Down The Road

An Interactive Toolkit for Caregivers About Driving

DVD Viewer Guidebook



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About Down the Road

Background and Content:

xperiencing declines in thinking abilities, receiving a diagnosis of dementia, or undergoing many of the other age-related changes in older adulthood can be frightening, overwhelming, and confusing not only for the person affected but for family and friends as well. Many issues need to be considered including the person's ability to safely drive a car. Down the Road aims to promote thought, discussion, and guidance for caregivers about navigating the topic of driving safety and cessation with their loved one. It is the first of its kind to use an interactive approach built around a theatre production titled, No Particular Place to Go, to bring to life the issues and struggles facing older adults and their families surrounding driving.

Down the Road consists of the 50-minute DVD, No Particular Place to Go, an accompanying viewer guidebook, and cards with information specific to your community. The content of the toolkit was developed through information from scientific studies and agencies concerned with traffic safety, as well as from ideas and themes emerging from focus groups and individual interviews with informal (e.g., family members) and formal (e.g., health care providers) caregivers. As a result, this research-based toolkit represents the expressed needs and suggestions of caregivers themselves.

About the DVD:

No Particular Place to Go is an applied theatre production that explores the impact of the issues surrounding older driver safety on an ordinary family. The production was collectively devised from data derived from an interdisciplinary research project, similar to the process described above, and later adapted to DVD format. The end result, No Particular Place to Go, depicts the lives of three fictional characters from a close-knit loving family: a single mother (Joanne), a young adult son (MJ), and an older adult (Grandpa). They lead an ordinary life until guestions are raised about Grandpa's driving. As the family struggles to deal with a number of multifaceted challenges, the underlying issues involved in older driver safety begin to surface.

How to Use the Toolkit:

own the Road is intended for use in educational workshops where a facilitator is present to guide the discussion with caregivers. It is possible, however, for a caregiver or anyone with concerns about how to navigate the topic of driving with an older adult to use the toolkit independently. It is important to note that the purpose of the toolkit is to promote open dialogue about older driver safety. It is not intended to provide definitive solutions or positions.

When watching the DVD, follow along in the viewer guidebook as pausing places are suggested for opportunities for discussion. First, questions are raised to facilitate conversation, then background information is provided for each of the eight major content areas or pausing places to supplement points that may be generated from the discussion questions. Facilitators can read the background information prior to leading a group so the material can be provided to caregivers as needed. Facilitators are also welcome to pose their own questions or may have the group identify issues that require additional research as 'homework' (e.g., reporting procedures in your jurisdiction, gathering information about community resources). Consult the cards in the left pocket for assessment procedures and resources in your community.

Facilitators should note that the DVD contains content specific to British Columbia, Canada, the region of production. In the DVD, Joanne makes reference to "ICBC", the Insurance Corporation of British Columbia, and MJ suggests Grandpa take a refesher class through "BCAA", the British Columbia Automobile Association. Issues of insurance, licensing, laws, and refresher courses differ by province/state and facilitators may wish to alert the audiences to this reference and regional differences before viewing the DVD to avoid confusion.

Online Access:

Toolkit: www.coag.uvic.ca/resources_research Down-the-Road.html

DVD:

www.donchaput.com/content/no-particular-place-go

Importance of Driving

CHAPTER 1: (~ min 3:20 to 5:22)

Grandpa discusses how important owning a car and driving is to him: "Back then, everybody took pride in their cars. The car was important ...it was a symbol ... independence, wealth, power ..."

QUESTIONS:

- In your view, what are the traditional values enshrined in the symbolism of the automobile? What views does your loved one hold?
- How do emotional ties to driving impact the driving cessation process?

CHANGING THE EMPHASIS:

 What if the main character of this story was Grandma instead of Grandpa? How might these issues be the same and/or different?

The title of the DVD. *No Particular Place to Go*, is taken from Chuck Berry's 1964 hit song, which tells the story of a date that goes wrong because of a malfunctioning seat belt. Driving around aimlessly, or cruising, was part of North American culture in the 1950s and 60s and many songs from that era extol the virtues of the automobile and its place in the lives of young people at that time. Today, most of the baby-boomer generation view owning a car as a symbol of independence, freedom, and power (Gardezi, Wilson, Man-Son-Hing, Marshall, Molnar, Dobbs, & Tuokko, 2006). Additionally, driving has been linked to a sense of personal identity, control over one's life, and belonging to a larger community (Gardezi et al., 2006). These views appear to be even stronger for men compared to women as men from this cohort have traditionally been the main drivers in households with more experience and confidence (Kostyniuk & Shope, 1998). However, these trends may be changing (Bush, 2005).

The Assessment Process

CHAPTER 3: (~ min 11:00 to 13:45)

Joanne sees that Grandpa received a letter from the Office of the Superintendent of Motor Vehicles requiring him to complete medical examination.

QUESTIONS:

- Who do you feel is responsible to intervene when there is a question of driver safety?
- What are the regulations and procedures in your jurisdiction?

CHANGING THE EMPHASIS:

• Imagine MJ says to Joanne, "It's not your responsibility, Mom. We pay taxes for the government to deal with this. If no one else is doing anything about it, why should we?" What implications would this hold for society? For Grandpa?

The issuing of driving licenses falls within provincial or state jurisdiction. Each province/state regulates the terms under which licenses are granted, refused, or suspended. Although anyone, including family members, friends, concerned citizens, doctors, and other healthcare professionals, can report unsafe drivers to the governing body, it is ultimately the decision of the governing officials to take a person's license away if he or she is deemed "unfit" to drive. "Fitness" to drive is automatically assumed once a person passes the examinations required to obtain a valid license and renewals are generally granted without follow-up.

However, an individual with known or suspected medical conditions may be required by the licensing authority to have further medical or functional evaluations before a license is renewed as the presence of health-related conditions has been shown to increase a person's risk on the road (Canadian Medical Association, 2006). Additionally, as people age they may accumulate medical conditions that can adversely impact their ability to drive safely (Ontario Ministry of Transportation, 2004). As a result, if concerns are raised, a medical doctor believes a person's driving abilities are compromised, and/or the driver is above a certain age (differs by jurisdiction), then medical or functional examinations are required. Therefore, while a diagnosis of dementia does not automatically mean a person will lose his or her driving privileges, it may result in the requirement of additional medical and functional tests.

Unfortunately, to date, there are no standardized assessment protocols for doctors to use to evaluate driving abilities, so often specialized follow-up examinations, including on-road testing, may be needed. Failure to complete these required examinations results in a denial of driving privileges. Since it is illegal to drive without a valid license, anyone found doing so is not covered by insurance and is in violation of the law and therefore subject to the penalties. Please refer to the card the left pocket titled *The Assessment Process* for details about the regulations and procedures specific to your jurisdiction.

Refreshing Skills

CHAPTER 3: (~ min 14:03 to 18:15)

MJ and Grandpa run through a mock "on-road" examination. At the end of the scene, MJ suggests that Grandpa's driving skills may need to be refreshed.

QUESTIONS:

- Should older adults with declines in their thinking abilities refresh their driving skills?
- How can older drivers check/upgrade their skills and learn about their level of competency?
- Would your loved one be willing to learn about or update his/ her driving skills? How could you present the idea if he/she is resistant?

CHANGING THE EMPHASIS:

• Imagine Grandpa is showing more advanced signs of dementia (e.g., increased forgetfulness, clouded judgment, problems with awareness), causing Joanne and MJ to become increasingly concerned about Grandpa's safety on the road. Grandpa insists on taking a refresher course so he can continue driving. How should Joanne handle this situation?

A number of different types of assessments, retraining courses, and workshops are available for people of all ages. Many cater to older drivers who are preparing for an upcoming license re-examination. They may include instruction on the road as well as in the classroom. Limited research is available about the effectiveness of these programs but studies have shown promise in terms of their ability to increase driver awareness and improve driver behavior (Kua, Korner-Bitensky, Desrosiers, Man-Son-Hing, & Marshall, 2007). It may also be helpful as a caregiver to read the driving manuals issued by the province or state for a reminder about the knowledge and skills that are needed for safe driving.

If your loved one is resistant to the idea of taking a refresher course and going to a driving school for a baseline assessment, you may consider refreshing your own skills and going through your own assessment so your loved one is not singled out. After all, we can all benefit from updating our skills now and again!

Please refer to the card in the left pocket titled *Refreshing Skills* for a list of senior-friendly options in your area.

Risk Factors & Warning Signs

CHAPTER 5: (~ min 18:42 to 21:10)

Joanne lists some problems associated with aging, like declines in thinking skills, and how they impact driving.

QUESTIONS:

- List the driving infractions identified during the play. Which of these do you consider to be serious causes for concern? Do you think they warrant intervention? Why or why not?
- What risk factors are associated with unsafe driving?
- How does dementia affect driving?

CHANGING THE EMPHASIS:

• If Grandpa has been given a diagnosis of dementia, what are the implications for the family? For Grandpa and his driving?

As we get older, there are many normal age-associated changes that can affect driving abilities including problems with sensory (e.g., poorer vision, hearing), physical (e.g., slowed reflexes, decreased range of motion/flexibility, decreased muscle strength), and cognitive (e.g., slowed processing speed, poorer memory) functioning (Anstey, Wood, Lord, & Walker, 2005). On top of these risk factors, taking medication, having medical conditions, and the development of other disorders, like dementia, have been linked to unsafe driving practices and increased risk of crashes (Anstey et al., 2005).

"Dementia" is a broad term used to describe a cluster of disorders affecting thinking and memory in individuals. The most common type of dementia is Alzheimer's Disease (Alzheimer's Association, 2011). Although symptom presentation differs between the various types of dementia, stage the disease process (mild, moderate, severe), and even between individuals, everday functioning is likely to be affected, including driving, especially as the disease progresses.

Here are some observable warning signs that your loved one may be unsafe on the road (Kingston, Frontenac, Lennox, & Addington Dementia Network, 2013):

- Involvement in car crashes or mild "fender benders".
- Receiving traffic tickets/violations.
- Getting lost while driving to familiar places.
- Forgetting where he or she is going.
- "Near misses" with other vehicles, pedestrians, or objects without realizing it.
- Needing a passenger to as a "co-pilot" to navigate/point out hazards.
- Other drivers honking or getting angry.
- Running stop signs/lights without realizing it.
- Confusing the gas and brake pedals.
- Going the wrong way against traffic.
- Merging without looking.
- Wandering over lanes lines.
- Passengers feeling uncomfortable in the car or refusing to drive with the person.

Starting the Conversation

CHAPTER 5: (~ min 21:11 to 22:23)

This is the first time Joanne starts the conversation about driving cessation with Grandpa by expressing her concerns and suggesting that Grandpa give up his license.

QUESTIONS:

- What are the pros and cons of how Joanne handled this conversation?
- How would you feel if you were in Grandpa's situation?
- How would you, or have you, started the conversation with your loved one? If you have had this conversation, what worked? What didn't?

CHANGING THE EMPHASIS:

• Imagine Joanne anonymously reported Grandpa. What ramifications would these actions have? What steps can be taken to faciliate the most positive outcome?

The topic of driving restriction and cessation is one that many older adults face (Baldock, Mathias, McLean, & Berndt, 2006). Although a person in the early stages of dementia may still be safe on the road (Fox, Bowden, Bashford, & Smith, 1997), due to the progressive nature of the disease and its affect on the abilities critical to safe driving, planning for eventual cessation must occur. At any point, this may be a difficult conversation for drivers, family members, friends, and health care professionals to have. Coming to the realization that one cannot drive and how to work around that loss is something that takes time. As a result, it is important to start the conversation early, even before concerns may be prominent, and re-examine the topic often.

Consider the following suggestions on having the conversation:

Note: It may only be possible to use only one or two approaches per conversation so as not to overwhelm the older driver. Additionally, the driver's personality and family dynamics need to be considered when using any suggestion.

- Be calm, respectful, open, and straightforward.
- Include important people involved in the older driver's life.
- Plan a specific time to have this conversation together.
- Schedule an appointment with a doctor to discuss.
- Family members, friends, and healthcare professionals should agree and provide consistent information.
- Strive for a collaborative conversation. That is, involve your loved one and provide him/her with a sense of autonomy and decision-making.
- Ask for and listen to your loved one's views (e.g., what it means to drive and give it up, the impact of not driving) and feelings (e.g., fears, worries, sadness). Be sure to validate what your loved one says. Remember that validation does not need to mean agreement.
- Share your personal views and feelings about driving as well.
- Gently voice concerns about the driver's own safety, the safety of others on the road, and the consequences of continued driving.
- Highlight the things in his/her life that are working.
- Come prepared with alternative options to propose (see the *Alternatives to Driving* section and cards in the left pocket for suggestions).
- For a quick reference of phrases to help you start the conversation, please refer to the card in the left pocket titled *Conversation Starters*.

Dealing With Resistance

CHAPTER 3: (~ min 24:26 to 25:37)

"I can't give up my car", says Grandpa as he talks to his wife, Sarah. "It's a man's god given right and no one is going to tell me what I can and cannot do". Throughout the story, Grandpa is adamant that he will not give up driving.

QUESTIONS:

- What makes Grandpa so adamant that he will not give up driving?
- How do Joanne and MJ handle Grandpa's reluctance?
- What would you do if you were concerned about a loved one's driving but he or she was resistant to change?

CHANGING THE EMPHASIS:

• What if Grandpa was willing to give up his driving but was concerned about how to get his needs met? What strategies might Grandpa, Joanne, and MJ employ?

Many older adults, including individuals with dementia, gradually self-restrict their driving and decide to give up driving on their own accord (Baldock et al., 2006; Hartford, 2010). However, since insight, awareness, and self-monitoring skills are often compromised in someone with dementia, especially in the later stages of the disease (Tomaszewski Farias, Mungas, & Jagust, 2005), some older drivers with cognitive difficulties insist on driving even when their abilities are impaired (Aronson, 1988). From caregivers and health care professionals' perspectives, dealing with resistance presents one of the most challenging situations they can encounter around the topic of driving. Resistance can take the form of denying problems, insisting they are safe, refusal to comply with recommendations or mandated evaluations, anger towards a caregiver, and even aggression. In these cases, it is especially important for family, friends, and healthcare professionals to work together. Certain times, resistance may be closely tied to a memory deficit, whereby placing large notes on the wheel stating "Do Not Drive" might be enough to thwart a person's continued efforts to drive. In other cases, more drastic measures like taking away a drivers license, removing the car keys, saying the keys are "lost", having new keys made, disabling the car, or selling the vehicle might need to be taken, although these options should be a last resort as they strip the driver of dignity and autonomy in the process.

Support System

CHAPTER 3: (~ min 22:16 to 29:39)

It is clear Joanne is under a lot of stress. She reaches out to MJ for support by talking with him about her concerns and intentions.

QUESTIONS:

- Why is it important for Joanne to have a support system during this time?
- How else can Joanne receive support?
- Who can you draw on for support?

CHANGING THE EMPHASIS:

 What supports do you predict Joanne will need down the road if Grandpa's cognitive, physical, and sensory problems worsen?

Often times, making plans for driving cessation falls to the caregiver (Perkinson et al., 2005), which has been shown to be an issue of considerable concern for individuals in this role (Wackerbath, 1999). Unfortunately, there is no widely accepted guideline for caregivers or clinicians to follow to help make these important and challenging decisions. As a result, caregivers are faced to make these decisions with little or no assistance. This added stress and responsibility can affect caregivers' mental and physical health. Caregivers have been shown to be prone to feelings of social isolation, depression, anxiety, and guilt around their abilities to manage the declining functions of individuals with dementia and are at a higher risk of medical illnesses than non-caregivers (Galvin, Duda, Kaufer, Lippa, Taylor, & Zarit, 2010; Gruffydd & Randle, 2006; Mahoney, Regan, Katona, & Livingston, 2005; Sanders, Ott, Kelber, & Noonan, 2008).

These facts underscore how important it is for caregivers to receive support. It is of utmost importance for the caregiver, family, and doctor/healthcare provider to be "on the same team" to provide support for each other. Additionally, caregivers can turn to family, friends, or other members in their social support system to share their concerns, give and receive emotional support, and organize respite. Counselors in the community are another great resource to provide added support.

Alternatives to Driving

CHAPTER 8 & 9: (~ min 41:49 to 42:35)

Joanne lists the benefits of taking taxis over owning a car. MJ lets Grandpa know about the public service of handyDART, and the Mature Drivers course offered through BCAA. He also says he is going to take the bus, prompting Grandpa to think about using this alternative.

QUESTIONS:

- Why might a driver be reluctant to use alternative forms of transportation?
- What are some of the reasons older drivers keep driving perhaps beyond the time when it is safe to do so?
- What are the benefits to using alternative options?
- What alternatives to driving are there in your community?
- Do you have a plan in place for when your loved one is no longer able to drive?

CHANGING THE EMPHASIS:

 If Grandpa was in a moderate to advanced stages of dementia, what alternative options could be appropriate for him to use?

The loss of driving needs to be replaced by another option. Fortunately, in many communities, a number of different alternatives for older adults are available and generally viewed as viable and important resources in the community (Allan & McGee, 2003). Alternative transportation options include public, volunteer, and private services, as well as independent methods (e.g., walking). In addition, there are many grocery stores and companies that provide delivery services if a senior is no longer able to drive to get their groceries or prepare their meals. Please refer to the cards in the left pocket for detailed descriptions and contact information for these alternative options in your community. The *Transportation Comparison* card shows the cost-savings for using some of these alternative options compared to the expenses of owning a personal vehicle.

When thinking about the transition from actively driving to limiting or stopping driving, it is important to plan ahead and think about and discuss the available options in advance. It may be helpful to consider the person's weekly needs (e.g., grocery shopping, attending medical appointments, socializing and activities) and how these needs can be met (e.g., grocery/meal delivery services for shopping; volunteers drivers, a companion from a private service, or family members for medical appointments; taxis, public transportation buses, or carpooling with friends for social activities). It is also important to consider the capabilities of the person and which alternative options provide enough support. Perhaps a person with mild declines in thinking abililties is still able to navigate public transportation services; whereas an individual in the more advanced stages of dementia may need a personal companion to take them to medical appointments and sit in on the sessions to accurately report back to family members if they are unable to attend.

General Discussion Questions

- How did the process of discussing Grandpa's driving safety unfold over the course of the story?
- "I'll try not to drive like an 'Old Person'", says Grandpa. Are older adults the only people at risk on the road? How is this depicted in the DVD?
- How does ageism play into our views of older drivers in our society? What examples of ageism exist with respect to older drivers?
- How can we guard against older driver ageism on both a personal and professional level?
- Are older adults more responsible than middle-aged or younger persons when it comes to maintaining their driving skills? (e.g., observation of hazards, stopping patterns, shoulder checking)? Discuss.
- Do you think the symbolism surrounding the automobile has changed over time?
- Is driving a right or a privilege?
- What is the correct balance between ensuring public safety and protecting individual rights?
- How can family members and healthcare professionals work together to best support an older adult who needs to give up driving?
- Every family has different ways of interacting with each other. How can family dynamics affect the driving cessation process for an older driver?
- What events would need to take place to ensure a healthy outcome for Grandpa?
- Can you identify any other issues related to older driver safety that were not addressed in the DVD?

Notes

Toolkit Acknowledgements

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