

Paratransit
Paratransit in the US is similar to Community Transport in Australia and the UK. Paratransit is described as an alternative mode of flexible passenger transportation that does not follow fixed routes or schedules. Paratransit services may vary considerably on the degree of flexibility they provide their customers. At their simplest, they may consist of a taxi or small bus that will run along a more or less defined route and then stop to pick up or discharge passengers on request. At the other end of the spectrum—fully demand responsive transport—offer on-demand call-up door-to-door service from any origin to any destination in a service area. Paratransit services are operated by public transit agencies, community groups or not-for-profit organisations, and for-profit private companies or operators.

Paratransit focuses on special transport services for people with disabilities and the elderly.
**DETAILED FIELDWORK FINDINGS**

**Profile of project participants**

**Survey respondents**

Five surveys were conducted as part of this project. This section presents the demographic details of these respondents.

**People with dementia and their carers**

There were 96 respondents to this survey. 77% were female. Most respondents (87%) spoke English at home. Other languages spoken at home included: Italian (6%), Chinese (3%) and Greek (3%).

44% of respondents were based in metropolitan Sydney, 32% in regional NSW and 24% in rural NSW.

The majority of carers were older people. Over half of the respondents who identified as carers were aged 66 or more. 10% were aged 85 or older.

82 carers answered a question about the age of the person they care/cared for.

- 10% were caring for someone aged 65 or less
- 26% were caring for someone aged between 66 and 75
- 40% for someone aged between 76 and 85
- 23% for someone aged 86 or more.

Just under half (44%) of respondents did not have a home care package.

**How people with dementia and carers described themselves**

Nine of the respondents to this survey were people with dementia, the remainder were carers.

While only 2 respondents to the survey were people living alone with dementia, a further 13 provided care for a person living alone with dementia.

The vast majority of people with dementia being cared for by respondents were older; however 17% of respondents had either been diagnosed with younger onset dementia or were caring for someone who had been diagnosed with dementia before the person was 65.

**Service providers**

51 service providers participated in the survey. The providers worked with people with dementia and their carers throughout much of NSW:

- 19 worked largely in metropolitan Sydney
- 7 in a regional city
- 6 in a regional town
- 15 in a country or rural area
- 1 in a remote area, and
- 3 worked equally across several areas.

The respondents came from a wide variety of roles including: dementia advisory workers, younger onset dementia key workers, counsellors, day care workers, occupational therapists, educators, nurses and GPs.

Asked whether they worked with specific groups of people with dementia, service providers reported that:

- 40 worked with people with dementia who live alone
- 34 with people with younger onset dementia
- 31 with people with dementia from CALD backgrounds
• 15 with Aboriginal people with dementia.

The providers also reported on the driving arrangements of their clients with dementia:
• 45 worked with people with dementia who have a carer who drives
• 36 with people with dementia who drive
• 39 with people with dementia who did not drive and who lived with a carer who does not drive.

**Community transport operators (CTOs)**
31 CTOs participated in the survey. As with the service providers, the operators covered a wide area of NSW:
• 11 covered rural and remote areas in the state
• 9 covered regional NSW
• 6 worked in outer metropolitan areas, and
• 4 inner metropolitan areas.

HACC provided most of the funding for the CTOs.

**Local governments**
Local Government NSW assisted AlzNSW to conduct a survey of local governments across NSW. 55 local governments completed the survey: 25% were based in inner metropolitan NSW, 25% in outer metropolitan NSW, 29% in regional NSW, and 22% in rural/remote NSW.

Of the 55 respondents, 28 worked in local governments that provide transport to the community. More than a third (39%) of these respondents were based in inner metropolitan NSW, while less than a fifth (19%) were based in regional NSW. 21% were based in outer metropolitan NSW and 21% in rural/remote NSW.

8 of the local governments that provided transport covered less than 50 square kilometres; 7 between 51 and 500 square kilometres and 5 covered more than 500 square kilometres.

23 of the local governments that provide transport for the community reported they used the following vehicles:
• 12 buses with 15 or more passenger seats
• 9 buses with 9 to 14 passenger seats
• 5 cars or station wagons
• 3 vans or buses with up to 8 passenger seats.

About a half of the local governments with vehicles for transport allow other organisations to use vehicles to provide community transport.

**Licensed clubs**
ClubsNSW conducted a survey of its members on behalf of this Project. 16 clubs participated in the survey. 6 of these were in outer metropolitan Sydney, 4 each were in inner metropolitan Sydney or a regional NSW city and 2 were in rural or remote NSW.

9 of the clubs had estimated gaming machine revenue of $10 million or more, 4 had revenues of between $1 and 10 million and 3 revenues of less than $1 million.

12 clubs provided community transport. These clubs had an average of 2 vehicles that were used for community transport.

Asked about usage of vehicles:
• 6 clubs indicated there were several hours each week day when at least one vehicle was not in use
• 5 said there were whole days during the week when at least one vehicle was not in use.
7 clubs lent or hired vehicles to other organisations so they could provide community transport. Half of the 6 clubs who did not do this would consider doing so.

**Interviewees**

Face to face or telephone interviews were conducted with:
- 30 people with dementia or carers of whom:
  - 5 interviews were people with dementia who lived alone
  - 18 were with carers
  - 7 interviews were with a carer and the person with dementia they cared for
  - 8 involved people diagnosed with younger onset dementia
  - 4 were based in rural or remote NSW, and
  - 12 came from CALD backgrounds – 4 were Italian, 4 were Chinese, 2 were Greek and 2 were Indian.
- 11 service providers, including dementia advisory workers, occupational therapists, younger onset dementia key workers, counsellors and educators.
- Stakeholders from 16 organisations many of which were focused on carers, people with dementia or transport. A list of the organisations can be found in Appendix 1.
- 10 people from 6 CTOs.
- 19 organisations that were involved in providing transport and social support using volunteers.

In addition, focus groups were conducted with 6 NSW Consumer Advisory Groups, 4 of which were in regional NSW.

**Summary of participants**

<table>
<thead>
<tr>
<th>Surveys</th>
<th>Number of Participants</th>
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<tbody>
<tr>
<td>Carers and people with dementia</td>
<td>96</td>
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<tr>
<td>Service providers</td>
<td>51</td>
</tr>
<tr>
<td>Community transport organisations</td>
<td>39</td>
</tr>
<tr>
<td>Local government</td>
<td>55 of which 28 provided transport</td>
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<tr>
<td>ClubsNSW</td>
<td>16 of which 12 provided transport</td>
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<tr>
<th>Interviews</th>
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<td>27</td>
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<tr>
<td>Service providers</td>
<td>11</td>
</tr>
<tr>
<td>Community transport organisations</td>
<td>6 organisations, 10 people</td>
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<tr>
<td>Stakeholders</td>
<td>30 people from 16 organisations</td>
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<tr>
<td>Organisations utilising volunteers (other than CTOs)</td>
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<table>
<thead>
<tr>
<th>Focus groups</th>
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<tbody>
<tr>
<td>2 metropolitan (Sydney, Wollongong)</td>
<td>60 people in 6 groups</td>
</tr>
<tr>
<td>4 regional (Cooma, Orange, Port Macquarie, Armidale)</td>
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</tbody>
</table>

Throughout the report the quotations attributed to SP refer to a service provider.

**The demand for transport**

This section reports on the levels of demand for transport, where and when people with dementia want to go, and the level of difficulty in meeting that demand.
As noted earlier, the paucity of literature on the topic could indicate that transport is not important to people with dementia. The feedback from participants in the Project detailed in this section was that transport was extremely important and that providing this transport is currently a strain, particularly for carers.

The relative importance service providers placed on transport is partly illustrated by their response to a question asking them to rank the various types of assistance they provided to people with dementia living in the community.

<table>
<thead>
<tr>
<th>The three most important types of assistance required by people with dementia living in the community</th>
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<tbody>
<tr>
<td>Rank 1</td>
</tr>
<tr>
<td>Assistance with managing medication</td>
</tr>
<tr>
<td>Assistance with meals and nutrition</td>
</tr>
<tr>
<td><strong>Access to transport</strong></td>
</tr>
<tr>
<td>Assistance with money management</td>
</tr>
<tr>
<td>Assistance with personal care and hygiene</td>
</tr>
<tr>
<td>Assistance with household maintenance</td>
</tr>
</tbody>
</table>

Responses from service providers (n=43)

There was widespread feedback that meeting the demand for transport was difficult and that there was considerable unmet demand for transport for people with dementia.

Ease of meeting the demand for transport

People with dementia and carers and service providers

Before people with dementia, carers and service providers provided feedback on where people with dementia wanted to go and how often; they were asked to disagree or agree with two statements:

> It is easy to meet the transport needs of people with dementia
> It is difficult to meet the transport needs of dementia.

As the following graphs show, there was widespread agreement among people with dementia, carers and service providers that it was difficult to meet these needs and relatively few agree that it was easy.
Agreement/disagreement with statements about the ease/difficulty of meeting the transport needs of people with dementia

Responses from people with dementia and their carers (n=88) compared with service providers (n=50).

Community transport organisations
CTOs were surveyed because feedback in the initial phase of the project suggested that they are likely to play a key role in meeting the transport needs of people with dementia.

The providers report they struggle to meet the existing level of demand and they believe this demand will grow significantly in the next five years. CTOs were almost seven and a half (7.5) times as likely to agree that there was significant unmet demand for people with dementia, as they were to disagree.

Level of agreement / disagreement on whether there is significant unmet demand for community transport by people with dementia.

Results displayed from community transport operators (n=30).
CTOs in regional NSW were particularly likely to agree with this statement, with three quarters agreeing there was significant unmet demand for transport from people with dementia.

Although nearly a quarter (23%) of CTOs reported servicing communities which did not have a significant demand from people with dementia, nearly all (90%) of the providers in the survey agreed that the demand for community transport from people with dementia will grow significantly over the next five years.

**Level of agreement/disagreement with the statement that demand for community transport from people with dementia will grow significantly over the next five years.**

![Bar chart showing level of agreement/disagreement with the statement.]

*Results displayed from community transport operators (n=30).*

**Local government transport**

The groups said to be the most likely to have unmet transport needs by all local government respondents were:

- the frail aged (74% of all respondents reported that this group was ‘very likely’ to have unmet transport needs)
- people with dementia (70%)
- people with physical disabilities (67%)
- people aged 66 or more (63%).

Unsurprisingly, these perceptions were very similar to those reported by the local governments that provided transport, as shown in the following chart.
Unmet transport needs of groups in local government areas

Results from local governments that provide transport (n=23).

Impact of unmet need for transport

Service providers, people with dementia and carers all reported that difficulties in access to appropriate transport led to frustration and social isolation for carers and for people with dementia. Service providers often noted in both discussions and in response to written questions that social isolation often led to an exacerbation of dementia symptoms and depression.

Both the carer and the person became socially isolated, depressed and frustrated. Social isolation can lead to an increase in the impact of dementia on the sufferer as they are not being engaged in activities that they previously enjoyed and decline faster than if they had been more socially engaged. SP

Insufficient social and community interaction is the most common cause for depression. They feel socially isolated and become withdrawn, then are reluctant to accept services. The carer becomes exhausted and frustrated and this has an impact on the care recipient. The health and well-being of the carer and care recipient declines more rapidly. This is where a crisis is more likely to occur. SP

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. SP

Sought after destinations and desired frequency of travel

People with dementia, carers and service providers

There was general agreement among people with dementia, carers and service providers that medical appointments and getting out of the house are extremely common needs that require transport.
Meeting the transport needs of people with dementia

Common destinations for people with dementia that require transport

Results displayed from people with dementia and carers (n=90) & service providers (n=44) 
local governments that provide transport (n=23)

According to people with dementia and carers, the most frequent need is to ‘get out of the house’, 24% respondents to this question said this was something that was needed every day. A further 54% stated getting out of the house was something the person with dementia wanted several times a week.

This information was particularly relevant when considering the role of community transport, where the focus is increasingly on providing transport to medical appointments. The focus on meeting the need to get medical appointments made it very difficult for community transport to meet the more frequent need of ‘getting out of the house’.

Frequency that the person with dementia wishes to get out of the house

Results from people with dementia and carers (n=76).
Meeting the transport needs of people with dementia

Frequency that the person with dementia wishes to travel to medical appointments

Results from people with dementia and carers (n=81).

Analysis of the need for people with dementia to get to particular destinations showed:
- 79% wanted to get to day care or respite several times a week or once a week
- 77% wanted to get out of the house every day or several times a week
- 68% wanted to go shopping several times a week or once a week
- 54% wanted to meet friends or family several times a week or once a week, a further 22% want to meet up every two or three weeks
- 48% wanted to get to sport or other leisure activities several times a week or once a week
- 52% wanted to get to medical appointments every two or three weeks or once a month, a further 37% want to get to these appointments every couple of months.

Service providers, people with dementia and carers were asked how difficult it was for the person with dementia to attend these activities. Overall social activities, such as meeting friends and family and travel and holidays were said to be the destinations most difficult to access transport for.

Over half of the people with dementia and carers said that getting out of the house was occasionally or very difficult (61%). Transport for travel and holidays was most often rated very difficult (30%). The activities that this group found least difficult to access transport for were medical appointments (41% said not difficult) and shopping (also 41%).

Generally service providers were more likely than people with dementia and carers to say that accessing transport to these destinations was difficult. At least three quarters of the service providers reported that it was occasionally or very difficult for people with dementia to access all these activities. 90% or more said that access to medical appointments, shopping and getting out of the house was difficult.
Meeting the transport needs of people with dementia

Perception of difficulty in accessing transport to attend activities for service providers and people with dementia and carers

Results displayed for service providers (n=44) and people with dementia and carers (n=82). Scale 1 = Not difficult, 2 = Occasionally difficult, 3 = Very difficult.

Dementia cafes would generally be much more effective if they could provide transport, people do come from a number of areas but a small van would make a big difference, perhaps with a volunteer to drive it. SP

Sometimes there are not transport options. We have people who want to come to courses which would greatly benefit them but transport just cannot be organised. SP

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. SP

Community transport
Community transport operators’ perceptions of demand for transport from people with dementia differed somewhat from service providers and people with dementia and carers. Although everyone recognised the need for transport to medical appointments, community transport operators reported less focus on people ‘getting out the house’ and more on ‘travel to day care centres’.
Meeting the transport needs of people with dementia

Community transport operators’ perceptions of demand from people with dementia for transport to specific destinations

Percentage response results displayed from community transport operators (n=29).

The focus on medical appointments was probably both a reflection of the level of demand and of the way that providers prioritised that demand.

*We really have a reasonable level of funding but demand just races ahead. We have to prioritise so we prioritise on medical. We know we are not meeting the social needs. Transport for health just eats up the resources.* CTO

Local governments

Local governments that provided transport reported high levels of demand for services to medical appointments, day care centres, social engagements and shopping trips.

Local governments’ perception of demand for transport to specific destinations
Meeting the transport needs of people with dementia

Percentage response results displayed from local governments that provide transport (n=24).

Transport needs of specific groups of people with dementia
Areas of unmet demand noted for specific groups were identified by service providers, community transport operators and people with dementia and their carers. This feedback was very similar to the findings of the Literature Overview.

People with dementia who live in regional and rural areas
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, medical and others are often considerable.
- Public transport and taxi options are usually very limited.
- Community transport options are also often limited. Distance issues are a significant problem for community transport in many areas. People may live out of town, sometimes on dirt roads. Medical appointments may be in neighbouring or regional centres.
- Lack of alternative transport options and the traditional reliance on the car means that driving cessation can be more of an issue for people in non-metropolitan areas.

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

People with younger onset dementia
Service providers noted that people with younger onset dementia were likely to:
- miss out on subsidised transport because they did not meet criteria
- have less support available from a carer to assist with travel either because the carers are working or looking after family or because they live alone
- be uncomfortable if they are younger than other people on community transport
- want to go to different locations than older people with dementia.

They can feel isolated when grouped with older people on community transport buses. They don’t want to visit traditional places that older people want to visit such as day care. They like to access more leisure type places like the beach. They may also need to go to specialist appointments outside the LGA. Resources for younger people are often more spread out. SP

Specific day centres for younger onset clients are not always located in local areas to the client and it is incredibly difficult to obtain transport to out of area venues. A lot of younger onset dementia clients are socially isolated and not being able to get a client to a venue, is incredibly disappointing for all involved. SP

Carers who are still in the workforce may require services to come early enough that the person with dementia is not left alone for too long. Often the services cannot oblige with specific times to suit working carers because they have set routes and timetables. SP

People with dementia who live alone
People with dementia who live alone face particularly challenging issues, including accessing appropriate transport. Some people who live alone may be driving themselves, others may have assistance in organising transport, some have non-resident carers who may drive them but many are non-drivers who have to organise their own transport

Service providers and community transport operators noted that common behaviours exhibited by a person with dementia who lives alone and organises community transport included:
- forgetting they have booked transport
- booking transport several times
- not being ready for the transport
- not having an escort available for transport
- getting lost on outings
- having trouble being at the pickup point for the return journey
- having difficulty in organising payment.

People with dementia who live alone often forget that they have an appointment, so even if there is a transport service available, when the service arrives the person has forgotten they are coming. Sometimes the service can’t wait; sometimes they need support to get ready. Sometimes the services will ring ahead but even that is forgotten as soon as the phone is put down. In addition there is often nobody to accompany the person with dementia to appointments and they may be left to find their own way after drop off and back to the pick up point, which may too hard for them. This is very stressful for everyone. CTO

Community transport operators noted in discussions that they often noticed symptoms of dementia developing in people who live alone and are unsure of how to handle this. Typically they attempted to provide transport for the client for as long as possible, but eventually the providers found it too difficult to continue, particularly if the nominated contact person for the client did not act as a carer.

Participants often noted that people with dementia who live alone are more at risk of becoming socially isolated, as organising transport can be too difficult.

Often they don’t have the capacity to organise transport for themselves and forget about arrangements that others make. They do not have the capacity to organise community transport and can become very socially isolated. CTO

Several service providers noted that people who lived alone were more resistant to giving up driving because they may not have a carer to encourage them and because they were at greater risk of social isolation when they did not drive.

People with dementia from CALD backgrounds
People from CALD backgrounds were most likely to face particular difficulties in accessing transport if they were not able to understand written and spoken English.

We always travel by train but we can only go on the routes our daughter has taught us. Chinese carer

My mother probably could still use the train for the route she knew so well but we don’t let her as if anything happened she could not communicate with anyone to get help. Unless she struck an Italian speaking transport worker that knew something about dementia! Italian carer

Service providers and community transport operators reported that:
- It is difficult to find culturally appropriate support to explain options or to accompany people with dementia.
- Drivers may not speak their passengers’ language and find it hard to ask them to do things such as putting on a seat belt.
- Information on transport in community language is usually difficult to find.
- People with dementia may miss out on services as they are unaware that they exist or how to access them.

Huge language barrier to using community transport. Hard to find information, let alone information in language and then they cannot book without an interpreter. These are available but it is all too
much for most people to coordinate. Every step is more complicated because of the language issue.

SP

Research shows older women from some CALD backgrounds are less likely to drive than older Anglo Australian women. There were several reports of older CALD women who had returned to driving but who were not confident in doing so.

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

Many Italian wives in the older generations don’t drive so when he has to give up they are stuck. Family helps but they have busy lives and the focus on family as the care provider means that people miss out on services. They just don’t look for them. The end result is that people don’t come looking for services until things are desperate.

SP

Stakeholders and service providers reported that there was a lack of awareness and understanding of services available in many CALD communities.

The whole family wanted to come along on the shopping trip when the service was for the person with dementia. It can be hard to explain how the funding works when there is a cultural and language barrier. The family could not see there was a problem.

SP

The families of CALD clients of our service attempt very hard to do things on their own. Because they are not proficient in English they miss out on what might be available.

How the travel needs of people with dementia are met

We do not know how many people with dementia use various modes of transport. The feedback from this study was that the great majority are driven in cars. There were few reports of people with dementia using public transport, more used community transport and taxis. Whatever mode of transport used, the carers were the group carrying the greatest burden for arranging transport.

The services that abrogate responsibility for transport can generally point to reasons why it is too hard. For example, most health organisations may not be funded or resourced to arrange transport. Other services pointed to the lack of available options or difficulties involved in trying to organise a particular mode of transport.

The medics think it is the responsibility of the transport sector and the transport sector wants to see health take some of the responsibility for the demand they create. Everyone just assumes that it is someone else’s responsibility. Stakeholder

I would like to organise transport for the cafes but people come from different areas so it would mean involving different CTs and then others would need taxis. I just don’t have the time to do that. I put the CT contact details on the brochure but really we rely on the carers to get them here.

SP

The role of carers

Overwhelmingly, the transport needs of the people with dementia in the survey were met by carers. When asked to indicate which statements were true for them, over three quarters (77%) of respondents agreed that the carer mostly drove the person with dementia to various places.

As reported in the literature, meeting the transport needs of people with dementia is a constant task for carers. Of the 80 carers who told us how often they organised transport for the person with dementia:

- 39% do so daily
- 37% several times a week
- 4% once a week
Meeting the transport needs of people with dementia

- 6% several times a month
- 11% once a month or less
- 2% never.

The role of private cars in transporting people with dementia was made clear when carers reported on the type of transport that they organised or provided for the person with dementia:
- 87% of the 79 respondents said they drove the person with dementia
- 29% said they got a friend or family member to drive the person with dementia
- 21% organised community transport
- 16% organised public transport
- 13% organised taxis
- 5% were a passenger when the person with dementia drove.

Included in other comments to this question were several references to walking with the person with dementia.

Carers and service providers reported that the toll of providing transport was high. As noted earlier, people with dementia need transport to numerous destinations on an almost daily basis. 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. Carers may be working and have other responsibilities. The strain of providing transport for a person with dementia was recognised as considerable.

*A constant drain! I accessed several support services for my husband but whenever he was out of the house I was constantly on the phone organising the next transport. The needs of a person with dementia change constantly so sourcing transport and other activities takes a lot of time and effort.*

*Carer*

*Carers just get overwhelmed. Too often it is a lose lose proposition. Either they have the stress of driving someone when they don’t feel safe to do this or they stay at home and become increasingly isolated and the person with dementia is frustrated which makes everything worse.*

*SP*

*It is often very stressful for carers. They can organise their whole day around the transport for their dementia patient. When you consider how old many of these carers are, many with health issues of their own, it is no wonder that it is such a burden. Even if there was a decent website that could help them they probably couldn’t use it.*

*SP*

**Driving**

The extent to which the transport needs of person with dementia were met by carers was evident when respondents reported on the most common forms of transport used for specific activities.

84 respondents reported that the carers drove the person with dementia to:
- get out of the house and medical appointments – 83%
- meeting friends or family – 81%
- shopping – 79%
- travel and holidays – 72%
- sport or other leisure activities – 62%
- day care/respite – 47%

Respondents from a regional or rural area were significantly more likely than respondents from other areas to have the carer drive the person with dementia to all locations.

Another relatively common means of travel was for someone other than the carer to drive:
- getting out of the house – 17%
- meeting friends or family – 16%
Meeting the transport needs of people with dementia

- sport or other leisure activities – 15%
- travel and holidays – 12%

Other forms of transport reported for specific locations were:
- day care/respite transport – used to get to 37% of day care and respite activity
- public transport – used to get to 17% of sport or other leisure activities, 16% or travel and holidays and 9% of medical appointments
- community transport – used to get to 12% of day care/respite
- taxis to get to 11% of medical appointments, and
- walking for 21% of people to get out of the house, 15% of sport or other leisure activities and 12% of shopping activities.

Community transport
While feedback from the people with dementia and carers showed low use of community transport, 93% of operators regularly provided transport for people in the early stages of dementia and 46% regularly provided transport for people with more advanced stages of dementia.

When asked how they transported people with dementia, CTOs reported that buses were most commonly used for shopping trips and day care centres, while cars were most commonly used for medical appointments.

Public transport
Nearly three quarters (73%) of the 86 respondents to the survey of people with dementia and carers said the person with dementia did not use public transport. Respondents from metropolitan Sydney were more likely to say that the person with dementia used public transport – 42% compared with 20% in a regional city and even less in regional, rural or remote areas.

Before they were diagnosed, 20% of respondents used public transport at least once a week. A further 11% used it several times a month and 25% once a month or less. 37% did not use public transport at all prior to diagnosis. Respondents based in metropolitan Sydney were more likely to be frequent users.

Taxis
Respondents reported that 5% of people with dementia used taxis once a week or more, a further 5% used taxis several times a month and 29% used them once a month or less. Sixty one percent never used taxis. People with dementia in metropolitan Sydney were more likely to use a taxi at least once a month and less likely to never use taxis.

Local governments
The local governments that provided transport offered services for shopping trips, day care centres, social engagements and medical appointments and to a lesser degree, connections to public transport, school transport and to sporting activities.

These local governments most commonly used buses to provide transport for shopping trips, day care centres and social engagements, but other vehicles were also used.
Meeting the transport needs of people with dementia

Provision of transport by local governments to specific destinations

Percentage results of the type of transport provided from local governments (n=23).

The local governments provided a mix of scheduled, pre booked and on demand services. Over half of the transport to day care centres is scheduled and more than 50% of transport to medical appointments, social engagements and shopping trips are pre booked by the client.

Most of the local governments offering transport services incorporated the following features:
- door-to-door transport for some clients (73%)
- transport for individuals to attend council program (68%)
- transport to locations outside the council area (64%)
- a community transport service with their own vehicle and paid staff to organise and or drive (59%)
- hire or loan self-drive buses or vans to community groups or other services (56%).

Less than half of these local governments provide:
- cab vouchers (45%)
- door-through-door transport services for some clients (36%).

When asked about the transport options these local governments provided:
- 12 people agreed that people with dementia used transport services that are primarily for the frail aged
- 6 agreed that their local government area had transport services geared to people with dementia
- 6 agreed that people with dementia must travel with a carer on the transport services offered
- 3 agreed that, because of the risks involved, their local government preferred people with dementia not use their transport services
- 2 agreed that people with dementia used transport services that are primarily for the physically disabled
- 2 agreed that people with dementia chose not to use the transport services they offered.

Licensed clubs

Nearly 80% of the clubs that provide community transport are unaware that any of their passengers have dementia.
The 13 licensed clubs that answered a question about the number of passengers who used club transport in an average month reported there were nearly 28,000 passenger trips per month.

Asked about the type of transport they provided:
- 8 of these clubs transport people between their homes and the clubs
- 4 transport people between their homes, the club and other destinations
- 3 transport people between fixed stops and the club
- 6 had a fixed timetable, and
- 4 provide transport on demand.

The most common destinations other than the clubs were sporting events (5 clubs).

**Challenges involved in meeting the transport needs of people with dementia**

**Issues affecting all modes of transport**

Common challenges that emerged across all modes and from all groups of people involved in the Project concerned:
- difficulties associated with behaviour caused by dementia
- availability of appropriate transport
- awareness of transport options
- the ability to source information on transport options
- lack of appropriate escorts to travel with people with dementia when a carer is not available
- lack of training in dementia awareness and management among transport providers
- funding issues, particularly in regard to meeting the particular needs of people with dementia
- difficulties in providing door through door service.

*It has become increasingly difficult to organise transport due to his challenging behaviours. It is difficult getting him to follow me when I have to manage luggage, when changing stations/terminal/buses and there are the objections of other passengers if he starts to sing. It is very stressful, often physically very hard and very nerve wracking. A constant worry about getting him to appointments on time and keeping the peace with others.* Carer

*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

The following charts show service providers and people with dementia and carers responses to a series of prompts about the difficulties in meeting the transport needs of people with dementia. Other difficulties are discussed throughout this section and the issues below are explored further in the sections on specific modes of transport.
Meeting the transport needs of people with dementia

Percentage of respondents who agreed that meeting the transport needs of a person with dementia was difficult because:

<table>
<thead>
<tr>
<th>Reason</th>
<th>% Agree</th>
<th>People with dementia and carers</th>
<th>Service providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is difficult to organise the person with dementia so they are on time</td>
<td>70%</td>
<td>70%</td>
<td>70%</td>
</tr>
<tr>
<td>The person with dementia sometimes behaves in challenging ways in public</td>
<td>50%</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Transport is not available when we need it</td>
<td>80%</td>
<td>80%</td>
<td>80%</td>
</tr>
<tr>
<td>Transport does not go where we need it to go</td>
<td>60%</td>
<td>60%</td>
<td>60%</td>
</tr>
<tr>
<td>Transport is expensive</td>
<td>65%</td>
<td>65%</td>
<td>65%</td>
</tr>
<tr>
<td>It is difficult to find useful information on transport options</td>
<td>55%</td>
<td>55%</td>
<td>55%</td>
</tr>
</tbody>
</table>

Results displayed from people with dementia and carers (n=78) and from service providers (n=45).

Percentage of respondents who didn’t know whether meeting the transport needs of a person with dementia would be difficult because:

<table>
<thead>
<tr>
<th>Reason</th>
<th>% Don't know</th>
<th>People with dementia and carers</th>
<th>Service providers</th>
</tr>
</thead>
<tbody>
<tr>
<td>It is difficult to organise the person with dementia so they are on time</td>
<td>15%</td>
<td>15%</td>
<td>15%</td>
</tr>
<tr>
<td>The person with dementia sometimes behaves in challenging ways in public</td>
<td>25%</td>
<td>25%</td>
<td>25%</td>
</tr>
<tr>
<td>Transport is not available when we need it</td>
<td>30%</td>
<td>30%</td>
<td>30%</td>
</tr>
<tr>
<td>Transport does not go where we need it to go</td>
<td>35%</td>
<td>35%</td>
<td>35%</td>
</tr>
<tr>
<td>Transport is expensive</td>
<td>30%</td>
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</tr>
<tr>
<td>It is difficult to find useful information on transport options</td>
<td>35%</td>
<td>35%</td>
<td>35%</td>
</tr>
</tbody>
</table>

Results displayed from people with dementia and carers (n=78) and from service providers (n=45).
Meeting the transport needs of people with dementia

Generally speaking, service providers were more likely to agree with statements about difficulties involving people with dementia and transport than were people with dementia and carers. However, they were also less likely to say that they don’t know in response to difficulties associated with availability and information on transport.

Driving
While many people with dementia give up driving at the appropriate time and travel in cars as passengers without incident, people with dementia can be difficult passengers and they may wish to continue driving when it is unsafe for them to do so.

Having a person with dementia as a passenger
There are widespread reports of difficulties encountered by carers in driving people with dementia. While some people with dementia are good passengers, there are also those who:

- harass the driver, either about their driving or where they are going

  I have learnt to agree with whatever directions he gives me, although obviously I don’t follow them. Carer

- attempt to get out of the car while it is moving

  The first time she tried to jump out was in the local shopping area and I could stop but the second time we were on a busy roundabout in the city and I was trying to drive and hold the door closed while she fought me. Carer

- are reluctant to get into or out of the car

  As the disease progressed my wife would not or could not get into the car. Eventually she forgot how to walk at all and become wheelchair bound. My problems were immense. Carer

- become agitated

  My husband is not a good passenger. He gets very excited and upset about the other cars. It is hard to concentrate on my driving. Carer

- are incontinent

  It is very distressing for everyone when this happens. We have to stop immediately. Carer

- want to drive

  He always says that he will drive. Nowadays I say that it is not far and I would like to drive for a change and he seems to accept that. Sometimes he makes a bit of a fuss. Carer

- have difficulty coping with limited parking arrangements.

  Parking is a big issue. Even with a sticker there are never any places near the clinic, even at 8 am. This means too much walking for my wife and too much driving around which makes her agitated. Carer

Many carers are elderly and may not be confident or particularly competent drivers themselves.

It gets harder every day as my health is not good. When I get really sick I have to call an ambulance and take us both to hospital though she is not sick. Carer

I hadn’t driven much for years but I now I have to do it all. I don’t go far and never at night, even though he wants to. I am not at all confident. Carer
Awareness of the regulations covering a driver with dementia

**Notifying the RMS**
There is considerable confusion about who is responsible for addressing the regulatory requirements of driving with dementia. As outlined in the Literature Overview, dementia is one of the conditions that must be reported to the RMS and a driver with dementia is not eligible for a full license.

In several of the discussions with service providers it was apparent they were confused about legal requirements. It was also reported that many doctors are not aware of the requirements and the prescribed assessment process. Other doctors were reported to be aware of the process but take responsibility for judging when the person with dementia is unfit to drive.

Among people with dementia and their carers awareness of the legal requirements is low. Just over half (51%) of respondents knew when a person was diagnosed with dementia they must notify the RMS if they intended to keep driving.

**Awareness of the requirement that a person with dementia must notify the RMS if they intend to continue driving**

![Pie chart showing awareness](chart.png)

Results displayed from people with dementia and carers (n=85)

There was more certainty on this point in regional, rural and remote areas than in metropolitan Sydney. 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.

**Changing to a conditional license**
While a half of the respondents were aware that drivers with dementia were required to notify the RMS, only just over a third believed that a person diagnosed with dementia needed to replace their full license with a conditional license if they intended to keep driving.
Meeting the transport needs of people with dementia

Awareness of that a person with dementia can only have a conditional license

Results displayed from people with dementia and carers (n=85)

Respondents in regional cities were more likely than others to know this.

Notifying insurance companies

The impact of driving with dementia on car insurance is another area of uncertainty among people with dementia and carers; overall 38% of respondents believed a person diagnosed with dementia needed to notify their car insurance company if they continued to drive.

Awareness of that a driver with dementia should notify their insurance company

Results displayed from people with dementia and carers (n=85)

Again, people based in a regional city were the most likely to think this was necessary.

The role of the RMS

Reporting and licensing requirements for people with dementia were not clear on the RMS website. Additionally, there were reports that some RMS offices did not follow the AusRoad guidelines regarding on road assessments. These assessments are supposed to be conducted by a qualified...
occupational therapist but several carers reported that their person was assessed by a regular RMS assessor. This may be because the person did not disclose their dementia, however several service providers in regional areas also reported that the local RMS did not require that tests for drivers with dementia be conducted by a suitably qualified occupational therapist.

The RMS has recognised that older drivers need special licensing requirements and data are available on the number of older drivers and on the accident rates of drivers by age. However, data on the number of drivers with dementia or on accidents involving drivers with dementia are not available.

The absence of statistics makes it difficult to assess the scope of the problem.

Driving cessation

Service providers and carers all reported there was not enough support to assist people with dementia to give up driving. As noted, some people with dementia gave up driving quite easily. For others, the process was drawn out and often traumatic for all concerned. Factors which contributed to making this process difficult included:

- poor access to information concerning the relevant regulations
- lack of clarity and consistency around the role of doctors in driving cessation
- cost of on road assessments
- limited access to on road assessments
- poor access to resources that may help all involved in the driving discussions
- lack of information about, and availability of, alternative transport
- the nature of the disease, which means the driver may lack insight into the problem.

It can be very challenging for a person with dementia to stop driving and for carers to manage that change.

Family and carers often threatened and abused if they mention driving problems. Often drivers fiercely oppose practical driving assessments and often they will not return to the GP if the GP is the perceived cause of license loss. SP

It is a significant emotional hardship to overcome, especially from male drivers. Access to alternative transport is the only way to keep them intact and manage their independent status without it there is significant deterioration in function which often leads to residential care as the only option. It is a significant cause of comorbid depression and behaviour difficulty including verbal/physical aggression and abuse to carers and family. SP

I will give up driving when I feel I cannot cope or when something stupid happens. I haven’t talked to the RTA. I want to avoid a flap and they might restrict me to a 10k radius and that would interfere with getting to my haircuts and church. Person with dementia

I know I could still drive. I am certainly a better driver than she is. It is one of the worse things about this whole business because getting around is so difficult and no one allows for that. Person with dementia who had failed an on road driving assessment three times

The role of doctors

While doctors were not specifically targeted for involvement in this project, several completed the service provider survey. The role of doctors was also raised in interviews.

The reports show an inconsistent approach by doctors to dealing with drivers with dementia. In some cases doctors did not raise the issue, others said the person must stop driving. There were few reports of doctors informing people that they must advise the RMS of their condition if they wished to continue driving and mixed feedback on whether doctors referred people to occupational
therapists for on road assessments. Some doctors reportedly told patients they would advise them when to stop driving.

*My doctor and I have agreed that we will know when I have to stop driving. I don’t drive as far as I did and I avoid busy intersections where I have to turn right.* Person with dementia

As noted in the Literature Overview, doctors are disadvantaged by the absence of a reliable off road assessment tool. In addition their role in relation to driving cessation can be difficult, as the person with dementia may see the doctor as the cause of loss of license and choose not to continue the relationship.

Several service providers and carers noted that they knew people with dementia who had chosen to avoid doctors known to actively address the issue of driving.

**Cost of on road assessments**

Low awareness of the need for some people with dementia to have an on road assessment with a qualified occupational therapist was one barrier to accessing this service; another barrier was the timely availability of the assessment service in some locations. However the biggest reported barrier was the cost of the service. Because the test involves a dual controlled car, a driving instructor and a qualified occupational therapist, it is costly. The tests usually take an hour but the elapsed time for each test, including travel and reporting, is considerably longer. One occupational therapist estimated the average total time was 5 or 6 hours.

The costs for the assessments are largely borne by the driver; some medical centres and some insurance programs provide a level of subsidiary, but generally the full cost is borne by the driver.

As one occupational therapist noted:

*They are not part of Medicare, not a hospital program, not a community health program, not covered by HACC, the RMS won’t cover them. It pretty much comes down to the driver and really the cost is prohibitive for many of them. There is a general problem with driving and dementia. The transport people think it is a health issue and the health people think it is a transport issue.* SP

Occupational therapists involved in this work report that the cost is difficult for everyone, especially if the driver fails the test. In some instances failure prompts aggressive behaviour and a reluctance to pay the bill.

Occupational therapists also report a disconnect between the RMS, doctors, drivers with dementia and occupational therapists. It is not always clear who should be sending out reminder forms when it is time for another test.

**Access to resources to assist the discussion**

In the discussion about driving cessation, participants noted the lack of resources. For example, there was little available to help people with dementia, carers and service providers navigate the whole, often challenging process. Many carers and service providers cited tips or tricks they found helpful but almost all of these were suggestions unrelated to the actual available resources.

*I told him that I had rung the NRMA and that they had said his insurance was invalid and he gave me the keys. I had to remind him every so often but eventually even the wish to drive fell away.* Carer

*I pretended to buy the car. The carer gave me some money which I put in his account so he could see it and then I drove the car away and hid it until the family could sort something out.* SP

*I involved our lawyer. He would not listen to me and the doctor didn’t want to get involved so I figured we needed someone else. I wish I had done it sooner. It would have saved a lot of heartache and arguments.* Carer
**Access to alternative forms of transport**

Low awareness and access to alternative forms of transport is a disincentive for people with dementia to give up driving and makes it more difficult for those who want to assist them in this process.

_He knows that when he gives up he won’t be able to go to the men’s shed, there is no other way to get there and I can’t drive him and then hang around while he does his thing._ Carer

Of course, access to transport is also needed for the wider population of people with dementia, not just those considering retiring from driving.

**Community transport**

As noted earlier in this report, carers who drove met most of the transport needs of people with dementia and 70% did not use community transport.

**Awareness of community transport services**

While use of community transport was low, 79% of 84 respondents were aware of community transport services. The highest level of awareness was for transport to medical appointments, shopping trips for older people and social outings and activities.

**Awareness of services provided by community transport**

<table>
<thead>
<tr>
<th>Service</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know</th>
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<td>Transport to medical appointments</td>
<td>75%</td>
<td>2%</td>
<td>23%</td>
</tr>
<tr>
<td>Shopping trips for older people</td>
<td>69%</td>
<td>2%</td>
<td>29%</td>
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<tr>
<td>Social outings and activities</td>
<td>62%</td>
<td>4%</td>
<td>34%</td>
</tr>
<tr>
<td>Transport for people in regional or rural areas</td>
<td>56%</td>
<td>1%</td>
<td>42%</td>
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<tr>
<td>Transport for people who cannot afford other forms of transport</td>
<td>51%</td>
<td>9%</td>
<td>40%</td>
</tr>
<tr>
<td>Trips to the local club</td>
<td>37%</td>
<td>2%</td>
<td>23%</td>
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</table>

Results displayed from people with dementia and carers (n=84)

As the table shows, a significant percentage of people with dementia and carers did not know whether community transport provided services to the prompted locations. The lack of knowledge was reflected in response to another question about aspects of community transport where respondents were asked to agree/disagree with a number of statements. Over half (56%) of the respondents agreed that they didn’t know much about the services provided by community transport, however nearly half (49%) thought it would be quite easy to find out.

Lack of knowledge was also evident among half of the people with dementia and carers who did not know whether community transport went to places the person with dementia wanted to go (50%). Other findings included: whether people with dementia were made welcome when using transport (56%) and whether the timing of services suited people with dementia (55%).

Service providers were also asked whether they agreed or disagreed with a series of statements about the role of community transport in the lives of people with dementia. Generally service providers appeared to know more about community transport than people with dementia and carers; there were considerably fewer ‘don’t know’ responses.
Meeting the transport needs of people with dementia

Service providers were less optimistic about people with dementia and carers being able to find out about community transport services. They were more likely to agree services did not go where they were most needed, that times were inconvenient and that people with dementia would make more use of the services if they were easier to use.

Almost all the service providers agreed that people with dementia who live alone faced particular challenges in using community transport.

**Service providers’ views of the role of community transport in the lives of people with dementia**

![Bar chart showing service providers' views](chart.png)

*Results displayed from service providers (n=43).*

**Characteristics of community transport that make it difficult for people with dementia**

As noted in the Literature Overview, community transport has many characteristics that make it well suited to providing services for some people with dementia. However, there are other aspects that make it difficult for clients with dementia.

Difficulties included:

- waiting periods
- time taken when there are several stops
- dealing with other people on the bus, especially if there is noise
- dealing with area, destination and timing restrictions, which make transport less flexible.
Meeting the transport needs of people with dementia

CT tends to have routes on special days, for example to the hospital, but people’s appointments often don’t match the days and if they do there is so much waiting around that the person with dementia gets very agitated. SP

He went on the bus once but it took too long as he was an early pickup and late drop off. He was very upset when he got home. Carer

Weekends and after hours can be a big problem. People are stranded at times when they want to meet friends or visit their spouse in care. SP

Often the specialists are in another area and community transport won’t go there and don’t seem to be able to coordinate with the other CTs. SP

People with dementia also may not understand where and when they have to be at a pick up point and therefore miss the transport home.

Mum used the shopping bus once but she got lost and missed the pick up point and then they could not find her. And so they will not take her again without me and I work on those days. Carer

CTOs often transport multiple clients simultaneously, which was said to be confusing for some people with dementia.

Characteristics associated with dementia that make it difficult for community transport

Factors that made it more difficult for community transport to have people with dementia as clients include:

- lack of diagnosis and appropriate back up for clients who need it
- some behaviour patterns evident in some clients with dementia
- people with dementia who do not have carers to help with transport arrangements and to accompany the person
- funding arrangements.

Lack of diagnosis and inadequate funding

Several community transport operators noted that some people with dementia had better access to transport because transport was part of a package and/or they attended a day care centre which organised transport. The providers noted the percentage of clients with dementia whose condition was recognised was small. One provider estimated their service provided transport to approximately 230 clients with early dementia but only 30 people with dementia were covered by an assistance program.

Lack of recognition that the person has dementia can be a significant problem for the providers, particularly if the person does not have a carer. Several providers reported they were unsure how, or even if, they should assist, especially when diagnosis was not sought.

There are a huge number of undiagnosed people with dementia on our client base. Sometimes family recognise there are problems but they may not push for a diagnosis or don’t want to know. Most people in community transport don’t have the training or knowledge to know what to do if they think they recognise symptoms. On the other hand, some providers have excellent processes that help. For example they will always ring the hospital on approach to ensure there is a handover. CTO

Lots of families don’t look for support. They think the person will be OK but they only see them when they are making a big effort. Families are often slow to hear or pick up on symptoms and often don’t want to hear or believe us when we tell them. CTO
Meeting the transport needs of people with dementia

CT is there to help people live independently for instance to give them the means to shopping independently in the mall however people (with undiagnosed dementia) tend to disappear and cannot get back to the bus. CTO

There are lots of people who have been with CT for a long time and staff see the symptoms start to develop. Very often they go the extra mile to keep them in the CT system, to help them so they continue to live independently but they need guidelines so they can help the person get the services they need. CT cannot become de facto carers but often our staff are at a loss as to how they can help. Especially when family doesn’t want to know or when the contact person is not really involved with the client. This is a real and widespread problem for people who live alone. Eventually we have to say the person cannot travel without a carer. We make more and more allowances but personal hygiene increasingly becomes an issue or the person is just not ready or gets lost. CTO

Managing people with dementia, especially those without carers

Even providers who have some dementia awareness and management training say they can find it difficult to manage some of the behaviours exhibited.

Problematic behaviours that CTOs noted were:
- clients not being ready when the transport arrives
- clients who forget that the transport has been ordered or that they have an appointment
- clients getting lost
- difficulty in communicating with clients
- behaving in a way that disrupts the service, particularly on mini buses.

People with dementia, especially those living on their own, sometimes book transport for appointments at the wrong time and place. Or they book the transport over and over again. Or they forget they have booked it or forget where they are supposed to be going. CTO

If people travel without a carer we need them to be able to be left unsupervised whether it is at an appointment or an outing. They need to be able to go to the bathroom independently. CTO

It is often hard to get them to travel on the vehicle. They refuse to get on the bus and sometimes this can make the whole run late or we have to allocate a separate vehicle. This is a cost to the service both in time and utilisation of the vehicles. Sometimes the client goes to the toilet on the bus and the vehicle and the client have to be cleaned up before continuing on the run. Some of the clients can be aggressive and disruptive; also some refuse to put on their seatbelt. CTO

The behaviour of a person with dementia can change daily or even in the course of the day. Sometimes they can be quite frightening. There have been a couple of incidents on the bus ranging from someone not bothering to wash or dress appropriately to a guy doing cartwheels in the aisle. There are not enough resources on the bus to deal with this. CTO

Funding arrangements and guidelines

Difficulties experienced in transporting some people with dementia included excessive time in providing services and more labour and vehicle resources, all of which make it more costly. Where funding is based on the number of trips provided, rather than the time taken, this is a disincentive. If unit cost becomes the measure it probably means less transport for people with dementia.

Our trips should be measured in hours, not number. Servicing people with dementia takes more time throughout the whole process especially for those without carers. The booking takes longer, often we have to ring ahead several times and often we wait for them. Their behaviours such as not wanting to get on or off the bus take time to manage. They may get lost or have the appointment time wrong. There is no end of things that can and do make those trips take much longer. CTO
You cannot charge for the time involved. It is high cost work in terms of time, levels of anxiety and stress. CTO

Doing dementia transport you need more resources. For example you might need an assistant to travel with the client or a seat for the carer. You need a larger fleet of cars for individual transport and more time to provide the transport. They can also require several reminder phone calls to ensure they don’t forget about the booking and to help them to be ready on time. Although even with these calls they may not be ready to go. CTO

Some CTOs reported that the guidelines meant they could not service people they felt had a legitimate need for transport. In particular, people in residential care and people whose needs cross several area boundaries.

We have tried coordinating with other CTs to ensure that people can get where they need to be, especially for medical appointments, but it has proved to be too hard. It is often hard enough to organise transport for our people with dementia in our own area. CT

**Responses to these challenges by community transport operators**

Feedback showed providers adopted a variety of ways to overcome community transport problems. Such a variety of responses were consistent with the diverse nature of CTOs.

The following remarks from different service providers illustrate how community transport responses vary by area.

Local community transport is very inflexible. The drivers are not trained to the level required and staff have no dementia training. They organise transport, not people. SP

Our community transport service is very helpful and flexible and is very aware of the needs of people with dementia. SP

It is a postcode lottery; some areas are better served than others. The nature of the clients, composition of the community, nature of the operating territory, all affect the nature of the trips and therefore the costs. And the way the service evolved makes them different from each other. Stakeholder

Some of the providers get put off after a couple of bad experiences but it can be done. If they coordinate with the ACAT, telephone them in advance. Whatever, it can be done. Although I can appreciate that the conditions in the area covered would make a huge difference. SP

**Public transport**

There are many reasons people with dementia find public transport difficult to use. The large majority of people with dementia and their carers found following situations difficult for the person with dementia:

- traveling alone on public transport (difficult for 85%)
- knowing when to get off the bus, train or ferry (89%)
- knowing which bus, train or ferry to catch (86%)
- finding information about public transport routes or times (85%)
- getting from the stop to their destination (84%)
- buying tickets (84%)
- coping with other passengers (73%).

The main difficulties for the carer were identified as:

- finding information about public transport routes or times (difficult for 19%)
- coping with other passengers (17%)
Meeting the transport needs of people with dementia

- knowing which bus, train or ferry to catch (17%)
- getting from the stop to their destination (11%)
- knowing when to get off the bus, train or ferry (10%).

I tried putting mum on the train to Central to be met by sister. It was incredibly anxious time for everyone. First there were lots of phone calls then she turned her phone off so we had no idea what was happening. We would not do it again. Carer

(He) 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 with dementia

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 with dementia

We used to have a pile of the right coins by the door but now she cannot work the ticketing. It all got too confusing for her and we all lost confidence that she was safe. Carer

Like many older people, some of those with dementia have other conditions, which make it physically difficult to access public transport.

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

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

In regional, rural and remote areas there is often very little public transport available.

We have limited access to public transport. The nearest train stations is 50 kms away, there is no taxi service. There is a V-line bus service that only stops in town three or four times a week. Carer

Taxis

For people with dementia and carers, taxis worked well because they:
- go directly to your destination (over 80% of people with dementia, carers and service providers noted this)
- are available on demand (over 60% of people with dementia, carers and service providers).

The main concerns about taxis are that they were:
- too expensive for the person with dementia to use regularly (76% of people with dementia and carers, 88% of service providers)
- sometimes driven by people who do not understand how to treat people with dementia (71% of people with dementia and carers, 95% of service providers)
- not useful for the person with dementia because sometimes they did not know where they are going (approximately 60% of service providers, people with dementia and carers).

Respondents disagreed that taxis were:
- too unreliable for the person with dementia to use (38% of people with dementia and carers and 31% of service providers disagreed with this statement)
- not available when the person with dementia needs them (29% of people with dementia, carers and service providers disagreed)
Service providers commented cost and availability were the main problems when using taxis, even with the TTSS.

**The NSW Taxi Subsidy Scheme**

More than half (55%) of people with dementia and carers were unaware of the TTSS.

Following a description of the TTSS respondents were asked whether the person with dementia would use the scheme; 69% said the person with dementia would use the scheme occasionally.

In the qualitative research it was evident there was confusion about whether people with dementia were eligible for the TTSS. There appeared to be a widespread belief that only people with physical disabilities were eligible. However there were numerous reports of people with dementia being provided with vouchers because their dementia symptoms meant they had difficulty accessing other modes of transport. Confusion was reported to be widespread among all groups – doctors, service providers and people with dementia and carers.

Carers who had access to TTSS noted the radius of use for taxis had grown progressively smaller as the price of trips increased.

**Door through door service**

This service does not meet with current regulations for taxi drivers. For instance, drivers are not meant to be three metres from their vehicle; drivers entering a passenger’s house can have insurance implications. Nevertheless, there was feedback that some taxi drivers in regional or rural areas provided door through door service on occasions, but it was said this is unlikely to become a regular aspect of taxi service.

**Local government**

The most commonly cited barrier to providing transport for people with dementia was access to trained staff or volunteers. Some local governments considered this was a particular barrier in providing escorts for people with dementia travelling alone. Others noted the lack of appropriate training impacted on the service in a more general way – affecting all staff who may interact with people with dementia using transport services.

Local governments noted other barriers, including: insufficient funding to provide escorts, poor communication between local governments and other support services and insufficient information on services for people who needed them.

**Making it easier to meet the transport needs of people with dementia and their carers**

**General principles**

Almost everyone involved in the project was asked their ideas about how to make it easier for people with dementia and their carers to use different forms of transport. Of course, the relevance of suggestions related to specific dementia symptoms experienced by an individual.

Suggestions most widely accepted were:

- having trained escorts for people with dementia who need them to travel on public or community transport
- training staff and volunteers who interact with people with dementia using transport in dementia awareness and support
- providing door to door service
- providing door through door service
Meeting the transport needs of people with dementia

- having clear, known paths to information on available transport
- having access to information and resources to assist people retire from driving.

In addition to the prompted suggestions, several participants raised the idea there should be an easy and visible way to identify that a person has dementia.

Discussion revealed differences in opinion on the various suggestions put forward. However overall there was general agreement on the types of services most helpful in giving access to appropriate transport. For example, three quarters of the carers nominated door through door escorted service as very important. Over four fifths (81%) of service providers stated this service was very important. The following charts show the relative support for a series of ideas tested with people with dementia, carers and service providers.

**People with dementia and carers’ and service providers’ rating of the importance of suggested features to assist people with dementia access transport**

![Chart showing people with dementia and carers' and service providers' ratings](chart.png)

Results from people with dementia and carers (n=79) and service providers (n=43). Scale 1= Not very important, 2 = Important, 3 = Very important.

In addition to evaluating a series of features that could assist people with dementia to access transport, carers and people with dementia responded to a series of specific ideas. These ideas were tested again in questions relating to specific modes of transport.

There was strong support for all of the ideas suggested to people with dementia and carers:
- 90% endorsed providing escorts for people with dementia when they used community transport
- 84% endorsed a program that linked volunteer drivers with people with dementia
- 81% agreed with having a case manager who would help work out travel options
- 78% agreed with providing escorts for people with dementia when they use public transport
- 71% agreed with having a website that provided information on all local transport options.
When the ideas were retested there was less support for websites as sources of information. This may be because the option presented in the general question stated that the website would provide information on all local transport options. In interviews, people often commented that it was difficult to find this information.

**Identification for people with dementia and for dementia friendly transport**

In discussions the various groups in the Project expressed their concern about how to accurately identify someone had dementia. A common suggestion was to develop a discreet identification symbol to detect those needing assistance, notably with transport.

**People with dementia need some sort of card that identifies them – something to show the driver. Ideally it would have their name and a contact number of who to call if they had difficulty.**

*Stakeholder*

**Most of the bus drivers are helpful but it would be better if there was something that meant they knew I had dementia. I don’t want to tell them but I want them to make allowances for me and to help me.**

*Person with dementia*

**They ask me what is wrong with him. I don’t want to have to tell the whole bus he has dementia. It would embarrass him.**

*Carer*

**It can be hard for our drivers to pick that the person is just not being difficult. If there was some way of adding that information when they made the booking or if they wore a bracelet or something it would help to avoid unnecessary confrontations.**

*Stakeholder*

However, there is little consensus on what form this identification might take. A number of carers and service providers noted some people with dementia would forget they had a card and would not show it; others were concerned about the stigma of people with dementia having a public label.

People with dementia and carers also suggested that dementia friendly transport could be identified. This would mean, for instance, that they would know that a service provider had appropriate training.

**I would feel happier about putting her in a taxi if I knew the driver had some training and wouldn’t do something silly like letting her out at a different destination.**

*Carer*

**Providing information on transport**

Almost all the participants agreed it was difficult for carers and people with dementia to access information on available transport services. Clearly, this would be useful information when retiring from driving and in enabling people to access the services and activities they need in order to remain living well in the community. However, there is less agreement on the best way to address this well recognised need.

Details of the preferred ways of accessing information about community and public transport are provided in the sections below. The following describes the relevant issues relating to all modes of transport: individual assistance, websites and apps.

**Individual provision of transport information**

There is widespread support for having someone work with the person with dementia and carers in order to work out travel options. Over four fifths of people with dementia, carers (85%) and service providers (83%) stated that having a case manager who could work out travel options was a good idea.
Meeting the transport needs of people with dementia

They need one on one attention or supervision to take them through the task at hand. They may not remember what they have read, or a new routine. Case managers often have to make all plans airtight and fail safe for them. SP

Definitely the case manager sounds good. They would have all the information about transport available. Not everyone has the Internet – I don’t. And not everyone can communicate well in English. Carer

More than half the service providers (55%) believed that having a case manager to help plan the trip would make it more likely that people with dementia would use public transport. Slightly less than a third (32%) of those with dementia and carers supported this concept.

Nearly three quarters (74%) of the CTOs agreed that allocating a volunteer travel buddy to make travel arrangements for a person with dementia would be a good idea.

A mobility manager who was aware of all of the available transport options could provide individual assistance to people, including people with dementia. However, while almost everyone agreed this was a good idea in principle, people involved in providing transport almost always pointed out that it would be difficult and expensive to establish and maintain these positions.

Websites and apps

There was limited support for websites as sources of information on transport for people with dementia and their carers. Nearly two thirds (63%) of service providers and nearly three quarters (71%) of people with dementia and carers agreed having a website that provided information on all local transport options was a good idea.

Participants commented on the limited ability of people with dementia and carers to find and navigate websites; even fewer were likely to use apps.

While this may be a reflection of the age of the carers and people with dementia, the comment was also common from carers of people with younger onset dementia and their service providers.

Depending on the stage that a person is at, timetables, training and apps would be impossible for some to cope with, especially, any which involve technology. Many are older and they, and their carers, cannot even manage to use a computer. SP

(She) could not possibly use an app. She is young but computers are beyond her. So is the phone. And I don’t have time to learn new stuff. Carer

Local governments generally do not see transport websites as an effective way of providing the information, particularly those based in regional, rural and remote NSW.

Only 15% of service providers and 11% of people with dementia and carers believed having an app that tells the person how to access and use public transport would make it more likely that people with dementia would use public transport.

Information on community and local government transport

Supporting the overall feedback about the advantage of having case workers help people with dementia make their transport arrangements, people with dementia, carers and service providers believed dementia service providers were the best source of information on community transport.

Furthermore, nearly all (90%) of CTOs and local governments (88%) nominated service providers, such as social workers, as an effective way of letting people know about community transport.

All groups nominated printed material such as brochures as a good source of information on community transport options.
As the following charts illustrate, there was remarkable consistency among participants on the most effective way for people with dementia to find out about community transport.

**Service providers’ and people with dementia/carers’ views on the best sources for people with dementia and their carers to find out about community transport services**

*Percentage response results displayed from service providers (n=43) & people with dementia/carers (n=81)*

Service providers also nominated day care centres and family and friends as very suitable sources of information on community transport for people with dementia and their carers.
CTO’s views on the most effective ways of letting people know about their community transport options

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<th>Service providers such as social workers</th>
<th>Printed brochures</th>
<th>Telephone service</th>
<th>Letter drops</th>
<th>Community Transport website</th>
<th>Local council website</th>
<th>Other dedicated transport website</th>
<th>Transport for NSW website</th>
</tr>
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<tbody>
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<td></td>
<td>Less effective</td>
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Percentage response results displayed from community transport operators (n=28).

Echoing feedback from service providers, people with dementia and carers, CTOs and local governments were not enthusiastic about websites as sources of information on services for the communities they service. In discussions with CTOs it was noted that their clients tended not to be proficient in using computers.

**Information on public transport**

Feedback from project participants on helping people with dementia access information about public transport echoed previous comments.

The survey showed:

- 42% of service providers think that it should be easier to find information on timetables and routes
- 55% think that having a case manager who could help the person with dementia plan their trip would make it more likely that people with dementia would use public transport
- there was somewhat less support for these two ideas among people with dementia and carers (35% and 35% respectively).

As noted above, there was little support for an app that tells the person how to access and use public transport.

**Training for everyone involved in transport for people with dementia**

Participants discussed the need for transport workers and volunteers to be trained in dementia awareness and managing people with dementia. Some groups already had exposure to limited training resources but the consistent feedback was that it had been insufficient.

**Training for community transport operators**

Most CTOs (96%) agreed that having staff and volunteers trained in dementia awareness and management was a good idea. Training was widely endorsed in all discussions that involved providers. Some had already attended relevant courses but there was a widespread perception the
sector was not well equipped to meet the current needs of clients with dementia, let alone with the numbers anticipated.

The questions that were commonly raised in discussion and in survey comments include:

- What is dementia?
- How does it affect people?
- What behaviours can we expect and how can these best be managed?
- Who can I refer a person in the community to if I think they have dementia?
- What training can we access that is affordable, convenient and flexible enough to cope with full time and part time workers, volunteers and paid staff?

In relation to dealing with individual clients with dementia, CTOs considered it important to know:

- Are people safe to travel alone?
- What is their history and background?
- What behaviours and anxieties do they have?
- How independent are they, what assistance do they require?
- Who is their emergency contact/their doctor?
- Do they have particular triggers that bring on anxiety or other behaviours?
- Are there clear instructions regarding the destination?
- What other service providers are involved with the person?

**Training for public transport workers**

Public transport workers have similar needs for training, although perhaps not as comprehensive as community transport providers.

The main issues raised in this context were ensuring that public transport workers could recognise when a passenger may be behaving in a particular way because they have dementia and know how to respond.

**Training for taxis**

The NSW Taxi Council provides training for some drivers on working with vulnerable groups, including people with dementia. At the time of writing some new intake drivers and drivers who elected to undergo training for vulnerable groups had exposure to the *Is It Dementia* resource noted in the Literature Overview. Ideally, this training would be more extensive and extended to cover more workers in the industry.

Typical kinds of problems drivers encountered were: unaccompanied people with dementia finding difficulty with payment, routes and destinations.

There is a need for drivers to be trained in recognising behaviours and developing strategies to deal with them, as well as being able to rely on support from their call centre.

*The driver is on their own out there. They need good back up.* Stakeholder

**Clubs’ attitudes to training**

A majority (64%) of clubs providing transport stated that training for paid staff in dementia awareness would help their club to provide transport for people with dementia. Just over a quarter (27%) said training for volunteers would have a similar effect.

A smaller majority (54%) reported that tip sheets for drivers on managing people with dementia would help provide transport.
Ideas that may make community transport more accessible
A number of ideas were tested with participants that aimed at making community transport more accessible to people with dementia. In addition most participants were asked for their suggestions about making this mode of transport more accessible.

The prompted ideas included: door through door and door-to-door service, provision of transport escorts and training.

Door through door/door to door service
There was widespread support for these services and most CTOs provided door-to-door services for at least some clients.

Three quarters of people with dementia and carers believed people with dementia would be more likely to use community transport if it included a pick up from home service (75%) and/or door through door (77%).

In a similar question to service providers, 80% said door through door service was a good idea for people with dementia.

CTOs were also very positive about this service, with nearly all (89%) agreeing that providing door through door service for clients who needed it, such as those with more advanced dementia, was a good idea. However, there were concerns about the practicality of providing door through door service. Some CTOs reported that it could have implications for insurance cover. It was also pointed out that it might be difficult to leave the person if they were unsettled.

Often CT will take the person to the door, open it and put the person through and close the door but there are a lot of issues about going in. For example, the vehicle and other passengers are left unattended or waiting. CTO

It is too open ended, even if we could do it. The person may insist on their shopping being unpacked or want help to go to the bathroom. CTO

Community transport escorts
Nearly all those with dementia and carers (90%) and the service providers (88%) agreed that providing escorts on transport was a good idea.

Over three quarters (79%) of CTOs also supported having transport escorts, however many reported this was difficult because there were too few available staff and volunteers. Some providers had links to organisations which can provide transport escorts. Nearly all CTOs (89%) agreed it was a good idea to work with other service providers, such as Neighbourhood Aid.

They may start with forgetfulness that just means they need a reminder of the pickup time through to can only travel safely with a carer. We do everything we can to transport for as long as we can however, we do not provide carers and our drivers, although very caring, are picking up and dropping off only. They do not accompany clients. We refer clients who require more assistance to our local Neighbourhood Aides. CTO

Driving and caring are two distinct roles and should not be crossed over. Safety at both levels should be paramount to service provision. CTO

While they supported the idea of having transport escorts and assisting people in the early stages of dementia, CTOs generally preferred this group to travel with carers. Indeed 70% of CTOs asked that people with dementia travelled with a carer.

There was some anecdotal evidence that community transport in rural areas had more flexibility around the role of drivers as carers.
Meeting the transport needs of people with dementia

Being in a small rural remote shire people are known to the service and they feel comfortable using transport. Drivers can accompany them to where they need to go and this makes them feel more at ease and secure. CTO

64% of clubs that provided transport also believed having travel escorts on their transport would assist people with dementia.

Responses to other tested ideas
CTOs were less supportive of the following:
- establishing a CTO subcommittee to focus on the transport
- providing on demand transport for people with dementia rather than scheduled or pre-booked services (15% thought it was a good idea, a further 41% thought it was a good idea but impractical).

Ideas that may make public transport more accessible
Despite the positive response to many of the ideas tested, it should be kept in mind that approximately half of the responses to almost all these ideas was they would not make a significant difference to the likelihood of public transport use.

The suggestion of the app generated the most negative response; with nearly three quarters of respondents stating this idea would not make a difference to public transport usage.

Public transport escorts
As discussed above, many people involved in this Project and much of the literature advocates for door through door escorts for people with dementia. There was also support for transport escorts on public transport. 40% of people with dementia and carers and 66% of service providers said that having an escort from station to station or stop to stop would make it more likely the person with dementia would use public transport. Having access to such a service would address many of the issues identified earlier as barriers to travel on public transport.

Of course, the usefulness of such a service will greatly depend on the dementia symptoms the person is experiencing, the skills and attitudes of the escorts and the characteristics of the public transport.

Travel training
Feedback on travel training was mixed. 40% of service providers believed it would make it more likely that people with dementia would use public transport but only 21% of people with dementia and carers believed this.

Stakeholder feedback was that if people learnt how to use public transport they would be more likely to use it. Possibly, this pattern would continue if they, or someone they cared for, developed dementia.

Only one instance was cited of a person with dementia undergoing travel training, unfortunately the training was not successful.

Companion Cards
This program was mentioned by several carers who commented how useful they found the cards. However, there was confusion among participants about the eligibility criteria for the program.

Two carers noted that drivers on public buses had questioned whether the person with dementia had a disability that entitled the carer to the card. These episodes had been upsetting for both carers and the people with dementia.
Taxis
Taxis transport many vulnerable people who may have difficulty in accessing other modes of transport.
Reducing the cost and developing stronger trust, participants believed would enable better access for people with dementia to taxi transport.
Increasing the TTSS and making it more widely available to people with dementia would have some impact on the cost, although the cost is likely to remain a significant hurdle in regional and rural areas because of the distances involved.
Some carers and people with dementia said that if they knew the driver was appropriately trained they might use taxis more often as they would be more likely to trust the driver. Successful trips with a specific driver could build a relationship of trust.
In regional areas, it was reported that some drivers would go out of their way to ensure a person with dementia remained safe and got to their destination. Drivers may also develop relationships with residential care and thus have a more informed idea of what is normal for a client.

Driving
Feedback on facilitating the transition to non-driving for people with dementia has been discussed elsewhere in this report.

Parking/mobility stickers/drop offs
Carers and CTOs commonly reported that it was often difficult to park close to the person with dementia’s destination. This meant:
  • drivers needed to drive around longer than was comfortable for the passenger with dementia
  • the person with dementia may need to be dropped off without an escort
  • the person with dementia and the carer may need to walk longer distances than desirable.

You cannot park at the doctors, even with the sticker, which means there is all the walking and then the stairs. Sometimes we just have to give up. Carer

I can’t let him out and drive off and find a park but then he gets agitated when we have to go around and around. It would be good if there was a secure drop off point, especially at the hospital. Carer

Volunteers
Volunteers are already involved in meeting the transport needs of people with dementia. For example, CTO services in NSW are supported by 3,500 volunteers. 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. Others predicted that the role of volunteers will dramatically decrease.
Because of the actual and potential importance of volunteers in the context of this project, we investigated how the sector saw their role. In addition to CTOs, local governments and clubs, interviews were conducted with a further 19 not-for-profit organisations that provide services to vulnerable populations. The programs and services offered by these 19 organisations provide a range of assistance to the aged, disabled and people with health conditions who have specific, medically-related transport needs. Medical transport is offered as a priority by many of the organisations; some offering a stand-alone service, others as part of social support and other programs.

Volunteers’ profile
Volunteers from the various organisations were of different ages, walks of life and had many reasons for volunteering, not always altruistic ones.
The majority of the volunteers were retirees, who usually started volunteering with the organisation in their early-to mid-sixties. It was said they are likely to remain committed until they are no longer able to continue in their role. Younger volunteers were typically students, people looking for work and/or on Centrelink benefits. The periods of service for these volunteers were often shorter because their circumstances were more changeable.

Perceived advantages and disadvantages of having volunteers

Overall feedback on the advantages and disadvantages of using volunteers was consistent. Volunteers were said to be valuable to the organisations because they were:

- relatively low cost
- brought skills and resources to an organisation that the organisation may not otherwise benefit from
- worked well with paid staff
- provided services to clients that may be beyond the reach of the organisation, such as volunteer transport escorts
- helped build the culture of the organisation.

*Our services are based on input from volunteers. Without them the service we offer would be greatly reduced. Not-for-profit organisation*

The perceived disadvantages of using volunteers were said to be:

- the level of responsibility they can be expected to carry is limited
- they can be difficult to recruit, particularly people who are trained and willing to work with clients who may exhibit challenging behaviours
- they may not be totally reliable as they are not obliged to be there
- they may move on after a relatively short time
- they often have health issues that affect how well they can assist people, especially larger people with physical disabilities
- difficulty in ensuring they are fully insured
- the costs involved.

*To have volunteers as escorts for people with dementia would be a big responsibility. It would take a very special trained up volunteer and these are hard to find. Stakeholder*

*I wonder if you want volunteers to look after our most vulnerable clients. Not-for-profit organisation*

*Volunteers may have a short-lived involvement. Often there are age and physical barriers for them. The constant turn over means a lot of time is spent recruiting. Not-for-profit organisation*

*Having had more than 100 volunteers I would say that they should not work with high needs clients. If they wanted to they would require extensive training and then there is no guarantee that they would stay. CTO*

*Volunteers are not free. They need a lot of support and supervision. They are not captive and can make themselves unavailable at any time. Also there is no proper insurance cover for them. Stakeholder*

**Recruiting and training volunteers**

Many organisations indicated that generally they did not have a problem recruiting volunteers. The volunteers came from a variety of sources, such as articles in local papers, word of mouth, general recruitment websites such as Seek, or specific volunteer recruitment and referral agencies. A small number of volunteers had themselves been clients of the organisation or had a relative who was a client, for example, they had received transport to medical treatment, and wanted to reciprocate.
Other organisations reported that recruiting volunteers was sometimes difficult. For example, almost all of ClubsNSW respondents who provided transport noted that volunteers were a scarce resource and most agreed that was becoming increasingly difficult to recruit them.

**Volunteer driver services**

Most of the organisations consulted about their use of volunteers noted that some volunteering jobs were harder to fill, including finding drivers. Partly this was due to volunteers’ reluctance to use their own cars, but also not wanting the extra responsibility of assisting frail and/or vulnerable clients, or not having a Light Rigid (LR) license (required for larger vehicles).

Organisations have employed a number of strategies to overcome the problems of volunteers using the organisation’s cars, their lack of skills and confidence. In relation to the need for LR licenses, one community aid has a staff member who recruits members of his golf club to drive the buses. Another organisation has made a partnership with 2 local service clubs, whose members undergo training to obtain their LR licenses and then drive buses for them. Others pay for willing volunteers to obtain their LR license.

Organisations that encourage volunteers to use their own car usually require the volunteer to have comprehensive insurance and offer reimbursement on a per kilometre basis.

*Volunteers use their own car and our cars. There is a program to check out all cars. Volunteers using their own cars usually get a kilometre allowance and we cover their extra insurance.*  Not-for-profit organisation

*All VA volunteers undergo a police check. Those who drive require a gold license, and, if they drive their own car, comprehensive insurance for their vehicle. Drivers over 75 undergo a NRMA safe driving test, funded by VA. Volunteers receive one full day of induction training as well as more specific client-related training with the case worker involved.*  Not-for-profit organisation

**Basic requirements for volunteer drivers**

The Community Transport Driver Authorisation Standards set out by Transport for NSW require that volunteer drivers have a current unrestricted NSW drivers license, an RMS driver history record check, be fit to drive and have a recent police check. The most common basic requirements reported by the organisations contacted for this Project were an unrestricted license and a police record check, usually paid for by the organisation.

Reported assessment of driving ability varied hugely from a short drive with a staff member to being tested by a qualified assessor. Driver training also varied from none to mentoring by another volunteer, or, in the case of medical transport, may have consisted of being shown regular routes and pick up and drop off points by an experienced volunteer.

Some participants expressed concerns about having volunteer drivers for people with dementia while others were comfortable with the prospect.

*I would not have a volunteer driving a person with dementia in a car. Perhaps you could have a trained volunteer providing assistance to the driver.*  CTO

*Our volunteers regularly drive people with early dementia. It can be time consuming but we have not had any problems so far.*  Not-for-profit organisation

A couple of stakeholders and community transport providers noted that driving accreditation requirement worked against recruiting and retaining volunteers. This is likely to be particularly an issue among CTOs now that they are covered by the NSW Passenger Transport Act.
Further involvement of volunteers

Despite the problems noted above, many organisations endorsed and encouraged the involvement of volunteers. The majority of participants from all groups believed that having more volunteers would help to meet the transport needs of people with dementia. Ideas for extending this involvement were explored and participants endorsed the following ideas for involving volunteers:

- Working with other service providers such as Neighbourhood Aid to provide support for people with dementia looking for transport (89% of CTOs).
- Providing volunteer escorts for people with dementia who travel on community transport (79% of CTOs, a further 18% thought it was a good idea but impractical).
- Allocating a volunteer travel buddy to make travel arrangements for a person with dementia (74% of CTOs, a further 11% thought it was a good idea but impractical).
- Using vetted volunteers with their own cars to transport people with dementia (84% of service providers, people with dementia and carers but only 30% of CTOs, a further 18% thought it was a good idea but impractical).

Suggestions arising in the additional, volunteer focused interviews included:

- Targeting recruitment of particular categories of volunteers, such as people with medical/allied health backgrounds, retired professional drivers, previous carers and members of service organisations.
- Providing appropriate training, supervision and support for people who volunteer to work with people with dementia.
- Trying to match volunteers and people with the early symptoms of dementia so the relationship can become well established and last when the symptoms become more marked.
- Offering service options outside office hours.
- Using existing referral agencies to co-ordinate or host new volunteer programs directed at providing services for people with dementia.
- Coordinating existing volunteer services to make better use of trips.
- Having a central register of all vehicles that could be used by volunteer organisations when they are available.
- Facilitating a Facebook application linking volunteer drivers and escorts and people with dementia who require transport – similar to HillsCarPal described in the Literature Overview.
- Creating virtual communities using an app/portal such as 'lotsahelping hands.com'. Possibly link this to a time banking arrangement.
- Creating a time banking arrangement \(^1\) for volunteer transport, utilising donated or Community Chest hours.
- Encouraging the use of car share cars such as ‘Go Get’ with the location of cars matched with the location of the person with dementia who required transport and the volunteer.
- An Uber-style taxi service offering different options of assistance such as drive only, door through door or full escort service with corresponding fee levels.

Several of these suggestions could be implemented for a wider population, including for people with dementia.

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\(^1\) Timebanking is a network of people who sign up to offer their services on a voluntary basis. Members receive time credits for their volunteering hours. These credits can be redeemed for services offered by other members or donated to benefit the community. It is expected that 64 communities across NSW will be involved in Timebanking by the end of 2014. Timebanking is supported by the NSW Department of Education and Communities.
Meeting the transport needs of people with dementia

Consumer Directed Care
The move to individuals specifying how their funding packages will be allocated means that people with dementia and their carers could play an even more direct role in organising transport.

To obtain some insight into whether people will allow for their transport needs, people with dementia and carers were asked about Consumer Directed Care (CDC). Less than a third (30%) were aware of this change in funding arrangements.

Respondents were informed that CDC means that individuals will have more say in how money allocated to them under various programs will be spent. They were then asked what percentage they would allocate to transport if they had a home care package.

- 15% of respondents stated that if they had a home care package they would allocate less than 5% to transport
- 9% thought they would allocate between 6 and 10%
- 4% between 11 and 25% and
- 2% more than 25%.
- 27% said they did not know.

44% reported they did not have a home care package.

When asked how likely they were to spend money on specific forms of transport for the person with dementia, respondents were most likely to spend it driving and most unlikely to spend it on public transport.

How people with dementia and carers would spend CDC money on various forms of transport for the person with dementia

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<th></th>
<th>Very likely</th>
<th>Neither likely nor unlikely</th>
<th>Unlikely</th>
</tr>
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<tbody>
<tr>
<td>Driving</td>
<td>64%</td>
<td>4%</td>
<td>33%</td>
</tr>
<tr>
<td>Community transport</td>
<td>48%</td>
<td>31%</td>
<td>21%</td>
</tr>
<tr>
<td>Taxi</td>
<td>35%</td>
<td>36%</td>
<td>29%</td>
</tr>
<tr>
<td>Employing someone to drive</td>
<td>26%</td>
<td>32%</td>
<td>41%</td>
</tr>
<tr>
<td>Public transport</td>
<td>22%</td>
<td>17%</td>
<td>62%</td>
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</tbody>
</table>

Responses from people with dementia and carers (n=82)

Feedback from stakeholders and service providers from initial experiences with people organising their own packages is that: recipients forget to allow for transport and people often don’t know what to allow for.

People tend to think transport just happens and they use packages for other essential needs. The role of the case manager is vital but it is not clear if everyone has one and whether the managers know enough about transport to ensure that appropriate transport is part of the package. CT

On the other hand, some interviewees believe it may be possible that money in individual packages could be used to fund informal transport or care arrangements. For example, paying a neighbour or family member or accessing a service provided by a volunteer service.

Several service providers expressed concern and two people with dementia living alone about how the latter group would manage CDC.

CDC without a carer to monitor, assess, reassess, advocate is a bad thing for a person with dementia living alone. It is really impossible. It should be the role of the service provider, not the person with the disability. Person with dementia
There is general agreement that service providers need to be aware of available transport options so that they can be discussed with clients and factored into their packages.

**DISCUSSION**

While almost everyone consulted during the research for this project agreed it is important action is taken to meet the transport needs of people with dementia, it is difficult to see where the required actions will come from. Apart from the carers, who are constantly facing up to the transport challenge, there is a widespread feeling that the problem lies with another organisation or sector.

The consequences of not taking action are expensive. Increased costs will come from:

- people with dementia moving into residential care when their symptoms become more marked because they cannot get their social and medical needs met in the community
- road accidents involving people with dementia who continue to drive when they shouldn’t
- deterioration in the health and wellbeing of carers.

The response needs to be multifaceted and will require an interdisciplinary holistic approach. It is unlikely that labelling the issue a ‘transport problem’, a ‘health problem’, a ‘disability problem’ or an ‘age care problem’ will lead to effective solutions. Sectors will need to work together to address the issue as a whole.

As noted in this report, governments have committed in principle to providing transport for vulnerable populations and, in particular, acknowledge the importance of community transport but, despite funding increases, transport services are not in a position to meet the current needs, let alone the coming demand for these services.

Governments are continually receiving feedback on the transport needs of vulnerable people; this feedback should always include the particular needs of people with dementia. Organisations that work with people with dementia need to sit on the relevant committees and contribute to submissions. While many recommendations made on behalf of other groups who find transport challenging will assist the wider vulnerable population, the needs of people with dementia are unique and need to be considered by all modes of transport in their own right.

Lack of ownership of the issue may be one of the reasons that actions have not been taken to meet well-established needs such as:

- Providing clear, easily accessible information to assist people with dementia, carers and service providers to help people with dementia retire from driving.
- Providing information on, and access to, alternative forms of transport for people with dementia, including being driven.
- Recognising and facilitating the non-medical transport needs of people with dementia, particularly the need for social interaction.
- Taking action to alleviate the pressure on community transport to meet requirements imposed by the health sector, a problem that has been documented for more than a decade.
- Providing access to affordable, relevant training for people involved in transport who interact with people with dementia.
- Recognising that most of the problems faced in meeting the needs of people with dementia are similar across the country, rather than state specific.

Apart from some knowledge gaps, which do need to be filled, inaction cannot be fully explained by a lack of information. There have been a succession of reports from a variety of organisations on the need for better transport for vulnerable populations and there is a plethora of resources that could be adapted to assist people involved in transporting people with dementia. Inaction on recommendations from organisations that know the needs of vulnerable populations and the patchy
development and distribution of much needed resources, is disappointing and adds to the burden placed on people with dementia, their carers and service providers.

More actions are needed to improve the flow of information and resources on driving cessation and alternative transport. Actions are also needed to improve the provision of appropriate transport. In some cases the changes could be relatively simple, for instance ensuring that functions for people with dementia and carers are scheduled at a time that does not involve travelling in rush hour. Other changes, such as implementing training programs for transport workers or extending the capacity of CTOs, require more investment.

**Access to information**

There are a number of obvious ways to fill some of the resource gaps. For example, there is scope for the RMS to make the communication on licensing arrangements for people with dementia clearer on its website. It would also be relatively straightforward to communicate with health professionals on dementia and driving issues through the various industry organisations. It is more difficult to determine how information and other resources can be gathered and made accessible to people with dementia and carers. For example, how to provide details of transport to dementia cafes and men’s sheds that pull from several community transport areas.

People with dementia and their carers need details of the transport that is available to them to meet their needs, both locally and beyond their local area. Ideally this information would come from a central source and be tailored to their needs. It is difficult to assign someone the responsibility of collating this information because it is a challenging/time-consuming task and will vary considerably by location.

Users generally value central sources of information on transport options, but they can be difficult to establish and maintain. Various stakeholders report the existing central source of information on public transport in NSW to be much valued, but it is struggling to provide the full range of information, particularly in regard to people with disabilities. However, some organisations have been quite successful in gathering a wide range of locally available transport services. The Northern Rivers Transport Guide is a good example of this. The NRMA’s website also provides a range of transport information, including the ability to search for CTOs by area.

Service providers, such as dementia advisory workers, are identified as the most desired source of information on transport options to meet the individual needs of each client. However, it is unlikely they will have the capacity to fulfil this role. Pulling together details of that information would be resource intensive and difficult in many locations where it is not easily accessible.

People with dementia and their carers also need information on various programs they may be eligible for that could assist with their transport issues, such as the Mobility Parking Permits, the TTSS and Companion Cards. Currently finding out about, and accessing, these services is somewhat random.

**Training**

While there is some training available for transport workers on dementia awareness and management, much more is needed. The training needs to be more extensive and to reach a much wider population of workers and volunteers. For example, training resources for driving cessation could be developed to apply across Australia. The symptoms of dementia exhibited by passengers are common to all jurisdictions.

The provision of training for transport workers and resources to assist people with driving cessation could be developed and distributed by a national body.
Meeting the transport needs of people with dementia

Driving
The juxtaposition of driving with dementia in an ageing population is going to become increasingly contentious. As the population ages the number of older license holders is expected to increase significantly. In June 2014 approximately 50,000 people aged 85 or older held a driving license\(^{227}\). We do not know how many of these older drivers have dementia but we do know that the incidence of dementia increases significantly with age. Approximately 30% of Australians aged 85 or older have dementia\(^{228}\).

A great deal has been written about driving and dementia and there is consensus about what needs to be done. There is a pattern of lack of planning for driving cessation, even though it is inevitable, organisations and individuals seem slow to take action. For individuals, including health professionals, the position is made worse by lack of access to appropriate support and resources. Given that such resources exist, albeit that some require modification to meet local needs, it places an unnecessary impost on people who have to cope with a difficult issue.

Two organisations which have been instrumental in assisting people with driving and dementia issues are the RACV and the NRMA. Both these organisations have worked with Alzheimer’s Australia to develop resources that help people with dementia to retire from driving in NSW and Victoria but still remain mobile.

Australia appears to be behind many developed countries in the provision of accurate, accessible and useful information on this issue. Most have central information sources on dementia and driving and resources are relevant to people across all jurisdictions.

Unfortunately more than just information is required on the assessment process. With little evidence available to support off road assessments and cost and availability issues affecting access to appropriate on road assessments, retaining a driver’s license for a person with dementia may be judged on their ability to access an appropriate assessment, rather than on their driving ability.

People with dementia, carers, service providers (including doctors) all need ready access to clear information on driving assessment and related legal requirements. Prescribed assessment procedures need to be available in a timely and affordable manner to those who are required to undergo them.

Also essential, are resources to assist people with dementia making a smooth transition to non-driving.

Examples of useful resources include:

- Clear information from all trusted transport, health and support sources including the RMS, Alzheimer’s Australia and service providers.
- Tip sheets, videos and other information for everyone who is involved in talking with the person with dementia about driving.
- Clear information about alternative transport and access to alternative transport.

The needs are clear; resources must be readily available to all parties.

It also needs to be remembered that many carers are willing to drive their person with dementia, which takes a considerable strain off the transport system. It should be made as easy as possible for carers to provide this service by providing assistance that is relevant to their conditions. In metropolitan areas this may mean suitable parking, in rural areas it may mean a fuel subsidiary.

Public transport
Because of a scarcity of information and a lack of understanding about how people with dementia experience public transport, it is unlikely that large scale changes will be made to meet the needs of this group. The current system requires significant investment to meet the existing and growing needs of the wider public; consequently transporting people with dementia is not seen as a priority.
However, there are some relatively low cost models that may improve the access of people with dementia to public transport:

- training of all personnel in how to recognise dementia and appropriate ways to respond to people with dementia
- escorted travel
- travel training.

In addition, many changes that benefit people with disabilities and older people are likely to benefit people with dementia. Changes, such as clear station announcements, will make the system easier to navigate and physically less demanding. Transport for NSW has made some progress in consultation with a variety of disability groups and people with a disability through the Accessible Transport Advisory Committee in identifying solutions to make public transport more accessible. Examples include: tactile surfaces on platforms, clearer announcements at stations, improved signage on buses, better design specifications on new bus orders for wheelchair accommodation. These successes need to be built on in the future for people with cognitive disabilities to experience improved public transport services.

**Community transport**

Transport funding is embedded in a number of HACC and other programs and services. The majority of the HACC transport funding is delivered via the CTOs.

Other community transport providers used by people with dementia, such as local governments and day care services, are also partly funded by government programs, including HACC. There is a complex system of multiple programs available, especially for health transport. All these services are important in meeting the transport needs of people with dementia, but the CTOs are particularly relevant.

**CTOs**

Providing transport for people with dementia can be seen as a core responsibility of CTOs. Key target groups for community transport are the frail aged and people with disabilities and carers. CTOs certainly provide a significant amount of transport for people with dementia and carers. Unfortunately, the system is under considerable strain due to over-demand (particularly for non-emergency medical appointments), confusion during the transition of a significant portion of its funding to the federal government and the current state of poor coordination. The growth of the number of people aged 65 years and over and the increasing number of people ageing in the community, rather than in residential care, will continue to drive the demand for community transport.

There have been several projects undertaken to see how CTOs can better meet the current and growing demand. Overall, the recommendations made in these studies are geared to making CTOs a more effective community transport system, which makes them pertinent to needs of people with dementia. Some projects have tended to focus on improving CTOs ability to meet the growing demand for health related transport. Improved access to health services is important for people with dementia but, just as important, they need transport to meet their social needs. Verso Consultants 2014 report recommends that CTOs focus on its role in providing access to community, rather than health, destinations.

If CTOs are expected to meet the current and growing demand for health transport without significant changes to infrastructure and funding they will not be in a position to meet the wider transport needs of people with dementia. It may therefore be worth considering supporting some of the other models suggested in this report. Increased capacity for providing transport for vulnerable populations may come from these models as they continue to evolve.
Whatever form of community transport is offered to people with dementia, it is vital that their particular needs are met. These needs are sometimes similar to other users, such as people with a mental illness, but they are not the same.

**Alternative modes of transport**
While few of the identified alternative transport organisations targeted people with dementia, many could potentially be useful in meeting their transport needs. The particular attractions of some features of the models are:

- available on demand (HillsCarPal)
- door through door or door to door service (Independent Transportation Network – US)
- flexible (VisionAustralia)
- inexpensive (most models).

It may be that this type of transport will grow to operate alongside more mainstream forms of transport, possibly funded and administrated in a way that allows the services to function more freely, less constrained by regulations.

There may be a role for an umbrella organisation to facilitate the development of some alternative models, similar to the work undertaken by the US Beverly Foundation and the STPs. Guidelines can be drawn up to guide new and existing players and assistance could be provided with training, insurance, reimbursements, police checks and other processes.

**Further research**
Currently there are gaps in our knowledge, in particular further research is required to:

- understand the challenges faced by special needs groups. Given that several of the identified groups are actually made up of many groups, this is an area where considerable research is needed
- develop better information channels for the many groups of people who need information driving and other forms of transport
- develop more effective driving assessment tests.
APPENDIX ONE

Organisations interviewed

ACON
BaptistCare (Auburn)
Cancer Council NSW
CarersNSW
Centre for Volunteering
Chinese Australian Services Society, CASS
Christian Community Aid (Eastwood) Co.As.It.
Community Connect Northern Beaches
Community Transport Organisation
Council on the Aging, COTA
Council of Social Service of NSW (NCOSS)
Country Care Link – Sisters of Charity
ClubsNSW
Gilgandra Community Care Centre
HillsCarPal for Seniors
Holdsworth Community Centre
Hunter Volunteer Centre
Hunters Hill Ryde Community services
Jewish Care
Leukaemia Foundation
Lifebridge
Lower North Shore Community Volunteers
Local Government NSW
North Ryde Community Aid
Occupational Therapy Australia
“Shirley Shuttle” Central Coast
Sir Roden and Lady Cutler Foundation
Taxi council NSW
Transport for NSW
Travel Training Easy Transport
Uniting Care Casino Transport Team (UCC TT)
University of Wollongong
Vision Australia
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