



# “Life Doesn’t Stop”: Using the Driving and Dementia Roadmap (DDR) to Support Driving Cessation

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ASC-CCNA Brain Xchange  
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Baycrest



CCNA  
Canadian Consortium  
on Neurodegenerative  
Disease in Aging



CCNV  
Consortium canadien  
en neurodégénérescence et  
associée du vieillissement



# **Land Acknowledgement**

# Our Research Team

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- Alzheimer Society of Manitoba
- Alzheimer Society of Niagara Region
- Alzheimer Society Nova Scotia
- Alzheimer Society of Saskatchewan
- Alzheimer Society Southwest Partners
- Alzheimer Society of Toronto

# Overview

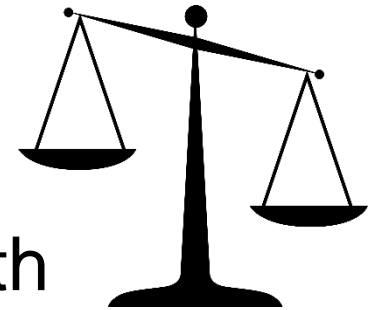
1. Background: driving and dementia
2. Development of the Driving and Dementia Roadmap (DDR)
3. Tour of the DDR
4. DDR early evaluation results
5. Next steps



# **Background: Driving and Dementia**

# Driving Cessation & Dementia

- Driving cessation is a complex, challenging and emotion-laden process for people living with dementia, their family/friend carers and their healthcare providers
  - Making the decision to stop driving
  - Transitioning to non-driving
- Requires a balancing of personal and public safety with psychosocial consequences



# COSID – People with Dementia Driving

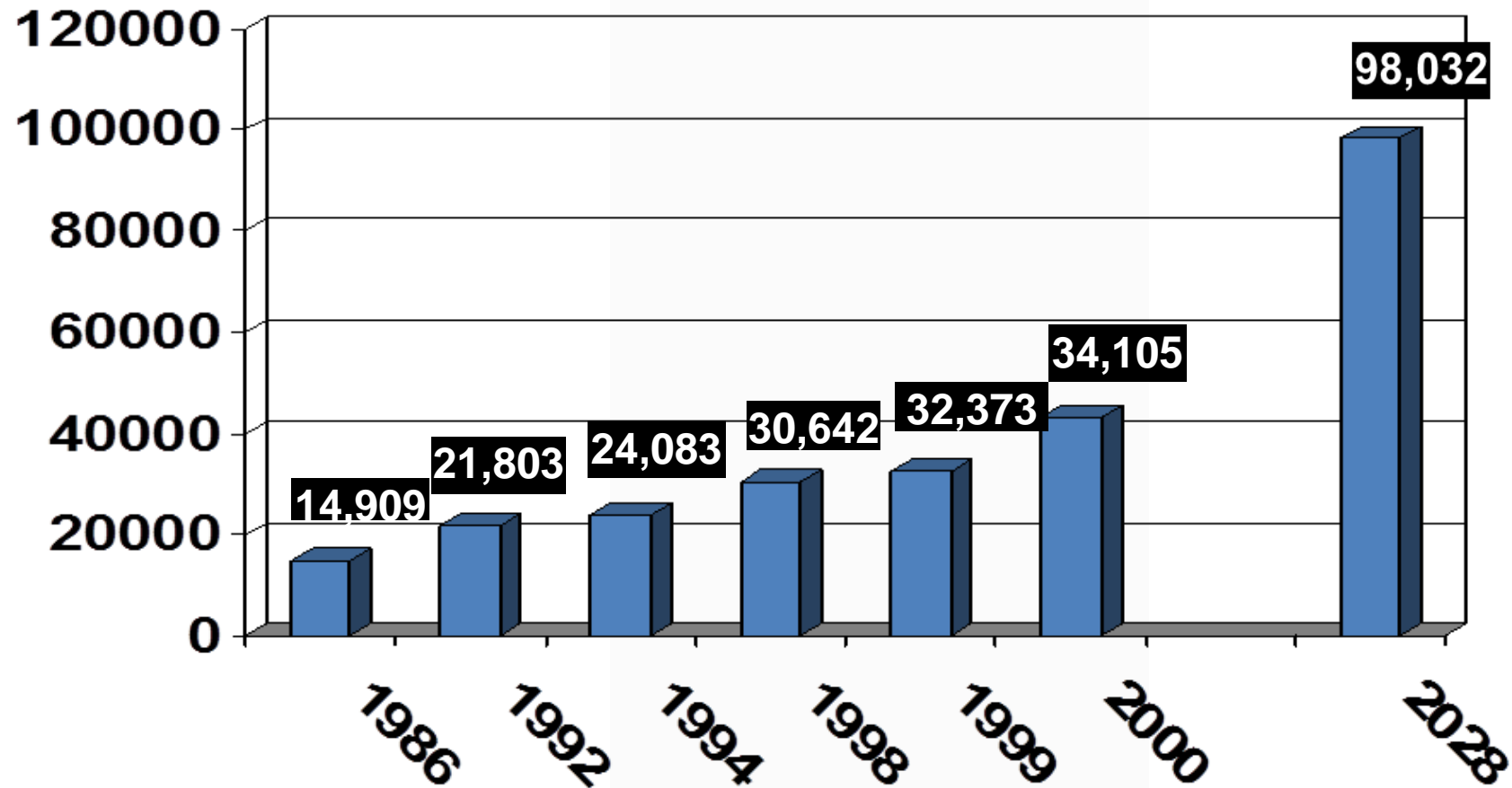
- Canadian Outcome Study in Dementia – mild and moderate dementia
- 28% driving at baseline

Time Period	% Still Driving
2 Years	~50%
3 Years	~25%

Herrmann et al., CMAJ 2006



# Estimated Numbers of Drivers with Dementia in Ontario



# Driving Performance with Dementia

- More problems with road rules, lane maintenance, lane changing, turning, maintaining road speed, stopping appropriately and avoiding collisions
- Less attention and slower decision-making
- Driving performance decreased with increasing dementia severity
- 6/10 studies found that drivers with dementia crashed more often than controls (~2x to 10x)
- 15-65% failed on-road driving assessment

Jacobs et al., J Neurol 2017

Man-Son-Hing et al., JAGS 2007

Chee et al., Am J Geriatr Psychiatry 2017

# On-Road Driving Performance Pooled Data

	Controls (n=102)	V. Mild AD (n=73)	Mild AD (n=61)
Clear Pass	79%	49%	37%
Marginal	19%	38%	31%
<i>Fail</i>	<i>2%</i>	<i>13%</i>	<i>32%</i>

Duchek et al., JAGS 2003; Ott et al., Neurology 2008

# Health and Psychosocial Outcomes of Driving Cessation

- Less social engagement and out of home activity
- More depressive symptoms
- Poorer general health
- Poorer functional status
- Greater cognitive decline
- Greater long term care placement
- Greater risk of mortality

# Emotional Impact of Driving Cessation



- People with dementia
  - Denial
  - Grief/sadness
  - Loss of identity, self-esteem
  - Depression
  - Anger directed at family members & healthcare providers

Sanford et al., Dementia, 2019

Sanford et al., Clinical Gerontologist, 2020

# Emotional Impact of Driving Cessation

## ➤ Family/Friend Carers

- Loss, sadness, grief
- Fear, anxiety
- Frustration, anger, guilt



## ➤ Healthcare providers

- Stress
- Remorse
- Emotional strain

# Challenges of Driving Cessation

- Lack of understanding about the relationship between dementia and driving
- No one likes to talk about driving cessation issues (including healthcare providers)
- Lack of training and knowledge among healthcare providers about assessing fitness to drive, supporting quality of life post-cessation
- Few established interventions
- Resources difficult to access and their credibility hard to determine

Sinnott et al., PLoS One, 2018

Silverstein & Turk, Gerontol Geriatr Educ, 2015

Stasiulis et al, Gerontologist, 2020



# **Development of the Driving and Dementia Roadmap**





# Project Aim

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- To develop a resource to support people with dementia, family/friend carers and healthcare providers in the decision-making and transitioning to non-driving

# Systematic Reviews

REVIEW ARTICLE

International Journal of  
Geriatric Psychiatry

## A systematic review of intervention approaches for driving cessation in older adults

Mark J. Rapoport<sup>1,4</sup>, Duncan H. Cameron<sup>1,2</sup>, Sarah Sanford<sup>2</sup>, Gary Naglie<sup>2,3,5,6</sup> on behalf of the Canadian Consortium on Neurodegeneration in Aging Driving and Dementia Team

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Correspondence to: Dr. M. J. Rapoport, E-mail: mark.rapoport@sunnybrook.ca

International Psychogeriatrics (2019), 31:3, 393–415 © International Psychogeriatric Association 2018  
doi:10.1017/S1041610218000972

## Interventions that support major life transitions in older adulthood: a systematic review

Brenda Vrkljan,<sup>1</sup> Ariane Montpetit,<sup>2</sup> Gary Naglie,<sup>3</sup> Mark Rapoport<sup>4</sup> and Barbara Mazer<sup>5,6</sup>

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Journals of Gerontology: Psychological Sciences  
cite as: *J Gerontol B Psychol Sci Soc Sci*, 2018, Vol. 73, No. 7, 1185–1189  
doi:10.1093/geronb/gbw158  
Advance Access publication December 26, 2016

OXFORD

Brief Report

## Meta-analysis of Driving Cessation and Dementia: Does Sex Matter?

Nicolette Baines,<sup>1</sup> Bonnie Au,<sup>2</sup> Mark J. Rapoport,<sup>1,3,4</sup> Gary Naglie,<sup>5,6</sup> and Mary C. Tierney<sup>1,2,7</sup>

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Decision Editor: Rob G. Knight, PhD

## SYSTEMIC REVIEW / META-ANALYSIS

## Psychotherapeutic Interventions for Dementia: a Systematic Review



Paweena Sukhawathanakul, PhD<sup>1</sup>, Alexander Crizzle, PhD<sup>2</sup>, Holly Tuokko, PhD<sup>3</sup>, Gary Naglie, MD<sup>4,5,6</sup>, Mark J. Rapoport, MD<sup>7</sup>

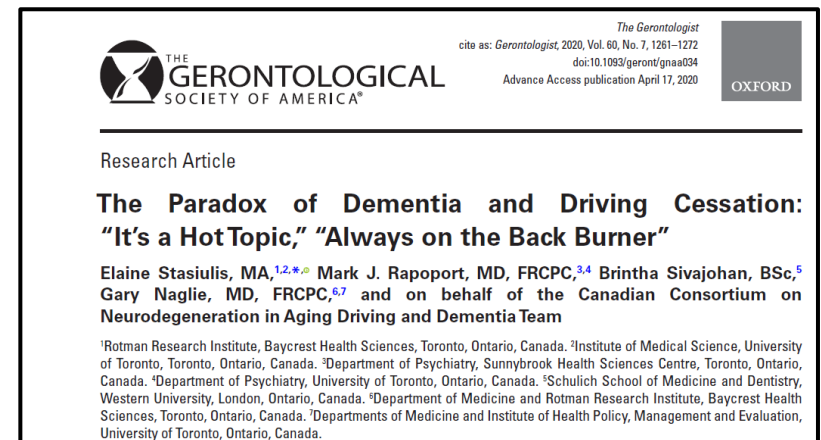
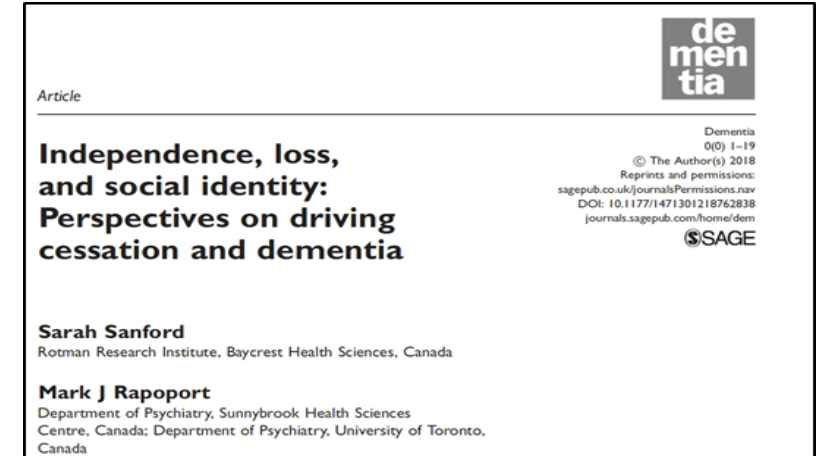
<sup>1</sup>Centre on Aging, University of Manitoba, Winnipeg, MB; <sup>2</sup>School of Public Health, University of Saskatchewan, Saskatchewan, MB; <sup>3</sup>Institution of Aging and Lifelong Health, University of Victoria, Victoria, BC; <sup>4</sup>Department of Medicine and Rotman Research Institute, Baycrest Health Sciences, North York, ON; <sup>5</sup>Department of Research, Toronto Rehabilitation Institute-University Health Network, Toronto, ON; <sup>6</sup>Department of Medicine and Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, ON; <sup>7</sup>Department of Psychiatry, Sunnybrook Health Sciences Centre, University of Toronto, Toronto, ON

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<https://doi.org/10.5770/cgj.24.447>

# Qualitative Studies

- Explored key stakeholders' perspectives of driving cessation and dementia
- Interviews and focus groups with 10 healthcare providers, 6 organizational reps, 13 family caregivers, 2 persons with dementia
- Examined factors relevant to effective implementation of a driving resource
- Interviews with 15 AS staff members in 4 provinces

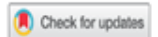


# Meta-synthesis of Qualitative Studies

- Meta-synthesis of qualitative studies on key informant subjective experiences of driving cessation and dementia
- Included 9 studies published between 2002 and 2016

CLINICAL GERONTOLOGIST  
<https://doi.org/10.1080/07317115.2018.1483992>

 Routledge  
Taylor & Francis Group



## Subjective Experiences of Driving Cessation and Dementia: A Meta-Synthesis of Qualitative Literature

Sarah Sanford PhD<sup>a</sup>, Gary Naglie MD<sup>a,b,c,d</sup>, Duncan H. Cameron MSc<sup>e</sup>, Mark J. Rapoport MD<sup>f,g</sup>, on behalf of the Canadian Consortium on Neurodegeneration in Aging Driving and Dementia Team

<sup>a</sup>Rotman Research Institute, Toronto, Canada; <sup>b</sup>Department of Medicine, Baycrest Health Sciences, Toronto, Canada; <sup>c</sup>Department of Medicine and Institute of Health Policy, Management and Evaluation, University of Toronto, Toronto, Canada; <sup>d</sup>Research Department, Toronto Rehabilitation Institute-University Health Network, Toronto, Canada; <sup>e</sup>Department of Psychology, Neuroscience & Behaviour, McMaster University, Hamilton, Canada; <sup>f</sup>Department of Psychiatry, Sunnybrook Health Sciences Centre, Toronto, Canada; <sup>g</sup>Department of Psychiatry, University of Toronto, Toronto, Canada

# Key Findings and Implications

- Perceived lack of education and resources for advanced planning and decision-making about driving cessation and the transition to non-driving
- Facilitating discussions about driving cessation are critical for early planning and promoting shared decision-making



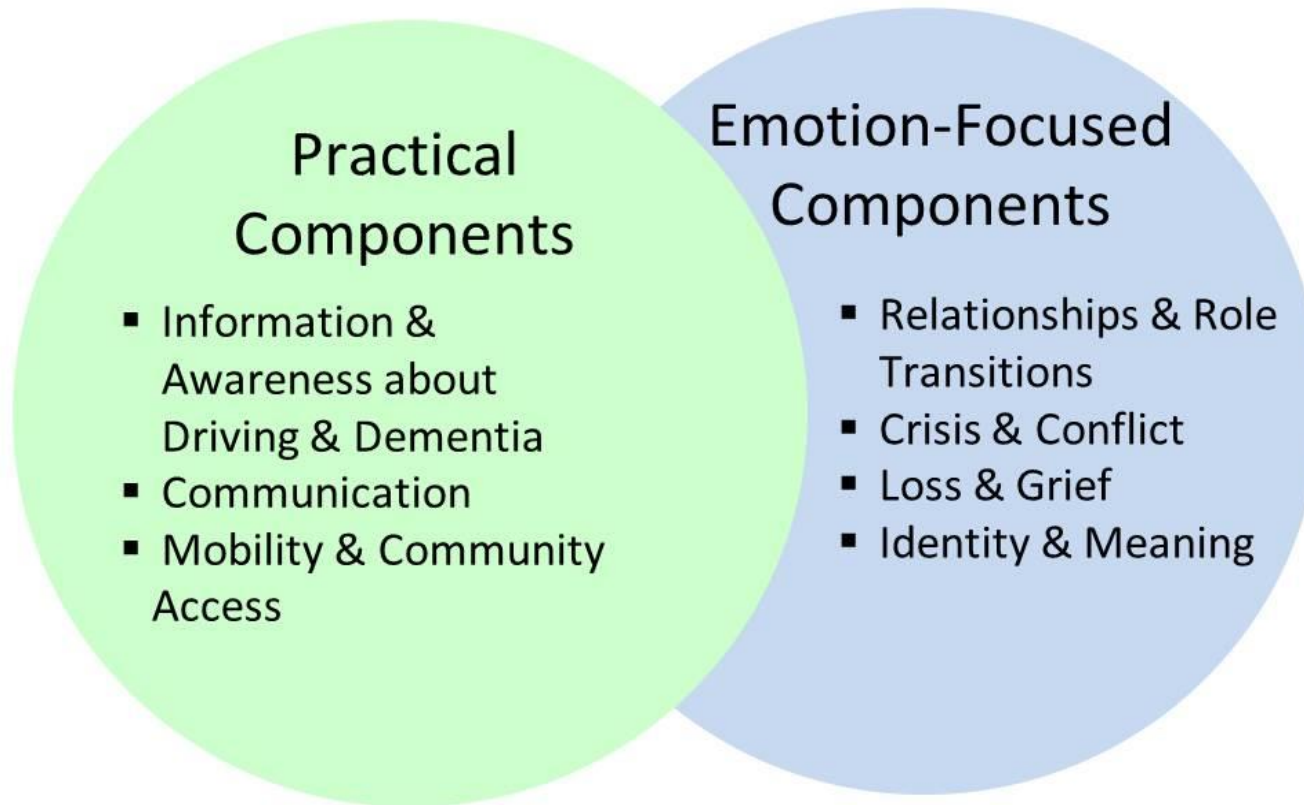
# Key Findings and Implications

- Addressing the emotional effects of driving cessation are as important as attending to the practical aspects (e.g., transportation planning)

*“The trauma of losing her vehicle, the use of her vehicle was as traumatic as losing my dad. It was like losing a spouse....” (Family Carer)*

- Family/friend carers need support in their role of maintaining purpose, roles and social participation of people with dementia

# Driving and Dementia Intervention Framework (DD-IF)



# Review of Resources & Tools

- Assembled resources and tools
  - Identified and assessed publically available resources and tools that address driving cessation
  - Assessment based on evidence base, relevance and usability
  - From a total of 75 tools reviewed, 24 tools were selected
- Curated the tools and resources to align with the Driving and Dementia Intervention Framework



# Advisory Group Engagement

- 4 people living with dementia and 4 family carers
- Recruited with help from the Murray Alzheimer Research and Education Program (MAREP)
- Provided on-going feedback on DDR's content and design

# Feedback from Healthcare Professionals & Driving Authority Representative

- Geriatric psychiatrist, occupational therapist and manager (driving authorities)
- Provided feedback on the healthcare professional portal

# Other Contributors

- Plain language writer with experience developing educational content for people with dementia
- Web developers
- Graphic designers



# **DRIVING & DEMENTIA ROADMAP**



Support for the driving with dementia journey

**I have dementia...**

and I am still driving.

and I am no longer driving.

**I am a family/friend caring for...**

a person with dementia who is still driving.

a person with dementia who is no longer driving.

**I am a provider who is...**

a healthcare professional.



Support for the driving with dementia journey



I have dementia...

and I am still driving.

and I am no longer driving.

I am a family/friend caring for...

a person with dementia who is still driving.

a person with dementia who is no longer driving.

I am a provider who is...

a healthcare professional.



# Person with Dementia Still Driving

I have dementia >

I am a family/friend caring for... >

I am a provider >

I have dementia and I am still driving. I am interested in:



Understanding how dementia can affect my driving

Recognizing when it becomes unsafe to drive

Getting help deciding to stop driving

Getting around without driving

Dealing with my emotions

Learning about licensing and reporting

I have dementia and I am still driving. I am interested in:

## Sections

- Understanding how dementia can affect my driving
- Recognizing when it becomes unsafe to drive
- **Getting help deciding to stop driving**
- Getting around without driving
- Dealing with my emotions
- Learning about licensing and reporting

## Getting help deciding to stop driving

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

### > Talk to someone you trust

### > Talk to your doctor

### ∨ Try these worksheets

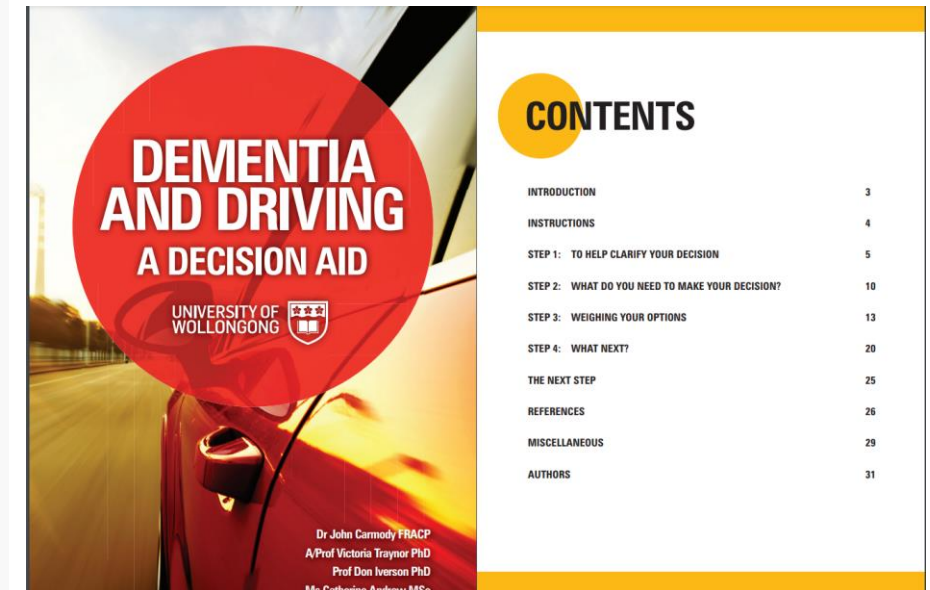
For help deciding when is the right time to give up driving, click on on the titles below. After you review each worksheet, when you close the worksheet's web page, it will automatically take you back to here.

- **Dementia and Driving – A Decision Aid** - produced by the University of Wollongong, Australia.
- **Warning Signs for Drivers with Dementia** produced by The Hartford.
- **Agreement with my Family about Driving** produced by The Hartford.

For help coming up with ways to get around when you are no longer able to drive, click on the titles below. Some parts of these worksheets may not be helpful if you live in a rural community.

- **Getting There: Using Alternative Transportation** produced by The Hartford.
- **Driving Activities: Where, When and Why?** produced by The Hartford.

# Getting help deciding to stop driving







**Support for the driving with dementia journey**

**I have dementia...**

and I am still driving.

and I am no longer driving.

**I am a family/friend caring for...**

a person with dementia who is still driving.

a person with dementia who is no longer driving.

**I am a provider who is...**

a healthcare professional.

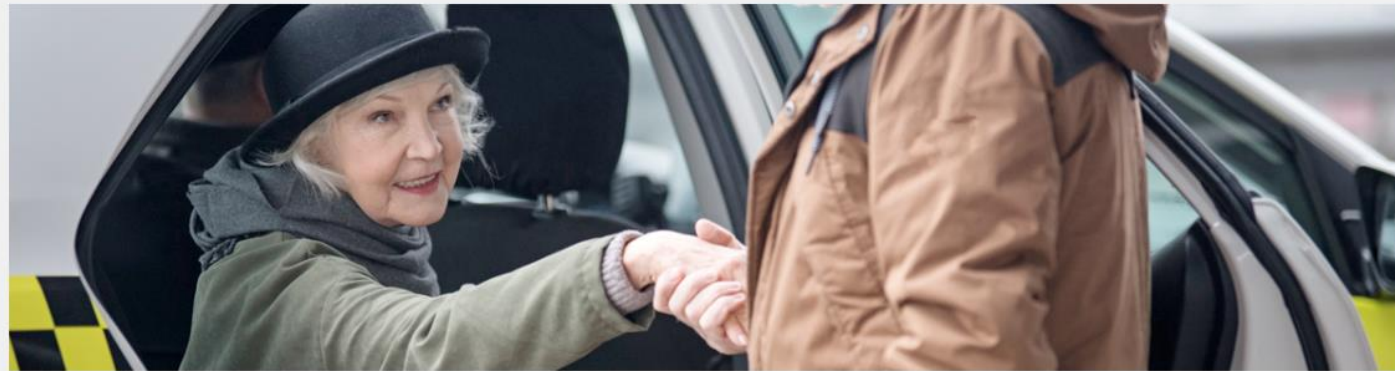
# Person with Dementia No Longer Driving

I have dementia >

I am a family/friend caring for... >

I am a provider >

I have dementia and I am no longer driving. I am interested in:



Understanding why it was necessary to stop driving

Getting around without driving

Dealing with my emotions

Learning about licensing and reporting

I have dementia and I am no longer driving. I am interested in:

### Sections

- Understanding why it was necessary to stop driving
- **Getting around without driving**
- Dealing with my emotions
- Learning about licensing and reporting

### Getting around without driving

Think of all the places you go to and then see if any of these options would work for getting there:

- Lifts from family and friends
- Carpooling
- Public transit
- Community organizations that offer driver services
- Taxis
- Ridehailing (e.g., Uber, Lyft)
- Retirement residences with van service
- Lifts from members of your religious organization

Consider changing some of your routines with the support 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 grocery and pharmacy delivery services, as well as services like Meals-on-Wheels.
- Instead of going out to services like the hairdresser or doctor, arrange for home visits.

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

- "People are there to help and they like to help. It makes them feel good to help. If you rely on people a little more it can actually be a good thing. It can bring you closer together."

[> Watch this video](#)

[> Try these worksheets](#)

# Getting around without driving

## GETTING THERE: USING ALTERNATIVE TRANSPORTATION



When looking for alternative transportation, you need to explore all options - from informal arrangements with relatives and friends, to formal public services. You can use this worksheet, along with the questions on the back side, as you explore all your transportation options.

Transportation Alternatives	Telephone	Availability, Destination (day, time, route)	Cost	Notes (pros & cons)
Family Members:				
Friends:				
Demand-responsive Services:				
Private Program Services:				
Taxi/Car Services:				
Mass Transit:				
Other Local:				





### Support for the driving with dementia journey

**I have dementia...**

and I am still driving.

and I am no longer driving.

**I am a family/friend caring for...**

a person with dementia who is still driving.

a person with dementia who is no longer driving.

**I am a provider who is...**

a healthcare professional.

# Family/Friend Carer of PWD Still Driving

I have dementia >

I am a family/friend caring for... >

I am a provider >

I am a family/friend caring for a person with dementia who is still driving. I am interested in:



Understanding the importance of giving up driving

Recognizing when it becomes unsafe to drive

Having conversations about giving up driving

Transitioning and planning ahead

Dealing with emotions

Managing when the person with dementia won't stop driving

Learning about licensing and reporting

# Having conversations about giving up driving

I am a family/friend caring for a person with dementia who is still driving. I am interested in:

## Sections

- Understanding the importance of giving up driving
- Recognizing when it becomes unsafe to drive
- **Having conversations about giving up driving**
- Transitioning and planning ahead
- Dealing with Emotions
- Managing when the person with dementia won't stop driving
- Learning about licensing and reporting

## 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.

> [Have ongoing discussions about driving risk](#)

> [Try these worksheets](#)

∨ [Watch these videos](#)

See a wife having a supportive conversation about giving up driving with her husband who has dementia.



Source: Alzheimer's Society

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.



# Healthcare Professional

I have dementia >

I am a family/friend caring for... >

I am a provider >

I am a healthcare professional and I am interested in:



Understanding my role

Understanding dementia and driving risk

Recognizing challenges

Assessing fitness to drive

Having discussions and managing emotions

Providing support after driving cessation

Learning about reporting and licensing

# Assessing Fitness to Drive

I have dementia >

I am a family/friend caring for... >

I am a provider >

I am a healthcare professional and I am interested in:

## Sections

- Understanding my role
- Understanding dementia and driving risk
- Recognizing challenges
- **Assessing fitness to drive**
- Having discussions and managing emotions
- Providing support after driving cessation
- Learning about reporting and licensing

## Assessing fitness to drive

The inevitability of driving cessation in people with a neurodegenerative dementia makes it essential to assess fitness to drive by conducting an in-office assessment at various stages of disease progression. This is important for the safety of people with dementia and the public. Given that a range of complex factors can affect driving ability, it's important to gather information from different perspectives during the assessment. Equally important is that you base your decision on the sum of the findings, rather than just from a specific component of the assessment. In addition, after the assessment, you must follow legislative requirements for your province or territory regarding reporting unsafe driving. Learn what it means to use a comprehensive approach to inform your decision and follow these steps to conduct an in-office assessment.

> Use a comprehensive approach to inform your decision

Follow the steps below...

> Step 1: Assess the type of the dementia

▼ Step 2: Assess the functional impact of dementia

### Functional impact of dementia

Assess the functional impact of dementia because as the disease progresses, functional abilities decline that may affect driving ability.

Basic ADLs = dressing, transfers/mobility, toileting, showering, grooming (e.g., shaving, brushing teeth, combing hair, applying make-up), eating

IADLs = work/volunteer-related activities, medication management, financial management, shopping, meal preparation, use of technology, housework, hobbies

- If any basic activities of daily living are impacted **due to cognitive impairment**, the severity of the dementia has progressed to the point where they are no longer safe to drive.
- If 2 or more IADLs are impacted **due to cognitive impairment** (but no basic ADL impairment), it is likely that driving is impaired as well. If the person with dementia desires to continue driving, a comprehensive driving evaluation is strongly recommended.

> Step 3: Assess other medical and psychiatric co-morbidities

> Step 4: Take a driving history

> Step 5: Conduct a cognitive assessment

> Step 6: Conduct a physical and neurological examination

> Step 7: Interpret the findings

> Step 8: Formulate the next steps



I am a healthcare professional and I am interested in:

## Sections

- Understanding my role
- Understanding dementia and driving risk
- Recognizing challenges
- Assessing fitness to drive
- Having discussions and managing emotions
- Providing support after driving cessation
- **Learning about reporting and licensing**

## Learning about reporting and licensing

Most if not all provinces and territories require that people with dementia declare that they have a medical condition. This is because a medical condition can affect driving. In addition, most if not all motor vehicle insurance policies include a clause requiring people with dementia to tell their insurer that they have a medical condition because it can affect their driving. Find out more about dementia and drivers' licensing and reporting below.

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### > [Public reporting of unsafe driving](#)

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### ∨ [Requirements for healthcare professionals to report dementia diagnosis](#)

As a health condition that could affect driving ability, all provinces and territories require mandatory and/or discretionary reporting by healthcare professionals of a dementia diagnosis. In many cases, healthcare professionals have a duty to make this report. For more information, please click on the region where the person with dementia lives below.

Please note, in some cases, although the link below provides this information, it also includes other information. You will have to browse through the link.

In other cases because this information is not available, we have included a link to the drivers' licensing authority. This way, you can follow-up directly with the authority to find out more.

- [Alberta](#)
- [British Columbia](#)
- [Manitoba](#)
- [New Brunswick](#)
- [Newfoundland and Labrador](#)
- [Northwest Territories](#)
- [Nova Scotia](#)
- [Nunavut](#)
- [Ontario](#)
- [Prince Edward Island](#)
- [Quebec](#)
- [Saskatchewan](#)
- [Yukon](#)

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### > [What to expect in a comprehensive driving evaluation](#)

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### > [Licence suspension appeal process](#)

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# Learning about reporting and licensing

# Qualitative Implementation Evaluation

- To explore the DDR's acceptability, adaptability and preliminary benefits and limitations
- 6 Alzheimer Society(AS) organizations in 4 provinces (NS, Ont, Man, Alb)
- 19 AS staff, 8 current and former drivers with dementia, 13 family/friend carers

# Qualitative Implementation Evaluation – Preliminary Findings

- Reported high levels of acceptability; found the DDR “very, very useful”, “very enlightening” and “absolutely necessary”
- Brought deeper awareness and understanding about driving cessation, which impacted participants’ approach (e.g., more diligent about observing warning signs)

*“Its (DDR) helping me to monitor her more. I’m going to make sure that every few months that I either go in the car with her or follow her and talk to her about it on a regular basis.” (Family Carer)*

*“It (DDR) made me realize there’s an end to driving, somewhere in the future. Actually, I hadn’t even thought of it. Somewhere along the line, I know I’ve got to stop.” (PWD)*

# Qualitative Implementation Evaluation – Preliminary Findings

- Emotion-specific content provided insight about grief and loss, enabling family members to attend to the emotional ramifications and initiate conversations with empathy and patience
- Strategies to remain mobile after driving cessation brought relief and hope

*"It (DDR) gave me a little bit of hope that together as a team with my siblings, we can figure out a plan..." (Family Carer)*

# Exploring the DDR's Uptake and Impact

- Official launch in mid-October 2022
- Research questions:
  - How does the DDR get taken up (i.e., adopted and utilized)?
  - How does the DDR impact the way users approach and manage driving cessation?
- Methods:
  - Google Analytics
  - Surveys
  - Interviews

# Questions?

[www.drivinganddementia.ca](http://www.drivinganddementia.ca)

(Link will be active on Oct 18, 2022)

THANK YOU!

**Contact:**

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