

# DEMENTIA AND DRIVING IN VICTORIA

ALZHEIMER'S AUSTRALIA VIC  
DISCUSSION PAPER **APRIL 2013**



**TALKING ABOUT ALZHEIMER'S  
ACROSS AUSTRALIA**  
FIGHTDEMENTIA.ORG.AU

## Acknowledgements

This report was prepared by Ms Dianne Biermann, Policy Officer, Alzheimer's Australia Vic.

Many others made contributions during the course of the project including Dr Elodie O'Connor, Dr Maree Farrow, Mr Jack Sach, Ms Lisa Reed, Mr David Hooker, Ms Kristen Holdsworth, and members of Alzheimer's Australia Vic Consumer Advisory Committee.

Much appreciation is given to the Client Services team at Alzheimer's Australia Vic who distributed the survey, and who on a daily basis assist people living with dementia to manage driving changes.

Finally, and most importantly, thank you to all the people with dementia, and all their families, who completed the survey. Sharing their experiences and opinions is essential to the development of effective policy.

# TABLE OF CONTENTS

- EXECUTIVE SUMMARY ..... 1**
- Priority Action Areas ..... 4
- BACKGROUND ..... 6**
- Purpose of the paper ..... 6
- Prevalence of dementia ..... 6
- Effects of dementia on driving ..... 6
- Evidence of crash risk ..... 6
- Drivers licensing in Victoria ..... 7
  - Reporting ..... 7
  - VicRoads Medical Review ..... 7
- ALZHEIMER’S AUSTRALIA VIC SURVEY ..... 8**
- Method ..... 8
  - Survey design ..... 8
  - Recruitment ..... 8
- Results ..... 8
  - Sample ..... 8
  - Driving arrangements for the person with dementia ..... 10
  - Impact of stopping driving ..... 12
  - Independence versus safety ..... 15
  - Fitness to drive ..... 15
  - On road driving assessments ..... 18
  - Improving transport options and services for people with dementia ..... 21
- DISCUSSION ..... 22**
- PRIORITY ACTION AREAS ..... 25**
- Education and information ..... 25
- Alternative mobility options ..... 25
- Research ..... 26
- Driver testing ..... 26



# EXECUTIVE SUMMARY

---

*Driving is much more than independence. Driving is a freedom and an affirmation of a level of competence and usefulness.*

Family carer of a person with dementia, 2013

---

With the increasing age of the population, and the subsequent increase in prevalence of dementia, there will be a growing number of older drivers who will experience impaired driving ability. However, although there is evidence that dementia increases crash risk<sup>1</sup>, it is also internationally accepted that not all people with dementia are incompetent drivers, particularly in the early stages of the condition.<sup>2</sup>

The ability to drive safely relies on memory, attention, decision-making, planning, reactions, vision and other sensory processing and these will be affected to various degrees.<sup>3</sup> Each person's experience of dementia is individual.

This paper presents the results of a survey with 139 family carers and friends of people with dementia, and 19 people with dementia. It describes their awareness of VicRoads regulations in relation to dementia, experience with on road driver testing, impact of ceasing driving, and on alternative mobility options.

Policy recommendations are presented consistent with supporting people living with dementia, in balance with the promotion of safety.

## **Monitoring drivers in Victoria with dementia**

In March 2012 VicRoads adopted new fitness to drive standards issued by Austroads and the National Transport Commission. Of particular note, the changes no longer allow a driver with dementia to have an unrestricted licence. The licence holder must report their diagnosis to VicRoads, and their licence becomes conditional.

A conditional licence stipulates a requirement of individual assessment and regular medical review, at a minimum of 12 monthly intervals. A medical review takes into account information provided by the treating doctor, or medical specialist, and may also include a practical 'on-road' driver assessment with a specialist occupational therapist.

Within this study cohort over 30% of family carers were unaware or unsure of the requirement for a person with dementia to report their medical condition to VicRoads. The two most common reasons were lack of awareness (33%), and keeping a licence for identity purposes (16.7%). Sustained and timely education would assist in improving awareness of the VicRoads requirements.

Whilst about half of family carers were satisfied with arrangements for an on-road occupational therapist driving test, 32% were not, with the main reasons being the cost of the test, waiting time for the test, test outcome, and the inability to be tested in one's own vehicle. Over 40%

---

<sup>1</sup> (Charlton J, November, 2010)

<sup>2</sup> Brown, L and Ott, B. Driving and Dementia: A Review of the Literature. *J Geriatr Psychiatry Neurol.* 2004 December. 17(4):232-240

<sup>3</sup> Charlton, J, Koppel S, Odell M *et al.* Influence of chronic illness on crash involvement of motor vehicle drivers: 2<sup>nd</sup> Edition. Monash University Accident Research Centre. Report No. 300. November, 2010. p.114.

of people paid between \$300 and \$500 for the on road test, almost 10% \$500 and \$700, and 5% paid over \$700. There is a need to make the testing equitable and accessible.

Around 33% of respondents found the on-road test to be a waste of money. This may reflect the outcome, as 31% were notified by VicRoads that they were unfit to drive. Those who found the testing to be money well spent (45%) appreciated the independence of testing, and reassurance around driving safety.

Only 15% of family carers felt the person having the on road assessment should pay for the test. Over half would like to see the testing rebatable through Medicare, 33% would like to see the Victorian Government partly subsidize the cost, and almost a quarter think it should be included in car or health insurance policies.

The cost of driving assessment has been a long standing issue for people with dementia, and the changes to VicRoads licencing provides an important opportunity to establish a Government response to this difficult topic.

As the implications for public health impact unfolds, alternative assessment tools for drivers with dementia is becoming a topic of increasing international research.<sup>4,5</sup>

### **Impact of driving cessation**

Losing the right to drive has a wide ranging impact on both individuals with dementia, and their family carers.

Part of this impact is the method of informing a person with dementia that they are no longer fit to drive. When family carers were asked their preferences as to who should tell the person with dementia to cease driving, over 70% preferred a GP or medical specialist, as an authoritative and respected figure. Almost 40% of family carers were also prepared to tell the person with dementia that they are no longer safe to drive. Qualitative evidence indicates many cases of ongoing anger and resentment on the part of the person with dementia.<sup>6</sup>

People with dementia also indicated a preference for a doctor or a family member to tell them it is time to stop driving. Varying levels of insight into their driving ability means that some people with dementia will choose to stop driving themselves, or self-regulate where and when they drive, such as day driving to local shops and for a medical appointment.

Thirty three percent of family carers reported that the impact of stopping driving on the person with dementia was greater than they had expected. Whilst a small number of people with dementia describe a relief and positive understanding of driving cessation, for many others there are issues around loss of self-esteem, identity and confidence; loss of independence and social opportunity; anger, confusion and depression.

The impact on family carers was even greater, with 39% finding the impact greater than expected. Reported issues included loss of freedom and spontaneity, impact on work/life, scheduling and logistics, and emotional impacts including worry, tiredness, and sometimes increased family conflict.

---

<sup>4</sup> Martin A, Marottoli R, O'Neill D. Driving assessment for maintain mobility and safety in drivers with dementia. Cochrane Database Syst Review. 2009 Jan 21;(1). [www.ncbi.nlm.nih.gov/pubmed/19160270](http://www.ncbi.nlm.nih.gov/pubmed/19160270). Accessed 15/11/2012

<sup>5</sup> Carr D, Barco P, Wallendorf M. Predicting road test performance in drivers with dementia. *J AM Geriatr Soc*. 2011 Nov;59(11):2112-7

<sup>6</sup> Alzheimer's Australia NSW. Driving and Dementia in NSW. Discussion Paper 1, April 2010.

When people stop driving, most rely on their spouse or partner to drive them. Many also rely on family members and taxis. Twenty five per cent of family carers report staying at home more which has significant implications for maintaining social connectedness, with resultant health and social impacts.

### **Mobility needs of people with dementia**

The ability to travel independently, either with a car or by public transport, is impacted by the stage of progression of dementia.

Twenty eight percent of family carers found transport arrangements to be inadequate or extremely inadequate. This rating was impacted by whether a spouse or family member was happy to drive and whether there were other public or community transport options available.

People with dementia and their family carers were asked for suggestions for alternative transport options. It was found that, like driving, even using public transport eventually becomes challenging. Few studies have evaluated public transport use for people with dementia. Suggestions by family carers include ensuring there is shelter, minimising waiting time, provision of straight forward routes, regular stops and services, and provision of an easy to use payment system.

People who have stopped driving are more reliant on their spouse (67%), family (41%), taxis (22%), walking (17%), volunteer drivers (12%), public transport (12%) and community transport (8%).

Door to door travel by taxi is frequently used. Half price taxi fares using Victoria's Multi-Purpose Taxi Program is appreciated, but can be difficult to obtain, as the scheme is weighted toward physical disabilities and low income earners.

Low cost flexible community transport is patchy in service delivery across jurisdictions. Rural and regional areas already experience transport disadvantage and coupled with some smaller Council's incapacity to fund and provide a local service, reduces social inclusion in many communities.<sup>7</sup> An Australian Institute of Health and Welfare analysis indicates that about three quarters of people with dementia in the community need help with private transport. Furthermore mobility was cited as a significant area of unmet need for assistance.<sup>8</sup>

Victoria needs a community transport system and strategy that reflects the important role that it plays in ensuring mobility and social connection for people who require door to door transport, but cannot afford taxis. The community transport sector needs to be incorporated into State Government transport policy including an adequate and sustainable funding commitment.

Some carers groups, support groups, social groups and churches provide transport assistance. Alzheimer's Australia Vic operates the Memory Lane Café program to provide people with dementia and their family an opportunity to provide a social outing, with transport to the events arranged upon request.

An adequately resourced volunteer drivers program, with drivers trained in understanding people with dementia and other disabilities, deserves greater priority.

---

<sup>7</sup> Municipal Association of Victoria. Submission to Taxi Industry Inquiry. 24 June 2011 <http://www.mav.asn.au/policy-services/transportinfrastructure/transport/related%20documents%20%20transport/submission%20to%20taxi%20industry%20inquiry.docx> Accessed 26 March 2013.

<sup>8</sup> AIHW 2012. Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW. p.58 and p.116.

Suggestions for aged care service providers to include more transport assistance to access appointments and attend errands also warrants further consideration.

Simple, practical mobility and social inclusion strategies from interstate and overseas, such as the WHO (World Health Organisation) *Age-friendly Cities Guide*, require further investigation for implementation in Victoria. In particular, it is important to implement the age-friendly transport recommendations of the Parliament of Victoria *Inquiry into Opportunities for Participation of Victorian Seniors, 2012*.<sup>9</sup>

With only 11% of people with dementia continuing to drive with a conditional licence, a co-ordinated strategy with a much greater investment in alternative mobility options is essential.

## Priority Action Areas

Alzheimer's Australia Vic identifies the need for priority action in the following areas:

### Education and information

1. Engagement with people with dementia as early as possible after diagnosis. Support people with dementia to make informed choices, so far as possible, with the aim of building effective partnerships between them, their families and their health professionals.
2. Introduction of sustained education campaigns by VicRoads encompassing responsibility to report dementia, explanations of conditional licences and medical review requirements.

### Alternative mobility options

1. Further development of dementia friendly mobility and social inclusion programs, funded by the Victorian Government.
2. Implementation of the age-friendly transport recommendations of the Victorian Family and Community Development Committee *Inquiry into Opportunities for Participation of Victorian Seniors, 2012*.
3. Incorporation of community transport into Victorian Government transport policy, including an adequate and sustainable funding commitment.
4. Simplification of the Multi Purpose Taxi Program approval process for people with cognitive impairment, and review of income threshold.
5. Further expansion of HACC services and packaged services for assistance with transport to attend appointments, particularly where there is no family to assist the person with dementia.
6. Exploration of innovative models of door to door transport.

### Research

1. Further investigation of driving and mobility experiences of people without family support<sup>10</sup>, and of people with dementia from culturally and linguistically diverse backgrounds.
2. Research on crash risk, or crash involvement of people with dementia.
3. Investigation of the number of people with undiagnosed dementia driving on Australian roads.
4. Further development of alternative valid and reliable office based driver testing tools.
5. Expanded research into the benefits of independent living devices/assistive technologies such as user friendly GPS, crash warning systems and exercise interventions directed at driving-related cognitive ability.

---

<sup>9</sup> Family and Community Development Committee. *Inquiry into Opportunities for Participation of Victorian Seniors*. Parliament of Victoria, 2012. p.205-222.

<sup>10</sup> AIHW estimates 12% of people with dementia live alone in private dwellings in the community.



6. A review of driver assessment compliance. Anecdotal evidence suggests that individuals with progressive cognitive conditions may forget or misunderstand that they are no longer fit to drive.

### **Driver testing**

1. Ensure that driver testing by occupational therapists to be equitable and consistent in cost, method and accessibility. The Victorian Government to subsidise the cost of testing.
2. Assessment of the supply of occupational therapists, particularly in regional areas with higher projections of dementia prevalence.
3. Ensure national uniformity in driving regulations/testing.

# BACKGROUND

## Purpose of the paper

Driving is a common topic of discussion amongst Alzheimer's Australia Vic clients. It causes considerable worry and stress for all involved. There is a fine balance between promoting independence and ensuring safety of drivers and pedestrians.

The paper seeks to answer a number of questions:

- How aware are people with dementia about the requirement to report their condition to VicRoads?
- How aware are people about changing to a conditional licence?
- Does stopping driving impact the person with dementia and family carers more or less than they had expected?
- What are the experiences of people who have an on-road driving assessment, and how do people think this test should be paid for?
- What alternative mobility options are available to people?
- What positive solutions can Alzheimer's Australia Vic promote which fairly balances independence and safety?

The paper examines existing evidence and expertise, as well as presenting the results of a Alzheimer's Australia Vic survey of people with dementia, family carers and friends.

The paper aims to influence policy and actions so that people with dementia and their families can be supported to remain active members of the community.

## Prevalence of dementia

There are around 75,000 people living with dementia in Victoria.<sup>11</sup> A 32% growth in dementia is projected between 2011 and 2020, when there is expected to be 98,100 Victorians with dementia.

## Effects of dementia on driving

A diagnosis of dementia does not preclude a person from driving. The stage of dementia does affect the ability to drive.

Safe driving places demands on memory, attention (both selective and divided), decision making, planning, reactions, vision and other sensory processing.<sup>12</sup> Diminished capability in these areas through the impact of dementia has the potential to compromise driving.

## Evidence of crash risk

Monash University Accident Research Centre, which is tasked with examining the influence of chronic illness on crash involvement of motor vehicle drivers, uses a risk rating system to assign cases to medical conditions. The international evidence reviewed from 15 studies relating to crash risk indicates that drivers with dementia have a higher risk of deficits in driving skill and crashes compared with normal healthy age-matched controls.<sup>13</sup>

---

<sup>11</sup> Deloitte Access Economics, Dementia Prevalence Data commissioned by Alzheimer's Australia Vic, 2012.

<sup>12</sup> Charlton, J, Koppel S, Odell M *et al.* Influence of chronic illness on crash involvement of motor vehicle drivers: 2<sup>nd</sup> Edition. Monash University Accident Research Centre. Report No. 300. November, 2010. p 114

<sup>13</sup> Charlton, J, Koppel S, Odell M *et al.* Influence of chronic illness on crash involvement of motor vehicle drivers: 2<sup>nd</sup> Edition. Monash University Accident Research Centre. Report No. 300. November, 2010.

However, evidence is not sufficiently robust to warrant that all people with dementia automatically have their licences restricted or revoked.<sup>14</sup>

There is evidence to recommend that once symptoms of dementia are detected, close monitoring of both driving abilities and cognitive state should be undertaken by family members, doctors and health professionals.

### **Driver licensing in Victoria**

Under Section 17 of the *Road Safety Act 1986*, VicRoads is responsible for ensuring that all licence holders and applicants can drive safely.

In March 2012 VicRoads introduced the new fitness to drive standards issued by Austroads and the National Transport Commission.

### **Reporting**

Drivers are required by law to report to VicRoads if they have a chronic medical condition, such as dementia. People with dementia can no longer hold a full licence and their licence becomes 'conditional'.

A conditional licence recognises that not all people with a diagnosis of dementia should have their licence revoked or restricted. However individual assessment and regular review is required, at a minimum of 12 month intervals. It recognises that dementia is a progressive and irreversible medical condition that will affect driving ability over time. A medical review of the conditional licence takes into account information provided by the treating doctor, or specialist, and may also include a practical 'on-road' driver assessment with a specialist occupational therapist.

In Victoria reporting of a dementia diagnosis to VicRoads by doctors or specialists is *not* mandatory. The onus is on *the driver* to report to VicRoads. However if a doctor or health professional believes there is a significant risk to public safety they can report, with indemnity, directly to VicRoads.

Similarly, any family member or member of the community, who is genuinely concerned about someone's ability to drive safely, can also notify VicRoads of their concern.

### **VicRoads Medical Review**

A VicRoads medical review evaluates a person's ability to drive safely. VicRoads requires the driver to provide a medical report from a doctor or specialist familiar with their medical history. Based on the doctor's report, VicRoads may advise of no further action, or may request further medical reports, or a review driving test, or an occupational therapy driver assessment.

The occupational therapy driver assessment is more detailed and includes an off road assessment of medical and driving history, understanding of the road rules and any functional limitations. It also includes an on road driving test which evaluates the impact that dementia (and any other co-morbidities) has on driving ability.

The licence holder incurs the cost of all tests.

---

<sup>14</sup> *Ibid.* p.123

# ALZHEIMER'S AUSTRALIA VIC SURVEY

## Method

### Survey design

A survey was designed by Alzheimer's Australia Vic in consultation with counsellors employed in the organisation, as well as Alzheimer's Australia Vic Consumer Advisory Committee. Two versions of the survey were developed – one for family carers and friends, and another for people with dementia. While most of the questions pre-coded ratings, several questions were open ended. All respondents were also invited to make additional comments of their choice.

### Recruitment

The surveys were available to people with dementia, and family carers and friends in Victoria who held a Victorian drivers licence, or had previously held a Victorian drivers licence.

A three month response time was set (December 2012 to March 2013). Questionnaires were distributed and promoted through existing networks and via Survey Monkey including:

- Physical distribution of questionnaires by Alzheimer's Australia Vic counsellors throughout Victoria.
- Email and physical distribution of forms to Aged Care Assessment Services and Cognitive Dementia and Memory Services.
- A link to an online survey to subscribers of Alzheimer's Australia Vic Dementia News.
- Hard copy and online distribution to people on Alzheimer's Australia Vic Consumer Advisory Committee, and Dementia Action Register participants.

Participants were encouraged to phone the National Dementia Helpline or VicRoads Medical Review, should they wish to discuss their personal circumstances or require further information.

There was limited coverage of the opinions of people with dementia that live alone, people from CALD backgrounds, people who are not accessing aged care services, and people who have cognitive changes but have not sought medical opinion.

The small number of people with dementia who responded made it difficult to make general inferences from the data. However the qualitative information they provided gives a useful perspective of their individual experiences and opinions.

## Results

### Sample

There were 139 responses to the family carers and friends survey and 19 to the survey of people with dementia.

Seventy five percent of respondents were a spouse or partner of a person with dementia, another 23% were a child or other relative of a person with dementia, and a small number of respondents were professionals such as a Case Manager or an Aged Care Assessor.

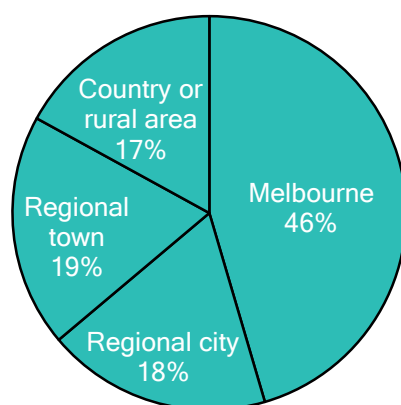
The survey profile is shown in Table 1. Over 97% of family carers spoke English at home. There were two respondents who spoke Italian at home, one Greek, three German, and one each of Polish, Sinhalese and French. The low numbers of CALD respondents may reflect that the survey was only available in English, and the distribution method used. Similarly, only one person of Aboriginal descent completed the survey.

**Table 1 Survey Participant Profile**

	Family Carers	People with dementia
<b>Age</b>		
Under 40 years	9	1
40-49	7	
50-59	29	
60-69	42	2
70-79	32	8
80+	18	8
<b>Gender</b>		
Male	43	11
Female	96	8
<b>Residence</b>		
Melbourne	64	4
Regional city	25	8
Regional town	27	7
Country or rural area	24	
<b>Language spoken at home</b>		
English	135	17
Italian	2	1
Greek	1	1
German	3	
Polish	1	
Sinhalese	1	
French	1	
Aboriginal or Torres Strait Islander	1	

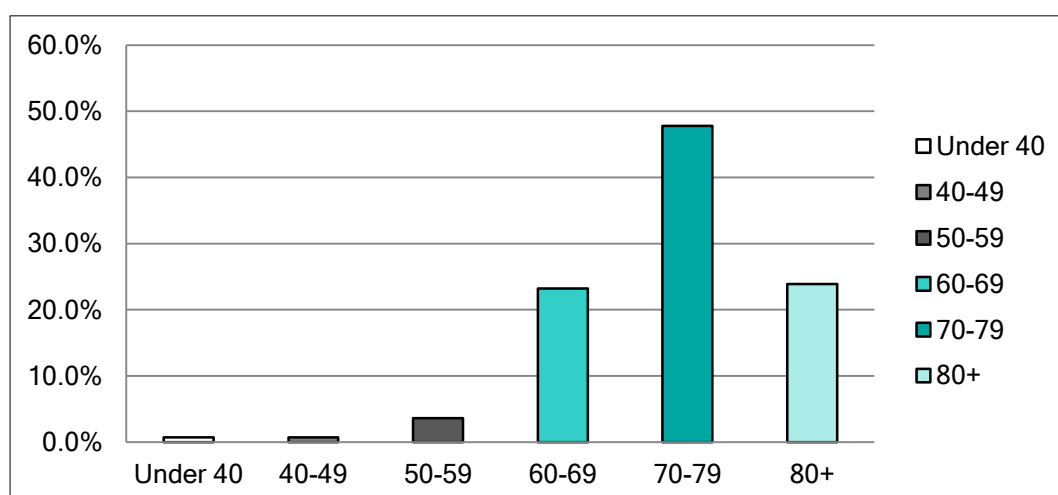
Over half of the family carers represented people with dementia residing in a regional city, regional town or country area (Figure 1). Regional towns (36.8%) and regional cities (42.1%) had an even greater proportion of respondents with dementia, compared to greater Melbourne (21.1%). This may reflect concern for driving and mobility in non-metropolitan areas, demographic ageing, or recruitment methods.

**Figure 1 Residential location**



Family carers represented people with dementia aged in the ranges under 40 to over 80 years. Seven people with dementia were aged less than 60 years. Ninety nine were over the age of seventy (Figure 2).

**Figure 2 Age of the person with dementia**



### Driving arrangements for the person with dementia

Seventy two percent of people with dementia were no longer driving, about 11% continued to drive with a conditional licence, and almost 17% of respondents believed the person with dementia was continuing to drive without any change to their licence. Interestingly about 10% did not respond to this question. It may have been that they did not know the licence status of the person with dementia. Of 15 additional comments, of concern were two additional responses, one of which indicated a failure to report the diagnosis to VicRoads, and a person with dementia continuing to drive despite their licence being cancelled after a test in 2012.

For those who no longer drive, (67%) rely on their spouse or partner to drive them to the shops, doctors appointments and social visits. Family members and taxis were also heavily relied upon.

Only 12% responded that they were using public transport or volunteer transport. Over 25% indicated they were staying home more. This is concerning where both the person with dementia and the family carers need to remain socially connected in order to cope with the impact of dementia.

**Table 2 Method of transport by people with dementia following cessation of driving**

Transport Options	Family Carer Response	People with Dementia*
Rely on spouse or partner to drive	67%	75%
Rely on neighbours or friends	17%	0%
Rely on Family members	41%	42%
Walking more	18%	25%
Public transport	12%	33%
Staying home more	25%	17%
Taxi	22%	25%
Volunteer transport	12%	17%
Community transport	8%	8%

\*note sample size n=12

Additional responses to the questions indicated that some people are receiving limited transport support from service providers; others are receiving help from social groups (carers groups or church) and friends. Some people with dementia only use public transport with someone to accompany them.

The adequacy of transport arrangements for people is indicated in Table 3.

**Table 3 Adequacy of transport arrangements for getting to the shops, doctor or social visit**

Options	Extremely adequate				Extremely inadequate
Family carer	30%	16%	26%	8%	20%
People with dementia*	12.5%	6.3%	56.2%	0%	25%

\*n=16

The large number of additional comments explains how family carers made their rating. Those who describe transport as adequate are usually those family carers who continue to drive the person with dementia, and accept that as their role, whilst they can.

*I provide this service totally!*

*I make sure I'm available – fortunately I can change my working days.*

Customer focussed, age friendly transport system is appreciated. In particular a volunteer driver system was very useful:

*Volunteers are also to be commended. I am forever grateful for all the assistance I am provided with.*

People who responded to the inadequacy of transport referred to the lack of alternative mobility options.

*No public transport, without family living nearby the patient would be in real trouble.*

*The nearest bus stop to our house is more 3 km away on the Portarlinton Highway.*

*Long waits for bus services. Elderly are left waiting in the hot sun or wet rain.*

Other factors affecting the adequacy of transport options include the stage of dementia and the presence of other additional health problems.

*Not suitable for the person who has more than one health problem (my mother had tunnel vision and dementia)*

In the early stages of dementia, some people with dementia can use public transport quite happily.

*I would be happy to drive my car to a tram stop. I enjoy tram travel.*

For those with advancing dementia, public transport is no longer a safe option. As dementia progresses, the use of public transport unaccompanied is not feasible.

*The dementia is so advanced that although my parents in law are assisted to remain living at home, they are not competent to cross the road, or use public transport.*

*I tried to teach him public transport but this was unsuccessful. Likewise he was not comfortable with using a taxi.*

*Public transport is not an option...as she has always driven everywhere and not utilised any public transport...and lives far from a stop...the family members share the transportation.*

*Too hard to follow MYKI system.*

There is a desire for more assistance with transport. Particular recommendations were made:

*More government services needed to offer escort to appointments with volunteers or paid staff that speak their language, not just a matter of transport to location, but escort & support at appointment.*

### Impact of stopping driving

Two questions asked about the impact of stopping driving on the lifestyle and wellbeing of the person with dementia, as well as the lifestyle and wellbeing of the family carer.

**Table 4 Extent of impact of stopping driving on lifestyle and wellbeing**

Impact	A lot less than expected	A little less than expected	No change	A little more than expected	A lot more than expected
Family carer perception of impact on the person with dementia	23%	9%	15%	20%	33%
Family carer or friend	12%	7%	17%	24%	39%
People with dementia*	50%	0%	17%	0%	33%

\*n=12

The impact of stopping driving, according to family carers, was more than expected for both the person with dementia, and for themselves.

When family carers were asked to describe the impact of stopping driving on the *person with dementia* there was a large number of responses. Most respondents referred to loss of independence:

*A degree of independence is lost and movements are restricted. In their own mind they believe they are still capable of driving, so this results in conflict.*

*Cannot go to shop or bingo without a driver. Depends on others to see friends.*

Many respondents described the person with dementia as angry, confused, depressed and isolated:

*My mother became more isolated and lonely which led to some depression and hastened her deterioration. She was angry and hurt about having her licence taken away.*

*Has become angry and frustrated, unable to understand why it [licence] was taken away. Has become socially isolated.*

*Miserable, angry, stuck at home.*



For some families there is ongoing resentment and conflict about not driving:

*She constantly remarks about not being able to drive.*

*He was affronted, irritated and annoyed because he believed others were judging his abilities wrongly. He thought it was a conspiracy against him by me (his wife). Finally, it forced him to accept (at least in part!) that he did have dementia. He then got even more depressed and angry.*

*She nags and gets angry about her loss of licence and blames the family members for this.*

A loss of social opportunities and spontaneity in life was also described:

*We no longer do volunteer driving - took away social opportunities. We live where there is NO public transport available so there is a loss of ability to go places.*

*Now feels unable to decide to see grandchildren - two blocks away on impulse. Very sad and depressed. Needs me to drive him every day.*

Some people described a proactive approach, or level of acceptance, by the person with dementia:

*He chose not to drive any more... all by himself. I suspect he got a fright.*

*When first cancelled, was somewhat upset. However as time goes on, she has shown no concern and happy for me to drive her.*

*Very little impact as he had been driving for many years with his job, and was over it.*

*The impact has been very hard for him to accept, but with my help, help from his friends and the acquisition of the 1/2 price taxi card, he has been able to get to all of the places he did in the past.*

A small number of respondents described a positive impact, or attitude to stopping driving.

*I found my mother to be a lot happier when she stopped driving...one huge less stress to worry about.*

*Positive because he no longer worries about possibility of causing an accident.*

Of the 12 people with dementia who had stopped driving, four described the impact. The discomfort of depending on others, and the impact on self esteem is evident:

*Totally rely on carer/wife to take me to appointments/outings, etc.*

*Affected my confidence level and my ego and I felt as though I was imposing myself on my partner to pick up the driving that I had previously done.*

*I feel I would become housebound and depend on other people to get me around and I enjoy my independence.*

*I ride my push bike or walk and have good family support or use taxi or local bus or train.*

The impact on family carers was also described extensively. The daily impact and the extra work required by the spouse, and family members (including impact on work life), was a very common theme:

*We now have to try to take time off work in order to take him to appointments.*

*It impacts on my schedule day to day, having to become the taxi and organise appointments for GP etc.*

*Have had to do a lot more driving of spouse, and have had to go to a lot of trouble to organise alternative arrangements.*

*I have to drive everywhere and he wants to come every time I go out in the car.*

*Having to be a 'taxi service' now takes up much of my personal time.*

*Along with dealing with everything, as my husband has other medical conditions, life is difficult and I have to drive everywhere.*

Emotional impact and carer burden was commonly described. This included depression, guilt, worry, resentment, family conflict, and the stress of increased responsibility.

*Also living with guilt and empathy for the person who can't drive. Knowing every movement of the person's day to day life. Guilt, burden and stress.*

*I have to drive him to all appointments he can no longer pop up the near-by shops for milk etc. I worry if I get sick he cannot drive me to HOSPITAL.*

*I get tired.*

Loss of freedom, extra planning and loss of spontaneity was also a common theme.

*I used to love heading off in the car, sharing the driving, always knowing I had a backup if I felt tired. We went to our country place each Friday night and I often slept much of the way after a busy week. This became unsustainable when I had to do all the driving, so we had to sell our weekender - a further loss!*

*Firstly dealing with depression then realising he could no longer just "pop out" for the paper or to buy fuel and clean the car - but the worst was having to sell our caravan! I did not want to drive the caravan as I had never done so over 28 year of traveling.*

*If enough people share the load it is not so bad. However, we can't go on holidays.*

*We have to plan now when and who will pick them up from a shopping outing.*

*I cannot drive in the dark or (on) a country road at night time. My husband used to do that. Country night driving now we must stay overnight at friends and return home the next day.*

*Can never get a connecting bus - leaving home earlier to catch public transport.*

Very few family carers described any positives, but some were more accepting, or resigned to the situation:

*It has made me appreciate my family and my father more - a good feeling to be able to give back and be of help.*

*Very little impact on my life, as I enjoy driving and he is quite happy for me to drive everywhere.*

*For me, it is part of the caring role*

*It has meant quite a bit of extra driving for me - but I am totally willing to do this rather than have him on the road. It has meant time organising other transport when I am unable to take him.*

## Independence versus safety

The question of independence versus safety is a very difficult issue to balance when discussing dementia. Whilst noting that dementia is a progressive disease, family carers were asked about the importance of independence as a reason for a person with dementia continuing to drive (Table 5).

**Table 5 Importance of independence as a reason for the person with dementia to continue to drive**

Answer Options	Extremely important	Important	Neither important or unimportant	Not important	Not at all important
Family carers	42%	13%	13%	8.5%	23%
People with dementia*	63%	0%	10.5%	5.3%	5.3%

\*n=19

Over 55% of family carers believe independence is an important or extremely important reason for a person with dementia to continue to drive, but they counterbalance their choice with safety being of utmost importance:

*Independence is important but it is essential that all medical and driving tests ensure that it is safe for the person with dementia to continue to drive.*

*Important but safety on the road (for others and for the driver) is of paramount importance. Can be difficult to monitor changes in the person's ability to drive.*

*For the sake of other road users they must not drive. Their concentration and judgement is impaired.*

*Responsibility for the lives of others is also extremely important and driving involves a huge range of skills e.g. alertness, mobility of body, eyesight, hearing.*

*Driving is much more than independence. Driving is a freedom and an affirmation of a level of competence and usefulness.*

People with dementia rated independence as extremely important. Response numbers are small so this may not be a general attitude amongst this cohort. There is variation in insight into driving skills, depending on the level of cognitive impairment.

*Lack of concentration and judgement could lead to an accident with other road users or pedestrians.*

*When I was driving it was paramount importance to me to continue to drive.*

*To be able to visit family and friends in country Victoria is vital to me, train travel would be difficult as I suffer from bad asthma and public transport & I don't get on!!*

## Fitness to Drive

If a person holding a Victorian drivers licence is diagnosed with dementia they are required to report this to VicRoads. The survey included a question around people's awareness of this requirement (Table 6).

**Table 6 Awareness of requirement to report dementia diagnosis to VicRoads**

Awareness of reporting to VicRoads	Family carers	Person with dementia*
Yes	54%	59%
No	25%	24%
Unsure	7%	6%
Person with dementia relinquished licence to VicRoads	14%	13%

\*n=17

Almost 54% of family carers were aware of the need to report a dementia diagnosis to VicRoads, or had already handed in a driver's licence. Of concern were the 32% who were unaware or unsure of this requirement. This is concerning because the bulk of people completing the survey were people who were already connected into services, either through Alzheimer's Australia Vic or through other aged care or health services (see recruitment). Many people may not have a diagnosis of dementia, and who are not connected into aged care service are quite probably unlikely to be aware of the risks they are facing.

For those family carers who did not notify VicRoads, they were asked why this had not happened (Table 7). Around 33% did not know this was required, and over 15% wanted to retain their licence for identity purposes. Only a very small number (5%) did not want VicRoads to know of the diagnosis. Similarly a small number thought that a doctor, or health professional, reports the diagnosis to VicRoads.

Two additional comments were concerning. The reliance on a person with dementia to disclose is problematic because of their memory or impairment in judgement:

*Placing the responsibility of notification on the person with dementia results in a failure in the circuit. My parents-in-law, despite fairly advanced dementia, thought they could still drive, and continued to do so. My wife ended up phoning VicRoads and a request from VicRoads to attend a driving test was ignored by her parents. They did not understand. The family ended up having to flatten the batteries on the car. It shouldn't have to be this way - what happens where there is no family to do this?*

Although there is little clear evidence to go by, anecdotally it appears that a small number of people may be in denial, avoiding getting a diagnosis of dementia in order to remain driving:

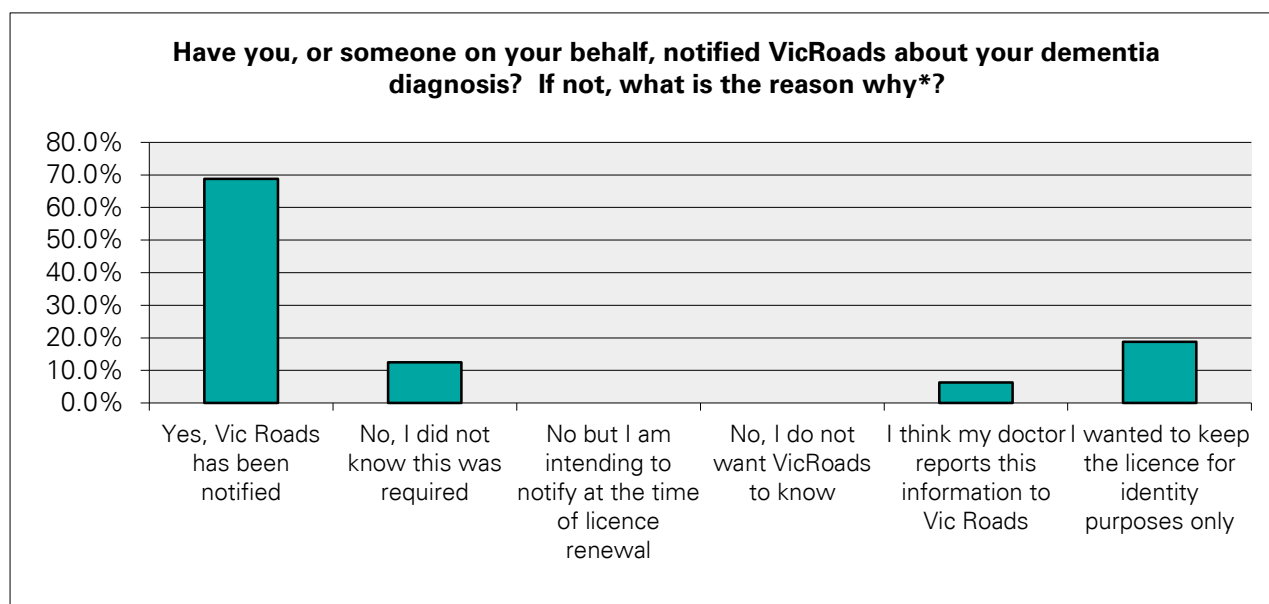
*This is a very important issue. I know a case where the driver clearly has dementia in mid 60's but both she and her husband are in denial and won't get a diagnosis. Family and friends are very concerned about her as her husband is always too intoxicated to drive home from social outings.*

**Table 7: Reason VicRoads not notified of dementia diagnosis.**

Reason VicRoads not notified	Response Percent	Number of responses
Not applicable (already notified, or no longer driving)	33%	20
Did not know this was required	33%	20
Intending to notify at the time of licence renewal	3%	2
Did not want VicRoads to know	5%	3
Thought the doctor reports this information to Vic Roads	2%	1
Wanted to keep the licence for identity purposes only	17%	10
Other (please specify)	7%	4

The small number of people with dementia who completed the survey seemed quite well informed of the requirement to report to VicRoads.

**Figure 3 Notification of VicRoads of a diagnosis of dementia**



\*n=16

The survey also asked who should inform the person with dementia that they are no longer fit to drive (Figure 4). Up to two preferences were permitted in response. Over 70% prefer a General Practitioner to inform the person with dementia they are no longer fit to drive. This preference was extended to include a medical specialist as a preferred source of this advice:

*A doctor who specialises in dementia, not our own general practitioner.*

*A difficult decision for the person with dementia - We had great advice from doctors.*

*Older people hold GP in high esteem usually.*

*Any one or combination of these "expert" opinions is generally better tolerated by the person with dementia.*

*Think it needs to come from someone external to the family - an authority of some sort.*

*Depends on degree of dementia...it is also often better for a specialist (rather than the GP who sees the patient often) to impart bad news about not being able to drive.*

Whilst families wish to be involved in providing advice about driving skill, there is concern that they are often not seen as authoritative enough to advise the family member with dementia that they are no longer fit to drive. It can become an ongoing source of friction.

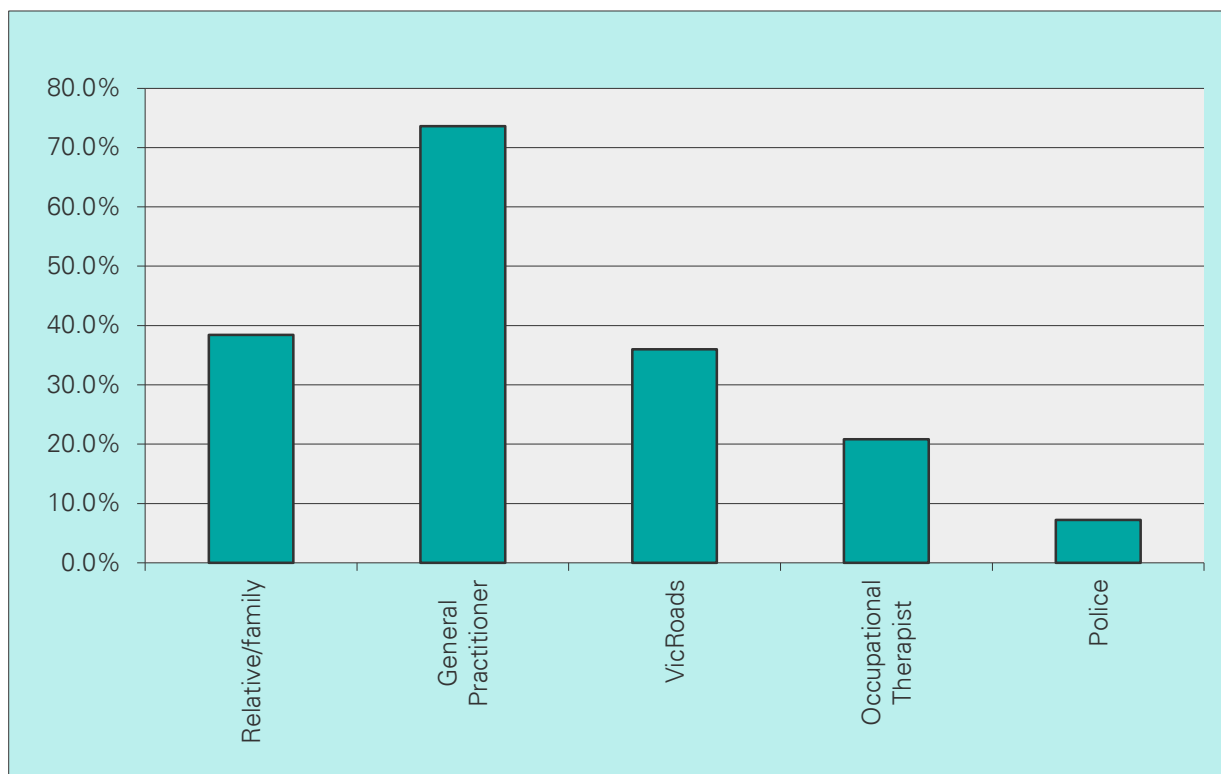
*This is one of the more difficult issues for many and can cause friction between partners.*

*It would not matter who tells him as he would not believe them as he thinks he will be fine. It needs to be in writing from police or Vic Roads so the PWD can see it in writing.*

*This person believes when he lost his licence that the Occupational Therapist was very harsh and not sympathetic. It wasn't the case, but he FIRMLY believes it.*

Family tried to tell my mother and father in law but this failed, the medical fraternity failed by not taking this to the next step of reporting, Vic Roads need information to act. There was a request from VicRoads to do a driving test and it was ignored. The dementia was advanced enough that they did not understand.

**Figure 4 Who should inform the person with dementia they are no longer fit to drive**  
 ☒family carer preferences



The same question was asked of people with dementia. Of the 13 people who answered the question, they too prefer a GP or medical specialist (n=9) to tell them they are no longer fit to drive. Being told by a relative or family member (n=8) was also preferred. Some people with dementia also make the choice themselves, recognising that their abilities have diminished. Others self-regulate by reducing distractions (e.g. radio off, limited dialogue with passengers) or limiting driving conditions (e.g. only day driving to shops and doctor).

*I personally knew I could no longer drive, as I became confused with directions.*

Very few people with dementia wanted VicRoads (n=2) or the police (n=1) to tell them they were no longer fit to drive. No respondent wanted an Occupational Therapist to inform them they were not fit to drive. Although a larger sample size is required to examine preferences further, it is plausible that preferences relate to trusted relationships:

*I would trust the opinion of my family, and I know they would be honest with me.*

### On road driving assessments

Although an on road assessment is legally required to maintain a conditional licence, the cost of the assessment is incurred by the driver. Questions about on road driving assessments were included in the survey because the cost and accessibility of on road tests is a source of regular complaint for Alzheimer’s Australia Vic clients. Twenty two family carers had experience with an on-road driving test with an occupational therapist. Nine people with dementia had experienced an on-road driving test with an occupation therapist.

Participants were asked to rate how satisfied they were with the arrangements to undertake an on-road driving assessment. Fifty percent of family carers were either satisfied or extremely satisfied with the arrangements. Six out of nine respondents with dementia were also satisfied or extremely satisfied. Almost 18% of family carers (and two people with dementia) were neither satisfied nor dissatisfied with arrangements with testing. Thirty two percent of family carers (and one person with dementia) were dissatisfied or extremely dissatisfied with the arrangements for driver testing. Comments indicated the dissatisfaction was around cost of the test, waiting time for the test, results of the test, and testing taking place in an unfamiliar car.

*Tested in a very small unfamiliar car -should have been tested in own car -acceleration, brakes, steering very different.*

*Indicator on test car was on the left - it caused great confusion.*

*Long wait time and expensive.*

*The arrangements were good, but I was amazed he was given a relatively good report and told he could continue driving. He has not driven as he had a personal accident and his condition has deteriorated since then.*

*We drive one hour to have lesson in Geelong as this is where OT will do test.*

*Paying an OT and driving instruction is over the top of adding to cost.*

*Too long a wait (2 Months) for the test.*

For people with dementia it is worthwhile validating their pride in their [usually excellent] driving record, but to clearly explain that testing is about recognising that they have a medical condition which will affect their driving record in the future.

*I had driven for 44 years, never caused an accident and had only 2 speeding fines in all of those years. I had thought I was doing well.*

*From my point of view I believe I am a reasonable driver. I drove to the airport recently doing the speed limit and drove behind an elderly lady doing 60kms. She appeared to be in her 80's and presumably didn't have Alzheimer's. But I think she caused a fair amount of frustration. She didn't appear to be aware of the situation she was causing.*

The outcomes of the last on-road driving test are shown in Table 8.

**Table 8 Outcome of last driving test**

Outcome after last driving test	Response Percent
Continue to drive without restriction	20%
Continue to drive with conditions on licence	33%
Recommendation to stop driving	20%
VicRoads deemed the driver unfit to drive and their licence was cancelled	31%

Over 30% of people fail the on road driving test which leads to the question of cost of testing.

Just over 18% of people had to pay between \$100 and \$300 for the test, almost 41% of people had to pay between \$300 and \$500. Almost 10% paid between \$500 and \$700 and over 5% paid over \$700. There appears to be a large variation in the cost of this testing

depending on which geographical area a person lives. There were additional comments on the strain the cost of these tests cause, particularly for a pensioner:

*The cost involved is very unfair especially if they need to re-sit the test every year and are pensioners.*

*Over \$300 was far too much but we did it because we had too much to lose if we hadn't.*

*Far too expensive as we had to do it twice.*

*OT able do this testing comes from 100 Km away.*

*The following year I made the decision that it was not economically viable to even sit the test*

*Should have a compulsory low cost testing every 12 months for people diagnosed with dementia. It is too expensive. Should be mandatory testing on recommendation from a doctor.*

*Test was expensive and unsuitable. Tester gave instructions orally when semantic expression is specifically the disability suffered. Occupational Therapist and tester chattered to simulate reality, but driver's practice is to avoid chatter and distractions.*

Whilst many people indicated the on road testing to be expensive, an additional question asked about whether the testing is value for money (within the context of VicRoads policy to keep people driving, and supporting a person with dementia to continue to drive).

Forty nine family carers rated the test on a scale from "money well spent" down to "a complete waste of money" (Table 9).

**Table 9 Value for money rating of an on road driving test**

Money really well spent					Complete waste of money
13	9	11	5		11

Almost 45% of family carers who responded to this question felt the on-road testing was money well spent.

*Yes...from the perspective of saving lives.*

*It turned out to be money well spent as the driving assessment helped to reassure my hubby it was time to give up something he loved.*

*After first assessment was issued with a restricted licence; failed at the 12 month review. Provided an independent assessment that was well worth having, as well as having legal standing.*

Almost 33% of family carers who responded to this question felt the on-road testing was money wasted.

*People on a pension are not going to be too inclined to pay for a test. Many will ignore this.*

*The cost really creates a problem especially as it can become a yearly assessment*

*My husband really should not have been driving and my expectation that the OT/ Vic Roads would come to this conclusion. Therefore a 3rd party making the decision did not occur and made our situation very difficult.*



Seven people with dementia also answered this question. For this group it was either money well spent or a complete waste of money, dependent on the outcome of the test.

*If I can continue to drive after the test, yes I would assume it is value for money.*

Given the inequity in the cost of the on road driving test, a question was also asked about how on road driving tests should be paid for (Table 10). Preference was clearly against the person with dementia paying for the test, although comments indicated a willingness to pay for part of the cost of the test, with subsidy through a Medicare or state government scheme.

*There should be financial support for those who are financially disadvantaged. However, if people can afford to run a car and can insure the vehicle, it would make sense to have some form of insurance cover to pay for OT assessments.*

*Perhaps this is an area for the Traffic Accident Commission. It needs accident prevention funding.*

*As we are both on pensions it would have to receive some rebate.*

*We feel for those people who haven't the resources to overcome the problems that living away from local buses and not having money for taxis give them.*

Some people with dementia felt that they had paid for their licence and if the government wanted more testing then they should pay. This may reflect the need for more discussion and education around driving responsibilities and rights.

*Why should I pay when I've already paid for my licence?*

*If the government want you to have the test, then they should pay for it.*

**Table 10 Opinion on how on road driving test should be paid for**

Payment Options	Family carer response	People with dementia response*
By the person having the test	15%	6%
State Government, with part rebate	33%	56%
Include in insurance schemes (e.g. car or health insurance)	24%	19%
Rebate through Medicare	55%	38%

\*n=16

### Improving transport options and services for people with dementia

A final question asked for suggestions for improvement in transport options and services for people with dementia, who no longer drive. There were seven responses from people with dementia and 63 responses from family cares to this question.

There were clear themes:

- 'Taxi cards' for subsidised taxi fares are very appreciated by people but are often difficult to obtain. Difficulties relate to perception that the scheme is for physical disabilities, time consuming paper work, long wait for cards, multiple rejection of applications, hesitancy by some doctors to authorise applications and ineligibility because the card is only available to pension card holders or people on lower incomes.
- Desire for volunteer drivers, who have an understanding of dementia.

- Service providers to include more transport assistance for appointments and errands, through packaged care or home care assistance.
- Community transport schemes through Councils are currently patchy in service delivery across jurisdictions.

*A pool of cars with drivers would be very helpful if a phone call could book a car to take dementia patients to appointments to relieve carers of one duty on some occasions.*

*I think half-price taxi fares should be available to all those people with dementia without means testing. The cost of caring for someone regardless of their illness places an unfair burden on a family...*

## DISCUSSION

Alzheimer's Australia Vic provides information, support and advocacy for people living with dementia. This includes the provision of information about the effect that dementia has on driving, the requirements for retaining a drivers licence, counselling people about driving retirement, preparing people for finding alternative mobility options, and coping with carer stress.

It is generally well accepted that a diagnosis of dementia does not automatically preclude a person with dementia from driving. Drivers with dementia have a higher risk of deficits in driving skill and crashes compared to healthy people the same age.<sup>15</sup> Although crash monitoring was not included in this study, a survey in the USA found 18% of active drivers with dementia had a crash in the past year.<sup>16</sup> Regardless of driving record, loss of ability to safely drive is an inevitable outcome as dementia severity grows.

### Impact of stopping driving

Seventy two percent of people with dementia in this sample were no longer driving. They relied mostly on their spouse (67%) and other family members (41%) to drive them. Twenty five percent of people were staying home more. These findings are consistent with published literature which report a loss of sense of independence and autonomy, and a reduction in mobility leading to social isolation.<sup>17</sup>

For both the family carer, and the person with dementia, the impact of stopping driving was greater than they had anticipated. Sixty three per cent of family carers reported that the impact of the person with dementia stopping driving was a lot more (or more than) expected. They describe a range of reactions to stopping driving including anger and resentment, depression, loss of social opportunity and spontaneity, loss of self-esteem, impact on the activities of daily life, additional logistics, emotional impact and carer burden. The provision of transport by a spouse or family member can create significant caregiver burden. According to AIHW people who live with a person with dementia provide 40 or more hours of care per week, and the care is physically, mentally, emotionally and economically demanding.<sup>18</sup> They often report negative consequences such as feeling weary, worried or sleep deprived due to their caring role.

Often people with dementia have other co-existing health conditions which have profound consequences not only for their own quality of life but that of their families and friends.

<sup>15</sup> Charlton, J, Koppel S, Odell M *et al*. Influence of chronic illness on crash involvement of motor vehicle drivers: 2<sup>nd</sup> Edition. Monash University Accident Research Centre. Report No. 300. November, 2010.

<sup>16</sup> Croston J, Meuser T *et al*, Driving retirement in older adults with dementia. *Top Geriatr Rehabil*. 2009 April 1; 25 (2):154-162. <http://www.ncbi.nlm.nih.gov/articles/PMC2805829> Accessed 29/11/2012

<sup>17</sup> National Highway Traffic Safety Administration. Community Mobility and Dementia. A review of the literature. November 2006. [www.nhtsa.gov/people/injury/olddrive/CommMobilityDementia](http://www.nhtsa.gov/people/injury/olddrive/CommMobilityDementia) Accessed 29/11/2012

<sup>18</sup> AIHW 2012. Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW. p 117.

## Driver Testing

Just over a third of family carers were either unaware or unsure of the requirement to report a dementia diagnosis to VicRoads, mostly due to lack of awareness. It is not unusual for lack of awareness to be at least 10% higher.<sup>19</sup> Keeping a licence for identity purposes, despite no longer driving, has been noted in other studies.<sup>20</sup>

Sustained and timely education is required to inform, and reduce misunderstanding. Key messages required include:

- A diagnosis of dementia does not mean a person can no longer drive, but requires a conditional licence necessitating at least an annual medical review, and possibly an on road driving test.
- There is no mandatory reporting by doctors in Victoria. A dementia diagnosis requires notification of VicRoads by the licence holder.
- Doctors, health professionals and members of the community can inform VicRoads of genuine concerns about the driving ability of a person with dementia.
- There are alternative identity cards available for people who need identification in lieu of a drivers licence.

There has been some suggestion that education also focus on driving as a responsibility rather than a right, and warning people that a lack of compliance with the legal obligations to abide by VicRoads rules can lead to criminal liability and car insurance breaches.<sup>21</sup> This may cause discomfort for some doctors.<sup>22</sup>

As awareness of the change to conditional licence increases, so too would one expect an increase in referral for on road driver testing. People appear to support an independent on road testing regime from a safety standpoint. However, there are many unresolved long standing issues around the cost and accessibility of on road driving assessments for people with dementia.

The practical driver test needs to be equitable and consistent in cost, method and accessibility. It is unjust that some people with dementia have lost their ability to drive because they could not afford the test. Whilst most people (41%) pay between \$100 and \$300 for an on road driving test, 5% (usually rural residents) are paying over \$700. Coupled with the expense of the doctor's examination, the cost of the driver assessment is a significant cost burden expense for a pensioner, particularly if an annual retest is required. Waiting times for testing also seem to indicate demand exceeding supply of occupational therapists trained in driving assessment.

The family carers opinion on driving is a useful additional insight into everyday driving ability. This is supported in the published literature where a study in Austria concluded that caregivers' risk judgements, and not accidents or licence issues, were the reason most people with

---

<sup>19</sup> Alzheimer's Australia NSW. Driving and Dementia in New South Wales. Discussion Paper 1, April 2010.

<sup>20</sup> Croston J, Meuser T et al, Driving retirement in older adults with dementia. *Top Geriatr Rehabil.* 2009 April 1; 25 (2):154-162. <http://www.ncbi.nlm.nih.gov/articles/PMC2805829/> Accessed 29/11/2012

<sup>21</sup> Beran R, Gerber P, Devereux J. Usefulness of Austroads' fitness to drive guidelines: lessons from the *Gillet* case. *MJA.* 2009; 190 (9): 503-505

<sup>22</sup> Moorhouse P, Hamilton L, et al. Barriers to assessing fitness to drive in dementia in Nova Scotia: Informing strategies knowledge translation. *Canadian Geriatrics Journal*, Vol 14, No3, 2011

dementia stopped driving.<sup>23</sup> Efforts to document abnormal driving behaviours by informants who have had direct observation of driving skills should not be ignored.<sup>24</sup>

A comprehensive review of the literature<sup>25</sup> found that several factors are useful for differentiating between people with dementia that presently remain safe drivers from those who have progressed to impaired driving:

- dementia severity and duration
- gender
- patient self-assessment
- family assessment
- neuropsychological measures
- on-road evaluations
- driving simulator testing

Whilst the family is noted to play a significant role in driving cessation, family carers and people with dementia preferred doctors (or medical specialists) to advise them when to cease driving. They were perceived to be authoritative and trusted. This is consistent with previous studies which note that families and doctors are the two major 'stakeholders' in driving retirement.<sup>26</sup>

### **Alternative mobility options**

A significant investment is made to monitor drivers with dementia and other morbidities. However, equal attention should be given to driving cessation counselling, helping people access alternative modes of transportation, and supplying quality alternative transport. Many are not 'age friendly' let alone 'dementia friendly'.

A 2009 Municipal Association of Victoria (MAV) review of Councils found that community transport is a significant financial challenge with Councils under pressure from petrol price rises, and a lack of secure funding for the purchase, maintenance and accreditation of vehicles.<sup>27</sup> The MAV found there was significant demand for community transport, particularly for transport disadvantaged country areas, and those people with a medical condition or disability requiring door to door transport. Some smaller Councils do not have the capacity to fund and provide a service, leaving significant gaps and unmet need in those communities. Similarly AIHW found that three quarters of people with dementia in the community required help with private transport.<sup>28</sup> They report mobility as a core activity with significant unmet need for formal assistance.

The high use of taxis amongst this sample indicate a strong need for door to door transport for people with dementia, and a lack of safe alternative. Although there are subsidies available for people who are eligible for the Multi-Purpose Taxi Program, there are many challenges for people with dementia to access this subsidy. Furthermore even half price fares can still be too expensive for those with a regular need to use taxis, or travel longer distances.

---

<sup>23</sup> Seiler S, Schmidt H, Lechner A, Benke T, Sanin G, et al. (2012) Driving Cessation and Dementia: Results of the Prospective Registry on Dementia in Austria (PRODEM). PLoS ONE 7(12): e52710. doi:10.1371/journal.pone.0052710, 2012

<sup>24</sup> Croston J, Meuser T et al, Driving retirement in older adults with dementia. *Top Geriatr Rehabil.* 2009 April 1; 25 (2):154-162. <http://www.ncbi.nlm.nih.gov/articles/PMC2805829/> Accessed 29/11/2012

<sup>25</sup> Brown, L and Ott, B. Driving and Dementia: A Review of the Literature. *J Geriatr Psychiatry Neurol.* 2004 December. 17(4):232-240

<sup>26</sup> Croston J, Meuser T et al, Driving retirement in older adults with dementia. *Top Geriatr Rehabil.* 2009 April 1; 25 (2):154-162. <http://www.ncbi.nlm.nih.gov/articles/PMC2805829/> Accessed 29/11/2012

<sup>27</sup> Municipal Association of Victoria. Submission to Taxi Industry Inquiry. 24 June 2011.

<sup>28</sup> AIHW 2012. Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW. p.58 and p.116

In 2012 the Family and Community Development Committee *Inquiry into Opportunities for Participation of Victorian Seniors* report made a number of age-friendly transport recommendations which included the need for a greater range of reliable community transport options to supplement the public transport system. A state-wide strategy to integrate age-friendly approaches to community 'door to door' transport will help to cater to the needs of people with dementia.

## **Conclusion**

A new Road Safety Strategy introduced by the Victorian Government aims to reduce deaths and serious injuries on Victorian roads by 30 per cent over ten years.<sup>29</sup> Among a number of identified issues was the estimate that 14 per cent of all driver fatalities were older drivers. Community expectation is that the balance between independence and mobility of the driver, and public safety is paramount. Deloitte Access Economics estimate a 32% growth in the number of people with dementia, expecting almost 100,000 Victorians with dementia by 2020. This creates a large number of people requiring regular monitoring of their driving and cognition, and increasing demand for alternative 'door to door' transport. This requires significant collaboration between health professionals, service providers, the transport industry, VicRoads and the Victorian Government to develop policy, program and research to meet these community needs.

## **PRIORITY ACTION AREAS**

Alzheimer's Australia Vic identifies the need for priority action in the following areas:

### **Education and information**

1. Engagement with people with dementia as early as possible after diagnosis. Support people with dementia to make informed choices, so far as possible, with the aim of building effective partnerships between them, their families and their health professionals.
2. Introduction of sustained education campaigns by VicRoads encompassing responsibility to report dementia, explanations of conditional licences and medical review requirements.

### **Alternative mobility options**

1. Further development of dementia friendly mobility and social inclusion programs, funded by the Victorian Government.
2. Implementation of the age-friendly transport recommendations of the Victorian Family and Community Development Committee *Inquiry into Opportunities for Participation of Victorian Seniors*, 2012.
3. Incorporation of community transport into Victorian Government transport policy, including an adequate and sustainable funding commitment.
4. Simplification of the Multi Purpose Taxi Program approval process for people with cognitive impairment, and review of income threshold.
5. Further expansion of HACC services and packaged services for assistance with transport to attend appointments, particularly where there is no family to assist the person with dementia.
6. Exploration of innovative models of door to door transport.

---

<sup>29</sup> <http://www.roadsafety.vic.gov.au/strategy/victoria-s-road-safety-strategy-2013-2022.html> Accessed March 27 2013.

## **Research**

1. Further investigation of driving and mobility experiences of people without family support<sup>30</sup>, and of people with dementia from culturally and linguistically diverse backgrounds.
2. Research on crash risk, or crash involvement of people with dementia.
3. Investigation of the number of people with undiagnosed dementia driving on Australian roads.
4. Further development of alternative valid and reliable office based driver testing tools.
5. Expanded research into the benefits of independent living devices/assistive technologies such as user friendly GPS, crash warning systems and exercise interventions directed at driving-related cognitive ability.
6. A review of driver assessment compliance. Anecdotal evidence suggests that individuals with progressive cognitive conditions may forget or misunderstand that they are no longer fit to drive.

## **Driver testing**

1. Ensure that driver testing by occupational therapists to be equitable and consistent in cost, method and accessibility. The Victorian Government to subsidise the cost of testing.
2. Assessment of the supply of occupational therapists, particularly in regional areas with higher projections of dementia prevalence.
3. Ensure national uniformity in driving regulations/testing.

---

<sup>30</sup> AIHW estimates 12% of people with dementia live alone in private dwellings in the community.



**[fightdementia.org.au/vic](http://fightdementia.org.au/vic)**

National Dementia Helpline

An initiative of the Australian Government

**1800 100 500**