

Mobility issues for drivers with dementia

Bradshaw^a, C.L., Di Stefano^b, M., & Catchpole^a, J.

^a ARRB Group, Vermont South, Vic, ^b La Trobe University, Bundoora, Vic

Abstract

The Royal Automobile Club of Victoria (RACV) identified that increasing numbers of older people with dementia need to be considered within transportation and licencing systems. RACV commissioned ARRB Group (ARRB) to investigate issues affecting drivers with dementia. A literature review was conducted to investigate the different types of dementia; road safety issues; the rate of progression of cognitive decline; and health professional and carer roles when supporting drivers with dementia. An evaluation of current information resources, services and programs was also completed. Interviews with key stakeholders in health, research and advocacy were undertaken, to seek expert opinions on the challenges related to safe driving. Dementia can present with varying types of cognitive impairment and individuals differ in how they experience the effects of the disease. Cognitive impairments become more severe over time, with the eventual need for all drivers with dementia to cease driving. Driver assessments and licence restrictions may be helpful for some individuals during the early stages of the disease. A number of gaps exist between the needs of people with dementia and their carers, and available community resources and services. This research highlighted the need for (a) more community and health professional education regarding road safety risks, driver assessment and licensing options (b) better integration of services, and (c) discussion of licensing and safety issues earlier in the disease process. The challenge of gradually phasing drivers with dementia to alternative and less 'independent' forms of mobility is also presented.

Introduction

From 1990 to 2010, the proportion of the Australian population aged 85 years or more doubled (from 0.9% in 1990 to 1.8% in 2010), and the proportion of people aged 65 years or over rose to 13.6% (from 11.1% in 1990). With a larger proportion of older individuals in the population, frequencies of age-associated diagnoses of disease and/or health disorders increase. People aged 85 or more years are particularly prone to developing dementia with some estimates indicating rates as high as one in four in this age group (Access Economics 2005).

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 was 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). In this paper, the term 'carer' will denote any person who takes the primary role in supporting driver mobility transitions, such as family, friends or neighbours.

People with dementia generally 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. 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 purpose of this paper is to present the findings of an investigation into the influence of dementia on older road user safety and mobility. The aims of this research were to identify key road safety issues that people with dementia face and information and service resources that assist people with dementia and their families about driving cessation. The interviews were conducted in Victoria

with state based organisations or Victorian subsidiaries of national organisations. Consequently, information and service gaps most applicable to the conditions in Victoria were identified. However, it is expected that many of the service issues and concerns raised are applicable to other Australian jurisdictions.

Method

Information made available to people with dementia and their carers, in Victoria, Australia and overseas, was evaluated. The literature review spanned the same areas. It examined the definition of dementia and sought research about dementia and driving specifically. The internet search used key words to gather general information about dementia; advice specifically in relation to driving; advocacy work being undertaken at local or national levels in relation to dementia and driving; and information about carers' roles, needs and rights. Journal article databases were also examined and we considered both national and international publications. The literature review was confined to full submissions (not abstracts only), articles and documents in the English language.

Nine interviews were conducted with individuals from organisations that were locally and/or nationally focused, and were identified as having a significant role in supporting people with dementia and their mobility needs. Interviews were conducted by the project team. Some interviews were audio-taped, others were recorded as typed notes as the discussion occurred. The following agencies were represented: Victorian Institute of Forensic Medicine (VIFM), Eastern Health, Caulfield Hospital Cognitive, Dementia and Memory Service (Caulfield CDAMS), Disabled Motorists Australia (DMA), Carers Victoria (Carers Vic), Council on the Ageing (Victoria) (COTA), VicRoads, Alzheimer's Australia (Alz Aust) and Austin Repatriation Health Service (Austin Repat). Issues addressed in interview items were derived from literature review prominent themes in addition to concerns known to the authors, one of whom is a trained occupational therapy driver assessor. Some interview questions were open-ended to encourage participants to raise additional concerns or issues (Appendix A). Responses to questions were collated and prominent themes and trends were identified.

Results

The information gained from the literature search and interviews aided the identification of key road safety issues faced by drivers with dementia and corresponding information and services that would be of assistance. A summary of this is outlined below. It is noted that much of the discussion that arose in interviews was also present in sources of literature, though it was possible to seek greater and more specific detail in the interview context. Due to the overlap of information provided by these sources, it was not explicitly identified where each piece of information originated.

Definition of 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. The majority of cases are related to Alzheimer's disease or to vascular dementia (Sadock & Sadock 2007). Different types of dementia impact drivers differently in terms of signs, symptoms, and the rate of progression of the disease. Although there is no definitive test for diagnosing dementia until post-mortem analysis is possible, there is a high degree of reliability and consensus among medical professionals regarding the signs, symptoms and definitions of dementia.

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 condition progresses to a moderate or severe stage, 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.

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

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). 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 traffic situations. The difficulties with driving-related skills may result 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 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 linking chronic illness with crash risk included dementia in the top eight conditions that were associated with significant road safety risks (Charlton et al. 2010).

Due to poor memory, apraxia (not knowing how to use objects) and lack of insight, drivers with advanced forms of dementia cannot be relied upon to remember or compensate for their limitations for (Australian and New Zealand Society for Geriatric Medicine 2009; Byszewski et al. 2010). This lack of insight is shown by discrepancies between self-reported driving and actual driving behaviour (Dalchow et al. 2010; Wild & Cotrell 2003). Previous research demonstrates that drivers with physical rather than cognitive deficits are more likely to be aware of their restrictions and to modify or stop driving voluntarily. Factors impacting on self-reported driving regulation, such as knowledge of health, 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). 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).

Interviewees indicated that a person with dementia may need to stop driving when problems with concentration were identified, if there were 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 can be 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 assesses 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/100 mL. However, drivers with Alzheimer's dementia with a CDR of 1.0 or more were found to pose a substantial traffic safety risk, with an eight-fold increase in crash rates.

Many drivers with dementia are required to complete some form of driver evaluation. The majority of stakeholders who completed an interview 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(s). There should not be sole reliance on a neuropsychological instrument, as previous research did not reliably indicate which tool(s) to use or what a fair 'cut-off-point' should be that might indicate when people with dementia should no longer be allowed to drive. Driving assessments would preferably occur as early as possible, but must be undertaken at the point of diagnosis, as stipulated by Austroads guidelines. It was agreed that complete cessation of driving will eventually be required for all people diagnosed with dementia.

Alternative transport options for drivers with dementia are limited due to the disease-related cognitive declines across skills needed to safely use public transport and motorised mobility devices. Oxley & Fildes (2003) identified that 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 over-representation of older people in pedestrian crashes (Fildes 2003). Thus, individuals with dementia, particularly those with advanced forms of the disease, are compelled to rely on carers to support their mobility needs.

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 and insight 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. Individuals may not present for medical assessment unless the condition is advanced or perhaps health professionals find it difficult to differentiate between the characteristics of memory loss associated with normal ageing compared to the symptoms of early dementia. The widespread perception of a stigma associated with 'mentally-related' illnesses is also likely to deter people from seeking medical advice on 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.

Increasing early diagnoses in the future would benefit individuals, families, health and medical professionals and the wider community, as it facilitates the necessary lifestyle changes that accompany this shift, and provide a longer transition time and provision of medications and rehabilitation efforts that 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 gradual de-licensing and transition process. This 'person-oriented' approach would not enforce blanket rules, such as excluding the possibility of licence restrictions or vehicle aids to help maintain mobility during the transition to non-driver. Specifically, vehicle aids were generally not regarded as helpful unless there was a comorbid condition that affected motor control. Furthermore, there was a strong view among interviewees that global positioning systems (which might help

healthy individuals with navigation) have a negative impact on the ability of people with dementia to drive safely, as they cause confusion rather than compensate for poor topographical memory.

Interviewees also commented that the diagnosis process can be an overwhelming experience, and therefore, those involved need information to be presented to them in a clear, factual and consistent manner. People with dementia and their families or carers often 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. 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.

Fitness to drive guidelines

Victoria does not apply mandatory age-based licence re-assessments. Instead, drivers must self-report any medical conditions or disabilities to VicRoads Medical Review. 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.

Following the release of the revised Austroads guidelines early in March 2012, drivers with a medical diagnosis of dementia are only permitted to hold a conditional private driver's licence (Austroads 2012). This means that private driver licence holders with dementia are required to have regular medical reviews and on-road tests to monitor the impact on driving skill associated with progression of the disease. Licence restrictions such as being confined to driving within certain areas or during daylight hours may be applied. Commercial licence holders with dementia are not permitted to drive trucks or passenger vehicles at all, 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 (Martin, Marottoli & O'Neill 2009; Man-Son-Hing et al. 2007). A number of researchers have argued that management strategies include regular reassessments every 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).

The role of health professionals

Doctors are the health professionals most commonly approached by carers for support with managing health-related declines in driver competence. When a diagnosis of dementia is made, drivers should be referred to VicRoads Medical Review by self-referral, healthcare professionals, family/friends or members of the public. The treating doctor is asked to complete the VicRoads Medical Report Form for drivers. Details on this form contribute to the VicRoads decision on whether the driver meets the Austroads medical guidelines and other licensing pre-requisites.

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). 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). It is possible that occupational therapist (OT) driving assessors may be among the best placed health professionals to take on the burden of initiating the driving cessation conversation and for discussing local area licence, other restrictions, or cancelling licences if required. This would help to leave the relationship (usually long-term and ongoing) between the patient and their general practitioner intact.

Unless the driver is eligible to have the cost paid by an insurer (such as the Transport Accident Commission or Workcover), or is eligible to receive a partially subsidised assessment via a health facility, OTDA assessment costs are otherwise borne by the driver, adding further to the financial burden of ill-health. 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 to \$100 to the instructor who supplies the vehicle and assists with the on-road assessment.

Previous research suggests 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 (O'Connor et al. 2010). Drivers with concerns in all four Cs should be referred for formal evaluation.

The authors suggested that additional or specialist training for general practitioners in relation to identifying memory decline and memory-related disease may be of benefit, as it can be difficult to differentiate between typical age-related memory decline and the early stages of dementia.

The role of carers in supporting management of driving transitions

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. Research by Di Stefano, Barber, & Wriedt (2010) revealed that 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.

Carers often have little background knowledge and few resources, yet play a primary role in helping drivers adapt to changes in transport independence (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). The person with dementia may become aggressive or otherwise upset at the assertion that they no longer possess the skills to drive, or are not allowed to drive anymore. The needs of carers can be complex and may differ across groups, as every situation and experience of dementia is unique. Carers need support from health and medical professionals through this process.

Some reports recommend discussion of transportation needs early in the disease management process and suggest that documenting arrangements in an 'agreement' that may be actioned later, may offer many benefits in optimising co-operation between carer, health professional and driver (Adler 2010; Stern et al. 2008). The authors of a systematic literature review commissioned by VicRoads in 2010, summarised findings within a 'carer-centric framework'. The framework

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).

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. Interviewers commented that 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.

Discussion and Conclusions

The aims of this research were firstly to identify the key road safety issues faced generally by people with dementia, and secondly, to determine what sorts of communication resources may assist people with dementia, their carers and families with information about driving cessation.

With increasing age, it is more challenging to maintain mobility, especially if a chronic disease impinges on the ability to drive. Drivers with dementia can experience problems with navigation, signal interpretation, problem solving, decision making, recognition, and awareness (i.e. insight into one's own limitations). The issues arise because cognitive impairments gradually affect memory, attention, judgement and motor coordination. If these impairments exist, driving is especially challenging in complex traffic situations.

People with dementia and their carers need readily accessible and trustworthy information to help them through the challenging process of coming to terms with a diagnosis. Support is also required to manage life changes that accompany living with dementia, including the eventual need to cease driving and seek out alternative, safe mobility options. It was identified from the interviews conducted with health professionals and carers that more readily accessible information was needed on 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. Advocacy may also be needed, to ensure that necessary services are provided by governments, businesses and charitable organisations.

Further investigation into the tools that can assist with safe driving assessments is warranted and may help to identify a suite of methods that can be employed to ensure a fair process that covers a range of skills and abilities. Previous research suggests that there may be potential for the Cognitive Dementia Rating to be used in conjunction with driving assessments.

This research led to the development of several recommendations made by ARRB Group to RACV about the types of communication messages that might be helpful to people with dementia and their carers, on how to communicate them, on programs and advocacy options that could be implemented, and about policies that RACV may adopt in the future. One such initiative launched in April 2013 was a brochure entitled 'Dementia, Driving and Mobility' (RACV n.d.b).

The full research report of this paper is available via the RACV website (RACV 2013).

Current information services and programs

A number of information resources, services and programs for people with dementia and their carers and/or friends and/or family are available and these are displayed in Table 1.

Table 1. Review of information, services and programs

Website/resource content	Victoria	Australia and NZ	Overseas
Dementia and associated symptoms	<ul style="list-style-type: none"> • <i>The Better Health Channel</i> (2010) • <i>Driving and dementia</i> (VicRoads 2011b). 	<ul style="list-style-type: none"> • Help sheets including examples (Alzheimer's Australia n.d.a) • Facts sheets (New Zealand Transport Agency 2009). 	<ul style="list-style-type: none"> • DementiaCareCentral, Maryland, USA (ClinicalTools 2012) • Mayo Clinic Health System, USA • AlzOnline, USA, including a checklist of warning signs in question format (Doty 2007a) • Alzheimer's Society, UK.
Dementia and driving	<ul style="list-style-type: none"> • <i>The Better Health Channel</i> (2010) • <i>Driving and dementia</i> (VicRoads 2011b); • Report on public safety, health and quality of life, legal issues and on-road driving assessments (Alzheimer's Association Victoria 2001). 	<ul style="list-style-type: none"> • Alzheimer's Australia • Facts sheets (New Zealand Transport Agency 2009). 	<ul style="list-style-type: none"> • DementiaCareCentral, Maryland, USA (ClinicalTools 2012) • The Jewish Council for the Aging, USA (Gamse 2003) • Mayo Clinic Health System • The Hartford (USA) • Alzonline, USA (Doty 2007b).
Legal obligations regarding driving with a medical condition	<ul style="list-style-type: none"> • The Better Health Channel (2010) • <i>Driving and Dementia</i> (VicRoads 2011b) • Alzheimer's Association Victoria 	<ul style="list-style-type: none"> • Alzheimer's Australia • Resource guides (Department of Health and Ageing 2010) • Facts sheets (New Zealand Transport Agency 2009). 	

Website/resource content	Victoria	Australia and NZ	Overseas
<p>Alternative transport options</p>	<ul style="list-style-type: none"> • <i>Getting around without a car</i> (VicRoads n.d.) • TAC Community Mobility for Older People (Transport Accident Commission n.d.a) • <i>Getting around if you no longer drive</i> (RACV n.d.a). 	<ul style="list-style-type: none"> • Alzheimer’s Australia • Resource guides (Department of Health and Ageing 2010); • <i>How will you get around when you stop driving?</i> (New Zealand Office For Senior Citizens n.d.) • Age Concern, New Zealand promote helpful transport schemes (Land Transport New Zealand 2008). 	<ul style="list-style-type: none"> • The Jewish Council for the Aging, USA (Gamse 2003) • Alzheimer’s Society, UK • Guidebook with tips for driving reduction and cessation (The Hartford & MIT AgeLab 1999) • Johnson & Johnson’s Patient Assistance Foundation operates StrengthForCaring.com (Eby n.d.). ‘<i>Taking away the keys</i>’ lists reasons people may stop driving and provides tips to manage the process.
<p>Training</p>	<ul style="list-style-type: none"> • Presentation <i>The Years Ahead</i> includes road safety tips and fitness to drive (RACV 2010) • <i>Wiser Driver</i> covers road rules, future planning and more (Hawthorn Community Education Centre n.d.) • Alzheimer’s Association Victoria on many topics. 	<ul style="list-style-type: none"> • Age Concern New Zealand offer classroom-based workshops aimed at helping senior drivers re-familiarise with traffic rules and safe driving practices (Age Concern 2011a). 	<ul style="list-style-type: none"> • Pines of Sarasota, USA, offer seminars, programs and DVDs that can be purchased online. They also offer specific training for medical professionals, paraprofessionals and at-home caregivers.

Website/resource content	Victoria	Australia and NZ	Overseas
Advocacy	<ul style="list-style-type: none"> Alzheimer's Association Victoria. 	<ul style="list-style-type: none"> Alzheimer's Australia Monthly magazine 'Alzheimer's Advocate' (Alzheimer's Australia New South Wales n.d.) New Zealand Transport Agency Various, including on decision-making and control (Advocacy Tasmania n.d) National leadership (Age Concern 2011b). 	<ul style="list-style-type: none"> Dementia Advocacy Network, UK Dementia Advocacy Support Network International, Kansas, USA.
Other	<ul style="list-style-type: none"> Dementia Services Pathways Project commission by The Department of Health and Ageing, to inform and assist jurisdictions with service planning to improve the services and care for people with dementia and their carers (KPMG 2011). 	<ul style="list-style-type: none"> Various programs including counselling and social support; and the National Dementia Helpline (Alzheimer's Australia n.d.b) Resources to help younger people support older people (Land Transport New Zealand 2006) Contracted services, education and resources (Age Concern 2011b). 	<ul style="list-style-type: none"> Television public service announcement about driving safety and dementia; also a website created for primary care physicians (Dalhousie University 2011) The Jewish Council for the Aging's 'Transportation Translator' lists different types of services available and how they work Monthly magazine on living with dementia (Alzheimer's Society 2007) Example agreement between the person with dementia and their family about not driving (The Hartford & MIT AgeLab 1999).

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Appendix A - Interview Questions

SECTION 1: THE EXPERIENCE OF DEMENTIA AND THE NEEDS OF THOSE AFFECTED BY IT.

1. What problems do drivers with dementia experience when driving?
2. 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?

LICENCE RESTRICTIONS:

AIDS:

3. 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?
4. Can drivers with dementia recognise when it is time to modify/ stop driving? If so, what are the signs they need to recognise?

How can carers, family and friends recognise when it is time for a person with dementia to stop driving?
5. How should carers and health professionals manage a person with dementia who needs to cease driving?

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

SECTION 2: INFORMATION & SERVICES.

6. 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?
 - (b) Would information on a web site be useful? Should it be aimed at patients or carers and family members?
 - (c) Would leaflets be useful? Should they be aimed at patients or carers and family members?
 - (d) Would any other services or information be useful? If so, what?
 - (e) Or is a screening test administered by a health professional the only worthwhile decision aid?
7. 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)?
8. What are the main challenges that you are aware of, or that your organisation faces in working with this population?

INDIVIDUAL LEVEL (knowledge, attitude, behaviours, skills):

FAMILY/CARER LEVEL (knowledge, resources, support):

SYSTEMS LEVEL (policies, licensing, funding):

9. Does your organisation have any current programs/resources for individuals with dementia, their carers or for health professionals working with patients with dementia?
10. Do you have any joint programs with other agencies that cater to the needs of this driver group?
11. 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?

SECTION 3: THE GAPS IN EXISTING INFORMATION &/ SERVICES.

12. Does your organisation have any goals/plans for future programs/resources to address needs for this group?
13. Are there any information or service gaps now or in the foreseeable future?
14. How could VicRoads or other road authorities assist? EG, 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?
15. How could local governments (e.g. councils, safety grps) assist? EG, 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?
16. How could State or Federal government departments (e.g. DoHS, DoH) assist? EG, 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?
17. What initiatives/changes do you believe should be a priority to stakeholder groups?
18. Would your organisation partner with relevant others to support initiatives of mutual interest?
19. Can you suggest any key organisations or program managers we should speak with about dementia and older drivers?

CONCLUSION