



MEETING THE TRANSPORT NEEDS OF PEOPLE WITH DEMENTIA

REPORT, NOVEMBER 2014

Prepared by Alzheimer's Australia NSW



Family &
Community Services
Ageing, Disability & Home Care

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Acronyms used in this paper

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
GLBTI	Gay, Lesbian, Bisexual, Transgender and Intersex
GP	General Practitioner
HACC	Home and Community Care
NSW	New South Wales
STP	Supplemental Transport Programs
RACV	Royal Automobile Club Victoria
RMS	Roads and Maritime Services
TTSS	Taxi Transport Subsidy Scheme
STP	Supplementary Transport Programs
US	United States

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 stakeholders, people with dementia, carers and service providers and six focus groups were run with AlzNSW Consumer Advisory Groups.

This document presents the Executive Summary, the Discussion and the Suggested Strategies to Address Key Areas of Need from the full report, which also includes a Literature Overview and Detailed Findings of the Fieldwork.

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 care^{6 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^{8,9}.

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 notice¹⁰.

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 Home and Community Care (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 varies, 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.¹¹

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^{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.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.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 appropriate¹⁶.

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 dementia¹⁷.

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.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^{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 Australia²¹.

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 discrimination²².

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.^{23 24}

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 straight forward 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 this²⁵. 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.

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 license²⁶. 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 dementia²⁷.

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.

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 and they certainly provide a significant amount of transport for people with dementia and carers.

Unfortunately, the system is already under considerable strain and 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 demand²⁸. 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 transport²⁹. 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, destinations³⁰.

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
- door through door or door to door service
- flexible
- inexpensive.

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.

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.

- 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.
- 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 staff³¹.

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.

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 (UCCTT)

University of Wollongong

Vision Australia

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