Research Spotlight No. 1: Dementia and Mobility
Introduction

The global popularity of motor vehicles has produced a generation of people who are largely reliant on car use for their everyday mobility. As the population ages, and as the prevalence of dementia increases, the number of drivers living with dementia is also increasing. An important question has emerged about when it is advisable to give up car use. Considerations include the current reliance on driving for mobility, legal obligations following diagnosis, establishing an appropriate assessment tool to determine driving ability, risks of harm (to self and others), transitions to alternative modes of transport (use of other drivers, public transport, and possibilities for walking and so on), and the impact of driving cessation on wellbeing.

Driving with dementia

It is estimated that 4% of current drivers have dementia (Foley et al 2000). The increased risk of driving with dementia is complex and under-researched, and existing findings give mixed messages. Some studies suggest there is no increased risk, and most suggest anywhere between a two to five-fold increase in risk of crash compared to age-matched controls (Carr et al 2010). The stage of dementia is relevant to ability to drive. 88% of drivers with very mild dementia, and 69% of drivers with mild dementia were still able to pass a formal road test (Duchek et al 2003 and Ott et al 2008). However, this is not straightforward, as other factors contribute to ability to continue driving following a diagnosis of dementia.

A literature review in the British Medical Journal conducted by Breen et al (2007) reviewed a number of studies that had been undertaken between 1966 and 2007. They found the risk of crashing is significantly increased as dementia progresses, but that the risk seems to be ‘acceptably low’ for the first three years after the onset of dementia. They note that research studies to date have failed to observe and examine differences in cognitive deficits between dementia subtypes, or in the variability of their sample in terms of the course/stage of dementia.
The European Council directive 91/439/EEC sets out minimum standards of physical and mental fitness to drive, but makes no specific reference to dementia. In the UK, the Driver and Vehicle Licencing Agency (DVLA) guidelines do not place an age restriction on holding a driving licence, only that a person at age 70 confirms there is no medical disability, renewable every three years. However, unlike other EU states, the UK DVLA must be notified by a licence-holder as soon as dementia is diagnosed. The guidelines state that ‘patients with poor short term memory, disorientation, and lack of insight and judgement are almost certainly not fit to drive’ (Breen et al 2007:1367). People with dementia must also inform their insurance company as failure to disclose may invalidate their policy. However, providing the DVLA are satisfied they can retain their licence, they should be treated no differently to other applicants.

**Common Issues**

Alzheimer’s.org compiled a list of warning signs that it’s time to stop driving:

- Forgetting how to locate familiar places
- Failing to observe traffic signs
- Making slow or poor decisions in traffic
- Driving at an inappropriate speed
- Becoming angry or confused while driving
- Hitting curbs
- Using poor lane control
- Making errors at intersections
- Confusing the brake and gas (accelerator) pedals
- Returning from a routine drive later than usual
- Forgetting the destination you are driving to during the trip


Evidence presented by Carr and O’Neill (2015) note similar problems that people with dementia face when driving, including: lane checking; changing lanes; merging lanes; left-turns (right turns in UK); problems when signalling to park; and route following (Akinwuntan et al 2005).
Driving Assessments

MMSE tests for estimating driving impairment have been mixed, and is not recommended for determining whether someone should be advised to stop driving. However, they may provide a rough estimate of risk which requires further assessment.

There may be specific risks for people with certain types of dementia, such as frontotemporal dementia causing disinhibition and Dementia with Lewy Bodies affecting visual perception, reduced attention and fluctuating alertness.

It is not only cognitive impairments caused by dementia that have an effect on driving ability. Other medical conditions may also impact on driving ability, such as: diseases affecting vision; cardiovascular diseases; respiratory diseases; neurological diseases; psychiatric diseases; metabolic diseases and musculoskeletal diseases. The effects of prescribed drugs can also impact on driving ability (Hetland and Carr 2014, in Carr and O’Neill 2015:1616). These can impact on functional abilities and traffic skills.

However, standard clinical tests have little congruence with modern models of driving behaviour (Fuller 2005) and more attention is needed upon behavioural norms when driving. The Adelaide Driving Self-Efficacy Scale (George et al 2007) and a scale of strategic and tactical compensation (Raedt and Ponjaert-Kristofferson 2000) may be useful, though these have not yet been tested for utility with drivers of dementia.

A Cochrane review conducted by Martin et al in 2009 considered existing literature on driving assessments as a means of maintaining mobility and safety in drivers with dementia. They suggest that the focus of much literature on driving and dementia is on the prevalence or risk or crashing, despite the evidence that this is a rare outcome for the majority of drivers. They argue that cognitive tests would prevent 6 crashes per 1000 over 65s, but at a price of stopping driving of 121 people who would not have had a crash.
Martin et al were also interested in establishing if there was any research into the assessments might be used as a tool to preserve mobility for longer. They found that no randomised study had evaluated the outcome of driving assessments, nor had any study discussed the long-term mobility outcomes for those passing or failing. Negative attributes of the test itself could lead to unnecessary cessation of driving (Hakamies-Blomqvist 1996). Use of simulators reduce risks in the assessment process, but are not strongly replicate on-road conditions. On-road tests themselves are variable, given the variations in route, vehicle and expected tasks. The British Psychological Society note that “no one test, or set of tests, can as yet be recommended for off-road assessment” (Breen et al (2007).

**Driving Cessation**

Driving cessation is linked to a decrease in social disintegration, decreased out-of-home activities and increase in depression and anxiety symptoms. It is also associated with a higher risk of entry to a nursing home (Freeman 2006). Carers may have a vested interests concerning driving. Some may wish to support ongoing independence if it would be difficult to find alternative solutions, or may wish a person to cease driving for fear of harm, depending upon their circumstances.

Alzheimer’s.org suggests that since ‘driving demands quick reaction time and fast decision making’, a person with Alzheimer’s will eventually be unable to drive safely. This can mean a loss of independence and can often be strongly resisted. However, they suggest a conversation is needed to ensure the safety of other people are not put at risk. The issue is reaching the public domain, with recent headlines in the UK such as ‘drivers with early dementia are a risk to the public’ ([http://www.bbc.co.uk/news/health-33232348](http://www.bbc.co.uk/news/health-33232348)) and ‘drivers as dangerous as gunmen’ ([http://www.telegraph.co.uk/news/uknews/road-and-rail-transport/11692749/Dementia-drivers-as-dangerous-as-gunmen.html](http://www.telegraph.co.uk/news/uknews/road-and-rail-transport/11692749/Dementia-drivers-as-dangerous-as-gunmen.html)).

It is often difficult to begin a conversation about the inevitability of driving cessation with people living with dementia as this will have a major impact on quality of life. People will on average be dependent on alternative sources of transport for 7-10 years after stopping driving (Foley et al 2002). The challenges of using alternative modes of transport are increased in rural environments.
Carr and O’Neill (2015) suggest that most people trust only advice given by their GP on their fitness-to-drive, though many GPs may be uncertain about how to assess this. It is not recommended to advise people to reduce exposure (such as limiting trips) or mandating a co-pilot. Data would suggest that older drivers at the highest risk are the infrequent drivers that are on the road less than 2,000 miles per year (Langford et al 2006).

Dr Peter Holden, GP member of BMA is proposing a motion to review current driving capability tests (http://www.independent.co.uk/life-style/health-and-families/health-news/rules-for-driving-with-dementia-are-out-of-date-say-doctors-10337816.html), and create a mechanism for GP’s to report dementia symptoms directly to DVLA, rather than be informed by drivers themselves. A useful pathway has been developed by Carter et al (2015) designed to support medical practitioners to discuss and assess the risks and benefits of driving, and the administrative issues and requirements involved in the pathway.

**Using public transport**

Being able to move around in the community using different modes of transport is important for increasing physical activity (Davis et al 2011), sustaining activities outside the home, and maintaining relationships – all of which support wellbeing. This becomes more important once a person with dementia gives up driving.

Research on the use of public transport by people with dementia is scarce. Risser et al (2015) conducted a literature review into the use of public transport for people with cognitive impairment. They argue that there is a need for the development and evaluation of user-centred approaches that are focused on real-world experiences of using public transport which takes the whole ‘travel chain’ into consideration.

A study in Japan (Arai et al 2011) considered the levels of mobility support services for older people who have stopped driving. They found that specialised bus services aimed at people with dementia were not sufficiently developed. They found rural locations caused residents to travel long distances to perform everyday activities. They suggest there should be training given to older people to help make a transition to other transport modes, more attention to neighbourhood design (such as pavements at bus stops).
Train travel can be problematic, especially in the event of cancellations and last minute changes to the itinerary, such as a change of platform. Yet research on rail travel for people in dementia is scarce. Some research by Innes et al (2015) considered the barriers to participation in leisure activities, which included a consideration of use of public transport. **They argue there are three principle types of barrier to participation: intrapersonal (those associated with one’s psychological state); interpersonal (such as negotiations with family) and structural (barriers outside one’s control such as the built environment).** Transport issues can be influenced by each of these. Removing structural barriers may not in itself enable increased leisure participation if the other two types are not addressed.

Trains can be problematic because of connection concerns, navigation through the station, time pressures, too many stairs, and ticket barriers, confusing station announcements, confusing signage, changing information and so on.

On the train itself, there are issues such as the need for ‘unisex’ toilets, door locks, and the uncertain location of toilets on the train to negotiate.

A project by British Transport Police, supported with funding from the Dementia Innovation Hub, involving members of the North East Dementia Alliance and Voice North, enables people with dementia to be supported through their rail journey, by ensuring station staff are trained to be dementia-aware, and that a person can be met at each stage of the journey, and supported to navigate any changes to schedules (see news item on the Dementia Hub website for details, [http://dementiainnovationhub/news](http://dementiainnovationhub/news)).

A similar initiative for travel by bus, ‘Drivers for Change’, is supported by the Alzheimer’s Society. This initiative, based in Northumberland, is raising awareness of dementia among bus drivers, and this is included in their certificate of professional competency. The training responds to concerns raised by local people about safety when using public transport, and the way staff respond to people with dementia.
Pedestrians with dementia

A literature review by Blackman et al (2003) found that many outdoor environments may be inhospitable for people with dementia because they are “disorienting, difficult to interpret and navigate, threatening or distressing” (Blackman et al 2003:357). Pedestrianisation of town and city centres can greatly improve the situation, however remaining issues include:

- Inaccessibility of some public buildings (despite recent legislation, poor enforcement means this can still be an issue)
- Inaccessibility of some forms of public transport
- Inadequacy of toilet facilities
- Lack of signposting
- Steep or uneven pavements
- Poor lighting
- Heavy traffic
- No shelter or seating
- Inaccessible bus stops

For people with dementia, loss of wayfinding ability and spatial disorientation can lead to reduced autonomy, and can lead to embarrassment or shame in public settings (Bond and Corner 2001). Faced with this, many people lower their aspirations and restrict their activities.

“Perceptual skills are often impaired so that there may be difficulty telling left from right or differentiating between shapes and sizes, while loss of higher cognitive skills impairs decision-making, spatial memory, spatial planning and mental mapping. Functional spatial skills are also affected so that people with dementia find difficulty using unfamiliar environmental cues for navigating” (Liu et al 1991, cited in Blackman et al 2003:361-2).

These issues create ‘disabling’ environments for people with dementia. However, as Blackman et al note, designing for dementia is not just about taking into account their ‘special needs’. They argue many other people experience forgetfulness and confusion – cognitive difference should be regarded as a feature of the ‘normal conditions of humanity’ (Freund 2001:693). Aiding navigation and comfort will therefore be beneficial more generally.
According to a number of academic studies, preferred destinations are likely to be:

- Familiar
- Legible
- Accessible
- Convenient
- Safe
- Comfortable

Information derived from studies of indoor spaces and dementia can sometimes be useful for the design of outdoor space. For example, Blackmann et al highlight how the disorientation effect of long uniform corridors can be mirrored by long repetitious streets. Grid street patterns, which might appear to be more legible, are actually likely to disorient people with dementia as one street looks the same as the next (Bovy and Stern 1990). Whilst some design features are more easily introduced than others in existing towns and cities, the authors suggest attention to maintenance of pavements and adequate street lighting are simple steps that can contribute to supporting people with dementia, and are beneficial to everyone.

A secondary issue is people with dementia are reported to be ‘lost’ or ‘wandering’ if they are outdoors without the supervision of a carer. **Estimates suggest that 10-35% of people display a ‘wandering’ behaviour over the course of dementia.** This may reflect spatial disorientation, reduced topographical memory, reduced visual-perceptual ability including object recognition and executive dysfunction (White and Montgomery 2015), however, it is important to distinguish interpretation as lost or missing from the intentions of the person with dementia, and distinguish between the objective risks of being outdoors alone from the risks that are perceived by carers.

There is limited research that examines factors that increase vulnerability and risk factors for harm while outdoors, and potentially ‘missing’. It is likely that many incidents where a person with dementia is apparently lost are resolved quickly by carers without recourse to the police upon the person’s safe return. Some carers may employ strategies to restrict freedom such as locking doors to ensure the safety of those they care for, thus they spend little time walking about outdoors without accompaniment. Issues can occur in public spaces even when accompanied, for instance, when using public toilets:
“If I want to go and I leave him outside, he’s gone. The toilet again, it always seems to be the toilet isn’t it. And a toilet big enough for two people to go in, otherwise you go in, you’ve lost him and … “(FG3C (19)” (Innes et al 2015:13).

The study by White and Montgomery (2015) suggests that people with dementia rarely sustain harm while missing, but the risks for some are high. Weather conditions, length of time missing and mode of transport play a role (increased distances because of car or public transport use add to the length of time missing and increase opportunities for harm to occur). Being older is a predictor of harm, but it is unclear whether this is associated with more severe stages of dementia, a greater number of co-morbidities or poorer functional status. However, a study based on police reports may not give a full picture of the outcomes for a large proportion of unreported incidents. The authors concluded that getting lost is a low-frequency high-cost event and suggest more research is needed on the issue.

**Additional Resources:**

http://www.publications.parliament.uk/pa/cm201314/cmselect/cmtran/116/116we07.htm


https://www.gov.uk/dementia-and-driving
**Referenced works**


