



Dementia, Driving and Mobility

RACV



Foreword

RACV has a strong commitment to our members and the Victorian community. We firmly believe that all drivers should drive for as long as they are safe to do so. However, some medical conditions impact on driving ability, and for the people affected this may mean that they need to re-consider their driving future.

There are around 70,000 people living with dementia in Victoria. For people with dementia, their families and carers, the decision about whether to continue driving can be challenging. Balancing safety considerations with independence and mobility is often difficult but it's important to talk about these issues.

About this guide

This guide has been developed for health professionals, carers, families, friends and for people with dementia. It provides a summary of the key issues surrounding driving and dementia and describes what other mobility options exist for people who can no longer drive. A list of important services and information sources are also included.

This guide has been developed by RACV, with input and advice from:

- road safety and mobility experts
- occupational therapists and medical specialists
- people with dementia and their carers

Suzanna Sheed
Chairman, Community Committee
RACV Director

Dementia and driving

How dementia affects driving

Dementia is the term used to describe the symptoms of a group of illnesses which cause a progressive decline in a person's functioning. Dementia may affect memory, concentration, judgement, vision or problem solving. It can affect a person's thinking, behaviour and the ability to perform everyday tasks, including driving.

Alzheimer's disease is the most common form of dementia.

What a dementia diagnosis means

The nature of dementia means that a person's ability to drive safely will decline to the point where they become unsafe. A person who is diagnosed with dementia will at some point need to stop driving. It is difficult to tell how long this will take and depends on many factors such as the cause of the dementia, other health conditions, when diagnosis is made and how quickly the disease progresses.





What to do after a diagnosis

After a diagnosis of dementia, it is important to start planning for lifestyle changes. The earlier the diagnosis, the more time there will be to plan effectively for the future.

Using transport and other services

A benefit of an early diagnosis means that a person with dementia still has insight into their condition and will be able to make plans and decisions for the future. This might mean that they decide to keep driving for as long as they are safe to do so. Others might make the decision to stop driving altogether.

"After a lot of thought I decided to stop driving after my diagnosis. I knew that I would need to stop driving sooner or later and I was worried that I might crash and hurt myself or someone else."

Investigating what transport options are available and accessible will be very helpful for maintaining mobility. Learning which services are available to alleviate reliance on the car will also help. Setting up online banking, and investigating which local services, such as supermarkets or pharmacies, offer home delivery services might be useful in the future. Also try having some 'no driving' days to become familiar with other transport alternatives.

For some people, relocating to be closer to transport, services, family or other support might be considered, especially if the diagnosis is early.

What are the legal requirements in relation to driving?

Changes in driving ability may develop gradually or suddenly.

People who are diagnosed with dementia are required to inform VicRoads about their condition.

Once informed, VicRoads will request a Medical Report Form to be completed by the treating doctor or medical specialist. After this, a formal driving assessment with a trained occupational therapist may be required. The occupational therapist will advise whether the driver is capable of continuing to drive. Sometimes this may be with some restrictions, such as only driving in the local area. Often the doctor and/or occupational therapist will recommend that the licence only be issued for a set period (such as 12 months) after which the driver should be re-assessed.





Although the occupational therapy assessment is legally required to retain a licence, the driver must pay for the cost of the assessment. Due to the level of training and expertise of the occupational therapist and the time involved, assessments can be very costly. These assessments cannot be claimed under Medicare or private health insurance and there may be long waiting lists. For safety, all assessments need to be undertaken in a car with dual controls, so the driver's own vehicle is not used.

Following an assessment, drivers with dementia may be able to continue to drive. However, it is still important for family and friends to monitor their driving between assessments as the condition can change quickly.

"Dad had a diagnosis of dementia, but it was detected early. He had to have annual driving tests but we agreed that I would also go for a drive with him every month just to make sure his driving wasn't getting worse."

People who have their licence suspended can request that VicRoads review the decision. For those people who must stop driving and give up their licence, they can apply to get another form of identification such as a proof of age card (see page 18).



People without a diagnosis

Not all people with dementia have a formal diagnosis and people may just notice some changes with their memory. They might have trouble remembering familiar routes, forgetting where they parked the car or the reason for their trip. If this is the situation, it is important to see a doctor.

"I was worried about my sister. She lived alone and I noticed that her driving had slipped a bit. She still drove but it was becoming a worry because she often got lost while driving. She had trouble making decisions and had a number of minor bingles in the car."

Some indicators of potential problems include a driver being more likely to:

- become disorientated or lost whilst driving in familiar areas
- forget the purpose of the trip
- lose the car in a familiar car park
- have difficulty making quick decisions at intersections or busy roads
- drive through Stop/Give Way signs or traffic lights without giving way
- fail to see vehicles, pedestrians or cyclists who are sharing the road
- have difficulty parking or driving into a carport or garage
- have slower reaction times, have difficulty using the brake, accelerator or steering wheel
- have unexplained dents and scratches on the car.

If any of these problems are noticed, it is important to monitor the person's driving ability regularly. If there is a pattern of unsafe driving it is time to take some action.



Benefits of getting a diagnosis

While it may seem daunting, it is important that anyone displaying these characteristics see a doctor. The benefits of getting medical help or even a diagnosis mean that treatment approaches and strategies can be put in place to try to delay the progression of the dementia or to better manage the consequences of the disease. The earlier a diagnosis is made, the earlier planning can begin for support and assistance with transport and mobility.

Having the difficult discussion

Dementia is a progressive condition and often people will lose the ability to have insight into their illness. They may not be able to make a judgement about their driving capacity on their own.

This lack of insight and the difficulty in accepting life without driving can mean some people are very reluctant to stop driving. There are some strategies outlined over the next few pages that may help you have the difficult discussion.



Enlisting the help of others – family, friends, partners

Trying to convince a person with dementia that they are no longer safe to drive can be very difficult and stressful. Seek the support of other family members to help you or at least to lend emotional support.

Raising concerns about driving

It is important to realise that very few people want to voluntarily stop driving and this is also the case for most people with dementia. Some suggestions for raising concerns about driving are to:

- discuss the person's driving when everyone is calm
- have the discussion when there have been changes in medications or health status, rather than after a driving incident
- have short and frequent conversations which are better for most people with dementia than a long one-off discussion
- concentrate on the person's strengths and the positive aspects of other options
- acknowledge that giving up driving is hard to do
- normalise the situation as everyone will have to stop driving at some point
- focus on the nature of the disease – many people with dementia have very safe past driving records, but this has no bearing on their safety as a driver with dementia in the future
- focus on the financial benefits of selling the car (see 'deciding what to do with the car', page 14)
- be respectful and try to understand how the person with dementia will be feeling.



Getting support from health professionals

Ensuring that health professionals are aware of family concerns and can reinforce the family or carer's efforts to get the person with dementia to stop driving is important. While health professionals cannot disclose information about a patient, they can receive information from concerned carers or family.

"I was concerned about my father-in-law's memory and his driving. When he saw his GP he didn't mention his forgetfulness. I decided to write to his GP about my concerns and what I had seen when I was a passenger. I asked that this be treated in confidence. I thought it was important that the GP was made fully aware of the situation."



The legal options

There may be situations where discussions and other persuasion are not effective and a person continues to drive even though there are serious concerns about their safety. In these instances, family members or friends can make a report to *VicRoads*. This report will be handled by the *VicRoads Medical Review team* and will usually result in the reported person being required to get a medical evaluation and possibly undertake a driving assessment with an occupational therapist.

Reports to *VicRoads* are confidential and can be anonymous.

Reinforcing the decision

Once the decision has been made to stop driving, some families choose to sell the car. If it is still being used by another driver in the household, the car keys can be kept in a safe, discreet location.

Support for carers and families

A diagnosis of dementia can be very confronting. Stopping driving is extremely difficult for many people and can be very stressful for drivers, carers and family members. Some organisations, like *Alzheimer's Australia* and *Carers Victoria* run support groups and counselling for people with dementia and their carers – see the back of this brochure for contact details.



Keeping mobile and connected

It is important that people with dementia and their carers maintain their mobility and retain social contacts.

If there is a driver in the household who can provide transport, the transition from driver to non-driver will be smoother. However this might mean a change in roles, such as letting a partner do all of the driving and it can sometimes be difficult for everyone to adjust.

The reality of stopping driving or living in a household without a car presents a range of challenges, especially for people living in rural and remote areas. While transport options are available, using them will require planning.

Make social trips a priority

When people stop driving, it is often the social trips, like visiting friends, family, attending functions or participating in hobbies that cease. It is very important that social contacts are maintained so try to continue these trips whenever possible.

Family and friends

Be sure to take up any offers of assistance or transport from family and friends, or ask for help with transport if needed. In most cases, friends and neighbours will be willing and able to help, even if only occasionally.

"One of our Mother's good friends wanted to help, so we asked her if she would take Mum out on a social trip every week or so. They go out for coffee or go shopping and we give her friend some petrol money so she isn't out of pocket."

Even if friends or family are not in the position to provide transport, ask them to visit regularly. This social contact is vital for the person with dementia and their carer.

Memory Lane Cafés

Maintaining social contact and getting support from others in a similar situation can help. Alzheimer's Australia operates the Memory Lane Café program to provide people with dementia and their family members an opportunity to enjoy time together with people in a similar situation.

These operate in Melbourne and regional areas and transport can be provided if needed (see page 18).





Minimising the number of trips needed

The immediate challenges of life without a car are to undertake essential errands, including getting groceries and medicines and getting to and from appointments.

However, some of these essential needs can be met without needing transport. This might be something that a friend or family member could help with. It is a good idea to:

- get groceries home delivered – ordering groceries online or even over the phone is an option in many areas
- speak to your pharmacist to see if they home deliver prescriptions. Also consider using online pharmacies
- set up online banking or telephone banking to avoid trips to pay bills. People with dementia are encouraged to appoint an enduring Power of Attorney to do this
- investigate whether your local library has a home library service, so that books, magazines or DVDs can be delivered to your home.

Deciding what to do with the car

When thinking about the decision to stop or limit driving, it is worthwhile to also think about transport costs. In many cases, it might be more financially beneficial to sell the car and use the money from the sale to fund other forms of transport.

A new medium sized car that is driven 15,000km annually can cost up to \$10,000 per year to run. Vehicle running costs will be less if you drive fewer kilometres or have a smaller or older car, but the costs of running a car are still significant. Selling a car and spending the money on other forms of transport like taxis and public transport will in many cases be cheaper.

Transport options

Travelling alone

Many people in the earlier stages of dementia can still travel independently either on foot, on mobility scooters or on public transport.

People with dementia should use familiar routes and carry relevant identification along with a contact person's details should they have some difficulties or get lost when travelling alone.

Deciding when it is time to stop travelling independently is an important decision for the person with dementia and their carer. Some indicators that a person should no longer travel alone include:

- frequently getting lost
- trips taking a lot longer than they should
- a person not recalling details of the trip
- forgetting the purpose of the trip before they arrive.

Walking

Walking is a convenient and healthy form of transport. For people with dementia, the ability to walk independently can have a huge impact on their wellbeing, self-esteem and physical health. However, dementia can impact on a person's ability to navigate and recall common routes. Getting lost can be very traumatic so planning is essential. One option for people with dementia is to consider getting a GPS device to enable a person's location to be detected using the internet. A device called safe2walk can be hired through Alzheimer's Australia (see page 19).



Mobility scooters

Mobility scooters are a good form of personal transport for some people who have difficulty walking. If a person with dementia used a scooter prior to diagnosis, get some advice from a treating health professional about their ability to continue to use the scooter. A GPS tracking system, like *safe2walk*, should also be considered.

However, for people with a dementia diagnosis it is not safe to start using a scooter as an alternative to driving. Ultimately, the progression of dementia will mean that scooter use becomes unsafe and other forms of transport will be needed.

Taxis

While taxis are usually more expensive than other forms of public transport they provide a door to door service. Using a taxi is often still cheaper than running a car.

"I was a bit worried about using taxis but we found a very nice reliable driver and we have arranged for him to take me to my regular appointments and to other social events."

Some concessions on taxi fares are available, subject to eligibility criteria. Victoria's *Multi Purpose Taxi Program* is designed to assist people who have a severe and permanent disability that prevents them travelling independently on public transport. To be eligible, medical reports are required and the program is only available to pension card holders or people on lower incomes. The program entitles users to half price fares. Limits on trip costs and annual fares can apply (see page 19).

Getting help

There are a number of services and organisations that can provide support and assistance to people with dementia and their carers. Many people try to cope on their own, when they could be getting some help.

"One mistake I made was not getting help earlier. I think it was mainly pride and wanting to be able to cope alone that stopped me from asking for help. When we did tap into the available services it helped both me and my wife a lot. I just wish we did it sooner."





Services

Proof of Age

Photo identification that is recognised throughout Australia is available from the Victorian Commission for Gambling and Liquor Regulation for people who don't have a current licence.

www.vcglr.vic.gov.au

1300 182 457

Selling a car and transferring ownership

The booklet '*Better Car Deals: A guide to buying, owning & selling a car*', by RACV, Consumer Affairs Victoria and VACC is a useful guide.

www.racv.com.au or www.consumer.vic.gov.au 1300 55 81 81

A Transfer of Ownership form is available from VicRoads.

www.vicroads.vic.gov.au/Home/Registration/ 13 11 71

Memory Lane Cafés

The program provides people with dementia and their family members, in Melbourne and regional areas an opportunity to enjoy time together with people in a similar situation.

www.fightdementia.org.au 1800 100 500

GPS tracking

GPS technology enables a person's location to be detected. Further information is available from Alzheimer's Australia.

www.safe2walk.com.au

1800 100 500

Multi Purpose Taxi Program

Concessions on taxi fares may be available to assist people who have a severe and permanent disability that prevents them from travelling alone on public transport.

www.taxi.vic.gov.au/passengers/mptp

1800 638 802





Public transport

Public transport might be an option for those in the early stages of the disease, especially if they are already accustomed to using it. Consider travelling on public transport with a carer or even planning trips in advance.

Concessions are available to individuals meeting eligibility criteria. Information on services, fares, tickets and initiatives is also available.

www.ptv.vic.gov.au

1800 800 007

Companion Cards

A second ticket is issued for the companion of a person with a significant disability at no charge.

www.vic.companioncard.org.au

1800 650 611

Victorian Seniors Card

Card holders are eligible for discounted fares, free weekend travel and other discounts.

www.seniorsonline.vic.gov.au

1300 797 210

Australian Pensioner Concession Card or Health Care Card

Pension card holders receive concession fares on public transport across Australia.

Health care card holders are entitled to concession fares on public transport within Victoria and on some interstate V/Line services.

www.humanservices.gov.au/customer/dhs/centrelink 132 300

Veterans and war widows

Card holders receive concession fares or free public transport depending on the type of pass they hold.

www.ptv.vic.gov.au/fares-tickets/concessions (03) 9619 1159

Community transport

Many Victorian councils and local organisations have community transport schemes using buses or cars providing low-cost flexible transport. Contact your local council to find out more about community transport options available in your area.





Contacts

Alzheimer's Australia Vic

For a range of services for people with dementia, their carers and families, including telephone services and regional centres, *Memory Lane Cafés* and *safe2walk*.

www.fightdementia.org.au

1800 100 500

VicRoads

For Medical Review.

www.vicroads.vic.gov.au/Home/Licences/Medicalreview 13 11 71

For families and friends of older or impaired drivers.

www.vicroads.vic.gov.au/familyandfriends

Carers Victoria

Information, education, support, counselling and respite links for carers.

www.carersvic.org.au

1800 242 636

Public Transport Victoria

Information on public transport services, fares, tickets and initiatives.

www.ptv.vic.gov.au

1800 800 007

Commonwealth Carers Respite and CareLink Centres

Information services providing links to a wide range of community, aged care and support services.

www.commcarelink.health.gov.au

1800 052 222

Aged Care information

Information about Government aged care services.

www.agedcareaustralia.gov.au

1800 200 422



Contacts and services

Alzheimer's Australia, Memory Lane Café, or safe2walk	1800 100 500
VicRoads	13 11 71
Carers Victoria	1800 242 636
Commonwealth Carers Respite and CareLink Centres	1800 052 222
Aged Care Information	1800 200 422
Public Transport Victoria	1800 800 007
Pensioner Concession Card Holders, or Health Care Card Holders	132 300
Multi-Purpose Taxi Scheme	1800 638 802
Companion Cards	1800 650 611
Victorian Seniors Card Holders	1300 797 210
Veterans and War Widows	(03) 9619 1159



www.racv.com.au/dementia

SUPPORTED BY

UNDERSTAND ALZHEIMER'S
EDUCATE AUSTRALIA
FIGHTDEMENTIA.ORG.AU