Conversations About

Dementia and Driving

The Alzheimer Society of Canada's "Conversations" series was created to help people with dementia, caregivers, and healthcare professionals have conversations about complex and sensitive topics related to living with dementia. This sheet provides information on things to consider when having conversations about driving cessation. To read other issues in the Conversations series please visit www.alzheimer.ca/brochures

People with dementia, caregivers and healthcare providers are encouraged to have conversations about all of the topics in this series early and throughout the progression of the disease. Even though talking about these topics can be difficult, it is only by having open conversations that it will be possible to be better prepared for the challenges that often come with the disease.

Dementia and driving

Driving represents freedom, independence and mobility. Driving a motor vehicle (such as a car or a bus) is a complex and potentially risky activity. Although driving is a privilege, some people incorrectly view it as a right.

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In this sheet you will find information about dementia and driving, including:

- How dementia may affect a person's driving abilities
- Issues to consider when thinking about driving cessation
- Strategies to help the person plan ahead for when driving is no longer considered safe
- Information about driving assessment
- Strategies to help caregivers, people with dementia and healthcare professionals have conversations about driving cessation
- A list of useful recourses

Dementia causes changes that affect a person's ability to safely drive a motor vehicle. However, a dementia diagnosis does not automatically mean that a person is incapable of driving. Some people may be capable of driving safely for some time after the diagnosis, depending on the timing of the diagnosis and how quickly the dementia progresses. Loss of driving skills may only be noticed when driving in unfamiliar environments and in emergency situations, when quick thinking is required. Throughout the early course of the disease, driving skills and abilities must be monitored by the individual, family members, a doctor or other healthcare professional, such as an occupational therapist.

Eventually a person with dementia must stop driving, as it will no longer be safe. While there are different approaches to assessing fitness-to-drive, there is currently no nationwide standardized testing to determine when someone with dementia is no longer safe to drive a motor vehicle. When deciding if a person with dementia should keep driving, it is important to remember that people with dementia who continue to drive when it is no longer safe for them to do so, create an unacceptable risk for themselves and others in the community.

Should the person with dementia continue to drive? Issues to consider

| Loss of independence, freedom and mobility | The loss of the privilege to drive is a major life transition that can have a devastating effect on some people. In order to prevent social isolation and maintain quality of life, it is important that people with dementia remain active members of their community. | | | |
|--|---|--|--|--|
| | When driving is no longer considered safe, a transportation plan for the person with dementia needs to be put in place to help them participate in their usual activities, including those enjoyable social activities that make life worth living. Although alternative transportation options may be relatively expensive, maintaining a vehicle and paying car insurance are also costly. | | | |
| Safety of the person with dementia and others | Although losing the privilege of driving can be difficult, it is important to remember that it can be equally, if not more devastating, to be involved in a motor vehicle collision. A collision can result in serious disability or death for the person living with dementia or in trauma and death of others. When deciding if the person with dementia should continue driving, families and caregivers should keep in mind the risk and consequences of the person with dementia getting into a motor vehicle collision and should acknowledge their social responsibility to not put other members of society at risk. | | | |

When deciding if the person with dementia should continue to drive, remember that losing the privilege to drive will make some people feel angry, sad, frustrated or hopeless. Having conversations about driving cessation will not always be easy, and it may add a strain on the relationship between the caregiver and the person with dementia. Refer to section "*Having conversations about driving cessation*" on page 5 for more information about how to have these difficult conversations.

When the person is still able to drive: plan ahead

To help you plan ahead for the time when driving must stop, consider the following:

- Talk to the person with dementia to find out when they most need to drive. For example, do they drive to medical appointments, to shop, to meet with friends?
- Have a discussion about alternative forms of transportation such as public transit, taxis, services provided by community organizations, and transportation organized by family members and friends.
- Have the person with dementia use alternative forms of transportation while it is still safe for them to drive. This will help them have a gradual transition to driving cessation.
- Look into companies that offer home delivery services, such as pharmacy or grocery home delivery services.

A toolkit for people in the early stages of dementia and their caregivers called, "Driving and dementia toolkit: For patients and their caregivers" has been created to keep drivers on the road safe and to prepare those who are starting to notice that the person with dementia should not be driving anymore. The toolkit can be accessed at www.rgpeo.com/dementiatoolkit

Use these questions to help guide your decision:

| | Yes | No | Sometimes | l don't know |
|--|-----|----|-----------|-----------------|
| Is the person able to respond quickly and accurately? | | | | |
| Does the person have the ability to stay focused in stressful situations (for example, finding a destination in an unfamiliar place)? | | | | |
| Can the person divide and maintain attention safely? (for example, watching traffic lights, or talking to someone sitting on the passenger seat while paying attention to the road) | | | | |
| Has the person shown any lack of good judgment? | | | | |
| Does the person understand the rules of the road? Can they be recalled quickly when needed? | | | | |
| Is the person able to find a destination and remain calm when lost? | | | | |
| Does the person have adequate eyesight and hearing? | | | | |
| Can the person recognize and admit that driving abilities have been lost? | | | | |

When driving is no longer considered safe

Signs that a person's driving abilities are declining include:

- Slow response times
- Traffic violations
- Collisions
- Taking too much time to reach a destination or not reaching the destination at all
- Driving too slowly or too fast
- Driving through stop signs or red traffic lights
- Stopping at green traffic lights
- Having difficulty merging with traffic
- Making left hand turns in the face of oncoming traffic and pedestrians crossing the intersection

Driving must be stopped immediately if there are safety concerns.

Driving assessment

When driving becomes a concern, look into the availability of a driving assessment. This could include a road test conducted by someone with experience in assessing drivers with cognitive problems. If an onroad driving assessment is not available, enlist the help of a doctor (primary care physician or specialist) to determine if and when the person is no longer able to drive and to be connected to available support and resources. The health care provider may ask the person and family member's questions about:

- Driving patterns (when and where the person drives)
- Any differences noticed in driving skills
- Any unsafe or abnormal driving behaviour
- Traffic tickets (for going too slow, too fast, improper turns, failing to stop)
- Crashes, fender benders or near-misses
- Instances where the driver has been lost
- How comfortable the person or family members feel about the person's driving abilities

The role of doctors

Doctors are bound by law, in most provinces, and by professional ethics, to report medical conditions that could be a serious risk to road safety. They also may be held liable if a person in their care who has dementia is involved in a motor vehicle collision and they have not reported the person's medical condition to provincial licensing authorities.

Doctors are not the ones who determine if the person with dementia is fit to drive. Doctors forward their medical opinion to the Ministry of Transportation and the Ministry of Transportation determines if the person should continue driving.

Having conversations about driving cessation

Within families, there may be disagreement about when the person with dementia should stop driving. Some family members may believe that the person should stop driving immediately upon diagnosis. Others may be inclined to overlook some risky driving behaviours in favour of maintaining the person's sense of independence, and to avoid conflict.

Family members and caregivers often find it difficult to suggest to the person with dementia that they should stop driving. They may fear that bringing attention to the person's loss of abilities and the need to stop driving may create difficulties in the relationship.

As the dementia progresses, the person's ability to reason and to engage in rational thinking may be impaired. Remember to take into consideration the person's ability to understand and appreciate the consequences of their actions when talking to them about driving cessation.

These are common reactions by people with dementia to driving restrictions:

- Immediate acceptance: Some will recognize that their abilities have changed and may limit their driving or stop driving on their own.
- Refusal and denial: Some may refuse to accept losing their driving privilege or simply forget that they are no longer able to drive.
- Others will accept the decision more readily if it is discussed openly in a trusting environment or if someone with an objective opinion (such as a doctor or another healthcare professional) explains to them why driving may no longer be safe.

Consider the following when talking to the person with dementia about their ability to drive:

- Have a doctor or another member of the health-care team, such as an occupational therapist or a social worker, talk to the person with dementia about the risks of driving. These discussions should not interfere with the provision of health care or support, which may happen if the person with dementia becomes angry with the doctor and fails to return for future appointments.
- Contact your local Alzheimer Society for support in having these difficult conversations.

If after having an open discussion about the risk of driving the person with dementia still does not want to accept the loss of driving privileges, then it may be necessary to use other means to prevent the person from driving, such as asking to move the car elsewhere for storage or repairs, or recommending that the person with dementia gift the car to a family member as a form of 'pre-heritance' (inheritance prior to death).

For more information about driving and dementia contact your local Alzheimer Society at 1-800-616-8816 or visit www.alzheimer.ca

Useful resources:

The Driving and Dementia Toolkit, the Champlain Dementia Network and the Regional Geriatric Program of Eastern Ontario, June 2009. Also available at: http://www.rgpeo.com/en/health-care-practitioners/resources/driving.aspx

Dementia and Driving Resource Centre from the Alzheimer Association of the US. Realistic scenarios to help families start the conversation about driving. Available at: http://www.alz.org/care/alzheimers-dementia-and-driving.asp

Driving and Dementia, a webinar hosted by brainXchange, focuses on how dementia affects the ability to drive and on the evaluation process to assess fitness-to-drive. Available at: https://vimeo. com/126498593

Driving and dementia, an online video with strategies for caregivers from the Alzheimer Society of B.C. Available at: https://www.youtube.com/watch?v=9rmt_Fs9RYg&lr=1



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