



DRIVING & DEMENTIA ROADMAP

For family/friends caring for a person with dementia who is no longer 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



CENTRE FOR AGING
+ BRAIN HEALTH
INNOVATION
Powered by Baycrest

Baycrest



Sunnybrook
HEALTH SCIENCES CENTRE



UNIVERSITY OF TORONTO
FACULTY OF MEDICINE

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.

Table of Contents

<u>What is the Driving and Dementia Roadmap?</u>	1
<u>Understand how dementia can affect your driving</u>	2
<u>Having conversations to adjust to no longer driving</u>	4
<u>Getting around without driving</u>	6
<u>Dealing with emotions</u>	9
<u>Learning about licensing, reporting and transportation options</u>	19
<u>Acknowledgements</u>	20

What is the Driving and Dementia Roadmap?

- It is a resource to help you understand why it was important that the person with dementia stopped driving.
- It will give you ideas on how to help the person with dementia get around now that they are no longer driving.
- It will show you how you can help the person with dementia continue to lead a fulfilling life now that they have stopped driving.
- The information is from a free website for people with dementia as well as their family/friend carers and healthcare providers:
www.drivingwithdementia.ca
- The website was developed by a team of researchers in consultation with people with dementia and family/friend carers.



Understanding why it was necessary to give up driving

Although there are different types of dementia, all types negatively affect the person with dementia's driving by damaging various brain functions that are essential for safe driving. Also, because dementia is progressive, the symptoms get worse over time, making the person with dementia's driving less and less safe. Giving up driving is necessary to keep the person with dementia, as well as others on the road, safe.

See ways dementia makes driving unsafe

Many people with dementia are able to drive safely for some time after diagnosis. However, research shows that the longer a person with dementia continues to drive after diagnosis, the chances of getting into an accident increase. The changes the person with dementia is experiencing are much more complex than the changes people without dementia experience like eyesight issues and slower reaction time. As a result, the person with dementia is not the best person to assess their own driving ability. For example, as you have likely already identified, the person with dementia may:

- Have lost a range of brain functions that are necessary to make the kind of fast decisions and reactions necessary to drive safely.
- No longer be able to make new memories or learn new skills. It's common that they will not recognize driving difficulties or be able to develop new behaviours to adjust to these changes.

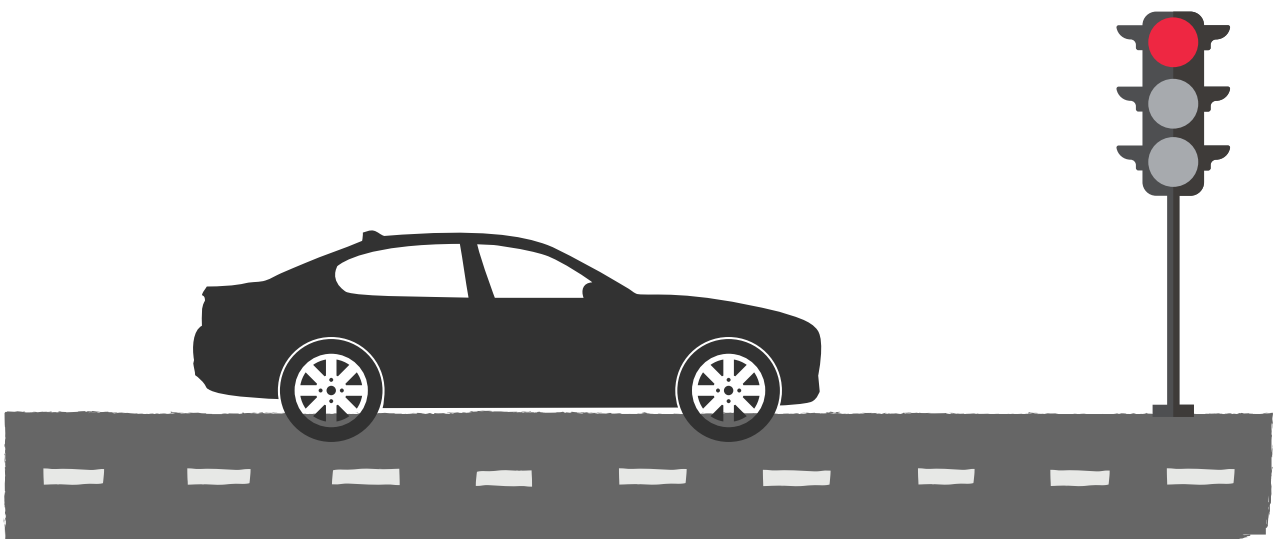
Inevitably dementia makes driving unsafe in numerous ways such as:

- 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)

Video available on the Driving and Dementia Roadmap website

On the Driving and Dementia Roadmap website (www.drivinganddementia.ca), watch the following video to see how dementia affects driving.

- **"Driving with Alzheimer's Disease"** by USDOTNHTSA (U.S. Department of Transportation's National Highway Traffic Safety Administration)



Having conversations to adjust to no longer driving

Although the person with dementia has stopped driving, discussions about how to help them maintain their independence should go on indefinitely. Keep the conversation going by having brief but frequent discussions.

Try these tips

Try these tips to make discussions about giving up driving productive:

- Include others on an ongoing basis: The person with dementia's family members and friends, as well as professionals like their doctor, lawyer, financial planner, and care manager can all provide support for both you and the person with dementia on an ongoing basis.
- Gauge the best times to talk: Pick times that work well for the person with dementia's attention span and energy level. If the person with dementia becomes angry or agitated, gently end the conversation and start it up again later.
- Be open: Make sure the person with dementia feels comfortable sharing their thoughts and feelings. Listen and appreciate what the person with dementia thinks, as well as what others involved in the discussion have to say.
- Be prepared for emotional reactions: Be ready for reactions like anger and/or sadness, which may seem especially extreme. Keep in mind that this may in part be due to the memory and insight issues that are often associated with dementia.

Here's what a family member has 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."

Try this worksheet

On the Driving and Dementia Roadmap website (www.drivinganddementia.ca) and in the Driving and Dementia Roadmap Package of Resources, the following worksheet is available to help you figure out all of the people who could provide support:

- **"Not going it alone: Who can offer support?"** Refer to page 15 of the Driving and Dementia Roadmap Package of Resources.

Videos available on DDR website

On the Driving and Dementia Roadmap website (www.drivinganddementia.ca), the following video are available:

1. **"Supportive conversation"** by Alzheimer's Society. See a wife having a supportive conversation about giving up driving with her husband who has dementia.
2. **"Starting the conversation - Changed conditions ahead - Dementia and driving in Victoria"** by Alzheimer's Australia Vic. See various family/friend carers having conversations about giving up driving with people with dementia. Although some of the content is specific to Australia, most of the ideas are helpful no matter where you live.

Getting around without driving

Help the person with dementia to still get around and to maintain their independence by working with them to develop a transportation plan. When developing the plan, it's important to involve the person with dementia so that they feel respected and have a sense of control. The plan should include everything from necessary appointments like the doctor and dentist to other important and fun activities like exercising and going to social events.

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."

Develop a transportation plan

Driving is certainly a convenient way to get around, and yet it is not the only way. Use the transportation planning worksheet (refer to page 13 in the Driving and Dementia Roadmap Package of Resources) or the driving activities worksheet (page 11 in the Driving and Dementia Roadmap Package of Resources) to help you plan how not to compromise the person with dementia's physical and social benefits now that they are no longer driving. They were produced by The Hartford.

Brainstorm together the best way for the person with dementia to do all the things they need to do and like to do. For instance, the person with dementia may be able to change certain routines like instead of visiting the bank, set up automatic bill payments. The transportation options will depend on the person with dementia's specific situation. Ideas include:

- Family and friends
- 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)
- Members of religious organizations

In addition, refer to the Driving and Dementia Roadmap website to learn about alternative transportation options for where the person with dementia lives.

Video available on the Driving and Dementia Roadmap website

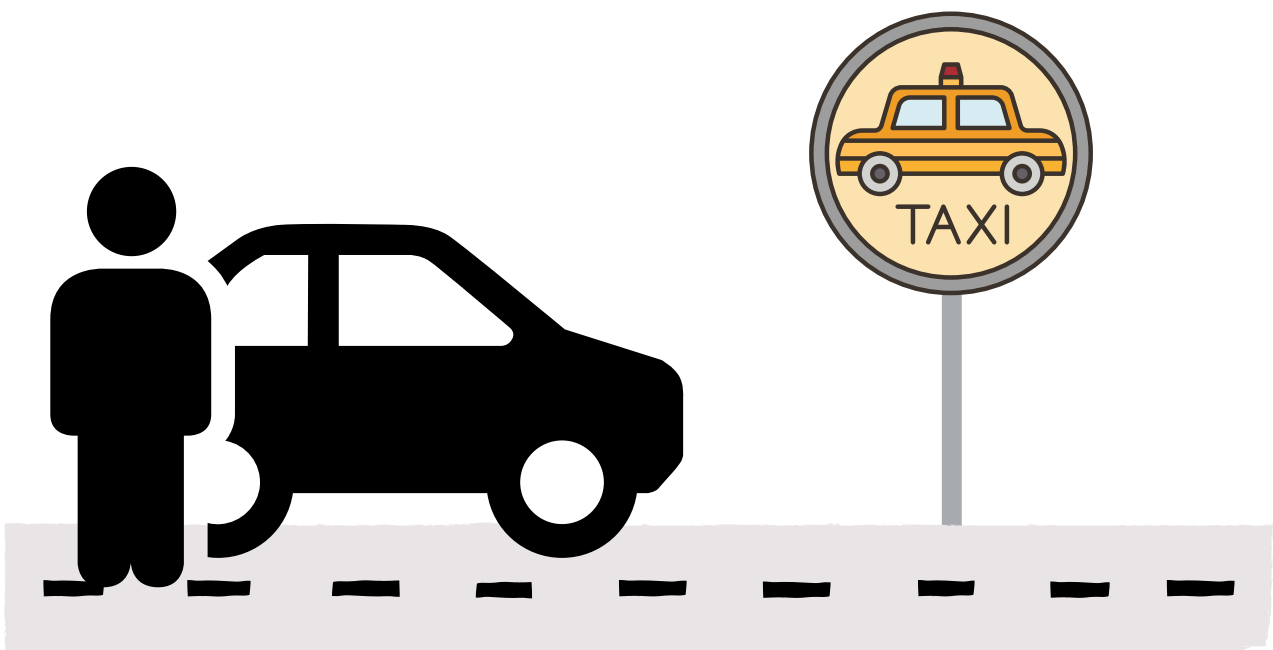
On the Driving and Dementia Roadmap website (www.drivinganddementia.ca), the following video are available:

- **"Staying active, mobile and connected - Changed conditions ahead - Dementia and driving in Victoria"** by Alzheimer's Australia Vic. See various family/friend carers providing helpful ideas about how to transition to no longer driving. Although some of the content is specific to Australia, most of the ideas are helpful no matter where you live.

Try these worksheets

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

- **"Getting there: Using alternative transportation."** Refer to page 15 of the Driving and Dementia Roadmap Package of Resources.
- **"Driving activities: When, where, why?"** Refer to page 11 of the Driving and Dementia Roadmap Package of Resources.



Dealing with emotions

The loss of driving is a major life event that affects both the person with dementia and you. Even after the person with dementia has made the transition to non-driving, you may both continue to experience a wide range of emotions. However, emotions can be unpredictable and everyone is different. Although some people with dementia have very strong negative feelings about having to give up driving, others are accepting or relieved. Likewise, you may find yourself having both negative and positive feelings about it.

Recognizing 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 various aspects of identity and lifestyle such as:

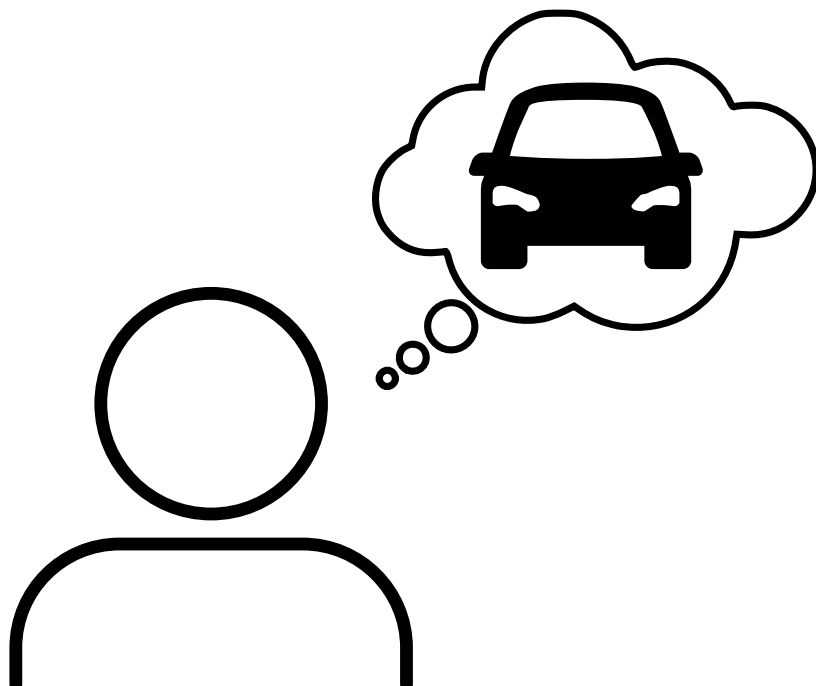
- Sense of freedom, independence, and control
- Work and livelihood
- Friendships and other forms of connection like attending faith services
- Roles like taking care of a spouse, children, or aging parents
- Enjoyment like a drive in the countryside
- Feeling youthful

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 emotional impact on me

Whatever specific emotions you are feeling, 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 like:

- Loss, sadness, grief: regarding that no longer driving is one of many ways that the person with dementia will eventually lose their independence. Stopping driving may represent the loss of your dreams for the future.
- Fear, anxiety: regarding how the person with dementia will get around and how everything will get done, as well as how to cope with both the person with dementia's and your own emotions around this major life change.
- Frustration, anger, guilt: regarding that, the transition from driver to a passenger was challenging and the person with dementia is experiencing intense sadness, withdrawal, anger, or blaming.
- Discouraged, irritated: regarding that although the person with dementia has given up driving, they are in denial and feel that they should still be allowed to drive.
- Overwhelmed: regarding the added responsibilities for all the driving; either you always have to be the driver or you have to make all the driving arrangements.

2) Be kind to yourself

Once you have identified what you are feeling—for example, sadness or anxiety or anger?—then to cope, don't try to avoid the emotion by simply continuing as if you aren't having these feelings. Instead, allow yourself to feel the emotion. For example, to heal feelings of loss, rather than denying yourself grief, 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) Find new ways to maintain your activities and connections with friends

In addition to finding new ways to get around (e.g., public transport), meet with friends in your home, let others drive you, and the person with dementia to activities.

4) Don't feel you have to go 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 might be able to provide valuable support.
- Talk to your doctor or other health and mental health care professionals.
- Communicate with other people who are taking care of a person living with dementia through in-person support groups or online forums.
- Use this circle of support worksheet (page 15 of the Package of Resources) to help build a support network. It was produced by The Hartford.
- Contact your local Alzheimer Society organization.

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."

5) Try to be empathetic

If you are finding it difficult to handle how the person with dementia is adjusting to no longer driving, empathy can help. Recognizing the emotions of the person with dementia 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 various aspects of their 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, the loss of 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 are often part of dementia. The lack of insight into the dangers of driving with dementia makes it especially hard for the person with dementia 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

By understanding the range of emotions the person with dementia may be feeling, you will be in a better position to help them adjust to life without driving. 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. No longer driving may represent yet another blow in terms of their dementia diagnosis and that they will gradually lose many abilities. They may also feel a loss of pride in ownership that can come from owning a valued possession like a car.
- **Fear, anxiety:** regarding what their life will be like without driving. For example, they may worry about how they will get around for not only practical reasons but for socializing and enjoying life.
- **Guilt:** regarding that all the driving responsibilities now fall on 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 feeling that they no longer have any control over when they can come or go.
- **Embarrassment:** regarding having to admit to others that they can no longer drive.
- **Agitated, irritated:** regarding not being able to express their feelings as the dementia progresses or not fully understanding that they have stopped driving. They may just have a generalized feeling that something is wrong.
- **Denial:** regarding they are no longer able to drive safely and it was time for them to give it up. This may be because they can't remember unsafe driving incidents or lack of insight into their loss of driving skills. This can lead to insisting that they should be allowed to drive.

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.

Here's what some family members have to say:

"Remain patient. You may have to explain several times the reason the family member 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 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 and volunteering with the Alzheimer Society can provide opportunities to socialize and help others, restoring their feelings of self-worth.. Also, work through the circle of support worksheet (page 15 on the Driving and Dementia Roadmap Package of Resources) to help identify who else they can turn to for support. It was produced by The Hartford.

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."

Try this worksheet

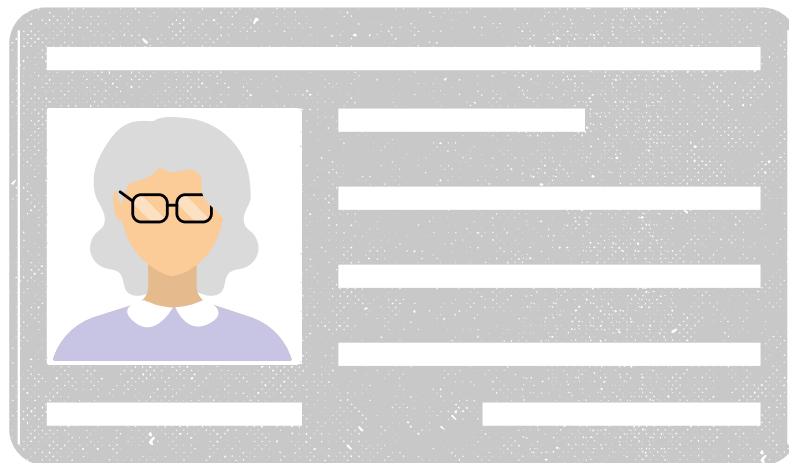
On the Driving and Dementia website (www.drivinganddementia.ca) and in the Driving and Dementia Roadmap Package of Resources, the following worksheet is available.

- "Not going it alone: who can offer support?" can help you identify who can provide support. Refer to page 15 of the Package of Resources.



Learning about licensing, reporting and transportation

If a drivers' licensing authority suspended the person with dementia's licence, they should have stopped driving immediately. Likewise, if a healthcare professional told the person with dementia that they were no longer safe to drive, they should have stopped immediately. If they continue driving, they put themselves and others at risk. In addition, if they get into an accident, there is a chance that their insurance will not cover any injuries or damage. To get around without driving, work with the person with dementia and their doctor to come up with an alternative transportation plan (see page 13 in the Driving and Dementia Roadmap Package of Resources). Please visit www.drivinganddementia.ca to view some specific ideas based on where the person with dementia lives.



Acknowledgements

Research Team

Principal Investigators:

Gary Naglie (Baycrest Health Sciences, University of Toronto)

Mark Rapoport (Sunnybrook Health Sciences, University of Toronto)

Research Associates

Elaine Stasiulis (Baycrest Health Sciences/Rotman Research Institute)

Sarah Sanford (Baycrest Health Sciences/Rotman Research Institute)

Co-Investigators

Michel Bédard (Lakehead University)

Patricia Belchior (McGill University)

Anna Byzsewski (University of Ottawa)

Alexander Crizzle (University of Saskatchewan)

Isabelle Gélinas (McGill University)

Shawn Marshall (University of Ottawa)

Barbara Mazer (McGill University)

Paige Moorhouse (Dalhousie University)

Anita Myers (University of Waterloo)

Janice Polgar (Western University)

Michelle Porter (University of Manitoba)

Holly Tuokko (University of Victoria)

Brenda Vrkljan (McMaster University)

Stephanie Yamin (Saint-Paul University)

Research Assistant

Sharan Mundy (Baycrest Health Sciences/Rotman Research Institute)

Plain Language Writer

Carolyn Wilby (Clear Language @ Work Inc.)

Funders:

The DDR was developed as part of the work of Team 16 of the Canadian Consortium on Neurodegeneration in Aging (CCNA). CCNA is supported by a grant from the Canadian Institutes of Health Research (CIHR) with funding from several partners. Other funders contributing to this project include the Centre for Aging and Brain Health Innovation (CABHI) and the Ontario Ministry of Health Academic Health Sciences Centres (AHSC) Alternative Funding Plan (AFP) Innovation Fund. Gary Naglie was supported by the George, Margaret and Gary Hunt Family Chair in Geriatric Medicine, University of Toronto. Research funding for Mark Rapoport was provided by Sunnybrook Psychiatrists.