



Discussion Paper #18
November 2016

DRIVING AND DEMENTIA

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ACKNOWLEDGMENTS

The material for this paper is largely drawn from the Alzheimer's Australia NSW (AlzNSW) research project, *Meeting the transport needs of people with dementia*, which was funded by Ageing, Disability and Home Care (ADHC) in the NSW Department of Family and Community Services (FACS).

We thank ADHC for allowing the information gathered to be shared in this Discussion Paper. While work for this paper was largely undertaken with funding assistance from ADHC, the information and views contained in this report are not intended as a statement of ADHC policy and do not necessarily reflect the views held by ADHC, the NSW Government or the Minister for Ageing, Minister for Disability Services. In addition to ADHC, AlzNSW gratefully acknowledge the following groups who generously participated in the research:

- People with dementia and carers
- Service providers
- Alzheimer's Australia NSW Consumer Advisory Group members
- Community transport operators
- Local Government NSW
- ClubsNSW
- And the many stakeholders and organisations who participated in interviews.

This paper has been developed by the Policy, Research and Information Department, Alzheimer's Australia NSW.

Alzheimer's Australia NSW respectfully acknowledges the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

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ABN: 27 109 607 472

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ABBREVIATIONS

ACT	Australian Capital Territory
ACAT	Aged Care Assessment Team
ADHC	Ageing, Disability, Home Care
AIHW	Australian Institute of Health and Welfare
AlzNSW	Alzheimer's Australia NSW
AlzVIC	Alzheimer's Australia Victoria
CALD	Culturally and Linguistically Diverse
FACS	Family and Community Services
GP	General Practitioner
HACC	Home and Community Care Program
LGBTI	Lesbian Gay Bisexual Transsexual Intersex
MMSE	Mini-Mental State Examination
NRMA	National Roads and Motorists' Association
NSW	New South Wales
RMS	Roads and Maritime Services
RACV	Royal Automobile Club of Victoria
TTSS	Taxi Transport Subsidy Scheme
UoW	University of Wollongong

EXECUTIVE SUMMARY

In 2014, more than 910,000 licence holders in NSW were aged 65 or over; approximately 142,000 were aged 80 or over and approximately 50,000 people aged 85 or older held a driving licence. It is not known how many of these older drivers have dementia, but research suggests that the incidence of dementia increases significantly with age.

As a result of Australia's ageing population, the number of older licence holders is expected to rise. Dementia will become an increasingly contentious issue amongst drivers. By 2050, the estimated number of people living with dementia is expected to reach 900,000, with approximately 272,000 living in NSW. According to ABS, in 2016 there were 486,671 people aged 85 and above and by 2050 this number will jump to 2,092,957 - an increase of 330% (refer to the chart in Appendix 3 on page 25). This growth places additional strain on the Government as the need to provide services and resources to assist in driving cessation and viable transport alternatives, will become more pressing.

Eighty per cent of people with dementia living in the community need help with transport.

Eighty per cent of people with dementia living in the community need help with transport. Social activities such as meeting friends and family as well as travelling and going on holidays are reported by people with dementia and their carers to be the destinations most difficult to access transport for. Often, the focus on travel needs for people with dementia is on travel to health appointments with not enough consideration being given to their social needs.

The ability to drive safely is dependent on decision-making capacity, reaction time, visuospatial perception and other sensory processing, as well as memory, judgement, attention and planning – all attributes that are eventually affected by dementia. Alzheimer's Australia NSW acknowledges that while some people can continue to drive safely for some time following a diagnosis, everyone with dementia will need to stop driving at some stage. Unfortunately as symptoms develop and begin to affect driving skills, a driver with dementia may be less likely to accept that they are driving unsafely.

Because giving up driving may be quite easy for some, but extremely difficult for others, it is important to ensure that appropriate supports and services are available to people with dementia and their carers. Transport provides a vital link between people and health services, social interactions and education, while also supporting a person's ongoing engagement with society, general health, wellbeing, and overall quality of life.

Much of the research for this paper was undertaken for the Alzheimer's Australia NSW 2014 report titled Meeting the Transport Needs of People with Dementia and is an important tool in continuing the dialogue between driver licencing authorities (DLAs), insurance companies, health professionals, policy makers, and all those living with, and supporting, people with dementia and their families.

The research found that the travel needs of people with dementia largely become the responsibility of the family carer as the condition progresses. Research participants identified the high value of having easily accessible and appropriate information and resources about the process of driving cessation for people with dementia. A number of issues explored by research participants include: a lack of clarity about the legal and licencing requirements for a person with dementia; the various barriers to timely driving cessation and; the lack of alternative transport options.

There is a need for continuing evaluation of new and existing models of driver ability assessment to best preserve transport mobility and minimise road traffic accidents among people with dementia. Clarifying the roles, rights, and responsibilities of medical professionals, the driver with dementia, and the RMS in navigating the path to driving cessation will assist in this.

EXECUTIVE SUMMARY CONTD.

In order to improve access to alternative forms of transport for people with dementia, the NSW Government should take action to revise the eligibility criteria for the current subsidised transport schemes to include people with dementia who are no longer in possession of a driver's licence.

Driving cessation is not a decision to be made by one party only. Rather, a multifaceted interdisciplinary approach to driving cessation allows health professionals, carers, and when practicable, the driver with dementia to make the decision to stop driving a smooth and easy one.

RECOMMENDATIONS

Based on the findings of the research, Alzheimer's Australia NSW recommends the following:

Australian Government

1. Fund programs that support early diagnosis of dementia so those diagnosed may participate in planning and decision-making regarding the transition from driver to non-driver.
2. Encourage and fund a multifaceted, interdisciplinary approach to address the transport needs of people with dementia.

NSW Government

1. Improve the guidelines for medical professionals to support their role in the transition from driver to non-driver.
2. Introduce policies that subsidise the issue of cost and accessibility of on-road driving assessments in order to make the service timely and affordable for people with dementia.
3. The NSW Roads and Maritime Services to develop a Driving and Dementia information pack for doctors in NSW to issue to patients with dementia at the time of diagnosis. This should include material highlighting the need to cease driving, the need to check their insurance liabilities and the need to disclose a diagnosis of dementia to the RMS. This material should also be available to Aged Care Assessment Teams (ACATs), Dementia Advisers, and other health professionals.
4. The RMS to provide clear information to drivers about their responsibility when driving after a diagnosis of dementia in hard copy formats such as brochures and booklets.
5. Consider mandatory reporting for health professionals to the RMS for conditions that are likely to affect public safety.
6. Improve the process of driving cessation by streamlining communication between doctors, the Roads and Maritime Services (RMS) and occupational therapists who undertake on-road assessments for drivers with dementia.
7. Fund the development of culturally appropriate resources for diverse communities.
8. Ensure Transport for NSW employees are provided with an opportunity to access dementia awareness training in order to better service people with dementia.
9. Revise the eligibility criteria of existing transport subsidies to include people with dementia.

Service providers

1. Ensure that the needs of people from diverse communities are accounted for in the provision of transport services under consumer directed care.

ISSUES RELATING TO DRIVING AND DEMENTIA

WHEN TO STOP DRIVING?

The nature of dementia makes it difficult to impose a blanket rule regarding when the best time to stop driving is. Driving, for many people in our society, but particularly for males, plays an important role in the formation of one's identity. The possession of a driver's licence represents a ticket to freedom and independence and, in some cultures, status. The loss of this entitlement can act as a devastating blow to someone living with dementia. A number of outcomes can result from driving cessation for a person with dementia. Some of these outcomes include a reduced sense of autonomy, identity and independence and a decreased sense of connectedness to their social and physical environments.

THE TRANSITION FROM DRIVER TO NON-DRIVER

As a result of the progressive and irreversible nature of dementia, people this diagnosis may eventually put themselves and others at risk when driving. The transition from driver to non-driver is about more than just no longer holding a driver's licence. For instance, drivers with a diagnosis of dementia will generally not meet the commercial licencing standards. As a result, those who are currently, or were previously, employed as commercial vehicle drivers may experience negative effects to their confidence, feel a reduced sense of meaning and purpose, and feel their identity and autonomy has been threatened.

Research conducted by Alzheimer's Australia NSW and others indicates that the earlier a person with dementia is given information about their condition and available support services, the better the chances of them participating in their future care plan. Therefore, if good, accessible information is provided about a person's driving capacity early in the diagnosis of dementia, the greater the opportunity to assist drivers who will eventually be required to relinquish their licences.

Feedback from carers, people with dementia and service providers indicates that discussing driving cessation early has the potential to make the transition easier. Identifying, discussing and practicing alternative transport options for the person with dementia and their carer in the early stages of the disease is important. At this stage, the driver with dementia is still able to process the information and understand that they will continue to remain mobile after they stop driving.

LICENCING REQUIREMENTS

In October 2016, AustRoads and the National Transport Commission released a revised version of the Assessing Fitness to Drive Guidelines. Under the revised guidelines, all people with a diagnosis of dementia who wish to continue to drive may be eligible for a conditional licence, but not eligible to hold an unconditional licence. A condition of this licence type is that the driver is reassessed, at least annually, either by an RMS driving assessor, by a medical practitioner or by a qualified occupational therapist. This licence type is also subject to medical opinion and a practical assessment as required.

If a driver's licence is revoked, the RMS can issue a Photo-ID card as an alternative form of identification. Carers of people with dementia reported that the photo ID card was useful for the person they care for in maintaining their personal and social identity.

“When we go to the club we need to show Photo ID to get in, I think he was more worried about not being able to get into the club than he was about no longer being able to drive.” – Carer

LEGAL REQUIREMENTS

The current research found that 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 that they were required to report a diagnosis of dementia to the RMS. Only one third of respondents were aware that a driver with dementia cannot hold an unconditional licence.



In NSW, Road Transport Driver Licencing Regulation 2008, c. 117 (5), requires that the holder of a Driver's Licence must, as soon as practicable, notify the road transport authority of any permanent or long-term injury or illness (such as dementia) that may impair his or her ability to drive safely.

Insurance companies do not have a standard approach regarding the notification of a driver's dementia diagnosis. However, if the driver has not reported their diagnosis of dementia to their insurance company, issues regarding driver liability emerge. Insurers and drivers with dementia would benefit from clearer guidelines with regard to the rights and responsibilities of customers living with dementia who wish to continue to drive.

Based on discussions with service providers, it is apparent that there is confusion about the legal requirements, with some respondents reporting that many doctors are not aware of their role in the assessment process. As a result, there is a need to clarify the role of medical professionals, the driver with dementia, and the RMS in navigating the path to driving cessation.

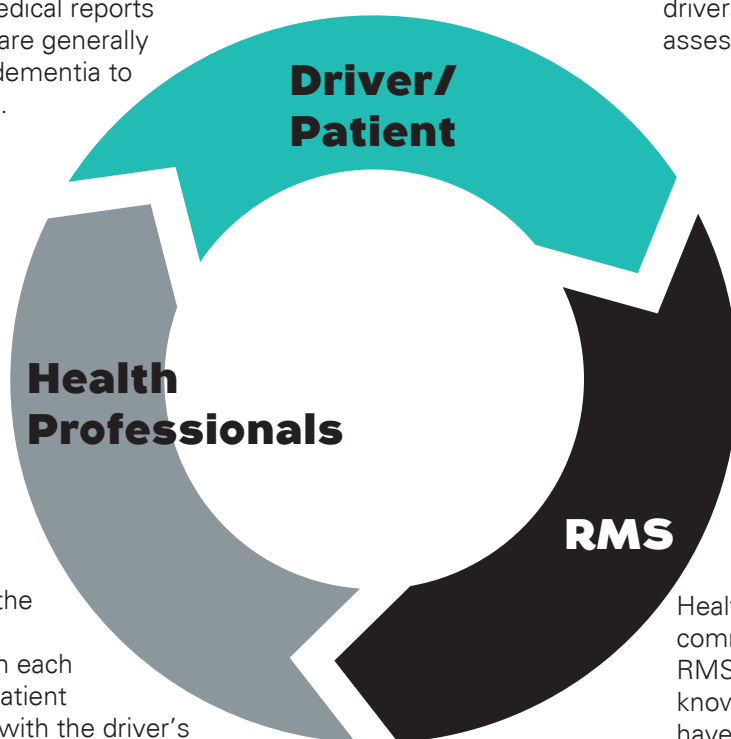
DRIVING CAPABILITY ASSESSMENTS

The AustRoads Assessing Fitness to Drive Guidelines highlight the importance of drivers with dementia, medical professionals and the RMS working together to assess driving ability.

The image below is adapted from the AustRoad Assessing Fitness to Drive Guidelines and outlines the relationship between the driver with dementia, the medical professional, and the RMS.

Health professionals should advise patients if a medical condition impacts on their ability to drive safely, whether in the short or long term. Medical reports regarding fitness to drive are generally issued to the driver with dementia to communicate to the RMS.

Drivers with dementia are required, by law, to inform the RMS of their condition. The RMS may request drivers to undergo a medical assessment.



Health professionals and the RMS do not normally communicate directly with each other in order to protect patient confidentiality. However, with the driver's consent, the RMS may contact the health professional if there is a need for clarification or further information is needed to make a licensing decision.

Health professionals may communicate directly with the RMS when patients, who are known to be a risk to road safety, have given consent. In NSW it is not mandatory for medical professionals to report drivers with medical conditions that are likely to affect public safety.

The above process may result in a driver with dementia being required to undergo an on-road assessment; granted a conditional licence; or having their licence revoked by the RMS and issued a Photo ID card in its place.

Holding a conditional licence could include one of, or a combination of: being able to drive during off-peak periods only; driving within a certain radius of the driver's place of residence; driving during daylight hours only; or not being able to drive on freeways.

However, the guidelines state that individuals lacking insight or those with significant visual, memory or cognitive-perceptual impairments are usually not suitable candidates for a radius restriction.

Medical Assessments

At this stage there is no universally accepted test or standard a doctor can use which defines when driving should stop. The Mini Mental State Examination (MMSE) 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 or safe driving ability. As a result, the MMSE, in relation to driving ability, serves the purpose of identifying those in need of more detailed assessment or an on-road assessment.

The Medical Specialist Fitness Assessment Report for Driver Licences form includes a number of sections for completion by the treating doctor, including a section on neurological conditions.

On-road assessment

Some people with dementia will give up driving either on their own initiative or on the recommendation of others; this can be done without a formal assessment process. Others will need to undergo an off-road or on-road assessment depending on the progression of their dementia.

There is no internationally accepted standard for an on-road assessment of driving for people with dementia. 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.

There is a need for a prospective evaluation of new and existing models of driver assessment to best preserve transport mobility and minimise road traffic accidents among people with dementia. In Australia, occupational therapists trained in on-road assessments for drivers with dementia conduct the tests in a vehicle with dual controls and a driving instructor. The tests usually take an hour but the reported elapsed time for each test, including reporting, is considerably longer. Assessments by occupational therapists can be costly and difficult to access, sometimes discouraging people with dementia from taking up the service.

NAVIGATING THE PATH TO DRIVING CESSATION

Many people with dementia decide to stop driving when they are diagnosed or before their driving becomes unsafe. It is the legal responsibility of the person with dementia who wishes to continue to drive to report their diagnosis to the RMS.

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

It is not always possible for people with dementia to successfully regulate their own driving. Many people, especially those with more advanced symptoms, do not understand how dementia impacts on their ability to drive safely. Thus it is often left to others, usually carers and medical professionals, to negotiate the move to driving cessation. Ideally, the driving decision is a responsibility shared between the driver and carer, the RMS and the health professional.

Medical Professionals

Some physicians who took part in the research expressed that they do not wish to be the 'licencing gatekeepers'. Unfortunately, it is not uncommon for doctors to be called on to facilitate driving cessation during a crisis, and in some instances at the same time as the driver is diagnosed with dementia. Addressing fitness to drive has been reported by health professionals to be one of the most difficult and emotional tasks they face in providing primary health care for people with dementia.

Interviews with doctors revealed that they often approached the issue by telling the driver that they must stop driving immediately, stating that the person could continue driving until they told them to stop with some not raising the issue at all. While driving cessation may be a fairly straight forward recommendation if a driver has moderate or more advanced symptoms, it is not clear what guidelines doctors follow in providing advice on driving cessation to a person with mild symptoms of dementia.

“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

The role of the medical professional can be complicated if the person with dementia sees the doctor as the cause of loss of licence. Several service providers and carers noted that some people with dementia had chosen to avoid doctors who are known to actively address the issue of driving.

While it is not mandatory in NSW for doctors to do so, they are able to report a patient to the RMS if they are concerned that a person with dementia is driving when they should not be.

While carers can assist in making assessments by submitting reports to doctors, some carers expressed concerns that their experiential knowledge of the capacity of the person with dementia is sometimes ignored, while other carers overstate the ability of the driver with dementia to continue driving. In the latter scenario, it was often carers who were not comfortable with driving or were inexperienced drivers and preferred not to drive if their spouse or partner still could.

Carers

Carers are often best placed to observe drivers with dementia and are therefore well positioned to identify risky driving behaviours.

Behaviours carers reported include:

- Memory difficulties
- Becoming lost in familiar areas
- Exhibiting inadequate driving performance including minor traffic events
- Misjudging distances
- Driving too fast for the 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.

Managing drivers with dementia can be stressful for carers. Carers reported that they felt unsupported in addressing the issue and that it sometimes caused considerable tension in their relationship with the person with dementia.

It appears that despite the lack of readily available tools and resources, carers develop their own coping strategies and mechanisms; 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 options, arranging for more home visits, and hiding the keys.

“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.”

Service provider

“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

The RMS

The RMS provides information on the requirements of drivers with dementia, undertakes the process of issuing conditional licences, revoking licences and issuing photo ID cards. The RMS also collects and publishes data on licence holders. The RMS has a number of resources for people considering driving cessation which are available on their webpage entitled ‘Are you fit to drive? Health, Medicals & Disabilities’. While there is a reasonable amount of information available on this webpage, research participants expressed little desire for this information to be presented on websites and apps. Instead, there was an expressed desire for this information to be available in hardcopy formats such as brochures, pamphlets, booklets, and help sheets.



ISSUES FACED BY CARERS

Driving with dementia has an effect on carers as well as the person with dementia. Findings from the 2014 Alzheimer's Australia NSW survey revealed that the transport needs of people with dementia were overwhelmingly met by carers. Over three quarters (77%) of respondents agreed that the carer mostly drove the person with dementia to various places. This suggests that meeting the transport needs of people with dementia is a constant task for carers.

"It is an everyday, every journey task. It takes up a lot of time and energy." – Carer

Carers were asked about the type of transport they organised for the person with dementia. Of the 79 respondents, 87% indicated that they primarily met the transport needs of the person with dementia or asked a friend or family member to do so. Only 13% of carers said they organised taxis or other public transport. These figures emphasise the heavy reliance on and need for private vehicles in meeting the transport needs of people with dementia.

Carers reported a number of difficulties encountered when driving people with dementia. They include:

- Harassing 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

- Attempting 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

- Becoming 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

- Reluctance 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

- 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

- Incontinence

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

- Wanting 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

While carers as drivers take a considerable strain off the transport system, carers and service providers both reported that the emotional toll of providing transport was high. Carers who are the primary providers of transport are often:

- Older, with many having their own health issues
- Non-drivers
- May care for someone who is a difficult passenger
- Working in paid employment
- Have other pressing responsibilities.

With a considerable strain being placed on carers to provide transport for a person with dementia, it is important that the public transport system is adapted to be suitable for and accessible by not only people with dementia but their carers too.

The strain of providing transport for a person with dementia has been recognised as considerable. For this reason, it is important that options are made available that can relieve some of this strain. In metropolitan areas this may mean offering suitable parking, in rural areas it may mean a fuel subsidy, or in cases where the carer does not drive, taxi subsidies should apply.

“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

BARRIERS TO TIMELY DRIVING CESSATION

Service providers and carers reported that there is not enough support to assist people with dementia to give up driving. While giving up driving can be easier for some than others, the process could be drawn out and sometimes traumatic. Factors identified by research participants as making this process difficult included:

- The nature of dementia
- High cost of on-road assessments
- Lack of information about, and availability of, alternative transport
- Poor access to information concerning the relevant regulations
- Lack of clarity and consistency around the role of doctors in driving cessation
- Limited access to on-road assessments in some cases
- Poor access to resources about driving cessation that are accessible and relevant

THE NATURE OF DEMENTIA

The lived experience of dementia varies significantly between individuals with dementia and their carers makes it difficult to impose a blanket rule when evaluating the driving capabilities of people with dementia.

The nature of the disease means the driver may lack insight into the problem, making them more resistant to giving up driving and causing more distress to the carer as they come to the realisation that the driver is unable to recognise changes in their symptoms.

“I know I could still drive. I am certainly a better driver than she is. It is one of the worst 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.

COST OF ON-ROAD ASSESSMENTS

Research participants demonstrated a low awareness of the need for people with dementia to have an on-road assessment with a qualified occupational therapist. Carers of people with dementia reported that the biggest barrier to assessment was the cost of the service followed by the timely availability of the assessment service in rural and regional areas. The costs of these assessments are largely borne by the driver; some medical centres and some insurance programs provide a level of subsidy, but the full cost is generally borne by the driver.

Occupational therapists involved in the research reported that the cost is a significant issue for everyone, especially if the driver fails the test. In some instances, failure has prompted aggressive behaviour and a reluctance to pay the bill at the conclusion of the assessment.

“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.” – Service provider



ACCESS TO ALTERNATIVE FORMS OF TRANSPORT

The research identified one way of making driving cessation less confronting for people with dementia is to ensure they have access to alternative forms of transport. Drivers need to know giving up their licence will not mean they will become isolated or have to give up their regular activities.

“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

There appears to be a low awareness of alternative transport options among many people with dementia and their carers. Transport for people with dementia needs to:

Involve people trained in dementia awareness and management – whether they are paid or volunteer workers

- Provide escorts, especially for people who do not travel with a carer and whose symptoms have developed to the stage they cannot travel alone
- Provide door-to-door, door-through-door, or curb-to-curb, service when and where necessary
- Involve little or no waiting
- Be flexible
- Be available at short notice.

Additionally, there is a widespread need for information on available transport. It is widely acknowledged in the literature that people need this information to assist with the smooth transition to becoming a non-driver while also enabling people to access the services and activities they need in order to live well in the community.

The cost of alternative transport is another issue for many people. The NSW Taxi Transport Subsidy Scheme, NSW Travel concessions for people with disabilities, and the NSW Companion Card are not currently funded to accommodate everyone with a diagnosis of dementia.

In order to improve access to alternative forms of transport for people with dementia, the NSW Government should take action to revise the eligibility criteria for the aforementioned subsidised transport schemes to encompass people with dementia who are no longer in possession of a driver’s licence.

ADDITIONAL CHALLENGES FOR DIVERSE COMMUNITIES

PEOPLE WITH DEMENTIA FROM CULTURALLY AND LINGUISTICALLY DIVERSE (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.

Feedback from research participants suggests older women from some CALD backgrounds are less likely to drive than older Anglo-Australian women. Being the driver in the household can make it more difficult for men from these communities to give up driving, while also placing additional pressure on their partners.

There were several reports of older women from CALD backgrounds 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

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE WITH DEMENTIA

Previous research indicates that the prevalence of dementia is up to five times higher among Aboriginal Australians than among non-Indigenous.

Although Aboriginal and Torres Strait Islander 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.

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 licences 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, and
- Culturally inappropriate transport services.

The report notes that many Aboriginal and Torres Strait Islander people rely on family and friends for transport to health services, or on community services that do not normally provide transport.

LGBTI PEOPLE WITH DEMENTIA

The best estimates of the number of LGBTI people with dementia are based on estimates on the proportion of the Australian population who are LGBTI and the prevalence of dementia in the total Australian population. A commonly accepted estimate of the proportion of LGBTI Australians is 8% suggesting that there are approximately 26,000 LGBTI people with dementia.

A paper produced for Alzheimer’s Australia in 2008 suggests that 46% of older LGBTI people in Australia live alone, compared to 23% of the general population. Living alone is especially difficult for a person with dementia as it often means fewer people to assist with the daily challenges, including the challenge of accessing transport if the person is no longer driving.

PEOPLE WITH YOUNGER ONSET DEMENTIA

There are approximately 25,000 people in Australia with younger onset dementia (when the onset of symptoms occurs under the age of 65).

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 are different from those of people who develop dementia at an older age.

Carers of people with younger onset dementia can face particular challenges that make it difficult to meet their needs. These carers often have to combine caring with keeping the household together, earning a living and raising children. The emergence of the National Disability Insurance Scheme (NDIS) may allow for people with younger onset dementia to include transport options in their NDIS plan, which would help them to remain engaged for as long as possible.

REGIONAL AND RURAL DRIVERS WITH DEMENTIA

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.

Accessing medical and social support in regional and rural areas often involves driving long distances. The distances involved can mean that trips are time consuming and tiring for both the person with dementia and their carer, there is high wear and tear on cars, while the fuel costs are often significant. It is also possible that driving longer distances increases the accident rate of drivers with dementia; however it is not possible to assess this in the absence of statistics on accidents that involve drivers with dementia.

Driving cessation 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 even the carer encouraging the person with dementia to continue to drive.

“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

A further barrier to driving cessation outside metropolitan areas is getting access to, and the cost of, on-road assessments. The cost of such 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.

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 substantially. Research indicates that up to one third of people with dementia who live in the community live alone. ,

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.

Research 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. – Community transport provider

Several service providers noted that people who lived alone were more resistant to giving up driving because they may not have a carer to tell them when their driving was becoming unsafe or to help them work through the driving cessation process.

CONCLUSION

As a result of Australia's ageing population, the number of older licence holders is expected to rise. Dementia will become an increasingly contentious issue amongst drivers. By 2050, the estimated number of people living with dementia is expected to reach 900,000, with approximately 272,000 living in NSW. According to ABS, in 2016 there were 486,671 people aged 85 and above and by 2050 this number will jump to 2,092,957 - an increase of 330% (refer to the chart in Appendix 3 on page 25). This growth places additional strain on the Government as the need to provide services and resources to assist in driving cessation and viable transport alternatives, will become more pressing.

Driving with a diagnosis of dementia is a serious concern for people with dementia, their carers and the wider community. The research at hand highlights the issues faced by people with dementia, their carers and health professionals throughout the transition from driver to non-driver. These issues include:

- Poor access to information concerning the legal and licencing requirements for people with dementia
- Lack of clarity and consistency around the role of doctors in driving cessation
- The high cost of and limited access to on-road driving assessments
- Poor access to relevant resources and supports that are appropriate and accessible
- Lack of information and support regarding alternative transport options for people with dementia who have had their licence revoked.

Communication between people with dementia and their carers, health professionals, the RMS and other government authorities is required in order to streamline the transition from driver to non-driver for people with dementia. However, it is important to ensure that the individual wants and needs of people with dementia are taken into consideration.

Driving cessation and its consequences are part of the wider issue concerning the transport needs of people with dementia. This paper is an important tool in continuing the dialogue between driver licencing authorities (DLAs), insurance companies, health professionals, policy makers, and all those living with, and supporting, people with dementia and their families.

RECOMMENDATIONS

Based on the findings of the research, Alzheimer's Australia NSW recommends the following:

Australian Government

1. Fund programs that support early diagnosis of dementia so those diagnosed may participate in planning and decision-making regarding the transition from driver to non-driver.
2. Encourage and fund a multifaceted, interdisciplinary approach to address the transport needs of people with dementia.

NSW Government

1. Improve the guidelines for medical professionals to support their role in the transition from driver to non-driver.
2. Introduce policies that subsidise the issue of cost and accessibility of on-road driving assessments in order to make the service timely and affordable for people with dementia.
3. The NSW Roads and Maritime Services to develop a Driving and Dementia information pack for doctors in NSW to issue to patients with dementia at the time of diagnosis. This should include material highlighting the need to cease driving, the need to check their insurance liabilities and the need to disclose a diagnosis of dementia to the RMS. This material should also be available to Aged Care

Assessment Teams (ACATs), Dementia Advisers, and other health professionals.

4. The RMS to provide clear information to drivers about their responsibility when driving after a diagnosis of dementia in hard copy formats such as brochures and booklets.
5. Consider mandatory reporting for health professionals to the RMS for conditions that are likely to affect public safety.
6. Improve the process of driving cessation by streamlining communication between doctors, the Roads and Maritime Services (RMS) and occupational therapists who undertake on-road assessments for drivers with dementia.
7. Fund the development of culturally appropriate resources for diverse communities.
8. Ensure Transport for NSW employees are provided with an opportunity to access dementia awareness training in order to better service people with dementia.
9. Revise the eligibility criteria of existing transport subsidies to include people with dementia.

Service providers

1. Ensure that the needs of people from diverse communities are accounted for in the provision of transport services under consumer directed care..



APPENDIX I

METHODOLOGY

This paper is based on work undertaken for the Alzheimer's Australia NSW 2014 report Meeting the Transport Needs of People with Dementia which was prepared with funding provided by Ageing, Disability and Home Care (ADHC) in the NSW Department of Family and Community Services and on research undertaken for the Alzheimer's Australia NSW 2010 Driving and Dementia in NSW paper.

THE 2010 PROJECT

Following a literature review in 2010, two surveys were conducted amongst Alzheimer's Australia NSW consumers. Of the 165 respondents, 104 were carers and 61 identified as people with dementia - 17 of these respondents, identifying as having dementia, were still driving.

Respondents resided in metropolitan, regional and rural areas of New South Wales. 13.5% of carers and 11.9% of people with dementia lived further than 10km from the nearest service or town centre.

THE 2014 PROJECT

Research for the 2014 report 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 licenced 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 Alzheimer's Australia NSW Consumer Advisory Groups.

Of particular relevance to this discussion paper is the feedback obtained from people with dementia, carers and service providers. Of the 96 people with dementia and carers who responded to the survey:

- 77% were female,
- 87% spoke English at home, and
- 44% 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 87 respondents who identified as carers in the survey were aged 66 or older, with 10% aged 85 or older. The interviews involved 27 people with dementia and carers who resided across NSW. The 51 service providers that participated in the survey and interviews came from a wide variety of roles including:

- Dementia advisory workers
- Younger onset dementia key workers
- Counsellors
- Day centre workers
- Occupational therapists
- Educators
- Nurses and GPs

APPENDIX 2

AVAILABLE RESOURCES

Below is a list of resources that may be helpful for medical professionals, carers, and people with dementia in addressing the issue of driving cessation.

Medical Professionals

- Dementia and Driving pathway: for clinicians and healthcare professionals
https://www.fightdementia.org.au/sites/default/files/VIC/documents/HP%20QUICK%20REFERENCECARD_FINAL.pdf
- Conversations about Dementia and Driving: for health professionals and clinicians
https://www.fightdementia.org.au/sites/default/files/VIC/D&DHelp%20Sheet_2015_FINAL.pdf
- Dementia and Driving: GP's Toolkit (Video)
https://www.youtube.com/watch?v=zJ0N12dC_lo

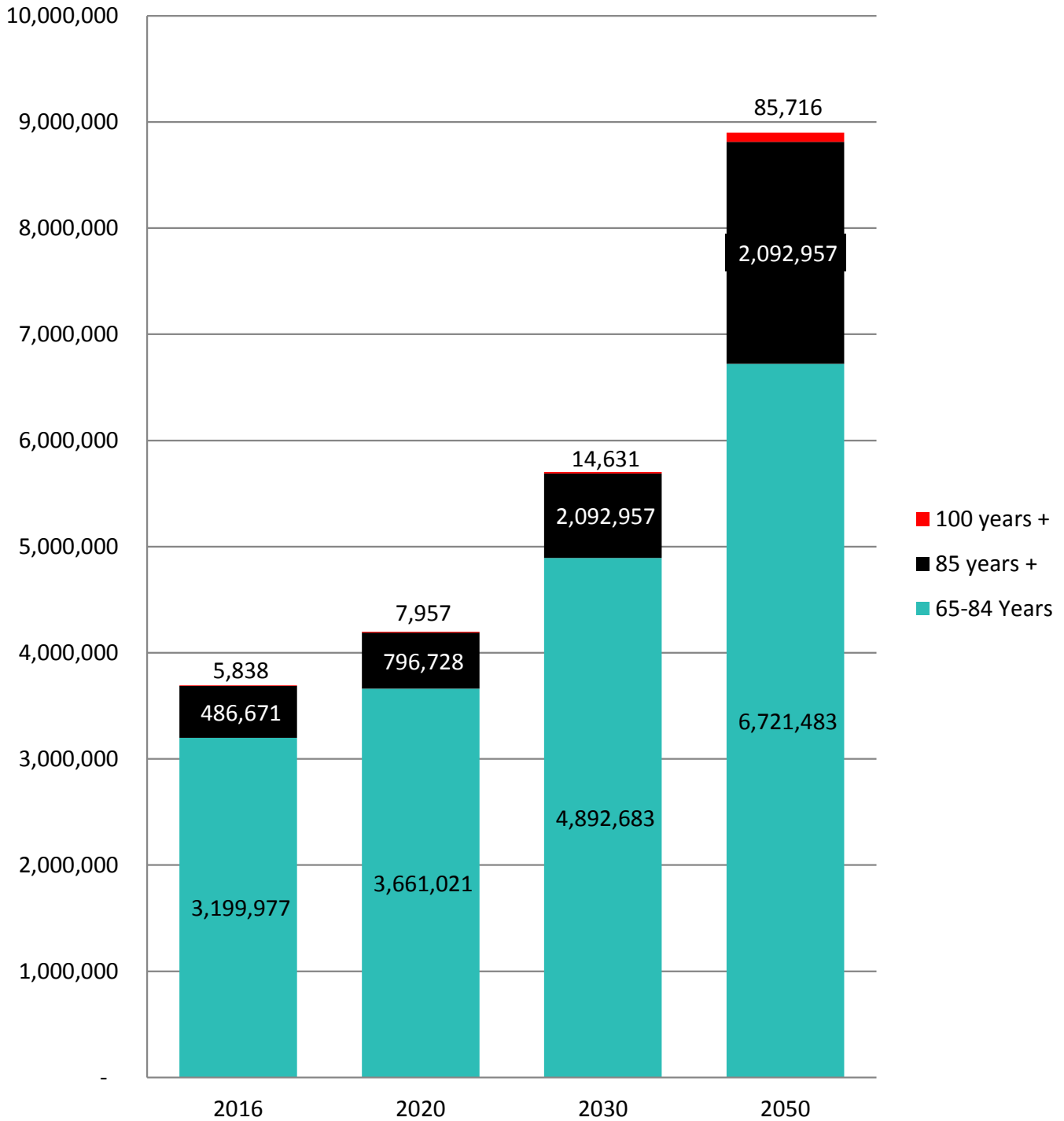
People with dementia and Carers

- Alzheimer's Australia Help sheet 4: Information for people with dementia – Driving
https://www.fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-InformationForPeopleWithDementia04-DrivingAndDementia_english.pdf
- Alzheimer's Australian Help sheet 7: Caring for someone with dementia – Driving
https://www.fightdementia.org.au/sites/default/files/helpsheets/Helpsheet-CaringForSomeone07-Driving_english.pdf
- Changed conditions ahead: Dementia and Driving Guide for Families and Carers
<https://vic.fightdementia.org.au/files/VIC/documents/Dementia-and-Driving-guide-for-family-carers.pdf>
- Staying on the Move with Dementia
<https://nsw.fightdementia.org.au/sites/default/files/NSW-Staying-on-th-move-with-dementia-booklet.pdf>
- On the road 65plus
<http://roadsafety.transport.nsw.gov.au/downloads/65plus.pdf>
- Dementia and Driving: A decision Aid
<http://smah.uow.edu.au/content/groups/public/@web/@smah/@nmih/documents/doc/uow179550.pdf>

APPENDIX 3

Australia population projections 2016 - 2050

(Source ABS, data released 29 Nov 2013)



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OUR OFFICES

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Coffs Harbour: 02 6651 6415
Forster: 02 6554 5097
Hunter: 02 4962 7000
Port Macquarie: 02 6584 7444

SYDNEY REGION

North Ryde: 02 9888 4268
St George/Sutherland: 02 9531 1928
Blacktown*: 02 9805 0100

**NATIONAL
DEMENTIA
HELPLINE**
1800 100 500

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SOUTHERN NSW

Bega Shire: 02 6492 6158
Eurobodalla Shire: 02 4474 3843
Bateman's Bay: 02 6492 6158
Cooma, Bombala &
Snowy Mountains Shires: 02 6452 3961
Yass, Young, Goulburn,
Queanbeyan, Harden,
Upper Lachlan &
Palerang Shires: 02 6241 0881
Moss Vale: 02 4869 5651
Wagga Wagga: 02 6932 3095
Wollongong*: 02 9805 0100

WESTERN NSW

Orange: 02 6369 7164

* Younger Onset Dementia Key Worker

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