Submission No 21

DRIVER EDUCATION, TRAINING AND ROAD SAFETY

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SUBMISSION IN RESPONSE TO THE PARLIAMENT OF NEW SOUTH WALES STAYSAFE COMMITTEE (JOINT STANDING COMMITTEE ON ROAD SAFETY)

INQUIRY INTO DRIVER EDUCATION, TRAINING AND ROAD SAFETY

February 2017

EXECUTIVE SUMMARY

Alzheimer's Australia NSW welcomes the Parliament of New South Wales Staysafe Committee (Joint Standing Committee on Road Safety) Inquiry into Driver Education, Training and Road Safety.

As our population ages, the number of older licence holders is expected to rise and, as a result, the number of people with dementia will also increase. In NSW, there is an estimated 138,700 people with dementia in 2017, which is estimated to increase to 175,000 by 2025 and 326,000 by 2056[1]. 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.

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[2]. 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[3]. 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.

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[4,5]. Much of the content for this submission is based on the Alzheimer's Australia NSW 2016 *Driving and Dementia* Discussion Paper and the 2014 report *Meeting the Transport Needs of People with Dementi*a. Research participants involved in the development of both these documents identified the importance 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 licensing 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[6]. Clarifying the roles, rights, and responsibilities of medical

[1] The Economic Cost of Dementia in Australia 2016-2056, commissioned by Alzheimer's Australia https://reports.fightdementia.org.au/costofdementia

[2] Charlton, J., Kippel, S., Odell, M., Devlin, A., Langford, J., O'Hare, M., Kopinathan, C., Andrea, D., Smith, G., Khodr, B., Edquist, J., Muir, C., & Scully, M (2010) Influence of chronic illness on crash involvement of motor vehicle drivers. Monash University Accident Research Centre Report No. 2009

[3] Brown, L. B. & Ott, B. R. (2004) Driving and Dementia: A Review of the Literature. *Journal of Geriatric Psychiatry and Neurology, 17, 4*, 232-240

[4] Dickerson, A., Molnar, L., Eby, D. W., Adler, G., Bedard, M., Berg-Weger, M., Classen, S., Foley, D., Horowitz, A., Page, O., Silverstein, N., Staplin, L. and Trujillo, L. (2007) Transportation and Ageing: A Research Agenda for Advancing Safe Mobility. *The Gerontologist, 47, 5,* 578-590

[5] Whelan, M., Langford, J., Oxley, J., Koppel, S. and Charlton, J. (2006) The Elderly and Mobility: A Review of the Literature. Monash University Accident Research Centre. Report No. 255

[6] Unpublished conversation with occupational therapists undertaken as part of the 2014 transport project.

professionals, the driver with dementia, and NSW Roads and Maritime Services (RMS) in navigating the path to driving cessation will assist in this.

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[7].

RECOMMENDATIONS

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

1. Improve the guidelines for medical professionals to support their role in the transition from driver to non-driver.
2. Introduce policies that address the issue of cost and availability of on-road driving assessments in order to make the service timely, accessible and affordable for people with dementia.
3. Improve the process of driving cessation by streamlining communication between doctors, NSW Roads and Maritime Services (RMS) and occupational therapists who undertake on-road assessments for drivers with dementia.
4. Fund the development of culturally appropriate resources for diverse communities.
5. Ensure Transport for NSW and RMS employees are provided with an opportunity to access dementia awareness training in order to better service people with dementia.
6. RMS 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.
7. 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.
8. Consider mandatory reporting for health professionals to the RMS for conditions that are likely to affect public safety.
9. Revise the eligibility criteria of existing transport subsidies to include people with dementia.

[7] Royal Automobile Club of Victoria (2013) Dementia and Driving

THE NEEDS RELATED TO DRIVING FOR PEOPLE WITH 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[8]. 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 with this diagnosis may eventually put themselves and others at risk when driving. Research conducted by Alzheimer's Australia NSW and others[9] 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.

[8] Perkinson, M. A., Berg-Wegerm M. I., Carr, D. B. (2005) Driving and dementia of the Alzheimer type: beliefs and cessation strategies among stakeholders. *Gerontologist, 45,* 676-685.
[9] Australian and New Zealand Society for Geriatric Medicine, Position Statement No. 11, Driving and Dementia, Revised 2009.

If a driver's licence is revoked, NSW Roads and Maritime Services (RMS) can issue a Photo-ID card as an alternative form of identification. Carers of people with dementia report that the photo ID card is 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

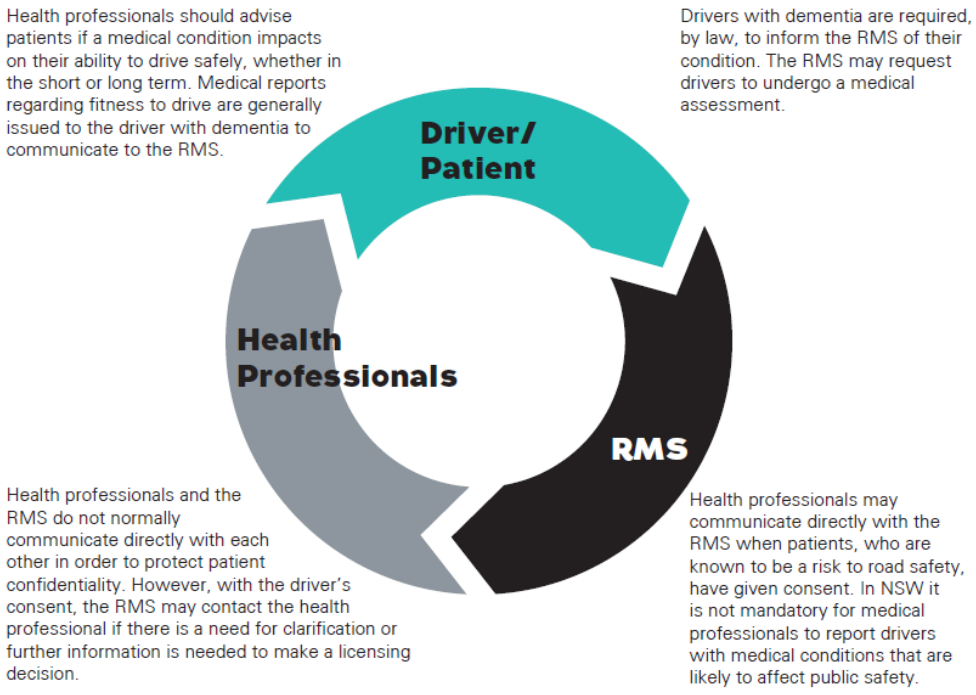
The lack of awareness of and confusion about the legal requirements for a driver with dementia is concerning. Close to half of the people with dementia and carers surveyed by Alzheimer's Australia NSW did not know that they were required to report a diagnosis of dementia to the RMS. Only one third of 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.

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.



MEDICAL ASSESSMENTS

At this stage there is no universally accepted test or standard a doctor can use which defines when driving should stop[10]. 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[11]. 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[12].

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.

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[13]. 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[14].

ON-ROAD ASSESSMENT

Some people with dementia will need to undergo and 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[15]. 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[16]. Assessments by occupational therapists can be costly and difficult to access, sometimes discouraging people with dementia from taking up the service.

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[10] Vanderbur, M. & Silverstein, N. (2006) Community, Mobility and Dementia: A Review of the literature for the Alzheimer's Association Public Policy Division and the National Highway Traffic Safety Administration.

[11] Joseph, P. G., O'Donnell, M. J., Teo, K. K., Gao, P., Anderson, C., Probstfield, J. L., Bosch, J., Khatib, R,m & Yusuf, S. (2014) The Mini-Mental State Examination, Clinical Factors and Motor Vehicle Crash Risk. *Journal of American Geriatrics Society, 62, 8,*1419-1426

[12] Martin, A. J., Marottoli, R., and O'Neill, D. (2011) Driving assessment for maintaining mobility and safety in drivers with dementia (Review) The Cochrane Collaboration in The Cochrane Library Issue 10

[13] Byszewski, A., Molnar, F., and Aminzadeh, F. (2010) The impact of disclosure of unfitness to drive in persons with newly diagnosed dementia: patient and caregiver perspectives. *Clinical Gerontologist, 33, 2,* 152 -163

[14] Alzheimer's Australia NSW Driving Survey 2009 (unpublished)

[15] Unpublished conversation with occupational therapists undertaken as part of the 2014 transport project.

[16] Alzheimer's Australia NSW (2010) Discussion Paper #1: Driving and Dementia in New South Wales

BARRIERS TO TIMELY DRIVING CESSATION

Service providers and carers report that there is not enough support to assist people with dementia to give up driving. While giving up driving may be relatively easy for some, the process can 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 make 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.

ACCESS TO ALTERNATIVE FORMS OF TRANSPORT

Alzheimer's Australia NSW 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.

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[17].

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.

[17] RACV (2013) Dementia, Driving and Mobility. http://www.racv.com.au/dementia (accessed September 2016)

CHALLENGES FACED BY DIFFERENT DRIVER GROUPS

CARERS

Driving with dementia has an effect on carers as well as the person with dementia. Findings from the 2014 Alzheimer's Australia NSW research revealed that the transport needs of people with dementia were overwhelmingly met by carers. Over three quarters (77%) of participants 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.

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.

A number of difficulties are encountered by carers when driving people with dementia. These include:

- Harassing the driver either about their driving or where they are going
- 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
- Reluctance to get into or out of the car
- 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
- 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

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.

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[18].

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[19].

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[20]. 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[21].

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[18] Currie, G., Stanley, J. & Stanley, J. (2007) No way to go: Transport and social disadvantage in Australian Communities. Monash University ePress, Clayton, Victoria.
[19] ibid
[20] Arkles, R.S., Jackson Pulver, L. R., Robertson, H., Draper, B., Chalkley, S., and Broe, G. A. (2010) Ageing, cognition and dementia in Australian Aboriginal and Torres Strait Islander peoples. *Neuroscience Research Australia and Muru Marri Indigenous Health Unit*, University of New South Wales

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[22]. 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[23,24]. 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[25].

> ***"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[26].

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.

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[21] Australian Institute of Health and Welfare (2012) Dementia in Australia. Cat no AGE70AIHW p.210
[22] Alzheimer's Australia (2007). Support Needs of People Living with Dementia in Rural and Remote Australia
[23] ibid
[24] Alzheimer's Australia NSW (2010) Discussion Paper #1: Driving and Dementia in New South Wales
[25] Royal Automobile Club of Victoria (2013) Dementia and Driving
[26] Kane, M., Cook, L.. (2013) Dementia 2013: The hidden voice of loneliness. Alzheimer's Society.

CONCLUSION

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

RECOMMENDATIONS

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

1. Improve the guidelines for medical professionals to support their role in the transition from driver to non-driver.
2. Introduce policies that address the issue of cost and availability of on-road driving assessments in order to make the service timely, accessible and affordable for people with dementia.
3. Improve the process of driving cessation by streamlining communication between doctors, NSW Roads and Maritime Services (RMS) and occupational therapists who undertake on-road assessments for drivers with dementia.
4. Fund the development of culturally appropriate resources for diverse communities.
5. Ensure Transport for NSW and RMS employees are provided with an opportunity to access dementia awareness training in order to better service people with dementia.
6. RMS 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.
7. 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.
8. Consider mandatory reporting for health professionals to the RMS for conditions that are likely to affect public safety.
9. Revise the eligibility criteria of existing transport subsidies to include people with dementia.

ABOUT ALZHEIMER'S AUSTRALIA

Alzheimer's Australia is the peak body providing support and advocacy for people with dementia and their families and carers in Australia. Dementia is the second leading cause of death in Australia, and there is no cure[27].

Alzheimer's Australia represents and supports the more than 353,800 Australians living with dementia, and the more than one million family members and others involved in their care[28]. Our organisation advocates for the needs of people living with all types of dementia, and for their families and carers; and provides support services, education, and information. We are committed to achieving a dementia-friendly Australia where people with dementia are respected, supported, empowered, and engaged in community life.

[27] Australian Bureau of Statistics (2015) Causes of Death, Australia, 2013: Cat no. 3303.0
[28] Australian Institute of Health and Welfare (2012) *Dementia in Australia.*