

# Supporting Persons with Dementia Face the Decision – and Effects – of Hanging up the Keys



**CCNA Team 16: Driving and Dementia**  
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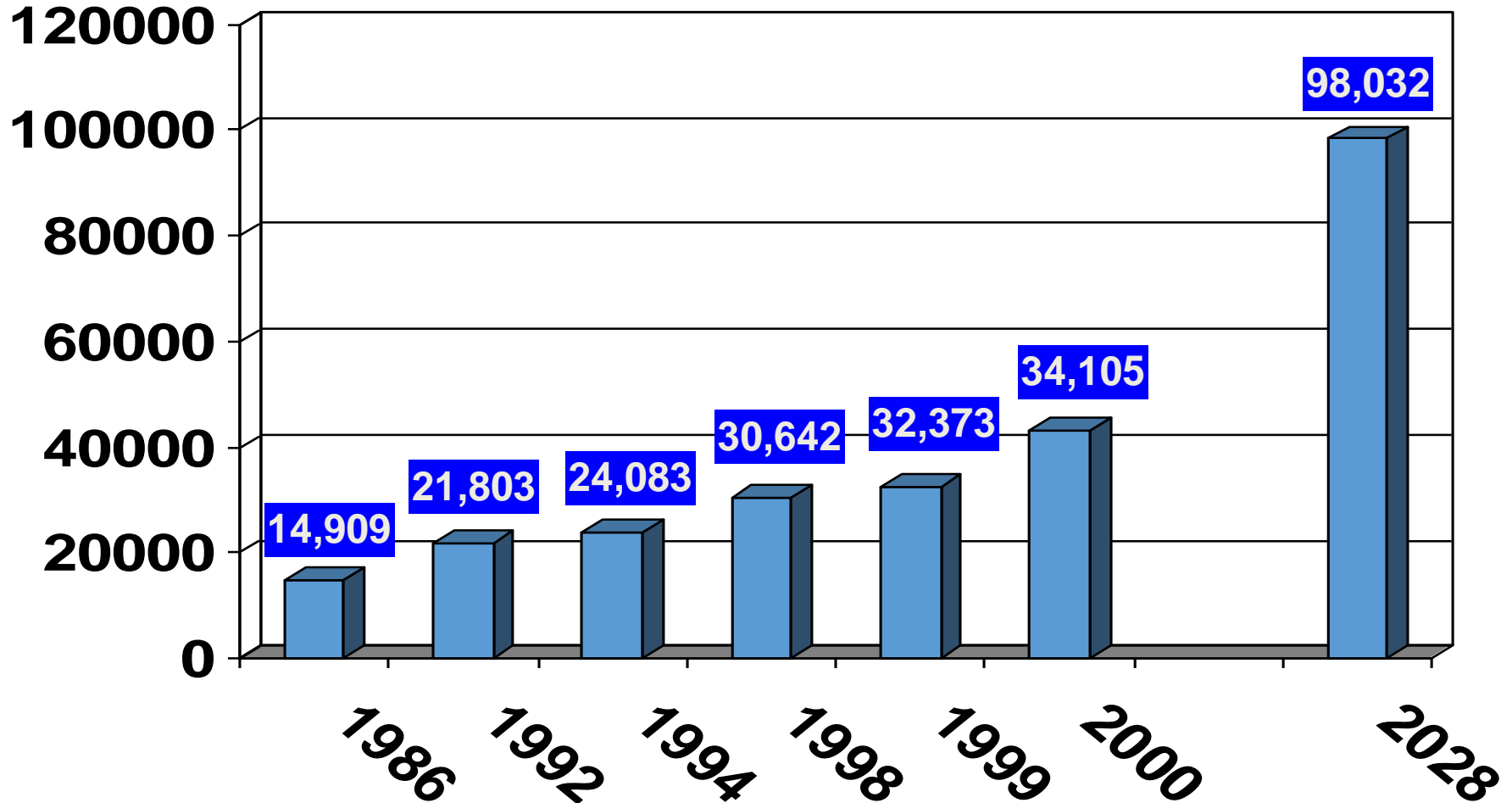
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1. Describe the challenges of driving cessation in people with dementia.
2. Outline the responsibilities and challenges healthcare/service providers (HCP) face in addressing these issues.
3. Discuss how the Driving Cessation in Dementia Framework and Toolkit (DCD-FT) will help HCPs support drivers with dementia and their families.

# Drivers with Dementia in Ontario



Hopkins et al. Can J Psychiatry 2004;49:434-8

- 17/17 studies of driver performance found that drivers with dementia performed significantly worse than controls
- 5/8 studies of crashes found that drivers with dementia crashed more often (2x – 11x) than controls



Man-Son-Hing et al. JAGS 2007;55:878-84

# What Does Driving Mean to Older Adults?

- Convenience
- Independence
- Autonomy
- Competence
- Freedom
- Personhood



- Greater dependency and loss of control
- Poorer functional status
- Less social engagement
- Poorer general health
- More depressive symptoms
- Greater cognitive decline
- Greater risk of mortality
- Greater nursing home placement

Chihuri et al. JAGS 2016;64:332-341

- Driving cessation becomes inevitable in people with dementia and represents a major life transition
- Decision-making about driving cessation and meeting post-driving cessation support needs are major challenges in dementia care





- **Reporting drivers with cognitive impairment**
  - In most Canadian provinces physicians are mandated to report medically impaired drivers
  - In July, 2018, Occupational Therapists and Nurse Practitioners will have new legislation regarding reporting in Ontario

- **Challenges**

- Lack of established intervention approaches to driving cessation
- Little accessible information about assessment process and how to support drivers as they transition to life post driving
- Physicians tend to avoid discussing issue of driving cessation due to concerns of negative impact on their relationship with patients

- **Objective of Driving Cessation in Dementia Framework and Toolkit (DCD-FT)**
  - To address gap in evidence-based interventions that support persons with dementia and their family caregivers in decision-making about driving and the transition to non-driving

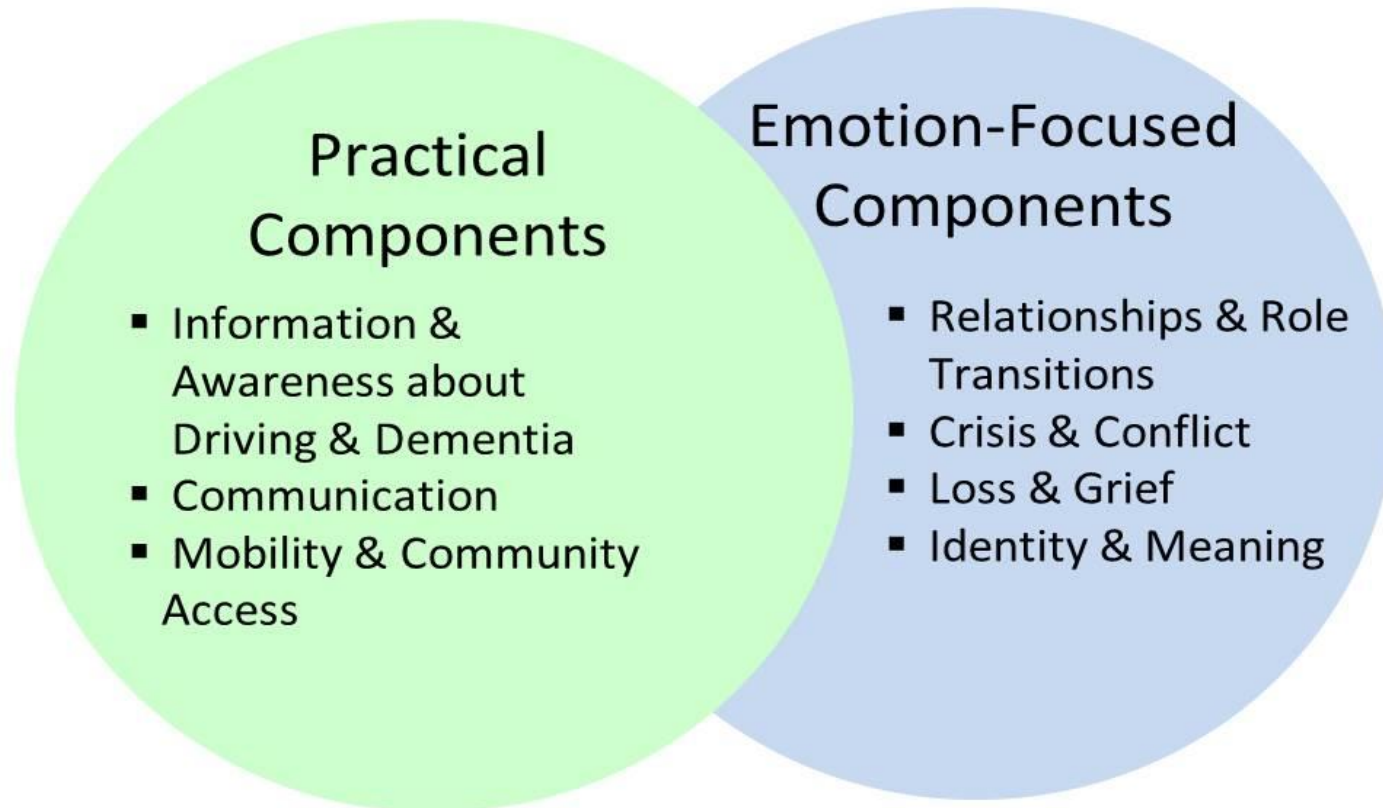
## Intervention Framework informed by:

- Series of systematic reviews
  - Review of controlled studies of driving cessation for older adults with and without dementia
  - Meta-synthesis of qualitative research studies on subjective experiences of decision-making and driving cessation in dementia
  - Review examining the effectiveness of interventions that target other major life transitions in older adulthood

- Qualitative research studies
  - In-depth interviews and focus groups
  - Explored experiences and perspectives of key stakeholders (e.g., healthcare providers, representatives from Alzheimer Society organizations, former drivers with dementia and family caregivers)

- Perceived lack of education and resources for advanced planning and decision-making about driving cessation and transition to non-driving
- HCPs and caregivers experience difficulty determining which resources are trustworthy
- Supportive approaches for emotional responses often overlooked due to narrow focus on practical approaches (e.g., transportation planning)
- After driving cessation, caregivers often assume the “burden” to maintain purpose, roles and social participation of person with dementia

- **Identification, Review and Curation of Resources and Tools**
  - Semi-structured website searches for relevant tools and resources
  - Review of publically available tools and resources in different formats
  - Assessment of resources for evidence base, relevance and usability







## Introduction and Background

Welcome to the first rendition of our Driving Cessation in Dementia Framework and Toolkit (DCD-FT). The purpose of this site is to introduce you to the resources and tools that comprise our current version of the DCD-FT, and to help us think about the best ways to organize and format it for implementation in Alzheimer Society organizations across Canada. We are also interested in knowing what you think about the content of the tools in the DCD-FT. For example: Are they user-friendly? Is the content appropriate for the clients that you support? As Alzheimer Society representatives, with knowledge and experience in working with adults with dementia and their family caregivers, your input to this project is critical.

## How We Developed the DCDT

Our research team, led by Drs. Gary Naglie and Mark Rapoport and funded by the Canadian Consortium on Neurodegeneration in Aging, developed the Driving Cessation in



## Framework Components & Examples of Tools

## 1. Information and Awareness

- The impact of dementia on driving skills
  - Public awareness tool
- Risk factors and warning signs
  - Risk factor and warning signs checklists
- Driving assessment
  - Self-assessment tools
  - Assessment tools for family or caregivers



**Source:** 2011, Canadian Dementia Knowledge Translation Network and the Nova Scotia Health Research Foundation, <https://www.youtube.com/watch?v=J0d3tjif9-8>

## 1. Information and Awareness

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## RED FLAGS

### HOW DO I KNOW WHEN TO STOP DRIVING?

When you are driving, do you experience one or more of the following problems? A person with dementia may not be aware of these changes, so it is very important that those close to him or her look for these signs of problems:

Have you noticed any change in your driving skills?

Do other drivers honk at you or show irritation?

Have you lost confidence in your driving ability?

Have you ever become lost while driving? Do you need a co-pilot?

Have you ever forgotten where you are going?

Have you had any accidents in the last year?

Have you had any minor fender-benders or minor accidents in the last year?

Have you received any traffic tickets or warnings for speeding, going too slow or improper turns?

Have others criticized your driving or refused to drive with you?

Are you confused when you enter or exit a road?

Do you have difficulty yielding the right of way?



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## Simple Driving Assessment

This simple driving assessment will help evaluate whether a senior driver needs to take steps to improve their driving skills, and pinpoint specific areas for improvement. It should take 10-15 minutes to complete the assessment.

### Instructions:

For each of the following 15 questions, check the symbol (✓) of the one answer that best describes you.

	Always or Almost Always	Some- times	Never or Almost Never
1. I signal and check to the rear when I change lanes.....	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I wear a seat belt.....	<input type="radio"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I try to stay informed on changes in driving and highway laws and techniques.....	<input type="radio"/>	<input type="triangle"/>	<input type="checkbox"/>
4. Intersections bother me because there is so much to watch from all directions.....	<input type="checkbox"/>	<input type="triangle"/>	<input type="radio"/>

**Source:** 2018, Canadian Automobile Association

## 2. Communication Support

- Communication with family members or loved ones
  - Conversation planners
  - Driving agreements and contracts
- Communication with healthcare professionals and other parties
  - Sample physician letter to patient

## CONVERSATION PLANNER: HOW CAN I HAVE GOOD CONVERSATIONS ABOUT NOT DRIVING?



You want your conversations with the person with dementia to be positive, progressive and productive. You can use these points to guide those conversations.

**Who** should be the messenger? The person who answers yes to these questions may be in the most favorable position. Is it you or someone else? If it's not you, you may need to have a preliminary conversation with the person in the most favorable position to take action.

Is the driver your spouse or your parent?	Yes___	No___
Do you have the person's best interests in mind?	Yes___	No___
Do you know the person's physical and cognitive condition?	Yes___	No___
Do you know the person's driving abilities?	Yes___	No___
Do you have a good relationship with the person?	Yes___	No___

**When** is a good time to talk? It's never too early to talk about driving issues, but these conversations warrant careful attention, planning and serious discussion. Here are some good opportunities to start a conversation naturally.

- Change in frequency or severity of warning signs

### Source

**At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia and Driving (2013, The Hartford Centre, United States)**



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## Driving contract

I, \_\_\_\_\_,  
(name of person with Alzheimer's disease or dementia) understand that due to the nature of Alzheimer's disease or dementia, there will come a day when it is no longer safe for me to drive. The purpose of this document is for me to share my directions for what I would like to happen when I cannot drive anymore.

I am aware that due to Alzheimer's or dementia, I may not be able to recognize when I am no longer driving safely. In that case, I have asked the following person (people) to tell me that it is no longer safe for me to drive.

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I understand that I may forget that I cannot drive anymore and may try to continue driving. If this happens, please know that I support all actions taken, including removing or disabling my car, to help ensure my safety and the safety of others.

\_\_\_\_\_  
Signature of person with Alzheimer's or dementia      Date

I, \_\_\_\_\_,  
(person appointed above) commit to telling \_\_\_\_\_  
(name of person with Alzheimer's disease or dementia) when it is no longer safe for him/her to drive. I commit to taking whatever actions are necessary from that time on to help ensure his/her safety and the safety of others, as he/she has requested.

\_\_\_\_\_  
Signature of person appointed above      Date

\_\_\_\_\_  
Signature of person with Alzheimer's or dementia      Date

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## SAMPLE DOCTOR'S WRITTEN STATEMENT TO THE PATIENT

*(This is an example of a letter the doctor can provide for the person with dementia to remind the person of the need to stop driving. A copy can be given to the family caregiver.)*

Date: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Dear Mr. (Mrs.) \_\_\_\_\_:

I realize that this is a difficult recommendation for you, but based on the results of tests performed, I am recommending you do not drive.

You have undergone assessment for memory/cognitive problems. It has been found by comprehensive assessment that you have \_\_\_\_\_ dementia.

The severity is \_\_\_\_\_.

Even with mild dementia, your risk of a car accident in the next year is eight times that of other people your age. Even with mild dementia, the risk of a serious car crash is 50% within two years of diagnosis.

Additional factors in your health assessment that raise concerns about driving safety include:

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As your doctor, I have a legal responsibility to report potentially unsafe drivers to the Provincial Registrar. I have no choice in this matter. Even with a previous safe driving record, your risk of a car crash is too great for you to continue driving. Your safety and the safety of others are too important.

Signature \_\_\_\_\_ M.D. Date \_\_\_\_\_

Copies given to: \_\_\_\_\_

## 3. Mobility and Community Access

- Alternatives to driving
  - Transportation Cost Worksheet
  - Alternative transportation planning worksheets
- Planning for the future



## Transportation Cost Worksheet

Owning and operating a vehicle can be more expensive than you think! By writing down your actual expenses, you can get an idea of how much money could be available for alternative transportation if you were to stop driving.

To determine the annual expense to own and operate a car, list all the related expenses below. Don't forget to multiply by 12 for monthly expenses, or by 52 for weekly expenses. For less frequent expenses, such as tires, estimate the cost and divide by the number of years between expenses. Once you have the annual expense for owning and operating the vehicle, you can get a better idea of how much you are already spending on transportation.

VEHICLE COST PER YEAR	ANNUAL COST
<b>Car/Lease Payment</b>	
<b>Regular Operating Expenses</b>	
• Gas .....	
• Washer Fluid .....	
• Parking .....	
• Tolls .....	
• Other .....	
<b>Regular Maintenance</b>	
• Oil Changes .....	
• Minor Tune-ups .....	

**We Need to Talk: Family Conversations with Older Adults  
(2018, The Hartford Centre, United States)**



## Routine Errands

(List activities such as going to the grocery store, the pharmacy, the hairdresser, or the doctor.)

Activity	How You Get There Now	New Ways to Complete Errand

## Regular Educational, Social or Religious Events/Activities

(List events that happen at least once a month, such as going to an adult learning center, senior center or attending religious services.)

**Source:** How to Understand and Influence Older Drivers  
(2013, US Department of Transportation and National Highway Traffic  
Safety Administration, United States)

## 4. Relationships and Role Transitions

- Family relationships and driving
- Support system for the driver and caregiver
  - Support network planner



## NOT GOING IT ALONE: WHO CAN OFFER SUPPORT?



Support from others can reduce stress and increase chances for success. Your circle of support can include people inside and outside the family who might provide emotional support, observe driving skills, discuss family concerns with the driver, pay for in-home services, provide alternative transportation, and look for public transportation alternatives.

Here's how you can identify, and possibly expand, your circle of support.

**Step 1.** On the next page are four circles.

1. In the inner circle, place the name of your loved one.
2. In the second circle, write the names or initials of those people currently providing ongoing assistance to you or your loved one.

### Source

**At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia and Driving  
(2013, The Hartford Centre, United States)**

## 5. Crisis and Conflict

- Dealing with resistance to driving recommendations
  - Teepa Snow Driving and Dementia video
- “Last resort” strategies to maintain safety





## Source

2011, Teepa Snow, Pines of Sarasota Education & Training Institute,  
United States

[https://www.youtube.com/watch?v=gr\\_47LOFp7M&t=2s](https://www.youtube.com/watch?v=gr_47LOFp7M&t=2s)

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### 3. Important safety issues

If you refuse to stop driving or keep forgetting that you are unfit to drive, your family/friends may need to do the following:

- Remove the opportunity to drive
- Remove the car
- Replace the keys
- Use a club to lock the steering wheel
- Disable the car
- Call the police
- Ask the doctor to provide a written statement (page 25) outlining why you can no longer drive. The statement should indicate that it is the doctor's legal responsibility to report unsafe drivers and that he or she has no choice but to notify authorities of a patient's driving status.
- See the back of the toolkit for more information.

#### Source

The Driving & Dementia Toolkit for Patients and Caregivers  
(2011, Regional Geriatric Program of Eastern Ontario, Canada)

## 6. Loss and Grief

- Communicating about the loss and grief associated with giving up driving

## 7. Identity and Meaning

- Addressing the importance and meaning of driving





Watch how four families deal with different issues related to dementia and driving.



**Supportive Conversation:** Frank has early stage Alzheimer's and the doctor said it's no longer safe for him to drive. His wife doesn't drive, but knows it's time to discuss finding alternative transportation.



**Source:** 2016, Alzheimer's Association,  
Dementia and Driving Resource Centre, United States  
<https://www.alz.org/care/alzheimers-dementia-and-driving.asp>

Watch how four families deal with different issues related to dementia and driving.

**A Close Call:** Martin has early stage Alzheimer's and hit a parked school bus today. No one was seriously hurt, but his partner, Dan, recognizes that Martin must stop driving — for everyone's safety and well-being.



**Source:** 2016, Alzheimer's Association,  
Dementia and Driving Resource Centre, United States  
<https://www.alz.org/care/alzheimers-dementia-and-driving.asp>

- Dementia Support Services
- Information and Resources about Driving Assessment
- Alternative Transportation Options
- Social Support Services
- Mental Health/Crisis Support Services
- Dementia and Older Adults Advocacy Groups
- Legal Considerations

- Address a range of needs by offering a detailed framework of important thematic components with relevant supportive tools and resources
- Increase accessibility of available resources
- Facilitate driving cessation decisions and improve safety for persons with dementia and the public
- Improve quality of life by maintaining social inclusion

- Refine and design DCD-FT in consultation with web developer, graphic artist and plain language writer. Advisory committee comprised of persons with dementia and family caregivers will provide input during this process
- Implement and evaluate DCD-FT in local settings— content, experience of delivery, use and early effects

1. Develop and evaluate a unique group-based intervention for persons with dementia and their caregivers based on the intervention framework and toolkit
2. Establish the unique driving intervention needs of rural drivers with dementia and their caregivers
3. Identify and evaluate a GPS-based outcome measure of life space for persons with dementia that can be used as an outcome measure of interventions for driving cessation

# Questions?