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Driving and dementia – call for feedback on decision aid booklet

How do you tell someone with dementia they should stop driving? According to University of Wollongong (UOW), Illawarra and Shoalhaven Local Health District (ISLHD) and Roads and Maritime Services researchers, the best approach may not be to confront the individual, but to give them the tools they need to make the decision for themselves.

The researchers, who have skills in medicine, nursing, occupational therapy, public health, psychology and road safety, spent several years considering the issue in light of the fact that families and health professionals do not always know how to approach the individual.

“GPs are often reluctant to discuss it because they are too worried that any conversation on will jeopardise a lifelong relationship with their patients at a time when they most need their GPs,” says UOW dementia researcher, Associate Professor Victoria Traynor.

“As a result, decisions are being made far too late in the journey, often when things have come to crisis point. I have heard of medical colleagues taking people’s licences away. I have also heard of families hiding car keys and disengaging car engines which, of course, antagonises the individual. We know that people feel driving retirement equals a loss of freedom; we want those losses to be less devastating,” she says.

After reviewing the literature and realising that decision aids, which provide individuals with guidance in a structured way, were successful in helping people manage a range of health issues, the team, which includes Occupational Therapist, Cathie Andrew, and ISLHD neurologist clinician, Dr John Carmody, decided to pursue this approach.

“One outcome from using a decision aid is a reduction in decisional conflict. This approach also has the potential to promote self-esteem because individuals make their own decisions and are not forced into a position where they feel they have no alternative.”

After talking to drivers over 55 and to health professionals, the team developed an innovative Driving and Dementia Decision Aid (DDDA) which was reviewed by local, national and international clinical and research experts and been piloted by individuals living with dementia. It is now ready for wider community testing before being made publicly available.

The booklet is divided into four stages of decision making, with prompts and questions around knowledge, values and support, and is designed to help both the individual and the families. If you have dementia and are still driving, the team would appreciate your help in assessing the booklet.

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