

Session 3

AT THE CROSSROADS

Knowing Your Options



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Session 3. *Knowing Your Options*

(Note: Although two hours are allotted for this last session, the three lessons are relatively short, compared with previous lessons. This gives you more leeway for participant comments and for refreshments at the end.)

Welcome to our third and last session of *At the Crossroads*. Today we will learn:

1. How can we add driving issues to other advance planning measures?
2. What can we realistically expect from doctors, and how can we encourage physician support?
3. What are some last resort options for when an immediate and serious risk is present?

Review

You're here because you want to handle driving concerns in the most sensitive and safest way possible. Each of you has your own story on how difficult it can be for a person with dementia to limit or stop driving. We realize that:

- The person's judgment is impaired.
- The person's self-identity may be closely connected to driving a car.
- Holding on to the car is a way to hold on to being a fully functioning adult.
- Driving provides a sense of independence that is difficult to give up.
- Transportation alternatives to driving are not as convenient.

We want to preserve the dignity of the person with dementia, while averting situations that compromise safety. Our approach has been to:

- Involve the person with dementia in the planning.
- Have multiple conversations over time.
- Consider the physical and social needs of the person.
- Encourage support from others.
- Limit driving, not living.
- Facilitate, not dictate, changes.
- If possible, make the end to driving a gradual process of evaluation and reduction in driving.

Experiences

So far we've assessed driving ability, activities and alternative transportation. We've planned conversations and looked for additional support.

What were some of your experiences this past week with any of these? ——*

(Additional probes:)

- What progress have you made in observing, discussing or planning? ——
- What have you noticed and documented in your observations of driving? ——
- Have you identified any new social activities? ——
- What new transportation support have you identified or put in place? ——
- How have you implemented changes? What obstacles are you facing? ——
- What has worked or not worked for you? ——

* Instructor's questions that invite participant comments are designated by long dashes (——).

- How are you managing to get more support from others? ———
- Do you feel more confident about broaching the subject with your relative with dementia or others? ———
- Who have you talked to and how did it go? ———

Transition to Lesson 7

Our next lesson will address the question: How can we make driving a matter for advance planning?

LESSON 7. Agreement with My Family: How can driving be included in advance planning?

Introduction

Legal advisors tell us to plan ahead. Our wills direct others how to handle our estates. Powers of attorney name those we want to make legal and financial decisions for us. Advance medical directives tell healthcare providers which emergency measures we want or don't want. Informal statements may outline our funeral requests. What types of advance planning have you done for yourself or your relative? ———

How has this gone? How did your loved one react to this? ———

How does advance planning help the family? ———

How can we direct family members if a cognitive impairment affects our judgment and driving skills? (**Distribute and read handout “Agreement with My Family about Driving.”**)

This document provides an opportunity for the person with dementia to discuss his or her desires about stopping driving. It gives family members advance directions for when cognitive impairment makes a person's driving no longer safe.

(Read aloud agreement form.)

“Agreement with My Family about Driving” handout in back pocket of this guide.

FOR THE FAMILY

SESSION 3: Knowing Your Options LESSON 7

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:

 THE HARTFORD

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Using this approach has some benefits and limitations. First, what advantages do you see? —— (Use participants’ comments to emphasize key benefits.)

- The person with dementia can have some sense of control by being involved in the decision-making.
- The agreement opens the door for the person with dementia to express feelings about driving, whether or not he or she agrees to signing it.
- It doesn’t restrict driving at the moment of signing.
- The person with dementia designates the individual he or she wants to be primarily responsible for driving safety issues.

- It focuses on the disease, not the individual, as the reason for driving restrictions.
- For caregivers, this information may provide a sense of support or authority to correct unsafe driving situations in the future, even if the person with dementia later objects to the intent of the agreement.
- It allows families to agree on a course of action before a crisis and while the loved one is capable of making decisions.
- The agreement form could be used with family members to discuss the need for planning for future transportation needs.

What are some limitations of this approach? ——— (Use **participants' comments to emphasize key limitations.**)

- The document is not a legal or binding contract (which is both an advantage and disadvantage).
- A person with dementia may not grant advance permission for someone to stop him or her from driving.
- It doesn't ensure that the person with dementia will later remember or readily comply with the agreement.
- The signed statement doesn't answer the question of when driving should stop.

Can you think of how you could present the agreement so that your relative would be more receptive? ——— (Use **participants' comments to emphasize key points.**)

- Choose an appropriate time and place to introduce the agreement.
- Perhaps introduce the agreement, but hold off any discussion for a later time.
- Reassure your loved one that you want him or her to drive for as long as it is safe.
- Keep the conversation positive.

- Listen attentively, especially about issues of dependency and the personal importance of driving.
- Don't try to force an agreement.
- Remember the objective is not to “win” an argument, but to come up with a plan together.
- Mention that authorities on dementia and driving recommend talking about the agreement.
- Silence or a simple acknowledgement can be more effective than a wordy rebuttal.

How do you think your relative would react to this document? ——

What objections might your relative raise? ——

How might you respond to such objections? ——

Transition to Lesson 8

We want to talk about the role of doctors – and what they can and cannot do. Can doctors know when a person should stop driving? Can doctors make a patient stop driving? What legal and professional limitations do doctors face? How can you increase the chances of a doctor being helpful? These are addressed in our last lesson, after our break.

Break 15 minutes

LESSON 8. The Role of Healthcare Providers: What can I expect from doctors?

Introduction

In general what have been your experiences working with doctors? ——

Have any of you already approached a doctor about driving concerns? If so, what happened? —— (**Connect participants' experiences to what will be covered in this lesson.**)

Research conducted by The Hartford and the MIT AgeLab found that besides family members, older adults are most likely to listen to their doctors about driving restrictions. So involving the physician will probably increase your chances of success in stopping the driving and relieve some of your burden.

If you haven't already done so, make sure the person with dementia sees a neurologist who specializes in cognitive problems. A physician can rule out treatable causes of confusion and mood change such as effects from medications, depression and nutritional imbalances. If you establish a good relationship with the doctor in all aspects of treatment, he or she is more likely to work with your family on driving matters.

It's important to establish lines of communication with doctors early in the disease process. Some doctors will involve the caregiver in discussions, but you may need to initiate discussions and be present during medical care of your relative. Knowing what to expect from doctors and how to work with doctors will help to avoid unrealistic expectations.

Why Doctors May Avoid Driving Issues

Why might some doctors be hesitant to get involved with driving issues?

There are several possible reasons:

- Doctors simply don't have an effective way to assess the level of impairment, especially at earlier stages of the disease. Don't expect a yes-or-no answer to the question, "Do you think my loved one is safe to drive?" Without first-hand knowledge of driving behaviors and clear medical standards for safe driving, doctors often feel ill-equipped to advise patients or give definitive answers to questions of driving safety. This is an added reason for family members to document observations over time and to share observations with the doctor.
- Doctors avoid "getting involved" in issues that are not directly related to medical treatment. Many doctors consider driving concerns to be the responsibility of the family or state motor vehicle agencies.
- Doctors don't want to risk damaging their patient's trust by offending that patient or stepping into an adversarial family matter. Maintaining a cooperative, reasonable position with the doctor and the person with dementia will help everyone to work together as problems develop.
- Doctors don't have the time to take on potentially time-consuming issues that are beyond their expertise.
- Federal privacy laws prohibit doctors from sharing information with others, including family members.

Legal Requirements

What legal documents do families need before talking freely with doctors? Ideally, a family caregiver should have two legal documents – HIPAA and a healthcare power of attorney, also known as a healthcare advance directive or healthcare proxy. How many of you already have implemented either of these documents? ——

(Bring a sample copy of both forms. While HIPAA forms may be standard, healthcare proxy forms often vary by state. Option: Have someone in the group explain these documents, making certain key points are covered.)

HIPAA. First, family members need to have the person with dementia sign a HIPAA release form, which allows healthcare providers to share patient information with designated family members. (HIPAA is a federal law designed to protect individuals' private health information. It is an acronym for the Health Insurance Portability and Accountability Act of 1996.) Without the signed HIPAA form, doctors can share information with family members only as it directly relates to their involvement in care. Family members can ask for a form when visiting the physician. Each doctor needs an original, signed HIPAA form.

Healthcare Proxy or Directive. Second, persons with dementia need to complete a healthcare power of attorney, known as a healthcare advance directive or healthcare proxy. This advance directive can facilitate the coordination and compliance of care. It appoints a patient's representative to make most health-related decisions at the time when the doctor determines that the individual is no longer capable of making such decisions. Forms that comply with state laws are available over the Internet and at local hospitals. You need two adult witnesses to the signing of this document. Copies of the document should be given to doctors, family members and others involved in legal and health-related decisions. Actually, we should all have a designated healthcare agent in the event of an emergency or incapacity. Having others in the family show copies of their own advance healthcare planning form may help a person with dementia not feel singled out.

If the person with dementia won't sign the healthcare directive and the HIPAA release, family members can still give information to the doctor about the patient. HIPAA regulations control the information that health professionals can tell families, not what family members can tell doctors. Family members can let the doctor know that they realize doctors cannot share detailed information with them, but that they want to pass on observations that may be helpful. This can be done in person, over the phone or in a note or letter.

What to Say to a Doctor

We've considered ways to approach a conversation with our relative, trying to be sensitive to when, how and what we discuss. We need to give similar attention to how we approach a physician. What pointers would you suggest in approaching a doctor? ———

Suggestions:

- Explain that you (the caregiver) are concerned about driving and ask if the physician plans on addressing this issue with your loved one. If not, ask why.
- Without the patient present, provide the physician with written documentation about the driving changes you've seen. You can use the warning signs form, noting the frequency and context of warning signs, changes in driving patterns and any increased agitation during driving.
- Ask if you can make a separate appointment, or come in early, to allow for time to discuss this issue.
- Ask the doctor his or her insights into health conditions or medications that have an impact on driving skills.
- Possibly seek out other healthcare professionals such as occupational therapists who can provide the family and physician their assessment of driving abilities.
- Consider a comprehensive driving evaluation for an outside, objective opinion. (See Appendix E for information on comprehensive driving evaluations.)
- If you have a serious concern about driving safety, ask the doctor to suggest or even prescribe that the patient stop driving. The words "stop driving" on a prescription note may be convincing.

If a doctor seems especially resistant or unresponsive, you may need to seek another healthcare professional.

Limitations of “Doctor’s Orders”

A doctor may suggest that the patient with dementia stop driving, but the patient may forget or not agree with what the doctor said. A patient may not comply and the doctor is not the enforcer.

However, if you are proactive as an advocate for your relative with healthcare professionals, you can increase support and your chances for success. You can also request a referral to an occupational therapist (OT) for a comprehensive driving evaluation.

Benefits of a Comprehensive Driving Evaluation

Because dementia affects each person differently, a comprehensive driving evaluation can help to determine if, or the extent to which, the person with dementia may continue driving. The goal of a driving evaluation with a specially trained OT is to evaluate your loved one’s current driving capabilities and to offer education and recommendations looking ahead to the future. It is a good idea for a family member or friend to participate in the discussion with the OT and to be a source of support for their loved one. The OT’s understanding of your loved one’s individual strengths, challenges and transportation needs will be important as your loved one makes the transition from driver to passenger.

During a driving evaluation, the OT will perform a clinical evaluation, an on-the-road evaluation and provide feedback and/or a report.

- In the clinical evaluation, the driver’s medical and driving history are reviewed. The OT will perform some clinical tests that are good indicators of the driver’s performance behind the wheel, including vision tests (depth perception, peripheral vision, visual spatial skills, and contrast sensitivity), cognitive tests, (judgment and memory, following instructions, speed with which brain reacts) and motor function tests (also range of motion, coordination, sensation, reaction time).
- Depending on the results of the clinical assessment, the OT will most likely watch how the driver does through an on-the-road evaluation. The driver will be rated not just on how he or she handles the car, but also on his or her problem-solving ability and judgment, and how well they negotiate the traffic around them.

- Immediately after the testing or at an agreed upon time in the future, the driver will meet with the OT to discuss the results, driving-related strengths and weaknesses, and any recommendations. The OT will review the results and help develop a plan. Such a plan will likely include suggestions about whether, and under what circumstances, the driver should continue to drive – or whether he or she will need to stop driving.

If the determination of the evaluation is positive and driving may continue there will likely be significant driving limitations recommended. If the person with dementia participates in such a program you can be sure that you have done everything you can to allow driving to continue only for as long as it is safe to do so.

Transition to Lesson 9

Sometimes our best efforts fail to achieve an easy resolution. What if a person should stop driving, but refuses to? Concern for the physical safety of your loved one and others on the road may require you to take more immediate and decisive measures.

LESSON 9. Last Resort Strategies: What if all else fails?

Introduction

We can make better decisions if we know our full range of options. Knowing that we have a reserve of last resort strategies may keep us even more mindful of exhausting the cooperative, gradual measures before we turn to more unilateral, final steps.

Last Resort Strategies

What are some common last resort strategies if a driver is unsafe and refuses to stop driving? ——— (Make a list on the board of participants' ideas, and then add from the following list.)

The most common responses:

- Take away the car keys.
- Take away the car.
- Take away a driver's license.

Some variations on the common responses:

- Replace the car key with another key that cannot start the car.
- Remove the car and keys from view. Seeing an object is often a visual trigger. If it's not in sight, the person may not think about it.
- Sell the car or give it to friend or relative. Giving the car to a friend or grandchild in need may be more agreeable. (Make appropriate changes to the auto insurance policy if the car is sold or gifted to another person.)
- For two-car couples, sell the car that is primarily used by the person with dementia.

Strategies that involve outside experts:

- Contact your department of motor vehicles on how to report an unsafe driver. (For current and specific state requirements, you'll need to contact your state's department. Facilitators may have this information for the group.)
- Conveniently arrange for the car to be "in for repairs." In some cases, a trusted mechanic could emphasize the costs of repairs or suggest that a car is not worth repairing.
- Ask a mechanic to disable the car. (A "no start" car battery switch can be installed at a reasonably low cost.)
- Insist on a comprehensive driving evaluation if conversations about family observations and concerns have not worked. Let the evaluator know what you've observed. Some people with dementia will choose to stop driving rather than be tested. (Instructors can make available information on local driving evaluation and rehabilitation resources. See Appendix F for a sample list.)

Problems with Last Resort Strategies

Family members may eventually need to use some combination of these last resort strategies, but why would we not want to use them in the early stages of dementia or before other options have been tried? ———

(Add the following points to participants' comments.)

- In the early stage of the disease, such actions seem abrupt, extreme, disrespectful, punitive and unnecessary.
- A person with dementia may forget that his or her license has been removed or may not care about driving illegally.
- A person with mild dementia can ignore, undo or maneuver around such strategies by driving without a license, enabling the disabled car or buying a new car to replace the one that was sold.
- Allowing a person to keep the keys, license, and car even after he or she has stopped driving may help that person maintain dignity. This confines the loss to an activity, without the added loss of ownership. Some people with dementia stop driving but carry their licenses as photo identification.

Bottom-line on Last Resorts

Do you want to use last resort strategies? Of course not. If that's what it takes to assure the safety of your loved one and others on the road, should you use these strategies? Absolutely yes.

Comments and Questions for Session 3

(Note: In order to avoid an abrupt ending on last resorts, these process questions are related to all three lessons in this session. This will help participants transition to the closing activity. The end of the course should be participant-focused, with highlights, information or reviews coming from the group, not the facilitator.)

- What are your thoughts or questions about last resort strategies, the advance planning agreement or working with doctors? ———
- Do you think you will share the “Agreement with My Family about Driving” form with other relatives? ———
- Do you think you might want to try this approach sooner or later? ———
- Do you already have some ideas on how you might solicit help from a doctor? Or lay the foundation for later help? ———

Closing Activity

(NOTE: This activity can be done in pairs. Have them discuss the sentences, jot down some answers and then share with the group.)

Would you take a moment to complete these sentences? **(Write the sentences on the board or have them printed on paper to distribute. This closing activity allows participants to review what was covered, to set personal goals and to provide the instructor with feedback and recommendations.)**

At the Crossroads

I learned. . . .

I will. . .

I wish. . . .

Next time. . .

(Allow a few minutes for participants to complete the sentences, and then ask them to share in pairs or small groups. Then with the entire group, invite comments triggered by the sentence stems. Acknowledge all comments. Avoid giving any last minute tips or review, but reinforce confidence that they are equipped with the necessary knowledge and resources.)

I commend you all for trying to handle this difficult situation in the most sensitive manner possible. On behalf of **(sponsoring organizations)**, I wish you and your family the best as you skillfully navigate the crossroads of dementia and driving.

These materials have been prepared to enhance the reader's knowledge of sensitive topics related to aging. They are general in nature and are not a substitute for a care strategy developed for a specific individual. Not all acceptable safety measures are contained in these materials. Additional measures may need to be explored in individual cases. Readers are encouraged to consult the appropriate professional for this purpose of planning detailed, individualized care strategies.



Agreement with My Family about Driving

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Signed _____ Date _____

Copies of this request have been shared with:

_____	_____
_____	_____
_____	_____
_____	_____

