



Dementia, Driving and Mobility

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Dementia, Driving and Mobility

Foreword

The RACT's vision is: *We find ways to enhance life in Tasmania.* A big part of that is to provide trusted mobility advice and expertise to our members and the wider Tasmanian community. We make it our business to understand what's happening in our community – and we know that dementia is a significant issue. While RACT believes that all drivers should be able to drive for as long as they are safe to do so, some medical conditions impact on driving ability. For the drivers affected this means that their future driving must be reconsidered.

There are around 7,600 people living with dementia in Tasmania. 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

RACT acknowledges the generous support of our Victorian sister organisation RACV in the production of this guide, which has been adapted from RACV's original document and design. It has been developed for people living with dementia, health professionals, carers, families and friends. 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 contacts is included.

This guide has been developed with input and advice from:

- Road safety and mobility experts
- Occupational therapists and medical specialists
- People with dementia and their carers
- Alzheimer's Australia, Tasmania

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Chief Executive Officer, RACT





Dementia and driving

How dementia affects driving

Dementia is the term used to describe the symptoms of a group of illnesses that cause a progressive decline in a person's functioning. Dementia will affect memory, concentration, judgement, vision or problem-solving. It will also 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 progressive nature of dementia means that a person's ability to drive safely can be compromised, due to a decrease in abilities such as problem-solving, reasoning, judgement, vision, planning, and insight. For this reason, many doctors and health professionals believe that a diagnosis of dementia is incompatible with holding a driver's licence. A person who is diagnosed with dementia will at some point need to stop driving.



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 stop driving.

"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.

When people with dementia are no longer driving, it is essential they receive the support of carers, family and friends.

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.

It is your legal responsibility to tell the Registrar of Motor Vehicles about any changes in your medical fitness to drive.

People who are diagnosed with dementia are required to inform the Registrar of Motor Vehicles about their condition.

Once informed, the Registrar of Motor Vehicles will request that you undergo a medical fitness to drive assessment.

Sometimes your doctor may decide that you are medically fit to drive but may recommend that conditions be imposed.



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If your doctor thinks that you are medically fit to drive but is not sure about your ability to drive safely, he or she may recommend that you have an on-road driving assessment. The Registrar of Motor Vehicles will write to you about this, once informed.

If your doctor refers you for an occupational therapy driving assessment, you will need to make arrangements with a private provider and you will be required to pay for the cost of the assessment. They will give you more information regarding the process and costs.

The Registrar of Motor Vehicles will write to you to let you know what steps you need to take. You will also receive a letter if a decision has been made to put conditions on your licence, or to suspend or cancel your licence, and you will be provided with information about how to request a review of a decision made about your driving.

For those people who stop driving and surrender their licence, they can apply at Service Tasmania to get a Personal Information Card as another form of photo identification (see page 22).

For more information regarding the driver licensing requirements, contact the Transport Enquiry Service (see page 22). The Tasmanian Older Drivers' Handbook contains useful information and is available from Service Tasmania or at www.transport.tas.gov.au





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 while 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 a pattern of these problems is noticed, it is important that the person is medically assessed, as such problems may be due to dementia, or some other treatable medical condition.

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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 minimise problems and 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, and other activities of daily living.

Having the difficult discussion

Dementia is a progressive condition and almost always 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.





Getting help from family, friends and 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 stop driving voluntarily 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

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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 may not be able to 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 a person continues to drive, even though there are serious concerns about their safety.

You can write to the Registrar of Motor Vehicles expressing your concerns about someone's ability to drive. You need to include your personal details (eg name and address), as well as details of the person you are concerned about, and the reasons for your concern.

Your request will be treated confidentially and your details will not be disclosed to the person. You can write to the Registrar of Motor Vehicles at GPO Box 1002, Hobart, Tasmania 7001 or by email to driver.licensing@stategrowth.tas.gov.au

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 Tas and Carers Tasmania run support groups and counselling for people with dementia and their carers (see page 19).

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. Sometimes a roster can be helpful.



"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.

Social Support Groups

Maintaining social contact and getting support from others in a similar situation can help. Alzheimer's Australia Tas operates a number of programs to provide people with dementia and their family members an opportunity to enjoy time together with people in a similar situation.

These operate in various regions of Tasmania and transport can be provided if needed (see page 19).



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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, telephone banking or direct debit 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 12,000km annually can cost up to \$11,800 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 first stages of dementia can still travel independently either on foot or on public transport.

People with dementia should use familiar routes and carry relevant identification along with a contact person's details in case 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 well-being, self-esteem and physical health. However, dementia can impact on a person's ability to navigate and recall common routes, so having a regular route is usually safer. Getting lost can be very traumatic, so planning is essential. One option for people with dementia is to consider getting a GPS tracking system to enable a person's location to be detected using the internet (see page 22).

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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 should also be considered (see page 22).

However, for people with a dementia diagnosis it is rarely 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 taxi services have wheelchair-accessible taxis available.

Concessions on taxi fares are available for eligible members of the Transport Access Scheme (for people with a severe and permanent disability) (see page 21).



Public transport

Public transport might be an option for those in the first stage 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 and tickets (see page 20).

Community transport

Many Tasmanian councils and local organisations have community transport schemes using buses or cars providing low-cost flexible transport. To find out more about community transport options available in your area (see page 21).



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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

Alzheimer's Australia Tasmania

For a range of services for people with dementia, their carers and families, including the National Dementia Helpline.

www.fightdementia.org.au

1800 100 500

Carers Tasmania

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

www.carerstas.org

1800 242 636

Commonwealth 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.myagedcare.gov.au

1800 200 422

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Public Transport

Information on public transport services, fares and tickets.

Metro (Hobart, Launceston and Burnie)

www.metrotas.com.au

132 201

Merseylink (Devonport Area)

www.merseylink.com.au

(03) 6427 7626

Redline (Statewide)

www.tasredline.com.au

1300 360 000

Tassielink Transit (Statewide)

www.tassielink.com.au

1300 300 520

Derwent Valley Link (Derwent Valley)

www.derwentvalleylink.com.au

(03) 6249 8880





Community Transport Services Tasmania

CTST is funded by the Home and Community Care Program (HACC) to provide social and non-emergency medical transport to the frail aged and younger disabled, enabling independence and quality of life.

www.ctst.org.au

(03) 6231 6974

Transport Access Scheme

Concessions on taxi fares are available for eligible members of the Transport Access Scheme (for people with a severe and permanent disability). Contact the Transport Enquiry Service.

www.transport.tas.gov.au

1300 851 225



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Registrar of Motor Vehicles and Transport Enquiry Service

www.transport.tas.gov.au

1300 851 225

Personal Information Card

www.service.tas.gov.au

1300 135 513

Tasmanian Seniors Card

www.seniors.tas.gov.au

1300 135 513

Australian Pensioner Concession Card or Health Care Card

www.humanservices.gov.au

132 300

Veterans and war widows

www.legacy.com.au

(03) 6234 6581 (Hobart)

(03) 6331 9369 (Launceston)

GPS tracking

www.fightdementia.org.au

1800 100 500

Hobart Community Legal Service

www.hobartlegal.org.au

(03) 6223 2500

Launceston Community Legal Centre

www.lclc.net.au

1800 066 019

North West Community Legal Centre

www.nwclc.org.au

(03) 6424 8720

Contacts

Alzheimer's Australia, Tasmania	1800 100 500
Carers Tasmania	1800 242 636
Commonwealth Respite and Carelink Centres	1800 052 222
Aged Care Information	1800 200 422
Metro (Hobart, Launceston and Burnie)	132 201
Merseylink (Devonport Area)	(03) 6427 7626
Redline (Statewide)	1300 360 000
Tassielink Transit (Statewide)	1300 300 520
Derwent Valley Link (Derwent Valley)	(03) 6249 8880
Community Transport Services Tasmania	(03) 6231 6974
Transport Access Scheme	1300 851 225
Registrar of Motor Vehicles and Transport Enquiry Service	1300 851 225
Personal Information Card	1300 135 513
Tasmanian Seniors Card	1300 135 513
Australian Pensioner Concession Card or Health Care Card	132 300
Veterans and war widows	(03) 6234 6581 (Hobart) (03) 6331 9369 (Launceston)
GPS tracking	1800 100 500
Hobart Community Legal Service	(03) 6223 2500
Launceston Community Legal Centre	1800 066 019
North West Community Legal Centre	(03) 6424 8720

