DRIVING and DEMENTIA

in New South Wales

Discussion Paper 1

April 2010

Alzheimer's Australia NSW
Living with dementia

Acknowledgements

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Executive Summary

The issue of driving for a person with dementia, their family and their friends is often a contentious and emotional one. For any individual a licence to drive provides access to mobility and represents independence, freedom and, in some cases, status. The loss of a driving licence due to dementia can be traumatic but necessary.

Some people with dementia have said that giving up their driver's licence was harder than coming to terms with the diagnosis of dementia itself. The emotions attached to driving and the decision to give up driving, the lack of clarity around access to information, and a driver's rights and responsibilities after a diagnosis highlights the urgent need for further discussion and action.

This discussion paper seeks to examine the current context of driving with dementia in NSW, to open a dialogue with all stakeholders about this important issue, and lay the ground work for people with dementia to make a smooth transition from driver to non-driver.

As Australia's ageing population increases so does the number of older drivers, and potentially, the number of drivers with dementia. While research has indicated that the crash rate for older drivers is not high, serious concerns have been expressed by some researchers and advocacy groups about the high crash risk for drivers with dementia. It has been suggested that the crash risk for a person with dementia is equal to, if not greater, than a person with a blood alcohol reading of 0.08[ii] and also, compared to older drivers without a diagnosis of dementia, drivers with dementia can have twice as many crashes in the years after the onset of the disease[iii].

Across Australia there are an increasing number of people diagnosed with dementia. Currently there are an estimated 257,000 people in Australia diagnosed with dementia and 88,000 people with dementia residing in NSW[iv]. Also, there are currently over 750,000 drivers on NSW roads with a Class C licence over the age of 60 and amongst these there are more than 90,000 drivers over the age of 80. Of those over 85 there is a one in four chance of developing dementia[v]. Consequently, many older drivers as they age will develop dementia and need to cease driving. For many, making the decision to cease driving will be easy, but for some the decision will be fraught with tension, anxiety and misinformation.

In the early stages of a person's cognitive impairment, due to dementia, the particular risks of driving with dementia can go unnoticed. This is partly due to the estimated average three year lag that exists between the presence of dementia symptoms and formal diagnosis.

Our research has found a lack of clarity in NSW Roads and Traffic Authority (RTA) information about driving and dementia, inconsistent and unclear advice from insurers, lack of a clear regime of information and testing for drivers with dementia and a lack of alternative transport options for those facing loss of licence due to dementia.

Consultations with consumers undertaken in 2009 revealed that many people with dementia are unaware of their legal responsibilities regarding driving, once diagnosed. Many, particularly males, resist giving up their driver's licence, even when their driving becomes unsafe, and many carers rely

on a person with dementia to be able to drive so that they can get out and about. Finally, many carers and people living with dementia have no viable alternative transport opportunities.

This can mean serious outcomes for people living with dementia and their carers, including lack of access to medical services, isolation, increased stigma and early placement into residential care. Providing information to support the difficult transition from driver to non-driver, and ensuring alternative transport is available, can help people with dementia to live at home, remain independent for as long as possible and delay admission to a residential care facility.

In summary, Alzheimer's Australia NSW recommends:

1. The Commonwealth and NSW Department of Health introduce programs that better enable early diagnosis of dementia so those diagnosed have the opportunity to participate in planning and decision-making regarding the transition from driver to non-driver.

2. The NSW Roads and Traffic Authority (RTA) develop a Driving and Dementia information pack for doctors in NSW to issue to patients with dementia at the time of diagnosis. This material should include the need for dementia patients to prepare to cease driving, the need to check their insurance liabilities and the need to disclose a diagnosis of dementia to the RTA. This material should also be available for Aged Care Assessment Teams (ACATs), Dementia Advisers and other health professionals.

3. The RTA develops driver testing regimes that more accurately assess a person's cognitive capacity to drive and ensure these tests are readily available at all RTA sites across NSW.

4. The RTA introduces a compulsory regular testing regime that applies to all licensed drivers diagnosed with dementia.

5. The RTA provides clear information to drivers about their responsibility when driving after a diagnosis of dementia. This includes:

    a. Updating the RTA's *A guide for older driver licensing* with a specific section on dementia and driving that stresses the legal duty on a driver to report a diagnosis of dementia.

    b. Updating the RTA website with a specific section outlining a person's responsibilities after a diagnosis of dementia and further helpful information such as the availability of an ID card in lieu of a driver licence.

    c. Ensuring NSW drivers' licences state the legal duty on a driver to report the diagnosis of any medical condition that may reduce a person's capacity to drive safely, including dementia.

    d. Ensuring all RTA staff are given dementia-specific training in consultation with Alzheimer's Australia NSW.

6. The RTA, with Alzheimer's Australia NSW, develops accessible community education and information that supports the person with dementia and their carer to make a smooth transition from driver to non-driver.

7. The NSW Government increase funding for a range of alternative transport options for people living with dementia, in particular for those living in rural and regional NSW. These should include increased funding for the NSW Community Transport Scheme (CTP) and the NSW Taxi Transport Subsidy Scheme to be expanded in line with the ageing of the NSW population and increasing numbers of people in communities across NSW living with dementia.

8. The NSW Government ensure all persons who lose or relinquish their licence after a diagnosis of dementia, regardless of their age, are entitled to access the NSW Taxi Transport Subsidy Scheme and NSW travel concessions.

9. The NSW Government subsidise the cost[1] of assessments conducted by occupational therapists for drivers with dementia.

10. The NSW Government require insurance companies to provide consistent, clear advice to policyholders about their responsibilities including disclosure of a diagnosis of dementia.

11. The NSW Government continue to work on dementia-specific driving initiatives such as improved signage and ensuring better transport options be provided by residential facilities.

12. The NSW Police and the RTA develop a robust tracking mechanism to report the actual number of dementia-related traffic accidents.

13. The Royal Australian College of General Practitioners acknowledge in the GP Guidelines the importance of general practitioners providing information to their patients about transitioning from driver to non-driver as soon as they are diagnosed so they can plan ahead and prepare for the change.

[1] Costs for assessments begin at $300 (communication with Occupational Therapists Australia NSW, Feb 2010)

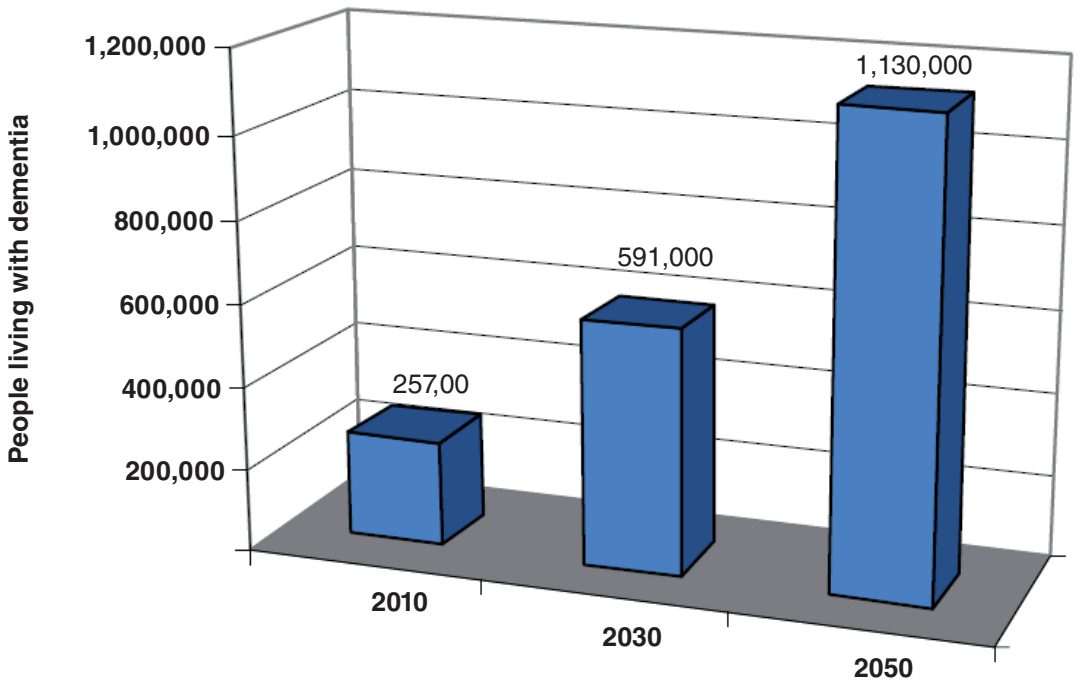
Background

According to recent data from the Australian Bureau of Statistics (ABS)[vi], the population aged 65 and over is projected to increase rapidly in the short and medium term thus ensuring a corresponding increase in drivers from this group. Current NSW Roads and Traffic Authority (RTA) statistics indicate that there are presently more than 750,000 drivers on NSW roads with a Class C licence over the age of 60[vii]. Of these, more than 90,000 are aged over 80. Many of these drivers will eventually relinquish their licences for a range of reasons, however there will be a cohort who will be diagnosed with dementia and continue to drive.

Recent figures from the Access Economics report *Keeping Dementia Front of Mind: incidence and prevalence 2009-2050* states that while the current number of people in Australia with dementia sits at 257,000 there is a projected increase to 591,000 in 2030 and a four-fold increase to 1.13 million people by 2050. Currently, in NSW there are an estimated 88,000 people with dementia. This is expected to grow to 188,000 in 2030 and again to 341,000 by 2050.

The rate of increase in diagnoses of dementia is often referred to as a tsunami heading toward us. So too is the projected number of drivers with dementia who will need support and assistance in making the inevitable transition from driver to non-driver.

Figure 1. Dementia Prevalence Projections for Australia 2010~2050



Source: *Keeping Dementia Front of Mind*. Access Economics (Aug 2009)

Why is this discussion necessary?

While steps have been taken to monitor the driving capacity of older drivers to ensure their safety and the safety of others on the road, the particular risks of someone driving with dementia often go unnoticed as signs of cognitive impairment can appear sporadically, causing driving to be good one day and not so good another. In addition, proper diagnosis of the disease is often delayed, and so many people continue to drive before an official diagnosis, and even after diagnosis of dementia, without proper monitoring.

A driver in the early stages of Alzheimer's disease can experience a decline in important cognitive functions such as visual and spatial orientation, judgement and visual selective attention. Drivers with dementia can experience memory loss, which affects their ability to remember important information such as warnings about changed traffic conditions and cognitive changes may also impact on their ability to recognise their own capacity to drive safely.

When the issue of capacity is in question, many people ask where the final decision with regard to a person's right to drive or not to drive should lie. In other cases, such as drunk driving, when a persons' capacity is in question, the final decision is made by the RTA. For people living with dementia, the decision to relinquish their driver's licence is often a difficult and emotional one. Their identity is altered and as their dementia progresses their insight and judgement decreases over time. Family members often find themselves in a difficult and compromising position. Carers talk about the enormous strain they face when the person they care for cannot accept the reality that eventually they will need to stop driving. General practitioners too often feel the burden of having to discuss, and in some cases, advise a person with dementia that they should no longer drive. Some have voiced concern that it may discourage people from visiting their general practitioner if they fear they have memory concerns but worry they may have their licence taken from them.

Anecdotal evidence from Alzheimer's Australia NSW service areas in education and carer support suggests that many carers and people with dementia have concerns with regard to driving and opinions vary widely. Alzheimer's Australia NSW acknowledges that all people diagnosed with dementia will be different in their unique experience of the illness. However, the wider community and people living with dementia have a right to good accessible information about the issues, rights and responsibilities of driving with dementia and should be supported in making the transition from driver to non-driver.

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

Purpose

This discussion paper seeks to examine the context of driving with dementia in NSW. It provides the results of a consumer-driven survey conducted by Alzheimer's Australia NSW and reviews current research and discussion on the important issue of driving and dementia. This paper is an imperative tool to open the dialogue between driver licensing authorities, insurance companies, driving assessors, occupational therapists, policy makers and all those living with, and supporting, people with dementia and their families. Increased accessible and appropriate information and service provision for drivers with dementia will allow them to participate in decision-making for their future in a holistic and worthwhile way.

Driver Licensing in NSW

In December 2008 the NSW Government introduced state-wide reforms for driver licensing regulations for older drivers. These reforms stipulated that all drivers from the age of 75 are required to have an annual medical check by a general practitioner to assess their fitness to drive and 'pick up issues such as deteriorating eyesight and dementia'[ix]. After the age of 85 a practical test is also undertaken with the medical report. Once the driver reaches the age of 85 medical reporting continues annually and testing biennially. If the driver is assessed fit to drive they have a range of options to suit their driving requirements.

If a driver has a long term injury or illness that may affect their ability to drive safely, the law requires the driver to notify the RTA as soon as possible[x]. Dementia is one of these illnesses, situated within the 'Neurological Disorders' category in Austroad's national medical standards and guidelines, *Assessing Fitness to Drive*[xi].

Current RTA Guidelines require that once a disclosure of dementia is made to the licensing body the driver must take a medical report form to a doctor for assessment. Guidelines for the assessment for fitness to drive are set out for the doctor and recommendations are made by the doctor accordingly. The doctor can either recommend that the driver is fit to drive, suggest restrictions on their licence, request an assessment by a specially trained occupational therapist for further driver assessment or deem the person unfit to drive. Under RTA guidelines, if the person is deemed to still be fit to drive after a diagnosis of dementia is disclosed, a review is undertaken every 12 months. The doctor can recommend more frequent reviews

if required, such as deterioration in the progress of the driver's dementia or if a concerned family member or friend makes an unsafe driving report to the RTA with regard to the driver.

If the doctor cannot make a firm decision, or the driver disagrees with the doctor's decision, the driver can be referred by the doctor for an occupational therapist review where a driving assessment will be undertaken and the outcome reported to the RTA.

Failure of the driver to disclose the illness can have serious ramifications as in the *Gillet Case* (2007)[xii]. This case found a person with epilepsy liable following a car accident. He had not reported his condition to the licensing authority even though two neurologists had found him fit to drive, based on the national medical standards and guidelines contained within the *Fitness to Drive* publication.

Table 1: Driver Licencing in NSW

Driver *without* dementia	**Driver *with* dementia**
Age: 75 to 84 • Legal requirement to disclose any illness or disability that may affect the capacity to drive safely • Annual medical check-up. Doctor completes medical form to assess fitness to drive and form is returned to the RTA • If the assessment rules unfit to drive the driver licence is revoked.	***Age: under 85*** • Legal requirement to disclose illness to RTA. Dementia classed as a 'neurological condition'. • Medical form to be filled by doctor to assess fitness to drive. Doctor can recommend: 1. Fit to drive (therefore NO TEST) 2. Restricted radius licence recommended by GP 3. OT assessment • Review – at least every year. GP can recommend more frequent reviews according to the perceived capacity to drive according to the *Fitness to Drive guidelines* (ref RTA).
Age: 85 and over • Legal requirement to disclose any illness or disability that may affect the capacity to drive safely • Annual medical check up continues • Practical driving assessments are conducted from age 85 and every 2 years following (85, 87, 89, etc) • If the doctor assesses the driver 'fit to drive' the driver has three options: 1. RTA driving test (no charge) 2. Driving assessment from home with an accredited assessor (fee for service) 3. Modified licence (as agreed with manager of RTA) NO TEST required	***Age: 85 and over*** • Legal requirement to disclose illness to RTA. Dementia classed as a 'neurological condition' • Medical review by doctor every year unless more frequency specified • If the doctor assess the driver 'fit to drive' the driver can choose from three options: 1. RTA driving test (no charge) 2. Driving assessment from home with an accredited assessor (fee for service) 3. Modified licence (as agreed with manager of RTA) NO TEST required
For all drivers • If the doctor deems the driver 'unfit to drive' due to a medical condition (including dementia) the driver licence is revoked by the RTA • If the doctor has concerns about the fitness of the person to drive or the driver disagrees with the doctor's decision referral can be made for a specialist occupational therapist assessment.	

The Alzheimer's Australia NSW Driving Survey

In 2009 two surveys were conducted amongst Alzheimer's Australia NSW consumers to investigate the views of both carers and people with dementia. 104 carers and 61 people with dementia responded to the survey. Respondents were drivers and non-drivers of varying ages, residing in metropolitan, regional and rural areas of NSW. 13.5% of carers and 11.9% of people with dementia lived further than 10 kilometres from the nearest service/town centre.

This consumer-driven study provides a preliminary investigation into the area of driving with dementia and the needs of all people living with dementia.

Results

People with dementia still driving

> *I remain aware of the fact I will probably have to give up driving when I am no longer capable (person with dementia)*

Of the 17 people with dementia still driving, 13 were men and 4 were women. 12 of the 17 drivers claim that it was 'important' or 'very important' for them to continue to drive. 81.3% of the people with dementia still driving responded that they did not worry about their driving skills and yet 40% claimed that they 'sometimes' got lost or disoriented when driving.

Most of this cohort (86.7%) realised that they would eventually have to give up their licence due to dementia and were aware of the risks associated with driving with dementia such as memory loss, disorientation, poor planning and inability to make quick decisions. However only 26.7% of these drivers had had their driving skills tested.

The most common reasons for drivers retaining their licences were 'transport for food shopping' and 'medical appointments' both rating 23.1% each. This was followed closely by 'my independence' (21.2%); 'leisure' (19.1%); 'assist partner/family member' (7.7%) and 'to assist with my mobility issues' (5.8%).

Approximately half of those still driving (56.3%) responded that they had taken the opportunity to make plans for a future without their licence and the qualitative responses indicated this would be reliant on another person being able to drive.

Caring for a person with dementia who still drives

Of the 104 carers who took part in the survey, 21 (20.2%) cared for a person with dementia still driving. The remaining 79.8% cared for someone who had given up driving at the time of diagnosis (40.3%), had given up since diagnosis (33.7%) or had given up prior to diagnosis for another reason (5.8%).

The majority of carers in this cohort claimed it was 'important' and 'very important' for the person with dementia to continue to drive which reflected a similar response given by the people with dementia.

Rationale to drive

The qualitative and the quantitative data reflected a strong rationale for independence as the most important factor that motivated drivers with dementia to keep driving. This notion of independence seems to have evolved from a notion of freedom and control.

> *Driving = freedom, no licence = no freedom (carer)*

The qualitative data also indicated that some people with dementia only drive when the carer is in the car to assist and monitor them and some believed they needed their licence as a form of ID, but this is no longer the case as the RTA now provides an ID card when a driver licence is revoked. One respondent characterised the thoughts of others when she reported the person with dementia had not given up their licence due to 'sheer bloody mindedness!'

Alternative transport

Most carers (95%) realised the person with dementia would eventually have to relinquish their driver's licence. Carers indicated that support from family, driving themselves, using community or public transport and taxis would all factor in as alternative means of transport. Three carer respondents claimed the person they cared for had no alternative means of transport.

Legal requirement to report

45.8% of carers were not aware that in NSW it is a legal requirement for a person with dementia to report the diagnosis of dementia to the RTA. Significantly, the same percentages (45.8%) of respondents with dementia were also unaware of this requirement.

Making the decision to stop driving

> *It was a long hard battle to convince the driver to give up (carer)*

The people with dementia who had given up driving claimed the general practitioner was the main person responsible for advising them to cease driving (25.5%) with a partner or family member an important influence (17.6%). 13.7% made the decision themselves.

86.6% of carers stated that people with dementia should not solely have the right to relinquish their driver's licence. Many claimed the general practitioner or other health professional should make this decision but 41.8% stated the decision should be a collaborative one that included a family member.

Both carers and people with dementia were fairly evenly divided about the time-frame for relinquishing a driver licence with the scales tipping very slightly toward drivers relinquishing their licences 'gradually over time' rather than 'upon diagnosis of dementia'.

Within this area of investigation there was, amongst the data collected by Alzheimer's Australia NSW, evidence of despair on the part of carers and the difficulty involved in getting the driver to make the decision to stop driving. Carers described the issue of the driver relinquishing their licence as 'a long hard battle'. Another iterated 'it is my experience that dementia patients have no idea they are dangerous and incompetent. My 'patient' still tells a person he is the best driver around'.

This evidence highlights the significance of decreasing insight in the progression of dementia and exemplifies the concern of carers and the wider community with regard to drivers with dementia. Often drivers have little insight into their diminished capacity to drive but at the same time experience anguish knowing that they will eventually be required to stop driving.

Conversely, this response came from a person with dementia:

> *When I knew I had Alzheimer's disease, I realized that I was not able to drive as I used to. Most of the time, my carer (with whom I share a home) does all the driving. I made the decision and my geriatrician agreed (person with dementia)*

Amongst the data there was little indication that information had been provided to either the carer or the person with dementia from health professionals or advisory bodies about the specific risks and responsibilities attached to driving with dementia. This indicates a possible lack of awareness of the seriousness of the issue.

Case study:

Accident rates reported in the survey were low. However, this case study reveals the importance of providing timely support to drivers with dementia before their condition causes them to risk the lives of their family, themselves and other road users.

A carer reported his father had experienced one minor and one major accident prior to relinquishing his licence. The son reported the vehicle had been 'written off' and both 'mum and dad had been hospitalised'. He stated 'the loss of licence occurred very quickly. There were no plans or suggestions offered by anybody at the time. Community help was offered some months later'. When asked if he felt a person with dementia should have the right to decide when to relinquish their driver's licence, he responded that a person should have to relinquish their licence 'upon the diagnosis of dementia' rather than doing so 'gradually over a period of time'. He advocated counselling upon the change from driver to non-driver and felt that 'public safety' was more important than 'the independence of the driver'. However, he claimed it was imperative not to disregard the driver's independence in the context of decision-making and support.

Support and assistance

Most of the respondents in both cohorts felt more support and assistance should be available to help both the person with dementia and the carer to make the transition from driver to non-driver. Practical suggestions included alternative methods of transport such as taxis to medical appointments and better public and community transport options.

> *Counselling should be given to both carer and the person with dementia (carer)*

Equally, counselling for both the carer and the person with dementia was suggested by respondents. The qualitative data indicated that losing a driver licence correlates with a significant loss of 'independence', 'freedom', 'mobility' and 'self-confidence', particularly for male drivers. Some also cited the tension that can exist between the person with dementia and other people with regard to this dilemma.

The dilemma: Public safety versus independence

> *Giving up was a great blow to his pride and a severe loss of independence. It has taken him a long time to accept (carer)*

95% of carers and 96.1% of people with dementia indicated 'public safety' to be more important than 'the independence and mobility of the driver'. However further comment was made by many of the respondents in relation to the importance of maintaining the independence of the person with dementia and the consequences of losing that independence.

Concerns

The notion that fewer people would report memory concerns to their general practitioner if a driver licence was revoked upon the diagnosis of dementia was proposed and the majority of both carer respondents (68.1%) and the people with dementia (66%) believed it would. This notion may also relate to issues concerning the perceived stigma associated with dementia and the desire to keep the condition hidden for as long as possible.

> *My husband blames the doctor for removing his driver's licence and will not go see him ever (carer)*

Discussion

The nature of dementia

The individual and unique experience of dementia for carers and those diagnosed with dementia is significant. This characteristic of dementia makes it difficult to impose a blanket rule when evaluating the driving capabilities of people with dementia. However, if the variant and unpredictable experience of dementia is a common theme then this needs to be addressed.

Driving, for many people, particularly males, forms a part of the identity of a person. A driver licence is a ticket to freedom representing independence and for some holds status in a family or spousal relationship when others do not drive. The loss of this feature of one's identity can be a devastating blow for a person with dementia. Despair on the part of the carer when a person with dementia loses sufficient insight to realise that they no longer have the capacity to drive safely can also be the cause of tension and anxiety in relationships.

> *My Alzheimer's patient never considered that he was anything but the best driver. He lacked concentration and didn't understand speed limits or indicators etc. For three years prior to losing licence I would not let him drive me. This went for family and friends as well. I was fearful each time he went out that he would harm someone. Not much traffic here, and the car came home with hazard lights going or he walked home as he lost the car. What a nightmare! (carer)*

Crash rate of drivers with dementia

> *I gave up driving before diagnosis after several minor accidents (person with dementia)*

While crash rates for older people do not indicate a high correlation between age and crash rate there is recent evidence to suggest that older age drivers do have a higher frequency of crash rate when a low-mileage variable is considered[xiii]. This is due in part to low-mileage restrictions on driver licences being allocated to those drivers with an illness that could impair their ability to drive.

Lipski's work provides strong evidence to indicate a significantly higher risk of car accidents for drivers with dementia compared to 'aged-matched cognitively normal drivers' based on the crash rate per kilometre driven[xiv]. Other research found that compared to older drivers without a diagnosis of dementia, drivers with dementia had twice as many crashes in the years after the onset of the disease[xv]. Furthermore, the Western Australian safe-driving advocate Drivable Australia suggests that a person with dementia has a similar if not greater crash risk than a driver with a blood alcohol reading of 0.08[xvi].

This evidence highlights the dilemma of people with undiagnosed dementia continuing to drive and the problems associated with late diagnosis. Early and better diagnosis is necessary along with better data collection techniques to capture appropriate and important dementia specific data across the transport, health and aged care systems.

Road testing and assessment for fitness to drive

After many years of good driving habits (54 years) it is a big shock to accept and understand that you can no longer drive (person with dementia)

Research undertaken by Hunt, et. al.[xvii] [xviii] supports the notion that drivers without cognitive impairment drive more safely than those with dementia and the percentage of unsafe drivers increases with dementia severity of the driver. Berndt[xix] agrees and argues that due to dementia's progressive nature, the use of dementia severity should continue to be discussed in a heuristic manner to assess risk, particularly for those with moderate to severe ranges. That is, the greater the dementia severity the greater the likelihood of poor driving ability.

Road testing can detect unsafe drivers. Driving takes place in an environment where the driver is required to respond quickly and appropriately to rapid and unexpected change. However, licensing tests are usually highly controlled by the assessor with cues such as 'turn right here' and do not include events that require the driver to rapidly process new stimuli. Hunt, et. al.[xx] suggest that drivers with dementia may pass a driving test under controlled conditions but may be unsafe in an uncontrolled environment when they must rely on their own cognitive abilities.

There is an urgent need for a dementia specific on-road and written test that can better determine a person's ability to drive safely on the road. The RTA should explore with relevant health professionals, including occupational therapists, the most appropriate testing that should apply.

When to cease driving

The Austroad Guidelines[xxi] suggest a driver is not fit to drive if there is significant evidence of loss of memory, visuo-spatial skills, insight or judgement. Some suggest that a driver licence should be revoked upon diagnosis of dementia, regardless of the severity[xxii] [xxiii].

Yet others purport that people in the early phases of dementia are still cognitively capable of driving safely[xxiv] and that revoking a driver licence upon diagnosis may deter people from presenting to their general practitioner for support with memory and cognitive concerns. Berndt[xxv], in her report on dementia severity and on-road assessment concludes that drivers with moderate to severe dementia do present significant risk to road safety; however drivers with very mild to mild dementia can exhibit varying capacities to drive safely and so suggests an on-road assessment to determine those at risk.

Upon diagnosis of dementia doctors are encouraged to inform patients with dementia of the person's legal duty to report their illness to the driver licensing authority. Once an assessment is made by the doctor for fitness to drive the doctor should inform the person with dementia of the outcome. At other times if the doctor submits an unsafe driving report to the RTA the person should be informed of this decision.

It seems sometimes the medical practitioner is reluctant to advise the patient to hand in their licence (carer)

Health professionals, especially general practitioners are in an onerous position with regard to driving with dementia.

In NSW doctors are not legally obliged to report the diagnosis of a patient with dementia however, the national *Assessing Fitness to Drive* guidelines encourage health professionals to act with ethical responsibility to the public good[xxvi]. The Australian and New Zealand Society for Geriatric Medicine[xxvii] recommend that the general practitioner or medical specialist be removed from the difficult task of having to make judgement about a person's ability to drive, often alone and for a long-standing patient, as the doctor's primary role is patient support.

Reports made by carers can be helpful in assisting doctors to make assessments yet carers have expressed concern that their experiential knowledge of the capacity of the person with dementia is sometimes ignored. On the other hand carers often overstate the ability of the driver with dementia to continue driving, despite evidence to the contrary[xxviii].

While consideration of individual and public safety is paramount when making a medical assessment for fitness to drive, the impact of driver licence cancellation needs to be acknowledged for both the driver with dementia and their family. The consequences of a licence cancellation can involve social isolation, loss of independence, loss of confidence, and depression for the driver and the carer.

The speed of the decline in capacity of the person to drive and the shift from early to moderate to severe dementia all contribute to the construction of serious issues with regard to driving that need to be addressed.

Decision-making capacity

The decision-making capacity of the driver with dementia raises questions, both practical and philosophical, about how people with dementia, their carers and their doctors respond to issues surrounding the notions of driving, the right to individual decision-making and the capacity to do so. The often close relationship between a person with dementia and their carer does not always allow for sufficient objective reasoning when both parties attempt to come to terms with the fact that the person with dementia may no longer be able to drive.

Currently in NSW the doctor appears to be the final arbiter in many cases of driver licence cancellation, following the submission of the medical form. For many doctors this is an unsatisfactory situation[xxix].

Responsibility for relinquishing the driver licence of a person with dementia requires further research and consideration as it impacts on the lives of all those living with dementia as well as the policy and protocols employed by health and other government sectors.

Supporting the transition from driver to non-driver

> *There were no plans or suggestions offered by anybody at the time (carer)*

The transition from driver to non-driver should be a smooth one. The driver with dementia should be involved in the decision-making process as early in the progression of dementia as possible with, if appropriate, collaborative input from their carer, family and doctor.

All attempts should be made to maintain an acceptable level of social inclusion, independence and mobility.

Amongst the research reviewed there was little indication that dementia-specific, practical, information is available in NSW for carers or for drivers with dementia who will eventually need to relinquish their licence.

A successful intervention called *At the Crossroads*, has been developed in the United States to provide information and support to carers to enable them to successfully address driving related issues with their loved ones[xxx]. It covers topics such as Balancing Independence and Safety; Easing the Transition from Driver to Passenger and includes practical suggestions for conversations with family as well as a list of warning signs to objectively monitor any changes in the driver's skill level over time.

This type of intervention enables families, carers and the person with dementia to work collaboratively through the transition from driver to non-driver and could fill the service gap that currently exists for drivers with dementia and their families.

Policy change

Current NSW government policy for older drivers is a well structured, comprehensive framework for the older healthy driver. This information can be readily found on the RTA website[xxxi] and in the RTA's *A guide for older driver licensing* (2008) and the leaflet entitled *Medical: medical and driving tests*[xxxii].

A guide for older driver licensing (2008) supersedes the *Guide for older drivers* (2007). The previous guide included an appendix about driving and dementia with advice to drivers to seek help from a doctor if difficulty with driving is experienced. However, the most recent guide has omitted this important information and makes no mention of the legal requirement to report any illness or injury that may impact on the safety of the driver's fitness to drive to the RTA.

Driving assessments conducted by occupational therapists for people with dementia who wish to continue driving are costly and are not covered by private health fund insurance. The initial standard assessment at the Royal Rehabilitation Centre in Sydney, for instance, costs $335[2] with further reassessments costing $225.

In our communication with Occupational Therapy Australia NSW we have learnt that: dementia specific driving assessments are costly to run; some occupational therapists are conducting assessments below cost for needy clients; there is often a lengthy period of time between referral and actual assessment due to the considerable waiting lists for occupational therapists; there are significant access problems for rural and remote drivers to specialised driving assessments; and, without subsidised support, some driving assessment services and occupational therapy private practitioners in regional and rural NSW have had to cease operating.

[2] Price quoted from Ryde Rehabilitation Centre (2 Nov 2009)

The availability of alternative means of transport is of particular concern. Immediately following the cancellation of a driver licence, a person with dementia and their carer may find themselves in an untenable situation while they make adjustments to life without the person with dementia driving, particularly if that person is not happy about the decision or if they were the only driver in the household. Further, people with dementia and their carers residing in regional and rural areas may encounter difficulties during this time if their accommodation is a significant distance from the nearest town or service centre.

The NSW Taxi Transport Subsidy Scheme and NSW Travel concessions for people with disabilities are not currently funded to accommodate all those with a diagnosis of dementia. In addition, younger people with dementia do not always qualify for the NSW travel concession and a person with dementia who is still able to travel without a carer is not eligible for the NSW Taxi Transport Subsidy Scheme.

Drivers with dementia in rural and remote areas

> *I will have to drive (but) as I work full time, unless it is urgent it will have to wait (carer)*

Alternative transport is a major concern for people with dementia and their carers living in rural and remote areas[xxxiii]; this is the reason that many people with dementia, often encouraged by their carer, continue to drive. Once the driver relinquishes his or her driver's licence, social isolation is increased and access to facilities is decreased. Alternative transportation in some areas consists of a limited public or community transport service or, at best, the reliance on busy adult children. The cost of air transport is expensive for some and often disruptive for a person with dementia.

Moving residence closer to services and public transport can often decrease the emotional and physical stresses for carers; however such a move can also be the cause of confusion and distress for the person with dementia.

Driver liability

There appears to be little consistency across the board with regard to motor vehicle insurance for drivers with dementia. In the course of this review three insurance companies were approached with a scenario that included a driver with dementia being found at fault following a car accident. There were inconsistent responses to the notion of driver liability and the issue of whether the driver had made the disclosure of a diagnosis of dementia held sway, even if the driver was a fully paid, long-term member of an insurance scheme. This preliminary investigation found that insurance company guidelines with regard to the rights and responsibilities of customers to disclose a diagnosis of dementia are not clear or consistent. Further, following the *Gillett Case*[xxxiv] a recommendation was given for 'a bold and unequivocal notice to appear on all drivers' licences indicating the need to report any medical conditions that may affect the capacity to drive'.

Conclusion

Driving with dementia is a serious concern for people with dementia, their carers and the community. There are significant indications that people living with dementia and their carers know little about their rights and responsibilities regarding driving a motor vehicle after a diagnosis of dementia.

Information is not easily accessible and people are unaware that it is mandatory for a driver to report a diagnosis of dementia to the RTA. The need for better information, as well as more timely and appropriate support when transitioning from driver to non-driver, is evident.

There is no clarity around policy and information regarding a person's insurance obligations and liabilities if they are driving with dementia and no consistent response from insurance companies. Dementia specific data regarding crash rates and the number of people with undiagnosed dementia driving on Australian roads is scant.

The need for better information as well as more timely and appropriate support when transitioning from driver to non-driver is evident.

In the face of increasing numbers of people being diagnosed with dementia in NSW, community expectation is that road and driver safety is maintained at an optimum level. Collaboration between health professionals, service providers, driver licensing bodies and government authorities is required to assist and enable people with dementia to make the transition from driver to non-driver with ease and as little impact on their lives and the lives of their carers as possible.

Locating the ethical balance between the independence and mobility of the driver and public safety is paramount. Yet, the clarity of vision around this concept for the community and drivers with dementia in NSW is currently, at best, muddy.

Recommendations

1. The Commonwealth and NSW Department of Health introduce programs that better enable early diagnosis of dementia so those diagnosed have the opportunity to participate in planning and decision-making regarding the transition from driver to non-driver.

2. The NSW Roads and Traffic Authority (RTA) develop a Driving and Dementia information pack for doctors in NSW to issue to patients with dementia at the time of diagnosis. This material should include the need for dementia patients to prepare to cease driving, the need to check their insurance liabilities and the need to disclose a diagnosis of dementia to the RTA. This material should also be available for Aged Care Assessment Teams (ACATs), Dementia Advisers and other health professionals.

3. The RTA develops driver testing regimes that more accurately assess a person's cognitive capacity to drive and ensure these tests are readily available at all RTA sites across NSW.

4. The RTA introduces a compulsory regular testing regime that applies to all licensed drivers diagnosed with dementia.

5. The RTA provides clear information to drivers about their responsibility when driving after a diagnosis of dementia. This includes:

    a. Updating the RTA's *A guide for older driver licensing* with a specific section on dementia and driving that stresses the legal duty on a driver to report a diagnosis of dementia.

    b. Updating the RTA website with a specific section outlining a person's responsibilities after a diagnosis of dementia and further helpful information such as the availability of an ID card in lieu of a driver licence.

    c. Ensuring NSW drivers' licences state the legal duty on a driver to report the diagnosis of any medical condition that may reduce a person's capacity to drive safely, including dementia.

    d. Ensuring all RTA staff are given dementia-specific training in consultation with Alzheimer's Australia NSW.

6. The RTA, with Alzheimer's Australia NSW, develops accessible community education and information that supports the person with dementia and their carer to make a smooth transition from driver to non-driver.

7. The NSW Government increase funding for a range of alternative transport options for people living with dementia, in particular for those living in rural and regional NSW. These should include increased funding for the NSW Community Transport Scheme (CTP) and the NSW Taxi Transport Subsidy Scheme to be expanded in line with the ageing of the NSW population and increasing numbers of people in communities across NSW living with dementia.

8. The NSW Government ensure all persons who lose or relinquish their licence after a diagnosis of dementia, regardless of their age, are entitled to access the NSW Taxi Transport Subsidy Scheme and NSW travel concessions.

9. The NSW Government subsidise the cost[3] of assessments conducted by occupational therapists for drivers with dementia.

10. The NSW Government require insurance companies to provide consistent, clear advice to policyholders about their responsibilities including disclosure of a diagnosis of dementia.

11. The NSW Government continue to work on dementia-specific driving initiatives such as improved signage and ensuring better transport options be provided by residential facilities.

12. The NSW Police and the RTA develop a robust tracking mechanism to report the actual number of dementia-related traffic accidents.

13. The Royal Australian College of General Practitioners acknowledge in the GP Guidelines the importance of general practitioners providing information to their patients about transitioning from driver to non-driver as soon as they are diagnosed so they can plan ahead and prepare for the change.

[3] Costs for assessments begin at $300 (communication with Occupational Therapists Australia NSW, Feb 2010)

Endnotes

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