



DRIVING & DEMENTIA ROADMAP

For family/friends caring for a person with dementia who is 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



CIHR
IRSC
Canadian Institutes of
Health Research
Instituts de recherche
en santé du Canada



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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 support the person with dementia make decisions about driving so that they only continue to drive if they can drive safely.
- It will provide you with strategies on how to have conversations about driving with the person with dementia.
- It will help you manage the emotional impact that stopping to drive can have on you and the person with dementia.
- The information is from a free website for people with dementia as well as their family/friend carers 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.



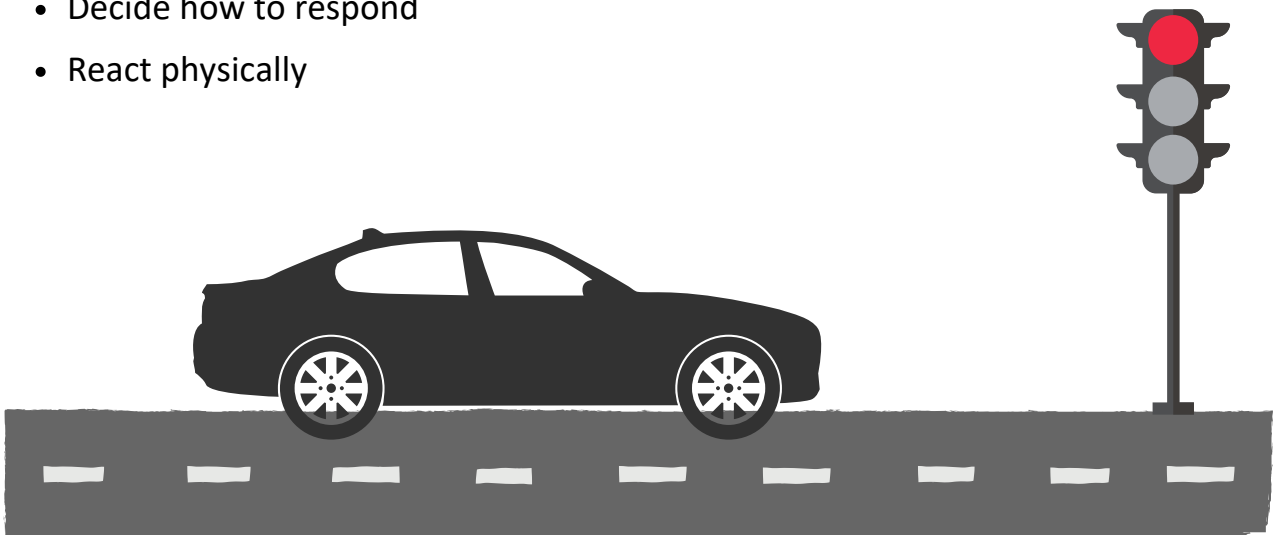
Understanding the importance of giving up driving

A person with dementia will eventually lose the brain functions necessary to make the kind of fast decisions and reactions they need to drive safely. This is because even though there are different types of dementia, all types are reflective of damage to the brain. Also, dementia is progressive so the symptoms will get worse over time. Alzheimer's disease is the most common type of dementia.

Ways dementia makes driving unsafe

How people with dementia's driving skills are specifically affected depends on how far the dementia has progressed, as well as which parts of the brain are damaged. To drive safely, different parts of the brain all work together in a complex process to:

- See and hear surroundings
- Guess what might happen
- Decide how to respond
- React physically



In addition, all of this has to happen quickly. Many additional problems that are common with dementia make driving unsafe, including:

- Increasing forgetfulness
- Limited attention span
- Limited ability to quickly process information
- Poor judgment and problem-solving ability
- Disorientation to place
- Low reaction ability
- Visual perceptual issues (how things are seen in space, in relation to each other)

Understand why you need to help assess driving risk

The changes the person with dementia is experiencing are much more complex than the changes people *without* dementia experience with age, like problems with their vision and slower reaction time. The person with dementia will eventually:

- Lose a range of brain functions that are necessary to make the kind of fast decisions and reactions necessary to drive safely.
- Lose insight into their abilities. So it's common that they will not recognize driving difficulties or be able to develop new behaviours to adjust to these changes.

In addition, some people with dementia don't realize or remember making unsafe decisions while driving. Not recognizing their driving difficulties, the person with dementia may be defensive. For example:

- They may say things like "I've been driving my whole life and I haven't ever had an accident."
- If they get lost, they may make excuses like, "I was planning to go there."
- With close calls, they may blame others, "She wasn't looking where she was going."

As a result, the person with dementia is not the best person to assess their own driving ability. You can help by:

- Becoming familiar with the warning signs, which indicate that the person with dementia may be experiencing difficulty driving. See the warning signs checklist on page 1 of the Driving and Dementia Roadmap Package of Resources.
- Visiting our website (www.drivinganddementia.ca) to take the online screening assessment if you are familiar with the person with dementia's driving. Locate the heading "I am a family/friend caring for..." and click on "a person with dementia who is still driving." Then, click on "Understand why you need to help assess driving risk."
- Visit page 32 of this document to learn what you should do if the person with dementia won't stop driving.

Learn about crashes

Some people with dementia are able to drive safely for some time after diagnosis. However, the longer a person with dementia continues to drive after diagnosis, the higher their chance of getting into a vehicle crash. The majority of studies show an increased risk of motor vehicle crashes among people with dementia. Research indicates that:

- Driving performance decreases with increasing dementia severity (Jacobs et al., 2017). Reviews have demonstrated that in all 17 that assessed driver performance, drivers with dementia performed significantly worse than study participants without dementia. In addition, in 6 out of 10 studies of caregiver and/or state-reported motor vehicle collisions, drivers with dementia were involved in a crashes more often than study participants without dementia (Chee et al., 2017; Man-Son-Hing et al., 2007).
- Most crashes happen close to home like on trips to the grocery store or mall. This is why even taking short trips to familiar places can be dangerous.

Try these worksheets

On the the Driving and Dementia Roadmap website (www.drivinganddementia.ca) and in the DDR Package of Resources, 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 website

1. **Dementia and Driving – A Decision Aid** can 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 am a family/friend caring for..." heading on the homepage of the website and then clicking "a person with dementia who is still driving." Then, click on "Understanding the importance of giving up driving."



Recognizing when it becomes unsafe to drive

At the earliest stages of dementia, the person with dementia may notice changes in their driving. As a result, they may make adjustments as to when they drive. For example, they may only drive in the daylight and/or only to places that they are familiar with. However, as the dementia progresses, they will lose their ability to determine on their own when they are no longer able to drive safely and that they should stop driving. To decrease the risk of accidents, it's important that you get involved.

Learn the warning signs

You can't rely on the person with dementia to recognize when their driving is unsafe. So you must regularly observe their driving and monitor any changes in their driving skills. To help you notice the warning signs indicating that their driving is unsafe:

- Use the warning signs checklist on page 1 of the Driving and Dementia Roadmap Package of Resources
- Visit our website (www.drivinganddementia.ca) and click on the following videos to learn about additional warning signs to look out for.
 - **"When is it time for your family member with dementia to stop driving"** by Reitman Centre, Sinai Health System
 - **"Signs your loved one with dementia is not safe to drive"** by Dementia Careblazers
- You can access these videos by locating the "I am a family/friend caring for..." heading on the homepage of the website and clicking "a person with dementia who is still driving." Then, click on "Recognizing when it becomes unsafe to drive."

Balance independence with road safety

The best approach is to base driving decisions as much as possible on objective information. As soon as there is a dementia diagnosis, observe the person with dementia's driving on a regular basis, and watch for signs of changes in how they drive. This will help you avoid delaying action or taking action too soon.

In addition, knowing the warning signs that the person with dementia's driving skills are changing helps make sure you don't miss any indications that their driving ability is declining. Keep in mind that:

- Minor incidents, even if they only happen once, may mean that it's time that the person with dementia seriously consider giving up driving.
- When minor incidents become more frequent—or there is a major incident—then it's time for the person with dementia to stop driving.

As you regularly monitor the person with dementia's driving, be sure to also:

- Have discussions with the person with dementia about their driving ability on a regular basis.
- Talk about any concerns you have with the person with dementia's healthcare providers.

Here's what some family members have to say:

"Have the person with dementia drive you places and be aware of their actions. If you question anything, it is time to act. It isn't just about your loved ones. It is also about others on the road who may be injured if something were to happen."

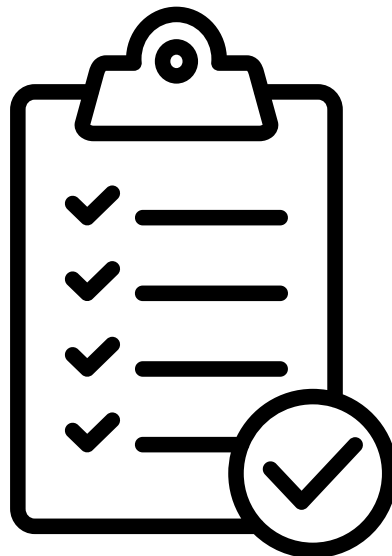
"Stay connected to the medical team for support if needed to reinforce the message about not driving when the time comes."

Learn when an in-car driving assessment is necessary

An in-car driving assessment is necessary as soon as you feel that the person with dementia's driving may be unsafe. The purpose of an in-car driving assessment is to determine if the person with dementia may continue driving and if so, to what extent.

Understand what an in-car driving assessment involves

An in-car assessment goes far beyond the type of driving test that the person with dementia took to become a licensed driver in the first place. Instead of testing general driving ability, it assesses whether the person with dementia's driving skills are affected by dementia. All driving assessments are not the same. They vary depending on where the assessment is offered, what it focuses on, and the type of assessor.



Specialized driving assessment centres

These centres specialize in assessing people with conditions that could make their driving unsafe, including cognitive issues like dementia. The assessment is conducted by a driving instructor and an Occupational Therapist (a type of health care professional).

For example, it typically includes:

- **Clinical Evaluation:** Review of medical and driving history and clinical tests related to driving performance:
 - Vision – like depth perception, peripheral vision, visual-spatial skills, and contrast sensitivity
 - Cognitive ability – like judgment and memory, following instructions, speed of brain reaction
 - Motor skills – like strength, range of motion, coordination, sensation, and reaction time
- **On-the-road Evaluation:** Assessment of negotiating traffic, attention, problem solving, and judgment.
- **Results:** Rather than just “pass” or “fail,” a written report provides the clinical results, driving strengths, and weaknesses, and recommendations. The recommendations include whether driving should stop or continue and if so, under what conditions. In addition to the written report, the Occupational Therapist will also discuss the results with you and the person with dementia

<p>Government driver’s licence authorities and driver training schools</p> <p>What is included in the driving assessment varies by region, but it usually does not specifically assess whether the person with dementia’s driving skills are affected by dementia.</p>	<p>For example, it typically does not include:</p> <ul style="list-style-type: none"> • Details of the strengths and weaknesses, just “pass” or “fail” • Cognitive test <p>Because the driving assessment is not aimed specifically at assessing driving skills of people with dementia, the person with dementia could pass the assessment but actually be unsafe to drive. This type of driving assessment is not a valid indicator of whether the person with dementia is safe to drive.</p>
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Get the most out of an in-car assessment

When making arrangements for the person with dementia to have an in-car driving assessment, ask the assessment centre these questions:

- Does the person with dementia's doctor need to send a referral?
- What is included in the assessment?
- What type of professional conducts the assessment?
- How much does the assessment cost?
- Is a written report provided after the assessment?

Understand how the doctor can help

The person with dementia's doctor is a valuable resource who can help by:

Discussing your concerns about unsafe driving

It's likely that the person with dementia's doctor has had experience with patients whose driving abilities have been affected by various conditions—including dementia. Think about meeting with the doctor privately without the person with dementia to discuss any driving issues that you have noticed. The doctor may then recommend that the person with dementia come in for an in-office assessment as described below.

Conducting an in-office assessment of driving ability

When a patient has a medical condition like dementia that increases the risk of car accidents, the doctor has certain legal obligations. For most provinces and territories in Canada, the doctor must assess the person with dementia's cognitive abilities and make a recommendation regarding whether or not they should continue driving.

At a doctor's appointment during an in-office assessment, the doctor will review any medications the person with dementia is taking, evaluate cognitive functions like memory and thinking processes, and may do a physical exam. Then the doctor will discuss the results of the assessment and recommendations with the person with dementia.



<p>If the recommendation is to stop driving</p>	<ul style="list-style-type: none"> • Most provinces and territories in Canada require doctors to send a report of their recommendation to the Ministry of Transportation. • In the United States, the laws about doctor reporting vary from state to state. • If you are worried that the person with dementia may forget that they are not supposed to drive, ask your doctor for a letter (see page 9 of the Package of Resources) to use as a reminder.
<p>If the doctor is unsure of driving ability</p>	<ul style="list-style-type: none"> • The doctor will likely refer the person with dementia for an in-car dementia driving assessment. • If the assessment determines that the person with dementia should stop driving, your doctor may need to let the driving authorities know this recommendation.
<p>If the doctor feels it's safe for the person with dementia to keep driving</p>	<ul style="list-style-type: none"> • The doctor will likely recommend monitoring the person with dementia's driving ability. • For example, the doctor may recommend having the person with dementia come in for a doctor's appointment about every six to 12 months to have another in-office assessment.

Videos available on the Driving and Dementia website

On the Driving and Dementia Roadmap website (www.drivinganddementia.ca), watch the following videos to see that there are a number of ways you can identify warning signs to unsafe driving. In addition, the third video discusses what to do when the person with dementia is reluctant to see a doctor regarding driving.

1. **"When is it time for your family member with dementia to stop driving?"** by Reitman Centre, Sinai Health System
2. **"Signs your loved one with dementia is not safe to drive"** by Dementia Careblazers
3. **"Find out if your loved one with dementia is safe to drive"** by Dementia Careblazers
4. **"Starting the conversation - Changed Conditions Ahead"** by Alzheimer's Australia Vic. See how various family/friend carers notice changes in the person with dementia's driving. Although some of the content is specific to Australia, most of the ideas are helpful no matter where you live.
5. **"A bump in the road"** by Alzheimer's Association. See how this daughter encourages her mother to think about having her driving assessed.

You can access these resources by locating the "I am a family/friend caring for..." heading on the homepage of the website and clicking "a person with dementia who is still driving." Then, click on "Recognizing when it becomes unsafe to drive."

Other resources available on DDR website

1. **Warning Signs for Drivers with Dementia.** Refer to page 1 in the Driving and Dementia Roadmap Package of Resources.
2. **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).

Having conversations about giving up driving

When starting a conversation about driving risk with the person with dementia, it is important to show compassion and empathy. Think about how it would feel to no longer be able to drive. Share your thoughts with the person with dementia while encouraging them to also talk about what the loss of driving means to them.

Here's what some family members have to say:

"Involve your partner in discussions and decisions. Chances are they will understand."

"Start talking about the need to stop driving with your family member (with dementia) early on. Make sure they are engaged in the decision if possible."



Having ongoing discussions about driving risk

The most appropriate person to start this conversation should be someone who is familiar with the person with dementia's health condition and their driving abilities. Of course, this person should also be someone whom the person with dementia trusts. Start the conversation early and have ongoing discussions that:

1) Involve the person with dementia

It's important to involve the person with dementia in driving discussions so that they feel respected and have a sense of control. Ideally, the person with dementia will transition to no longer driving over time, providing the opportunity to work together on a plan of action.

Be prepared for reactions like anger or sadness, which can sometimes be extreme due to the memory and insight issues that are often part of dementia. Once the person with dementia buys into the idea of no longer driving, use the "Agreement with my Family about Driving" worksheet on page 8 of the Driving and Dementia Roadmap Package of Resources.

Try these tips:

- Allow the person with dementia to express how they feel about driving.
- Try to remain calm, without sounding angry, even though you may feel anxious and fearful.
- For example, you can ask them for their opinion and ideas with questions like:
 - How important is driving to you?
 - Have you ever thought about stopping driving?
 - Are you considering stopping driving now that you have the diagnosis of dementia?
 - If you stopped driving, do you have ideas of how you would get around?

2) Involve family members

Family members often have different ways of approaching difficult issues, such as stopping to drive. However, family members can provide support for both you and the person with dementia as you face tough decisions. Try to create opportunities for family members to observe the person with dementia's driving abilities.

For example, the person with dementia may:

- Take control and not consider others' opinions.
- Avoid dealing with the issue altogether.
- Not disclose their concerns because they think it could be hurtful, disloyal, or cause conflict.

3) Involve friends

In addition to family members, you might also want to encourage the person with dementia to reach out to others regarding a future without driving. You might also find talking to a friend or joining a support group helpful.

For example, you could encourage the person with dementia to:

- Talk to a good friend about their feelings regarding a future without driving.
- Talk to or read online about other people with dementia and what it means to them to give up driving.



Try these worksheets

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

1. **Conversation planner: How can I have good conversations about not driving?**
Refer to page 6 of the Driving and Dementia Roadmap Package of Resources.
2. **Not going it alone: Who can offer support?** Refer to page 15 of the Driving and Dementia Roadmap Package of Resources.

Other resources available on DDR website

On the Driving and Dementia Roadmap website (www.drivinganddementia.ca), watch the following videos.

1. **"Supportive conversation"** by ActionAlz
2. **"Starting the conversation - Changed Conditions Ahead"** by Alzheimer's Australia Vic. See how various family/friend carers notice changes in the person with dementia's driving. Although some of the content is specific to Australia, most of the ideas are helpful no matter where you live.
3. **"When is it time for your family member with dementia to stop driving?"** by Reitman Centre, Sinai Health System

You can access these resources by locating the "I am a family/friend caring for..." heading on the homepage of the website and clicking "a person with dementia who is still driving." Then, click on "Having conversations about giving up driving."

Transitioning and planning ahead

For many people with dementia, there are ways to make the transition to no longer driving more of a natural progression than an abrupt stop. However, of course, they must stop driving immediately if their driving is already at the unsafe level. Otherwise, try these ideas to create opportunities to naturally limit how much the person with dementia drives, as well as tips for planning ahead.

Try to naturally limit driving.

Consider trying these ideas:

1) Make driving less appealing

Here are some ways to try to decrease the person with dementia's interest in driving.

- Highlight the cost of owning and operating a car and how much it's possible to save by giving up driving. Try the transportation cost calculator on page 10 of the Driving and Dementia Roadmap Package of Resources.
- Use changes in the person with dementia's symptoms, other health conditions, or medications as a chance to appeal to their sense of responsibility that it's time to stop driving because they are not the only ones at risk.
- Emphasize poor traffic or weather conditions and how much less stressful and more comfortable it is to be a passenger than a driver.

2) Making driving less necessary

Driving is certainly a convenient way to get around, and yet it is not the only way. The person with dementia may be able to change certain routines like instead of visiting the bank, you could set up automatic bill payments. The transportation options will depend on the person with dementia's specific situation. Brainstorm together to come up with ideas like:

- Family and friends
- Members of a place of worship
- Carpooling
- Public transit - but if the person with dementia tends to get lost, they need someone to take them to the transit option and meet them at their destination.
- Taxis and ridehailing (e.g., Uber, Lyft) - but if the person with dementia tends to get lost, they need someone to meet them at their destination.
- Community organizations that offer driver services
- Retirement residences with van service
- Delivery services and online ordering (e.g., groceries, prescriptions, books, newspapers)
- Services offering home visits (e.g., hairdressers, doctors, laundry pick-up)
- Meal delivery services (e.g., Meals-on-Wheels)

3) Consider what action to take as a final recourse

Consider gifting the car to a family member and, when appropriate, with the agreement that the family member, in return, will provide a certain number of drives a month for the person with dementia. Only consider taking away the car keys or selling or disabling the car as a last resort and, when appropriate, with the agreement that the family member, in return will provide a certain number of drives a month for the person with dementia. Otherwise, it can create conflict or hurt feelings because the person with dementia may find this abrupt, extreme, disrespectful, insensitive, or like you are punishing them.

Plan ahead for no longer driving

Help make the transition to no longer driving easier on the person with dementia, as well as everyone involved by:

- Working together with the person with dementia to decide when is the right time for them to give up driving by using the Driving and Dementia - Decision Aid available on our website (www.drivinganddementia.ca).
- Using the "Agreement with family about driving" worksheet on page 8 of the Driving and Dementia Roadmap Package of Resources. This is an agreement that outlines the person with dementia's wishes regarding when they can no longer make the best decision about driving for their safety and the safety of others. Accordingly, it is useful as a way to discuss planning ahead for when the person with dementia can no longer drive. In addition, it also acts as a helpful reminder if the person with dementia doesn't remember that they are not supposed to drive.
- Discussing ways to get around without a car and working together to develop a transportation plan. Make sure the plan includes not only necessary appointments like the doctor and dentist, but also important and fun things like doing exercise and going to social events. Try using the alternative transportation planning worksheet on page 13 of the Package of Resources or the driving activities worksheet on page 11 of the Package of Resources. Also, try the transportation cost calculator on page 10 of the Package of Resources, which highlights the cost of owning and operating a car. The money saved by giving up driving can be used to cover the costs of taxis and ridehailing (e.g., Uber, Lyft) services.

In addition, learn about alternative transportation options for where the person with dementia lives on page 35 or on www.drivinganddementia.ca.

Here's what some family members have to say:

"Getting a taxi out here would be very expensive because we're in the country, so it's really depending on a car and depending on other drivers. One day I asked a neighbour to take me somewhere, which I've never done before. They responded, 'Absolutely, whenever you need anything'. So, I know they're there."

"I use the attitude that, 'I'll take you wherever you want to go'. I never make him feel bad about wanting to get a drive somewhere. I think having that attitude to support him has been helpful. It changes the dynamic between us when he has to depend on me. We've tried to plan so that we do things together instead."

"Life doesn't stop. There are friends that will pick him up to do activities. You can walk. There is bus service and there's family. Nothing has to drastically change. He can stay the same, even if he doesn't have his own means of transportation."

Other resources available on the Driving and Dementia Roadmap website

On the Driving and Dementia Roadmap website (www.drivinganddementia.ca), watch the following videos about how to transition to longer driving.

1. **Staying active, mobile and connected - Changed Conditions Ahead - Dementia and Driving in Victoria** by Alzheimer's Australia Vic
2. **Common Challenges: Driving | UCLA Alzheimer's and Dementia Care Program** by UCLA Health

You can access these resources by locating the "I am a family/friend caring for..." heading on the homepage of the website and clicking "a person with dementia who is still driving." Then, click on "Transitioning and planning ahead."

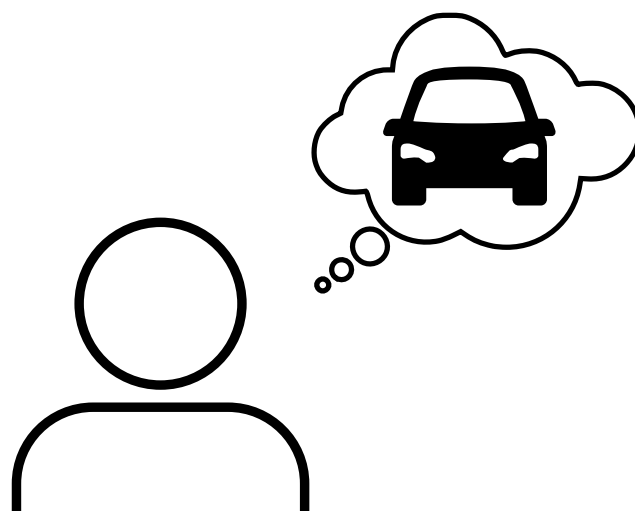
Dealing with emotions

It's important to recognize that the person with dementia's ability to keep driving affects both of you. It's common to experience a wide range of emotions that can be unpredictable, and everyone is different. Although some people with dementia have very strong negative feelings about giving up driving, others are accepting or relieved. Likewise, you may find yourself having both negative and positive feelings about it.

Recognize that driving fulfills various emotional needs

Giving up driving can be very emotional because driving fulfills different needs for different people. As a result, giving up driving can have a serious impact on the person with dementia's sense of identity and self-worth. For example, driving can be connected to numerous aspects of their identity and lifestyle such as:

- Sense of freedom, independence, and control
- Work and livelihood
- Friendships and other forms of connection like attending faith services
- Roles like taking care of a spouse, children, or aging parents
- Enjoyment like a drive in the countryside
- Pride of ownership of affording and maintaining a much-loved possession of a car
- Feeling youthful



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

"I've always loved driving. There's something about it. I love cruising down the road, on the highway, down the back roads and just looking. It's relaxing. It's therapeutic. When you get really upset or whatever, sometimes you go take a look at nature. You just drive to the park. Or you can just jump into the car and go visit."

"It gives me freedom. I don't have to worry about somebody else taking me somewhere. If I want to decide to just go for a coffee with my girlfriends, I just get in the car and go."

"It's just independence, especially rural. When you're living in the country in small towns you don't have the option of just every half an hour, the bus comes."



Cope with the emotional impact on me

You need to take care of your own emotional needs on an ongoing basis, not just the person with dementia's needs. Try these ideas:

1) Pay attention to your emotions

Loss of driving is just one of the many significant transitions you may face as the person with dementia's disease progresses. You may feel like you are on an emotional roller coaster. To cope, it's important to recognize that it's normal to experience a range of emotions such as:

- **Loss, sadness, grief:** regarding the person with dementia's inability to continue to drive safely. In the bigger picture, it's a reminder that they will eventually lose their independence. Stopping driving may represent the loss of your dreams for the future.
- **Fear, anxiety:** regarding how to cope with the emotions of the person with dementia and your own emotions around the transition to no longer driving. In addition, fear about the possibility of the person with dementia getting into an accident and hurting themselves or others. There is the fear of the accident itself as well as the fear of being blamed for not being able to prevent it from happening.
- **Frustration, anger, guilt:** regarding how the transition from driver to a passenger is going, especially if the person with dementia has responded to the idea of no longer driving with denial, intense sadness, withdrawal, anger, or blame.
- **Discouraged, powerless:** regarding the person with dementia's insistence on continuing to drive.
- **Overwhelmed:** regarding added responsibilities, of having to do all/most of the driving or, if you do not drive, having to make all the driving arrangements.

2) Be kind to yourself

Once you have identified what you are feeling—for example, sadness, anxiety or anger—then to cope, don't try to avoid the emotion by simply continuing on as if you aren't having these feelings. Instead, allow yourself to feel the emotion. For example, to heal feelings of loss, be kind to yourself by allowing yourself to grieve. Signs that you may be experiencing grief include:

- Physical signs of grief include shortness of breath, dry mouth, tightness in your chest, difficulty sleeping or lack of energy.
- Behavioural and emotional changes that may be indicators of grief include crying, restlessness, misplacing items, confusion, disorientation, or worrying.

3) Don't feel you have to go it alone

Far too often family/friend carers take it upon themselves to meet all the transportation needs of the person with dementia. But they should not have to do it alone. Identify people in your life who may be able to provide support. For example:

- Connect with family members.
- Reach out to friends who have been there for you in good times and bad.
- Consider whether any of your neighbours, co-workers, and/or faith leaders may be able to provide valuable support.
- Talk to your doctor or other healthcare professionals.
- Communicate with other people who are taking care of a person with dementia through in-person support groups or online forums.
- Use the circle of support worksheet on page 15 of the Driving and Dementia Roadmap Package of Resources to help build a support network.
- Contact your local Alzheimer Society organization. They can provide support and resources.

Here's what some family members have to say:

"Talking to someone about my side of the situation when I had to become the only driver, and thus the only person to do all the errands, grocery shopping, business, etc. It's a huge load for any one person."

"See if you can have other family members or friends take your family member with dementia out for coffee, lunch or to sporting events or maybe a movie from time to time. Just to give yourself a break."

4) Try to be empathetic

If you are finding it difficult to handle how the person with dementia is reacting to the idea of no longer driving, empathy can help. Recognizing their emotions can increase understanding of their situation. Driving fulfills different needs for different people. As a result, giving up driving can have a serious impact on the person with dementia's identity and self-worth. For example, driving can be connected to numerous aspects of identity and lifestyle such as:

- Sense of freedom, and independence
- Work and livelihood
- Friendships and other forms of connection like attending faith services
- Roles like taking care of a spouse, children, or aging parents
- Enjoyment like a drive in the countryside

Manage the emotional impact on the person with dementia

As a major life change, giving up driving can lead to a range of emotions even for people without dementia. For people with dementia, reactions can be even stronger due to poor memory and lack of insight that is often a part of dementia. The lack of insight into the dangers of driving with dementia makes it especially hard for the person to appreciate the limitations being imposed. Also, their emotions may change over time. To help the person with dementia cope with the range of feelings they may be experiencing now—or in the future—try these ideas:

1) Anticipate a range of emotions

Not only is it common for people with dementia to experience a range of emotions around giving up driving, sometimes their emotions can be so strongly negative that it prevents them from agreeing to stop driving. In other cases, the person with dementia may recognize that their driving abilities are declining and they are at ease with the decision to give it up. Sometimes they may even feel relieved because they find driving makes them anxious.



By understanding their feelings you will be in a better position to help them stop driving, as well as cope with their emotions. Try to relate to what the person with dementia is going through by recognizing that typical emotions include:

- **Loss, sadness, grief:** regarding whatever driving represents to the person with dementia—for many, driving means independence and self-sufficiency. Giving up driving may also represent yet another blow in terms of their dementia diagnosis and that they will gradually lose many abilities. This may include a sense of loss regarding pride of ownership as they lose a valued possession of a car.
- **Fear, anxiety:** regarding what their life will be like when they can no longer drive. For example, they may worry about how they will get around for not only practical reasons but for socializing and enjoying life.
- **Guilt:** regarding how giving up driving may inconvenience others. This may compound guilt they are already feeling regarding the help they are getting in relation to their dementia diagnosis overall.
- **Frustration, anger:** regarding a sense of what they perceive as no control or no say about stopping driving. They may think that they aren't being treated fairly, which may be intensified due to the nature of dementia and inaccurate memory and insight.
- **Agitation, irritation:** regarding not being able to express feelings as the dementia progresses or not being able to fully understand what's going on, left with just an overall, generalized feeling that something is wrong.
- **Embarrassment:** regarding having to admit to others that they are no longer able to drive safely.
- **Denial:** regarding they are no longer able to drive safely. This may be because they can't remember unsafe driving incidents or lack insight into their loss of driving skills. This can lead to stubbornness and a refusal to stop driving.

Here's what various emotions may sound like:

- **Denial:** "This isn't happening to me.... I can drive just as well as I ever could." "I am as smart as I always was."
- **Anger:** "Why is this happening to me? This is not fair. How am I supposed to get our groceries?" "These tests they did (to test my driving skills) were silly and childish" "What do these doctors know about me anyway?"
- **Bargaining:** "I'll drive more carefully if you let me keep my license.." "I won't drive on the highway, only to the church or grocery store."
- **Depression:** "My life is over."
- **Acceptance:** "If you help me with the bus schedule, I'll give it a try."

2) Acknowledge emotions

No matter what emotions the person with dementia is experiencing, an effective way to help them cope is by acknowledging and validating what they are feeling.

For example:

- Help them identify what they are feeling (as needed) and encourage them to talk about what they are going through.
- Listen with empathy and show that you understand their feelings by providing reassurance with comforting words.
- Encourage them to face painful feelings like sadness and loss rather than avoid them. This often helps people process their feelings leading to an improved state of mind.
- Avoid saying anything that might come across like you are denying or discounting their feelings.
- Encourage them to talk to other supportive people in their life, like family members and friends as well as their doctor, other health and mental health care professionals and faith leaders.
- Suggest they contact their local Alzheimer Society for support and resources.

Overall, creating a trusting relationship and open dialogue will help the person with dementia cope with their emotions.

- Try these tips on page 14 of this document for starting the conversation about driving risk and making it an ongoing discussion that is positive.
- Work with the person with dementia on the circle of support worksheet (page 15 of the Driving and Dementia Roadmap Package of Resources) to help identify who else they can turn to or support.

Here's what some family members have to say:

"Talking about it is good to dispel feelings of frustration and loss. It's a big thing to give up driving after a long time. It signifies a big change and can be very difficult."

"Remain patient. You may have to explain several times the reason the family member (with dementia) can't drive."

"Allow them to be back seat drivers. Be patient when they tell you how to drive. Let them be part of the experience."

"Assure your family member (with dementia) that not driving isn't who they are and that driving them places is an opportunity to spend time together. Do not make them feel that it is a chore. Assure them often of your unconditional love."

3) Find new ways to maintain purpose and meaning

To help offset the loss of identity and purpose that the person with dementia may be experiencing, encourage them to try new activities. For example, attending adult day centres or volunteering with the Alzheimer Society can provide opportunities to help others and restore their feelings of self-worth.

Here's what some family members have to say:

"She gave her car to my niece, which made her feel helpful and was a way for her to give up driving with dignity."

"Let them know they are doing the right thing for the community at large and for them as well to be safe and happy."

Resources available on the Driving and Dementia Roadmap website

On the Driving and Dementia website (www.drivinganddementia.ca) and in the Package of Resources, the following worksheet is available:

1. Conversation planner: How can I have good conversations about not driving?

Refer to page 15 of the Driving and Dementia Roadmap Package of Resources.

On the Driving and Dementia Roadmap website (www.drivinganddementia.ca), watch the following video about how to transition to longer driving.

- 2. A Close Call** by ActionAlz. See how a family/friend carer handles a person with dementia's emotional reaction when the conversation about giving up driving does not go well.

You can access these resources by locating the "I am a family/friend caring for..." heading on the homepage of the website and clicking "a person with dementia who is still driving." Then, click on "Dealing with Emotions."

Managing when the person with dementia won't stop driving

There are a number of things you can do if the person with dementia refuses to stop driving or if they keep forgetting that they are unfit to drive.

Try these ideas

Try to be patient, but firm. Also, don't blame yourself or the person with dementia for the difficult transition. Dementia can impair insight and judgement so the person with dementia may not fully understand that their driving is unsafe. The dementia may also cause mood or personality changes that lead to reactions that seem extreme like very strong anger or despair. To help manage the situation when the person with dementia won't stop driving try these ideas:

- Ask authority figures within the person with dementia's family, or professionals like a lawyer, to reinforce the message to your loved one that they must not drive anymore.
- Appeal to the person with dementia's sense of responsibility by emphasizing that they need to consider the safety of other people on the road.
- Consider gifting the car to a relative, possibly in return for the recipient of the vehicle to provide a certain number of drives a month for the person with dementia.
- Consider, as a final recourse if nothing else is working, taking away the car keys, selling or disabling the car, or using a type of lock that makes it impossible to use the steering wheel.
- Call the police if you feel the person with dementia or others on the road are in immediate danger.

- Ask the person with dementia's doctor for a letter, such as the one on page 9 of the Driving and Dementia Roadmap Package of Resources, outlining why the person with dementia can no longer drive. Use this letter to reinforce to the person with dementia that they are legally no longer allowed to drive. It was produced by the Regional Geriatric Program of Eastern Ontario.
- Learn about licensing and reporting responsibilities on our website www.drivinganddementia.ca.

Videos available on the Driving and Dementia Roadmap website

On the Driving and Dementia Roadmap website (www.drivinganddementia.ca), watch the following two videos of leading educator in dementia, Teepa Snow, recommend strategies for talking to people with dementia about giving up driving.

1. "**Dementia and Driving - with Teepa Snow of Positive Approach to Care.**" Here she recommends how to talk to a person with dementia who is reluctant to stop driving.
2. "**Dementia and Driving**" by Teepa Snow's Positive Approach to Care. Here she recommends what **not** to say to a person with dementia who is reluctant to stop driving.

View the following videos for additional information on what to do as a family or friend carer of a person with dementia who is still driving.

1. "**How to stop your loved one with dementia from driving**" by Dementia Careblazers. Learn some ideas about what to do when a person with dementia is no longer safe to drive.
2. "**A Close Call**" by Alzheimer's Association. See how a family/friend carer handles a person with dementia's emotional reaction when the conversation about giving up driving does not go well.

You can access these resources by locating the "I am a family/friend caring for..." heading on the homepage of the website and clicking "a person with dementia who is still driving." Then, click on "Managing when the person with dementia won't stop driving."

Learning about licensing, reporting & transportation options

When you are helping the person with dementia renew their driver's licence, you will discover that most, if not all, provinces and territories require that people with dementia declare that they have dementia when they renew their licence. All medical conditions that can affect driving must be declared. In addition, most, if not all, motor vehicle insurance policies include a clause that requires the person with dementia to tell their insurer that they have a medical condition that can affect their driving. To get around without driving, ask your family/friend carers and doctor to help you come up with an alternative transportation plan (see page 13 transitioning and planning ahead). Visit our website, www.drivinganddementia.ca to view **alternative transportation options** based on where you live in Canada, as well as additional information about licensing and reporting.

Public reporting of unsafe driving.

If you, or other family or friends, are concerned that the person with dementia's driving may be affecting their ability to drive safely, try talking to them about it. If they are not open to discussing your concerns, consider talking to the person with dementia's healthcare professionals. In addition, in many provinces and territories, the person with dementia's family and friends, as well as concerned citizens can report unsafe driving to the drivers' licensing authority. For more information, visit our website (www.drivinganddementia.ca) for province and territory specific details.

Requirements for healthcare professionals to report a dementia diagnosis

All provinces and territories require some form of reporting by healthcare professionals of medical conditions that affect driving. Dementia is one such health condition that could affect driving ability. In many cases, healthcare professionals have a duty to make this report. For more province and territory specific information, please visit www.drivinganddementia.ca.

What to expect in a comprehensive driving evaluation

To determine if the person with dementia can continue driving and if so, to what extent, the driver's licencing authority in most provinces and territories may request that the person with dementia take a comprehensive driving evaluation, which is sometimes called a functional assessment. It typically includes two parts: an in-office evaluation and an on-road driving evaluation. For more province and territory specific information, please visit the Driving and Dementia Roadmap website.

Appeal process for drivers' licence suspensions

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

Alternative transportation options

You can provide support for the person with dementia by helping them come up with an alternative transportation plan (page 13 of the Driving and Dementia Roadmap Package of Resources). For specific ideas based on where the person with dementia lives in Canada, visit our website at www.drivinganddementia.ca.

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