

Staying on the move with dementia



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Foreword

Why is this guide necessary?

At some point all people with dementia must stop driving although many people with dementia can continue driving safely for some time. Working out when a driver with dementia should give up driving can be traumatic for the driver, carers and health professionals. The need to balance safety with independence and mobility often means that the decision to stop driving is an emotionally charged and difficult topic.

This guide has been developed by The National Roads and Motorists' Association (NRMA) and Alzheimer's Australia NSW for people with dementia, carers, family and friends and health professionals. It provides a summary of the key issues surrounding driving and dementia and describes other mobility options that exist for people who can no longer drive.

If you live in a state or territory other than New South Wales (NSW) or the Australian Capital Territory (ACT) please check with your local driver licensing authority regarding any specific reporting or licensing requirements.



Driving and dementia

How does dementia affect driving abilities?

Driving is a complex task requiring concentration, problem-solving skills, quick reactions, vision and memory. People with dementia eventually lose these abilities and skills. Unfortunately many people with dementia do not recognise these losses when they happen.

Warning signs that dementia may be affecting a person's driving skills include:

- forgetting how to get to and from familiar places
- getting lost or losing the car
- failing to observe traffic signs
- making slow or poor decisions in traffic
- slow reaction times
- driving at an inappropriate speed
- misjudging speed, distance or turns
- becoming angry, stressed, agitated or confused while driving
- hitting curbs
- poor lane control
- making errors at intersections
- confusing the brake and accelerator pedals
- returning from a routine drive later than usual
- an increased number of dents and scratches on the car.

What are the legal requirements for a driver with dementia?

The law requires drivers to report any permanent or long-term illness that is likely to affect their ability to drive safely to Roads and Maritime Services (RMS) in NSW or the Road Transport Authority (RTA) in the ACT. Dementia is one of the conditions that drivers are required to report. However, reporting the illness doesn't necessarily mean that a driver's licence will be taken away. It does mean that the RMS or RTA will request that a health professional complete a Medical Report Form. Sometimes it can be difficult to make an assessment and a doctor may refer a driver with dementia for a practical driving assessment or to a medical specialist.

Due to the progressive nature of dementia and the need for frequent review, a person diagnosed with dementia may not hold an unrestricted licence. A restricted licence may be considered by RMS or the RTA subject to at least an annual review, taking into account:

- the nature of the trips the driver makes, for example where they drive
- information provided by the treating doctor regarding the level of impairment of any of the following: vision, spatial perception, insight, judgement, attention, reaction time or memory and the likely impact on driving ability
- the results of a practical driver assessment if required
- the opinion of an appropriate specialist may also be considered.

If a person is referred by a doctor, RMS or the RTA for an on-road driving assessment the assessment is conducted by a qualified occupational therapist. The cost of the assessment, which varies, is paid by the driver.

For more information on the assessment process, or to locate suitably qualified occupational therapists, contact Occupational Therapy Australia: phone (02) 9648 3225 in NSW, or (02) 9648 3352 in the ACT. The website is otaus.com.au.

When assessing a driver's ability to drive safely, a doctor will refer to the Assessing Fitness to Drive, national standards which describe specific requirements for various diseases and conditions. These standards can be viewed on the internet at: austroads.com.au/assessing-fitness-to-drive.

If a driver does not report their condition to the RMS or the RTA the driver is not fulfilling their legal responsibility. If a driver with dementia continues to drive despite a doctor's advice and is involved in a crash the driver may be prosecuted and their insurance may not be valid.

If a doctor is aware that a driver is continuing to drive and feels that their driving is a serious risk to themselves and other road users, the doctor is legally authorised to notify the RMS or the RTA directly.

"After dad drove on the wrong side of the freeway the doctor reported him to RMS."

Car insurance

Insurance companies' guidelines around the rights and responsibilities of customers to disclose a diagnosis of dementia vary. Drivers with dementia should check with their insurance company whether the diagnosis affects their car insurance cover.

Talking about driving and dementia

Some people diagnosed with dementia give up driving easily but for others the transition to non driver can be very difficult.

It is important to engage people diagnosed with dementia, who are able and who want to continue to drive, in discussions about their driving soon after diagnosis. An early diagnosis tends to make it easier to involve the person with dementia in discussions about when they will stop driving. It is likely there will need to be many conversations about driving.

Open and honest discussion with family and health professionals can help to develop a joint approach to the issue. It may be helpful if a health professional explains how the progression of dementia will eventually affect driving ability, even for the very best of drivers. It can be useful to get this explanation in writing so it can be referred to in subsequent discussions.

Short frequent conversations will probably be less stressful and more useful for the person than a long one-off discussion and will allow for changes in symptoms to be addressed as they happen.

During discussions about driving and dementia it is important that the person with dementia is given opportunities to express their feelings, fears, needs and to explore solutions. These solutions should include possible alternative transport arrangements to meet their needs once they stop driving. By making an informed plan about when they will give up their licence, they maintain some control over this aspect of their future.

Considering the benefits and risks of driving with dementia

When discussing or thinking about giving up driving the person with dementia and carers need to consider the benefits and risks of driving. Before doing so, it is important for the person and their carers to acknowledge that the risks will eventually outweigh the benefits. The benefits of continuing to drive include: maintaining independence, getting to appointments, the shops and other places they may want to go, getting out of the house, visiting family and friends, travel and the pleasure of driving.

The risks of driving include: becoming lost, having an accident and causing injury or death to the driver and others, becoming stressed and agitated while driving and causing carers and family to worry about these risks.



Having the conversations about when to give up driving

Discussions on giving up driving can be tense. Suggestions that may help the discussions go well include:

- plan what you want to convey in the discussion and instigate it when everyone is relaxed
- express your concerns about the safety aspects of driving with dementia. It may help to mention specific instances when there has been cause for concern about the driving
- 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
- acknowledge the benefits of driving and suggest alternative ways of meeting these needs. You may need to think about these options before having the conversation
- concentrate on the person's strengths and the positive aspects of other options
- normalise the situation, everyone will have to stop driving at some point
- acknowledge that giving up driving is hard to do. Try to understand how the person with dementia will be feeling
- discuss the financial benefits of selling the car. Owning and maintaining a car is often more expensive than people realise when insurance, registration, depreciation, petrol costs and maintenance are factored in. Very few cars cost less than \$100 a week and many cost more
- appeal to the person's desire to act responsibly
- be patient and firm.

How often does the decision to continue driving need to be reviewed?

The symptoms of dementia are unpredictable and change over time so there needs to be ongoing monitoring of the driving of people with dementia. Keep an eye out for the warning signs, keep talking with health professionals and perhaps have a set period when the issue will be revisited, such as every couple of months.

Strategies for dealing with an unsafe driver who continues to drive

Dementia can affect self-awareness and some people with dementia cannot recognise deterioration in their driving skills. It is not known how many people with dementia continue to drive when their cognitive abilities no longer let them drive safely. Sometimes a person who has agreed to stop driving will forget that they can no longer drive or that they made an agreement not to drive.

“He was very upset when we sold the car, even tried to buy another one. It didn’t matter that everyone, including the doctor and the licence people had told him he couldn’t drive. Every time he thought about it he wanted to get into his car.”

If the conversations about giving up driving aren’t going well, don’t blame yourself. Dementia can impair insight and judgment, making it difficult for people to understand that their driving is no longer safe. It can also cause mood and personality changes that make reactions more pronounced.

It may help to ask a respected family member or a health professional to reinforce the message about not driving.

As a last resort, a person with dementia may need to be forced to stop driving by taking away the car keys, disabling the car or removing the car completely. When any of these strategies are called for it is important to provide a safe, reliable alternative transport option.



What if the driver does not have a diagnosis of dementia but is driving in a manner that is concerning?

It is important that anyone displaying unsafe driving patterns sees a health professional. There are several medical conditions that affect driving ability and which may mean that someone needs to stop driving.

The benefits of getting medical help or even a diagnosis of dementia mean that treatment and strategies can be put in place that may delay or manage symptoms. The earlier a diagnosis of dementia is made, the earlier planning can begin for support and assistance with transport.

The impact of retiring from driving

The loss of a driver's licence makes some people with dementia feel that they have lost their independence and their role in the household, particularly if they were the primary driver. Surrendering a licence can lead to a loss in confidence and to feelings of isolation and unwanted dependency. It is important to support people with dementia as they deal with this loss.

“When they took his licence away he was totally dependent on his son. The power in the household shifted. He really went downhill from that day.”

Other people in the household can also find the loss of the person's licence challenging. If the person was the only driver, others in the household may become isolated. Carers who do drive may find meeting the transport needs of the person with dementia overwhelming.

“At first I cut back my work hours but I couldn't juggle everything so I had to give up my job. We couldn't cope if I didn't drive her everywhere.”

It is important that people with dementia and carers maintain their mobility and retain social contacts. 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 whenever possible. This requires planning.

“Mum would like to get out more, to see people and just get out of the house but we are flat out just making sure we can get her to the appointments and doing a bit of shopping.”

Be sure to take up any offers of assistance 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. If friends or family are not in the position to provide transport, ask them to visit regularly. Social contact is vital for people with dementia and for carers.



Alternatives to driving with dementia

It is important to identify and explore ways that people with dementia and their carers can meet their practical needs and stay connected to their community once they stop driving. Alternative transport options should be discussed and tried soon after the diagnosis, ideally before the person gives up driving. This helps to make the transition to other forms of transport smoother and can make the prospect of giving up driving less intimidating for the person and for carers.

Minimising the number of trips required

It can be very useful to minimise the number of trips that require transport. Ways of doing this can include encouraging the use of home delivery services for food, medical prescriptions and the local library and setting up online banking or telephone banking to pay bills.

Friends or family may be able to help set up these services for you. They may also be able to help identify alternative transport options for the person with dementia.

Transport options

Alternative ways of getting around other than driving include:

- being driven
- the Australian disability parking scheme
- organisations that drive people with dementia
- being escorted or travelling
- walking
- mobility Scooters
- community transport
- taxis
- public transport.

Being driven

This is a widely adopted strategy for meeting the transport needs of people with dementia who do not drive. Being driven by others can be very effective but it is not without challenges. If a carer is not a confident driver, they may consider taking a driving refresher course.

Designated drivers can feel somewhat overwhelmed by the ongoing need to provide transport and people with dementia can be challenging passengers, particularly if they become agitated in the car.



Depending on the dementia symptoms the passenger is experiencing, some ideas that can help are:

- be patient and allow them plenty of time to get ready and to get into the car
- be prepared with relaxing music, sunglasses, food, water and possibly distractions
- try to ensure that they are calm before entering the car
- ask them to use the bathroom before getting into the car
- have a mobile phone in the car, but remember it is illegal to use a hand held phone while you are driving
- give brief, step by step instructions and information in small bits
- reminisce
- stay calm, or at least appear to be calm, and be aware of your body language
- agree with them where ever possible
- know where you are going and where you can park.

If the passenger's symptoms are causing dangerous or unpredictable behaviour, you might consider:

- seating them in the rear passenger side seat with seat belt and child locks on
- covering the door handle with dark tape to make it less visible if you are concerned that the person may try to open the door
- covering the seat belt buckle with a lap blanket or a buckle guard if the passenger wants to undo the seat belt when you are driving.

The Australian Disability Parking Scheme

Driving a person with dementia can be easier if they are eligible for the Australian Disability Parking Scheme (ADPS). The ADPS is the national scheme for disability parking permits which helps eligible people park nearer to their destination. The scheme is progressively being rolled out in States and Territories.

For information on the Mobility Parking Scheme in NSW, phone RMS on 132 213 or go to rms.nsw.gov.au/usingroads/mobilityparking.

For information on the Mobility Parking Permit in the ACT phone the RTA on 132 281 or go to rego.act.gov.au/parking.

The ADPP is recognised Australia wide. However, when travelling interstate, permit holders should check local parking concessions as they vary between states.

Organisations that drive people with dementia

Many day care and respite services provide transport from the home of the person with dementia to the centres.

There are also some private transport services that provide transport for people with health issues, including people with dementia. Health professionals, your local council or a search of the yellow pages may direct you to providers who service your area.

Being escorted or travelling alone

Many people in the earlier stages of dementia can still travel independently either on foot, on mobility scooters, in taxis, on public or community 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 for carers. The decision may vary according to the mode of travel, for example a person may be able to travel alone by taxi while they cannot travel alone on public transport.

Some indicators that a person should not travel alone include:

- frequently getting lost
- trips taking a lot longer than they should

- becoming agitated while travelling
- not recalling details of the trip
- forgetting the purpose of the trip before they arrive.

“He stopped travelling on the train by himself after he got off at the wrong stop and could not work out what to do. He was very agitated and upset by the time I found him.”

Some community transport operators, neighbourhood centres, community centres and local councils provide escorts for people with dementia who cannot travel alone.

Walking

Walking can have a positive impact on the wellbeing, self-esteem and physical health of people with dementia. However, dementia can impact on a person's ability to navigate and recall common routes. Getting lost can be traumatic so planning is essential. One option to assist people to walk independently is to consider getting a GPS device which enables a person's location to be detected on the internet. At a minimum the person should have the contact details of someone who can be called should they become lost.





Mobility scooters

If a person with dementia used a scooter prior to diagnosis, a treating health professional will be able to advise them whether they can continue to use the scooter. If a person with dementia does use a scooter, a GPS tracking system should be considered in case the person becomes lost. However, for people diagnosed with dementia who are not safe to drive, it is not safe to start using a scooter as an alternative to driving. Ultimately, the progression of dementia will mean that scooter use will be unsafe for all users with dementia and other forms of transport will be needed.

Community transport

Community transport provides access to shopping, medical and social services, recreation and social contact for people who cannot use regular public transport such as:

- isolated families
- older people who are frail and their carers
- people with disabilities and their carers.

Current providers of community transport include community organisations, local councils and members of the National Aboriginal and Torres Strait Islander Community Transport Network.

The NRMA's **Living Well Navigator** provides a directory of community transport providers in NSW and the ACT. The website includes a search function to locate nearby services and a range of other information on getting around. It can be found at: mynrma.com.au/living-well-navigator/getting-around.

The Regional Transport Coordination Program may assist people who live outside metropolitan Sydney and experience transport disadvantage to access services. The contact list for the regional transport coordinators can be found at: transport.nsw.gov.au/content/regional-transport-coordinators.

Taxis

Taxis are usually more expensive than other forms of public transport but they provide door to door service and some people with dementia find them easy to use. Taxis can be particularly useful for people with dementia if they develop a trusting relationship with a regular driver.

The cost of using taxis can be partly alleviated by the Taxi Transport Subsidy Scheme (TTSS) which provides subsidised travel. The TTSS is available to people who are unable to travel on public transport without the constant assistance of another person.



In NSW further information can be obtained by calling TTSS on [1800 623 724](tel:1800623724) (toll free) or from: transport.nsw.gov.au/ttss.

In the ACT further information can be obtained by calling [\(02\) 6205 1012](tel:0262051012) or from: assistance.act.gov.au/adult/transport_and_registration/taxi_subsidy_scheme.

Public transport

Many people in the earlier stages of dementia, especially those who have used public transport regularly prior to the diagnosis, can continue to use public transport for some time, particularly on familiar routes. People with more advanced dementia symptoms may need to be accompanied on public transport.

Information on routes, timetables and accessibility for NSW public transport can be found at transportnsw.info, by phone: [131 500](tel:131500) and TTY: [1800 637 500](tel:1800637500). In the ACT contact the Internal Omnibus Network (ACTION) at action.act.gov.au.

Companion card

The Companion Card allows people with a severe and profound disability, who require attendant care at events and venues, to participate without having to pay for a second ticket for their attendant. The Companion Card is recognised on most public transport.

For more information in NSW call [1800 893 044](tel:1800893044) during business hours or visit nswcompanioncard.org.au.

In the ACT phone [\(02\) 6207 1086](tel:0262071086) or visit communityservices.act.gov.au/companion_card.

Support for people with dementia, carers and families

A diagnosis of dementia can be very confronting. There are resources that provide help and support for people with dementia, carers and families.

Remember help is available, you are not alone.

Alzheimer's Australia NSW and Alzheimer's Australia ACT

The Alzheimer's Australia National Dementia Helpline provides a range of services for people with dementia, their carers and families, including telephone services, regional services, counselling and information on support groups such as dementia cafes.

The National Dementia Helpline number is [1800 100 500](tel:1800100500).

Alzheimer's Australia provides Helpsheets on a variety of topics, including driving. The website can be found at fightdementia.org.au.

Other useful contacts and information

Dementia Cafés provide people with dementia, carers and family members an opportunity for mutual support and to enjoy time together with people in a similar situation. The National Dementia Helpline can provide details of dementia cafés in your area.

NSW Roads and Maritime Services

Phone: [132 213](tel:132213) Web: rms.nsw.gov.au

ACT Road Transport Authority

Phone: [132 281](tel:132281) Web: rego.act.gov.au

Carers NSW and **Carers ACT** provide information and resources for carers. The Carer Line operates Monday to Friday between 9am and 5pm and can put carers in touch with a range of services and supports.

Carers NSW Freecall: [1800 242 636](tel:1800242636) **Carers ACT** Freecall: [1800 242 636](tel:1800242636)

The **Aged Care Information Line** can provide support and assistance with queries about access to home and community care, respite fees, and bonds and charges.

Phone: [1800 200 422](tel:1800200422) Web: myagedcare.gov.au

The **Dementia Behaviour Management Advisory Service** is a national telephone advisory service for families, carers and care workers who are concerned about the behaviours of people with dementia. The service provides support 24 hours a day, 7 days a week and can be contacted on [1800 699 799](tel:1800699799).

For language assistance phone the **Telephone Interpreter Service** on [131 450](tel:131450).

A **Photo Card** can be used by people who do not hold a current driver licence, or other form of photo identification, to help them show who they are. It may be used to help access a number of everyday services such as sending or receiving international mail, opening bank accounts and entering licensed premises. Contact RMS or the RTA for more information.

The NSW Photo Card application is available online or from any Roads and Maritime Services registry. To obtain an ACT Photo Card, applicants need to visit to a CanberraConnect shopfront.

The **NRMA** has advice on buying and selling a car as well as information on the costs of running a car. The website also links to senior driver refresher courses which may be useful for carers. Visit mynrma.com.au/motoring.



References and acknowledgements


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Contacts & services

- **NRMA**
W: mynrma.com.au P: 13 11 22
9A York Street Sydney NSW 2000
- **Alzheimer's Australia**
W: fightdementia.org.au P: 1800 100 500

Other useful contacts for staying on the move with dementia include:

- **Community Transport Search**
mynrma.com.au/living-well-navigator/getting-around
- **Translating and Interpreter Service** 
P: 131 450

NSW

- **Roads and Maritime Services**
P: 132 213 E: RMS.Contact.Centre@rms.nsw.gov.au W: rms.nsw.gov.au
- **Public transport info**
W: transportnsw.info P: 131 500 TTY: 1800 637 500
- **Carers NSW**
Freecall: 1800 242 636

ACT

- **Road Transport Authority**
P: 132 281 E: rus@act.gov.au W: rego.act.gov.au
- **ACTION Buses**
W: action.act.gov.au P: 131 710 TTY: (02) 6207 0494
- **Carers ACT**
Freecall: 1800 242 636