



DRIVING & DEMENTIA ROADMAP

For people with dementia who are still driving

A print version of the Driving and Dementia Roadmap website.



CCNA
Canadian Consortium
on Neurodegeneration
in Aging



CCNV
Consortium canadien en
neurodégénérescence
associée au vieillissement



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Preface

- This document is a print version of the Driving and Dementia Roadmap website and was created for individuals without access to a computer or the internet.
- This PDF contains the written content available on the Driving and Dementia Roadmap website.
- The Driving and Dementia Roadmap website, which can be accessed through the internet, contains additional videos, links, worksheets and resources that are not included in this PDF document.
- If you are able to access the internet, please visit www.drivinganddementia.ca.

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What is the Driving and Dementia Roadmap?

- It is a resource to help you make decisions about driving with dementia so that you only continue to drive if you can still drive safely.
- It will help prepare you for when the times comes that you can no longer drive safely.
- In addition, it will show you how you can continue to lead a fulfilling life after you stop driving.
- The information is from a free website for people with dementia as well as their family/friend caregivers and healthcare providers:
www.drivinganddementia.ca
- The website was developed by a team of researchers in consultation with people with dementia and family/friend carers.



Understand how dementia can affect my driving

- Dementia can affect various brain functions that are necessary for safe driving.
- How your driving skills are specifically affected depends on how far your dementia has progressed, as well as which parts of your brain are affected.
- Problems that are common with dementia include:
 - Forgetfulness
 - Getting lost
 - Slower reaction time
 - Low attention span

Recognize that unsafe driving is inevitable

- Some people with dementia may be able to drive safely for some time after diagnosis. However, some people may have to stop driving at the time of diagnosis.
- Over time, most people with dementia will lose the ability to drive safely.
- This is because even though there are different types of dementia, all types affect the brain.
- The longer someone with dementia continues to drive after diagnosis, the higher the chances are of getting into an accident.
- Accidents can happen close to home like on trips to the grocery store or mall. This is why even taking short trips to familiar places is dangerous.

Here's what some people with dementia have to say:

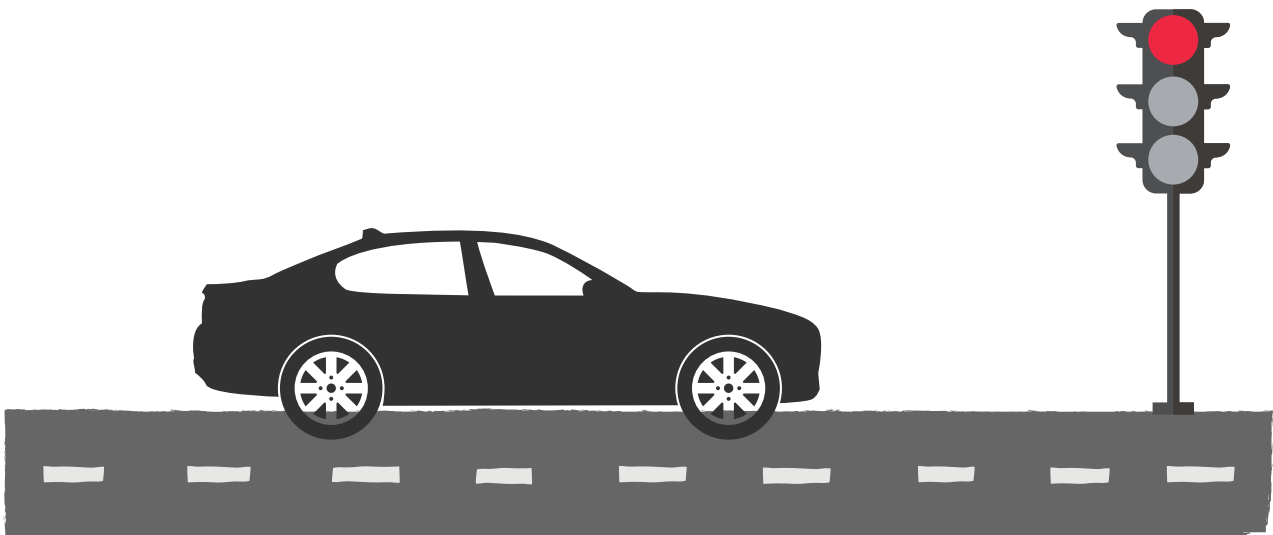
“It's very hard to give driving up. But, you have to think about other people around you. You could cause some serious damage to someone if you did get into an accident, just because you were being stubborn about not wanting to give up your licence.”

“It's a hard thing to do (stop driving), but in the long run it's better for everybody involved. Nobody is worried about me driving the car and having an accident. I would feel terrible if something happened.”

Video available on DDR website

On the Driving and Dementia Roadmap website (www.drivinganddementia.ca), click on the video titled "**Driving with Alzheimer's disease (National Highway Traffic Safety Administration)**" to see how dementia can affect driving.

You can access this video by locating the "I have dementia" heading on the homepage of the website and clicking "and I am still driving." Then, click on "Understanding how dementia can affect my driving."



Recognize when it becomes unsafe to drive

- As soon as you have a dementia diagnosis, it is important to keep checking whether your driving is safe.
- If you notice changes in your driving, you should start thinking about whether you are still able to drive safely.
- It may become more difficult to recognize that you are no longer able to drive safely.

Here's what a person with dementia has to say:

“Be aware of yourself and stand up for yourself and don't deny if you realize you may have a problem. Or if someone says, 'Hey I don't think you should drive anymore', don't just go, 'Yes, I can'. Be mindful of all of that.”



Assess your driving

Answer these questions **on a regular basis** to check whether your driving is safe:

- Do you sometimes feel unsure of yourself or anxious while driving?
- Have you had any close calls such as almost hitting a person or another car?
- Do other drivers honk at you?
- Have you driven through a stop sign or red light or have you stopped at a green light?
- Have you ever gotten lost while driving?
- Have you noticed issues with your driving skills like difficulty keeping in your lane, staying within the speed limit, changing lanes, turning or merging?
- Has anyone told you that your driving skills are deteriorating or that your driving is unsafe?
- Has anyone refused to drive with you?

If you answer yes to some of these questions, perhaps it's time to start having conversations with someone you trust about your driving. For example, family member, friend, neighbour, or doctor. Also, ask a family member or friend to drive with you so that they can observe how you drive. For getting help regarding deciding to stop driving, see page 8.



Learn how others assess your driving

- A healthcare professional or a drivers' licensing authority may request that you take a comprehensive driving evaluation. It is sometimes called something else such as a functional assessment.
 - It assesses whether your dementia is affecting your ability to drive safely.
 - It is not the same as the government driving test you took to get your licence for the first time.
 - It involves specialized driving tests typically conducted by an occupational therapist and driving instructor.
- Here is what you can expect during the evaluation:
 - A healthcare professional called an occupational therapist will review your medical and driving history.
 - The occupational therapist will also assess your sensory, physical, and mental abilities related to driving.
 - A driving instructor and occupational therapist will go out for a drive with you and check how well you handle the car on the road.
 - The occupational therapist will review the results with you and recommend whether you should continue or stop driving.



Try these worksheets

On the Driving and Dementia Roadmap website (www.drivinganddementia.ca) and in the Driving and Dementia Roadmap Package of Resources (available in printed form), the following worksheets are available:

1. **Warning Signs for Drivers with Dementia.** Refer to page 1 in the Driving and Dementia Roadmap Package of Resources.
2. **Simple Driving Assessment.** Although it is not an official driving assessment, use it as a starting point to assess your ability to drive safely. Refer to page 2 in the Driving and Dementia Roadmap Package of Resources.

Other resources available on the Driving and Dementia Roadmap

1. **Dementia and Driving – A Decision Aid** to help you decide the right time to stop driving. This document is only available on the Driving and Dementia Roadmap website (www.drivinganddementia.ca).
2. On the Driving and Dementia Roadmap website (www.drivinganddementia.ca), click on the video titled "**A bump in the road**" in which a daughter and mother discuss the possibility of the mother having a driving assessment and about other ways to get around.

You can access both of these resources by locating the "I have dementia" heading on the homepage of the website and clicking "and I am still driving." Then, click on "Recognizing when it becomes unsafe to drive."



Get help deciding to stop driving

- Deciding to stop driving can be a difficult decision.
 - Make sure to get support.

Talk to someone you trust

They can help by:

- Driving with you so that they can observe how you drive.
- Reviewing with you the warning signs checklist on page 1 in the Driving and Dementia Roadmap Package of Resources.
- Discussing with you how you would answer the following questions:
 - How important is driving to you?
 - Have you ever considered giving up driving now that you have a diagnosis of dementia?
 - If you give up driving, how would you get around?
 - Creating an agreement with you by using the document on page 8 of the Driving and Dementia Roadmap Package of Resources.



Here's what some people with dementia have to say:

“That’s always been a real question. I’ve tried to be proactive. To my wife and my kids I say, I might be mad at them at the time, but I give them permission to be the ones to say - 'This is enough, you won’t be able to drive anymore.'”

“I think that you have to be aware, period. So, if you are questioning your ability, if you feel like, I can do this, but actually you can only do a little bit of it, take someone for a drive. Ask your family, 'Can you come to the store with me? I’ll drive, and tell me how I’m doing.’”

Talk to your doctor

Your doctor can help by:

- Providing support by talking to you and sharing ideas.
- Discussing the results of the in-office assessment and recommendations with you.
- Possibly referring you to a specialized driving assessment if the doctor is unsure of your driving ability.

If your doctor recommends that you stop driving, they may have to notify the responsible government authority. This authority may then suspend your driver’s license. If your doctor does not make such a report, they can be held legally responsible if you get in a car crash.

Try these worksheets

For help deciding when is the right time to give up driving, review these worksheets in the Driving and Dementia Roadmap Package of Resources.

1. **Warning Signs for Drivers with Dementia.** Refer to page 1 in the Driving and Dementia Roadmap Package of Resources.
2. **Agreement with my Family about Driving.** Refer to page 8 in the Driving and Dementia Roadmap Package of Resources.

For help coming up with ways to get around when you are no longer able to drive, review these worksheets in the Driving and Dementia Roadmap Package of Resources.

1. **Driving Activities - Where, When, Why?** Refer to page 11 of the Driving and Dementia Roadmap Package of Resources.
2. **Getting there - Using Alternative Transportation.** Refer to page 13 in the Driving and Dementia Roadmap Package of Resources.

Some parts of these worksheets may not be helpful if you live in a rural community.

Other resources available on DDR website

Dementia and Driving – A Decision Aid. This document is available on the Driving and Dementia Roadmap website (www.drivinganddementia.ca).

You can access this resources by locating the "I have dementia" heading on the homepage of the website and clicking "and I am still driving." Then, click on "Get help deciding to stop driving."

Get around without driving

Driving is certainly a convenient way to get around, and yet it is not the only way. Think of all the places you go to and then see if any of these options would work for getting there:

- Rides from family and friends - For example, they might agree to drive you a certain number of times each month in exchange for giving them your car as a gift.
- Carpooling
- Public transit - but if you tend to get lost, you need to have someone take you to the transit option and meet you at our destination.
- Taxis or ridehailing services (e.g., Uber, Lyft) - but if you tend to get lost, you need to have someone meet you at your destination.
- Community organizations that offer driver services
- Retirement residences with van services
- Rides from members of religious organizations or clubs

Consider changing some of your routines with the help of someone you trust such as a family member, friend, or neighbour. For example:

- Instead of visiting the bank, set up automatic bill payments.
- Instead of going to the grocery store, mall, and pharmacy, shop online and use delivery services.
- Instead of going out to services like the hairdresser or doctor, arrange for home visits.
- The Driving and Dementia Roadmap website contains information about alternative transportation options in your province or territory.

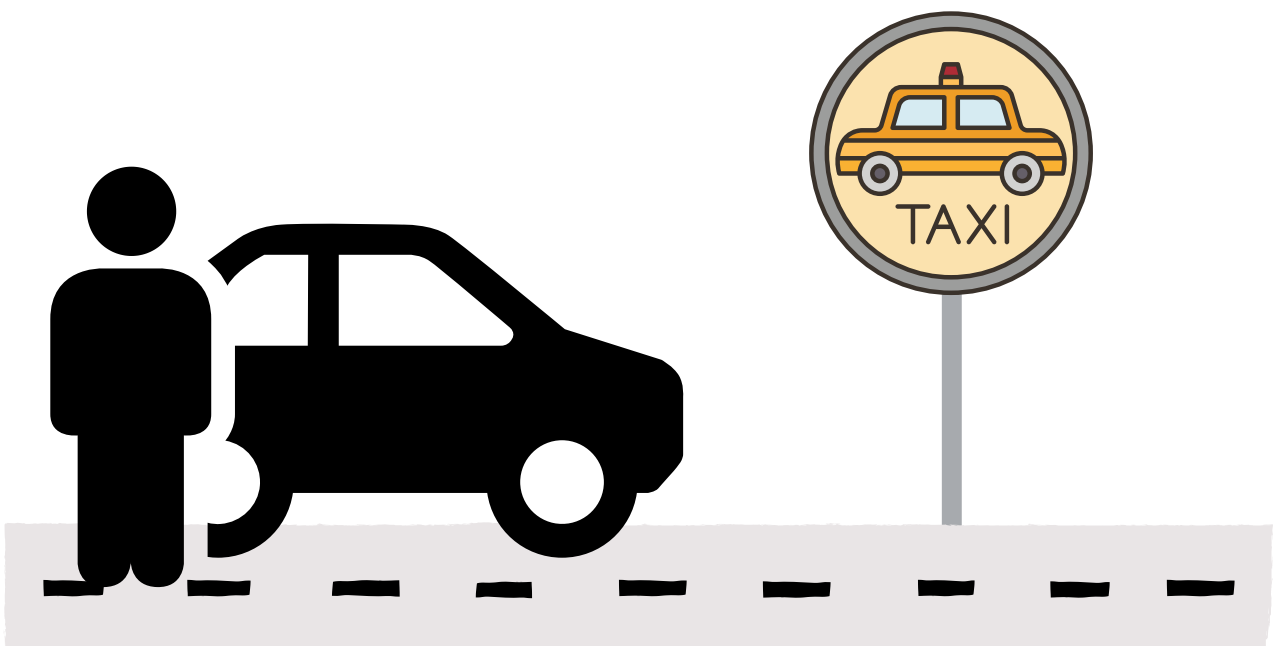
Video available on the Driving and Dementia Roadmap website

On the Driving and Dementia Roadmap website (www.drivinganddementia.ca), click on the video titled "**Plan in place (The Alzheimer's Society)**," in which a woman with dementia plans with her family for when she can no longer drive. You can access this video by locating the "I have dementia" heading on the homepage of the website and clicking "and I am still driving." Then, click on "Get around without driving."

Try these worksheets

Try these worksheets from the Driving and Dementia Roadmap website and the Package of Resources.

1. **Agreement with my Family about Driving.** Refer to page 8 in the Driving and Dementia Roadmap Package of Resources.
2. **Driving Activities - Where, When and Why?** Refer to Page 11 in the Driving and Dementia Roadmap Package of Resources.
3. **Getting There - Using Alternative Transportation.** Refer to page 13 in the Driving and Dementia Roadmap Package of Resources.



Dealing with my emotions

- Having to stop driving is a major life change for many people.
- It is understandable that you may be experiencing grief and feeling a variety of emotions.
- Give yourself the space and time to feel all of them.

Sometimes it is hard to know how you are feeling. Try to identify your emotions by answering these questions:

- Do you feel **sad** because you think giving up driving means giving up your independence?
- Do you feel **angry** because you don't think you should have to give up driving?
- Do you feel **confused** because you don't understand why you have to give up driving?
- Do you feel a **loss** in terms of pride of ownership because giving up driving means giving up the car you love?
- Do you feel **worried** because you don't know how you will get around without driving?
- Do you feel **embarrassed** by the idea of having to tell others that you are no longer able to drive?
- Do you feel **guilty** because if you give up driving, you will need to ask others to help you get around?
- Do you feel **relieved** and you are okay with giving up driving?

All these feelings are common. Next, try these ideas:

- Talk to someone you trust like your family, friends, neighbours or faith leaders.
- Talk to your doctor or other healthcare professionals.
- Join an in-person or online support group.
- Contact your local Alzheimer Society for support and resources

Here's what a person with dementia has to say:

“Take a deep breath. Let it out. Everything will be fine. It's really scary at first. It seems like you're giving up your freedom, but actually, there's a freedom also in not having your licence.”

Try this worksheet

For ideas of who to talk to about your emotions, use this worksheet from the Driving and Dementia Roadmap website and the Driving and Dementia Roadmap Package of Resources.

- **Not Going it Alone: Who Can Offer Support.** Refer to page 15 in the Driving and Dementia Roadmap Package of Resources.

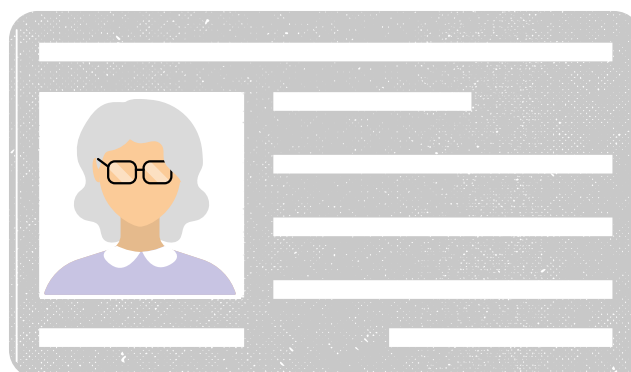


Learn about licensing, reporting, & transportation options

- When you are renewing your driver's licence, most, if not all, provinces and territories require that you declare if you have a medical condition. Accordingly, because dementia is a medical condition, you must report it.
- In addition, most, if not all, motor vehicle insurance policies include a clause that requires you to tell your insurer that you have a medical condition, such as dementia, because it may affect your driving.
- To get around without driving, ask your family/friend carers and doctor to help you come up with an alternative transportation plan. For more details about making a plan, go to page 13 in the Driving and Dementia Roadmap Package of Resources.

Public reporting of unsafe driving

- In many provinces and territories, your family and friends, as well as concerned citizens can report unsafe driving to the driver's licensing authority. On the Driving and Dementia Roadmap website we have details about each province and territory.



Requirements for healthcare professionals to report a dementia diagnosis

- All provinces and territories have some form of reporting requirements for healthcare professionals treating people with health conditions.
- Because dementia is a health care condition that affects your driving ability, your health care professional may need to make a report. Visit www.drivinganddementia.ca for more details.

What to expect in a comprehensive driving evaluation

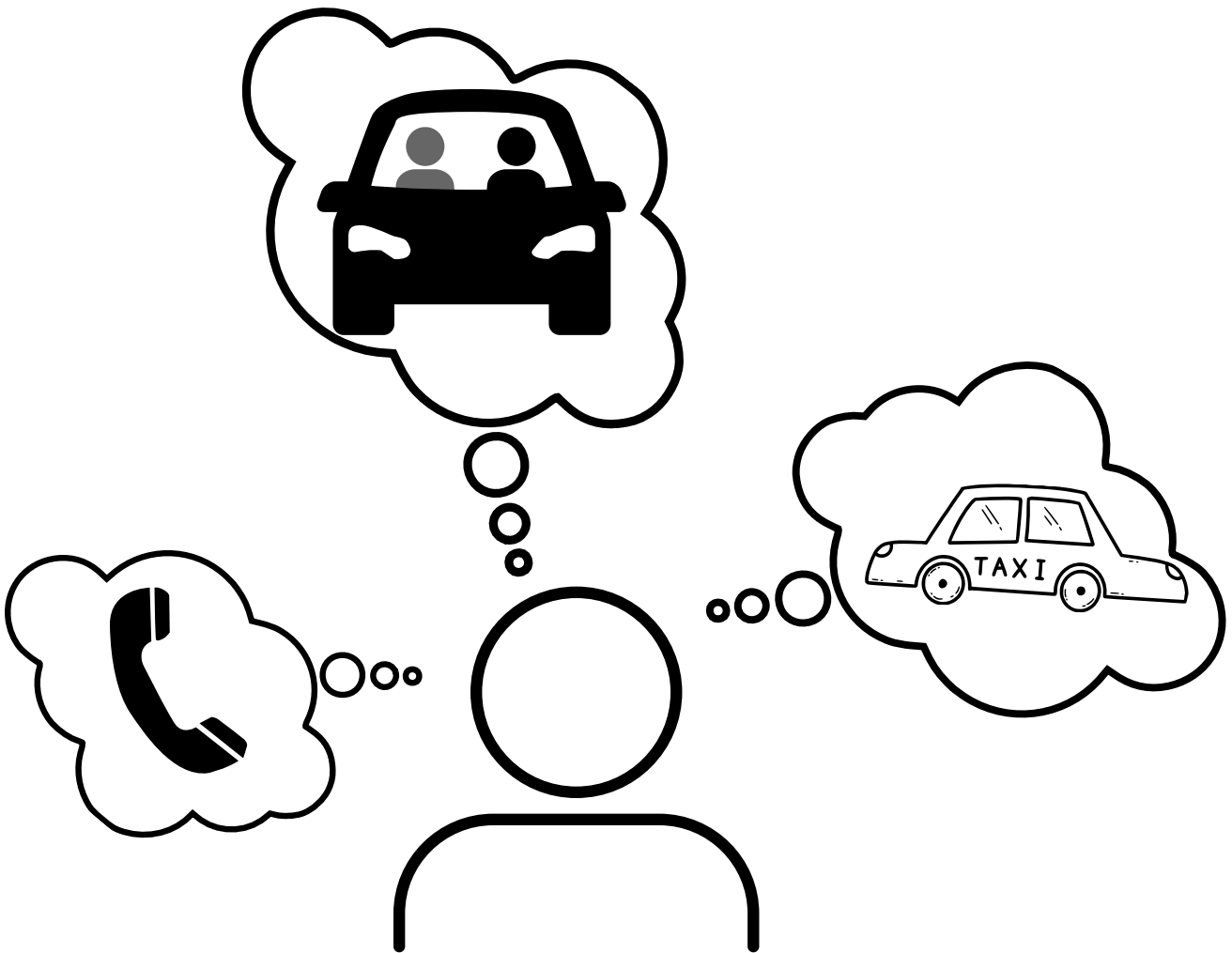
- To determine if you can continue driving and if so, to what extent, the drivers' licensing authority of most provinces and territories may request that you take a comprehensive driving evaluation. It is sometimes called something else such as a functional assessment.
 - It assesses whether your dementia is affecting your ability to drive safely.
 - It is not the same as the government driving test you took to get your licence for the first time.
 - It involves specialized driving tests typically conducted by an occupational therapist and driving instructor.

Appeal process for drivers' license suspensions

- Most provinces and territories have a process for appealing licence suspensions.
- On the Driving and Dementia Roadmap website, you can find out details about each province and territory.

Alternative transportation options

- When you are no longer safe to drive due to your dementia, ask your family/friend carers and doctor to help you come up with an **alternative transportation plan**.
 - See page 13 in the Driving and Dementia Roadmap Package of Resources for more details about making an alternative transportation plan.
- There are also province and territory specific resources for alternative transportation on our website.



Acknowledgements

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