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Supporting the practical and emotional process of giving-up driving in later life for those living with dementia

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A commentary on Developing the Driving and Dementia Roadmap: A knowledge-to-action process by Stasiulis et al

Changes that happen everyone as they age (albeit at different rates), including for example changes in eyesight or hearing, and changes in cognition (such as attention, overload, speed of processing etc), can often combine in later life, making it hard to perform complex tasks, for example the tasks required to drive a vehicle in a safe manner (see Musselwhite, 2017 for a review). Giving-up driving is a not just a cognitive or skills-based decision and is part of a wider social process. Many people are often involved in the decision alongside the older person themselves, including family and friends and health professionals. Advice from health professionals is welcomed, and support of family and friends are a vital protective factor in reducing negative affect of giving-up driving (Musselwhite and Shergold, 2013). But many people involved in the driver decision process are often reluctant to initiate conversation, offer advice or get involved altogether (see Musselwhite and Shergold, 2013). Dementia adds a further layer of complexity on the situation; as noted in previous research people living with dementia and their families lack knowledge of when and how to approach giving-up (LaFrance et al., 2021). Dementia is a term used to cover many different neurodegenerative diseases, but characterized by cognitive and functional impairment, which impact everyday activities. To make matters more complex, dementia is not categorical, and it is generally accepted that cognitive decline is on a continuum from subjective (undiagnosed) through mild cognitive impairment to medically-diagnosed dementia (see Pini and Wennberg, 2021), meaning diagnosis is not necessarily synonymous with skills, insight and ability to drive (Scott et al., 2020). To support the driving cessation process, Stasiulis et al (2023) present the Driving and Dementia Roadmap (DDR) (see https://www.drivinganddementia.ca/) , a toolkit

which provides information for people involved in the process of giving-up driving to make informed choices. To be commended, the DDR toolkit is developed systematically, using a Knowledge to Action (KTA) framework, and is informed by evidence and has been co-developed and tested with people living with dementia and other actors involved in the decision.

Being mobile in later life is linked with satisfaction and quality of life and having to give-up driving is associated with decreases in health and wellbeing, including feelings of stress and isolation and also increased mortality (Edwards et al. 2009; Musselwhite and Haddad, 2010, 2018; Musselwhite and Shergold, 2013; Ragland, et al., 2005; Windsor et al., 2007). This may in part be due a reduction in activity out of home (Harrison and Ragland, 2003) and resulting decreases in physical and social functioning (Edwards et al., 2009), less frequent health care use for check-ups and chronic care (Arcury et al., 2005), reduced social networks (Mezuk and Rebok 2008) and social and leisure activities (Marottoli et al., 2000). In car-dominated societies, giving-up driving is perceived to be something that could cause people to be unable to meet their needs and can cause isolation and loneliness. The issue is amplified in rural areas, where shops and services are further dispersed (Musselwhite, 2023). Naismith et al (2022) remind us how a diagnosis of dementia is linked with depression and even attempts at suicide, and although the relationship as to why is not clearcut, issues surrounding the implications of the diagnosis and labelling are noted, alongside biological or physiological reasons. Giving-up driving alongside a diagnosis of dementia is therefore going to be an extremely emotional and vulnerable time for the individual. Scott et al (2019) have developed the excellent CarFreeMe programme of social support to help older people and those living with dementia normalise the process of giving-up driving and navigate alternatives to the car. The DDR covers these aspects well through supporting older people's needs beyond driving in the "getting around without driving" section.

Further, the car can be seen to meet psychological needs of independence, of freedom, of status and help ensure roles (Musselwhite and Haddad, 2010, 2018). In societies where freedom and independence are championed the potential loss of a driving licence can be seen to be hugely detrimental on wellbeing and make the decision to stop driving less rational. Many older people in individualistic cultures, like the United Kingdom for example, do not like to have to rely on others, such as family, friends or neighbours, to support their mobility and may go to extreme lengths to keep driving themselves to avoid dependency on others (Murray and Musselwhite, 2019, Musselwhite and Shergold, 2013). The normalness of the

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car in car-centric societies is also hugely influential, with strong cultural and social norms of driving very hard to operate against, feeling unusual or for the first time feeling old as a result of not being able to do what the dominant culture expects people to do in society (Musselwhite and Haddad, 2010, 2018).

Older people and especially people living with dementia may lack insight into their driving capability. This means they may not be aware they need to stop driving (Scott et al., 2019) and hence support is needed and indeed often welcomed, especially from healthcare professionals. However, research suggests driving is not an issue often discussed in primary care; a synthesis of 18 studies suggested many primary care physicians feel uncomfortable and lack confidence in judging whether someone would be fit to drive, in the context of possible cognitive impairment (Sinnott et al., 2018). Reasons for this include lack of familiarity with legal requirements, potential to damage the doctor-patient relationship, and impact on the patient's quality of life, health and wellbeing. Studies conclude that primary care physicians and general practitioners would like education and training to help them make decisions about fitness to drive (Scott et al., 2019; Sinnott et al., 2018). In addition, people living with dementia would really like more support but also crucially more agency surrounding decisions to stop driving (Sinnott et al., 2018). In order for this to happen, people need more insight into their driving ability. The DDR with its focus on helping people recognise when it might be a good idea to stop driving is very useful in this regard and it does this not just for the older person themselves, but for friends and family and also healthcare workers. The DDR picks up well the key reasons why people lack insight into their own driving which are only made worse with cognitive impairments and dementia:

- **Older people compensate well for changes effecting driving performance.** When people have made changes to their driver behaviour, these are largely done in a small, incremental manner, and may be part of an automatic unconscious process, where the person themselves may not have insight and have noticed the changes they have made. Hence, older people do not have insight into how they have adapted and how the adaptation has changed how they are performing, and whether they need to make more drastic change or stop driving altogether.
- **The lack of detecting feedback from the driving process.** There is a disconnect between a person's ability and skill and their performance**.** Driving as a skill often has little to no feedback for the user to learn or act upon. Roads have been designed in a way to reduce collisions and injuries, creating a relatively forgiving environment

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where errors and misjudgements often go unpunished. Drivers can drive relatively poorly and receive no negative feedback, for example through not crashing, and not even experiencing a near-miss collision. Older drivers may therefore be very unaware that they have been driving in a dangerous manner, and have not learnt to adapt or change from feedback.

- **Compensation.** Older people are often able to compensate for driving when the task demand is too high, but these are often situations where older people may not have to drive anymore. For example, older people may not have to drive in busy traffic, having retired from work, hence they may not be in situations of high demand where they may be more likely to notice their skills are deteriorating. They are also able to pick and choose routes, when to travel reducing the demand on their skills and allowing them to compensate for changes in ability without having to give-up driving, but also reducing insight into the need to stop driving altogether.

There is tentative evidence that training and education surrounding driving can have a positive effect on driver performance, though this may not be long lived, and there is a lack of evidence around which training and education works most effectively, and whether it actually converts into reducing collisions (see Musselwhite, 2017 for review). However, there is evidence that those who access training and education voluntarily are the "worried well", that is they are performing the task well (Musselwhite, 2017). Some of the most over confident or the least aware drivers, do not access training voluntarily. The need to encourage insight into behaviour and discussions with family members and healthcare professionals taking the lead are needed, and are covered in the DDR.

Countries that offer more stringent process for carrying on driving in later life, including places that have on-road testing, cognitive or medical screening, have no fewer collisions or injuries on the road than countries that have relatively relaxed measures (for example self-declaration at 70 years, and then every 3 years as is the case in the United Kingdom) (see Mitchell, 2018). In the absence of tests that clearly demarcate someone as safe or unsafe as a driver, there needs to be support for initiating insight. This is obviously hard to do with cognitive decline and dementia that may affect people's insight. The social issues surrounding driving, the loss of freedom, independence, the feeling of being out of touch with society, make it hugely emotional. Overall, then there is no panacea to support giving-up driving. It is moreover a process that has to be "smoothed" through encouraging insight, helping the older person or person living with dementia make the decision to stop themselves,

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with the practical and emotional support of family and friends. The DDR toolkit reflects the social process, encouraging the initiation of conversations among family and from healthcare professionals, and emphasises the importance of having insight into driving. The next stages for the DDR will be to evaluate its effectiveness, and allowing it to adapt to changes and developments in our understanding cognitive impairment and dementia, alongside changes in design and the use of vehicles; for example in the future will a person living with dementia have similar issues giving up being the "driver" of a more automated vehicle?

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