

Role of carers in managing driving transition for individuals with cognitive decline

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Drivers with certain medical conditions are known to present road safety risks. Individuals with late stage dementia have an increased risk of vehicle crashes. Evidence indicates that people with dementia or other forms of cognitive decline do not adhere to the advice to stop driving. Drivers, especially those with low insight, continue to drive even after licence cancellation, posing challenges for family or carers who seek to curb this illegal behaviour.

The role of carers in managing the transition from driving to non-driving for individuals with cognitive decline has received little focused attention in the research literature. The importance of, and need to engage with, carers of people with cognitive decline has been recognised. The collated evidence for issues carers face, how best to offer support and which resources and strategies are the most useful, is currently lacking. VicRoads commissioned a review of the literature to provide a synthesis and judgement of best available research evidence to address this need.

This paper presents the results of this review which addressed two inter-related questions:

1. What is the current best available evidence on the role of, and support available for, carers in managing driving transition for individuals with cognitive decline?
2. What does the current best available evidence highlight in terms of operationalising and implementing the role of, and support to, carers (i.e. the “how to”) in managing driving transition for individuals with cognitive decline?

Interrogation of the literature identified 16 primary research studies which addressed the role of carers in managing driving transition for individuals with cognitive decline. Of the studies examined, seven represented the qualitative research paradigm whilst nine represented the quantitative research paradigm. Existing gaps in the literature were also identified.

The findings verified the important role of carers in facilitating driving cessation for individuals with cognitive decline. Data across the studies reviewed highlighted a number of consistent issues and themes such as timely communication, concern about upsetting drivers, lack of practical transport alternatives and drivers ignoring advice from carers and health professionals.

In addressing the key research questions, the reviewers proposed a carer-centric framework comprising four constructs: the decision making process; strategies for driving transition; barriers; and innovative solutions. (See Attachment 1)

At the core of the conceptual framework, is the involvement of the carers in the decision making process (*construct one*). Evidence indicates that a number of issues confront carers during the decision making process and these issues need to be considered during the development of strategies for driving transition (*construct two*). Implementation of driving transition also relies on carers, who are confronted with barriers during this process (*construct three*). For driving transition to be successful and sustainable, in addition to addressing barriers, research highlights that innovative solutions could be usefully employed to support individual needs during the implementation process (*construct four*).

The findings of this review indicate that carers play a pivotal role in driving transition for cognitively compromised drivers, at each stage of the process. Their involvement should be acknowledged and supported by both health and licensing agencies. The carer-centric framework is proposed as a model to conceptualise the role of carers in providing support from the “ground up” and it reinforces their important contribution in managing driving transition for these drivers.

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