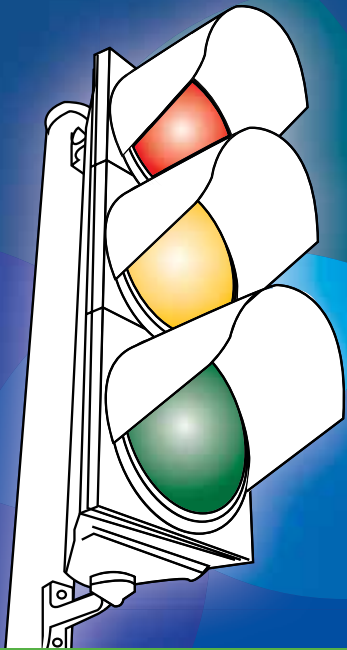


The Driving and Dementia Toolkit



For Patients and Caregivers

1st Edition



Champlain Dementia Network
Réseau de la démence de la région Champlain



Regional Geriatric Program
of Eastern Ontario
Programme gériatrique régional
de l'Est de l'Ontario

Your Name: _____

Given By: _____

We are pleased to offer you the Driving and Dementia Toolkit, a companion resource to the toolkit originally developed for health professionals. We are hoping this toolkit will be a helpful resource for persons in the early stages of dementia and their caregivers (family, friends and other support persons). It may also be useful to health professionals.

A diagnosis of dementia does not automatically imply loss of driving privileges. However, the doctor must ask if the person with dementia drives and if he/she does drive, then the doctor has a legal responsibility to evaluate his/her fitness to continue to do so.

As we age, we need to consider and plan for an eventual retirement from driving. While most people make a sound decision to stop driving when they are no longer able, some continue to drive when at risk.

Although some people with early-stage dementia can continue to drive after diagnosis, they need to

- a) discuss their driving fitness with a doctor
- b) monitor their driving ability with the help of their family
- c) change their driving habits to compensate for changes
- d) prepare for an eventual retirement from driving

This toolkit has been developed with the help of the Alzheimer Society by a team of health professionals from different backgrounds (including medicine, nursing, social work and occupational therapy). A series of focus groups were held with people with early-stage dementia and with caregivers (spouses' and daughters' groups) to explore and advise on the content.

To date, there is little information from research on how to assess driving safety in a doctor's office. The companion booklet developed for health professionals contains some information that can assist health professionals with the process. In some situations, the doctor may need to recommend an in-depth on-road driving evaluation. This may be costly for the person with dementia and of limited availability in some geographic regions. In addition, in the case of a progressive condition such as dementia, the results could be considered time limited.

The goal of this toolkit is to keep safe drivers on the road and to prepare those who are at risk of being involved in car crashes to eventually stop driving.

In most situations, health professionals recommend driving cessation based on their evaluation of cognition (thinking processes) and its' impact on function. Other medical conditions may contribute to the decision (including Parkinson's disease, arthritis, vision loss or heart condition) as well as medications taken.

This toolkit is divided into four main sections: 1) a general overview of dementia and driving and a road map (algorithm) to help you understand the health professional's assessment process; 2) a description of the assessment process; 3) what to do depending on the outcome of the assessment (a safe-to-drive "green" section; an unsure "yellow" section and an unsafe-to-drive "red" section, including tips for an alternate transportation plan); 4) resources, including a sample advance directive (reprinted with permission from The Hartford Financial Services Group, Inc.), a sample letter from the doctor and a list of additional resources. At the back of the toolkit, there is a separate section for pamphlets that may be helpful for caregivers/families and a list of resources in your region.

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We hope you will find the materials of benefit and we welcome feedback (see back of toolkit), especially from persons in the early stages of dementia, that will allow us to revise the information as necessary. This toolkit is also available in French and can be accessed on the Regional Geriatric Program of Eastern Ontario website at www.rgpeo.com.

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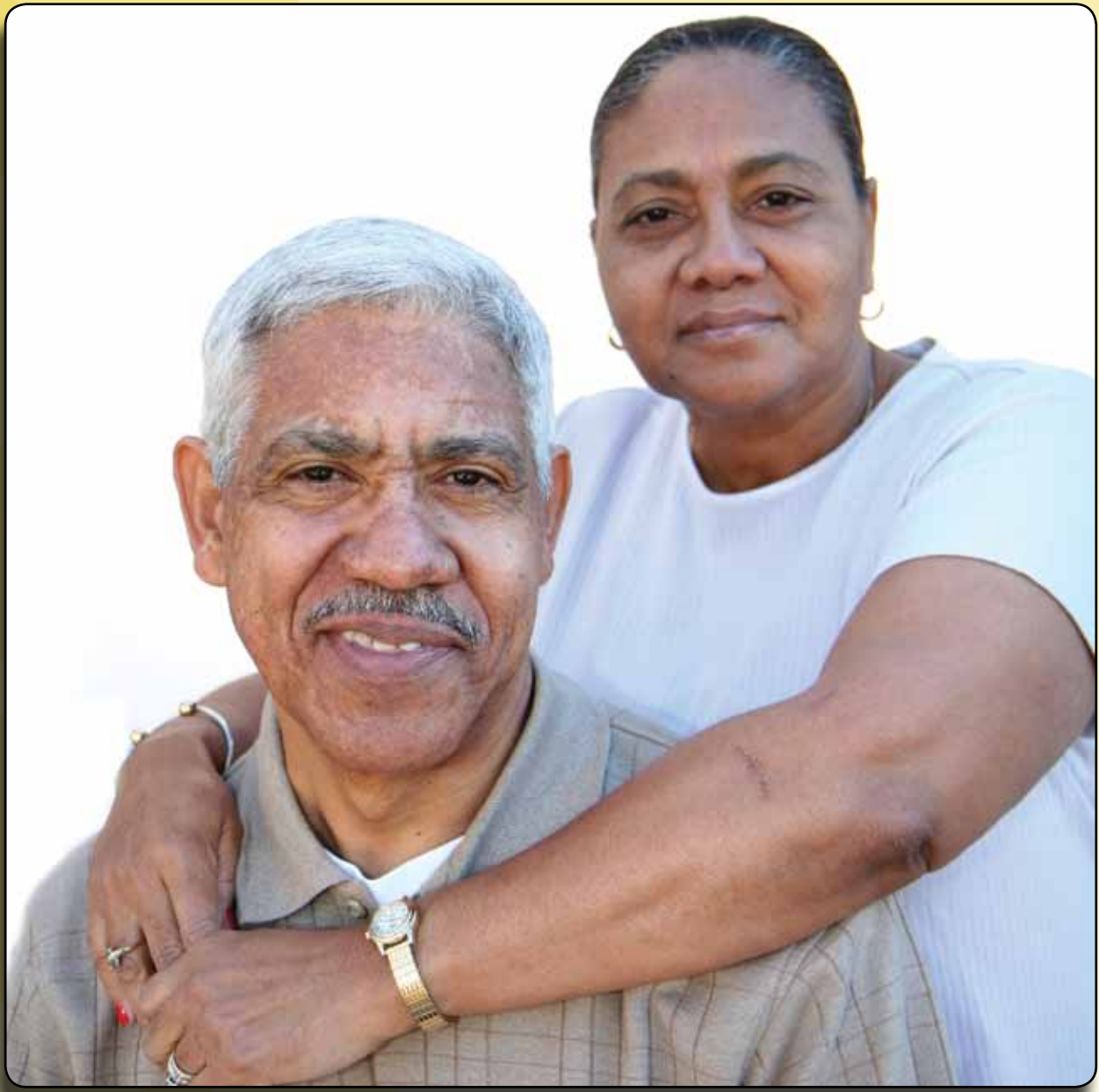
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TABLE OF CONTENTS

	Page
I. GENERAL INFORMATION.....	3
INTRODUCTION.....	4-6
• Background information on dementia and driving • Warning signs • Physician responsibilities	
ASSESSMENT ALGORITHM/ROAD MAP	7
FREQUENTLY ASKED QUESTIONS	8-9
RED FLAGS – WHEN SHOULD YOU WORRY	10
2. ASSESSMENT	11
OFF- AND ON- ROAD ASSESSMENTS	12
3. AFTER THE ASSESSMENT – NEXT STEPS.....	15
A. STILL SAFE BUT NEEDS FOLLOW- UP.....	16-17
i. Planning for driving retirement ii. Questions to consider iii. Compensatory strategies and self-regulation iv. Preparing for the day to stop driving v. Follow-up	
B. UNCERTAIN	18
i. Strategies	
C. UNSAFE TO DRIVE.....	19-20
i. Meeting with the doctor ii. Alternate transportation plan iii. Important safety issues	
4. USEFUL RESOURCES.....	23
SAMPLE ADVANCE DIRECTIVE FOR DRIVING CESSATION	24
SAMPLE DOCTOR'S WRITTEN STATEMENT TO THE PATIENT.....	25
LIST OF RESOURCES	26
REMOVABLE SECTION	27



I. GENERAL INFORMATION

INTRODUCTION

I. Background information on dementia and driving

Driving is very important in countries like Canada because of the wide geographic distribution of the population. In many areas, particularly rural communities, public transportation alternatives are limited. Regardless of the necessity of driving to get places, it is important to remember that driving is a privilege not a right. As the population ages, medical conditions and medications can affect driving fitness. Their impact can be unpredictable and sudden, leaving a person unprepared and at risk of car crashes.

Most older drivers wish to continue to drive as long as possible. But driving an automobile is a complex task that requires many skills and abilities, including the following:

- a) Good understanding of road safety rules, road signs and traffic signals
- b) Good vision
- c) Quick reflexes and excellent reaction time (especially as other drivers on the road may take risks)
- d) Good memory and exercise of judgement (including awareness of one's limitations)

Dementia is a general term for a disease that affects the chemicals and structure of the brain. Alzheimer's disease and stroke are the two most common causes of dementia. Many problems commonly experienced in dementia can seriously limit a person's ability to drive safely. Examples of such problems are as follows:

- a) Increasing forgetfulness
- b) Disorientation to time and place
- c) Difficulty concentrating and shifting attention
- d) Deficits in thinking and judgement
- e) Visual perceptual problems (how things are seen in space, in relation to each other)

Dementia is a condition that is progressive, meaning that the symptoms will worsen over time. There is currently no cure for dementia, only medications that can slow its progression. The symptoms and speed of change are different for each person. It is impossible to tell how fast any one person will progress through the stages. The stages of a dementia are commonly named as

early, middle and severe. People in the early stage of disease have only minimal impairments and may be able to drive safely with some adjustments. But as the disease progresses, memory and functional abilities worsen, increasing the risk of accidents that could injure or kill the person with dementia or others. The risk of accident doubles every five years from dementia onset. To help one prepare for eventual driving retirement, discussion about driving must begin at the first sign of memory loss.

2. Warning signs: When should you worry?

Questions for the person with dementia

- Have you noticed any change in your driving skills?
- Do other drivers honk at you?
- Have you lost confidence in your overall driving ability, leading you to drive less often or only in good weather?
- Have you ever become lost while driving?
- Have you ever forgotten where you were going?
- Have you ever mixed up the gas and brake pedals?
- Have you had any car accidents or minor fender-benders in the last year?
- Have you received any traffic citations for speeding, going too slow, improper turns, failure to stop, etc.?
- Have others criticized your driving?

Questions for caregivers

- Do others feel uncomfortable driving with the person with dementia?
- Are others forced to drive defensively to accommodate the person with dementia's driving style?
- Is a co-pilot needed to navigate the automobile or to alert the person of potential hazardous events or conditions?
- Has there been evidence of loss of ability in other areas of daily living activities such as medication use, financial management (banking), cooking and shopping?

3. Physician responsibilities

Persons with dementia must have fitness to drive evaluated and monitored. In most provinces, physicians (and certain other health professionals) are legally responsible for identifying people who may be at risk for accidents and are required by law to notify responsible authorities. In Canada, these authorities are the Provincial Registrars. If a person at risk of unsafe driving due to a medical condition is involved in a motor vehicle crash, the physician can be held legally responsible. If the person continues to drive without a valid license, then his or her automobile insurance is not valid and he or she can be charged by the police.

In most situations, a doctor's decision to recommend that a patient stop driving is based on evaluation of cognition (thinking processes) as well the impact of other medical problems, such as poor vision, neurological disorders (Parkinson's disease or stroke) or heart conditions (fainting, chest pain), and medications.

As a **person with dementia**, you need to ask yourself the following question:

“Am I still able to get behind the wheel without risking an accident that could injure me or someone else on the road, or even a family member who is a passenger in my car?”

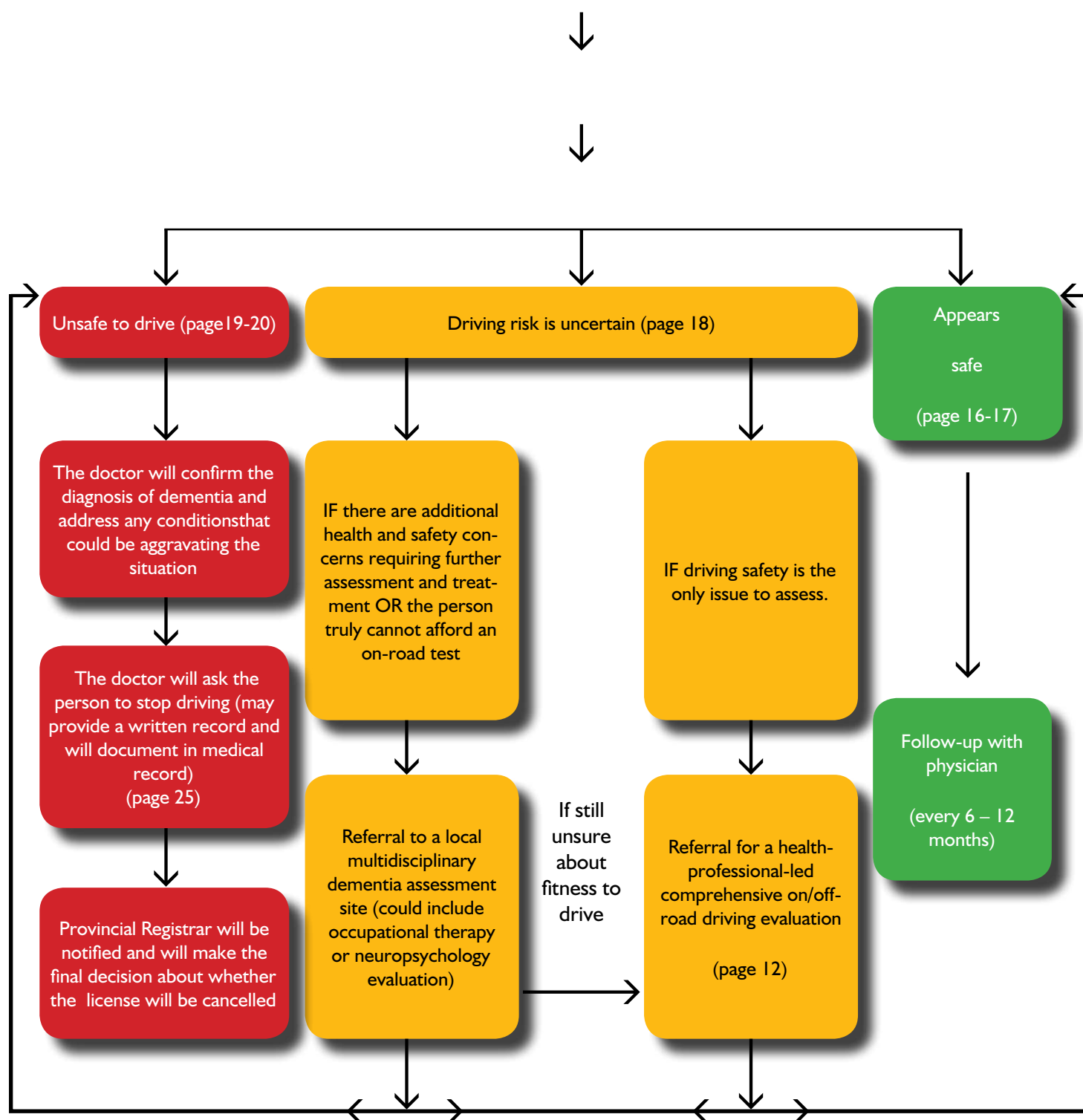
As a **relative assisting a person** who is making the decision, you can formulate the question as follows:

“Is your relative with dementia still able to get behind the wheel without risking an accident that could injure himself/herself or someone else on the road, or even a family member who is a passenger in the car?”

If you can no longer confidently answer “yes” to this question, options for getting around other than driving a motor vehicle should be considered. Discuss this with a health professional, such as the family physician, an occupational therapist or a nurse.

Sometimes a “letter” outlining the issues can serve as a written reminder (page 25), if it is deemed that a person with dementia cannot drive safely.

ROAD MAP FOR ASSESSMENT OF A DRIVER WITH DEMENTIA



FREQUENTLY ASKED QUESTIONS AND ANSWERS

Q. What are the legal obligations of health professionals with respect to driving privileges for someone experiencing cognitive decline?

A. In most provinces, legally qualified medical practitioners (doctors) must perform an assessment and notify the Provincial Registrar in case of a medical condition that increases the risk of a motor vehicle crash (except in Quebec, Alberta and Nova Scotia, where reporting is at the discretion of the doctor).

Q. Why does dementia make a person an unsafe driver?

A. Dementia not only causes loss of memory but also affects other thinking skills that are important when we drive. These include the ability to shift attention, problem-solving skills, orientation, judgement and speed of reaction to emergencies on the road. Often the person with dementia may not be aware of these difficulties, and it is those around them that notice these changes.

Q. But I only drive short distances, so why worry?

A. Most accidents occur close to home, on trips to the grocery store, in mall parking lots or on the way to the church, for example. This places the person with dementia, family members, friends and neighbours at risk.

Q. How will the doctor know if it is safe or unsafe for the person with dementia to drive?

A. The doctor will ask the person detailed questions about his or her medical history and complete a thorough physical exam that includes evaluation of what is called “cognitive function” (memory and thinking processes). As well, the doctor will review the medications the person is taking and perform other investigations as required.

Q. What if the doctor is unsure of the risks/safety of the person’s driving?

A. The doctor can refer the person for further assessment (page 12) and inform the Provincial Registrar that arrangements have been made for further assessment.

Q. What if, based on the initial assessment, the doctor is very concerned about the person's driving risk and is certain the person should stop driving immediately?

A. The doctor may decide to call the Provincial Registrar and ask for immediate suspension of driving privileges. The doctor should inform the person and his or her family/caregiver(s) of this decision and may arrange assessment at an appropriate site. It is important to note that from this point on the person may no longer be covered by auto insurance in the event of an accident.

Q. If someone has early dementia and the doctor feels it is still safe for him/her to drive, how often should the driver have a follow-up evaluation?

A. Driving safety should be re-evaluated every 6-12 months.

Q. Whose decision is it that a person is no longer able to drive?

A. Some people give up driving voluntarily or on the advice of their doctor, family or friends as they get older and develop medical conditions or when they begin to have difficulties with memory. Some believe they can still drive safely, but the doctor's evaluation and other tests as shown in the toolkit indicate they are no longer safe drivers. It is ultimately the doctor's legal responsibility and decision to report an unsafe driver. An advance directive for driving cessation (page 24) can be used to prepare for the future.

Q. What action can friends or family take if they think someone can no longer drive safely and the person concerned disagrees?

A. Family or friends may need to ask the person to see his or her doctor for a driving safety evaluation. If the person is found unfit to drive and he or she disagrees with the doctor's evaluation and continues to drive without a valid license, the family has a responsibility to protect the person from the safety, financial and legal risks of doing so. The family may be concerned about the person's health and safety as well as the safety of others who share the car or the road with the person. The family is also responsible for reminding the person that it is illegal to drive without a valid driver's license. Finally, in case of an accident, insurance will not cover the cost.

Q. What if the person doesn't want to stop driving?

A. The doctor will explain the reasons for his/her concern and must inform the Registrar. The person's license and auto insurance will no longer be valid and he or she can be charged by police if found driving without a valid license.

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?

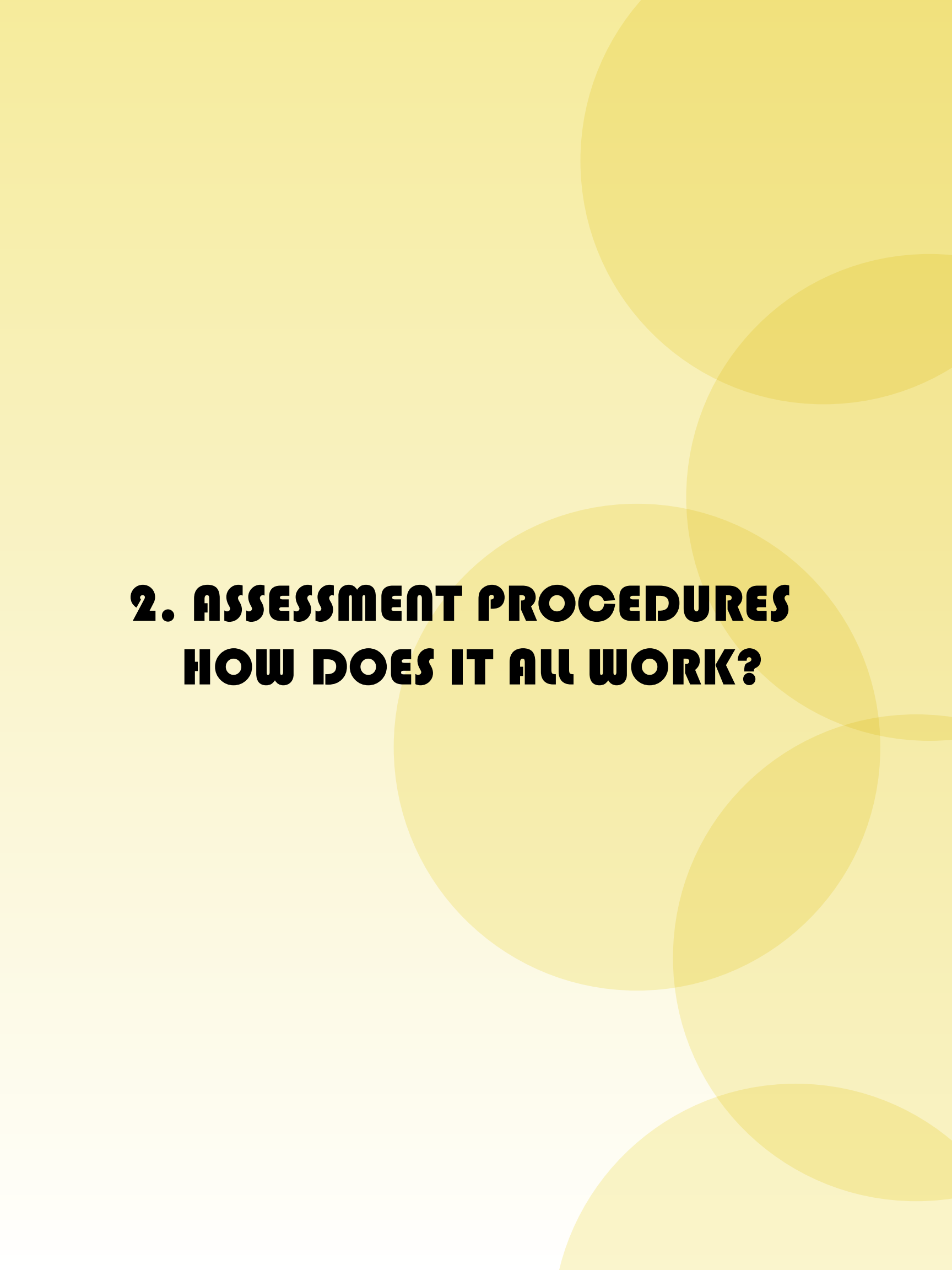
Have you received any traffic tickets or warnings for speeding, going too slow or improper turns?

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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2. ASSESSMENT PROCEDURES

HOW DOES IT ALL WORK?

OFF- AND ON- ROAD ASSESSMENTS

1. In most provinces in Canada, older people must have a periodic evaluation of their driving abilities in order to maintain their driving privilege. In Ontario, for example, older people are asked to take a three-part test every two years starting at age 80. This consists of a vision test, a multiple-choice written test of driving rules of the road and a group session. Unfortunately, this test does not properly assess driving skills typically affected by dementia. As a result, a person with dementia may pass this three-part test even if he or she is at high risk of accidents and unsafe to drive.
2. For persons with dementia, a visit to the doctor can sometimes help decide if the person is fit to drive (see road map, page 7). If there is any doubt, the doctor might refer the person to a specialized memory loss clinic for a complete assessment (paper-and-pencil-based tests) of driving fitness.
3. In more complex situations, a person can be referred by the doctor or the Provincial Registrar for a specialized on-road test (see road map, page 7). The list of centres in your area is provided in the removable section at the end of the toolkit.

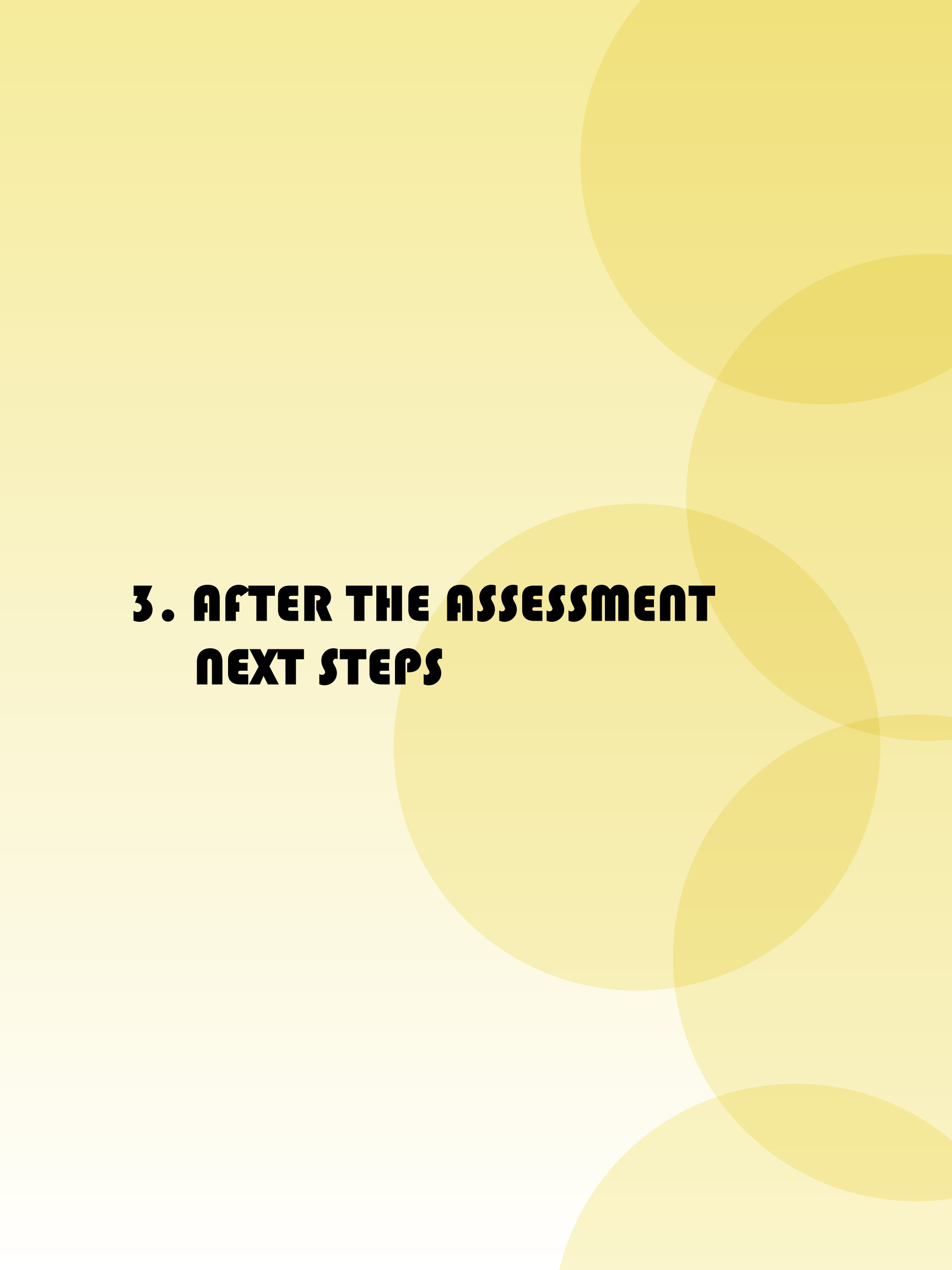
These tests usually involve the following:

- Paper-based screening test of cognition (memory, reaction time, etc.)
- Possible test in a car simulator
- On-road test in a dual-brake car driven on a set route

The in-car assessment is conducted with a driving instructor and an occupational therapist. These evaluations are not covered by most healthcare plans and can be very expensive (\$500 to \$800). A person will be referred only if it is deemed that he or she may have a chance of passing the test or to have further driving retraining. Some third-party payers may provide coverage. For example, if the person is a veteran, the DVA (Department of Veteran Affairs) may cover the cost with a physician's letter.





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3. AFTER THE ASSESSMENT NEXT STEPS

A. STILL SAFE TO DRIVE – BUT NEEDS PERIODIC FOLLOW-UP EVALUATION

1. Planning for driving retirement: This should be discussed as early as possible. Although a person with early dementia may still be able to drive safely, he or she needs to plan for eventual driving retirement. Some of our patients tell us that being told they need to stop driving undermines their dignity and may lead to loss of self-worth and a depressed mood. This section gives tips on how to prepare for this unavoidable transition.
2. Questions to consider: The following questions may help you in how you approach driving safely and in preparing for driving retirement.
 - o How much do you drive?
 - o Can you say, in your own words, why driving is important to you?
 - o Have you ever considered stopping driving?
 - ☐ Yes - under what circumstances?
 - ☐ No - would you ever consider it given the diagnosis of dementia?
 - o What would it mean to you to stop driving?
 - o If you stopped driving, how would you get around?
 - o Who are the people that can help you get around after you stop driving?
 - o How accessible is your current residence to alternate means of transportation such as public buses?

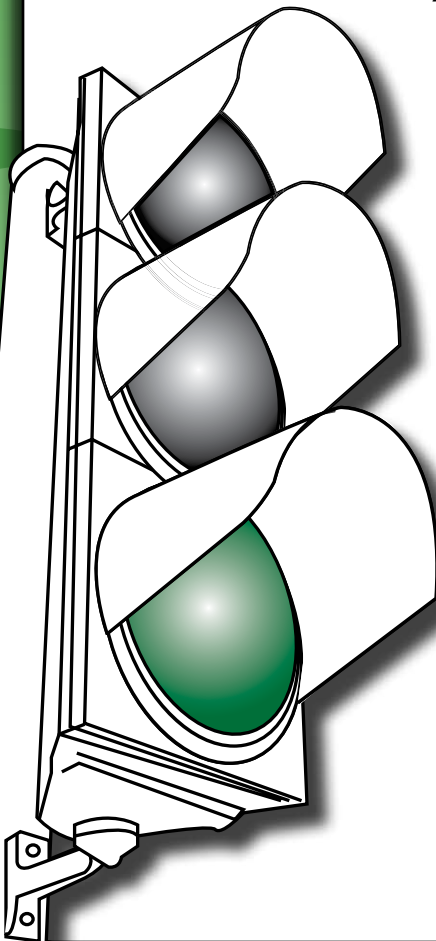
3. Consider the following compensatory strategies to help you drive safer:

Driving only familiar routes

Driving slowly

Not driving at night or in poor weather

(Continued on the next page.)



Not listening to the radio while driving

Avoiding busy intersections

Not driving with distracting companions such as children or pets

Taking a 55 Alive course or a driving refresher course

Avoiding expressways

Avoiding rush-hour traffic

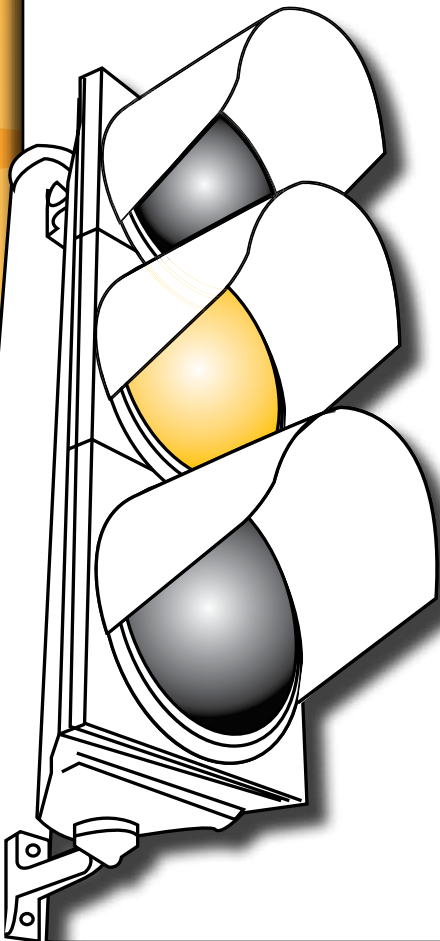
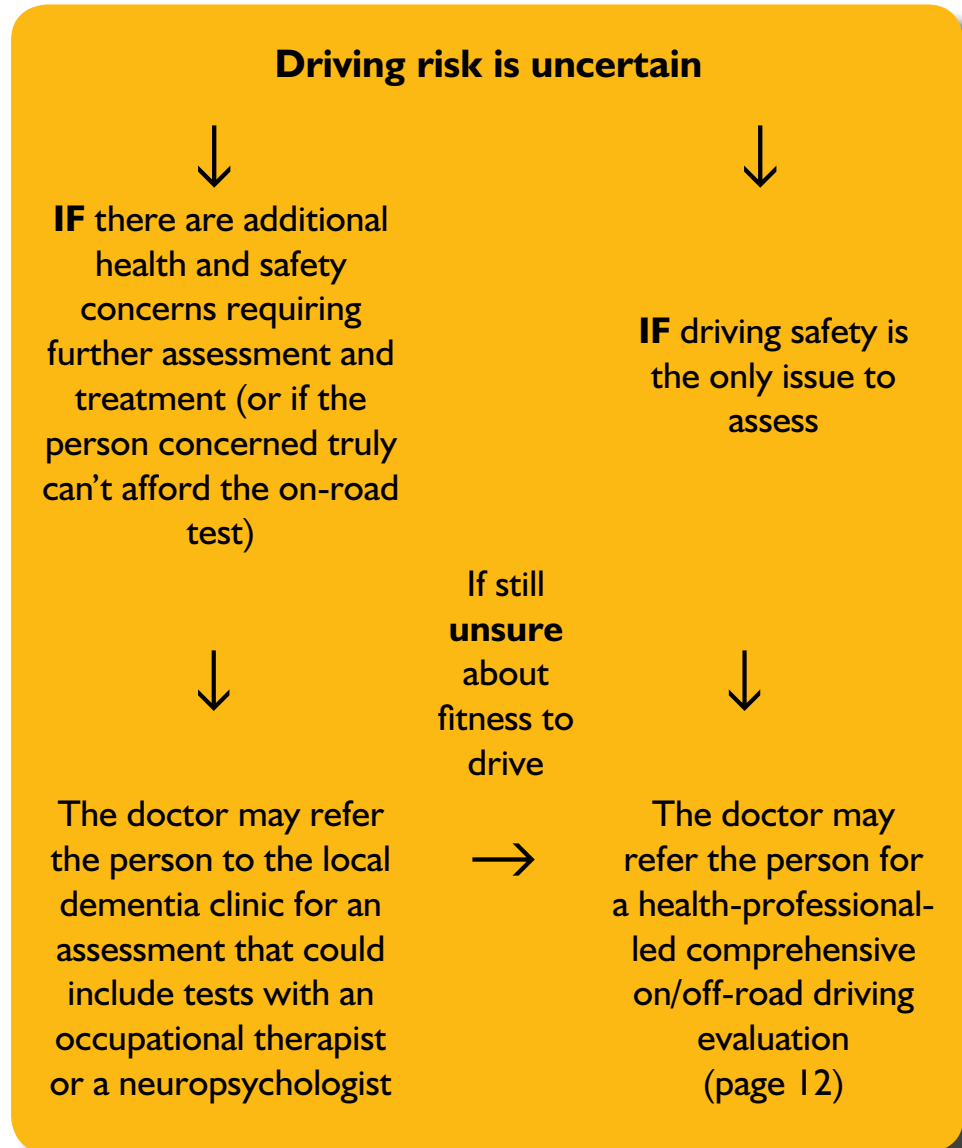
Using assistive devices such as wide-view mirrors/GPS

Considering a car that is easier to drive (automatic transmission, power windows/seat adjustments)

4. Preparing for the day you need to stop driving: Despite your best efforts, eventually you will lose the ability to drive safely as the dementia progresses. Even though you may have a perfect driving record, skills are affected as dementia progresses (page 4-6). Initially these may be emergency response skills rather than skills used in routine driving. Coming to the realization that you can no longer drive requires careful thought and the support of family and health professionals. This is a difficult decision to make. This is why it is important to prepare for eventual driving retirement ahead of time. Having to act suddenly will leave you ill-prepared. Begin by gathering information about alternative means of transportation that may be available to you. Consider the Hartford advance directive for driving cessation that you can give to your family or doctor (page 24).
5. Need to follow up:
 - You need to schedule a follow-up appointment with your doctor in 6 to 12 months (or sooner depending on your doctor's recommendation). You or your family should notify the doctor if there is earlier deterioration (such as more problems with memory, reaction time or overall medical condition) before this appointment.
 - If a person is unable or unwilling to return for follow-up, the doctor may need to notify the Provincial Registrar that follow-up is required.

B. UNCERTAIN RISK

If the risk of continuing to drive in a person with dementia is unclear, a more in-depth evaluation may be required, as per the diagram on this page.



C. UNSAFE TO DRIVE

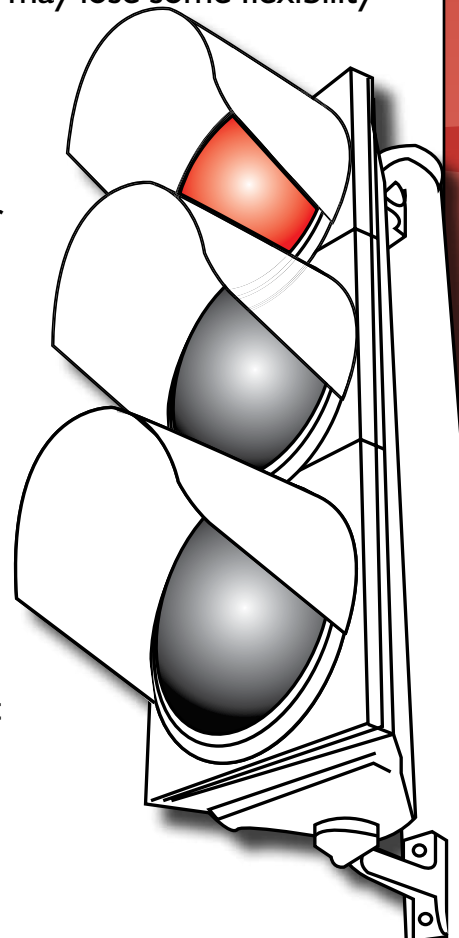
1. Finding out you are unfit to drive – meeting with the doctor

The doctor will explain the concern for your safety and the safety of others. He/she should clearly outline the results of the evaluation, explain why you are no longer fit to drive and remind you that the goal of a driving assessment is to prevent injury or death (of yourself or others). Giving up driving is not an easy decision. It may leave you with mixed emotions. On the one hand you may experience a sense of relief retiring from driving. On the other hand, you may have feelings of loss and sadness. Some people experience anger towards health professionals and family members who recommended they stop driving. These are normal grief reactions. Some people may experience a sense of uncertainty and anxiety, thinking that they can no longer maintain their independence and may no longer have a social life.

2. Alternate transportation plan

Hopefully you have had a chance to plan ahead and create a personal transportation plan. This would include listing where you need to go in a usual week and how you might be able to get there when you stop driving. It might involve some changes in your routine, such as automatic bill payments and direct deposits instead of driving to the bank.

No matter how good your network of family and friends may be, you may lose some flexibility and spontaneity in your life. It is very important to carefully plan for this transition and consider all alternative means of transportation to best meet your needs. The choices depend on each individual's resources and unique requirements. In large cities, there are public bus services (such as Para Transpo). For others, a taxi may be a better option. The cost of using taxi services may be no more expensive than owning and operating a motor vehicle that is driven 6,500 km or less per year (once you factor in the cost of gas, repairs and insurance). Family members could share driving responsibilities. This can be an opportunity for renewed closeness with parents or grandparents with those who take on this transportation role. Some people living in retirement residences have access to a limousine or transportation van. A number of community organizations offer volunteer driver services. It is important to work out a transportation schedule. Remember to plan for transportation not only to required appointments (e.g., bank, doctor's visits) but also to social events that make life worth living and prevent social isolation.



Examples of how to get around without a car:

(It helps to obtain names of services and phone numbers)

- o Enlist help of family
- o Enlist help of friends
- o Public transit
- o Para Transpo
- o Volunteer drivers
- o Taxi company vouchers
- o Shuttle service (call the local community centre)
- o Explore local services that deliver groceries, books, prescriptions (including on-line ordering) and newspapers
- o Catalogue shopping/online shopping (just about everything can be ordered from catalogues: pet food, gifts, clothing, etc.)
- o Carpooling
- o Disabled parking pass, if appropriate
- o Services offering home visits: doctor, hairdresser/barber, laundry pick-up, etc.
- o Meal delivery service (such as Meals-on-Wheels) or chef-at-home service
- o List of activities that can create a sense of purpose

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:

- o Remove the opportunity to drive
- o Remove the car
- o Replace the keys
- o Use a club to lock the steering wheel
- o Disable the car
- o Call the police
- o 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.
- o See the back of the toolkit for more information.





4. USEFUL RESOURCES

SAMPLE ADVANCE DIRECTIVE FOR DRIVING CESSATION

(This is an example of a letter of agreement you might consider preparing in advance to plan for driving retirement. Suggestion: give copies to your family and your doctor.)

Agreement with My Family about Driving

To my family:

The time may come when I can no longer make the best decisions for the safety of others and myself. Therefore, in order to help my family make necessary decisions, this statement is an expression of my wishes and directions while I am still able to make these decisions.

I have discussed with my family my desire to drive as long as it is safe for me to do so.

When it is not reasonable for me to drive, I desire _____ (person's name) to tell me I can no longer drive.

I trust my family will take the necessary steps to prohibit my driving in order to ensure my safety and the safety of others while protecting my dignity.

Signed _____ Date _____

Copies of this request have been shared with:



www.thehartford.com/alzheimers

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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:

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: _____

USEFUL RESOURCES

(Publications and On-line)

1. First Link® (Alzheimer Society), Ottawa Community Support Coalition, Council on Aging.
<http://www.alzheimer-ottawa-rc.org>
2. From Home to Retirement Home - A Guide for Caregivers of Persons with Dementia, July 2009, available at: http://www.rgpeo.com/en/resources/RRR_Guide_Sept_09.pdf
www.rgpeo.com.
3. Keeping on the go: Driving safely as you age. National Blueprint for Injury Prevention in Older Drivers. <http://www.olderdriversafety.ca/documents/CAOT%20Eng%20ALZHEIMERS.pdf>
4. "Driving and Dementia: A Guide for Patients and Families." Kingston, Frontenac, Lennox & Addington Dementia Network and the Ministry of Transport. http://www.providencecare.ca/objects/rte/File/Health_Professionals/drivinganddementia_patient.pdf
5. LePore, PR (2000). When you are concerned: A guide for families concerned about the safety of an older adult. Albany: New York State Office for the Aging.
6. "Navigating the Road: Knowing when to hang up your keys." Toronto Rehabilitation Institute.
7. Tappen, R, Kathleen J, Rosselli M, "Is it Time to Stop Driving? Plain talk about Driving and Memory Problems." Florida University.
8. "Older Driver Safety Project." National Association of Area Agencies on Aging, Washington, D.C.
9. RGPEO website. www.rgpeo.com.
10. CanDRIVE, a Canadian interdisciplinary health-related research program dedicated to improving the safety of older drivers. www.candrive.ca.
11. "At the crossroads: Family conversations about Alzheimer's disease, dementia and driving." <http://hartfordauto.thehartford.com/UI/Downloads/Crossroads.pdf>
12. www.alz.org/living_with_alzheimers_driving.asp
13. "Health in the driver's seat." Société de l'Assurance Automobile du Québec.
http://www.saaq.gouv.qc.ca/publications/prevention/health_driver.pdf.

REMOVABLE SECTION/FOLDER

1. Alzheimer Society information sheet on dementia and driving – updated form:
<http://www.alzheimer.ca/english/care/ethics-driving.htm#Top>
2. Information on local dementia assessment sites
<http://champlaindementianetwork.org/>
3. Local resources page:
 - a. Para Transpo
<http://www.octranspo1.com/about-octranspo>
 - b. Para Transpo taxi subsidy
http://www.octranspo1.com/community-events/taxi_coupon/
 - c. Local volunteer drivers
http://www.communitysupportottawa.ca/english/services/main.php?service_id=2
4. Listing of area driving assessment centres
<http://www.mto.gov.on.ca/english/dandv/driver/medical-review/eval-centres.shtml#medical>
5. Grief and Adjustment to Driving Cessation insert
6. Feedback form



Champlain Dementia Network

Réseau de la démence de la région Champlain



Regional Geriatric Program
of Eastern Ontario

Programme gériatrique régional
de l'Est de l'Ontario

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