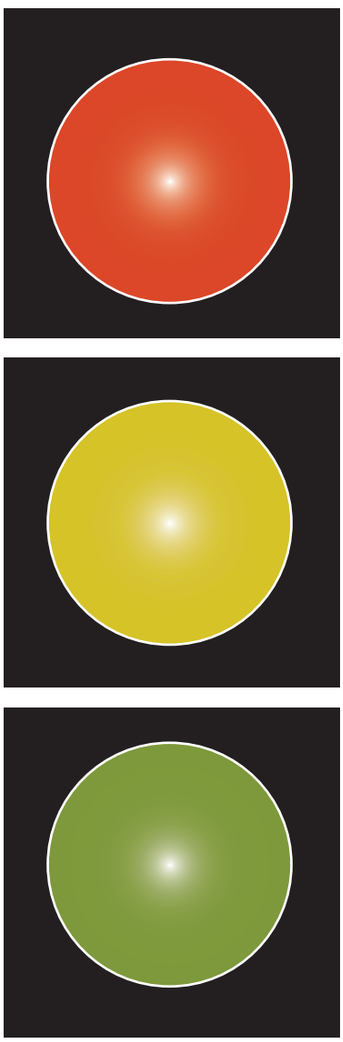
THE DRIVING AND DEMENTIA TOOLKIT

(3RD EDITION)

(FOR HEALTH PROFESSIONALS)



The Champlain Dementia Network

Réseau de la démence de la region Champlain

Regional Geriatric Program of Eastern Ontario

Programme gériatrique régional de l'Est de l'Ontario

Dear Colleagues:

This is the third updated edition of the Driving and Dementia Toolkit for Health Professionals. The Toolkit was originally developed in 1997 by the Dementia Network of Ottawa *(now renamed the Champlain Dementia Network)* and by the Regional Geriatric Assessment Program of Ottawa *(now renamed the Regional Geriatric Program of Eastern Ontario)*.

The diagnosis of Dementia does not imply an automatic license suspension as some people with very mild dementia can continue to drive for a limited period of time. However, you **must ask** if your patient with dementia drives, and if he/she drives, **you must evaluate** their safety to continue to do so.

This is a challenging area of dementia care with limited research. The toolkit is meant to bridge the gap by providing background information on driving and dementia, an algorithm on how to navigate the process of assessment of fitness-to-drive, and resources which can be adapted as required to your local needs. The new edition updates and expands upon the earlier versions of the toolkit in that we are offering additional information related to the assessment of one's driving ability as well as how to effectively communicate verbally (and in writing) the findings to the patient, the caregivers and to the legal authorities. A separate Driving and Dementia Patient/Caregiver Toolkit will be available as well, specifically designed for those who must face this issue.

This toolkit has been developed by an interdisciplinary team of health professionals from geriatric medicine, physiatry, family medicine, occupational therapy, social work, nursing and the Alzheimer Society. The material is Copyrighted © by the Copyright Act of Canada. **This means you are welcome to reprint or photocopy (for individual use but not for commercial purposes) any of the materials as required, whenever you come across a patient whose cognitive changes may affect their ability to drive. Please acknowledge the source, if you use this material in presentations or publications.**

We hope you will find the materials of benefit. This toolkit is also available in French and it can be accessed as well on the Regional Geriatric Program of Eastern Ontario website at www. rgpeo.com. We welcome your feedback to improve future editions (please use the feedback form located in the back pocket of the toolkit, or email:abyszewski@ottawahospital.on.ca)

Thank you,

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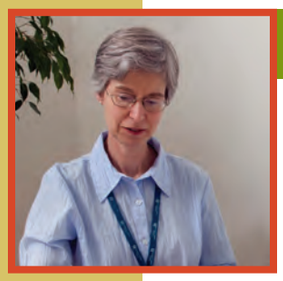

INTRODUCTION

In Canada, because of the wide geographic distribution of our population, driving is very important. In many areas, including rural communities, public transportation alternatives are limited. As our population ages, numerous co-morbidities can contribute to increased risk for the person who drives. We also do not prepare well for the possibility that one day we may need to stop driving, and most people incorrectly assume they will drive for the remainder of their lives.

Dementia impacts on driving safety and is increasingly prevalent with age. Although a diagnosis of dementia does not mean an automatic license suspension in Canada, (as in the state of Oregon and California in the United States), driving fitness must be evaluated in a person with dementia. Crash risk doubles every five years from dementia onset. The skills that are most impacted include divided attention, visual-spatial skills and speed of response.

Physicians in most provinces (and certain other health professionals, but one needs to verify with their respective regulatory bodies) are responsible for identifying potential crash risk and for notifying the responsible authorities, which in Canada are the Provincial Registrars. There is limited evidence-based research and recommendations on how to properly assess driving safety in persons with dementia in the office. The "gold standard", health professional led comprehensive off road/on road evaluation, is of limited availability and is associated with financial cost to the person with dementia. In most situations the decision to recommend driving cessation to persons with dementia is based on evaluation of cognition as well the impact of other co-morbidities such as poor vision, neurological conditions (Parkinson's disease or stroke) and cardiac (syncope, angina).

The recommendation not to drive can seriously impact on the patient-physician relationship. If this disclosure is not done well it can jeopardize this relationship. Even when disclosure is done well it can lead to isolation, depression, negative emotional reactions and increased caregiver stress.

This guide is meant as a resource for heath professionals who care for older persons with dementia. It includes an assessment algorithm, in- office assessment tools, as well as recommendations on how to disclose and how to support the person with dementia and their caregiver post-disclosure.

ASSESSMENT ALGORITHM/ROADMAP

INITIAL CONTACT WITH DRIVER WITH DEMENTIA

Do the 10 minute Office Dementia and Driving Checklist - page 10

Clearly unsafe

Inform the patient to stop driving (give patient/family written notification and document in chart) (page 17)

Notify the Provincial Registrar - (See Insert Back pocket)

Follow up regarding: (page 17&18)
- confirmation of driving cessation
- Isolation
- Depression
- Use of alternative transportation

Driving risk is uncertain

IF there are dementia-related issues <u>other than driving</u> which assesment and treatment (or if paient truly cannot afford on-road test

Refer to local multidisciplinary dementia assesment site (could include occupational therapy or neuropsychology evaluation)

If still unsure re: fitness to drive

IF driving is the <u>only</u> dementia-related issue to address.

Refer to health professional led comprehensive driving evaluation- on/off road (see Insert Back pocket)

Appears safe

Follow Up

(every 6 - 12 months) (page 15)

FREQUENTLY ASKED QUESTIONS AND ANSWERS FOR HEALTH PROFESSIONALS

Q. What are my legal obligations with respect to driving privileges for someone who is unsafe to drive?

A. In most provinces, every legally qualified medical practitioner (physician) must assess and notify the Provincial Registrar if a medical condition exists that increases the risk of motor vehicle crashes (exceptions are Quebec, Alberta and Nova Scotia). Refer to individual provincial driving authority for regulations. In all provinces, physicians are protected against losing lawsuits brought against them regarding this issue, if they have followed the law. While patients and families can still launch lawsuits or can report physicians to their provincial colleges, physicians are protected from losing such challenges if they have properly followed their provincial reporting duties and process.

Q. What is the responsibility for other health professionals?

A. Other Health Professionals who feel a patient may be unsafe to drive should communicate their findings verbally and in writing to the physician responsible for the care of the patient. If there is no responsible family physician, then they should verify their responsibilities with their respective professional colleges.

Q. What should I do if I am unsure if the patient is safe or unsafe to drive?

A. Refer the patient for further assessment (follow algorithm on page 5) and inform your respective Provincial Registrar that you have arranged for further assessment and that you are unsure of the risk.

Q. Is there a cut-off score on cognitive tests, such as the Folstein MMSE, with which I can determine the level of risk/safety with driving?

A. The MMSE is not sensitive, or specific enough to determine if someone is safe to drive. It is insensitive (i.e. does not detect crash risk early on in a dementing illness) because it does not test executive function, judgement, divided attention, and perception, all of which are vital to driving. As the dementia progresses it becomes more useful. A low score (<20/30) should raise significant concerns regarding fitness-to-drive unless you feel the low score reflects low educational level or a language/communication barrier. Due to its lack of sensitivity to crash risk in earlier stages of dementia, higher MMSE scores are more difficult to interpret. Patients who score more than 20/30 may not be safe to drive and require further evaluation.

Q. What other tests can I use to assess driving safety?

A. Other tools can be used such as those outlined in this toolkit under the " 10 Minute OFFICE based Dementia and Driving Checklist"(page10). Consider other medical conditions (vision, alcohol use, medications) that can impact on driving safety. Ultimately the decision to suspend the license is a clinical decision based on the

evaluation of all the risks. If unsure a health professional led comprehensive driving evaluation-(on/off road test) may be indicated. These are usually not covered by the provincial health plans and cost the patient $500-700 in Ontario (but may be lower in other provinces).

Q. I am unsure but suspect that there may be a significant risk to driving. I am arranging further assessment and have recommended, to the patient and caregiver as well, that the patient not drive until the assessment is completed. Is this sufficient?

A. If there is any **concern that the driver will not stop driving, notify your Provincial Registrar and document this in the chart.**

Q. Based on my initial assessment, I am very concerned about the patient's driving risk and I am certain the person should stop driving immediately. What should I do, knowing there is often a delay before the information is processed by the Provincial Registrar?

A. You should contact the Provincial Registrar and ask for immediate suspension of driving privileges. If you fax the information keep a record of this. Inform the patient (and caregivers) in writing and arrange assessment at the appropriate site if required. Inform the patient and caregiver that, given your findings, the patient may not be covered by automobile insurance in the event of a motor vehicle crash. Refer to material in this toolkit to help you in this process. Document these communications in the patient's chart.

Q. Can I bill my provincial plan for the driving evaluation?

A. A physician needs to check with the respective provincial health plan. For example in Ontario, physicians can bill code K005 for driving counselling and K035 for filling out the reporting form. You can bill "out of basket" for family health teams and organizations.

Q. If someone has dementia and is felt to be safe to drive, when should re-evaluation for driving safety take place?

A: Small clinical trials suggest that in 1 year follow up of drivers previously considered safe, 50% were considered unsafe, thus the Canadian Consensus Guidelines recommend repeat assessment of driving safety every 6 to 12 months.:

(i) if there is felt to be significant cognitive or functional decline, rather than stability, then driving safety should be reassessed at 6 months or

(ii) if there is felt to be clinical stability with minimal deterioration then driving reassessment could reasonably be delayed to 12 months follow up.

2. ASSESSMENT

10 MINUTE OFFICE BASED DEMENTIA AND DRIVING CHECKLIST

(Based on Clinical Opinion and Experience not Evidence. Development lead by and copyright held by Dr. W. Dalziel).

The checklist can take 10 minutes or less to complete as it is not necessary to complete all 10 items if it is obvious the patient is unsafe to drive based on early items.

PROBLEM

☐ 1. **Dementia Type:**
Generally Lewy Body dementia (fluctuations, hallucinations, visuospatial problems) and Frontotemporal dementias (if associated behaviour or judgment issues) are unsafe.

☐ 2. **FUNCTIONAL IMPACT of the Dementia** - According to *CMA guidelines* **Unsafe** if:
- impairment of more than 1 Instrumental ADLs due to cognition
(IADLs = **SHAFT**: Shopping, Housework/Hobbies, Accounting, Food, Telephone / Tools)
- OR impairment of 1 or more Personal ADLs due to cognition (PADLS = **DEATH**: Dressing, Eating, Ambulation, Transfers, Hygiene)

☐ 3. **Family Concerns: (ask in a room separate from the person)**
Family feels safe/unsafe (make sure family has recently been in the car with the person driving)
* The grand daughter question - Would you feel it was safe if a 5 year old grand daughter was in the car alone with the person driving (often different response from family's answer to previous question)
Generally if the family feels the person is unsafe they are unsafe. If the family feels the person is safe, the person may still be unsafe as family may be unaware or may be protecting patient.

☐ 4. **Visuospatial: (intersecting pentagons/clock drawing numbers)**
If major abnormalities – likely unsafe

☐ 5. **Physical inability to operate a car (often a "physical" reason is better accepted):**
Medical/Physical concerns such as musculoskeletal problems, weakness/multiple medical conditions (neck turn, problems in the use of steering wheel/pedals), cardiac/neurologic (episodic "spells")

☐ 6. **Vision/Visual Fields:**
Significant problems including visual acuity, field of vision.

☐ 7. **Drugs: (if associated with side effects: drowsiness, slow reaction time, lack of focus)**
Alcohol/Benzodiazepines/Narcotics/Neuroleptics/Sedatives
Anticholinergic–antiparkinsonian/muscle/relaxants/tricyclics/antihistamine(OTC)/antiemetics/antipruritics/antispasmodics/others

PROBLEM

☐ 8. **Trailmaking A&B: (available at www.rgpeo.com)**
Trailmaking A - Unsafe = > 2 minutes or 2 or more errors
Trailmaking B - Safe = < 2 minutes and < 2 errors (0 or 1 error)
Unsure = 2-3 minutes or 2 errors: (consider qualitative dynamic information regarding HOW the test was performed: slowness/hesitation/anxiety or panic attacks/impulsive or perseverative behaviour /lack of focus/multiple corrections/forgetting instructions/inability to understand test etc.)
Unsafe = > 3 minutes or 3 or more errors

☐ 9. **Ruler Drop Reaction Time test** (Accident Analysis & Prevention 2007; 39(5): 1056 – 1063): The bottom end of a 12" ruler is placed between thumb and index finger (1/2" apart) let go and person tries to catch ruler (normal = 6-9"/abnormal = 2 failed trials)

☐ 10. **Judgment/Insight (Ask the person):**
What would you do if you were driving and saw a ball roll out on the street ahead of you?
With your diagnosis of Dementia, do you think at some time you will need to stop driving?

CONCLUSION:

Safe	Unsafe	Unsure
↓	↓	↘ / ↗
Reassess 6-12/12	Report to Provincial Registrar	If only driving an issue – refer to Specialized On Road Assessment If driving and other dementia related issues refer to specialized dementia assessment services.

(reference Age and Aging 2009 and https://akeontario.editme.com/Driving)

HOW TO EFFECTIVELY FILE THE REPORT TO THE PROVINCIAL REGISTRAR

1. Ensure the driver's full name is listed

2. If possible list the patient's driver's license number. If this is not available, the patient's correct name, date of birth and residential address will be sufficient. Action on behalf of the Provincial Registrar depends on quickly and correctly identifying the driver on the driver data base. Incomplete reports and reports without a driver's license number or date of birth may unnecessarily lengthen time before a Provincial Registrar takes appropriate action.

3. Note the medical condition(s) and physical / cognitive examination findings and why, in your opinion, these conditions indicate the person is at risk of unsafe driving.

4. If the case is considered a high risk – note on the report: "driver unfit to drive". The Provincial Registrar has a review process that identifies high risk cases and expedites them for appropriate action. Physicians need to indicate in their report that the person is unfit to drive and to include sufficient detail on their patient's medical conditions that contribute to the individual being at high risk for driving. For example: that the patient has had uncontrolled seizure, impaired memory (provide testing results), uncontrolled diabetes, advanced Alzheimer's etc.

5. Include in the space provided in the report on the Provincial Registry form: relevant clinical data, results of investigations, frequency of episodes, medications, treatment and prognosis and whether or not the condition is a serious risk to road safety, threat to road safety is unknown or condition is temporary - weeks/months . This information will help the Provincial Registrar take appropriate action.

6. In extreme cases, fax and call the Provincial Registrar (in Ontario: 416-235-1773 or 1-800-268- 1481) and state to the staff person that it is an emergency so that an immediate license suspension can be issued. Note the date and time of this phone call in the patient chart. If the report is faxed, keep a copy for your records and call to confirm the report has been received. Note the time of the fax and phone call in the patient's chart.

3. AFTER THE ASSESSMENT- NEXT STEPS

GENERAL PRINCIPLES - CESSATION TO DRIVE

Recommendations for Health Care Professionals who are caring for patients who have dementia and drive:

1. Before driving cessation become necessary, prepare the patient for the inevitable fact that sooner or later they will lose their license.
2. Understand that normal reactions when one loses their driving privileges may include anger, bargaining, depression, a sense of demoralization. Health care workers need to be prepared to deal with emotions that arise.
3. Be prepared to offer transportation alternatives; discuss subsidized transportation system for persons with disabilities, volunteer drivers, taxis (e.g. these can be much more economical than upkeep of a car if driven< 4000 miles per year).
4. Involve family and caregivers in the discussion; solicit their support and advice regarding how to help the patient accept this difficult recommendation.
5. Recognize your own discomfort in having to discuss this with your patients. Solicit support and evidence from as many sources as necessary.
6. Patients often request information regarding why they cannot drive and they want more detailed explanation of test results. Be prepared to provide concrete information regarding why a patient can no longer drive.
7. Focus on physical problems, such as vision loss or medications. This may make the reason to cease more acceptable to the patient.
8. Be firm, yet empathic and avoid getting into argumentative discussions. Emphasize your ethical and legal responsibility and the fact that dementia is progressive and irreversible.
9. Provide a letter to the patient explaining the reasons for driving cessation. This can help the family refer to a written account of what was discussed, should the patient forget.
10. If necessary explore ways with caregivers to deter the person from driving. This may include removing the keys, disabling or physically removing the car.
11. Referral to another physician such as a neurologist or geriatrician for a second opinion if needed to help preserve the patient-family-physician relationship.
12. Given the negative reactions of some patients (e.g. anger toward the physician, threat of legal action) and the fact that some patients continue to drive despite a recommendation to stop, it is strongly recommended that health care professionals clearly document the date and the content of the discussion regarding driving cessation, as well as the names of the caregivers present.

(ref. Byszewski A, Molnar M, Aminzadeh F. Clinical Gerontologist, in print)

A. STILL SAFE TO DRIVE – BUT NEEDS FOLLOW UP

1. Planning for driving retirement: discuss as early as possible

- That we probably all need to prepare for driving cessation at some point, especially when there is an element of early cognitive loss
- How much do you drive?
- How did you get here today?
- Can you tell me, in your own words, why driving is important to you?
- Have you ever considered stopping driving?
  - ☐ Yes- under which circumstances?
  - ☐ No – would you ever consider it given the diagnosis of dementia?
- What would it mean to you to stop driving?
- If you stopped driving, how would you get around?

2. How to prepare patients to eventually stop driving

- Our patients tell us that being told they need to stop driving is worse than being told they have cancer
- Consider the tips on page 14
- You may want to integrate into your own practice a script such as this:

Mr. T, I know driving is very important to you. Based on the results of your tests, I am concerned that in the future you will likely need to stop driving. To protect your safety and the safety of others, you need to consider the future need to retire from driving…I am sorry…

3. Follow **up:**

- Pre-schedule a follow-up appointment in 6 – 12 months (timing as per MD judgement). Ask family to notify you if the patient deteriorates before this appointment.
- If the patient refuses to return for follow-up, notify the provincial registrar that follow-up is required.

B. UNCERTAIN RISK

Driving risk is uncertain

IF there are dementia-related issues other than driving which require assessment and treatment (or if patient truly cannot afford on-road test).

↓

Refer to local multidisciplinary dementia assessment site-could include occupational therapy or neuropsychology evaluation (see inserts back pocket)

If still unsure re: fitness to drive →

IF driving is the only dementia-related issue to assess.

↓

Refer to health professional led comprehensive driving evaluation-on/off road (see inserts back pocket)

Additional Points:

- **Local multidisciplinary dementia assessment sites** – information enclosed at the back of the folder, or contact the local Ministry of transportation office or Alzheimer Society
- **Health Professional led comprehensive Driving Evaluation sites**(on/off road) – information enclosed at the back of the folder or contact the Provincial Registrar
- Document the discussion with the patient/caregiver in the patient chart
- Document plan of action and how you will follow up on these issues

C. UNSAFE TO DRIVE

DISCLOSURE MEETING: When your patient is unfit to drive: 4 steps to driving cessation

1. Meet with family first. Help them assume a positive and supportive role. Explain concretely and empathically your concern for the safety of the patient and others. Clearly outline your findings that the patient is not fit to drive, and explain that the law requires you to report the patient to the authorities.
Remind family members that the goal of driving assessment is to prevent a collision, and they carry some responsibility because they are aware of the potential risk of letting their family member continue to drive. If necessary, have family members witness a repeat performance by the patient on the most revealing test. Discuss the importance of finding alternate transportation to reduce the risk of isolation and depression that can follow driving cessation.

2. Meet with the patient. Having the family present can be helpful, but ask them to assume a supportive role. Give the patient a positive role by recognizing that he or she has been a responsible driver, and part of this responsibility is to stop driving before an accident occurs. Acknowledge that it is normal to be unhappy upon learning that one's driving privileges are being revoked.
Sometimes it helps to give the patient a prescription in their name that says, "Do not drive." Families who receive a copy may find this very helpful, too, for reminding the patient later about what you said.
If your patient argues with your position, remain firm and do not argue. Indicate that you have made notes on the meeting and are notifying the authorities about the patient's unsafe driving. You can add that your chart could be subpoenaed and the patient may be legally liable and financially responsible should he or she continue to drive and have a collision.

3. Talk about transportation options. Family members could share driving responsibilities. Taxi rides can cost less than maintaining (including insurance, registration etc) a car if the patient drives <4,000 miles per year. Suggest that patients or families find volunteer drivers or contact helpful taxi drivers a day before an outing is planned.

4. If your patient refuses to comply, meet with the family again and encourage them to remove the patient's opportunity to drive (confiscate the keys, disable the car, or remove the car altogether).
Provide a written statement to the patient and family outlining why the patient can no longer drive. Indicate that it is your legal responsibility to report unsafe drivers, and you intend to notify the authorities regarding the patient's driving status. If the patient remains noncompliant, continue to encourage family to remove the opportunity to drive.

(ref. Rappaport and Molnar - reprinted with permission)

EMOTIONALLY SUPPORTING THE PATIENT/CAREGIVER AS A HEALTH PROFESSIONAL

How to emotionally support the patient/caregiver:

a. At disclosure

- Allow person to express his/her point of view
- Be understanding and empathic
- Explain that you are sorry that you need to address this complex issue and that you recognize it will have great impact on their life
- Recognize and validate emotions expressed such as anger or sadness
- Do not argue with the person

b. After the disclosure/follow up meeting:

- Ensure there is a support network for the person after the disclosure
- Try to involve the family in this first follow-up meeting and solicit their support.
- Ask patient if s/he has any questions or concerns regarding the assessment and your recommendation and provide further explanation. Allow them to ask questions and give them a venue to contact you in the future if necessary to clarify reasons for the decision.
- Inquire about the patient adherence with the recommendations to stop driving
- Understand normal grief reactions (e.g., sadness, anger, negotiation, etc.) and give patient the opportunity to ventilate. Be attentive and empathic and try to provide emotional support the patient/family
- If needed reinforce the key messages from the disclosure meeting regarding the reasons for the recommendations
- If there are signs of severe grief reaction to the loss of driving privileges, such as depression, and/or social isolation, refer patient for further assessment and, if justified, treatment (e.g. counseling, medications).
- Recognize the impact on the caregiver as they assume transportation responsibility for the person with dementia
- Make sure that the patient's transportation needs are met and try to address any barriers that they may face in accessing alternative means. You may want to encourage patient/family to develop a transportation plan.
- How to get around without a car: discuss transportation alternatives:
    - Public Transit
    - Para Transpo
    - Volunteer drivers
    - Taxi company vouchers
    - Family/Friends

SAMPLE - WRITTEN STATEMENT TO THE PATIENT

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, compared to people your age, you have an 8 times risk of a car accident in the next year. Even with mild dementia, the risk of a serious car accident is 50% within 2 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. Even with a previous safe driving record, your risk of a car accident is too great to continue driving. Your safety and the safety of others are too important.

..... M.D. ..... Witness

4. RESOURCES

USEFUL RESOURCES

1. CMA guide: Determining fitness to operate motor vehicles (7th edition) – covers all medical conditions that can affect driving with useful recommendations for health practitioners. A separate section on the aging driver and the driver with dementia.

   CMA members are entitled to 1 complimentary print copy. Please contact the Member Service Centre 888 855-2555.

   www.cma.ca/index.cfm/ci_id/18223/la_id/1.htm

2. AMA guidelines : www.nhtsa.dot.gov/people/injury/olddrive/OlderDriversBook

3. Alzheimer Knowledge Exchange: www.DrivingandDementia.org

4. RGPEO website : www.rgpeo.com

5. CanDRIVE program – a Canadian national research team dedicated to developing research into driving as it affects the older driver. The goal is t improve the health-related safety of older drivers.: www.candrive.ca

6. Guide:At the Crossroads – conversations about Alzheimer's disease, dementia and driving: http://thehartford.com/alzheimers/brochure.html

7. Article: Practical Experience-Based Approaches to Assessing Fitness to Drive in Dementia: www.geriatricsandaging.ca/drivinganddementia.

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