



Dementia and Driving

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Title

Dementia and Driving

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Abstract

People with dementia and their carers need comprehensive and trustworthy information to help them transition from driver to non-driver. The ageing of the population means that the number of people suffering from dementia in the coming years will increase. Many people with dementia do not understand their condition or its impact on driving safely and therefore cannot self-regulate their driving. Giving up driving is a difficult decision that limits independence and access to services. While all drivers with dementia will eventually need to cease driving, people with dementia and their carers are not always aware of the resources available or where they can be obtained.

RACV commissioned this report to generate a better understanding of the mobility issues affecting people with dementia. The project includes a review of relevant research literature; information and services currently available; and interviews with health professionals and other stakeholders in the field of dementia and mobility.

Key Words

road safety; dementia; driving; carers; health professionals; mobility; self-regulation; independence; risk; fitness to drive; driving transitions;

Disclaimer

This report is based upon work supported by ARRB Group Ltd. Any opinions expressed during the interviews were those of individual interviewees and do not represent the official policy of the organisations to which they belong.

Executive Summary

Dementia involves impairments to cognitive functions including memory, visuo-spatial perception, orientation to time and place, judgement, attention and insight. The ageing of the population means that an increasing number of RACV members and/or aged family members for whom they care will suffer from dementia in the coming years. Most drivers with dementia will need initially to curtail their driving and eventually to cease driving altogether. Giving up driving is a difficult decision that entails reduced independence, limitations on access to services and fewer opportunities to participate in community and social activities. People with dementia and their carers need trustworthy information to help them through this process. They may also need advocacy on their behalf to ensure that necessary services are provided by governments and other organisations.

This project was commissioned to generate a better understanding of mobility issues affecting people with dementia. The project includes a review of relevant research literature; a review of information and services currently available in Victoria and elsewhere to people with dementia and their carers; and interviews with health professionals and other stakeholders in the field of dementia and mobility.

The investigation revealed that many people with dementia, especially those in the more advanced stages of the disease, do not understand their condition or its impact on their ability to drive safely. As a result, they cannot be relied on to regulate their own driving. Due to memory problems and lack of insight, they may fail to comply with licence restrictions on where or when they can drive. All drivers who have been diagnosed with dementia require periodic assessment to determine whether they can still drive safely. Blanket rulings about driving privileges are not possible. Each person's suitability to continue driving must be assessed on a case by case basis. All drivers with dementia will eventually need to cease driving altogether.

There is a need to expand the provision of transport services suitable for people with dementia. Due to the nature of functional deficits, as the condition progresses, independent use of public transport and taxis as an alternative to driving becomes unsafe, so only door-to-door transport services are suitable.

Information and advice is available to people with dementia and their carers from a range of sources, including telephone help lines, webpages and printed materials. However, people with dementia and their carers are not always aware of what information is available or where it can be obtained. Many people with dementia and their carers are not aware that a licence holder is legally required to report a diagnosis of dementia to VicRoads and may also need to report the diagnosis to their vehicle insurer. There is a need for a comprehensive guide of available services and information sources that can be provided following the diagnosis of dementia.

The report concludes with recommendations for actions to disseminate key information to people with dementia and their carers.

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1 Introduction

1.1 Dementia and driving

The ageing of the population means that an increasing number of Victorians will suffer from dementia in coming years and decades. Most of these people will initially need to curtail their driving and eventually cease driving altogether. Giving up driving is a difficult decision that entails reduced independence, with limitations on access to services and fewer opportunities to participate in community and social activities. People with dementia and their carers need trustworthy information to help them through this process, including information about where and how to have driving skills assessed, when to give up driving, what other forms of transport are available and what services are available to assist with the transition from driver to non-driver. They may also need advocacy on their behalf to ensure that necessary services are provided by governments, businesses and charitable organisations.

This project was commissioned to generate a better understanding of road safety and transport issues for people with dementia. This improved understanding will help inform policy and assist in providing information to people with dementia and to their families and carers.

1.2 Project aims and scope

RACV Ltd commissioned ARRB Group Ltd to undertake a project to:

- review relevant literature on dementia and driving
- review Australian and overseas communication materials about driving and dementia available to older people and their families
- conduct interviews with health professionals, other key experts and stakeholder groups about the issues surrounding dementia and driving
- identify key road safety issues facing drivers with dementia
- develop messages for drivers with dementia and their families to assist them with driving cessation
- Recommend how to communicate key messages to drivers with dementia and their families
- Make recommendations to assist drivers with dementia and their families.

The literature review was confined to articles and documents in the English language. With one exception, the people interviewed did not themselves have dementia. People with dementia often lack the insight into their own condition necessary to describe their information and service needs, so it was more productive to interview experts, stakeholders and organisation representatives who were familiar with their characteristics and needs.

This report sets out the context, methods, findings and recommendations of the project.

2 Review of previous research

2.1 Older people and community mobility

Mobility within the community is necessary for quality of life. Mobility allows for access to employment, social and leisure activities, goods (such as groceries) and services (such as health care) (Byszewski, Molnar & Aminzadeh, 2010; Stav, 2008). The private car is the transport option of choice for older Australians, either as driver or passenger. Public transport is not frequently used as a mode of transport by people aged 65-75 years, and the longer the trip, the more likely a private car will be taken (Alsnih & Hensher, 2003). A key reason for older people's preference for the private car is the convenience of being able to travel where and when the person wants via a direct, door-to-door means, which most public transport systems cannot provide (Nielsen & Lange, 2007; Oxley & Whelan, 2008). Older people who do not drive may be restricted from participating in a variety of activities. RACV completed a major survey of non-drivers in Victoria and reported that a lack of transport alternatives resulted in at least half of the surveyed 225 non-driver older people foregoing social events and opportunities to visit family and friends (RACV, 2009). As people age, they face particular challenges for maintaining mobility, especially if they develop a chronic disease that restricts their ability to drive.

2.2 The ageing population and dementia

The Australian population is ageing. From 1990 to 2010, the proportion of the population aged 85 years or more has doubled (from 0.9% in 1990 to 1.8% in 2010), and the proportion of people aged 65 years or over has risen to 13.6% (from 11.1% in 1990). By 2056, the proportion of people aged 65 and over is expected to be between 23% and 25%; and across Australia the proportion of people aged 85 years and over is expected to reach between 4.9% and 7.3% (Australian Bureau of Statistics, 2011). With a larger proportion of older individuals in the population, the frequency of age-associated diagnoses of disease and/or disorder will increase. The frequency of dementia related diagnoses and the likelihood of an individual being diagnosed with dementia is also expected to increase (Meadows, Singh & Grigg, 2007). People aged 85 years or more are particularly prone to developing dementia with some estimates indicating rates as high as one in four (Access Economics, 2005). The expected growth in the total populations of Australia and Victoria will also contribute to growth in the number of people diagnosed with dementia.

Dementia is a term used to describe a collection of symptoms. These symptoms tend to involve impairments that impact upon cognitive domains, such as memory, visuo-spatial functioning, orientation to time and place, judgement, attention and insight. Behavioural changes are also common, including anxiety, emotional instability, aggression, wandering and disinhibition (World Health Organisation, 2007).

There are different forms of dementia caused by various patterns of central nervous system pathology. This pathology is associated with neurological diseases (e.g., Parkinson's, multiple sclerosis), infections (e.g., AIDS, meningitis), nutritional disorders (e.g., related to thiamine or Vitamin B12 deficiency) and metabolic disorders (e.g., related to renal or liver deficiencies). A number of specific dementia disease types exist, but the majority of cases are related to Alzheimer's or vascular dementia (Sadock & Sadock, 2007). Alzheimer's disease is characterised by abnormal damaged brain cells which cause disruption to neural pathways and messages. Vascular dementia is associated with hypertension and other cardiovascular disease leading to blockages or plaques in cerebral vessels. Other types of dementia include Lewy body disease, Huntington's disease and Korsakoff's syndrome (Meadows, Singh & Grigg, 2007).

Dementia typically affects older people, although the young onset type can be diagnosed in people aged in their 30s or 40s (Alzheimer's Australia, 2010; American Psychiatric Association, 2000). Dementia has been identified as the main cause of disability for older Australians aged 65 years or older and one of the major reasons for admission to residential care facilities (Access Economics, 2009). Family, friends and neighbours often provide care-giving support to individuals with dementia, particularly in the early and middle stages of the disease.¹

Throughout this document, the term carer will denote any person (family member, neighbour, friend etc.) who takes the primary role in supporting driver mobility transitions.

People with mild forms of dementia may initially experience fluctuating symptoms, with those in older age groups inappropriately ascribing some of their behaviours to 'old age'. A delay in seeking medical advice and treatment means that formal diagnosis may not occur until the disease has progressed to the moderate or severe forms of the disease when family/carers become highly concerned (Access Economics, 2009; Alzheimer's Australia, 2010). The number of symptoms and their pervasiveness increases over time and daily living abilities continually deteriorate. Significant loss of personal independence is associated with advanced forms of the disease, eventually impacting on all forms of personal, domestic, vocational and community activities of daily living.

2.3 Dementia and its impact on driving, self-regulation and mobility independence

For drivers who develop dementia, early changes in behaviour (forgetting the purpose of a trip or where the car was parked) will progress to significant deficits (spatial disorientation along familiar routes, poor judgement, gaps in attention and difficulty handling multiple stimuli). The person may eventually experience difficulties with many driving-related skills, resulting in minor incidents (misjudging the space available for parking, hitting stationary objects like the fence post) and/or crashes (misjudging gaps for turning or overtaking, or failing to respond to traffic signals) (Lovell, Di Stefano & Unsworth, 2009). A recent US study investigating drivers with dementia found that becoming lost whilst driving may have significant consequences including injury and death (Hunt, Brown & Gilman, 2010). Eventually, the progressive, irreversible nature of dementia and its associated cognitive and other decrements will lead to driving cessation (Herrmann et al., 2006; Talbot et al., 2005).

The number of people who relinquish driving due to dementia in Australia is unknown, although it is accepted that all drivers with the disease will eventually need to stop driving (Australian and New Zealand Society for Geriatric Medicine, 2009). Due to poor memory, apraxia (not knowing how to use objects) and lack of insight, drivers with advanced forms of dementia cannot be expected to reliably remember their limitations or compensate for them (Australian and New Zealand Society for Geriatric Medicine, 2009; Byszewski et al., 2010). For drivers with dementia, this lack of insight is shown by discrepancies between self-reported driving and actual driving behaviour (Dalchow et al., 2010; Wild & Cotrell, 2003).

Alternative transport options for drivers with dementia are limited due to the disease-related cognitive declines affecting memory, spatial orientation, problem solving and decision making. These cognitive skills are needed to safely use public transport and motorised mobility devices. Furthermore, Oxley & Fildes (2003) identified that ageing, medication use and health-related issues including dementia may contribute to difficulties in older people's ability to use roads as a pedestrian. The symptoms associated with dementia may even contribute to an overrepresentation of older people in pedestrian crashes (Fildes, 2003).

Thus, individuals with dementia are compelled to rely on others (family and carers) to support their mobility needs. Carers play an important role in helping to manage the mobility transitions of drivers with dementia (Williams & Di Stefano, 2011).

2.4 Dementia and associated road safety risks for drivers

Cognitive and perceptual abilities that impact on driving performance (including attention, visuo-spatial perception, processing speed and reaction time) were identified as more significant than many physical defects (such as hand strength or musculo-skeletal function) when predictors of crash risk and driving performance in older drivers were examined (Anstey et al., 2005). Researchers suggested that drivers with physical rather than cognitive deficits were more likely to be aware of their restrictions and to modify or stop driving voluntarily. Whilst driving regulation based on self-report amongst older drivers appears to be common, factors impacting on this (e.g., knowledge of health and impact on driving, self-confidence, crash rates and exposure) and their interaction make it difficult to identify who will or won't routinely modify their behaviour (Charlton et al., 2006; Windsor et al., 2006). There is emerging evidence that some older drivers have little insight into their own driving ability (Horswill et al., 2011). Older people with particular cognitive and sensory processing difficulties cannot be relied upon to routinely self-regulate (Owsley et al., 1998). Furthermore, older adult self-monitoring beliefs that determine insight into one's own driving capacity underpin personal choices about where, when and how to drive (Anstey et al., 2005).

A recent review of studies examining dementia and driving found that drivers with the condition were "at a substantially higher risk for unsafe driving" (Iverson et al., 2010, p. 1320). A review by Man-Son-Hing et al. (2007) concluded that drivers with dementia demonstrated worse driver performance with crash risks ranging from 2–8 times higher than controls based on simulated driving, caregiver reports or on-road testing. A recent revision of the Monash University Accident Research Centre study of the evidence associating chronic illness with crash risk included dementia in the top eight conditions that demonstrated significant road safety risks (Charlton et al., 2010).

2.5 Victorian and Australian guidelines on fitness to drive

Victoria has no age-based mandatory licence reassessment requirements. Instead, drivers must meet their national legal requirements to self-report any medical conditions or disabilities to VicRoads Medical Review. Consistent with this, VicRoads current policy for all drivers is that “*you can drive to any age as long as you are safe to do so*” (VicRoads, 2010, p. 12). VicRoads and all Australian driver licensing authorities are bound by the AustRoads guidelines for Assessing Fitness to Drive (AustRoads, 2012), which apply to all drivers with medical conditions and disabilities.

The AustRoads guidelines were recently revised and updated to reflect the emerging evidence base for associations between medical conditions and crash risk (Charlton et al., 2010). Following the release of the new guidelines early in March 2012, drivers with a diagnosis of dementia are only permitted to hold a conditional private driver’s licence (AustRoads, 2012). This means that private driver licence holders are required to have regular medical reviews and on road tests to monitor the progression of their disease. Some drivers may face restrictions such as being confined to driving only within a certain radius from home or only during daylight hours. Such conditions are only viable if the driver can be reasonably expected to remember them. The guidelines also continue to preclude commercial licences. As a result, commercial licence holders with dementia are not permitted to drive trucks or passenger vehicles, potentially impacting on their livelihood.

Individual on road testing requirements reflect research recommendations that diagnosis alone should not preclude most drivers from retaining driving privileges (Man-Son-Hing et al., 2007; Martin, Marottoli & O’Neill, 2009). A number of researchers have argued that management strategies should require regular reassessments (e.g., each six or twelve months) (Adler & Silverstein, 2008; Lovell & Russell, 2005; Martin, Marottoli & O’Neill, 2009). Tougher restrictions on commercial drivers are consistent with the potentially greater road safety risks associated with driving larger vehicles that are more difficult to manoeuvre and cause greater damage when involved in a crash (VicRoads, 2011a). Commercial licence restrictions are also more stringent because licence holders may carry passengers or dangerous goods (AustRoads, 2012).

2.6 The role of health professionals

Doctors are the health professionals most commonly approached for support with managing health related declines in driver competence. When a driver is reported to VicRoads Medical Review, they are required to have a medical assessment and to ask their treating doctor to complete the VicRoads Medical Report Form (shown in Appendix A). This form elicits health and medical data relevant to driving functional abilities, including past and current medical history, relevant symptoms and signs, medication and treatment compliance (VicRoads Medical Review, n.d.). Details on this form contribute to the VicRoads decision regarding whether the driver meets the AustRoads and other licensing prerequisites, and if there is a need to conduct a practical on road competency test.

Drivers with medically diagnosed dementia in Victoria are usually required to undertake an occupational therapy driver assessment (OTDA) which will identify whether their health status negatively impacts upon safe driving capacities and performance (VicRoads & OT Australia Victoria, 2008). In the assessment, off road screening tests and on road performance tests under real world conditions are conducted. Drivers with advanced forms of dementia usually demonstrate deficits on both of these test components (Clark et al., 2003; Lovell & Russell, 2005).

Driving independence may be maintained by restricted driving licence provisions. For example, drivers may be required to use vehicles with automatic transmission, to refrain from night driving, or to stay within local geographical areas. VicRoads accepts the results of an OTDA as a valid test of driver competence and will consider the results in conjunction with other information about the driver when determining licence outcomes. Licence restrictions assume that the driver can be relied upon to remember and apply such requirements (VicRoads & OT Australia Victoria, 2008).

The national body representing geriatricians and the AustRoads guidelines for Assessing Fitness to Drive endorse the application of the aforementioned driver assessments and licensing restrictions as a valid way to balance disease progression and personal mobility autonomy with public health risk (Australian and New Zealand Society for Geriatric Medicine, 2009; AustRoads, 2012).

Unless the driver is eligible to have the cost paid by an insurer, such as the Transport Accident Commission (TAC) or WorkCover, OTDA assessment costs are usually borne by the driver, adding further to the financial burden of ill health. Discounted OTDA services may be available to drivers who are patients at public health facilities [e.g., community health centres or Cognitive, Dementia and Memory Assessment Services (‘CDAMS’)], or if they are eligible for health subsidies via the Commonwealth Department of Veterans Affairs. A full off road and on road assessment requires at least two hours of face to face client time in addition to time spent writing reports to the referrer and/

or VicRoads. For a full off road and on road assessment, fees charged by Occupational Therapists (OTs) at a public health facility range from no cost to around \$250, depending on the extent of the subsidy provided by the health service. Fees charged by OTs operating privately range from around \$250–\$350 if little or no travel is involved up to almost \$1000 if the OT has to travel for several hours to conduct an assessment in a remote part of Victoria. In addition to the OT's fee, the client will have to pay around \$70–\$100 to the instructor who supplies the vehicle and assists with the on road assessment; this additional cost for the instructor applies regardless of whether the OT operates privately or through the public health system.

2.7 The role of carers in supporting management of driving transitions

Due to the disease process, drivers with dementia often require support in managing mobility transitions, identifying functional declines, seeking medical and other assistance, monitoring transport requirements and making decisions about modifying or stopping driving. Carers commonly help a driver to adapt to changes in transport independence, often with little background knowledge and few resources (D'Ambrosio et al., 2009; Perkinson et al., 2005). Carer effectiveness in negotiating and supporting a driver with dementia can be impacted by the carer's reliance on the driver for transport (Adler et al. 2000), the driver's lack of insight (Persson, 1993), the carer's ambivalence or discomfort regarding removal of driver privileges (Stern et al. 2008) and lack of support from other family members (Herbert et al., 2002). Furthermore, limiting mobility options for the care recipient adds to the carer's burden, as people with dementia become increasingly dependent on others for transportation due to their inability to use alternative mobility options without supervision (Taylor & Tripodes, 2001).

A systematic review was commissioned by VicRoads in 2010 to examine the evidence for the role of carers and support provided to them in managing drivers with cognitive decline (Williams & Di Stefano, 2011). The review found that the focus of most literature examining drivers with dementia concentrates on screening and driver assessment. There was a small body of evidence from outside Australia that highlighted the important role of carers for this driver group. The literature detailing carer interventions highlighted that transitions were either gradual or sudden and that carer strategies could be categorised as either 'imposed' on the driver (e.g., removing the means of transport or invoking outside authority) or 'involved', requiring the driver to be an active participant in complying with suggestions led by doctor or the family (Jett et al., 2005). Some reports recommended discussing transportation needs early in the disease management process and suggested that documenting arrangements in an 'agreement' that may have to be actioned later, offered many benefits in optimising carer, health professional and driver co-operation (Adler, 2010; Stern et al., 2008). The review findings were summarised within a 'carer-centric framework', which acknowledged that carers face issues and barriers that impact upon decision making but that strategies and innovative solutions can support and validate the driving to non-driving management process (Williams & Di Stefano, 2011).

Only a few very recent Australian studies have examined how carers support transitions for drivers with cognitive decline caused by conditions including dementia. Compared to health professionals, carers are able to observe care recipients regularly in a broad range of contexts and are therefore well placed to identify risky driving behaviours. Interviews with 30 carers in Victoria identified a range of signs that accompanied drivers' cognitive decline. The signs were related to health and to road safety. Carers consistently reported memory difficulties, inadequate driver performance including minor traffic events and low driver insight as issues that triggered responses. Carers applied a broad range of strategies according to individual driver needs, including practical means of impeding driving, family collusion, seeking professional assistance and reporting the driver to appropriate authorities. Carers often revealed poor knowledge of available licensing authority medical review procedures, health and competency assessments and related resources (Di Stefano, Barber, & Wriedt, 2010).

A recently completed study (Di Stefano, Roic & Williams, 2012) that examined Victorian caregiver experiences and risk perceptions via a self-completion survey supported the aforementioned findings. The study also highlighted several other important practical and road safety factors. Twenty-six of the forty respondents indicated that they either observed or had reported various specific inappropriate or dangerous driving behaviours, including misjudging distances, driving too fast for conditions, difficulty with lane keeping, drivers becoming distracted and involvement in 'near misses'. When asked to rate the personal safety risks of a range of daily activities, tasks rated the most frequently as medium to high risk were driving (n=32), and cooking (n=22). Participants also rated the likely risk of the driver being involved in certain adverse driving situations. Ratings of moderate to high were noted for minor incidents or violations by almost all respondents (n=36), and for major incidents by more than half (n=25).

Other findings from this study highlighted that, on average, around half of the carers who asked for help received useful assistance from other family members and doctors. In addition, more than two thirds of carers applied and found effective strategies, such as accompanying the care recipient to appointments, offering to transport more

frequently and visiting the care recipient at home more often. Less commonly applied strategies included travelling with the driver as a passenger (n=15), and hiding the car or keys (n=11). These strategies were rated less effective, although the majority of respondents who sold or removed the car rated this strategy as highly effective (6 of 10). These results indicated that carers do not always obtain support for implementing their mobility transition role and that drivers with cognitive decline pose significant road safety risks to both themselves and the broader community.

Previous research highlights the important role of information from carers and of carer input into driving decisions for at risk drivers (O'Connor et al., 2010). In relation to assessing the fitness to drive of people with dementia, the 2012 AustRoads guidelines state that *Relatives may be a useful source of information regarding overall coping and driving skills. They may comment about the occurrence of minor crashes, or whether they are happy to be driven by the person with dementia* (AustRoads, 2012, p. 72). It is important for families and physicians to work together to support drivers with dementia, particularly as memory loss and lack of insight can limit self-regulation (AustRoads, 2012). Researchers have suggested that physicians should begin using the '4Cs' approach to screen individuals possibly at risk of unsafe driving. This approach requires physicians to consider the person's crash history, family concerns about the individual's driving, health condition, and cognitive functioning. Drivers with concerns in all four Cs should be referred for formal evaluation.

Alzheimer's Australia New South Wales produced a discussion paper in April 2010, based partly on two surveys that were conducted to investigate consumer views. Respondents included people with dementia (n=61) and carers (n=104), and they shared their views on the value of driving independence, carer concerns, making decisions to stop driving and support needs (Alzheimer's Australia New South Wales, 2010a). The majority of carers (around 80%) supported people with dementia who were former drivers at the time of the survey and most carers indicated that driving had been either important or very important to the care recipient. Almost half the carers and respondents with dementia (46%) were unaware of legal requirements to report the diagnosis of dementia to the Roads and Traffic Authority (RTA). The majority of carers (87%) felt that the driver should not be the sole decision maker in relation to driving cessation plans and many (42%) indicated that decisions should be collaborative, involving health professionals and family members. Key recommendations outlined in the paper included the need for:

- programs to facilitate earlier diagnosis of dementia, enabling those diagnosed to participate in planning for their transition from driver to non-driver
- RTA information explaining driver and carer responsibilities
- health professionals to raise driving issues early in the diagnosis/ support process
- better community education and information
- improved resourcing of OTDA assessments and alternative transport options including taxi schemes.

Although the paper was written for the NSW licensing context, many of the driver and carer concerns raised may equally be applicable in Victoria.

3 Current information services and programs

A search was conducted for existing information sources and programs aimed at people with dementia and/or their carers. Available resources relating to mobility issues are described in this section by subject matter and according to their origin (Victoria; the rest of Australia and New Zealand; or the rest of the world). Some additional resources about dementia not specifically related to mobility are summarised in Appendix B.

3.1 Victoria

3.1.1 General information about dementia and driving

The Better Health Channel is a Victorian Government website that provides health and medical information. The page on dementia explains why the condition can make driving dangerous, what the laws in Australia are regarding driving with a medical condition and the driver's responsibility to report any medical conditions that may affect their driving (Better Health Channel, 2010). Importantly, the page discusses variability in individual responses and coping styles regarding an individual's declining abilities and lists the warning signs to help with the decision on whether a person can still drive safely. Finally, the website lists other organisations and groups where help may be sought and provides phone numbers for the Alzheimer's Australia National Dementia Helpline and the Dementia Behaviour Management Advisory Service (DBMAS).

Victoria's driver licensing authority, VicRoads, distributes a leaflet entitled *Dementia and Driving*. The same information is also available from a dedicated webpage of the same name. Both offer a brief definition of dementia, list warning signs and discusses legal issues and medical condition reporting requirements (VicRoads, 2011b).

Transport Accident Commission (TAC) and the School of Occupational Therapy at La Trobe University developed a program for healthy older road users called *Community Mobility for Older People*. The program delivers health promotion sessions to community groups and discusses road safety issues and mobility options, such as cycling, public transport, and motorised scooters (Transport Accident Commission, n.d.a). Sessions are often delivered in conjunction with the RACV's *Years Ahead* program.

A variety of information is available from the Alzheimer's Australia website (Alzheimer's Australia, n.d.b). This includes a help sheet with information for family and friends that discusses memory loss and includes an example that relates to driving (Alzheimer's Australia, n.d.b).

3.1.2 Resources that aid driving reduction and cessation

The TAC's *Community Mobility for Older People* program provides information on alternative transport options and keeping mobile (Transport Accident Commission, n.d.a).

The Better Health Channel's online resource provides tips for carers in managing the situation of their relative or friend who has been advised not to drive any more (Better Health Channel, 2010).

A brochure called *Getting around if you no longer drive* is provided by RACV (RACV, 2007). It contains information on health related transport concessions, using public transport, taxis and community transport. Some information is provided on travelling with other people, walking, using mobility scooters and other general travel advice

The VicRoads webpage on driving and dementia provides a link to the VicRoads Medical Report Form. This form is completed by medical practitioners and is used by VicRoads Medical Review when determining whether or not an individual can continue to drive safely (see Appendix A). The webpage explains how VicRoads is involved in the licence review process and what licence restrictions mean. There is also some information aimed at drivers of commercial vehicles. In addition, the page discusses the sequence of events that follows a person having their licence suspended or cancelled and what the person can do if they disagree with VicRoads' decision. Finally, the webpage provides tips for how individuals can maintain their mobility (VicRoads, 2011b).

VicRoads also provides more general information about driving cessation on a webpage called *Getting around without a car* (VicRoads, n.d.). This page discusses the decision making process; what to do with a car that is no longer needed; using public transport; planning trips; discounts and concessions; taxi services; walking and cycling; community transport; motorised mobility devices; and alternatives to travel. It also provides links to other useful resources.

3.1.3 Workshops

RACV offers a one hour education session for older road users. The *Years Ahead* presentation covers road safety tips for drivers, passengers and pedestrians; choosing a safe vehicle; fitness to drive; the impact of health and medications on driving; and how to assess one's own driving ability (RACV, 2010). Information about alternative transport options and how to plan for future mobility is also provided.

A course for older drivers called *Wiser Driver* was originally developed by the Hawthorn Community Education Centre and is now available through many local councils. The course revises road rules, road safety, planning for future transport and lifestyle needs and issues related to health and confidence (Hawthorn Community Education Centre, n.d.).

3.1.4 Advice on safe driving for older drivers

TAC publishes statistics on their website about the relative risk of older drivers being killed or seriously injured in a crash (Transport Accident Commission, n.d.b). The site also lists warning signs that continued safe driving may be difficult, suggests ways to manage the risks and provides tips for staying safe.

3.1.5 Research

Alzheimer's Association Victoria commissioned a paper on driving and dementia (Alzheimer's Association Victoria, 2001). This report presents issues related to public safety, health and quality of life for older people, legal issues, on road driving assessments, information on driver licensing in Australia and the views of people with dementia and their carers.

3.2 Rest of Australia and New Zealand

3.2.1 General information on dementia and driving

Alzheimer's Australia operates a National Dementia Helpline that provides information about dementia and support services and offers understanding and support for people with dementia, their family and carers (Alzheimer's Australia, n.d.g).

The Department of Health and Ageing (DOHA) provides a dementia resource guide, both online and in hard copy format (Department of Health and Ageing, 2010). The section on driving discusses key issues for both drivers and the broader community and the driving assessment process. It also provides recommendations, a case example and other useful contacts.

The New Zealand Transport Agency (NZTA) has published a factsheet on dementia and driving (New Zealand Transport Agency, 2009). It provides a brief definition of dementia and suggestions for what to do if someone close to the reader may have dementia. It provides lists of the skills needed to drive safely and the early warning signs of dementia. The factsheet mentions the impact of a medical condition on insurance cover and suggests coping mechanisms when a person stops driving. Finally, the factsheet mentions the role and responsibilities of the NZTA, the role of doctors and provides contact details in case further information is needed from the NZTA.

3.2.2 Resources that aid driving reduction and cessation

The New Zealand Office For Senior Citizens offers a downloadable brochure called *How will you get around when you stop driving?* The brochure provides information for older people who may need to cease driving in the near future. There is discussion of the person's residential location in relation to other important factors that can impact mobility and lifestyle. The brochure promotes positive thinking about driving cessation and continued independence. It encourages planning ahead for future transport and mobility needs and provides potential solutions to mobility beyond driving a car. The document also provides a list of groups and organisations that provide information on community mobility without a car. This includes local councils, volunteer based organisations, community service providers, doctors, libraries, neighbourhood support groups, recreation centres and citizens' advice centres (Office For Senior Citizens New Zealand, n.d.).

Land Transport New Zealand (now the New Zealand Transport Agency) has published information targeted at younger people suggesting how they might support their older relative or friend to safely stay mobile (Land Transport New Zealand, 2006). The resource discusses the vulnerability of older drivers in crashes; the uniqueness of each individual's timeline for driving reduction and cessation; the importance of planning ahead; and suggestions for recognising changes in driving behaviour, including differences between the minor and serious warning signs. Importantly, the resource acknowledges that speaking with an older friend or relative about driving reduction and cessation can be very difficult. It provides tips for how to approach the conversation and how to offer solutions.

Finally, the resource offers suggestions for managing the situation when an older driver does not listen or respond appropriately to concerns about driving reduction or cessation.

3.2.3 Workshops

Age Concern New Zealand is a volunteer based support organisation that publishes details of classroom based workshops that are aimed at helping senior drivers re-familiarise with traffic rules and safe driving practices (Age Concern, 2011a). The *Staying Safe* workshops are for persons aged 70 years and over. Although the workshops are not specifically for people with dementia or their carers, the workshop promotes discussion of safe alternatives to driving in relation to their different uses for a car, and it prompts participants to think about the positives and negatives associated with each of the alternative transport modes.

3.2.4 Support services

Age Concern New Zealand aims to serve the needs of older people through contracted services, education, resources and national leadership (Age Concern, 2011b). For example, Age Concern has published information on the New Zealand Transport Agency Total Mobility program. This program is a nationwide scheme that provides eligible clients with a 50% discount on door-to-door transport services in many urban areas across New Zealand. Land Transport New Zealand supported local authorities to provide the scheme through transport providers in their local area. The eligibility criteria for people to qualify for the scheme are broad (Land Transport New Zealand, 2008).

3.2.5 Advocacy

Alzheimer's Australia is an organisation funded by Government bodies and other partners. It provides programs, support services and advocacy for people with dementia and their families, and provides national policy on issues related to Alzheimer's dementia. Government submissions are available to view online, including the 2012 budget submission that was presented in September 2011 (Alzheimer's Australia, n.d.h).

Alzheimer's Australia New South Wales publishes a monthly magazine called Alzheimer's Advocate, which converts clinical findings to policy and call-to-action items. The magazine also includes other relevant short news articles (Alzheimer's Australia New South Wales, n.d.). For example, in April 2010, Alzheimer's Advocate published an article showing that in 2008, dementia was the third leading cause of death in Australia (Alzheimer's Australia New South Wales, 2010b). The discussion paper discusses the lack of information available on the rights and responsibilities of a driver after a diagnosis of dementia and calls for process improvements, clearer legal obligations, improved alternative transport and better support for people transitioning from driver to non-driver.

Advocacy Tasmania Inc. conducts a range of advocacy activities, including support services for people with dementia. The dementia advocacy service assists people with memory loss and dementia to maintain decision making control over their lives via professional advocacy that assists with information needs and future planning (Advocacy Tasmania, n.d.).

Age Concern New Zealand advocates nationally and internationally on policy and a variety of issues that relate to older people and ageing (Age Concern, 2011b).

3.2.6 Research

The Department of Health and Ageing commissioned work to develop a *Dementia Services Pathways Project*. The project report is intended to inform and assist jurisdictions with service planning in an effort to improve the services that care for people with dementia and support carers (KPMG, 2011). The report considers the needs of people with dementia and their carers, service requirements, populations with specific requirements, care settings, geographical location and the progression of dementia.

3.3 Rest of the world

3.3.1 Resources that aid driving reduction and cessation

Dementia Care Central is an online resource centre developed by a physician run business known as *ClinicalTools.com* based in Maryland, USA (ClinicalTools, 2012). The page on safety and driving lists the tasks required of drivers and the warning signs that carers can look for as markers of their friend's or relative's declining ability to drive safely and responsibly. Suggestions to assist caregivers are offered, as well as strategies for bringing in more support if the person with dementia resists intervention. It also suggests researching transport options to assist with keeping the person with dementia as mobile as possible.

In the Faculty of Medicine, Dalhousie University in Canada, the Geriatric Medicine Research Team is currently developing a 30 second television public service announcement about driving safety and dementia, in an effort to raise awareness of the problem (Dalhousie University, 2011). The second phase of this project will see a website created for primary care physicians. The website will consist of in-office tools and forms, as well as specific links to community resources and relevant materials.

In the USA, the Johnson & Johnson Company's Patient Assistance Foundation operates the *StrengthForCaring.com* website, which suggests ways that carers or friends can positively frame the inability to drive (Eby, n.d.). The page *Taking away the keys* also lists the many and varied reasons people may stop driving and provides tips for how to manage the bruises to self-esteem that can be associated with driving reduction and cessation. The webpage offers suggestions for managing difficult conversations with a driver about cessation and provides tips on car-pooling, alternative transportation, removing car keys and dealing with a car that is no longer used.

The Jewish Council for the Aging in the USA has published a document for older drivers on safe driving and transport alternatives (Gamse, 2003). It explains why older drivers can find driving difficult, provides examples of how older people who are transitioning from driving may feel, offers safe driving tips, discusses car-less travel, provides mobility 'secrets' to make alternative transport options more appealing and includes a 'transportation translator' (a table that lists different types of services available, what they mean and how they work).

The Alzheimer's Society (UK) website discusses a diagnosis of dementia and its impact on driving. There is information on the ability to drive, reducing risks while continuing to drive and giving up driving (Alzheimer's Society, 2011). There are tips for helping someone transition from driving, such as highlighting cost savings and the benefits of increased exercise and socialisation. This website also provides a list of other useful organisations that people may wish to contact.

The Mayo Clinic Health System is a non-profit network that covers more than 70 communities across Minnesota, Wisconsin and Iowa in the USA. Work covers medical care, research and education. The website provides a wealth of information, as well as podcasts on dementia and Alzheimer's disease. The *Alzheimer's: When to stop driving* page discusses the impact of Alzheimer's disease on a person's ability to drive and provides warning signs of unsafe driving to help decide when the person should stop driving (Mayo Clinic Health System, 2011).

3.3.2 General resources for caregivers

AlzOnline is an online resource sponsored by the State of Florida Department of Elder Affairs and the University of Florida. It is aimed at caregivers of persons with Alzheimer's and other memory problems. The website provides an article on driving and progressive dementia (mild cognitive impairment) and provides a checklist of warning signs in question format for a person with mild cognitive impairment to complete using Yes and No answers (Doty, 2007a). Depending on the responses to this checklist, it provides feedback and may recommend a driver assessment. Doty (2007b) also authored a paper on safe driving in relation to Alzheimer's disease and other memory disorders. It explains the types of memory, motor, visual and thinking skills needed for driving and provides tips for helping someone to stop driving and for how to stop an unsafe driver.

The Hartford is a financial services organisation providing insurance and wealth management services in the USA. Its website provides information on dementia and driving and it also developed a guidebook out of a partnership between The Hartford and MIT AgeLab. The guidebook is accessible to the public. It provides suggestions for monitoring, limiting and stopping driving and supports persons with dementia and their families to maximise independence while minimising driving risk. Topics include the difficulties associated with driving and dementia, how to fairly assess concerns, warning signs, the transition from driver to passenger, reducing the need to drive, early planning, support options, how family relationships can be affected by driving decisions and advice from experienced caregivers (The Hartford & MIT AgeLab, 1999). A novel feature is a model agreement between the person with dementia and their family about not driving. It also provides a work sheet for recording the warning signs that drivers with dementia may exhibit. Evidence recorded on the work sheet can help carers make a decision about when driving should be restricted or should cease altogether.

Pines of Sarasota is a non-profit corporation in Florida (USA) that operates a facility offering care in assisted living, skilled nursing and a secured Alzheimer's unit. The corporation also operates the Pines Education Institute, which is a regional training centre for medical professionals, paraprofessionals and at-home caregivers. A variety of information and support materials are available via seminars and programs or DVDs that can be purchased online (Pines of Sarasota, 2010). Most of the DVDs are training programs around 2.5 hours in length aimed at carers of dementia patients. They include topics such as how to have a difficult conversation, how to frame something challenging positively and how to get buy-in from someone with dementia, all of which could be very valuable to a carer who needs to discuss driving reduction or cessation with a person with dementia.

3.3.4 Advocacy

The Dementia Advocacy Network in the UK is a national support network of advocates working with people with dementia. The network provides advocacy tips, training events, networking opportunities, and publishes documents relating to dementia and advocacy activities (Dementia Advocacy Network, n.d.).

The Dementia Advocacy Support Network International grew from a membership base that originated in Kansas, USA. It is a worldwide internet based organisation run by and for those diagnosed with dementia. As well as providing a forum for people to exchange information and support, it advocates for services for people with dementia (Dementia Advocacy and Support Network International, n.d.).

The guidance provided by the Dementia Advocacy Network and the activities of the Dementia Advocacy Support Network International are relevant to a broad range of dementia related issues, including driving and mobility issues.

4 Consultation with stakeholders

4.1 Method

A total of nine interviews were conducted with experts from various organisations either over the phone or in person. Most interviews had a duration of at least 60 minutes.

4.2 Summary of stakeholder responses

This section summarises the responses received to each of the interview questions. The full text of each question and a longer summary of the responses received can be found in Appendix C (Stakeholder interview responses). Question numbers used in this section (Q1, Q2 etc.) refer to numbered questions listed in Appendix C. The summary in this section attributes many of the responses to the organisation represented by the person interviewed.

The first interview question (Q1) asked what problems drivers with dementia experience when they are driving. Respondents referred to cognitive impairments such as memory loss, attention difficulties and impaired judgement (especially of space and speed). These deficits were associated with several activities, including a decreased ability to recognise places and recall words, poor handling of the motor vehicle in complex situations, poor navigational skills, poor problem solving and decision making, the misinterpretation of signals and confusion. Many respondents also referred to elevated aggression, anger and/or irritability, a lack of self-insight, and some physical impairments, such as difficulties with motor coordination and impaired vision. Near misses and small incidents were a common result of the aforementioned cognitive impairments. One respondent said it can be difficult to know which symptoms form part of the typical ageing process and which result from the dementia.

Interviewees were then asked (Q2) if the problems that drivers with dementia experience could be overcome with licence restrictions and/or driving aids, or whether complete cessation was required. Taking responses to later questions into consideration, it is apparent that all respondents agreed that complete cessation would be required at some point, though there were some differences concerning when that point in time should occur. Respondents emphasised the importance of an individualised, case-by-case approach to dementia patients and their driving. A respondent highlighted that patients can be affected at different times of the day, depending on their type of dementia. With respect to licence restrictions, three respondents suggested local area driving, two said that licence restrictions would help only when driving problems related to memory and not perception or praxis (the execution of driving skills) and another suggested that avoiding night driving and complex traffic situations may be useful licence restrictions to apply. Two respondents said that licence restrictions were not much use or should not be accommodated and that retaining a licence should be assessed in terms of skill and competency. Regarding the use of aids, most respondents said that GPS systems were not helpful; differences between instructions delivered by voice or on a visual display were not discussed.

Respondents were asked (Q3) at what stage in the progression of the disease that drivers with dementia should have their driving skills assessed or stop driving for safety reasons. It was clear that a 'black and white answer' was difficult because of the many relevant variables, including age, type of dementia, rate of progression, medications, how stable the person is, any comorbidities, their ability to judge, their previous driving style, their nature of driving, their cognitive profile, and the changes that are occurring. Some respondents suggested that a driving assessment should occur at the point of diagnosis, highlighting legal and insurance implications as support. When families report problems with driving, or frequent occasions of getting lost, having near misses or crashes were other points frequently cited. Other suggestions included when visuo-spatial cognitive deficits are identified and trying to find a reliable neuropsychological assessment to distinguish an appropriate cut-off point. One respondent referred to the Clinical Dementia Rating scale as a tool for providing guidance on driving ability and crash risk.

The theme of needing to take a sensitive case-by-case approach to people with dementia and their driving continued throughout the interviews. Respondents did not support sole reliance on a neuropsychological assessment tool when deciding whether or not a person could continue driving. In response to Question 4, most respondents said that although people with dementia usually lack insight and are often unaware that their driving skills have declined or that they are driving inappropriately, the time to modify or stop driving and the signs that can be used to make this judgement still depend on the type of dementia, the progress of the condition and the degree of impairment. The signs that people with dementia could use as feedback that driving modification or cessation might be required include getting lost, near

misses, forgetting how and when dints or scrapes appeared on a car, and having crashes. However, because insight is so affected by dementia, the driver's ability to be aware of these signs would be dependent on the type of dementia and how far it has progressed.

In terms of the signs that carers, family and friends might use to recognise when it is time for a person with dementia to stop driving (Q4), respondents cited trips taking far too long with no sensible explanation, difficulty concentrating, different personality and altered emotional state in general (such as changes in impulsivity, aggression and patience). Another sign mentioned was when vehicle passengers feel unsafe in the car when the person with dementia is driving.

When asked how health professionals should manage a person with dementia who needs to cease driving (Q5), respondents generally wanted health professionals to take more of a leading role in order to take the burden away from family, friends and carers. Respondents also said that health professionals should be thoroughly informed about legal obligations and support services. They should provide resources on how carers can speak with the person with dementia in a positive manner around alternative transport options and driving cessation.

Responses were fairly evenly split on the matter of whether a telephone service line would be useful (Q6). About half said that efforts should be focused on improving existing services and better promoting them, or that face-to-face interaction would be more valuable. Several respondents said that a telephone service line and other resources would be used mostly by carers, especially when people with dementia find it difficult to self-educate. If a new telephone service was developed, it would need to reference other resources and they should also provide consistent messages. The importance of engaging a suitably qualified person for any telephone hotline was highlighted. Most respondents believed that information on a website would be useful (Q6), but that it would be mostly used by carers. Others said that any website should address issues for both patients and carers. Respondents also tended to support the idea of brochures, especially for use in the waiting rooms of general practitioners and other health professionals. Other ideas around useful information and services included the following:

- educational sessions (especially for carers)
- self-help groups and forums
- community support (especially regarding alternative transport and for people living in rural areas)
- a service that teaches people how to use alternative forms of transport
- engaging counsellors to support people around the time of diagnosis
- a case-detection system that signals the need for a licence assessment.

To help people with dementia and their carers to cope with driving reduction and cessation (Q7), respondents said that access to the Multi-Purpose Taxi Program (reduced-cost taxis) and community transport options (especially in rural areas) needed review and improvement. A more comprehensive legislative framework, legal advice and support, case management support, and clear information about their responsibilities were also cited. Several respondents said that a cost-benefit analysis that compared private car usage to other forms of transport would be valuable to help people with dementia and their carers better understand that using taxis and other forms of transport is not as expensive, when compared with owning and driving a car, as is often assumed.

Interviewees were asked about the main challenges their organisation faced in working with drivers with dementia (Q8). At the level of the individual, respondents often cited the individual variability associated with the different types of dementia and the way symptoms inconsistently impact on people's driving skills and competencies. A respondent regarded the sensitivity of the topic as a core challenge, also mentioning the lack of support after driving assessment and licence removal. Another respondent highlighted the difficulty of receiving the correct information on driver assessment forms so that drivers are paired with the most appropriate assessor, as well as the issues associated with people with dementia who do not have a regular carer.

At the family and carer level, many respondents cited the difficulty for carers when they too might lose their independence, because they typically rely on the person with dementia to drive. Some respondents also said that drivers with dementia who are vulnerable and can easily get involved in road rage were of concern. A respondent mentioned difficulties caused by privacy laws, because carers who report drivers to VicRoads never receive any feedback on the process or outcome (unless they have power of attorney). At the system level, many respondents cited the lack of alternative and community transport options, community awareness, resources not being widely available, being under-resourced (especially with respect to driving assessment wait lists), the need for a medium to long-term plan, the lack of funding, the lack of carer support services or initiatives, and the medical review process at licensing authorities.

Question 9 asked interviewees whether their organisation had any programs or resources for people with dementia, for their carers or for health professionals working with patients with dementia. Table B.1 in Appendix B lists the programs and services offered by Alzheimer's Australia and Table 4.1 overleaf lists programs and resources currently provided by organisations other than Alzheimer's Australia.

Table 4.1

Dementia specific programs and resources offered by organisations

Program or Resource	Organisation
Diagnostic	Caulfield CDAMS, Eastern Health, Austin Repat
Internal staff training	Austin Repat
training for (external) health professionals	VicRoads 'SafeDrive Medical Program for Health Professionals'
Driver assessment	Austin Repat, Eastern Health, Caulfield CDAMS, VIFM via St Vincent's Hospital
General advice – not dementia specific	DMA
Non Carers Vic	COTA

Question 10 asked interviewees if their organisation ran any joint programs with other agencies that catered to the needs of drivers with dementia. None of the respondents was involved in any joint programs at the time of the interview. However, some of the organisations did report working collaboratively with other organisations on research projects and preparing resources such as brochures and documents.

When asked if they were aware of any programs or messages from their own or another organisation that were considered to be effective (Q11), one organisation referred to its recent work with the Victorian Human Rights and Equal Opportunity Commission on issues relating to ageing and driving, including discrimination and stereotyping of older people. Another organisation referred to the VicRoads brochures on offer, the *C_Drive* program in Queensland, RACV's *Years Ahead* and TAC's *Community Mobility programs*. One respondent suggested reviewing assessment policies and tools and licensing schemes for drivers with disabilities. Another respondent also mentioned a program in Northern Europe or Dubai, where driving simulators were used as diagnostic assessment tools, and that newer technologies such as vehicle control systems could improve driver safety performance. The Hawthorn Community Education Centre's *Wiser Driver* program was also suggested. One organisation commented that evaluating effectiveness is difficult because traffic breaches are a police matter and this affects the collection of data before and after treatments are administered.

Question 12 asked interviewees if their organisation had any goals or plans for future programs or resources to address the needs of drivers with dementia. One respondent was seeking funding for a diagnostic simulator to be used for driver assessment. The simulator would demonstrate to a driver how well they managed driving tasks and whether they needed training. The tool would be able to pinpoint specific deficits. Another respondent was involved in developing Home And Community Care (HACC) Assessment Services for the Department of Health. This was a local government community care initiative that involved a reference group on dementia pathways, including matters surrounding dementia and driving. One respondent said that it continued existing research efforts and that there may be a role in the future to expand existing clinics, as it is currently unable to keep up with demand.

All interviewees provided a response to Question 13, concerning information or service gaps existing now or in the foreseeable future. The gaps identified by respondents included:

- a need for alternative transport, particularly in rural areas
- improved community awareness and education
- a need for improved access to a discounted taxi scheme
- more funding to improve the assessment process
- a clearer message about information sources and requirements by drivers with dementia and their carers
- case management services
- greater funding for rural and remote residents
- support after driving cessation
- assessment tools for foot and lower limb coordination assessment
- appropriately experienced instructors in cars with modifications
- an effective neuropsychological test battery
- a more accurate method for testing driver skills
- more support and education for general practitioners so that they better understand fitness-to-drive issues.

Finally, one organisation mentioned a current project which is funded by the Australian Research Council. This project aims to provide insight into the problems faced by older drivers. This respondent also mentioned the *RACV Sir Edmund Herring Memorial Scholarship* that may offer some assistance in addressing some of the aforementioned gaps.

When asked how road authorities could assist (Q14), most respondents referred to the need to provide alternative transport. Other responses included:

- greater promotion of its role and services and being more proactive
- promoting existing information and education services
- providing more support to families and carers about medical problems, changes and implications, or looking to implement a unique licensing points scheme following diagnosis
- supporting more regular medical checks
- monitoring of at-risk drivers
- joining the Australian Disability Parking Scheme
- providing more support for specialist researchers so that they are funded to study issues that need urgent attention
- reviewing the use and reliance on the Useful Field of View test of eye and brain function because it is not an accurate tool
- more advertising of existing services
- greater consultation with health professionals before making decisions
- not monitoring the driver because this is something for health professionals.

Question 15 expanded on the above by asking how local governments could assist. Almost every interviewee stated the need for increased community support services and/or volunteer programs, especially in rural areas. These services were mentioned in the context of how important it is for individuals to remain in social contact with others. Alternative transport was also frequently cited, along with funding and safety measures such as lighting, so that people felt comfortable to use alternative transport services. One respondent suggested working with taxi companies regarding subsidy schemes, access to disabled stickers for carer drivers, greater consistency between local councils in terms of what services are offered, and specialist training for driving assessors so that they are sensitive to the situation and communicate with older drivers more appropriately. There was also support for in-home services, addressing pedestrian environments, tram stops, bus shelters and footpaths, less confusing street signs and better engineered road user environments, and consultation with health professionals when making decisions.

Interviewees were then asked how State or Federal Government departments could assist (Q16). Many respondents cited the adoption of policies that promoted community awareness and road safety for all older drivers, and more funding to decrease driving assessment waiting lists and the expense incurred by people who need to undertake a private driving assessment. Other suggestions included specialist training and education programs for health professionals and driving assessors, funding for medical transport, clarification of AustRoads guidelines on driving and dementia, replacing any age-based testing with problem driver management systems and processes, engagement with politicians on matters relevant to drivers with dementia and their carers, and providing services to help people with dementia maintain quality of life. One respondent suggested promoting national consistency of schemes, policies and education; improved planning of communities for public transport access and use; funding to bring goods and services to people; and support for people who have ceased driving.

When asked what initiatives or changes should be a priority to stakeholder groups (Q17), almost all respondents said education and community awareness. Many cited alternative transport options, and some others said improved community transport options, better resources for existing services, increased funding for screening and assessment, and planning ahead in terms of resourcing and anticipating changing needs. Other responses included improved data collection to aid research, a fair approach, addressing discrimination, increased funding for research, post-driving cessation support, diagnostic services, relinquishing age-based testing, well lit train stations and maintained footpaths, social support, and a shift in thinking about licences as a privilege.

All interviewees said their organisation would partner with relevant others to support initiatives of mutual interest (Q18).

5 Discussion

The aims of this project were to identify the key road safety issues faced by people with dementia and key communication messages for people with dementia to assist them and their families with information about driving cessation. This report also contains recommendations on how these key messages may be communicated, suggested programs or advocacy initiatives that may be implemented and policy considerations in relation to driving with dementia.

This report includes a literature review of topics related to driving and dementia, such as the ageing population, community mobility, fitness to drive, driving assessments, and the driving reduction and cessation process. Existing information and programs for people with dementia and their carers were also reviewed, along with key advocacy initiatives of organisations that support people with dementia and/or their carers. These information sources were used to inform the questions asked when interviewing health and medical professionals and other stakeholders on issues relevant to drivers with dementia.

5.1 The impact of dementia on driving

Different types of dementia impact drivers differently in terms of signs, symptoms, and the rate of progression of the disease. An individual's trajectory is likely to depend on factors such as age, type of dementia, medications, cognitive profile (the person's characteristics and abilities regarding attention, language, perception, memory, decision making and problem solving) and comorbidities. Over time, cognitive impairments will affect memory, attention, judgement and motor coordination. As a result, drivers with dementia can experience problems with navigation, signal interpretation, problem solving, decision making, recognition, and awareness. Difficulties with these skills make it especially challenging to handle a motor vehicle in complex situations. As a result, drivers with dementia can potentially pose a significant risk to themselves and others on the road.

The investigation identified a range of indicators that a person may need to stop driving. These include problems with concentration, frequent occasions of the driver getting lost or being gone for long periods of time without sensible explanation, frequent near miss incidents, involvement in crashes, forgetting how and when dints on the vehicle were incurred, and an altered emotional state in general (changes in impulsivity, aggression and patience). Another informative indicator occurs when family or friends feel unsafe in the vehicle when the person with dementia is driving.

The crash risk of a driver with dementia is largely dependent on the type of dementia and how far it has progressed. The Clinical Dementia Rating (CDR) scale is a tool that was developed to assess the stage of cognitive decline (i.e., the severity stage) of dementia. A CDR of between 0 and 0.5 signals very mild dementia, from 0.5 to 1 indicates mild dementia, between 1 and 2 is moderate and greater than 2 indicates severe dementia. Dubinsky, Stein and Kelly-Lyons (2000) used this tool in research that studied the crash risk of drivers with Alzheimer's dementia. It was found that although driving was mildly impaired in drivers with probable (early stage) Alzheimer's dementia (CDR of 0.5), it was no greater than the impairments tolerated in other segments of the driving population, such as in young driver age groups or those driving under the influence of alcohol at a blood alcohol concentration level of less than 0.08 g/100mL. Drivers with Alzheimer's dementia with a CDR of 1.0 or more were found to pose a significant traffic safety risk. The potential for the CDR to be used in conjunction with driving assessments in Victoria and Australia warrants further investigation. The outcomes of such investigation would be relevant to policy positions and advocacy activities.

Most interviewees considered that a driving assessment should be a multi-faceted review of driving skills, including a practical component, pencil and paper test(s) and use of a neuropsychological instrument. There should not be sole reliance on a neuropsychological instrument, as previous research did not reliably indicate which tool to use and whether a fair cut-off-point as to when people with dementia should no longer be allowed to drive could be identified. Driving assessments would preferably occur earlier, but must be undertaken at the point of diagnosis, as stipulated by AustRoads guidelines. It was generally agreed that complete cessation of driving will eventually be required for all people diagnosed with dementia.

5.2 The needs of drivers with dementia

Early diagnosis of dementia related conditions is likely to facilitate a smoother driving reduction and cessation experience, as a person's cognition is less diminished and their driving skills maintain some stability. However, early diagnosis can be difficult to achieve. It may be that carers protect themselves and/or the individual and exaggerate the driving competence of the person with dementia, or it may be that medical staff found it too difficult to differentiate between normal ageing and memory loss and the symptoms of early dementia. The widespread perception of a stigma associated with 'mentally related' illnesses is also likely to impact on the diagnosis process, with fewer diagnoses occurring as a result. This stigma can encourage avoidance behaviours regarding the seeking of medical advice in relation to cognitive decline. Furthermore, as people typically associate independence and quality of life with the ability to drive, seeking medical advice about difficulties with driving is even less likely.

These challenges around early diagnosis suggest that there is a need for some health and medical professionals (particularly general practitioners, with whom the diagnosis process generally begins) to improve their skills in recognising the signs and symptoms of dementia. An increased number of early diagnoses in the future would benefit individuals, families, health and medical professionals and the wider community, as it facilitates a smoother transition process to non-driving and the necessary lifestyle changes that accompany this shift. Earlier diagnoses may also facilitate a longer transition time, as earlier use of medications and rehabilitation efforts may help to slow the rate of degradation.

Results from the interviews indicate that although complete driving cessation will eventually be required of drivers with dementia, it is important to take an individual, case-by-case approach to the process. This 'person-oriented' approach would not enforce blanket rules, such as excluding the possibility of licence restrictions or vehicle aids to assist in the maintenance of mobility during the transition to non-driver. Specifically, vehicle aids were generally not regarded as helpful unless there is a comorbid condition that affected motor control. There was a strong view that global positioning systems have a negative impact on the ability of people with dementia to drive safely because they are confusing.

People with dementia and their families may not receive clear messages about where dementia related information sources can be found, particularly with respect to rights and responsibilities in relation to driving. As the diagnosis process can be an overwhelming experience, those involved need information to be presented to them in a clear and consistent manner rather than being left to find it for themselves. People with dementia and their families or carers felt confused about where to find information sources and did not understand their legal obligations. As a result, there may not be consistent declaration to VicRoads of medical conditions that may impair a person's ability to drive. Interview respondents considered that the community at large appears to be unaware of their legal obligation to do this. The lack of awareness regarding responsibilities with respect to medical conditions and driving may also impact on the legitimacy of vehicle insurance policies, as people unknowingly neglect to inform their insurers.

5.3 The needs and challenges of people caring for drivers with dementia

The needs of carers can be complex and may differ across groups, as every situation and experience of dementia is unique. As stated earlier, the signs and symptoms of dementia differ depending on factors such as type of dementia and severity stage. In the early stages, it may be possible for the person with dementia to understand elements of their condition, with a capacity for self-reflection. This self-insight may lead to awareness of impairments such as forgetfulness and near misses or crashes on the road. A person with self-insight tends to experience fright or shock after a near miss or crash. Following an incident, a person with mild dementia may self-regulate or choose to cease driving. However, due to the infrequency of early diagnosis, it is more usual for there not to be self-insight around the time that families are concerned, a driving assessment is needed or there is a diagnosis. Therefore, carers need support from health and medical professionals through this process.

Carers provide the most help regarding mobility transitions to non-driving and often become responsible for the mobility needs of the person with dementia. Certainly, drivers with dementia need to rely on others to monitor and support them. It is a difficult time as a persons with dementia may forget that they should not or can no longer legally drive. The person with dementia may seek the car keys and go to the vehicle despite their carer's concerns. Carers may need to hide keys or disable the vehicle. The person with dementia may become aggressive or otherwise upset at the assertion that they no longer possess the skills to drive, or they are not allowed to drive anymore.

Carers could benefit from support in the form of written guidance, telephone or face-to-face communication. Alzheimer's Australia currently provides a telephone line for assisting with matters related to the behavioural management of a person with dementia. Greater promotion of this service would be of benefit to carers. Carers could be further supported in this process by care-relief, home-support and improved community mobility services.

5.4 Currently available resources and services

A wide range of information sources are available to drivers with dementia and their carers when seeking help related to driving or community mobility:

- The National Dementia Helpline and the Dementia Behaviour Management Advisory Service, both operated by Alzheimer's Australia, provide advice via telephone.
- Relevant webpages and printed information are provided by VicRoads, RACV, Better Health Channel (operated by the Victorian Government) and the Commonwealth Department of Health and Ageing.
- Seminars and workshops specifically relevant to dementia are provided by Alzheimer's Australia. Sessions relevant to people who may be in the process of giving up driving are also provided by TAC (*Community Mobility for Older People*), RACV (*Years Ahead*) and Hawthorn Community Education Centre (*Wiser Driver*).
- The Alzheimer's Australia library provides access to books, videos and the internet.

Other services provided by Alzheimer's Australia include carer support groups, social contact for families affected by dementia, a telephone outreach service and GPS devices to track the location of a person with dementia. Services funded by the Commonwealth Department of Health and Ageing include the National Carer Counselling Program and the National Respite for Carers Program. Finally, driver assessment services are offered by public health facilities, such as hospitals and memory clinics, and by OTs in private practice.

Despite the wide range of resources and services currently available, people with dementia and their carers are often not aware of what resources and services exist, where to find them or how to access them.

The ageing of Australia's and Victoria's population means that the number of people living with dementia is expected to increase substantially in coming years, placing greater demands on existing services and requiring increased funding to keep pace with the increased demand.

5.5 The resource gaps

Although a range of sources of information are available from various organisations, there is no single website or paper based resource that compiles and organises the information. It was apparent from the interviews that some stakeholders were unaware of the resources of other stakeholder agencies; for example, not all interviewees were aware of the VicRoads brochure *Dementia and Driving*, which has been available since mid-2011. A compilation would make the information more accessible to people with dementia and their families and carers, to the general public and to information deliverers such as health professionals in key support roles and telephone advisory service personnel.

Results from the interviews suggest that refresher lessons are useful only in the early stages of dementia. As the condition progresses and driving skills decline, there is a need for a driving assessment to be undertaken. Individual assessments are a more accurate way to evaluate driver capacity (as opposed to relying on diagnosis alone). However, assessment by an occupational therapist is very expensive, especially in rural and remote areas, ranging from \$250 to almost \$1000, and is out of reach of many families. Assessment is available at lower cost through hospital based assessment services, but a lack of resources means that the waiting time for assessment at a hospital can be as long as nine months. The frequency of the driving assessment must also be factored into considerations regarding cost, as drivers with dementia are often required to be assessed at six-monthly intervals. The need for more assessment services was highlighted as a top priority area for initiatives by interviewee stakeholders.

Funding was reported by interviewees to be inadequate in the area of dementia and driving and was highlighted as a top priority for initiatives. Drivers with dementia cannot easily access the alternative transport modes currently available. In the early stages of dementia when a person is transitioning from driving to non-driving, greater funding for mobility, such as community transport services, would facilitate independence and alleviate some of the strain that carers and others experience when they are relied upon for the mobility needs of the person with dementia. In the moderate to severe stages of dementia, a person is unable to recall where they are going and why. Transport systems that require the traveller to make independent decisions therefore do not meet the needs of people with moderate or severe dementia. In-person support is needed to help the person with dementia move between two points, provide instructions to remain seated or to leave the transport service, recall the purpose of the trip and so forth. The multi-purpose taxi scheme is generally unavailable to people with dementia and their carers, because of its eligibility criteria. Increased funding may help to alleviate the problems that people with dementia and their carers experience in relation to the lack of alternative transport options, especially in rural and remote areas.

Interviewees urged that health professionals should take the lead in initiating driving cessation for people with dementia. This is important to support and ease the burden on family, friends and carers of the person with dementia, as carers will in many cases have difficulty persuading the person with dementia of the need to give up driving. To enable health professionals to fill this role, it will be necessary to ensure that they are given the necessary information and training. As the first point of contact with the person with dementia and the family or carer, it will also be necessary for the health professional to be given information about the services and resources to which drivers with dementia can be referred to help them with the difficulties associated with giving up driving.

The interviews revealed that stakeholder groups do not often work with other agencies and would welcome the opportunity to collaborate on projects. More communication and collaboration between stakeholders would also help to disseminate information about changed laws and requirements related to dementia and driving.

5.6 Policy considerations

5.6.1 Information provision

The research found a community need for increased education relating to dementia and driving, including what is needed to care for someone with dementia. Greater community awareness of dementia could facilitate greater acceptance of conditions that are characterised by cognitive decline, and of the problems that people with dementia face. One of the top priority areas identified by interviewees was the need to provide educational resources to facilitate community awareness.

Enhanced awareness may also positively impact on the frequency and likelihood of health and medical advice being sought and early diagnoses. If the frequency of early diagnosis were to increase, there would be a positive outcome for driver assessments, because the transitional phase to non-driving may be longer, allowing the person more time to adjust and accept the transition. Carers need to be provided with useful strategies, to know where help is available from and what the person with dementia and their own legal obligations are.

Increased community education on ageing and driving could facilitate greater understanding of issues such as licensing options, alternative and community transport, what is involved and the benefits of planning ahead. The community as a whole needs to understand that the transition from driving to other forms of mobility is inevitable for most people. In addition, this may help people to more fully consider amenity and transport options when planning for retirement.

A key need is to ensure that people with dementia and their carers are aware of the range of information sources and services available to assist them with continuing to drive if possible, with driving cessation when necessary and with adopting other transport options when driving is no longer possible. Section 5.4 lists a range of helpful resources and services. A catalogue of such resources would be useful to general practitioners and neurologists for distribution to people newly diagnosed with dementia and their carers. The catalogue would need to be updated periodically as the range of resources and services offered by various organisations changes over time.

A further need is for greater understanding of alternative transport options. Individuals and families need assistance to appreciate real differences in cost between private vehicle use and the alternatives, especially with respect to taxi use. Financial information and cost comparison examples could be a way of highlighting the benefits of no longer owning and operating a vehicle.

Carers have a crucial role not only in maintaining the mobility of a person with dementia but also in helping to ensure that the person reduces or ceases driving when that becomes necessary. The carer's task may be very challenging. Carers need a wide range of strategies available to them because every situation is different, depending on the abilities and disabilities of the person with dementia and the physical and social environment in which they live and are active. However, carers are often not aware of the range of options open to them. A comprehensive guide describing a wide range of strategies may be useful for carers in various situations. The guide could include information on:

- helping the person to research alternative transport options
- encouraging the person to drive only as far as the nearest suitable public transport
- travelling as a passenger with the person to monitor their driving
- offering to transport the person or visiting them at home more often so they have less need to drive
- initiating a discussion about driving cessation at a time when the person is still able to understand the problem and participate in planning
- entering into an agreement or contract with the person regarding what will happen when they can no longer drive safely

- monitoring and recording signs, such as minor traffic incidents, that indicate the person may no longer be able to drive safely
- highlighting to the person the cost savings available through not owning and operating a car and the number of taxi trips these savings could pay for
- seeking support from other family members and/or medical practitioners to help convince the person that they must restrict their driving or cease driving altogether
- reporting the person to VicRoads Medical Review
- hiding the car keys, disabling the car or selling the car
- seeking advice and support from the National Dementia Helpline or the Dementia Behaviour Management Advisory Service, both operated by Alzheimer's Australia.

5.6.2 Opportunities to improve services

There is a significant need among people with dementia and their families and carers for improvements to the alternative transport and community mobility options available to them. There is a need for support across the transition to non-driving both in terms of human support and the availability of alternative transport options. Human support could be made available under a case management model and is expected to benefit both psycho-social and actual mobility needs. There is a need for increased and improved community based, local council operated transport systems that offer door-to-door services. Door-to-door taxi services should be available to accommodate the mobility needs of people with dementia. These initiatives could be achieved via strategic membership of lobby groups, direct appeals to government and obtaining funding trial projects.

A working party or committee needs to be formed to discuss issues of mutual concern and develop options for cross-promotion of services, sharing of resources, and educational interventions.

5.6.3 Other initiatives

The issue of the community requiring more assessment services must be addressed. Waitlists for driving assessments hamper personal mobility and increase safety risks if people continue to drive when they are not fit to do so. There needs to be a specialist driver assessment service that collaborates with occupational therapist driving assessors (OTDAs). There needs to be more training of OTDAs and funding provided so that hospitals or clinics could offer driving assessments at a discounted rate.

6 Conclusions and recommendations

The literature review, the review of current information sources and programs and the stakeholder interviews yielded a wealth of information about dementia, its impact on drivers and carers and the services available to help people deal with these impacts. The key findings and recommendations are summarised below.

6.1 Conclusions

- The ageing of the population and the expected increase in the prevalence of dementia mean that it will become an increasingly important public health problem over the next few decades. Services of all types for people with dementia and their carers will need to expand to keep pace with increasing demand.
- In many cases, dementia is not formally diagnosed until the disease is relatively advanced and the abilities of the person are substantially affected. Earlier diagnosis would allow the person diagnosed to participate in the planning of their response to the disease, would facilitate a smoother transition from driver to non-driver and would permit earlier commencement of treatments that may slow the progress of the disease.
- Every driver should take responsibility for their own driving ability and be able to continue to drive for as long as they are safe to do so. However, many people with dementia, especially those in the more advanced stages of the disease, do not understand their condition or its impact on their ability to drive safely, so they cannot be relied on to regulate their own driving. Due to memory problems and lack of self-insight, they may fail to comply with licence conditions that restrict where or when they can drive.
- As the disease progresses, drivers with dementia will eventually need to cease driving and on-road testing is part of the process of determining when that point has been reached.
- The degree of disability suffered by a person varies according to factors including the type of dementia and the stage to which the disease has progressed. As a result, blanket rulings about driving privileges are not appropriate and compulsory retesting of drivers should not occur. Each person's suitability to continue driving must be assessed case-by-case as no current licence screening test can predict subsequent crash involvement.
- The driving ability of people with dementia generally deteriorates over time, so a diagnosis must be reported to VicRoads Medical Review. Depending on the circumstances of the individual driver, periodic on-road test may form part of a reassessment.
- The reassessment guidelines have an exception that relates to driving commercial vehicles. The recently-revised AustRoads guidelines for Assessing Fitness to Drive preclude holding a licence to drive commercial vehicles after a diagnosis of dementia.
- Symptoms may fluctuate in the early stages of dementia, but the condition becomes progressively worse, increasing dependence on carers and public health supports.
- Carers play a major role in supporting drivers with dementia and assisting with the transition from driver to non-driver.
- Carers face various challenges ranging from difficulties asking GPs to intervene, to having to take significant steps to hide keys or remove vehicles to stop affected drivers from driving.
- Doctors and other health professionals play an important role in raising mobility and driving related issues with affected drivers, removing the onus of initiation from the carer and helping to preserve relationships between the carer and the affected driver.

6.2 Recommendations

- Governments at all levels should take steps to raise community awareness of the key messages regarding dementia and driving.
- Information and advice is available to people with dementia and their carers from a range of sources, including telephone help lines, webpages and printed materials. However, people with dementia and their carers are not always aware of what information is available or where it can be obtained. There is a need for a comprehensive guide to available services and information sources that can be provided following the diagnosis of dementia.
- The cost of using alternative transport should not be seen as a barrier to driving cessation. To facilitate the transition to non-driver, people with dementia and their carers need information about the costs of owning and driving a car in comparison with the cost of alternative transport modes to better understand the affordability of options other than driving.
- Ways of reducing the cost of driving assessments by an occupational therapist need to be explored. The State and Commonwealth Governments should ensure that assessment of driving ability by an occupational therapist is financially affordable for drivers who require multiple assessments following a diagnosis of dementia. Subsidised assessments are available through hospitals but the waiting time for these services can be as much as nine months. There is a need for improved access to subsidised assessments, either through increased resourcing of hospital assessment services or provision of subsidies for private assessments.
- The State and Commonwealth Governments should provide increased access to subsidised driver assessment services by providing increased funding for hospital-based assessment services and/or by providing subsidies (such as Medicare rebates) for private assessments that are required by VicRoads Medical Review.
- Governments at all levels should provide expanded and improved transport services for people with dementia, taking into account:
 - a. the inability of people with advanced forms of the disease to use public transport (including taxis) when travelling alone
 - b. expected future increases in demand resulting from the ageing of the population.
- The Victorian Government should expand the Multi-Purpose Taxi Scheme to provide services suited to the needs of people with dementia, taking into account the need of people with advanced dementia to be escorted from door-to-door, not just from kerb-to-kerb. People with advanced dementia cannot use taxis or public transport safely when travelling alone (even using a taxi requires the person to navigate from the vehicle to their intended destination, such as a particular shop or a doctor's room in a hospital), so escorted transport literally from door-to-door is required to enable them to participate in the activities of daily life. There is a need to expand the provision of transport services suitable for people with dementia.

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Please complete your licence and personal details and give this form to your practitioner.
Please print clearly in ink using BLOCK letters.

Licence/Learner permit no.

Licence / Permit type

- ☐ Car/Motorcycle/Light Truck (LR)
☐ Bus/Truck (MR, HR, HC, MC)
☐ Marine
☐ Personal Watercraft Endorsement

Licence/Permit status

- Current
- Applying for
- Variation to

Personal and/or health information that we collect from you in connection with the administration of your driver licence will be used for that purpose and may be used for other purposes permitted by the *Road Safety Act 1986* and the *Marine Safety Act 2010*. Your personal and/or health information may be disclosed to contractors and agents of VicRoads, the Victorian Institute of Forensic Medicine or other body advising on the medical or medical-legal aspects of driver licensing, law enforcement agencies, other road and traffic authorities including the Victorian Taxi Directorate, the Transport Accident Commission, courts and other persons authorised to obtain it such as Transport Safety Victoria. You are required to give this information to VicRoads by the *Road Safety Act 1986*, *Marine Safety Act 2010* and associated regulations. Failure to provide this information may result in your application not being processed or driver licence records not being properly maintained. For further information about our use of your personal and/or health information and your rights of access to it, see VicRoads brochure *Protecting your privacy* or contact VicRoads. For other agencies or persons authorised to obtain your personal and/or health information, you should contact the agency directly for further information about their use and your rights of access to it.

I agree to the practitioner named on this form completing the report and forwarding it to VicRoads and agree to VicRoads' use and disclosure of personal and health information contained in the form in accordance with the above statement. I agree to pay all expenses in connection with this report.

Signed _____

OFFICE USE

Your personal details

Surname

Date of birth

First given name

Second given name

Home address

Postcode

Examination – to be completed by a medical practitioner

You must complete this section

Visual acuity, unaided	R 6/	L 6/	Binocular 6/
Visual acuity, aided	R 6/	L 6/	Binocular 6/

Does the patient have any of the following conditions? Please cross all circles that apply and provide details in *Comments* section.

- ☒ **Cardiovascular problems** Please specify reason
- ☒ **Diabetes – controlled by** ☒ diet ☒ oral ☒ insulin
- ☒ Hypoglycaemic reactions
- ☒ Consciousness impaired or hospitalisation required?
(specify cause of reaction and date of last attack)

- | | | | | | | | |
|----------|---------------------|---|-------|-------|---|---|---|
| Epilepsy | Date of last attack | U | U + M | M + Y | Y | Y | Y |
| | Type of epilepsy | | | | | | |

- Mental/psychiatric disorder (specify disorder)**
Was psychiatric treatment or hospitalisation required?
(specify name of hospital, admission date, discharge date)

- Musculo-skeletal disorders**
Neurological disorders (excluding epilepsy)
Other (e.g. blackouts, cancer, dizziness, HIV/AIDS, metabolic/ endocrine, excessive use of alcohol and drugs, hearing, liver, renal, respiratory, sleep, syncope and/or vestibular disorders)

- | | |
|---|---|
| <input type="checkbox"/> Visual problems | <input type="checkbox"/> Visual field defect (to confrontation) |
| <input type="checkbox"/> The patient has seen a specialist(s) | |
| <input type="checkbox"/> A specialist report is required | Specify |

You must complete this section

- ☒ Yes ☐ No **Driving assessment required to determine fitness to drive**
If Yes, assessment by ☒ VicRoads ☐ Occupational therapist

Please specify reason

- Special conditions/restrictions should apply (please specify)**
Further examinations required
The patient is aware that this form is to be sent to VicRoads
 The patient is aware that if a follow-up medical certificate is required, they are responsible for sending it to VicRoads. *(Applicable to holders and applicants of marine licences or personal watercraft endorsements only.)*

You must complete this section

How long have you known/treated the patient? Years Months

- ☐ Yes ☐ No Do you know the medical history of the patient?

Comments (Please specify medical condition and indicate how the patient's driving ability may be affected by the medical condition. Provide clinical data, final diagnosis and current treatment, including medication and any likely side effects.)

You must complete this section

- | | | |
|--------------------------------------|--------------------------|--|
| <input checked="" type="radio"/> Yes | <input type="radio"/> No | The patient meets the national medical standards to hold a licence/permit to drive a car (includes light truck) or motorcycle. |
| <input checked="" type="radio"/> Yes | <input type="radio"/> No | The patient meets the national medical standards to hold a licence to drive a bus or heavy truck. |
| <input checked="" type="radio"/> Yes | <input type="radio"/> No | In assessing the patient, I am of the opinion the patient is fit to operate a vessel safely. |
| <input checked="" type="radio"/> N/A | | |

Practitioner's details (please use BLOCK letters or official stamp)

Name of practitioner

Address

Postcode

Phone

Qualifications

Signature of practitioner

Date _____

Medical report

Notes	<p>VicRoads has a legal responsibility under section 17 of the <i>Road Safety Act 1986</i> and the <i>Marine Safety Act 2010</i> to ensure that all drivers have the appropriate skills and abilities, and are medically fit to hold a licence. To meet this responsibility, section 27 of the</p>	<p><i>Road Safety Act 1986</i> and the <i>Marine Safety Act 2010</i> gives VicRoads the authority to ask any motor vehicle or marine licence holder or applicant to provide medical evidence of their suitability to drive and/or to undergo a driving assessment.</p>
To the practitioner	<p>The examination must be conducted in accordance with the national medical standards <i>Assessing Fitness to Drive for Commercial and Private Vehicle Drivers 2012</i> available at austroads.com.au</p> <p>This publication provides medical standards for licensing and clinical management guidelines for health professionals in Australia.</p> <p>VicRoads has expert medical advisors who assist in determining fitness to drive when medical conditions are complex. VicRoads Medical Review will be greatly assisted if you provide all relevant details. All information is treated in accordance with the law.</p>	<p>If you have doubts about your patient's suitability to drive, you may like to suggest a driving assessment. This does not apply to marine licence holders.</p> <p>If you have any doubts about the information required, or wish to discuss the case personally, please contact VicRoads Medical Review (vehicles) on 9854 2407 or Transport Safety Victoria (boats) on 1800 223 022.</p> <p>Indemnity – Victorian legislation provides legal indemnity to practitioners who conduct an examination and provide VicRoads with an opinion on the basis of that examination.</p> <p>Criminal liability and insurance – Health professionals may be liable under civil law in cases where a court forms the opinion that they have not taken reasonable steps to ensure that impaired drivers drive only in circumstances that do not place them and other members of the community at increased risk. Professional indemnity insurers are aware of the potential liability of health professionals and may reasonably expect health professionals to comply with the national medical standards.</p>
To the applicant	<p>You must make an appointment with your practitioner. As the examination and completion of this report may take longer than a routine consultation, you are advised to inform your doctor (or the receptionist) that you are attending for this purpose.</p> <p>You should make the doctor aware of any medical conditions you may have. If the medical report has been requested for a particular reason, you should let your practitioner know this reason.</p> <p>You are required by law to advise VicRoads of any serious or chronic medical condition or disability that may affect your ability to drive. If you provide this information, your doctor can advise VicRoads, on your behalf, using this form.</p> <p>You should take any corrective lenses and hearing aids that you normally use, to the examination.</p>	<p>You should let your doctor know if you hold or are applying for a heavy vehicle licence, as the medical requirements for drivers of such vehicles are stricter. If you are required to provide a medical report to other agencies it is in your interest to keep a copy of this report.</p> <p>Withdrawal of licence – If VicRoads takes away your licence on the basis of a medical report, you may be relicensed when you provide medical evidence which indicates that you have met the national medical standards and are qualified to be relicensed. You also have the right of appeal to a Magistrates' Court.</p>
VicRoads driving assessment (Not applicable to marine licences)	<p>Where there is a concern about a person's ability to drive safely, a driving test is necessary.</p> <p>When retesting current licence holders the on-road test may commence from the person's home, ensuring that the customer is tested in a familiar area and allowing a local area restriction to be imposed if appropriate.</p>	<p>The on-road assessment is conducted in a vehicle with dual controls fitted with automatic transmission. Customers are allowed time to become familiar with the vehicle. The licence may be immediately suspended if the test is failed.</p>
Occupational therapy driving assessment (Not applicable to marine licences)	<p>Victorian law gives specially trained occupational therapists the right to conduct a driver assessment where there is a medical concern about the customer's ability to drive safely. The aim of the occupational therapy assessment is to assist people with impairments to resume or continue driving. There are two components of the assessment. The off-road assessment aims to evaluate the person's fitness. This involves an interview, vision screen, cognitive function test, assessment of physical strength, motor skills, reaction time, road law and road craft. The need for specialist equipment or vehicle modifications is considered at this time.</p>	<p>The on-road test takes a standard approach but can be designed to meet individual needs. It is conducted in a vehicle with dual controls accompanied by a driving instructor and where necessary set up with special requirements or modifications to meet the needs of the customer. The test is structured to assess the impact of injury, illness or the ageing process on driving skills such as judgement, decision making skills, observation and vehicle handling.</p>
Conditions and restrictions	<p>If appropriate, the customer's medical practitioner may make recommendations to VicRoads, allowing the customer to continue driving on a conditional licence (e.g. no night driving).</p> <p>An occupational therapist after completing a driving assessment may also make recommendations to VicRoads. The final decision is made by VicRoads.</p>	<p>If the practitioner believes that vehicle modifications are necessary (e.g. hand controls, left foot accelerator), or a prosthesis is necessary to drive safely, or that a local area driving restriction is appropriate, the customer will need to demonstrate the ability to drive safely with these restrictions. In these cases a driving assessment is necessary.</p>

Post: VicRoads Medical Review, GPO Box 2504, Kew, Victoria, 3101 Call: 13 11 71 (TTY 13 36 77, Speak and Listen 1300 555 727) Web: vicroads.vic.gov.au

B Appendix B

Additional resources on dementia

Current information sources of information about dementia and its impacts on driving and mobility were described in Section 3. This appendix lists some additional sources of information about dementia not specifically related to driving or mobility. These resources are likely to be of considerable interest to drivers with dementia and to those caring for drivers with dementia.

B.1 Victoria and Australia

B.1.1 About dementia

People with dementia and their carers can join the Alzheimer's Australia library to gain access to a variety of resources, including books, journals, DVDs/videos, computers and photocopiers (Alzheimer's Australia n.d.a). There is a general helpline that provides information about dementia and relevant services and offers understanding and support for people with dementia, their family and carers.

Information is available from the Alzheimer's Australia website, including help sheets that define dementia and the different types of the condition (Alzheimer's Australia, n.d.b). They also provide information about the diagnosis process, early planning, memory changes, progression, drug treatments, and heredity. Finally, there is information for family and friends about people with dementia.

The DOHA provides a dementia resource guide, both online and in hard-copy format. The guide discusses dementia symptoms, common comorbidities, different types of dementia, and prevention and risk reduction. There is information on assessment and diagnosis, medical treatment options, forward planning, behavioural and psychological symptoms of dementia, quality of life, quality care, social and emotional issues, community groups, support services, government policy, training for carers and health professionals, audio-visual resources and further information and links (Department of Health and Ageing, 2010).

B.1.2 Support services

The Better Health Channel offers a factsheet with information on some of the support services available to people with dementia and their carers and how to access these services (Better Health Channel, 2012). The factsheet lists where to find information post-diagnosis and details some of the services offered by Alzheimer's Australia, such as support groups and the counselling service. The factsheet also discusses some helpful health and home-support services, including respite care. It also provides contact numbers for other sources of help.

Several Victorian based support programs are run by Alzheimer's Australia (shown in Table B.1 overleaf), with similar programs run in other States and Territories (Alzheimer's Australia, n.d.c). Support programs for families and carers provide detailed online information across topics including coping with behaviour changes, preparing the home, personal care, residential care and taking care of oneself; however, none of the modules specifically addresses transport issues (Alzheimer's Australia, n.d.d).

In Victoria, DBMAS operates under the auspice of St Vincent's Health, Melbourne Aged Psychiatry Services (Dementia Behaviour Management Advisory Service, n.d.). It provides services to care workers, aged care service providers and carers of people with dementia who receive support through Australian Government funded aged care services. DBMAS supports people with diverse needs, such as those who need language translation and interpreting, those with atypical dementia or younger onset dementia and those with both learning disabilities and dementia. DBMAS services are focused on the management of behavioural and psychological symptoms of dementia.

Table B.1

Victorian support programs and services run by Alzheimer's Australia

Program Name	Details
Living with Memory Loss Program	A group program delivered by two counsellors over 6 weeks. The program is for people with early-stage dementia and family members and provides information, practical advice, emotional support, peer support and shared experiences.
Support Groups for Carers	Support groups meet regularly and offer people a way of sharing experiences. They support each other in working towards overcoming the challenges they face as carers.
Counselling	Available to carers, families, people with dementia and professional staff.
Telephone Service on Dementia Behaviour Management	A specialist 24-hour phone service that provides advice about managing behaviours of concern in people with dementia. This includes assessment of the person with dementia; clinical support; information and advice (can be face-to-face, phone or email); care planning; case conferences and case management; mentoring and clinical supervision; and education and training for carer providers.
Memory Lane Café	Provides an opportunity for people with dementia and the family to enjoy time together with refreshments and entertainment in the company of others in the same situation as themselves.
Safe2Walk	A GPS-based personal alert and location service. It provides increased independence for people living with dementia and peace of mind to family and carers. The map shows the location of the person with dementia. There is a small, all-inclusive monthly rental fee.
Telephone Outreach Program	Provides regular support to people with dementia, their families and carers through a fortnightly or monthly telephone call by trained advisors. Particularly helpful for people in rural and remote areas.
Telesupport Program	A group telephone program for people caring for a family member or friend with dementia. There are six to eight people in a group and participants are able to discuss experiences and challenges.

The Commonwealth Respite and Carelink Centre is a community program of the Ageing and Aged Care Division of the DOHA (Community Programs Branch, 2009). This information service provides centres for older people, people with disabilities and for those who provide care and services. Information is available for people wanting to learn about the types of assistance, accommodation and services available in their community, and is available in 17 languages other than English. There are also resources for indigenous Australians and vision-impaired clients. Contact with centres is made via a free-call telephone number or walk-in shopfront. The website references the National Respite for Carers Program, which supports carers of older people and those with disabilities to take time from their caring roles; and also the National Carers Counselling Program, where carers have access to short-term professional counselling and assistance.

B.1.3 Workshops

Alzheimer's Australia offers a range of workshops and courses for people with dementia and their families and carers, as outlined in Table B.2 (Alzheimer's Australia, n.d.e). A range of workshops for health professionals are also offered, with accredited programs on dementia care, support planning, palliative care, rehabilitation therapies, spaced retrieval technique (an exercise designed to improve memory in people with cognitive impairment) and a Certificate IV in Dementia Practice (Alzheimer's Australia, n.d.f). There are over twelve dementia care specific courses offered, as well as an advanced course on dementia education for care managers. There are eleven courses for health professionals on leisure and lifestyle programs and activities, plus other free seminars, workplace education programs and access to specialist speakers.

The DOHA provides information for people receiving general community care, information on workshops for dementia care workers and information on day therapy centres (Department of Health and Ageing, 2011).

B.2 Rest of the world

B.2.1 About dementia

The UK National Health Service (NHS) is reported to be the world's largest publicly funded health service (National Health Service, 2011). NHS Choices is the online service, the UK's biggest health website. Its webpage on dementia provides information about the condition and the different types, and provides links to other key websites such as the Alzheimer's Society in the UK. There is also a page on living with dementia which discusses practical tips, self-care, staying independent, living at home, keeping active, social life, driving, sleeping well, feeling down, work, relationships, care at home, support for carers, and palliative care. The information on driving is brief, suggesting people contact the licensing authority to notify them of any diagnosis, and refers readers to information about driving and dementia on the Alzheimer's Society's website (NHS Choices, n.d.).

B.2.2 For carers

AlzOnline is an online resource sponsored by the State of Florida Department of Elder Affairs and the University of Florida. It is aimed at caregivers of persons with Alzheimer's and other memory problems. The website provides online classes on care-giving basics; care-giving challenges; managing the carer's wellbeing; daily activities and skill building; learning about memory problems and dementia; and safety and injury prevention in care-giving (AlzOnline, 2008). The site also provides a link to the American Alzheimer's Association chat room and also offers links to a variety of its literature resources.

The Johnson & Johnson StrengthForCaring.com website provides caregivers with information, an online community, daily inspiration and support. Johnson & Johnson's Patient Assistance Foundation launched a free software application on iTunes for the iPhone or iPod touch that provides a care planner where information on insurance, health-care providers, and emergency contacts may be stored (Johnson & Johnson Patient Assistance Foundation, 2009). The application includes a prescription icon that links to the patient's prescription history and lists the upcoming prescriptions or treatments for the day, week and month. There is also a journal where caregivers can add notes or photographs related to the care of their loved ones.

Table B.2

Workshops and courses offered in Victoria by Alzheimer's Australia

Program Name	Details
Introduction to dementia and services – a good place to start	For family and friends of a person diagnosed with dementia and for the person diagnosed. Provides an introduction to dementia, causes, symptoms, typical changes that may occur and support services.
Effective communication	For family and friends of a person diagnosed with dementia who already have some understanding of dementia. This focuses on how dementia changes communication, possible alternate communication strategies, dealing with over-reactions of a person with dementia and how to support the person who is distressed.
Mild cognitive impairment – what this diagnosis means for you	For people who have been diagnosed with Mild Cognitive Impairment (MCI) and their families. Discusses differences between normal ageing, MCI and dementia. Identifies some of the cognitive difficulties experienced by people with MCI. Helps participants to understand the possible causes of MCI and the changes in brain function that can be experienced; be more aware of current thinking about MCI diagnosis, progression and treatment; and be better prepared to deal with the impact of MCI.
The caring role – a compassionate approach	For family carers who are ready to reflect on their new role and relationship with their loved one with dementia and who can participate in a longer (4 week) group program. The program includes information about dementia, changes and communication. It also incorporates the loss and grief associated with becoming a carer of a loved one with dementia; how to create an environment to facilitate the caring role; and maintaining and getting support as a carer.
Coping with carer stress	For carers to learn strategies to improve their well-being. These sessions provide participants with the opportunity to meet other carers in a similar situation to themselves and to learn new skills to better manage the emotional demands of being a carer.
Considering residential care	For family carers at the point of considering the option of residential care for their loved one with dementia. This program considers the issues related to residential care, as well as the barriers to making the decision. Information is provided about the types of residential care, the residential care system, including different types of care available and costs, and the key features of a good facility. Important legal issues are also outlined. The emotional issues regarding the placement of a loved one in residential care are also discussed.

C Appendix C

Stakeholder interview responses

Currently available sources of information about dementia as it impacts driving and mobility were described in Section 3. This appendix lists some additional sources of information about dementia not specifically related to driving or mobility. These resources are likely to be of considerable interest to drivers with dementia and to those caring for drivers with dementia.

C.1 The experience of dementia and the needs of those affected

Q1. What problems do drivers with dementia experience when driving?

- Cognitive impairments:
 - Memory loss (impaired ability to recognise places and recall things, including words).
 - Impaired judgement (space, speed), poor handling of car in complex situation, poor navigational skills, poor problem solving, decision making.
 - Misinterpreting signals.
 - Attentional deficits.
- Elevated aggression/ anger/irritability.
- Lack of self-insight.
- Confusion.
- (Physical) motor coordination.
- It can be difficult to know which symptoms form part of ageing and which dementia is responsible for.
- Vision.
- Near misses and small incidents due to cognitive impairments.

Q2. Can any of these problems be overcome, such as by restricting driving to local areas or daylight conditions or using vehicle-based aids, or is complete cessation of driving usually required?

- Complete cessation is eventually required, but should be determined on an individual-case basis.
- De-licensing should be a gradual process. This would help families. However this is difficult to achieve because early diagnosis is rare and because people don't tend to practice using alternative transport when they still can drive. Alternative transport options may also be limited, acting as a barrier to driving cessation.
- Driving refresher lessons may provide some assistance in the early stages.

Licence restrictions:

YES/PERHAPS

- Local area driving.
- Might help when driving problems relate only to memory - not later when perceptual and praxis issues develop/ need to be able to self-monitor.
- Can be effective at helping to strike balance between an individual's need for independence and mobility, and the community's need for safety.
- Not sure about compliance though (especially in consideration of memory impairment).
- Avoiding night-time driving.
- Avoiding complex traffic situations.
- Can be unnecessary because some older drivers with dementia will self-restrict after a scare in the car.

- Some types of dementia (e.g. Lewy body disease) result in patient feeling fine in the morning but tired and not able to drive in afternoon.
- Perhaps in the early stages licence restrictions to local routes, but a licence is a legal document that says to VicRoads that they can cope with hazards, altered traffic conditions etc.

NO

- Not much use/licence restrictions should not be accommodated/ better to stick to a 'pass' or 'fail' approach.

Vehicle-based aids:

YES/PERHAPS

- Could help to enforce licence restrictions, e.g. technology could be designed to monitor and assist with compliance. But older people tend to have older cars.
- Should be considered on a case-by-case basis.

NO

- GPS systems are not helpful. They're too distracting or difficult to use and often make people feel more in adequate. GPS could lead people to believe they have a false sense of capacity. Combined with impaired judgement, the outcome could be worse (less helpful than otherwise).
- Not enough research to support use of aids.
- Co-piloting is not appropriate.
- Aids could be difficult for people with dementia because they have trouble learning how to do/use new things.

Q3. At what stage in the progression of the disease should drivers with dementia

(A) Have their driving skills assessed?

(B) Stop driving for safety reasons?

- At the point of diagnosis (need this for car insurance anyway).
- There are so many variables (e.g. age, type of dementia, rate of progression, medications, how stable person is, comorbidities, ability to judge, previous driving style, nature of driving, nature of cognitive profile and the changes that are occurring). Needs to be on a case-by-case basis.
- When families report the need or when poor driving is observed.
- If there's been frequent occasions of getting lost, or more than one bingle per 12 month period, or a high number of near misses.
- Family need to help make this decision.
- Some patients have a fright when driving and self-restrict.
- When frontal or visuo-spatial problems are identified. It may be possible to determine a cut-off point on a neuropsychological assessment, but it's difficult because the condition fluctuates and there may not be a single event that highlights the need for an assessment.
- Having crashes as a result of reduced skill/reflexes or because of confusion, such as hitting the accelerator instead of the brake.
- Could refer to the Clinical Dementia Rating scale (www.neurology.org/cgi/reprint/54/12/2205 and can see third reference Morris), where a rating of between 0 and 1 represents the same risk on road as legal intoxication level, but 1 or above means crash risk is too high to keep driving.
- Making the decision is especially difficult when it's a younger patient.

Q4. (A) Can drivers with dementia recognise when it is time to modify/ stop driving? If so, what are the signs they need to recognise?

- Depends on the type of dementia and degree of impairment. A diagnosis can help with recognition. Signs: getting lost, near misses, forgetting how dints/scrapes got onto car, having crashes.

- People with dementia usually lack insight and have no idea their skills aren't as good as they were. They get angry and upset because they can't believe you're saying that they're doing something wrong behind wheel – they feel there is no way that what you're saying could be true.

(B) How can carers, family and friends recognise when it is time for a person with dementia to stop driving?

- When passengers feel unsafe in a car with affected person driving. Family/friends tend to recognise earlier than person with dementia. It is burdensome for them, especially if it is in their interests to lie about the condition because lying is burdensome.
- Signs: altered emotional state in general – impulsivity, aggression, lowered patience; road rage; different personality; trips taking far too long (person gone for long time without a sensible explanation); difficulty concentrating.
- Assessment process can be useful for decision making.

Q5. (A) How should carers and health professionals manage a person with dementia who needs to cease driving?

- Health professionals should listen to the patient's family members, because if family are alarmed then this is significant. Then systems need to be put in place to help the family with next steps, and give them someone to talk to.
- Health professionals could use a questionnaire in conjunction with other measures like neuropsychological tests, rather than relying just on the results of one test. Have a question or section for family/friends to complete so they can describe what concerns them. Health professionals could take on the responsibility of being the one to say that they can't drive any longer, or to put restrictions in place. This is too difficult for family to take on.
- Health professionals should know how to help the patient gain as much support as possible, including access to services and funding. For example, what they should say to describe the situation when the patient is feeling at their worst (rather than at their best), as this helps to gain more support.
- General practitioners are a reasonable place to start, but they often don't get exposure to the full impact of the cognitive decline, or they may be elderly themselves and not acknowledging the difference between typical memory decline and cognitive impairment. Carers should provide input but general practitioners need to understand that family situations differ and some family members will not want to say things that 'dob' the patient in.
- Health professionals should acknowledge the patient's rights.
- Provide resources that contain important information, including positive talk around alternative transport options and information for family/friends/carers.
- It would be good to have screening tools to help health professionals, especially where there are medications or multiple medical conditions present.
- Health professionals need to understand how difficult it is to give up driving as a result of dementia. When possible, they should cite physical impairments (comorbid conditions) as the reason for driving reduction or cessation, because this is more acceptable to people than cognitive decline.
- Health professionals could talk about legal obligations in terms of duty of disclosure and what would happen if the patient killed someone on the road. Hitting the 'hip-pocket' nerve is usually very persuasive.

(B) What if the driver has multiple medical conditions: what impact does this have on management?

- Multiple medical conditions can help management because you can blame another condition as the reason to reduce or cease driving. Physical impairments don't carry the same level of negative stigma as mental ones such as dementia.
- It can compound the issues to assess because the more conditions mean there is more to review regarding fitness to drive.

C.2 Information and services

Q6. What information or services would help drivers with dementia and their carers to recognise when the driver should be professionally assessed or stop driving

(A) Would a telephone hotline service be useful? Should it be aimed at patients or carers and family members?

YES

- If it's for carers/ most calls would come from carers [3/9].
- Anonymity helpful (people can be scared to go to general practitioner) [2/9].
- Good for initial information gathering, driving assessment referral options, medical advice [1/9].
- Useful for drivers and carers [1/9].
- If there was a new one, existing services would need to collaborate and places like VicRoads, RACV, Carelink would all need to reference the new hotlink and advertise consistent messages [1/9].
- Need to have someone suitably qualified to respond. To be useful for patients they need to be able to describe their wellbeing clearly and accurately. A hotline may be more useful for 3rd parties such as carers [1/9].

NO

- We don't need another one/ existing services could be improved and better promoted [3/9].
- Face-to-face interaction may be more effective for discussions with patients, but then it depends on who is calling and their reason for the call [2/9].
- Not for person with dementia [1/9].
- Very few people with dementia can self-educate. Written information sources need to be careful because you have nervous people who read things and stop driving when they don't necessarily need to; and macho people who don't read things and keep driving when they should stop [1/9].

(B) Would information on a website be useful? Should it be aimed at patients or carers and family members?

YES

- Would be mostly used by carers [4/9]
- Website should address issues for both patients and carers, including tips for carers and what they should do if the person with dementia is denying or unaware of their problems [2/9].
- More older people are using online resources [1/9].

NOT SURE

- Usefulness depends on patients' insight [1/9].
- Older people may not be on web [1/9].

NO

- VicRoads already have a website with information for dealing with various situations. It's called 'Family and Friends of Older or At Risk Drivers'. This was launched with Vic Police in October, 2011. Build on and promote existing resources [1/9].

(D) Would any other services or information be useful? If so, what?

YES

- Educational sessions especially for carers [4/9].
- Radio segments/advertisements [2/9].
- 'My forum' website, self-help groups [2/9].
- Need more community support for patients to access supported transport options, as ½ price taxis are very difficult to meet eligibility criteria for. Especially need support (e.g. volunteer drivers) in rural areas [2/9].
- Note that educational workshops for care support groups are already run by Carers Vic.
- A service to up-skill people to use public transport or look for other transport options (for people in the early stages) [1/9].
- Could get counsellors in to assist patients around time of first finding out/diagnosis [1/9].
- A case-detection system that signals the need for a licence assessment. For example, family members' comments or PDO crash history act as triggers. Surveillance should increase and licences renewed for shorter (than 10 year) periods [1/9].
- A specific organisation to support them [1/9].

(E) Or is a screening test administered by a health professional the only worthwhile decision aid?

YES

- A maze test is used to identify cognitive decline. Screening tests may need more promotion by GPs [1/9].

NOT SURE

- Unsure how doctors use screening tests [1/9].

NO

- Screening test should only form part of the decision-making process – need to take a case-by-case assessment approach [6/9].
- Really need increased community awareness to help with early diagnosis [1/9].
- Encourage older persons to go in person for licence renewals and tests, as this is more likely to yield true results. Can more easily justify licence changes on basis of vision impairments detected. In-person helps to identify individuals with dementia because they have to interact with staff. Alternative is family member renewing licence online for them at home and it doesn't get picked up. There is US research to support this [1/9].
- TRAILS-B is a better neuropsychological test, but cultural bias is an issue as some cultures aren't exposed to maze tests. On-road driving assessments are still the gold standard as there's not strong evidence regarding predictive value of existing screening tests [1/9].

Q7. What services do drivers with dementia and carers need to help them cope with driving reduction and cessation (e.g. info about alternate transport, advice on how to remove or disable the patient's car, legislative support for removing the patient's car)?

- A better legislative framework, legal advice and more support to help family/friends 'take the keys away'. Need a concrete process with all of the steps explained logically. Carers need to understand legal provisions and power of attorney but carers should only take control when it is warranted and there needs to be safeguards in place to avoid potential abuse. There needs to be individual case assessments to protect people.
- Support for carers so they have others (e.g., health professionals) communicating the same message to person with dementia, but support probably shouldn't go as far as legislating.
- Case management support to help patients and carers deal with the major life transitions experienced.
- Improved access to taxis and community transport, especially in rural areas. The taxi scheme eligibility criteria should be expanded.
- Information that outlines cost-benefit ratios of using alternative transport compared to a private car. This points out the benefits of saving on having a private car and also that taxis are not as expensive to use as people often assume.
- A program that teaches older people to use public transport. They can build confidence and learn about how to keep mobile using public transport when they are still healthy, so it's not as difficult a transition when they can't drive due to a health impediment.
- Information about what alternative transport options there are and how to access and use them.
- Acknowledging how important transportation is as it underpins older people's participation in many activities and in daily living.
- Tips sheet e.g. some taxi drivers really dislike people doing short trips. But if you organise the same taxi driver to do the drivers regularly, the driver doesn't mind as much because it's a regular gig every week. It's also a way to build rapport and older people may feel more comfortable with a driver they are familiar with. Advice about home delivery would also be useful.
- Information about moving home from a rural to city location.
- A common link/resource house e.g. all local councils.
- Clear information so that people know that their car insurance is void and they may be breaking the law if they are driving with a condition that they do not report.

Individual level (knowledge, attitude, behaviours, skills):

- A challenge is the way that the condition is so variable, as driving skills and competencies are equally as variable.
- That it's a sensitive issue and some people don't want to revisit things like driving assessments each 6 months.
- Follow-up post assessment and licence removal support is lacking – community health centre social workers don't have time.
- Having the driver assessment forms filled out correctly so that the right instructor is paired with the right driver.
- Situations where an individual doesn't have a regular carer.

Family/carer level (knowledge, resources, support):

- Carers facing that a driver may lose their independence is very difficult for them. It also means they may have to take on the responsibility of transporting the patient everywhere.
- Drivers with dementia who shouldn't be driving but keep driving are very vulnerable, especially in instances of road rage.
- If a carer reports someone to VicRoads they never receive any feedback because of privacy laws (unless they have power of attorney).

Systems level (policies, licensing, funding):

- There used to be a ten year plan for senior Victorians (got scrapped with new government). The current government is conducting an enquiry into the participation of senior Victorians in the community.
- Improve the multi-purpose taxi scheme (it must support people with cognitive impairments just as it does physical disabilities). The scheme still needs to be monitored – everyone old can have a little dementia – so need to protect against it being abused, e.g., make an annual-dollar commitment.
- More accessible public transport options.
- Less inconsistency with community transport (all councils to offer a community bus).
- Improved information resources, including individual legal obligations and issues.
- Make resources more widely available (such as the VicRoads Older Driver Handbook).
- Need more community awareness.
- Funding for driving assessments, so that people don't have to give up driving due to the cost of having to self-fund assessments so frequently.
- Provide a companion card so that carers can use services free or at a heavily discounted rate.
- Increased number of services to deal with increased projection of diagnoses.
- The VicRoads medical review process is too bureaucratic and time-consuming. It needs to be revised.
- Review Privacy Act so that carers can be given feedback.

Q9. Does your organisation have any current programs/ resources for individuals with dementia, their carers or for health professionals working with patients with dementia?

Programs/ Resources	Organisation (excluding Alzheimer's Australia)
Diagnostic	Caulfield CDAMS, Eastern Health, Austin Repat
Internal staff training	Austin Repat
Training for (external) health professionals	VicRoads 'SafeDrive Medical Program for Health Professionals'
Driver assessment	Austin Repat, Eastern Health, Caulfield CDAMS, VIFM via St Vincent's Hospital
General advice – not dementia specific	DMA
None	Carers Vic, COTA

Alzheimer's Australia

Programs/ Resources

Living with Memory Loss program (Vic)	A group program delivered by two counsellors for 6 weeks. The program is for people with early-stage dementia and family members.
Support groups for carers (Vic)	Support groups meet regularly and offer people a way of sharing experiences. They support each other in working towards overcoming the challenges they face as carers.
Counselling	Available to carers, families, people with dementia and professional staff.
Telephone service on dementia behaviour management (Vic)	A specialist 24-hour phone service that provides advice about managing behaviours of concern in people with dementia. This includes assessment of the person with dementia; clinical support, information and advice (can be face-to-face, phone or email), care planning, case conferences and case management; mentoring and clinical supervision; and education and training for carer providers.
Information about dementia	It is possible to join the Alzheimer's library and gain access to a variety of resources including books, journals, DVDs/videos, computer access, photocopiers. There is also a general helpline that provides information about dementia, information on services, and offers understanding and support for people with dementia, their family and carers.
Memory Lane Café (Vic)	Provides an opportunity for people with dementia and their family to enjoy time together with refreshments and entertainment, in the company of others in the same situation as themselves.
Safe2Walk (Vic)	A GPS-based personal alert and location service. It provides increased independence for people living with dementia and peace of mind to family and carers. You simply log on to the site to find where the person with dementia is. There is a small, all inclusive monthly rental fee. There is also a general helpline that provides information about dementia, information on services, and offers understanding and support for people with dementia, their family and carers.
Telephone outreach program (Vic)	Provides regular support through a fortnightly or monthly telephone call by trained advisors, to people with dementia, their families and carers. Particularly helpful for people in rural/remote areas.

Q10. Do you have any joint programs with other agencies that cater to the needs of this driver group?

Q11. Are you aware of any programs/messages from your own/other agencies (in Australia or elsewhere) that are considered to be effective? What are they? Where can we get information?

- COTA is working with Victorian Human Rights and Equal Opportunity commission on issues relating to ageing and driving, e.g., discrimination and stereotyping of older people. Outcomes of this should be in the public domain in the next month or so.
- Caulfield CDAMS offer people VicRoads brochures. Also mentioned C_Drive in QLD (about relinquishing driving), RACV's Years Ahead and TAC's Community Mobility programs.
- DMA suggested there are some good assessment policies and tools, and licensing schemes for drivers with disabilities. It heard of a program in Northern Europe or Dubai where they use driving simulators as diagnostic assessment tools for drivers. Also mentioned use of newer technologies such as vehicle control systems that act to improve safety performance.
- Not sure about effectiveness but it may be worth looking into the Wiser Driver book or Safe Driver Program by VicRoads.
- Evaluations could be difficult regarding before/after criteria, because breaches are a police matter.

C.3: The gaps in existing information and/or services

Q12. Does your organisation have any goals/plans for future programs/resources to address needs for this group?

- DMA is looking for funding for a diagnostic simulator to be used to assessment purposes. It would demonstrate to driver whether or not they can manage driving requirements, or if they need training. It's helpful to pinpoint specific deficits.
- Not really, because it depends on funding or political outcome.
- Carers Vic was involved in developing Home And Community Care (HACC) Assessment Services (Department of Health). It's a local government community care initiative that involved a reference group on dementia pathways, including dementia and driving. It's almost finished. It will end up on Department of Health website, though the intention is it's targeted towards HACC Assessment Services.
- Continuing existing research efforts and there may be a role to expand existing clinics. Currently can't keep up with demand.

Q13. Are there any information or service gaps now or in the foreseeable future?

- Need alternative transport, especially in rural areas and greater promotion of public transport [4/9].
- Improved community awareness and broader education [3/9].
- Access to discounted taxi scheme [3/9].
- More funding to improve the assessment and process [2/9].
- Need a clear message about where to access information and what to expect/know about the process e.g. duty of disclosure. There needs to be one resource to collate everything and provide links to other resources [2/9].
- Need to offer case management services [2/9].
- Greater funding support for rural/remote residents [2/9].
- Post-driving cessation support (follow-up) [1/9].
- Assessment tools for foot and lower limb coordination assessment [1/9].
- Appropriately experienced instructors with cars that support modifications [1/9].
- An effective test battery (neuropsychological test) that could more accurately and effectively help with understanding driving skills and on-road competency [1/9].
- A more accurate way of assessing a driver's skills [1/9].

- More support/education for general practitioners as it doesn't often deal with fitness to drive issues. The ageing population will see even more of a need for specialist skills in health professionals in this area [1/9].
- Eastern Health is collaborating with various others on a research project called Aus Can Drive, funded by the Australian Research Council. It involves following older drivers to better understand the problems they face.
- The RACV Sir Edmund Herring Memorial Scholarship offers some assistance re addressing gaps [1/9].

Q14. How could road authorities assist? For example, through:

- **education (of the driver/carer/public /health professionals)**
- **monitoring (the driver)**
- **decision making (to modify/stop driving)**
- **providing alternate transport; or**
- **bringing goods/services/activities to the patient?**
- Providing alternative transport.
- VicRoads could promote its role as a support service more. Currently it is seen as a place to get something done about a licence or car. It needs to be more service oriented and could be more proactive.
- Promote existing information and education services e.g. VicRoads could promote the Dementia hot line and Carers Victoria.
- VicRoads could do more to alert families to medical problems, changes and implications, or look to increase loss of points after a diagnosis.
- VicRoads could support more regular medical checks.
- Monitoring 'at risk' drivers.
- Join the 'Australian Disability Parking Scheme', a national harmonised parking scheme for people with disabilities that encourages consistent eligibility criteria and minimum parking concessions.
- Support more research by providing funding to specialist researchers.
- Review the use and reliance on the Useful Field Of View test of eye and brain function – it's not an accurate tool.
- More advertising to existing services to address common issues.
- VicRoads should not have a role in monitoring the driver, this is for health professionals.
- Consult with health professionals when making decisions.

Q15. How could local governments (e.g., councils, safety groups) assist? For example through:

- **education (of the driver/ carer/ public /health professionals)**
- **monitoring (the driver)**
- **decision making (to modify/ stop driving)**
- **providing alternate transport; or**
- **bringing goods/ services/ activities to the patient?**
- Providing more community support services or coordinating volunteer programs, especially in rural areas where transport needs to get to farms and take people into townships, or deliver goods/services to farms. There's also social contact that people in rural areas need support to access [8/9].
- Alternative transport [7/9].
- More funding or more staff to decrease driving assessment waiting lists [2/9].
- Safety measures so that people feel safe using public transport [2/9].
- Work with taxi companies regarding subsidy schemes [1/9].

- Access to disabled stickers for carer drivers [1/9].
- More consistency between councils in terms of what services are provided [1/9].
- Raising community awareness [1/9].
- Councils could organise for information to go in pharmacies [1/9].
- Support in-home services [1/9].
- Better address pedestrian environments, tram stops, bus shelters and footpaths [1/9].
- Less confusing street signs, better engineered car parks and roads, less visually confusing environments, more clearly marked speed restrictions especially where there is a high risk of pedestrian-to-car contact [1/9].
- Consult with health professionals when making decisions or councils should not be involved in making them at all – it's not good to have too many decision makers [1/9].
- Special training for driving assessors so that they are sensitive to the individual's situation and deal with older drivers with dementia more appropriately [1/9].
- Local councils should not be involved in monitoring/decision making because there would be too many people involved in the process [1/9].

Q16. How could State or Federal government departments (e.g., Department of Human Services, Department of Health and Ageing) assist? For example, through:

- **education (of the driver/ carer/ public / health professionals)**
- **monitoring (the driver)**
- **decision making (to modify/ stop driving)**
- **providing alternate transport; or**
- **bringing goods/ services/ activities to the patient?**
- Specialist training and education programs for health professionals and driving assessors.
- Policies that promote community awareness and road safety for all older drivers (as the years before a diagnosis of dementia are just as important but require a different focus).
- More funding to decrease driving assessment waiting lists and private expense to individuals.
- HACC funding for transport, especially medical transport.
- Clarify AustRoads guidelines on driving and dementia.
- Promote national consistency of schemes, policy, education.
- Planning communities for public transport access and use.
- Funding to bring goods/services to individuals.
- Supporting people who have ceased driving.
- Replace age-based testing in some states with problem-driver management systems and processes.
- Engage with politicians on all of this.
- Services/support to help people maintain quality of life. Degradation can increase if social life and mobility is poor.
- It currently provides a service for carers called CareLink.

Q17. What initiatives or changes do you believe should be a priority to stakeholder groups?

- Education and community awareness [7/9].
- Alternative transport options [4/9].
- Improved community transport options [2/9].
- Improving information products and better resourcing existing services [2/9].
- Increased funding for screening and assessment [2/9].
- Improved and focused data collection so that we know more about the involvement in crashes of people with medical conditions. Research needs to be about the medical condition rather than the individual's age [1/9].
- A fair approach: while driving is a privilege (and not a right), heavy-handedness or age-related restrictions are not fair [1/9].
- Address discrimination [1/9].
- Increased funding for research [1/9].
- Post-driving cessation support [1/9].
- Diagnostic services [1/9].
- Not emphasising age-based testing [1/9].
- Planning ahead and resources/anticipate changes that will come with an ageing population [1/9].
- Well-lit train stations, maintained footpaths. [1/9].
- Social support [1/9].
- A shift in thinking about licences as a privilege [1/9].

Q18. Would your organisation partner with relevant others to support initiatives of mutual interest?

YES

Q19. Can you suggest any key organisations or program managers we should speak with about dementia and older drivers?

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