Becoming car-free

Advising patients about when to stop driving is one of the most challenging aspects of clinical dementia care for GPs. A team of Queensland researchers has developed the CarFreeMe education program to support GPs and their patients in decision-making and the transition to driving cessation. **Theresa Scott, Jacki Liddle, Nancy Pachana, Elizabeth Beattie** and **Geoff Mitchell** report

In Australia general practitioners (GPs) are often the first health professional consulted about memory problems. GPs tell us that one of the most challenging aspects of clinical dementia care is the assessment of driving safety (Scott *et al* 2019a).

We conducted a series of focus group discussions with a total of 29 GPs at their primary care practices in metropolitan and regional Queensland in 2016-2017. Our research identified that a lack of resources, support programs and referral pathways make it more difficult for GPs and other health professionals to facilitate driving cessation in their patients with dementia (Scott *et al* 2019a). While some drivers living with dementia may voluntarily stop driving, many others will resist their doctor's advice and continue to drive, for emotional, logistical and mobility reasons, or lack of insight and awareness into their own driving abilities (Liddle *et al* 2013; Scott *et al* 2019a).

Huge expectations

GPs tasked with managing the complex issues around driving and required to assess competence of drivers living with dementia have huge expectations placed on them. While medical professionals have a duty of care to the wider Australian community to monitor unsafe driving in their patients with dementia, GPs recognise that they are also advocates for their patients' health and this creates tensions around their relationship of trust with patients.

GPs acknowledge that they are best placed to diagnose health conditions that impact driving competence. However, they question whether it should also be their role to 'police' fitness to drive with their patients. In particular, a concerning outcome for GPs of monitoring driving with patients with dementia is worrying that patients who fear losing their licence will withhold important clinical information from their GP, or fail to report memory issues or to seek medical attention for other health conditions (Scott *et al* 2019a). The Australian Medical Association's 2008 position paper pronounced that a treating doctor should not be the decision-maker in licensing due to the unacceptable ethical conflict that arises and the negative impacts on the therapeutic relationship (AMA 2008). With increasing numbers of older adults driving in later life and increasing numbers of people living with dementia, perhaps it is time that we re-examined Australia's system of managing driver retirement with people with dementia.

A complex issue

Driving is a complex task requiring the functions that dementia affects; not memory alone, but also visuo-spatial skills, reaction time, judgment, attention, and psychomotor functioning. Managing driving decisions with patients with dementia in primary care presents complex issues and difficult decisions for GPs, further complicated by lack of access to consistent medical information and advice. While a specialist driver-trained occupational therapist on-road assessment remains the gold standard, these can be associated with lengthy waiting periods or high out-of-pocket expenses for patients. There are no suitable off-road tests for identifying potentially at-risk drivers without also falsely identifying a large proportion of drivers as unsafe when in fact they are safe.

The CarFreeMe program supports people with dementia to stay active after they stop driving and continue to engage in their normal activities out and about in the community.
Photo: rawpixel.com/Freepik

While there have been several attempts to develop suitable tests to be used in primary care, these have not yielded valid and reliable tests or batteries of tests (Rapoport *et al* 2018; Rapoport *et al* 2015). GPs must therefore resort to using what tests are available to them, often memory tests (Scott *et al* 2019). The problem with these tests is that they may impart the wrong message to patients – that safe driving requires memory only. If patients do not perceive the relevance of the tests to their own driving and perceive their own performance accurately, they may feel that the decision was unfair, or reject their doctor's advice and doctor-shop with the intention of getting a licence approval, or continue to drive unlicensed (Scott *et al* 2019).

The need to reduce stigma around a dementia diagnosis is internationally recognised (Batsch & Mittelman 2012). The stigma surrounding the potential loss of a driving licence must also be addressed because stigma is a noticeable barrier to disclosing driving difficulties and acceptance of decisions, according to our research (Scott *et al* 2019).

Community education and awareness about the impact of dementia on driving is particularly important for the person with dementia and their family members, to ensure acceptance of the decision to eventually cease driving. Similarly, the general public would benefit from awareness-raising campaigns about the existing testing protocols to reduce stigma around people with dementia who continue to drive while safe to do so.

Significant personal cost

For people living with dementia, the transition to non-driving comes at significant personal cost to their social and occupational wellbeing. Being told that you can no longer drive can seem unfair and unbearable. Without necessary planning and supports in place, it can be overwhelming to think that you might not be able to do the things that driving enabled you to do, or get to the places that driving allowed.

While some people with dementia may voluntarily stop driving before they are advised to, for many, especially those who are unprepared, or informed that they must no longer drive at

the same time as receiving a diagnosis of dementia, the decision is often not accepted. Driving is a privilege, it is not a right. Nonetheless, immediate revocation of a driving licence should not be an outcome of a diagnosis because individual differences and disease progression is so variable, and because people have a right to drive for as long as they are safe.

Be prepared

Preparation is key. According to GPs, unprepared patients react with the most anger or grief when told that they can no longer drive. However, they report that such preparation is not always possible because of the difficulties already mentioned of objectively identifying when driving was likely to be impaired enough to impose restrictions (Scott *et al* 2019). Acceptance of the decision to stop driving is fundamental to successfully managing the transition to no longer driving, and finding, trying out and becoming comfortable with alternative modes of transport.

CarFreeMe

There are several driving 'decision aids' available which aim to support people with dementia to arrive at the decision to stop driving on their own. Our intervention, 'CarFreeMe', aims to fill a gap in clinical practice. We have developed the education and support-based driving cessation program for people living with dementia and their family members to support GPs and their patients in decision-making and transition to driving cessation. The focus is on early intervention, an approach which GPs tell us is pivotal to optimal management of patients with dementia. However, our intervention also supports people who have stopped driving, eg to deal with grief and loss associated with giving up their licence, to develop other habits and look for practical solutions to access the community and stay engaged (Scott *et al* 2019b).

Table 1: The CarFreeMe for people living with dementia intervention modules

Modules	Title and example content
1	**Living with dementia:** focuses on the changes that may occur with dementia, and strategies to live positively.
2	**Balancing independence and safety:** provides information about driving safety in later life and things for consideration regarding retirement from driving.
3	**Adjusting to losses and changes:** covers changes that may occur to lifestyle and feelings of loss and grief that may result from retiring from driving. It also includes strategies to use to help with adjusting.
4	**Experience of retiring from driving:** covers what it can be like to give up driving. Stories from other retired drivers and family members are included to highlight different ways that people have adjusted to giving up driving.
5	**Alternative transport:** covers the range of alternatives to driving that may be useful and ideas of where to find out more.
6	**Lifestyle planning:** covers things to consider in planning for achieving a balanced lifestyle.
7	**Advocacy and support:** focuses on services that are available to participants and the steps to take to improve the service/s, and to make service providers aware of these needs.

CarFreeMe is a seven-week, workshop-style individual and small-group program facilitated by a professional CarFreeMe coach. The program includes seven modules (see Table 1 above) that are delivered by a health professional (eg occupational therapist, psychologist) who is trained in CarFreeMe delivery. The modules are delivered in person or by telehealth, on a portable computer or tablet.

Content and delivery

The content and delivery is designed to be person-centred and flexible, eg one-to-one, in-home, or small groups in community settings. Each individual session is one hour and each group workshop is between two to three hours. The intervention is individualised according to geographic location and participants' needs. For example, participants are encouraged to consider future transport arrangements, plan for lifestyle changes, and form realistic expectations of life changes after driving cessation. The experienced health professional will plan practical outings and practice using alternative transport with participants. Importantly, participants are supported in their emotional adjustment to the role loss.

In the telehealth format the program is delivered by a mix of local health professional support (eg practical outings and local transportation use) as well as the health professional delivering content from the Telerehabilitation Clinic at The University of Queensland (UQ) in Brisbane via a secure telehealth videoconferencing app at the client's end.

Development

The CarFreeMe for people with dementia intervention is an adaptation of an effective driving cessation intervention for older people *without* cognitive decline: formerly known as UQDRIVE (Liddle *et al* 2014). It has been modified for people living with early-onset as well as late-onset dementia. The effectiveness of the original UQDRIVE program has been systematically examined with a general older adult population in a randomised controlled trial (Liddle *et al* 2014). Participants reported improvement in community mobility outcomes, self-efficacy, individualised transport and lifestyle goals, and high levels of satisfaction following their participation.

How to participate

The dementia-specific program is available via participation in our current randomised controlled trials. At the moment we are offering our CarFreeMe program to people living with dementia in Queensland, ACT and southern NSW.

If you are outside these recruitment areas and are interested in referring a client or becoming involved, please contact us because we will have further trials and locations opening up across Australia to meet demand.

New participants can be enrolled in the study immediately. All participants and care partners are interviewed about their community life and wellbeing and then allocated to a CarFreeMe program.

Following our research trials, it is expected that the program will be made available to people living with dementia via service providers and health professionals who are trained in CarFreeMe delivery. To this end, an online training program is being developed and will be available via Uniquest at www.carfreeme.com.au ➤

CarFreeMe Coaches

CarFreeMe Accredited Coaches are qualified and registered allied health professionals who have successfully completed the CarFreeMe Coach Accreditation Course, enabling them to conduct CarFreeMe Program workshops in their local area. For further information, contact Theresa Scott at theresa.scott@uq.edu.au.

Conclusion

For people living with dementia, stopping driving can signal the loss of independence, mobility, and a pleasurable activity. For GPs, who play a key role in identifying changes in functioning that impact driving competence, driving cessation is one of the hardest conversations to have. There is an urgent need for clear protocols for optimal patient management of driving and dementia and a national standardised approach to medical assessment of driver fitness, including appropriate referral pathways to other health professionals who may contribute positively to transitioning someone from driving to non-driving. ■

For more information

For information about CarFreeMe, visit the website www.carfreeme.com.au. To find out more about our current face-to-face and telehealth-delivered CarFreeMe trials for people living with dementia in Queensland email Theresa Scott at theresa.scott@uq.edu.au or Donna Rooney donna.rooney@uq.edu.au; and in the ACT and southern NSW areas, Amy Nussio at a.nussio@uq.edu.au.

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