

DEMENTIA AND DRIVING A DECISION AID



UNIVERSITY OF WOLLONGONG AUSTRALIA

Dr John Carmody FRACP

A/Prof Victoria Traynor PhD

Prof Don Iverson PhD

Ms Catherine Andrew MSc

CONTENTS

INTRODU	ICTION	3
INSTRUC	INSTRUCTIONS	
STEP 1:	TO HELP CLARIFY MY DECISION	5
STEP 2:	WHAT DO I NEED TO MAKE MY DECISION?	10
STEP 3:	WEIGHING MY OPTIONS	13
STEP 4:	WHAT NEXT?	20
THE NEXT STEP		25
REFERENCES		26
MISCELLANEOUS		29
AIITHORS		21

Recommended citation

Carmody, J, Traynor, V, Iverson, D and Andrew, C., 2017. Dementia and Driving: a decision aid. Version 4 (U.S. ed.), University of Wollongong, viewed (insert date), www.adhere.org.au/drivingdementia.html

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 crash 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.

The aim of this booklet is to assist you in deciding when to stop driving after receiving a diagnosis of dementia. This booklet is intended to be used by consumers but family caregivers and practitioners will 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 produced in 2017

All rights reserved (c) 2017 University of Wollongong, Australia

INSTRUCTIONS

- Please read this booklet from beginning to end
- You will be guided through 4 steps
- Use a pencil to answer questions
- Check these green boxes if you agree
- Please write your answers on the dotted lines _____
- You may reuse this booklet as often as you wish

STEP 1



TO HELP CLARIFY INIY DECISION

What is dementia?

Usually, dementia is a condition which 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 eleven per cent of people aged 65 and over in the U.S. have a diagnosis of Alzheimer's disease. 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 upon a variety of skills such as judgement, memory, attention 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 crash rises significantly.

What are my options?

- Continue driving with no change
- Stop driving now
- Drive less
- Stop driving later

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 cope 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 traveling. Many are afraid to discuss driving safety for fear of losing their license.

Fortunately, there are alternatives I can consider

- Family or friends giving me a ride
- Use public, community or volunteer transport:

 Buses, trains, ferries, subway, hospital shuttles, religious groups or senior vans.

- Private transport: Hire a driver or helper. Taxis (subsidies may be available). Rideshare services like Uber.
- Use the internet for online shopping or communicating with family and friends
- Get active: Walk or ride a bicycle.
- Relocate or move home: Living closer to a town center.
- More hobby time maintaining and fixing bikes and cars

Many people underestimate how much money they could save by retiring from driving. One no longer needs to pay for annual registration, car insurance, maintenance checks, repairs and ever increasing fuel costs.

What warning signs of unsafe driving have I noticed?

Driving errors are a sign that your driving skills may no longer be safe. Have you experienced any of the following warning signs while driving?

- Changing lanes difficult to do
- Crossroads or traffic lights difficult to use
- Drive very slowly
- Confuse left and right

- **Become 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
- **Traffic fine or penalty**

How often do I experience these warning signs?

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



STEP 2



NHAT DO INEED TO INAKE 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?



Certainty

Do I feel sure about the best choice for me?



Keep reading for further guidance.



STEP 3



WEIGHING MY OPTIONS

Support

Who else is involved with my decisions about driving?

What option does this person prefer?

No change Stop driving now

Drive less Stop driving later

Is this person 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 crash. Some researchers have found the risk of crash 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
- Pleasure of driving
- Visiting family and friends
- Going to appointments

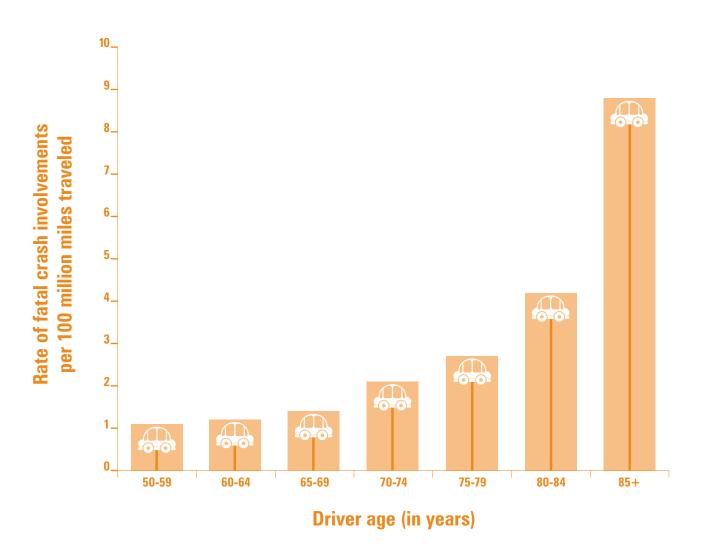
WHAT ARE THE RISKS **OF DRIVING?**

- Becoming lost
- Car crash
- 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 drivers who are involved in fatal car crashes according to age. Drivers with dementia are estimated to be at an even higher risk (up to 10 times greater).

Passenger vehicle fatal crash involvement per 100 million miles traveled by driver age



What are the recommendations?

The American Geriatrics Society and National Highway Traffic Safety Administration say:

- Some drivers with dementia are competent to drive in the early stages.
- When individual driving ability poses a heightened risk to self or others, driving privileges need to be withheld.

The Alzheimer's Association say:

- A diagnosis of dementia does not necessarily mean an immediate loss of driving privileges.
- It is important to plan ahead for driving retirement.

Contact your state licensing agency for information.



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

Independence
Pleasure of driving
Visiting family
Visiting friends
Going to appointments
Traveling to new places
Going to place of worship
Shopping
Poor access to public transport
Other

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

- My family practitioner or specialist
- Spiritual guide
- A nurse or someone else from the medical profession
- My family
- My friends
- Clergy
- Alzheimer's Association 24/7 Helpline: 1 800 272 3900



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 later to remind you.

- My family practitioner or specialist
- My local library
- Alzheimer's Association www.alz.org
 24/7 Helpline 1 800 272 3900
- Driving Evaluations

American Occupational Therapy Association www.aota.org

Association of Driver Rehabilitation Specialists www.aded.net

Transport Options

Eldercare www.eldercare.gov

Rides in Sight www.ridesinsight.org

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

What questions need answering to help you decide?

Details available from Alzheimer's Association 24/7
 Helpline 1 800 272 3900

Questions

You might want to show these to other people, such as your family practitioner, specialist, family or friends. Discussing this booklet with others can often be very helpful.
1
2
3

By using this booklet I have now considered

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

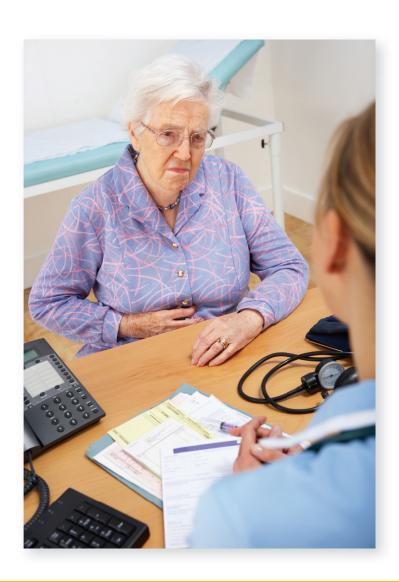
Decision

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

- I will continue driving with no change
- I will stop driving now
- I will drive less
- I will stop driving later
- I am unsure

THE NEXT STEP

Arrange an appointment with your family practitioner, specialist, 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.



REFERENCES

Alzheimer's Association 2016, 2016 Alzheimer's Disease Facts and Figures. Alzheimer's and Dementia; 12(4) Washington DC http://www.alz.org/documents custom/2016-facts-and-figures.pdf>.

Alzheimers Australia 2005, About you driving: information for people with dementia. www.fightdementia.org.au/common/files/NAT/20050700_Nat_HS_8.4Driving.pdf

Alzheimer's Association 2011, Driving and Dementia, Alzheimer's Association, viewed 28 November 2016, http://www.alz.org/documents_custom/statements/ Driving and Dementia.pdf>.

American Geriatrics Society and A. Pomidor (Ed) 2016, Clinician's Guide to Assessing and Counseling Older Drivers, 3rd edition. Washington, DC: National Highway Traffic Safety Administration The American Geriatrics Society.

Breen, DA, Breen, DP, Moore, JW, Breen, PA and O'Neill, D 2007, 'Driving and dementia', British Medical Journal, vol. 334, pp. 1365-1369.

Carr, DB, Duchek, J and Morris, JC 2000, 'Characteristics of motor vehicle crashes of drivers with dementia of the Alzheimer's type', Journal of the American Geriatric Society, vol. 48, pp. 18-22.

Dubinsky, RM, Stein, AC and Lyons, K 2005, 'Practice parameter: risk of driving and Alzheimer's disease (an evidence-based review)', Neurology, vol. 54, pp. 2205-2211. Man-Son-Hing, M, Marshall, SC, Molnar, FJ and Wilson, KG 2007, 'Systematic review of driving risk and the efficacy of compensatory strategies in persons with dementia', *Journal of the American Geriatric Society*, vol. 55, pp. 878–884, 2007.

Insurance Institute for Highway Safety 2013. [Unpublished analysis of 2008 data from the U.S. Department of Transportation's Fatality Analysis Reporting System and the National Household Travel Survey]. Arlington, VA. http://www.iihs.org/iihs/topics/t/older-drivers/fatalityfacts/older-people/2015

Martin, AJ, Marottoli, R and O'Neill, D 2009, 'Driving assessment for maintaining mobility and safety in drivers with dementia', Cochrane Database of Systematic Reviews, issue 1.

Tefft, BC 2012, 'Motor Vehicle Crashes, Injuries, and Deaths in Relation to Driver Age: United States, 1995–2010', AAA Foundation for Traffic Safety, Washington DC, https://www.aaafoundation.org/sites/default/files/2012OlderDriverRisk.pdf.

Thal, LJ, Grundman, M and Klauber, MR 1988, 'Dementia: characteristics of a referral population and factors associated with progression', *Neurology*, vol. 38, pp. 1083-1090.

Uc, EY, Rizzo, M, Anderson, SW, Shi, Q and Dawson, JD 2004, 'Driver route following and safety errors in early Alzheimer disease', *Neurology*, vol. 63, pp. 832–837.

Van der Flier, WM and Scheltens, P 2005, 'Epidemiology and risk factors of dementia', *Journal of Neurology, Neurosurgery and Psychiatry*, vol. 76, pp. 2-7.

Zuin, D, Ortiz, H, Boromei, D and Lopez, OL 2002, 'Motor vehicle crashes and abnormal driving behaviours in patients with dementia in Mendoza, Argentina', *European Journal of Neurology*, vol. 9, pp. 29-34.



MISCELLANEOUS

CONFLICT OF INTEREST

Financial support was provided by (i) Wollongong Hospital, (ii) NSW Roads and Maritime Services (RMS) and (iii) the University of Wollongong, Australia. Neither the authors nor their affiliated organizations stand to gain financially from the use of this booklet.

ADAPTED FROM

The Ottawa Personal Decision Guide © 2006, O'Connor, Jacobsen & Stacey. Ottawa Hospital Research Institute (OHRI), Ottawa, Canada.

DISCLAIMER

This booklet is not intended to replace the advice of your family practitioner, specialist or health professional. All efforts have been taken to ensure the content of this booklet is accurate at the time of publication.

ACKNOWLEDGEMENTS

The authors wish to acknowledge the work of Professor Annette O'Connor and Professor Dawn Stacey (The Patient Decision Aids Research Group, OHRI, Canada). We wish to thank the reviewers of this booklet: Associate Professor Guy Bashford; Dr Vida Bliokas; Professor Andrew Bonney; Ms Jenny Davies; Professor Glyn Elwyn's Decision Laboratory (Cardiff University, Wales); Ms Robyn Faine (Alzheimer's Australia NSW); Ms Kate Lewis; Professor Elena Marchetti; Professor Jan Potter; Mr Anton Saarimaki (OHRI, Canada); and Associate Professor Christine Stirling. We would also like to thank the patients, caregivers and family members who contributed to the creation of this decision aid. Without their kind assistance, this work would not have been possible. The invaluable support of Mr Robert Reynolds, Roads and Maritime Services, Wollongong, NSW is gratefully acknowledged. Version 4 (U.S) was developed from a partnership grant with the University of North Carolina Wilmington with Associate Professor Diane Pastor. Thank you to U.S based practitioners, caregivers and consumers who assisted with the development of this version and the support of Professor Elena Marchetti, Dr Heather Jamieson and Associate Professor Melanie Randle.





Dr John Carmody

MB BCh, MRCPI, FRACP Staff Specialist Neurologist, Wollongong Hospital Clinical Associate Professor, University of Wollongong john.carmody@sesiahs.health.nsw.gov.au

A/Prof Victoria Traynor

BSc, RGN, PGCHE, ILM, PhD Associate Professor, University of Wollongong victoria_traynor@uow.edu.au

Prof Don Iverson

BSc, MSc, DSc, PhD Executive Dean, Faculty of Health, Arts and Design University of Swinburne

Ms Catherine Andrew

BAppSc, MSc **Occupational Therapist** Lecturer, Australian Catholic University

