

Supporting drivers with dementia and their carers to stay safe, mobile and connected.

**CHANGED
CONDITIONS
AHEAD**

**DEMENTIA
AND DRIVING
GUIDE FOR
FAMILIES AND
CARERS**





FURTHER INFORMATION ON DEMENTIA AND DRIVING

Contact the National Dementia Helpline on **1800 100 500**

For language assistance phone the Telephone Interpreter Service on **131 450**

Arabic

معلومات إضافية حول الخرف والقيادة

إتصل مع خط المساعدة الوطنية للخرف على الرقم **1800 100 500**. وللحصول على المساعدة اللغوية إتصل مع خدمات الترجمة الشفهية عبر الهاتف
131 450 على الرقم Telephone Interpreting Service

Cantonese

有關癡呆症與駕駛的詳情

請與全國癡呆症幫助熱線聯絡，電話：**1800 100 500**

若需要語言方面的幫助，請致電電話口譯服務，電話：131 450

Mandarin

有关痴呆症与驾驶的详情

请与全国痴呆症帮助热线联系，电话：**1800 100 500**

若需要语言方面的帮助，请致电电话口译服务，电话：131 450

Dutch

Verdere informatie over dementie en rijden

Neem contact op met de Nationale Dementie Hulplijn op **1800 100 500**

Voor hulp met taal kunt u de Telefonische Tolkdienst bellen op 131 450

German

Weitere Auskunft über Demenz und Autofahren

Wenden Sie sich an die australienweite Telefonauskunftsstelle zum Thema Demenz unter **1800 100 500**

Wenn Sie einen Dolmetscher benötigen, rufen Sie den Telefondolmetschdienst unter 131 450 an

Greek

Περισσότερες πληροφορίες για την άνοια και την οδήγηση

Επικοινωνήστε με την Εθνική Γραμμή Βοήθειας Άνοιας στο **1800 100 500**

Για γλωσσική βοήθεια τηλεφωνήστε στην Τηλεφωνική Υπηρεσία Διερμηνέων στο 131 450

Hindi

डिमेंशिया (मनोभ्रंश-रोग) व ड्राइविंग से संबंधित अधिक जानकारी

नेशनल डिमेंशिया हेल्पलाइन से **1800 100 500** पर संपर्क करें

भाषाई सहायता के लिए टेलीफोन दुभाषिया सेवा (Telephone Interpreter Service) को 131 450 पर फोन करें

Italian

Per maggiori informazioni sulla demenza e la guida

Contattate il Servizio Telefonico Amico per la Demenza al **1800 100 500**

Per assistenza linguistica, telefonate al Servizio Telefonico Interpreti al 131 450

Polish

Więcej informacji na temat demencji i kierowania samochodem

uzyskasz dzwoniąc do National Dementia Helpline **1800 100 500**

Pomoc językową uzyskasz dzwoniąc do Telephone Interpreter Service 131 450

Vietnamese

Thông tin thêm về bệnh lú lẫn và việc lái xe

Liên lạc với Đường Dây Giúp Đỡ Toàn Quốc về Bệnh Lú Lẫn (National Dementia Helpline)

ở số **1800 100 500**

Muốn được trợ giúp về ngôn ngữ, xin gọi cho Dịch Vụ Thông Ngôn qua Điện Thoại

(Telephone Interpreter Service) ở số 131 450



CONTENTS

About this guide	3
Dementia and driving overview	4
Recognise the warning signs	6
Worksheet 1: Warning signs	7
Respond to changes in driving ability	9
When safety is an immediate concern	10
Start the conversation	11
Worksheet 2: Conversation planner	13
Work with health professionals	15
Stay active, mobile and connected	16
Worksheet 3: Driving activities	19
Worksheet 4: Getting there	21
Worksheet 5: Not going it alone	23
Who to contact for more help	25

ACKNOWLEDGEMENTS

Thanks and appreciation are given to the many individuals who have contributed to the development of this guide, with special thanks to the following:

RACV

Members of the Alzheimer's Australia Vic Dementia and Driving Project Group

Consumer interviewees Sofia and Maria Danyluk, Glen Davis, Anne Fairhall, Bob and Anne Grierson, Robyn Langworthy, Jane Sandow and Rob Trinca, Sue and Bob Walsh

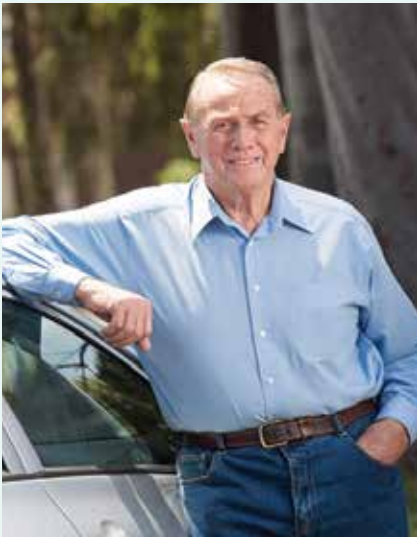
The Hartford Center for Mature Market Excellence

Elizabeth Wright, volunteer with Alzheimer's Australia Vic

Terence Donovan, Dementia and Driving Ambassador



“He just took it for granted that he would always be able to drive.” Sue, carer



Like most Australians, I have encountered dementia among my loved ones. I know from experience that a diagnosis can not only impact on the individual but also their families and carers. The importance of this issue became even clearer to me recently while playing Doug – a character on the TV show ‘House Husbands’ who was living with dementia.

With an ageing population and the projected increase in the prevalence of dementia there will be a growing number of older drivers who will experience impaired driving ability. While it is internationally accepted that not all people with dementia are incapable drivers, particularly in the early stages of the condition, dementia does produce a progressive and irreversible loss of mental functioning which will inevitably mean that, at some stage, the person will need to stop driving.

Families and carers play an important role in supporting drivers with dementia going through the process of giving up driving. This *Changed Conditions Ahead* guide provides information about the system of support available in Victoria to help determine when and how to stop driving. The guide will also help carers support a driver through the often difficult and emotionally challenging process of giving up driving, taking into consideration their dignity and wellbeing and the safety of other road users.

This guide forms part of the *Changed Conditions Ahead* kit, a dementia and driving information kit for people with dementia and families and carers. To obtain copies of the kit phone the National Dementia Helpline on 1800 100 500 or visit www.fightdementia.org.au/dementiaanddriving

I would like to thank RACV for funding this kit and Alzheimer’s Australia Vic for their work in developing it. Together, we can make a real difference to the lives of people living with dementia.

Terence Donovan

Actor and Alzheimer’s Australia Vic
Dementia and Driving Ambassador

ABOUT THIS GUIDE

This guide is for carers, family members and friends of a person with dementia who is driving. It will answer your questions about what happens when someone’s driving ability begins to be affected by dementia and what to do if they are faced with the need to stop driving.

It will also provide you with information about the system in place in Victoria to help drivers and carers to know when and how to stop driving. Importantly, you will also find ways to support drivers through the practical and emotional impacts of giving up driving and help them to stay active, mobile and connected.

As a carer, family member or friend, you play an important role for a driver with dementia. You are often the first to observe changes in the person’s driving skills. You may also be the first to notice symptoms of dementia before a formal diagnosis is made. You are also likely to be the person closest to the driver during the often challenging transition to non-driving.

Alzheimer’s Australia Vic hopes this guide will provide you with the information you need, as well as offering a range of strategies to support drivers to step out of the drivers seat as smoothly and as successfully as possible.

This guide is complemented by RACV’s *Dementia, Driving and Mobility* brochure.

Refer to this brochure for more information about:

- general legal, practical and medical matters relating to dementia and driving;
- the range of supports and services in place for drivers and carers in Victoria, and
- ways to stay active, mobile and connected in the transition to non-driving.



DEMENTIA AND DRIVING OVERVIEW

Currently, there are more than 5.7 million Victorians who drive some 4.3 million registered cars.¹ Driving is something most people take for granted. It gives us freedom, flexibility and independence. We drive for practical purposes, like going grocery shopping, but also for leisure and social purposes, to see friends and family.

It's not something that many of us stop to consider, but the fact is that, while driving is integral to our lives, we will all need to step out from behind the wheel one day. In most cases, people reduce and eventually stop driving as a result of changes in health associated with ageing, for example, declining eyesight. Other people stop driving because of the impact of disability, or because of the progression of a chronic medical condition such as diabetes, epilepsy or dementia.

Conditions such as dementia or other forms of cognitive impairment are not simply a part of the ageing process. However, their progression can mean that the decision to stop driving needs to be planned for and made much earlier than expected.

What is Dementia?

The term 'dementia' is an umbrella term for changes in thinking and behaviour caused by brain disease. Every person with the condition is impacted differently. The most common form of dementia is Alzheimer's disease. Other common forms include vascular dementia, frontal lobe dementia and Lewy body disease.

Dementia already affects more than 75,000 people in Victoria. It also impacts on their families, carers and loved ones. Unless there are significant medical breakthroughs, it's expected that more than 246,000 Victorians will have some form of dementia by 2050.² This means that a large number of Victorian drivers will develop, or know someone who will develop, dementia.

A large number of people with dementia are older, but it is important to remember that not all older people get dementia. It is not a normal part of ageing. Dementia can happen to anybody. It is more common after the age of 70; however, people in their forties and fifties and even earlier can also have dementia.

The first and most important point that drivers and carers need to be aware of is that all people who are diagnosed with dementia are required by law to inform the Victorian driver licensing authority, VicRoads, of their condition.

This important legal obligation leads to the VicRoads medical review process, which determines a person's ability to continue to drive. Further information about this is outlined on page 9 of this guide.

It's important to keep in mind that a diagnosis of dementia does not always mean that someone has to give up driving straight away. A person in the early stages of the condition may still be a capable driver. Because the disease involves a gradual decline in cognitive and physical ability however, they will need to stop driving at some point.

¹ Australian Bureau of Statistics (ABS), *Australian Demographic Statistics*, 3101.0 (September, 2013), p.1; ABS, *Motor Vehicle Census*, 9309.0 (January, 2013), p.4.

² Deloitte Access Economics, *Projections of dementia prevalence and incidence in Victoria 2010-2050* (2010).

“The first signs were very hard to pinpoint. It seemed that Rob was just not as confident and decisive about driving.” Jane, carer



“He felt confident in what he was doing, but we could see that he was not driving well.”

Anne, carer

Why diagnosis is important

Some people are hesitant to follow up on a diagnosis of dementia due to the stigma associated with the disease, or because they believe memory loss is a natural part of ageing. In these circumstances, a decline in driving ability will often come before a diagnosis. When a diagnosis is made at a late stage of the disease, or when no diagnosis has been made but cognitive impairment is evident, the risk of a driving incident significantly increases.

Challenges for drivers with dementia

The experience of giving up driving can be very difficult for a number of people with dementia, and the sense of grief and loss can be ongoing. For some, driving represents a way to hold onto being a fully functioning adult. For others, giving up the role of driver involves some loss of identity.

Try to imagine what your own life would be like if you felt competent to drive a vehicle but had someone close to you hide your car keys or take your car away.

How would you feel if someone told you that you are ‘an unsafe driver’ and ‘have to stop’?

How would you travel to do your shopping or see your friends and family?

It’s important for carers and families to support a person with dementia through the process of giving up driving in a way that involves the person and supports their sense of independence, dignity and wellbeing.

RECOGNISE THE WARNING SIGNS

For experienced drivers, driving may seem to be a largely automatic activity. However, driving is a complicated task that requires a split-second combination of complex thought processes and manual skills.

To drive safely, a person needs to:

- have a good working knowledge of current road law;
- make sense of and respond to everything they see, including road signs and obstacles;
- maintain attention while 'reading the road';
- anticipate and react quickly to the actions of other road users;
- take appropriate action (e.g. braking, steering) to avoid crashes, and
- plan and remember where they are going.³

The symptoms and the progression of dementia are different for everyone. It is therefore very difficult to judge whether a person will need to stop driving in the future or immediately. This reinforces why a diagnosis should be notified to VicRoads, where an assessment of driving ability can be made.

Depending on its form, as dementia progresses it impacts on memory, reactions, perception and the ability to perform tasks. Some people may lose the ability to have insight into their illness, which means they may not be able to make a judgement about their driving capacity on their own. Other people experiencing memory loss may simply forget that they are no longer safe to drive, or forget the incidents that occur when they are driving.

Refer to Worksheet 1 'Warning signs' to identify driving warning signs for a driver with dementia and document your observations of driving.

"It first came to light when Anne came home one day and said she wasn't quite sure how to handle the air conditioning controls." Bob, carer

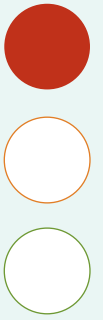


"He was going to my sisters, which we would do daily, and he says, 'Oh, if you should ask me where I should turn Sofia, I don't know'." Sofia, carer

³ Edited excerpt from Alzheimer's Society, *Driving and Dementia*, http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=144.



WARNING SIGNS



Use this checklist to document your observations of driving and support a driver to take the necessary steps to reduce and stop driving. It may also be useful in conversations with family members and healthcare professionals. Look for changes in driving ability. Avoid an alarming reaction if an incident occurs, and where possible, have conversations at a later time.

Early warning signs of impaired driving include the following:

- Decrease in confidence while driving
- Forward-focused vision and less awareness of surrounding cars
- Less awareness of road rules

The following **red light** warning signs indicate the need to stop driving:

- Loss of confidence while driving
- Difficulty turning to see when reversing
- Riding the brake
- Easily distracted while driving
- Other drivers often sound horns
- Incorrect signalling
- Difficulty parking within a defined space
- Hitting kerbs and gutters
- Scrapes or dents on the car, mailbox or garage
- Increased agitation or irritation when driving
- Failure to notice important activity on the side of the road, such as road works
- Failure to notice traffic signs
- Difficulty navigating turns
- Driving at inappropriate speeds
- Not anticipating potentially dangerous situations
- Relying on a 'co-pilot' such as a friend or carer
- Near misses
- Delayed response to unexpected situations
- Moving into the wrong lane
- Difficulty maintaining lane position
- Confusion at exits
- Traffic infringement notices or warnings
- Getting lost in familiar places
- Car crashes
- Failure to stop at a stop sign or red light
- Confusing the accelerator and brake pedals
- Stopping in traffic for no apparent reason

If someone you know exhibits any of these warning signs but they haven't been diagnosed with dementia, talk with the person about your observations and encourage them to consult a doctor. Where necessary, you can also make an anonymous written report of unsafe driving to VicRoads. Refer to page 10 for more information.



OUR STORY

ROB AND JANE

Rob and Jane live in an inner suburb of Melbourne. Rob says driving was a pleasurable activity that gave him independence and freedom.

Jane says the first signs of a change in Rob's capacity to drive were very hard to pinpoint, "It seemed that Rob was just not as confident and decisive about driving. I no longer felt comfortable about sleeping when he drove and I felt the need to be alert as co-driver".

Jane noticed a further decline in Rob's driving skills over time. "He became more tentative about location on the road and lacked the confidence for easy lane changes," says Jane. This observation of Rob's driving skills was one of the first things Jane mentioned to the specialist, who later diagnosed Rob with younger onset dementia.

Shortly afterwards, the specialist recommended that Rob notify VicRoads and undergo a driving test. Rob received the news that he would have to stop driving from an occupational therapist driver assessor immediately after performing a driving test in which he thought he drove reasonably well. "After a few hours of reflection", Rob says wryly, "I started to muse about my options – Segway, powered skateboard or harness the dogs." Since stopping driving, Jane now drives Rob to various activities and they take public transport together too.

RESPOND TO CHANGES IN DRIVING ABILITY

Many people diagnosed with dementia and in the early stages of the condition are aware of their driving ability and stop driving before becoming seriously impaired. For those experiencing a loss of confidence in driving, moving out from behind the wheel can come as a relief.

For a number of drivers, however, assessing their own driving ability and knowing when and how to stop driving is more difficult. The best approach to ensuring that drivers do not continue to drive beyond the point where they are safe and legal to do so is to support them to notify VicRoads of their diagnosis immediately. If a driver is interested in continuing to drive, he or she can then go through the process of medical review.

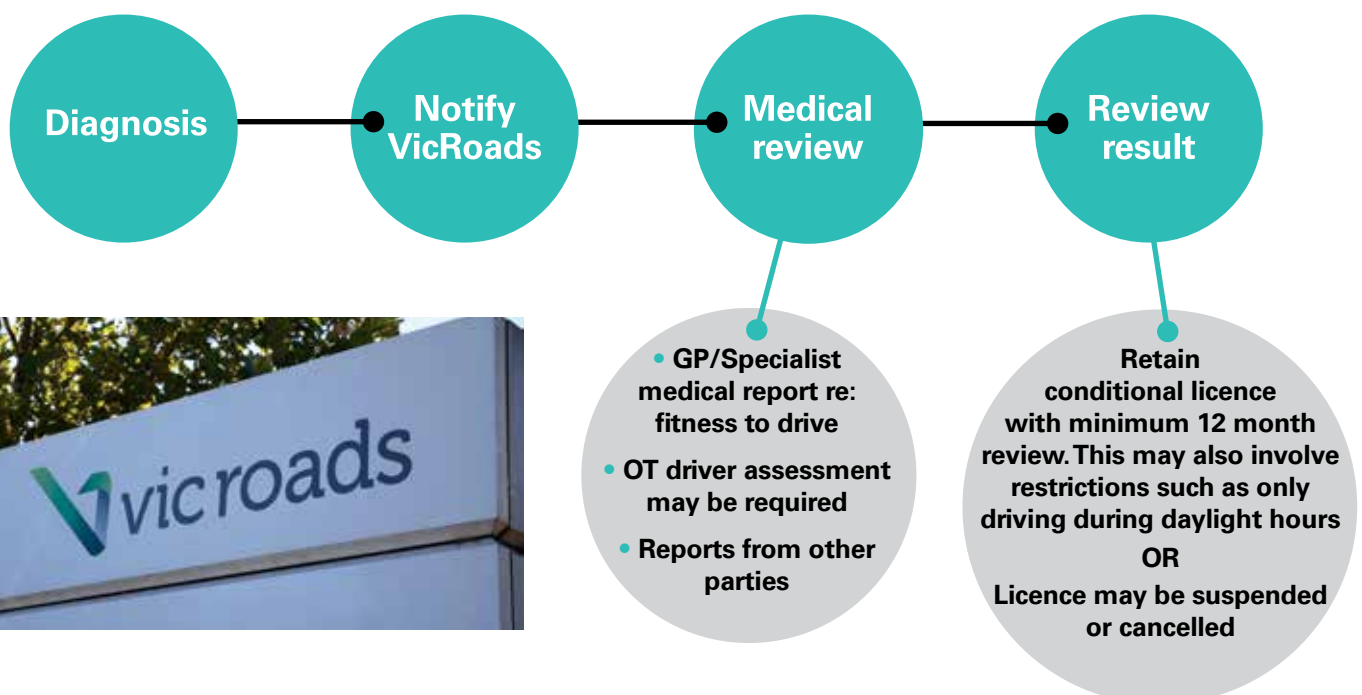
A medical review is the assessment process VicRoads follows to determine whether a person is fit and able to continue to drive. Once notified of a diagnosis of dementia, VicRoads will request a Medical Report form be completed by the person's treating doctor or medical specialist. Medical Report forms are available from VicRoads.

After this, a formal driving assessment with a trained occupational therapist may be required. After conducting the assessment, the occupational therapist will advise whether the driver is capable of continuing to drive. Sometimes this may involve restrictions, such as only driving in the local area or during daylight hours. The licence will only be issued for a set period (maximum of 12 months) after which time the driver will be reassessed.

The driver needs to pay for the cost of the assessment with an occupational therapist. It is worth being aware that assessments cannot be claimed under Medicare or private health insurance and there may be long waiting periods. For safety reasons, all assessments need to be undertaken in a car with dual controls. The driver's own vehicle cannot be 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. People who have their licence varied, suspended or cancelled can request that VicRoads review the decision.⁴

VicRoads Medical Review



WHEN SAFETY IS AN IMMEDIATE CONCERN

Notifying VicRoads of a dementia diagnosis and going through the medical review process with the support of health professionals, carers and family is the best course of action for drivers needing help with the decision to stop driving.

However, there may be some situations where this course of action doesn't work out and the person with dementia continues to drive despite serious concerns about their safety and the safety of other road users. Suggestions for how to approach conversations with a driver and work with health professionals to help reinforce your efforts to support the person to stop driving can be found on pages 11-15.

Strategies and solutions for dealing with immediate and urgent situations are outlined below:

- You can write to VicRoads to report an unsafe driver. Reports are confidential and can be anonymous. You will need to provide the driver's name, date of birth and address if possible, and the reasons for your concerns.

- If you observe unsafe driving but you don't know who the driver is you can phone Victoria Police and report an unsafe driver. Police will establish who was driving at the time and notify VicRoads.
- You can remind drivers about their responsibility as a licensed driver to ensure that the roads are safe not only for their own use but also for other road users.

If a person with dementia continues to drive and they have not notified VicRoads, or if they continue to drive after VicRoads have cancelled or suspended their licence, there can be serious consequences. If the driver is in a crash they could be charged with driving offences or be sued. In addition, their insurance company may not provide cover.

For someone in the early stages of the disease, actions such as hiding the car keys, taking away a driver's licence, or selling or disabling the car could seem disrespectful or hostile. For others, these 'last ditch' attempts by carers may not even succeed as the person may continue driving without a licence, fix their car or even buy a new one.⁵

⁵ The Hartford Center for Mature Market Excellence, *At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia and Driving*, (March 2013), p.7.



START THE CONVERSATION

Alzheimer's Australia Vic has many conversations with people about the impact of dementia on driving. We are aware that talking with drivers about issues like driving warning signs, the need to report a diagnosis, the need for a driving assessment or the need to explore alternative transport and mobility options can be a challenging and emotional matter for all involved.

There can be added difficulty broaching conversations. Carers, family members or friends may rely on the person with dementia for their own mobility needs, or an adult child may not feel comfortable in challenging a parent. Or, very often a carer may already be feeling overloaded with other caring responsibilities.

While it may be tempting to delay these discussions until they 'absolutely need to happen', putting in some advance thought may remove some of the distress of having to deal with the many changes involved in giving up driving. It can also allow everyone time to plan and get used to other transport and mobility arrangements. Early discussions will also avoid the need to raise the subject during a heated conversation or at a crisis point.

There is no single way to approach a conversation about driving. What you talk about and the way

you discuss it will depend on the personality of the person involved and their individual experience of their condition.⁶

Start conversations when everyone is in a calm and balanced mood. It is usually better to have a series of short conversations over a period of time rather than a prolonged, one-off conversation.

Refer to Worksheet 2 'Conversations planner' (page 13) to guide your conversations.

Getting everyone on board

Individual responses and opinions of carers, family members and friends of a driver with dementia can vary or conflict. For example, adult siblings may have different opinions as to the severity of their parent's symptoms or one may find the concept of talking to their parent about driving more uncomfortable than another. A well-meaning sibling may take control of their parent's situation without consulting other family members. The partner of a person with dementia may want to overlook some of their driving incidents in an attempt to prolong their independence and sense of dignity.

With some planning and consideration these challenging scenarios can be avoided. Share some of the observations that you have documented in the warning signs checklist to help different people gain a clearer understanding of the situation. Allow everyone's opinions to be expressed, and listen and respond respectfully. Focus on key issues during the discussion, such as the need to preserve the self-respect and dignity of the person with dementia and the safety of road users.⁷

"I thought, I can't deal with this, so I rang a daughter that he speaks really well with and she talked to him about the assessment." Robyn, carer



⁶ Ibid., p.9.

⁷ Ibid., p.8.

Other things that may help

Here are some other things to consider when approaching conversations about the need to stop driving:

- acknowledge that giving up driving is hard to do;
- normalise the situation by reminding the person that everyone will have to give up driving at some point in their life;
- 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 now and into the future;
- affirm the important roles the person continues to play in other areas of life, for example, as a parent or partner;
- consider the meaning driving has to the person. Owning a car and driving can mean more than just mobility to a driver, it can be a sign of status, a hobby, it may even have been their job. Think about ways that this relationship to the car and driving might be addressed in other ways, and
- focus on the financial benefits of selling the car.⁸

MY STORY

ANNE

The first sign of impaired driving Anne noticed with her husband Geoff was erratic driving. "He would drive quite fast when perhaps he shouldn't be driving fast and then, when he should have been driving steadily on a freeway he would be getting slower and slower but he didn't realise it. It was certainly out of character. He felt confident in what he was doing, but we could see that he wasn't doing his driving well," says Anne.

Anne's conversations with Geoff about having an assessment were very challenging. "It was clear to me that Geoff wasn't going to take any notice of me. He became quite hostile about it, so before one of our visits, I organised a conversation with our specialist," Anne continues. "He listened to the specialist, he didn't agree with him though, he really honestly believed there was nothing wrong with his driving."

Anne continued to bring up the topic of driving with Geoff. "There was an incident in NSW where an elderly gentleman had knocked into a pram and badly injured a young child, who was a similar age to one of our grandchildren" says Anne. "We discussed that, I picked a good time when he was listening and I said, 'isn't that a terrible thing?' He went very silent and thought about it, and I kept on it and built it up with the specialist as well and then he reached a point where he said, 'well, I'm not going to drive anymore'."

Watch Anne's story on video at www.fightdementia.org.au/dementiaanddriving

⁸ RACV, *Dementia, Driving and Mobility*, (2013), p. 9.



CONVERSATION PLANNER



HOW CAN I HAVE GOOD CONVERSATIONS ABOUT NOT DRIVING?

You want your conversations with the person with dementia to be positive, progressive and productive. You can use these points to guide those conversations.

Who should be the messenger?

The person who answers yes to these questions may be in the most favourable position. Is it you or someone else? If it's not you, you may need to have a preliminary conversation with the person in the most favourable position to take action.

- | | | |
|-----------------------------------------------------------------------|---------|--------|
| 1 Is the driver your spouse or your parent? | Yes ___ | No ___ |
| 2 Do you believe you have the person's best interests in mind? | Yes ___ | No ___ |
| 3 Do you know the person's physical and cognitive condition? | Yes ___ | No ___ |
| 4 Do you know the person's current driving abilities? | Yes ___ | No ___ |
| 5 Do you have a good relationship with the person? | Yes ___ | No ___ |

When is a good time to talk?

It's never too early to talk about driving issues, but these conversations warrant careful attention, pre-planning and serious discussion. Here are some good opportunities to start a conversation naturally.

- Change in frequency or severity of warning signs
- Change in health, medication or cognitive status
- Change in financial situation or vehicle ownership

What do you want your conversation to accomplish?

Keep your conversations simple, short and direct. Focus on one or two key points at a time. Here are some appropriate topics with some sample conversation starters. Which of these topics do you need to discuss?

- ___ Family's willingness to help. "When you go to the grocery store, can I go? Or instead, let me drive." "We're willing to drive, but you have to let us."
- ___ Transportation needs and alternatives. "The shop is having a sale. What if I pick you up at 10?"
- ___ Observations of warning signs. "How did those scrapes get on your car? They may mean that there could be a problem judging distances. What do you think?" "We need to talk to your doctor about this."
- ___ Planning alternative transportation. "The van driver said he would make sure you got to your appointment on time."



WORKSHEET 2

CONVERSATION PLANNER

- ____ Potential risks to self or others. “I know you think you’re okay driving. But you always said, ‘Better safe than sorry.’”
- ____ Need to stop driving. “We don’t feel safe when you drive.” “I would feel awful if something terrible happened to you or someone else on the road.”
- ____ Getting support from others. “I’ve noticed changes in his driving. Could you ride with him and see what you think?” “Can we take turns taking her to the grocery store?” “She needs to hear this from more than just me.”
- ____ Other:

Personal Conversation Plan

What is your next conversation strategy? Who do you need to talk to? When will you talk?
What do you hope to accomplish from the conversation?

Additional Notes:

WORK WITH HEALTH PROFESSIONALS

Involving a GP or medical specialist may help to reinforce your efforts to support a person with dementia to reduce and give up driving.

In Victoria, a GP's roles and responsibilities in relation to a driver with dementia include:

- advising the person about the impact of their condition on their ability to drive;
- discussing with the person the legal requirement to report the condition to VicRoads, the licensing system and medical reports; and
- assessing a person's fitness to drive based on the relevant medical standards.

The best way to encourage doctors to play a role in supporting the person to stop driving is to establish good communication early on in the course of the disease. Some doctors will want to involve carers and family in discussions, but not all will automatically do so. You may need to begin the discussions and try to be present during appointments.

Doctors are sometimes reluctant to discuss driving with their patient because they don't want to damage the relationship of trust they have with them. They can also be hesitant to discuss driving in the space of a short consultation or without first-hand knowledge of driving behaviours. This is another opportunity for you to share the driving behaviours you have observed and documented in Worksheet 1.



Can GPs make a patient stop driving?

No, this decision is made by VicRoads. GPs can advise a person to stop driving, but there is a risk that if the person with dementia attends the appointment alone, they may forget or disagree with and ignore the doctor's advice.

Doctors can make an independent report to VicRoads about a patient's fitness to drive, but they are not legally obliged to do so. In Victoria, the legal obligation to report rests on the driver. The doctor's report will be handled by VicRoads Medical review and will usually result in the reported person being required to go through the medical review assessment process.

VicRoads ultimately make the decision as to whether a driver can continue to drive or not.

Occupational Therapists

Occupational therapists are health professionals who can assist people living with dementia to maintain their mobility and health and wellbeing. Occupational therapists, like doctors and optometrists, are independent specialists working in the field of health care. Some have additional qualifications, which allow them to conduct driver evaluations. They are called occupational therapy driver assessors.

Generalist occupational therapists can help families and carers monitor the personal and domestic functional status of a person with dementia, as well as their driving situation, as part of a general community mobility assessment. They can also recommend if/when referral to an occupational therapy driver assessor is warranted.

If you are concerned about someone's driving and want to get an independent assessment of their ability by an occupational therapy driver assessor, notify VicRoads and proceed through the medical review process, as outlined on page 9. VicRoads provides a list of driver assessors when they send a letter requesting that the driver undertake an assessment. The evaluation will be conducted to determine the extent to which the person with dementia may continue driving safely. Occupational therapy driver assessors can only undertake an assessment as part of VicRoads Medical review.

STAY ACTIVE, MOBILE AND CONNECTED

For most people with dementia, reducing or giving up driving has a significant effect on their ability to move around, attend to day to day practical needs, participate in activities away from home and connect with friends, family and community. In the interest of maintaining wellbeing and quality of life, it's vital to think about and plan ways that people with dementia, and their families and carers, can keep mobile, active and socially connected.

Refer to Worksheet 3 'Driving Activities' (page 19) to plan and identify ways for someone still driving to reduce the need to drive.

Refer to Worksheet 4 'Getting There' (page 21) to plan and identify alternative transport options for a person who has stopped driving, or will stop driving soon.

Refer to Worksheet 5 'Not Going it Alone' (page 23) to identify and possibly widen the circle of support for someone with dementia and for families and carers. This can reduce the stress of going it alone.

"Keep your social connections going. Sometimes that means more phone calls than physical visits, sometimes that means emails or texts or something instead of physical visits, but just do whatever is necessary."

Glen, carer

OUR STORY

BOB AND SUE

Bob and Sue live in a residential estate in regional Victoria. Sue says that the first sign of changes in Bob's driving ability were very subtle. "Maybe his judgement wasn't quite as sharp as it had been, but the one thing that I did notice on our trips to the golf course was that he was driving slower than he had previously."

After Bob stopped driving, his friends provided transport to golf games and social gatherings. "He had great support from the golf club where he'd been a member for 20 years, a friend used to come and pick him up twice a week and play golf with him, and another group of friends used to take him out to another club once a week. It was great to have such support and people that shared his passion," says Sue.

Sue shares the following advice for carers looking for ways to support a person to stay active, mobile and connected: "For someone with Alzheimer's you don't want them to give up everything that they've been able to do and to lose their identity... you have to encourage them to participate in all the things they have been doing, to keep contact with all their friends, and it just means that you go about it in a different way, we do everything together now."

Watch Bob and Sue's story on video at www.fightdementia.org.au/dementiaanddriving



Becoming the main driver

Being driven by others can be a very effective way for a person with dementia to stay mobile, but it can come with challenges for carers. If you are not feeling confident to drive, you might want to consider taking a driving refresher course.

The ongoing need to provide transport can sometimes feel overwhelming, and occasionally passengers with dementia can become agitated in the car. Some things you can do to help ensure a smoother driving journey include:

- be patient and allow the person with dementia plenty of time to get ready and to get into the car;
- be prepared with relaxing music, sunglasses and food;
- try to ensure that the person is calm before entering the car;
- ensure all passengers use the bathroom before getting into the car;
- keep a mobile phone in the car;
- encourage reminiscences;
- stay calm and try to maintain an appearance of calmness;
- know your route ahead of time;
- take regular breaks if you are taking a long journey, and
- plan where you park ahead of time.

Disability Parking Scheme

Driving a person with dementia can be easier if the person is eligible for a disability parking permit. Information about eligibility and application forms are available from your local council. Permits are only issued to residents living in the council area.

“I felt that he probably didn’t have the skills to have a gopher. Because a lot of the skills that you need for a gopher or scooter are the same as driving skills.”

Robyn, carer

MY STORY

GLEN

Glen and Carole live on a farm in rural Victoria. Driving is the only way they can get to the nearest town.

"Carole was devastated by the news that she had lost her licence. She felt that she was the victim of injustice because she hadn't crashed the car, she hadn't even scratched the car, she hadn't hurt anybody, she hadn't been the subject of any convictions or even demerit points. She continues to take the loss very hard," says Glen.

"The decision was correct, the timing was good, but the process was difficult" says Glen. "One of the things that helped Carole with the loss was a certificate I made recognising her long and safe driving history. Recognition of driving history is very important to drivers, an official certificate would be very beneficial."

Living far away from services and supports has become increasingly challenging for Glen and Carole. Glen says that their best option at the moment is to move. "We've got the farm for sale and we're planning to move house... we'll go to NSW and we'll live within 20 minutes of Carole's son, where we'll get a little more support and a little more help, and she gets access to her granddaughter."

Watch Glen's story on video at www.fightdementia.org.au/dementiaanddriving





DRIVING ACTIVITIES



WHERE, WHEN AND WHY?

This worksheet can help you determine where, when and why your relative with dementia drives, and then how to reduce the need to drive without compromising the physical and social benefits of driving.

Type of activity	Activity or destination	How often? What day or time?	Who is he/she with while going to or participating in activity	What changes could reduce the need to drive?
Routine: Frequent trips (daily or weekly), usually for tasks (shopping, exercising, visiting, etc)	Example: <i>To a local shop for milk, bread, etc.</i>	<i>2 or 3 times/ week</i>	<i>Travels alone. Chats with store manager.</i>	<i>Neighbour to provide lift to store when she goes for her own regular supplies.</i>
Periodic: Regular, maybe monthly (e.g. doctor's visit, card games with friends)				
Occasional: Special events like a holiday, concert, sporting event, family celebrations, out-of-town visits				

* scenarios to consider on next page



WORKSHEET 3

DRIVING ACTIVITIES

Consider these possible scenarios that will allow a person to satisfy physical and social needs without driving:

- Can the person share the activity with a friend who can drive?
- Can someone take responsibility to drive to an activity on a regular basis?
- Are home-deliveries possible (e.g. prescriptions, groceries, online ordering)?
- Can someone 'make a day of it' by visiting and completing errands?
- Can services be brought to the home (e.g. home hairdressing visits)?
- Can telephone or e-mail conversations occasionally substitute for personal visits?
- Is public transportation available for some trips?

Additional Notes:



USING ALTERNATIVE TRANSPORTATION

When looking for alternative transportation, you need to explore all options – from informal arrangements with relatives and friends, to formal public services. You can use this worksheet with the questions on the next side as you explore all your transportation options.

Transport alternatives	Telephone	Availability, destination (day, time, route)	Cost	Notes (pros and cons)
Family members:				
Friends:				
Taxi/car services:				
Public Transport:				
Other local programs eg. community transport:				
Other:				



WORKSHEET 4

GETTING THERE

Family and friends:

Getting rides from family and friends is usually the first alternative to driving, for reasons of ease and familiarity. The degree of willingness and the cost of mileage and time need to be considered. Consider the following:

- 1 Who is available to provide rides at the times required?
- 2 Will they provide rides willingly or resent personal inconveniences?
- 3 What informal arrangements might give the rider opportunities to give something in return (e.g. making dinner, taking the driver to lunch, paying for petrol)?

Demand-responsive and local services:

Elderly and disabled transportation services offer door-to-door services by appointment. These are often government-subsidised and/or are available at reasonable fees. Types of destinations may be limited to medical or grocery shopping purposes.

Private program services may be available from adult day centres, assisted living facilities, malls or stores.

Some councils and non-profit organisations provide older adults transportation for donations or nominal fees. Consider the following:

- 1 What are the criteria for using the service (e.g. minimum age, disability, affiliation)?
- 2 How much does it cost? Do passengers tip drivers? Can an account be set up in advance with the service?
- 3 How far in advance should arrangements for a ride be made?
- 4 Is there a limit to the number of trips or types of trips (medical or grocery only)?
- 5 Where and when does the service run?
- 6 Will drivers provide assistance to people with physical or other health constraints?
- 7 Can companions accompany the person on the service?

Taxis or car services:

These offer flexible scheduling and can actually be cheaper than owning and maintaining a car. Some car services may be willing to set up accounts for relatives to pay for services. Consider the following:

- 1 How is the cost calculated?
- 2 How long in advance should I call for a ride?
- 3 Can an account be set up in advance? How are tips handled with an account system?
- 4 Will drivers provide assistance with bags or packages?

Public transport:

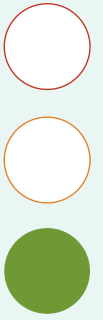
This may be appropriate for those with mild dementia who are accustomed to taking a bus, tram or train. Consider the following:

- 1 How much does it cost? Are there concessions for older or disabled people?
- 2 Can an account be set up in advance with the service? Are there monthly passes?
- 3 What are the hours and geographic area of service?
- 4 Most important, is public transport appropriate, considering the person with dementia's cognitive or physical limitations?





NOT GOING IT ALONE



WHO CAN OFFER SUPPORT?

Support from others can reduce stress and increase chances for success. Your circle of support can include people inside and outside the family who might provide emotional support, observe driving skills, discuss family concerns with the driver, pay for in-home services, provide alternative transportation, and look for public transportation alternatives.

Here's how you can identify, and possibly expand, your circle of support.

Step 1

On the next page are four circles.

1. In the inner circle, place the name of your loved one.
2. In the second circle, write the names or initials of those people currently providing ongoing assistance to you or your loved one.
3. In the third circle, indicate those who look after your loved one in a limited way – perhaps neighbors, friends, relatives or healthcare professionals.
4. In the outer circle, indicate those who are not currently involved but who could be asked, even if only in a limited or professional way.

Step 2

1. How comfortable are you with the number of available support people?

Uncomfortable Comfortable

1 2 3 4 5

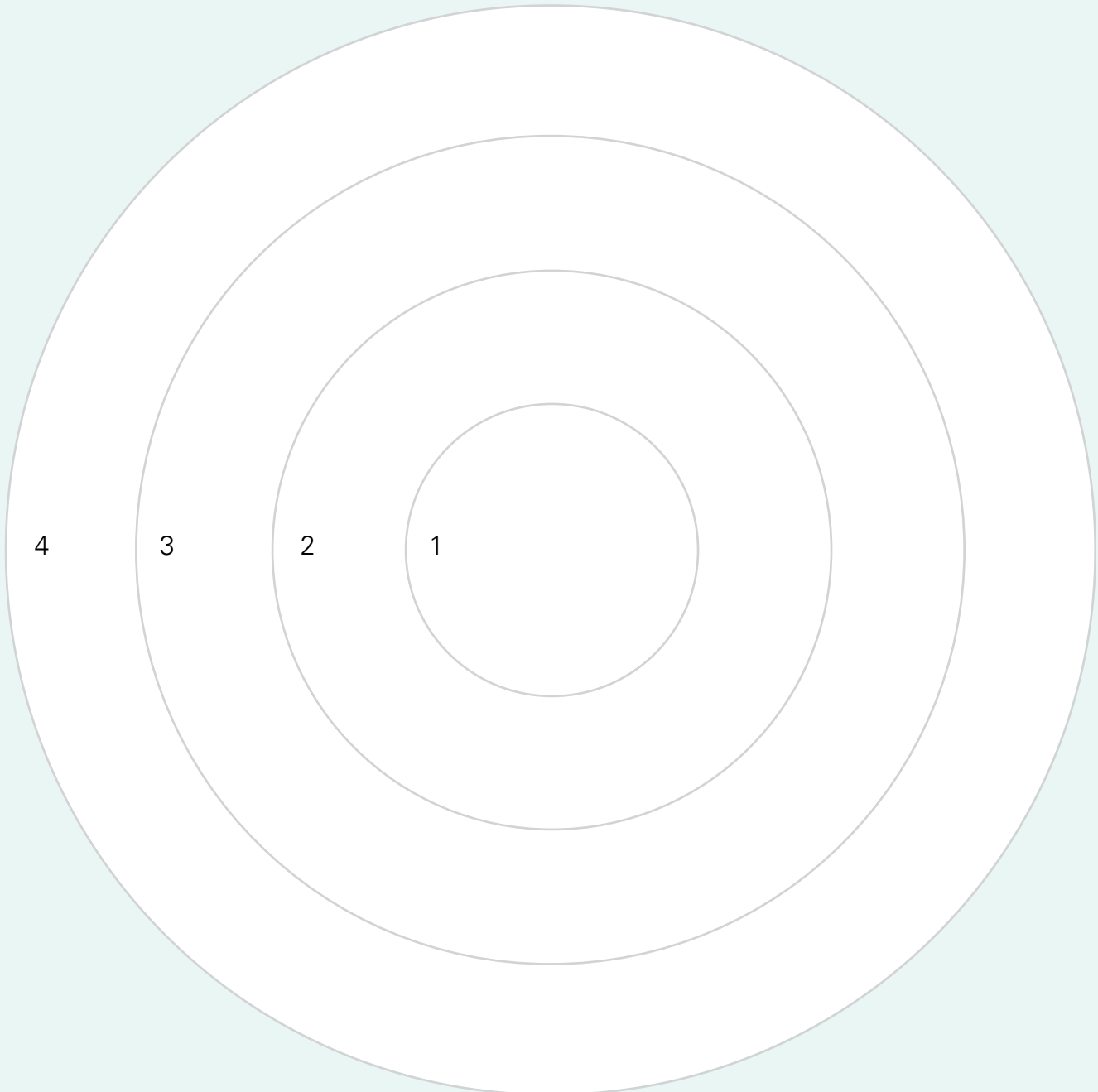
2. Are you using your support network to the fullest extent you need? Yes ___ No ___
3. If you are underutilising your support network, what is keeping you from it? (Examples: beliefs, attitudes, concerns, relationships)
4. In what ways could you encourage improvement in the quantity and quality of support that you and your loved one receive?

Person	How they help now	Realistic helpful changes



WORKSHEET 5
NOT GOING IT ALONE

Circle of support





WHO TO CONTACT FOR MORE HELP

Alzheimer's Australia Vic

The process of giving up driving can be difficult and stressful for drivers, carers and family members. For further support, you can contact Alzheimer's Australia Vic.

Our services include the National Dementia Helpline, telephone and face-to-face counselling and a variety of support groups. We have a range of information resources on dementia and driving which are available from our website. Our library, which can be used by anyone and can also be accessed online, has an extensive collection of books, journals and DVDs on dementia and driving.

National Dementia Helpline 1800 100 500
fightdementia.org.au/dementiaanddriving

"It's the disease, not the person, and it takes a lot for the person with dementia and the carer to come to grips with this as well." Anne, carer

Dementia Behaviour Management Advisory Service (DBMAS)

If the distress around the need to stop driving is prolonged and intense, contact the Dementia Behaviour Management Advisory Service (DBMAS). This is a national telephone advisory service for families, carers and care workers who are experiencing difficulty dealing with changed behaviours of people with dementia.

Phone: 1800 699 799
<http://dbmas.org.au/>

VicRoads Medical Review

VicRoads Medical Review can be contacted in confidence to discuss any concerns about driving.

Phone: 03 9854 2407
vicroads.vic.gov.au/olderdrivers
vicroads.vic.gov.au/familyandfriends



NATIONAL DEMENTIA HELPLINE
1800 100 500

FIGHTDEMENTIA.ORG.AU/DEMENTIAANDDRIVING

