Navigating the road to retirement from driving

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Publication Details  
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Abstract
Victoria Traynor, Cathie Andrew and John Carmody report on the resource they are developing to help people make decisions in the early stages of dementia about retiring from driving, rather than being forced to stop.

Keywords
road, retirement, navigating, driving

Disciplines
Medicine and Health Sciences | Social and Behavioral Sciences

Publication Details
Navigating the road to retirement from driving

Our journey as research colleagues in the area of driving and dementia began in 2006 following a conversation at the University of Wollongong between Victoria Traynor and fellow academic and Occupational Therapy Driving Assessor Cathie Andrew about her experiences of people with dementia who had failed a driving skills test.

“The clients explain away the result I give them,” Cathie said. “They say to me, ‘It’s just a bad day for me,’ or ‘This part of town is more difficult today – it’s not usually like this’.”

This was the impetus for the establishment of our driving and dementia research team – comprising medical, nursing, occupational therapy, public health, psychology and road safety colleagues – and the development of the Driving and Dementia Decision Aid (DDDA) booklet.

Coming to the decision

GPs often refer individuals living with dementia to take the on-road driving test, conducted by a registered driving assessor who is also an occupational therapist, because they know the individual is no longer safe to drive but were unsuccessful in discussing the topic of driving retirement with that person. The on-road skills tests are not Government funded and therefore, ironically, individuals living with dementia often pay to be told they are unsafe to drive when they themselves, their families and their healthcare practitioners already know what the result of the test will be.

Those who do retire from driving tend to do so very late in their journey of dementia and often only when forced into it. At aged care conferences over the years we have heard alarming comments made by medical colleagues during presentations about driving and dementia: “In the end, I had to take his licence off him. He just wouldn’t stop so I asked him to give me his licence and I cut it up in front of him,” revealed one speaker.

Family carers also report resorting to extreme measures when not knowing how to manage a situation where the person with dementia continues to drive beyond when it is safe for them to do so: “We hid the car keys and in the end we had to disengage the engine. He wasn’t happy and got very angry but what else could we do?” There needs to be a better way to deal with this difficult subject.

More recently, a medical specialist colleague who joined our driving and dementia research team described his distressing clinical experiences of discussing driving with patients who have a dementia: “The issue of driving is just left too late. Too few clinicians talk to patients about driving. It’s a sensitive topic and GPs are reluctant to discuss it because they are too worried that any conversation on the topic will jeopardise a lifelong relationship with their patients at a time when they most need their GPs. There needs to be a new way to tackle this.”

We still don’t really understand the ethical responsibilities of practitioners regarding driving and dementia (Carmody et al, in press) and we know that doctors delay these conversations because of their own lack of knowledge and uncertainty of alternative options (Carmody et al 2013). Recently we heard a positive story from a GP about how he tackles driving retirement: “When a fella is in his late 70s and early 80s I start conversations with him about the car he bought when he retired 10 or 20 years ago. I ask him how much longer he thinks his Holden Commodore will last. We start talking about the costs of maintaining his old car and the higher insurance fees and how taxis might be a cheaper option and whether he might consider moving closer to town. This is much less direct and a more acceptable way of talking about driving retirement.”

Unfortunately these types of positive stories are less common than the difficult ones. The overall goal of our driving and dementia research group is to develop a sensitive approach to driving retirement which enables individuals living with a dementia to make decisions early in their journey of dementia and prevent feelings of disempowerment. We know the losses are great after driving retirement, but we want them to be less crushing. A review of the literature on driving and dementia revealed that this more sensitive approach to the topic was unusual, with most research papers focused on how to test the driving capacity of individuals living with a dementia (Andrew et al 2012a). Our approach has been more person-centred and we deviate from the traditional driving literature to pursue a different clinical and research goal. Our starting point was enabling individuals living with dementia to make a decision about driving retirement rather than being forced to stop driving.

Decision aids

We found that the area of literature which provided this alternative direction was ‘decision aids’ (O’Connor 2006). This specialist field provided a more collaborative and supportive approach for individuals living with a dementia and their family carers considering driving retirement at an early stage of their dementia. A decision aid provides individuals with guidance about a health issue and a structured way to consider alternative pathways and the

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Victoria Traynor (far left) is Associate Professor (Rehabilitation Continuing and Aged Care), Associate Director NSW/ACT Dementia Training Study Centre and Postgraduate Co-ordinator for the Graduate Certificates and Masters of Science in Gerontology and Rehabilitation Studies and Dementia Care, University of Wollongong.

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Cathie Andrew is an occupational therapist working as an academic and injury management co-ordinator at the University of Wollongong. She is a qualified Occupational Therapy Driving Assessor (DECA 1984) and has worked in the community supporting drivers with dementia and their carers navigate the road to driving retirement.

Dr John Carmody is a neurology Staff Specialist at The Wollongong Hospital, NSW and a member of the research team developing the DDDA booklet.

If you have dementia and drive a car, or know of anyone else with dementia who does, the research team would like to invite you to participate in a telephone survey. All participants will be mailed a free information booklet on driving and dementia. The aim of the study is to seek your feedback on this booklet. To learn more about joining this study, contact Dr John Carmody at: john.carmody@sesiahas.health.nsw.gov.au or (02) 4253 4430 or 0427 468 544.

References


Available from https://decisionaid.ohri.ca/docs/develop/OOSF.pdf


Acknowledgements
Don Iverson, Kate Lewis, Road Maritime Services (NSW Office) and The Wollongong Hospital, NSW.

Driving and dementia: when is the right time to retire?

This University of Wollongong (UOW) driving and dementia blog contains information, research and links to resources to inform difficult decisions faced by drivers with dementia, carers and healthcare practitioners about the time to consider driving retirement. It also includes information about:

• how to get involved with the UOW team’s dementia and driving research
• links to freely available consumer resources on the web

http://uowblogs.com/dementiaanddrivingdecisions/2013/05/06/driving-decisions-resources-publically-available/