

Dementia and driving: Guide to mobility for health professionals, carers, families, friends and people with dementia.

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Abstract

The decision to cease or limit driving can be challenging for people with dementia, their families and carers due to limitations on independence and access to services. Balancing safety considerations with independence and mobility can also be difficult. To address these issues, RACV commissioned research to generate a better understanding of the mobility concerns affecting the increasing number of people with dementia. RACV commissioned research in 2011-12 to examine the road safety and mobility issues facing people with dementia. The research report recommended the development of a comprehensive guide on the mobility services and information sources available to health professionals, carers, families, friends and people with dementia as these people are not always aware of the information that is available or where it can be obtained. To address this, RACV developed the *Dementia, Driving and Mobility* guide. Consultation and feedback was received from health professionals; road safety and mobility experts; people with dementia and their carers. The guide provides strategy options surrounding issues related to dementia and driving and describes what other mobility options and services exist for people who can no longer drive. The official launch of the guide was held to promote the guide amongst those who have an interest in road safety and dementia. The brochure has been widely distributed by RACV, health professionals and other stakeholders with an interest in dementia and driving. Additional information on dementia, driving and mobility is also available on the RACV website.

Background

The Royal Automobile Club of Victoria (RACV) is a diverse membership organisation with a wide range of services and benefits. As a membership organisation representing over 2 million members, RACV provides advice and information to members and advocates on their behalf on issues around road safety and mobility.

Dementia is an emerging health issue that can affect memory, concentration, thinking, judgement, behaviour, vision or problem solving which are crucial to being able to drive safely. Research suggests one in four people over the age of 85 years will develop dementia and will need to assess their driving future when driving cessation becomes necessary (Access Economics, 2005). There are currently approximately 74,600 Victorians living with dementia and this is increasing (Alzheimer's Australia Vic, 2013). Furthermore, the crash risk of a person with dementia is two to eight times higher than those without the condition (Man-Son-Hing et al, 2007). For many, making the decision to cease driving will be easy, but for some the decision will be fraught with anxiety and misinformation. An early diagnosis may alleviate the tension associated with transitioning to non-driver which can be compounded by difficulties accessing mobility alternatives.

RACV commissioned research to better understand the key road safety and mobility issues affecting people with dementia. The report reviewed Australian and international literature; catalogued current information and services; interviewed stakeholder and health experts; provided guidance on policy directions and identified areas which RACV could help drivers with dementia. The interviews with stakeholders and health experts included discussions around the issues that drivers with dementia, their carers and medical staff faced and highlighted the key messages that would need to be communicated to assist with driver cessation (Bradshaw et al, 2013). The report also outlined resource gaps and key messages that could be communicated.

The research was developed into an RACV report, distributed to stakeholders and is available on the RACV website (RACV, 2013). The key experts that were involved in the research report include ARRB, Victorian Institute of Forensic Medicine, Eastern Health, Caulfield Hospital Cognitive, Dementia and Memory Service, Disabled Motorists Australia, Council on the Ageing, Alzheimer's Australia Vic, Carers Victoria, Austin Repatriation Health Service and VicRoads.

Key findings

Many people with dementia, especially those in the more advanced stages of the disease, do not understand their condition and cannot be relied upon to regulate their own driving. Due to memory problems and lack of insight, they may fail to comply with licence restrictions on where or when they can drive. All drivers who have been diagnosed with dementia require periodic assessment and will eventually need to cease driving altogether.

Information and advice is available to people with dementia and their carers from a range of sources, including telephone help lines, webpages and printed materials. However, people are not always aware of what information is available or where it can be obtained. It is important to note that a licence holder is legally required to report a diagnosis of dementia to VicRoads and possibly their vehicle insurer. There is a need for a comprehensive guide consolidating these available services and information sources that can be provided following the diagnosis of dementia.

Development of the guide

Based on the findings and recommendations of the research, RACV commissioned Anne Harris Consulting to develop a comprehensive guide on dementia and driving. The process involved reviewing relevant existing local and international resources and consulting with a wide range of health experts and stakeholders to prepare a draft guide. Input and advice was sought from road safety and mobility experts, occupational therapists (OTs), medical specialists, people with dementia and carers. The draft guide was reviewed by experts from Alzheimer's Australia Consumer Advisory Committee, Victorian Institute of Forensic Medicine, Ballarat Health Services, Monash University, Council on the Ageing, Disabled Motorists Association of Victoria, La Trobe University Occupational Therapy Department, Cognitive, Dementia and Memory Service, Caulfield Hospital and The Australian and New Zealand Society for Geriatric Medicine. This process ensured that all material was relevant, appropriate, examples were credible, information was based on best advice and the strategies were useful. Positive feedback was received on much of the content and suggested changes were incorporated where appropriate.

The guide is aimed at health professionals, carers, families, friends and for people with dementia. It summarises key issues surrounding driving and dementia and describes the mobility options for people who can no longer drive. There is advice for people who have concerns about driving ability while other topics include how dementia affects driving, what needs to be done after a diagnosis, issues for people without a diagnosis and tips on having sensitive conversations with people with dementia. The importance of keeping mobile and connected is discussed including information about transport services. A list of important support services and information sources are also included.

Launch and distribution

The RACV report and guide on *Dementia, Driving and Mobility* were officially launched in April 2013. The launch was well attended by key stakeholders and media including the Herald-Sun, 3AW, 3MP and Channel 9. In addition to the launch, an article featured in the May edition of RoyalAuto on some of the key findings identified in the research as well as a personal story from a carer to help promote the guide. Information on dementia, driving and mobility and a downloadable

version of the guide is available on the RACV website with links to other organisations and services (RACV, 2013).

Information on dementia has also been incorporated into RACV's *Years Ahead* program which is an information session for older drivers. The guide has been distributed to RACV outlets, stakeholders who assisted with the development of the guide, Victorian libraries, local councils, Medicare locals, and other health industry organisations with an interest in dementia. The resource has proven to be extremely popular with more than 9,000 guides to health organisations and individuals distributed in less than 3 months. It has also attracted over 2,500 visitors to the dementia, driving and mobility web pages.

The launch of the guide on dementia has enabled RACV to further promote a series of existing resources for older, retired and disabled drivers. The *Make the right choice* brochure covers the importance of vehicle safety for older drivers. The *Keeping mobile* brochure discusses vehicle modifications for drivers and passengers that have a disability. All of these resources provide RACV members with comprehensive information to assist them select the right options to suit their needs, help them travel safely and remain mobile for as long as possible.

Policy directions

The research report and consultations for development of the guide raised a number of pertinent policy issues related to dementia and driving that RACV will be pursuing. These relate to the affordability of driving assessments, funding for the training of specialised OTs and expansion of alternate transport options.

Assessment of driving ability

The assessment of driving ability by an OT must be affordable. This can be achieved by allowing driving assessments required by VicRoads to be claimable under Medicare.

The cost of OT driving assessments performed by VicRoads can typically range from \$300 to \$900. The financial costs associated with dementia can be significant, particularly for drivers that require regular reassessments to retain their licence. Currently these costs are not claimable under Medicare. The State and Commonwealth Governments should ensure that driving assessments are financially affordable for those drivers who require assessments following a diagnosis of dementia.

Training for Occupational Therapists

The State Government should provide funding for further specialised OT training to ensure that an adequate number of OTs are available across Victoria.

The Victorian Government relies on OTs to assess the driving ability of a number of drivers who come to the attention of VicRoads medical review, including those with dementia. OTs need to undertake further specialised training to be able to undertake these assessments. However, the Victorian Government does not provide any funding or financial support to ensure an adequate number of OTs undertake this training in Victoria. As a result, access to OT driving assessments in many rural areas is limited and OTs are required to travel significant distances to conduct assessment which only adds to the financial impost.

Alternative Transport Options

The Victorian Government should expand and improve alternative transport services suited to the needs of people in various stages of dementia.

All drivers with dementia will eventually need to cease driving altogether and will require alternative transport options to aid their mobility. Governments at all levels should provide improved transport services for people with dementia considering that people with advanced forms of the disease cannot travel alone. Expected future increases in the demand for services resulting from the ageing of the population will mean that more people with advanced dementia will need to be escorted from door-to-door, not just from kerb-to-kerb. The Victorian Government should also expand the Multi-Purpose Taxi Program to provide services that are suited to the needs of people in the later stages of the condition.

Ongoing partnership with Alzheimer's Australia Vic

Alzheimer's Australia Vic (AAV) is a non-profit organisation and Victoria's peak body dedicated to supporting people with dementia, their families and carers. They work in the areas of dementia policy, risk reduction, research, and provide education, counselling and referral services.

The current project has facilitated a partnership between RACV and AAV on the issue of dementia, driving and mobility. RACV has spoken at a forum on dementia and driving run by AAV in May 2013 and also partnered with them on their Parliamentary Friends of Dementia initiative to engage politicians on issues associated with dementia. RACV and AAV will jointly pursue the policy issues identified that relate to dementia and driving.

RACV is currently partnering with AAV on a community project to develop a dementia resource kit that provides families with important information when someone is diagnosed with dementia. It is likely that this kit will provide detailed coping strategies and general help when caring for someone with the condition.

Conclusions

RACV has developed a comprehensive guide covering the mobility related services, available information sources and strategies to help maintain the mobility of a person with dementia. The guide has been a valuable resource to people with dementia, their families and health professionals. Research into policy issues surrounding dementia has identified areas that RACV will be actively pursuing. These include ensuring that driving assessments are affordable by making them claimable under Medicare, increasing access to trained OTs through government funding for specialised training and expanding alternative transport options for people with dementia.

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