

DEMEN TIA AND DRIVING

A DECISION AID



UNIVERSITY
OF WOLLONGONG
AUSTRALIA

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The content and presentation of this decision aid was informed from interviews with drivers living with dementia and their family members. Names have been changed and stock photos are used.

Suggested citation: Carmody, J., Traynor, V., Iverson, D., & Andrew, C. (2017). *Dementia and Driving: A decision aid*. Version 4.1 (UK edition, 2023). University of Wollongong, Australia.

Introduction

A diagnosis of dementia can come as quite a shock. It is accompanied by a variety of changes to one's lifestyle and needs. This booklet may be used by any driver who has dementia.

Most older adults have driven safely and remained accident-free for many years. Unfortunately, dementia can silently disrupt driving skills. At times, family members notice unsafe driving behaviour before you do. For a variety of reasons, the issue of driving safety is often not raised by doctors, nurses, family or friends.

This booklet is intended to be used by people living with dementia. However, family members and professionals may also find it useful when helping people with dementia consider driving retirement. It is hoped that early planning for retirement from driving will avoid the need to suddenly stop driving.

Version 4 (UK edition) produced in 2021.

Version 4.1, 2023.

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Instructions

- **Please read this booklet from beginning to end**

- **You will be guided through 4 steps**

- **Use a pencil to answer questions**

Tick these green boxes if you agree

- **Please write your answers on the dotted lines** -----

- **You may reuse this booklet as often as you wish**

John, 70, driver living with dementia

“Dementia affects parts of your life, including driving, and this is one of the things to consider”.

Step 1



**To help clarify
my decision**

What is dementia?

Dementia is a condition which usually gradually disrupts one's memory, speech, concentration, judgement and ability to plan. The most common forms of dementia are Alzheimer's disease, vascular dementia, Lewy body disease and Frontotemporal dementia. Approximately one in 14 people aged 65 and over, in the UK, have dementia. Dementia is associated with many other conditions and medication use. Some forms of dementia increase your risk of seizures and strokes.

Can dementia affect my driving skills?

Yes. Eventually, most people with dementia become unsafe to drive. Driving is a complex task. In order to drive safely, you rely on a variety of skills such as judgement, memory, attention, reacting quickly and the ability to assess your surroundings. Unfortunately, people with dementia often lose these important skills. For many, this happens without you realising it. Over time, your risk of becoming lost or having a car accident rises significantly. At some point you may need to retire from driving.

What are my options?

- **Continue driving with no change**
- **Continue driving with changes**
- **Stop driving later**
- **Stop driving now**

Consider these options while reading through the decision aid.

How far along am I with making a decision about driving?

- I have not yet thought about my options
- I am thinking about my options
- I have almost made my decision
- I have already made my decision

How will I manage without my car?

People with dementia wish to drive for a number of reasons: the pleasure of driving; independence; shopping; work; visiting family or friends; going to appointments and travelling. Many are afraid to discuss driving safety for fear of losing their licence. It can be helpful to plan and prepare for other ways to get around. Discounts may be available on public transport.

For more information visit: www.ageuk.org.uk/information-advice/money-legal/benefits-entitlements/free-bus-pass-and-transport-concessions/

Fortunately, there are alternatives I can consider

- **Family or friends giving me a lift**
- **Use public, community or volunteer transport:** Buses, trains, ferries, hospital shuttles or car lift schemes.
- **Get active:** Walk or ride a bicycle
- **Relocate or move home:** Living closer to a town centre or your support network
- **Use the internet for online shopping or communicating with family and friends**
- **Private transport:** Hire a driver or helper, taxis, Ring and Ride (door-to-door accessible transport service), rideshare services like Uber, carpooling with others

Many people underestimate how much money they could save by retiring from driving. You will no longer need to pay for MOT, vehicle tax, car insurance, maintenance checks, repairs and ever increasing fuel costs.

What warning signs of unsafe driving have I or others noticed?

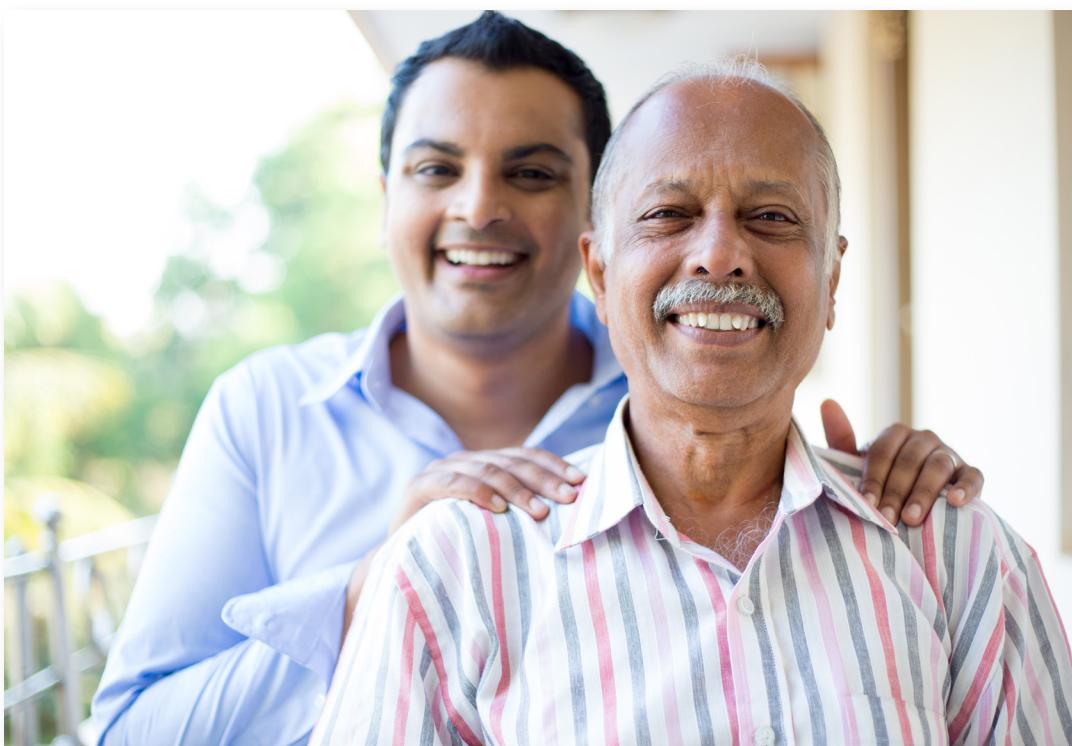
Have you, your family or friends noticed any of the following warning signs while driving?

- Find changing lanes difficult to do**
- Find roundabouts difficult to use**
- Drive very slowly**
- Confuse left and right**
- Get lost on short trips**
- Drive on the wrong side of the road**
- Notice damage to my car that I cannot explain**
- Car accident or a near miss**
- Driving offences**

How often do I experience any of these warning signs?

- Never**
- Once before**
- A few times in a month**
- Every week**

If you have experienced any of these warning signs talk to your doctor, eyecare professional, dementia care advisor or consider a driving assessment.



Step 2



**What do I need
to make my
decision?**

Support

- **Do I have enough help or advice from others to make a choice?**

Yes No

- **Am I being forced by others to make a choice?**

Yes No

Knowledge

- **Do I know my options?**

Yes No

- **Do I know the benefits and risks of each option?**

Yes No

Values

- **Am I clear about which benefits and risks matter most to me?**

Yes No

Certainty

- **Do I feel sure about the best choice for me?**

Yes No

Keep reading for further guidance.



Step 3



Weighing up my options

Support

- Who else is involved with my decisions about driving?

- What option does this person advise?

- Continue driving with no change
- Continue driving with changes
- Stop driving later
- Stop driving now

- Do I feel this person is pressuring me?

- Yes
- No

- Can this person help me?

- Yes
- No

- What do I prefer?

- I prefer to decide for myself
- I prefer to let someone else decide
- I prefer to share the decision with others

Knowledge

Most experts would agree that drivers with dementia are at a higher risk of getting lost or having a car accident. Some researchers have found the risk of accident to be 2.5 to 10 times higher than other people of the same age. This is a difficult topic to research and your exact risk is uncertain.



What are the benefits of driving?

- Independence and convenience
- Pleasure of driving
- Visiting family and friends
- Getting to appointments

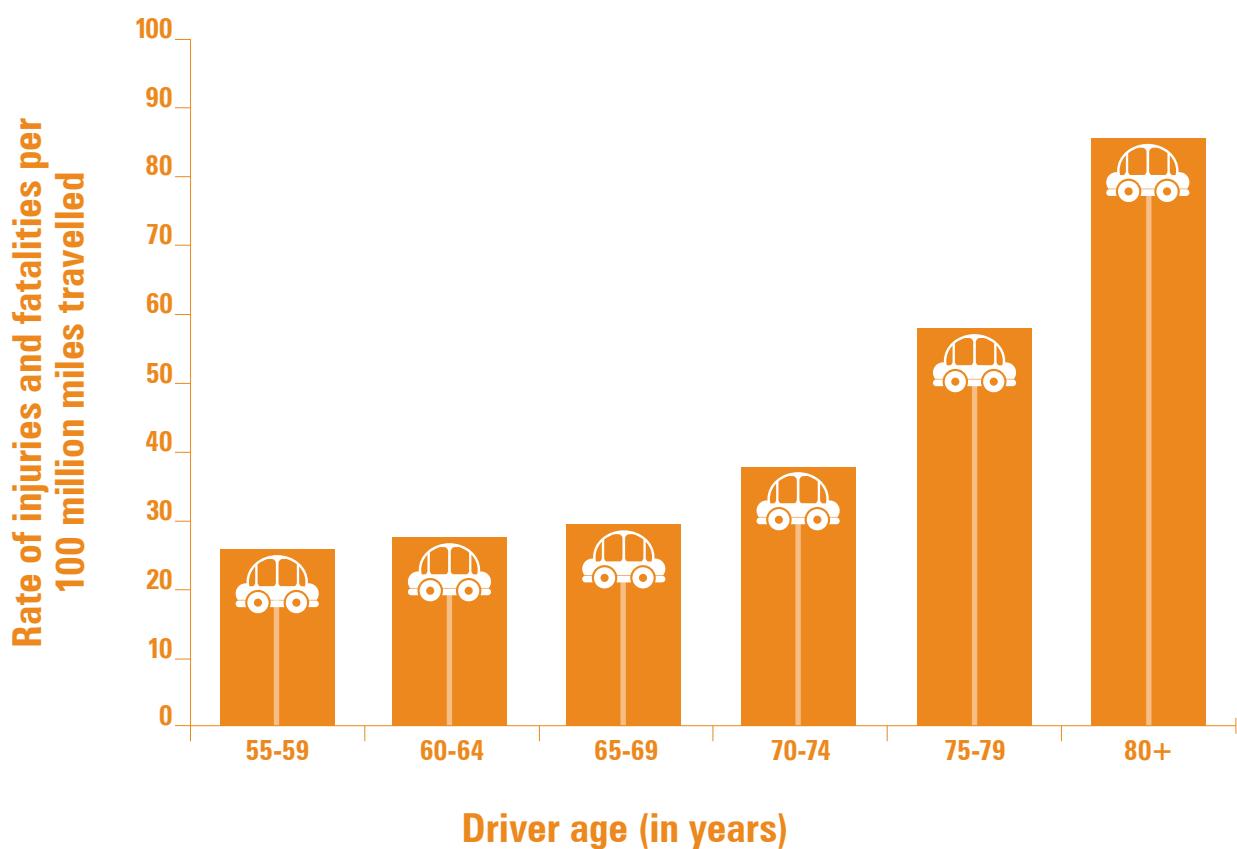
What are the risks of driving?

- Becoming lost
- Car accident
- Personal injury
- Injury to others

Does my risk change over time?

Yes, it does. Your driving skills will worsen over time. Your risk of serious injury or death following a car crash rises as you get older. This bar chart shows the number of healthy drivers who are injured or killed in car crashes according to age. Drivers with dementia are estimated to be at an even higher risk.

**Driver fatal crash and injury involvement
per 100 million miles**



What are the recommendations?

Alzheimer's Society says:

- **A diagnosis of dementia is not in itself a reason to stop driving. One in every three people with dementia still drives**

The DVLA/DVA national guidelines state that:

- **A licence holder who is diagnosed with dementia must contact the relevant licensing agency promptly, or risk a fine of up to £1,000**
- **The final decision to renew a persons licence is made by the DVLA or DVA**

Contact your driver licensing authority for further information.

- For DVLA enquiries call **0300 200 7861**
or visit: **www.gov.uk/dementia-and-driving**
- For medical questions call: **0300 790 6806**



The most important reason for me to continue driving is...

- Independence
- Pleasure of driving
- Visiting family or friends
- Going to work
- Going to appointments
- Travelling to new places
- Shopping
- Poor access to public transport
- Other - -----

Rose, 82, retired driver

“It was a really hard decision to stop driving. The first few months were awful. But look, I use taxis, it’s cheaper and I’m safe and everyone else is safe”.

Of all the items on this page - the single most important reason for me to stop driving is...

- Risk of getting lost
- Risk of a car crash
- Risk of injury or death to others
- Risk of injury or death to me
- Worried family or friends
- Reduce feelings of stress or anxiety
- Don't feel as confident driving as I used to
- Save money on petrol and car servicing
- Other _____

Of all the items on this page – the most important to me is...

Step 4



What next?

Support

If you feel you do not have enough support to make a decision, you can seek additional support from others. Who do you prefer to speak to? You can use this list later to remind you.

- My doctor (general practitioner or specialist)**
- A nurse or someone else from the medical profession**
- My family**
- My friends**
- Age UK 0800 678 1602**
- Age NI 0808 808 7575**
- Alzheimer's Society Helpline 0333 150 3456**
- Driving mobility centres www.drivingmobility.org.uk**
- Somebody else from my support network** -----
- Talk to someone who has already made the decision**



Knowledge

If you feel you do not have enough information to make a decision, you can seek additional information from others. Who do you prefer to ask for information? You can use this list later to remind you.

- My memory service or memory nurse**
- My doctor (general practitioner or specialist)**
- Dementia UK Hotline [0800 888 6678](tel:08008886678)**
- Alzheimer's Society for information about dementia
www.alzheimers.org.uk / [0333 150 3456](tel:03331503456)**
- For information about driving licences visit
www.gov.uk/browse/driving**
- For information about driving assessments
www.drivingmobility.org.uk or www.olderdrivers.org.uk**
- DVLA medical enquiries [0300 790 6806](tel:03007906806)**

Values

Here are a few tips on how to clarify the values that mean the most to you. You may choose as many of these options as you wish:

- **Talk to others who have made the decision**
- **Discuss with others what matters most to me**
- **Consider joining a local support group**
- **Contact the Dementia Connect support line 0333 150 3456**

Questions

What questions do you need answered to help you decide? You may find it helpful to share this booklet with others, such as your doctor, family or friends. Discussing this booklet with others can often be very helpful.

1. -----

2. -----

Jack, 80, retired driver

“I did a lot of driving and never had an accident or parking fine. I knew I was a good driver. But the last few months before I retired from driving I had not been very good. I hadn’t realised this myself, as the changes with dementia are slow”.

By using this booklet I have now considered

- **How dementia affects my driving skills**
- **My options regarding driving**
- **What I, or other people, have noticed about my own driving**
- **What support I have**
- **The reasons for and against my driving**
- **Where I can go for more information or support**

Decision

Having read this booklet, have you reached a decision about driving? What have you decided?

- I will continue driving with no change**
- I will continue driving with changes**
- I will stop driving later**
- I will stop driving now**
- I am unsure**

The Next Step

If you are still unsure

Arrange an appointment with your doctor, a nurse or someone else who can help you discuss this further. You may find it helpful to bring this booklet with you. Please reuse this booklet as often as you wish.

Retire from driving

Retiring from driving can be more relaxing for some people. However some people experience feelings of loss and grief. It might be helpful to:

- Ask others for help to get to your activities
- Try out your preferred non-driving options in advance

Continue driving

Tell the DVLA or DVA and your car insurer about your diagnosis.

Consider driving:

- In local areas you know well
- During daylight hours
- In good weather conditions
- When roads will be quiet
- Drive without distractions in the car
- Avoid driving when you are tired

Planning ahead for a time when you are no longer able to drive can help.

Activities How will I get there without driving myself?

Miscellaneous

Acknowledgements

We wish to acknowledge the individuals and organisations who contributed to the original Australian edition of the *Dementia and driving: a decision aid* booklet. Thank you to individuals living with dementia and family members in the UK who provided their time to review and provide feedback on the UK draft version. We also thank the many organisations and individuals who provided their feedback through an online consultation. We acknowledge the invaluable support of staff at Oldham Memory Service, Pennine Care NHS Foundation Trust and Dorset HealthCare University NHS Foundation Trust who provided their time and expertise.

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Adapted from: The Dementia and Driving Decision Aid (UK version) was adapted from the dementia and driving decision aid developed for Australian drivers living with dementia. For full details regarding the development process see Carmody et al. (2014).

Disclaimer: This booklet is not intended to replace the advice of your doctor or health professional. All efforts have been taken to ensure the content of this booklet is accurate at the time of publication.

Funding: Financial support was provided by the The University of Wollongong through the Health Impacts Research Cluster small grants scheme and the Global Challenges Program.

Conflict of Interest: Neither the authors nor their affiliated organizations stand to gain financially from the use of this booklet.

Last reviewed: October 2021

References: Alzheimer's Society (2017) What is dementia? Factsheet 400LP. Available at: www.alzheimers.org.uk/sites/default/files/2019-09/400%20What%20is%20dementia_0.pdf

Alzheimer's Society (2020) Driving and dementia Factsheet 439LP, Driving and Dementia Factsheet 439LP. Available at: <https://www.alzheimers.org.uk/sites/default/files/2022-10/439LP-driving-and-dementia.pdf>

Carmody, J., Potter, J., Lewis, K., Bhargava, S., Traynor, V., & Iverson, D. (2014). Development and pilot testing of a decision aid for drivers with dementia. *BMC Medical Informatics and Decision Making*, 14(19), 7.



Driver and Vehicle Licensing Authority (2016) Psychiatric disorders: assessing fitness to drive, Dementia – and/or any organic syndrome affecting cognitive functioning. Available at: <https://www.gov.uk/guidance/psychiatric-disorders-assessing-fitness-to-drive> (Accessed: 13 August 2021).

Driving & Dementia Working Group (2018) Driving with dementia or mild cognitive impairment: Consensus guidelines for clinicians. United Kingdom. Available at: <https://research.ncl.ac.uk/driving-and-dementia/consensusguidelinesforclinicians/> (Accessed: 13 August 2021).

Légaré F, Kearing S, Clay K, Gagnon S, D'Amours D, Rousseau M, O'Connor AM (2010) Are you SURE? Assessing patient decisional conflict with a 4-item screening test. *Can Fam Physician*. 56(8):308-14

Martin, A. J., Marottoli, R. and O'Neill, D. (2013) 'Driving assessment for maintaining mobility and safety in drivers with dementia', *Cochrane Database of Systematic Reviews*, 2013(5). doi: 10.1002/14651858.CD006222.pub3.

O'Connor, A. M., Stacey, D., & Jacobson, T. (2015). *Ottawa Personal Decision Guide*. Ottawa Hospital Research Institute & University of Ottawa, 1–2.

Prince, M. et al. (2014) *Dementia UK: Update (second edition)*, Alzheimer's Society. doi: 10.1007/s13398-014-0173-7.2.

Rapoport, M. J. et al. (2018) 'An International Approach to Enhancing a National Guideline on Driving and Dementia', *Current Psychiatry Reports*. *Current Psychiatry Reports*, 20(16), pp. 1–9. doi: 10.1007/s11920-018-0879-x.

Sanford, S. et al. (2020) 'Subjective Experiences of Driving Cessation and Dementia: A Meta-Synthesis of Qualitative Literature', *Clinical Gerontologist*. Routledge, 43(2), pp. 135–154. doi: 10.1080/07317115.2018.1483992

Other references are available on request at www.adhere.org.au



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