



AT THE CROSSROADS

The Support Group Kit
on Alzheimer's Disease, Dementia & Driving

AT THE CROSSROADS

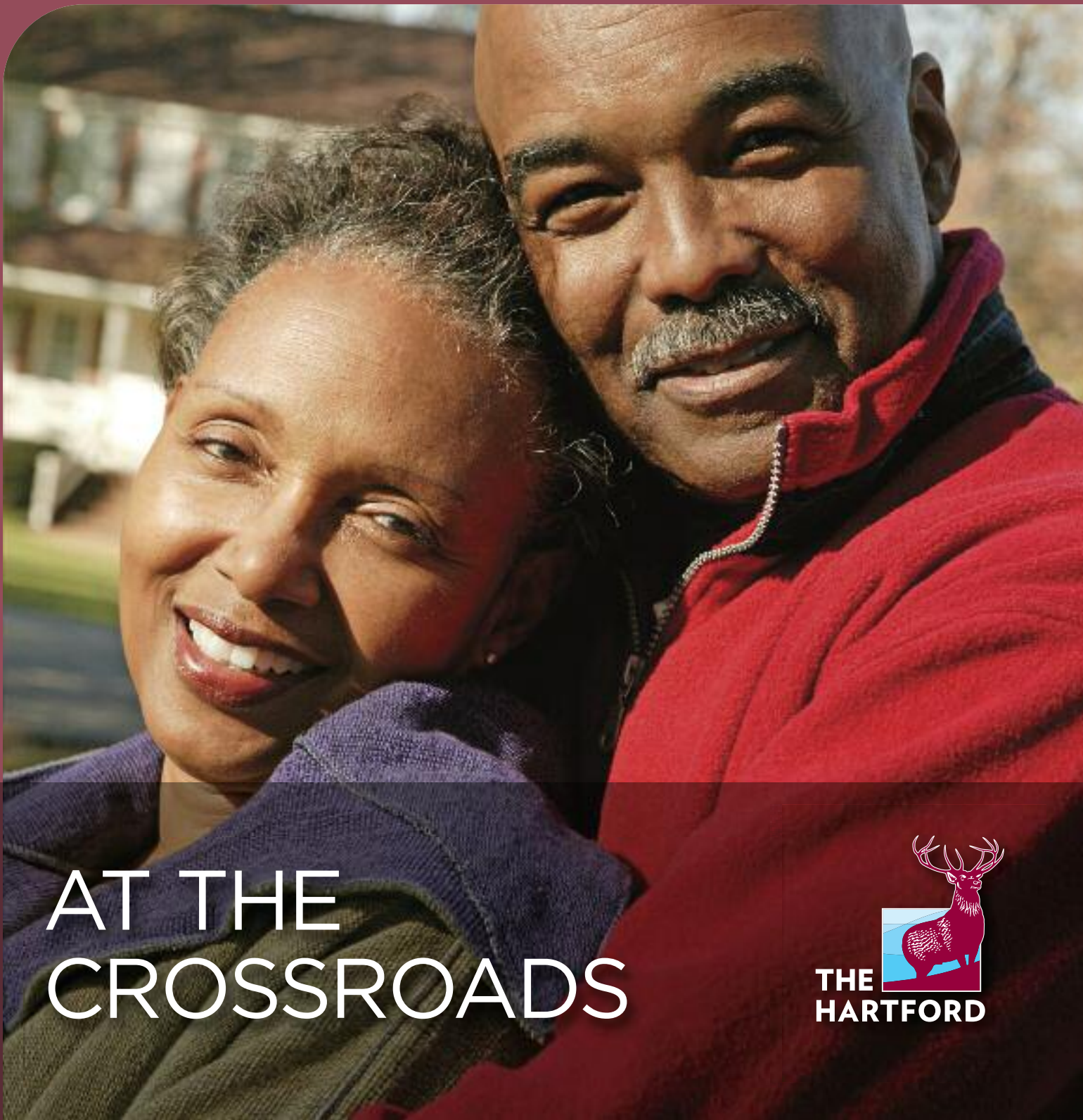
The Support Group Kit on Alzheimer's Disease, Dementia & Driving

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Introduction

For Support Group Leaders

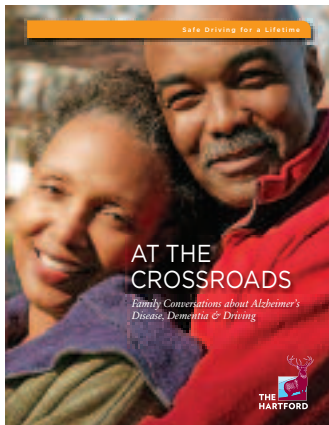


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The Hartford Financial Services Group, Inc., produced this course to help family members decide when and how individuals with dementia should limit or stop driving. The goal is to prolong independence while protecting the safety of drivers with dementia.



This course corresponds to the publication, *At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia & Driving*, which offers practical suggestions for monitoring, limiting and stopping driving. Organizations serving caregivers of persons with dementia can use this tested model of instruction and support.

History of Involvement

The information in this course comes from several years of focused, collaborative work. Beginning in 1999, The Hartford, together with the MIT AgeLab and Connecticut Community Care, Inc., began investigating how family caregivers of persons with dementia handle driving and transportation issues. The first edition of the booklet, *At the Crossroads: A Guide to Alzheimer's Disease, Dementia & Driving*, is based on in-depth, structured interviews with 50 family caregivers of drivers with dementia and input from experts in medicine, gerontology and transportation.

In 2003, The Hartford produced the booklet, *We Need to Talk: Family Conversations with Older Drivers*, based on findings from the first nationally representative survey of its kind of more than 3,800 drivers age 50 and older, conducted in collaboration with the MIT AgeLab.

In 2009, The Hartford partnered with MIT AgeLab and the American Occupational Therapy Association (AOTA) on a study with specially trained Occupational Therapists who conduct comprehensive driving evaluations and the drivers who completed this kind of evaluation. The guidebook *Your Road Ahead: A Guide to Comprehensive Driving Evaluations* was produced based on findings from that study.

Results from *At the Crossroads* Program Evaluation

In 2005, The Hartford worked with the MIT AgeLab and Boston University School of Medicine's Alzheimer's Disease Clinical and Research Program to develop, pilot and test a four-session course for caregivers on dementia and driving. Comparisons were made among three groups: those who attended the course; those who received only the *At the Crossroads* booklet; and those in a control group.

Compared to the other two groups, those who attended the *At the Crossroads* course reported that they:

- Felt more certain they would be able to handle driving-related issues
- Felt better prepared to address the issue of limiting or stopping driving with their relative
- Were more likely to have made a plan to talk with their relative about limiting or stopping driving
- Were more likely to express their feelings about the situation
- Were more likely to have talked to their relative about his or her driving

More detailed summaries of the findings can be found at www.bu.edu/alzresearch/driving.

Based on participant feedback, the piloted course was modified to the current version by changing the order and formatting of some activities, and reducing the number of sessions from four to three.

In addition, the feedback shaped changes to the original *At the Crossroads* booklet. The revised edition, now called *At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia & Driving*, incorporates new materials adapted from these educational sessions to provide caregivers with additional support and tools.

As an instructor, you can use these materials with confidence. They are designed for practical application and based on solid evaluation research.

Course Format and Procedures

You'll find this course is organized into three two-hour sessions, with a total of nine lessons. If you cover the course during three consecutive weeks, participants will have time to apply the information between sessions and will benefit from having all the lessons covered within a relatively short period. This approach provides optimum learning within a realistic time-frame. The course is intentionally designed in a simple, step-by-step format. Having two or three organizations co-sponsor a course can ease the load for any one organization and increase the number of participants.

You can cover the material adequately by adhering to the recommended schedule, but you may want to change the timing or approach to suit your audience's needs. For example, an ongoing Alzheimer's caregiver group might cover the modules over a longer period of time and with emphasis on group support. A lunchtime course might require abbreviated modules with emphasis on providing information. The number of participants also will determine the time allotted for each lesson.



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To set expectations and keep the group on task, participants should know the agenda, objectives and timeframe up front. The Course Overview handout (in Session 1, *Assessing Driving Ability and Activity*) provides this information.

In preparation for the course, you should do the following:

- Check with your state motor vehicle department for current regulations on driving tests and to find out how the state handles notifications of potentially unsafe drivers.
- Order copies of *At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia and Driving* booklets. Multiple copies may be ordered free of charge from www.safedrivingforalifetime.com/publications. Please allow 2 to 4 weeks for delivery.
- Make copies of the handouts to distribute to each course participant. Single copies are located in the back pocket of each session's support group leader guide and can be photocopied.
- Create a list of local and regional transportation resources for your area.
- Create a list of local driving evaluation and rehabilitation resources in your area. Use the sample in Appendix G as a guide.
- Locate, and bring for all participants copies of healthcare proxy forms acceptable for your state (local doctors' offices or hospitals may be helpful in securing copies of these).
- Bring copies of HIPAA release forms for all participants (local doctors' offices or hospitals may be helpful in securing copies of these).

The suggestions in *At the Crossroads* offer sensible guidance for even the most complicated situations. Unfortunately, difficult circumstances prevent "quick fixes." Participants should be commended for their efforts to work with their situation as best they can, given the complexities and the many options involved.

The Hartford appreciates the efforts of all those who use these materials in our shared goal to help families at the crossroads of dementia and driving.

The Hartford assumes no responsibility or liability in connection with these materials or instructor's presentations of the material. It cannot be assumed that all acceptable safety measures are contained in this publication or that other or additional measures may not be required under particular conditions or circumstances. The Hartford does not endorse any products or services related to this program.

Support Group Leader Guide

Session 1

AT THE CROSSROADS

Assessing
Driving Ability
& Activity



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Welcome and Course Goals

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Session Summary and Homework

Session 1. *Assessing Driving Ability and Activity*

Welcome and Course Goals

Welcome to our special series on dementia and driving. We appreciate your efforts to be here and look forward to working with you. Our goals are to:

- Help family members decide when and how a person with dementia should limit or stop driving; and
- Prolong the independence of drivers with dementia while protecting their safety and the safety of others on the road.

We'll learn ways to monitor driving, talk about driving, limit driving and plan for not driving.

Introductions

My name is _____ and I am (title/position/role). Please tell us (1) your name, (2) your relationship to the person with memory loss, and (3) in one sentence, what you would do or not do if you couldn't drive for one week. ——*

(Option: Depending on the number of participants and available time, have participants first answer the questions with the person next to them, and then introduce their class partner to the group.)

Course Overview

We'll be working together on the concepts in this booklet, *At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia & Driving*, provided by The Hartford. Our course is divided into three main topics.
(If participants do not already have it, distribute the booklet and the "Course Overview" handout.)

Today we'll learn how to assess driving abilities and activities. Next week, we'll focus on how to build family support for eventual cessation of driving. During our third meeting, we'll add to our options and outside support.

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

“Course Overview”
handout
in back
pocket of
this guide.

FOR PARTICIPANTS

AT THE CROSSROADS:

Course Overview

The purpose of this course is to:

- Help family members decide when and how a person with dementia should limit or stop driving, and
- Prolong the independence of drivers with dementia while protecting their safety and that of others on the road.

TIMEFRAME
3 sessions, 2 hours each

SESSION 1: Assessing Driving Ability and Activity Date/Time _____


APPROXIMATE TIMING	ACTIVITIES AND LESSONS	MAIN QUESTIONS TO BE ANSWERED
15 Minutes	Introductions and course overview	
30 Minutes	Lesson 1: Driving and the Brain	How can cognitive changes affect driving skills?
15 Minutes	Break	
30 Minutes	Lesson 2: Warning Signs for Drivers with Dementia	How can I know if a person should stop driving?
20 Minutes	Lesson 3: Assessing Transportation Needs	Where, when and why does my relative drive?
10 Minutes	Homework and Summary	

SESSION 2: Building Family Cooperation and Communication Date/Time _____

15 Minutes	Experiences	
15 Minutes	Lesson 4: Getting There	What are my transportation alternatives?
30 Minutes	Lesson 5: Not Going It Alone	Who can offer support?
15 Minutes	Break	
30 Minutes	Lesson 6: Conversation Planner	How can I have good conversations about not driving?
15 Minutes	Homework and Summary	

SESSION 3: Knowing All Your Options Date/Time _____

20 Minutes	Experiences	
20 Minutes	Lesson 7: Agreement with My Family	How can driving be included in advance planning?
20 Minutes	Lesson 8: The Role of Healthcare Providers	How can I get doctors to help?
15 Minutes	Break	
25 Minutes	Lesson 9: “Last Resort” Strategies	If all else fails, then what?
20 Minutes	Closing Activities	



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Ground Rules

Timing. To benefit fully from the course, you really should attend all three sessions. Please arrive on time, and we’ll take a break about halfway through each session. Restrooms are located _____.

Confidentiality. All information shared in the group is confidential. However, I am obligated to tell authorities if someone is in danger of hurting themselves or others. This legal requirement doesn't pertain to driving safety issues.

Additional information. If you have questions about dementia that aren't related to driving, you can see me after class, and I can refer you to additional resource material. (See Appendix A, Overview of Dementia) You can contact me or my colleague(s) during the week at _____ (phone number). We have a lot to learn from each other, so we invite you to share your thoughts, ideas and questions.

Transition to Lesson 1

This course is not about older drivers, but about drivers with dementia. Older adults as a whole are safe drivers and capable of determining when and where they can drive – such as not driving during rush hour or at night. (For background information, see Appendix B, Facts about Older Drivers) But people with dementia lose driving skills and awareness of their declining abilities. In cases of dementia, families must be more proactive. First, let's see how cognitive changes affect driving.

LESSON 1. Driving and the Brain: How can cognitive changes affect driving skills?

Introduction

(Distribute handout “Driving and the Brain.” Ask for volunteers to read aloud the handout narrative up to the section with the chart. The facilitator can then highlight selected functions associated with each brain part shown in the diagram.)
What information in this reading was the most interesting or important? ———

“Driving and the Brain” handout in back pocket of this guide.

FOR THE FAMILY

SESSION 1: Assessing Driving Ability and Activity

LESSON 1

Driving and the Brain

How Can Cognitive Changes Affect Driving Skills?

To grasp the brain's complexity, imagine what it would take to connect six billion people around the world by telephone. Now consider the greater complexity of an estimated 100 billion brain cells, each capable of almost simultaneously connecting to hundreds – and sometimes thousands – of other neurons.

When you drive a car, different regions of your brain cooperate to receive sensory data, prioritize information, recall related past experiences, anticipate likely scenarios, analyze options, and synchronize movement responses.

Nerve connections carried through the brain stem help a driver sense a bump in the road or a skid of the tires. A slight turn of the steering wheel to adjust direction is possible because of stored learned reflexes in the cerebellum. The brain's temporal lobe decodes slight variations in auditory signals, analyzing the position and intensity of sounds – from the car radio, a nearby car's honk or an ambulance siren in the distance.

Countless visual images compete for a driver's attention – the speedometer, the rearview mirror, a speed limit sign, the yellow divider lines, an oncoming truck or a pedestrian in the crosswalk. The frontal lobes allow you to juggle the competing tasks of paying attention to the road in front of you, changing the radio station, being aware of the ambulance in the rearview mirror, watching the speedometer, recalling the directions to your destination, and making a decision of what to do when a child steps off the curb in front of you. Through an elaborate process, different brain parts are responsible for determining shape and color, tracking motion, comparing memory of past experiences, and prioritizing optical signals.

Today's fast-paced roadways can challenge any brain. But what if neurons and connectors in different parts of the brain become diseased or damaged?

Driving with Dementia


Driving with dementia is not just about remembering how to get home. Slower neural connections can delay reaction time. When trying to avert danger, milliseconds matter. A difference of 100 milliseconds in response time can translate into several feet when braking at highway speeds, a difference between life and death.

Safe driving is not just a matter of concentration, as if driving were a single act. A person with dementia can lack the rapid, flexible response patterns needed to handle unusual, unexpected or new situations.

By definition, most types of dementia (e.g., Alzheimer's Disease, Frontotemporal Dementia, Vascular Dementia, Dementia with Lewy Bodies) involve a progressive decline in functioning due to the degenerative nature of the brain disease. As such, all people with degenerative dementia will eventually become unable to drive safely.

No two brains are the same. The initial parts of the brain involved in dementia, the progression of the disease, and the profile of cognitive strengths and weaknesses all vary. Although no one knows precisely what happens in an individual's brain during every act of driving, an overview of how the brain works helps us understand how dementia can affect driving.

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(Emphasize the following.)

- Driving requires highly complex and sophisticated thinking processes.
- Cognitive deficits seriously compromise driving abilities.
- The problem is the disease, not the person.

(Depending on available time and the size of the group, participants may be divided into pairs or small groups to answer the discussion questions.

Then, together as a group, draw from participants' comments to the discussion questions.)

Discussion Questions

(Emphasize the following key points to each question as shown below.)

1. Using the chart on the handout, which parts of the brain would be necessary for turning on the radio while responding to a yellow light? ——
 - Every major part of the brain plays an essential role in good driving skills, especially in this example where both auditory and visual messages must be processed simultaneously.
2. Are persons with dementia likely to be aware of when they need to limit or stop driving? Why or why not? —— (For additional information, see Appendix C, Facts About Drivers with Dementia.)
 - Most people tend to overrate their driving skills, but this is especially true when a cognitive impairment affects judgment and analytical skills.
 - Persons with dementia lose the ability to assess their situation.
 - They can lack judgment, become overly confident and be unaware of the cognitive changes affecting their driving.
 - People with dementia can falsely reason:
 - “Just because I got lost doesn't mean I can't drive.”
 - “I've driven for years without an accident.”
 - “I make sure to look where I'm going.”

3. Are family members always aware of the driving risks when a person has dementia? Why or why not?——
 - Changes in the brain can be slight, gradual and not immediately apparent.
 - Family members can overlook, deny or make excuses for driving errors.
4. Based on this information, why would co-piloting – giving instructions on how to drive – be unsafe? Similarly, why might a GPS (global positioning system) make driving more risky for a person with dementia? ——
 - A co-pilot cannot foresee dangerous situations far enough in advance to relay instructions to the driver, who then must react in time to avoid an accident. The delay could be deadly. Driving is not a game of chance.
 - Co-piloting and co-navigating are different. As passengers, we all occasionally give directions or point out dangers to a driver. This co-navigating is supplemental help. But, it isn't safe to act as a co-pilot, giving the driver instructions on what to do next.
 - A safer situation is to have the person with dementia be a co-pilot while someone else drives.
 - Navigational systems such as a GPS require additional cognitive agility and may only add distraction and confusion for a person with dementia. Drivers who are at risk of getting lost probably are at risk in other ways.
5. Why is the family's role important in decisions about driving and dementia? ——
 - A family member who observes driving skills can assess abilities better than the person with dementia can.
 - Everyone with Alzheimer's disease or other degenerative dementias, which progressively worsen, eventually must stop driving. They need encouragement and support from the family during this process.

Transition to Lesson 2

Some people with dementia can drive safely for a while after a diagnosis. A family member wants to avoid either overreacting or underreacting – being either too quick to restrict driving or too slow to respond to unsafe driving. The challenge is to preserve a person’s sense of independence for as long as possible, and simultaneously protect the safety of the person and others. How can family members know when a person with dementia should limit or stop driving? We will address this question after break.

Break 15 minutes

LESSON 2. Warning Signs for Drivers with Dementia: How can I know if a person should stop driving?

Introduction

What are some driving behaviors you might see if someone’s driving was impaired? ——— (Make a list of questionable driving behaviors that the group identifies as warning signs.) Distribute handout “Driving Warning Signs.”

“Driving Warning Signs” handout in back pocket of this guide.

FOR THE FAMILY

SESSION 1: Assessing Driving Ability and Activity

LESSON 2

Driving Warning Signs

A diagnosis of mild dementia alone is not an automatic reason to stop driving. Families can use this list as an objective way to monitor any changes in driving skills over time. The signs are ranked from minor to serious. Written notes of observations can help you make informed decisions and may be useful in conversations with healthcare providers.

Consider the frequency and severity of incidents. Several minor incidents or an unusual, major incident may warrant action. Look for patterns of change over time. Isolated or minor incidents may not warrant drastic action. Avoid an alarming reaction. Take notes and have conversations at a later time, instead of during or right after an incident.

Driving Behavior Warning Signs – When Noticed, How Often	
1. Decrease in confidence while driving	16. Uses a “copilot”
2. Difficulty turning to see when backing up	17. Bad judgment on making left hand turns
3. Riding the brake	18. Near misses
4. Easily distracted while driving	19. Delayed response to unexpected situations
5. Other drivers often honk horns	20. Moving into wrong lane
6. Incorrect signaling	21. Difficulty maintaining lane position
7. Difficulty parking within a defined space	22. Confusion at exits
8. Hitting curbs	23. Ticketed moving violations or warnings
9. Scrapes or dents on the car, mailbox or garage	24. Getting lost in familiar places
10. Increased agitation or irritation when driving	25. Car accident
11. Failure to notice important activity on the side of the road	26. Failure to stop at stop sign or red light
12. Failure to notice traffic signs	27. Confusing the gas and brake pedals*
13. Trouble navigating turns	28. Stopping in traffic for no apparent reason*
14. Driving at inappropriate speeds	29. Other signs:
15. Not anticipating potential dangerous situations	

* Stop driving immediately

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This handout gives a systematic, objective approach to help assess someone's driving skills.

(Read aloud the opening paragraphs to the warning signs list. Briefly compare the list of warning signs on the handout with the list the group developed.)

Have you already observed your relative making any of these driving errors? ——— How many of these mistakes have you yourself made? (Jokingly)——— Could someone build a case for why you or I should not be driving? ———

The point is: a one-time offense might not warrant an end to driving. On the other hand, frequent minor errors could indicate that the cognitive impairment is affecting driving abilities. When in doubt, err on the side of safety.

Now take a moment by yourself and put a check mark beside the warning signs list that you or someone in your family have already observed in your relative's driving, then count the number of warning signs you have. **(Allow time.)**

Let's see how much of a range in numbers we have in our group. Tell us how many warning signs you've observed. ———

(This question is intentionally specific to avoid opening the discussion up to individual, lengthy stories. If participants do tell about individual accounts, listen attentively but be ready to move to the key point.)

Emphasize the following main points.

- Consider the frequency and severity of incidents. Warning signs can be few or many, minor or major. Several minor incidents may warrant action. An unusual, major incident – such as confusing the gas and brake pedals – may call for an immediate end to driving. Getting lost in familiar places may be related to a medication or physical illness, or it might indicate serious cognitive changes affecting driving. This should be brought to the attention of a doctor immediately.
- Look for a *change* in driving skills. Consider the driver's previous driving behavior. Did the person always drive this way? Is this something he or she did in the past but is now doing more frequently? You need to know what "normal" driving behavior is for your loved one in order to recognize changes in behavior.
- Look for *patterns*. Monitor and document incidents over a period of time. Isolated or minor incidents don't warrant immediate or drastic action. Everyone makes mistakes while driving. But if you're noticing more mistakes or progressively more serious mistakes, then driving skills probably are diminishing.

- Avoid an alarming reaction. When you see a warning sign, consider the circumstances. Avoid pointing out mistakes while the person with dementia is driving, unless immediate safety is at risk. Having a conversation at a later time will likely be more productive.
- Track observations over time. A written record will give you confidence that you're making an informed decision to allow or restrict driving. It can provide useful information to your loved one's primary care physician, neurologist or other family members.
- Try not to be obtrusive in the car. Don't sit in the passenger seat with the sheet in front of you as you take notes. Also, don't start the discussion of driving or driving behavior while the person is at the wheel.

Benefits of Using the Warning Signs

How can you benefit from using this driving assessment tool? (**When possible, use participants' comments to emphasize these key points.**) ——

- The form helps family members avoid overreacting to single or minor incidents.
- It provides a more objective, less emotional basis for decisions.
- It can help the person with dementia – and other family members and medical professionals – understand the situation.
- Family observations over time may be more informative than one-time professional driving evaluations, and without the added expense and time. Outside evaluations may be useful later on, especially if another opinion would carry more weight.

Homework

During the next week, can you make the time to observe your relative's driving and later jot down what you observed? Next week you can share what you observed – good and bad.

Transition to Lesson 3

In order to observe driving, you need to know where and when your relative is driving. Do you know how driving relates to the social interactions and quality of life for your relative? This will be covered in our next lesson.

LESSON 3. Assessing Transportation Needs: Where, when, and why does my relative drive?

Introduction

Why do we drive? When we first started driving, we drove for the fun of it – especially if Mom and Dad paid for the gas. We still might like to “go for a drive” occasionally. But as adults, driving is mostly a way to fulfill physical needs – a trip to the bank or the grocery store. It can also be our social lifeline, connecting us to friends, family and the community.

Earlier we talked about how not driving for a week might affect us. Now, imagine for a moment that you couldn’t drive for a month, a year – or ever. How would this change your life? Your activities? Your relationships with others? -----

Exercise

(Distribute the handout “Driving Activities.”) This next handout will help us identify driving-related activities for your relative. (Read the introduction to the lesson chart.)

“Driving Activities” handout in back pocket of this guide.

FOR THE FAMILY

SESSION 1: Assessing Driving Ability and Activity

LESSON 3

Driving Activities:

Where, When and Why?

Driving allows us to take care of basic physical needs such as banking and shopping, and our social needs of connecting with other people. Family members need to know where, when and why their relative with dementia drives.

Most accidents happen close to home. The risk of being in an accident decreases every time the need to drive – even short distances – is reduced. Family members can look for ways to reduce the need to drive, but still fulfill those basic physical and social needs.

Type of Activity	Activity	Frequency/Time How often? What day and time?	Social Interactions Who is he/she with while going to, or participating in, activity?	Transportation Alternatives What changes could reduce the need to drive?
Routine: Frequent trips (daily or weekly), usually for tasks (e.g., shopping, exercising)				
Periodic: Regular, maybe monthly (e.g., doctor’s visit, card games with friends)				
Occasional: Special events (e.g., vacation, concert, sporting event, family celebrations)				

* questions to consider on other side

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Think of the types of activities your relative drives to on a regular, periodic and occasional basis. You probably don't know all the activities, but you can start the process. First, list the activity and then write when and how often he or she does that. Also list the people he or she interacts with at the activity or going there. For now, do not complete the last column on possible changes to reduce driving. We'll consider this later. **(Give examples from the chart below to help participants get started.)**

Chart Examples

Please take a couple of minutes to start your chart and then we'll discuss it as a group.

Type of Activity	Activity	Frequency/Time	Social Interactions	Transportation Alternatives
Routine	Drives to the local store to buy newspaper or milk	Every other day	Travels alone. Chats with people behind the counter, buys a cup of coffee, reads the newspaper and visits with friends.	Ask a neighbor if they could go to the market together; will buy him coffee and introduce to friends.
Periodic	Fills prescription at local pharmacy	Once or twice a month	Travels alone. Chats briefly with pharmacist.	Relative can pick up prescription(s) before a weekly visit.
Occasional	Ball game	Every other month or so	Drives with son (person with dementia picks him up), sometimes granddaughter comes along. Stops at a favorite restaurant on the way to the game, knows the restaurant owner.	Older cousin can come along and drive.

Questions for Discussion

1. For the most part, do you know where and when your relative drives, or do you need to discuss this with him or her? ——
2. Why is it important for families to consider the physical and social aspects of driving? (Consider some of the activities and interactions a person has because of their driving.) ——
 - Many driving-related activities relate to one's quality of life. For example, when we go to the post office, we might greet and chat with the clerk. As much as possible, you want to make sure your relative doesn't lose social connections.
3. What can you do to increase social contacts while reducing driving? ——
 - Schedule people to visit regularly, either as volunteers or for pay.
 - Arrange for friends to take the person with mild dementia on errands or to social or religious events.
 - See that visits from friends include outings, such as eating out or going to the park.
 - Find replacement social activities at local associations and centers (senior centers, adult day programs, support groups or local Alzheimer's Association). These may provide support and social activities for you and your relative.

Session Summary and Homework

In this session we considered (1) brain changes that affect driving, (2) warning signs of impaired driving, and (3) assessment of transportation-related activities. (**Show handouts that are related to each lesson.**) We'll get the most from this information by using it.

- (1) During the next week, you might want to help other relatives understand how dementia can affect driving by sharing the handout on "Driving and the Brain."
- (2) Do you think you'll have opportunities to observe driving this week? You can jot down personal notes using the "Warning Signs" checklist.

(3) You've started to identify transportation-related activities. Can you talk with the person with dementia or other family members to identify other current transportation activities? Begin thinking about possible changes that can reduce the need for a person to drive. (Read suggestions in the bottom section of the handout.) Perhaps you could keep these two worksheets in a handy spot as a reminder to use them.

Later we will add to our possibilities for alternative transportation.

Do you have any questions or comments about what we've covered so far? -----

Next week, we'll learn about your experiences from these assignments.
Then we'll consider:

- (1) What are some other transportation alternatives?
- (2) Who can be a source of support so you don't bear the responsibility alone?
- (3) How can you have positive, progressive and purposeful conversations about someone not driving?

Would answers to these questions be helpful? -----

See you next week.

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.



AT THE CROSSROADS:

Course Overview

The purpose of this course is to:

- Help family members decide when and how a person with dementia should limit or stop driving, and
- Prolong the independence of drivers with dementia while protecting their safety and that of others on the road.

TIMEFRAME

3 sessions, 2 hours each

SESSION 1: Assessing Driving Ability and Activity

Date/Time _____

APPROXIMATE TIMING	ACTIVITIES AND LESSONS	MAIN QUESTIONS TO BE ANSWERED
15 Minutes	Introductions and course overview	
30 Minutes	Lesson 1: Driving and the Brain	How can cognitive changes affect driving skills?
15 Minutes	Break	
30 Minutes	Lesson 2: Warning Signs for Drivers with Dementia	How can I know if a person should stop driving?
20 Minutes	Lesson 3: Assessing Transportation Needs	Where, when and why does my relative drive?
10 Minutes	Homework and Summary	

SESSION 2: Building Family Cooperation and Communication

Date/Time _____

15 Minutes	Experiences	
15 Minutes	Lesson 4: Getting There	What are my transportation alternatives?
30 Minutes	Lesson 5: Not Going It Alone	Who can offer support?
15 Minutes	Break	
30 Minutes	Lesson 6: Conversation Planner	How can I have good conversations about not driving?
15 Minutes	Homework and Summary	

SESSION 3: Knowing All Your Options

Date/Time _____

20 Minutes	Experiences	
20 Minutes	Lesson 7: Agreement with My Family	How can driving be included in advance planning?
20 Minutes	Lesson 8: The Role of Healthcare Providers	How can I get doctors to help?
15 Minutes	Break	
25 Minutes	Lesson 9: "Last Resort" Strategies	If all else fails, then what?
20 Minutes	Closing Activities	

Driving and the Brain

How Can Cognitive Changes Affect Driving Skills?

To grasp the brain's complexity, imagine what it would take to connect six billion people around the world by telephone. Now consider the greater complexity of an estimated 100 billion brain cells, each capable of almost simultaneously connecting to hundreds – and sometimes thousands – of other neurons.

When you drive a car, different regions of your brain cooperate to receive sensory data, prioritize information, recall related past experiences, anticipate likely scenarios, analyze options, and synchronize movement responses.

Nerve connections carried through the brain stem help a driver sense a bump in the road or a skid of the tires. A slight turn of the steering wheel to adjust direction is possible because of stored learned reflexes in the cerebellum. The brain's temporal lobe decodes slight variations in auditory signals, analyzing the position and intensity of sounds – from the car radio, a nearby car's honk or an ambulance siren in the distance.

Countless visual images compete for a driver's attention – the speedometer, the rearview mirror, a speed limit sign, the yellow divider lines, an oncoming truck or a pedestrian in the crosswalk. The frontal lobes allow you to juggle the competing tasks of paying attention to the road in front of you, changing the radio station, being aware of the ambulance in the rearview mirror, watching the speedometer, recalling the directions to your destination, and making a decision of what to do when a child steps off the curb in front of you. Through an elaborate process, different brain parts are responsible for determining shape and color, tracking motion, comparing memory of past experiences, and prioritizing optical signals.

Today's fast-paced roadways can challenge any brain. But what if neurons and connectors in different parts of the brain become diseased or damaged?

Driving with Dementia

Driving with dementia is not just about remembering how to get home. Slower neural connections can delay reaction time. When trying to avert danger, milliseconds matter. A difference of 100 milliseconds in response time can translate into several feet when braking at highway speeds, a difference between life and death.

Safe driving is not just a matter of concentration, as if driving were a single act. A person with dementia can lack the rapid, flexible response patterns needed to handle unusual, unexpected or new situations.

By definition, most types of dementia (e.g., Alzheimer's Disease, Frontotemporal Dementia, Vascular Dementia, Dementia with Lewy Bodies) involve a progressive decline in functioning due to the degenerative nature of the brain disease. As such, all people with degenerative dementia will eventually become unable to drive safely.

No two brains are the same. The initial parts of the brain involved in dementia, the progression of the disease, and the profile of cognitive strengths and weaknesses all vary. Although no one knows precisely what happens in an individual's brain during every act of driving, an overview of how the brain works helps us understand how dementia can affect driving.

(continued on other side)



Brain Functions During Driving

The chart shows the main functions of major parts of the brain. As you read about the various functions, which brain parts would you say are essential for good driving?

BRAIN PARTS	FUNCTIONS
Frontal Lobe	<ul style="list-style-type: none"> • Anticipates potential danger • Decides how to respond to situations • Helps plan, organize and carry out activities • Controls the ability to multi-task • Controls emotional response • Oversees problem-solving and decision-making • Controls memory of habits, muscles, and body movement
Parietal Lobe	<ul style="list-style-type: none"> • Involves visual-spatial perception • Recognizes movement and manipulation of objects • Integrates signals from all senses • Coordinates visual attention and touch perception
Occipital Lobe	<ul style="list-style-type: none"> • Controls visual response
Temporal Lobe	<ul style="list-style-type: none"> • Controls hearing • Manages memory acquisition/storage • Processes some visual perceptions • Categorizes objects
Cerebellum	<ul style="list-style-type: none"> • Coordinates voluntary muscle movement • Maintains balance • Holds memory for reflex motor actions
Brain Stem	<ul style="list-style-type: none"> • Controls reflexes • Affects alertness • Affects sense of balance

What Do You Think?

- Using the information above, what parts of the brain would be necessary for turning on the radio while responding to a yellow light?
- Are persons with dementia likely to be aware of when they need to limit or stop driving? Why or why not?
- Are family members always aware of the driving risks when a person has dementia? Why or why not?
- Based on this information, why would co-piloting – giving instructions on how to drive – be unsafe? Similarly, why might a GPS (global positioning system) make driving more risky for a person with dementia?
- Why is the family's role important in decisions about driving and dementia?

Resources

Robert P. Lehr Jr., Ph.D., Brain Functions and Map, Centre for Neuroskills, at <http://www.neuroskills.com/brain.shtml>, accessed June 20, 2007.

U.S. National Institutes of Health, 2000. Lesson 1-The Brain: What's Going on in There?, at <http://science.education.nih.gov/supplements/nih2/addiction/guide/lesson1-1.htm>, accessed June 26, 2007.

Myeonggi Jeong, Manabu Tashiro, Laxmi N. Singh, et al, 2006. Functional brain mapping of actual car-driving using FDG-PET, *Annals of Nuclear Medicine* (20:9, 623-628).

Jonathan Levy, Harold Pashler, Erwin Boer March 2006. Central Interference in Driving. Is There Any Stopping the Psychological Refractory Period?, *Psychological Science* (17:3,p. 228).

Driving Warning Signs

A diagnosis of mild dementia alone is not an automatic reason to stop driving. Families can use this list as an objective way to monitor any changes in driving skills over time. The signs are ranked from minor to serious. Written notes of observations can help you make informed decisions and may be useful in conversations with healthcare providers.

Consider the frequency and severity of incidents. Several minor incidents or an unusual, major incident may warrant action. Look for patterns of change over time. Isolated or minor incidents may not warrant drastic action. Avoid an alarming reaction. Take notes and have conversations at a later time, instead of during or right after an incident.

Driving Behavior Warning Signs - When Noticed, How Often

1. Decrease in confidence while driving	16. Uses a “copilot”
2. Difficulty turning to see when backing up	17. Bad judgment on making left hand turns
3. Riding the brake	18. Near misses
4. Easily distracted while driving	19. Delayed response to unexpected situations
5. Other drivers often honk horns	20. Moving into wrong lane
6. Incorrect signaling	21. Difficulty maintaining lane position
7. Difficulty parking within a defined space	22. Confusion at exits
8. Hitting curbs	23. Ticketed moving violations or warnings
9. Scrapes or dents on the car, mailbox or garage	24. Getting lost in familiar places
10. Increased agitation or irritation when driving	25. Car accident
11. Failure to notice important activity on the side of the road	26. Failure to stop at stop sign or red light
12. Failure to notice traffic signs	27. Confusing the gas and brake pedals*
13. Trouble navigating turns	28. Stopping in traffic for no apparent reason*
14. Driving at inappropriate speeds	29. Other signs:
15. Not anticipating potential dangerous situations	

* Stop driving immediately



Driving Activities:

Where, When and Why?

Driving allows us to take care of basic physical needs such as banking and shopping, and our social needs of connecting with other people. Family members need to know where, when and why their relative with dementia drives.

Most accidents happen close to home. The risk of being in an accident decreases every time the need to drive – even short distances – is reduced. Family members can look for ways to reduce the need to drive, but still fulfill those basic physical and social needs.

Type of Activity	Activity	Frequency/Time How often? What day and time?	Social Interactions Who is he/she with while going to, or participating in, activity?	Transportation Alternatives What changes could reduce the need to drive?*
Routine: Frequent trips (daily or weekly), usually for tasks (e.g., shopping, exercising)				
Periodic: Regular, maybe monthly (e.g., doctor's visit, card games with friends)				
Occasional: Special events (e.g., vacation, concert, sporting event, family celebrations)				

* questions to consider on other side

Questions to Consider

Here are some questions to consider in identifying alternate options that can satisfy the physical and social needs of the person with dementia:

- Can the person with dementia share the activity with a friend who can drive?
- Can you identify someone who can drive the person with dementia to an activity regularly?
- Are home deliveries possible (e.g., prescriptions, groceries, online ordering)?
- Can you encourage others to visit regularly and also run errands with the person with dementia?
- Can services be brought to the home (e.g., a hairdresser who makes home visits)?
- Can telephone or e-mail conversations occasionally substitute for personal visits?
- Is public transportation or publicly provided special needs transportation available for some trips?

Session 2

AT THE CROSSROADS

Building Family Cooperation & Communication



Session 2. *Building Family Cooperation and Communication*

It's good to see everyone again. I'm eager to hear about some of your experiences from this past week. Today we'll consider additional transportation alternatives and learn practical ways to build family cooperation and communication. We'll answer three more questions: What are my transportation alternatives? Who can be a source of support so I don't bear the responsibility alone? How can I have positive, progressive and purposeful conversations about someone not driving?

Review and Experiences

Last week, we considered the effects of brain impairments on driving, warning signs of declining driving skills and transportation-related activities. What were some of your experiences this past week as you considered your relative's driving abilities and needs?

_____*

(Additional question regarding brain functioning and driving:)

- Did you share the information about the brain and driving with anyone?

(Additional questions regarding driving observations:)

- Was this the first time you've seen that driving behavior? _____
- Is this different from the way your relative usually drives? _____
- How serious do you think this is? _____
- Has your level of concern changed – either less or more concerned – after observing your relative driving?
- Did you discuss the warning signs or take any action about your observations?

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

(Additional questions regarding transportation-related activities:)

- Do you have a better idea of where and when your relative is driving? ——
- Were the activities less or more than you expected? ——
- Did you see natural opportunities to reduce driving? ——
- What did you learn about the social significance of trips your relative takes?

Transition to Lesson 4

Have you already been able to identify transportation alternatives for some routine, periodic and occasional activities? ——

We want to explore all transportation alternatives. This leads to our next lesson.

LESSON 4. Getting There: What are my transportation alternatives?

Introduction

(Distribute handout “Getting There.” Transportation options in communities vary greatly. Instructors can make available information on local and regional transportation sources.)

(Read the opening two paragraphs in the handout, then review the brief descriptions of different types of transportation and the questions on the back side of the handout.)

“Getting There”
handout
in back
pocket
of this
guide.

FOR THE FAMILY


SESSION 2: Building Family Cooperation & Communication LESSON 4

Getting There: Using Alternative Transportation

When a person with dementia limits or stops driving, the responsibility to provide or find transportation usually falls on the family. The most effective approach involves gradual replacement of driving with alternative transportation. The primary caregiver needs to explore all options – from informal arrangements with relatives and friends to formal public services. You can use this worksheet with the questions on the back to help explore all your transportation options.

Transportation Alternatives	Telephone	Availability, Destination (day, time, route)	Cost	Notes (pros & cons)
Family Members:				
Friends:				
Demand-responsive Services:				
Private Program Services:				
Taxi/Car Services:				
Mass Transit:				
Other Local Programs:				

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Creating a “Getting There” Plan

The most effective approach to cutting back driving involves progressive steps and a combination of strategies that fit the family’s unique situation. For people in the early stages of dementia, driving is best reduced over time rather than all at once. An already established routine of having others drive may help smooth the transition to not driving.

The reasons you give for changes in transportation don’t have to be about driving safety, but can be reasons anyone might choose not to drive – to save money, time and aggravation. Changes in transportation can be discussed and agreed to, or you might subtly introduce a change and then make the new arrangement a routine over time.

In many cases, people with dementia begin limiting where and when they drive. These may be opportunities to introduce alternative transportation.

Social activities and transportation services that are appropriate now may not be feasible in the future as the disease progresses. For example, your relative may be able to take the bus now, but that might become too difficult in the future. So it's important to consider all of your options and to stay open to services that may not seem appropriate now.

Homework

During the next week, see if you can add local or private program services to your list of alternatives. Which transportation alternatives can you begin to incorporate? Review your "Driving Activities" worksheet from last week along with the "Getting There" worksheet. Try introducing one or two alternatives to driving.

Transition to Lesson 5

Planning transportation alternatives can reduce your stress. Another way to reduce stress is to increase your support system. The next lesson will help you identify potential sources of support and consider ways to increase your support network in specific, tangible ways.

LESSON 5. Not Going It Alone: Who can offer support?

Introduction

Why do you think it's usually better to involve other family members to provide help and support to your relative with dementia? —— **(Add the following reasons to participants' comments.)**

- Sharing the load can avoid "burnout."
- One person doesn't have to take the blame for anything that goes wrong.
- Some people need to know exactly when and how to help.
- Small gestures of support can mean a lot.
- A driver with dementia will feel the care and concern from more than one person.
- Problem-solving from a cooperative core group can be more creative and successful than from just one person.

Sometimes we overlook people who can be useful, or we fail to give an assignment that’s appropriate for someone. For example, we might be focused on one person who can drive on a particular date and time, and overlook the grandchild or next-door neighbor who is willing and able. A long-distance relative cannot personally provide transportation, but can lend a sympathetic ear or money for an occasional taxi.

Circle of Support Exercise
 (Distribute handout “Not Going It Alone.” Read the opening paragraph.)

“Not Going It Alone” handout in back pocket of this guide.

FOR THE FAMILY

SESSION 2: Building Family Cooperation & Communication
LESSON 5

Not Going It Alone:

Who Can Offer Support?

Support from others can reduce stress and increase chances for success. Your circle of support can include people inside and outside the family who might provide emotional support, observe driving skills, discuss family concerns with the driver, pay for in-home services, provide alternative transportation, and look for public transportation alternatives. Other people can just listen or provide an outsider’s perspective.

Here’s how you can identify, and possibly expand, your circle of support.

STEP 1 On the next page are four circles.

1. In the inner circle, place the name of your loved one.
2. In the second circle, write the names or initials of those people currently providing ongoing assistance to you or your loved one.
3. In the third circle, indicate those who look after your loved one in a limited way – perhaps neighbors, friends, relatives or healthcare professionals.
4. In the outer circle, indicate those who are not currently involved but who could be asked, even if only in a limited or professional way.


STEP 2

1. How comfortable are you with the number of available support people?

Uncomfortable					Comfortable
1	2	3	4	5	

2. Are you using your support network to the fullest extent you need? Yes _____ No _____
3. If you are underutilizing your support network, what is keeping you from it?
 (Examples: beliefs, attitudes, concerns, relationships)
4. In what ways could you encourage improvement in the quantity and quality of support that you and your loved one receive?

Person	How They Help Now	Realistic Helpful Changes



THE HARTFORD

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(Read directions for Step 1 and answer any questions, then allow about five minutes for participants to complete the Circle of Support diagram and answer the questions in Step 2 by themselves.)

Questions for Discussion

1. What did you learn from looking at your circle of support? ——
2. What changes, if any, would you like to make in your support system? ——
3. Good communication can strengthen family support and reduce disagreements. Perhaps it's time for an informal family meeting or a conference call that includes a long-distance relative in the planning. Who should you include? ——
4. How can you get support without sounding critical, complaining or demanding? —— **(Add to participants' ideas the following thoughts.)**
 - Focus on the problem, not the person.
 - Show respect for the person with dementia and others.
 - Acknowledge any physical or emotional limitations of others to help.
 - Allow a tone of reasonableness to override any strong, negative emotions.

Homework

During the next week, can you talk with at least one or two people in your circle of support? You can thank them for what they've already done, ask for their opinions, or let them know what would be helpful.

Transition to Lesson 6

Some of you may be thinking, "You don't know my family." Or "This person or that person will never change." You may be right, but how can we increase the chances of having positive, purposeful and productive conversations with a relative who has dementia and with family members? We'll address this question after our break.

Break 15 minutes

LESSON 6. Conversation Planner: How can I have good conversations about not driving?

Introduction

Telling someone basically that he or she is a bad driver can be a sensitive matter. Talking with a person whose judgment is impaired can be even more challenging. By a show of hands, how many of you have already brought up the topic of driving in your family? ——

What are some reasons we might avoid having conversations about driving? ——
(Examples:)

- Worry about how the person will react
- Want to avoid conflict or hurt feelings
- Feel uncomfortable telling a parent or spouse what to do
- Overloaded with other things to take care of
- Not sure what to do if the person limits or stops driving

How to Plan a Conversation

(Distribute handout “Conversation Planner.”)

This exercise can help you have positive, progressive and productive conversations. (For additional background information, see Appendix D for research findings on family conversations about driving.)

“Conversation Planner” handout in back pocket of this guide.

FOR THE FAMILY

SESSION 2: Building Family Cooperation & Communication LESSON 6

Conversation Planner:

How can I have good conversations about not driving?

You want your conversations with the person with dementia to be positive, progressive and productive. You can use these points to guide those conversations.

Who should be the messenger? The person who answers “yes” to these questions may be in the most favorable position. Is it you or someone else? If it’s not you, you may need to have a preliminary conversation with the person in the most favorable position to take action.

Is the driver your spouse or your parent?	Yes ___ No ___
Do you have the person’s best interests in mind?	Yes ___ No ___
Do you know the person’s physical and cognitive condition?	Yes ___ No ___
Do you know the person’s driving abilities?	Yes ___ No ___
Do you have a good relationship with the person?	Yes ___ No ___

When is a good time to talk? It’s never too early to talk about driving issues, but these conversations warrant careful attention, pre-planning and serious discussion. Here are some good opportunities to start a conversation naturally.

- Change in frequency or severity of warning signs
- Change in health, medication or cognitive status
- Change in financial situation or vehicle ownership


What do you want your conversation to accomplish? Keep your conversations simple, short and direct. Focus on one or two key points at a time. Here are some appropriate topics with some sample conversation starters. Which of these topics do you need to discuss?

___ Family’s willingness to help. “When you go to the grocery store, can I go? Or instead, let me drive.” “We’re willing to drive, but you have to let us.”

___ Transportation needs and alternatives. “The mall is having a sale. What if I pick you up at 10?”

___ Observations of warning signs. “How did those scrapes get on your car? They may mean that there could be a problem judging distances. What do you think?” “We need to talk to your doctor about this.”

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(Read the *Who* section.) Sometimes families make the mistake of having the person farthest away or least emotionally vested act as the bearer of bad news. Yet, both the nature and quality of the relationship with the messenger can influence how receptive the older driver is.

By a show of hands, are you the messenger in your family? ——— If not, then who is? ——— How do you feel about having this responsibility? ———

(Read the *When* section.) Remember that drivers with dementia lack the judgment to assess their own driving skills. If the topic of driving safety has crossed your mind, it's time to begin talking about it. Early conversations allow the person with dementia and family members to adjust to the idea of stopping driving. Doctor's visits and changes in medication or health are often missed opportunities for meaningful conversations. Sometimes families wait to have a conversation until an accident or traffic violation happens. Drivers with or without dementia, however, probably won't think an accident alone warrants changes in driving behavior.

(Read the *What* section.) It's better to have more frequent, short conversations than a long, one-time conversation. With a clear objective, ask yourself: What information am I seeking? What information do I want to share? Or what changes am I seeking? If safety is a serious concern, you may need to be even more direct and specific in your discussions. The purpose of any conversation is not to prove who is right, but to solve a problem. A calm, reasonable, informative tone will help your relative not be emotional or defensive.

Which of these topics would be appropriate in your present situation? ———

Which of these openers would you feel comfortable using? ——— Can you think of other conversation openers that would work in your situation? ———

Personal Conversation Plan

Now take just a minute or so and complete your personal conversation plan. Share the plan with the person next to you. **(Put participants in pairs. Allow time for partners to share plans.)**

(With the group as a whole:) Who would like to share your next conversation plan? ———

Homework

Having sensitive and successful conversations about changing driving habits can be challenging. This week, try to have at least one short conversation about driving with your relative with dementia or with others who can help.

Review

So far, what have we accomplished?

1. We realize how cognitive changes can seriously affect driving skills.
2. We've started a systematic approach to observing driving skills over time.
3. We're assessing current driving-related activities.
4. We're exploring various transportation alternatives to driving.
5. We've examined our support system and can look for specific ways others can help.
6. We have practical tips on how to have positive, purposeful and progressive conversations about someone not driving.

Comments and Questions

Do you have any questions or comments about any of these? ———

So far, which of these has been the most useful? ———

This coming week you may want to:

- Observe driving
- Share observations with other family members
- Start a conversation about driving with your relative with dementia

What do you hope to accomplish or what is your goal for this coming week? ———

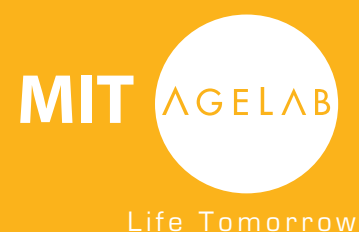
Preview of Next Session

Next week we look forward to learning about your experiences. In our final session we'll consider:

- How can you include driving issues in your advance planning?
- What can you realistically expect from doctors?
- If all else fails, what are your "last resort" options?
- Would answers to these help?

See you next week.

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.



Getting There:

Using Alternative Transportation

When a person with dementia limits or stops driving, the responsibility to provide or find transportation usually falls on the family. The most effective approach involves gradual replacement of driving with alternative transportation. The primary

caregiver needs to explore all options – from informal arrangements with relatives and friends to formal public services. You can use this worksheet with the questions on the back to help explore all your transportation options.

Transportation Alternatives	Telephone	Availability, Destination (day, time, route)	Cost	Notes (pros & cons)
Family Members:				
Friends:				
Demand-responsive Services:				
Private Program Services:				
Taxi/Car Services:				
Mass Transit:				
Other Local Programs:				

(continued on other side)



Family and friends. Getting rides from family and friends is usually the first alternative to driving, for reasons of ease and familiarity. The degree of willingness and the cost of mileage and time need to be weighed. Consider the following:

1. Who is available to provide rides at the times required?
2. Will they provide rides willingly or resent personal inconveniences?
3. What informal arrangements might give the rider opportunities to give something in return (e.g., making dinner, taking the driver to lunch, paying for gas)?

Demand-responsive services, private programs or other local services.

Demand-responsive services such as Dial-a-Ride or elderly and disabled transportation services offer door-to-door services by appointment. These are often government-subsidized and are available at reasonable fees. Types of destinations may be limited to medical or grocery shopping purposes. Private program services may be available from adult day centers, assisted living facilities, malls or stores. Other local programs, often sponsored by faith-based or non-profit organizations, provide older adults transportation for donations or nominal fees. Consider the following:

1. What are the criteria for using the service? (e.g., minimum age, disability, affiliation)
2. How much does it cost? Do passengers tip drivers? Can an account be set up in advance with the service?
3. How far in advance should arrangements for a ride be made?
4. Is there a limit to the number of trips or types of trips (medical or grocery only)?

5. Where and when does the service run?
6. Will drivers provide assistance to people with physical or other health constraints?
7. Can companions accompany the person on the service?

Taxis or car services. These offer flexible scheduling and can actually be cheaper than owning and maintaining a car. Some car services may be willing to set up accounts for relatives to pay for services. Consider the following:

1. How is the cost calculated?
2. How long in advance should arrangements for a ride be made?
3. Can an account be set up in advance? How are tips handled with an account system?
4. Will drivers provide assistance with bags or packages?

Mass transit. This may be appropriate for those with mild dementia who are accustomed to taking a bus, subway or train. Consider the following:

1. How much does it cost? Are there discounts for older or disabled people?
2. Can an account be set up in advance with the service? Are there monthly passes?
3. What are the hours and geographic area of service?
4. Most important, is mass transit appropriate, considering my relative's cognitive or physical limitations?

Not Going It Alone:

Who Can Offer Support?

Support from others can reduce stress and increase chances for success. Your circle of support can include people inside and outside the family who might provide emotional support, observe driving skills, discuss family concerns with the driver, pay for in-home services, provide alternative transportation, and look for public transportation alternatives. Other people can just listen or provide an outsider's perspective.

Here's how you can identify, and possibly expand, your circle of support.

STEP 1 On the next page are four circles.

1. In the inner circle, place the name of your loved one.
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STEP 2

1. How comfortable are you with the number of available support people?

Uncomfortable					Comfortable
1	2	3	4	5	

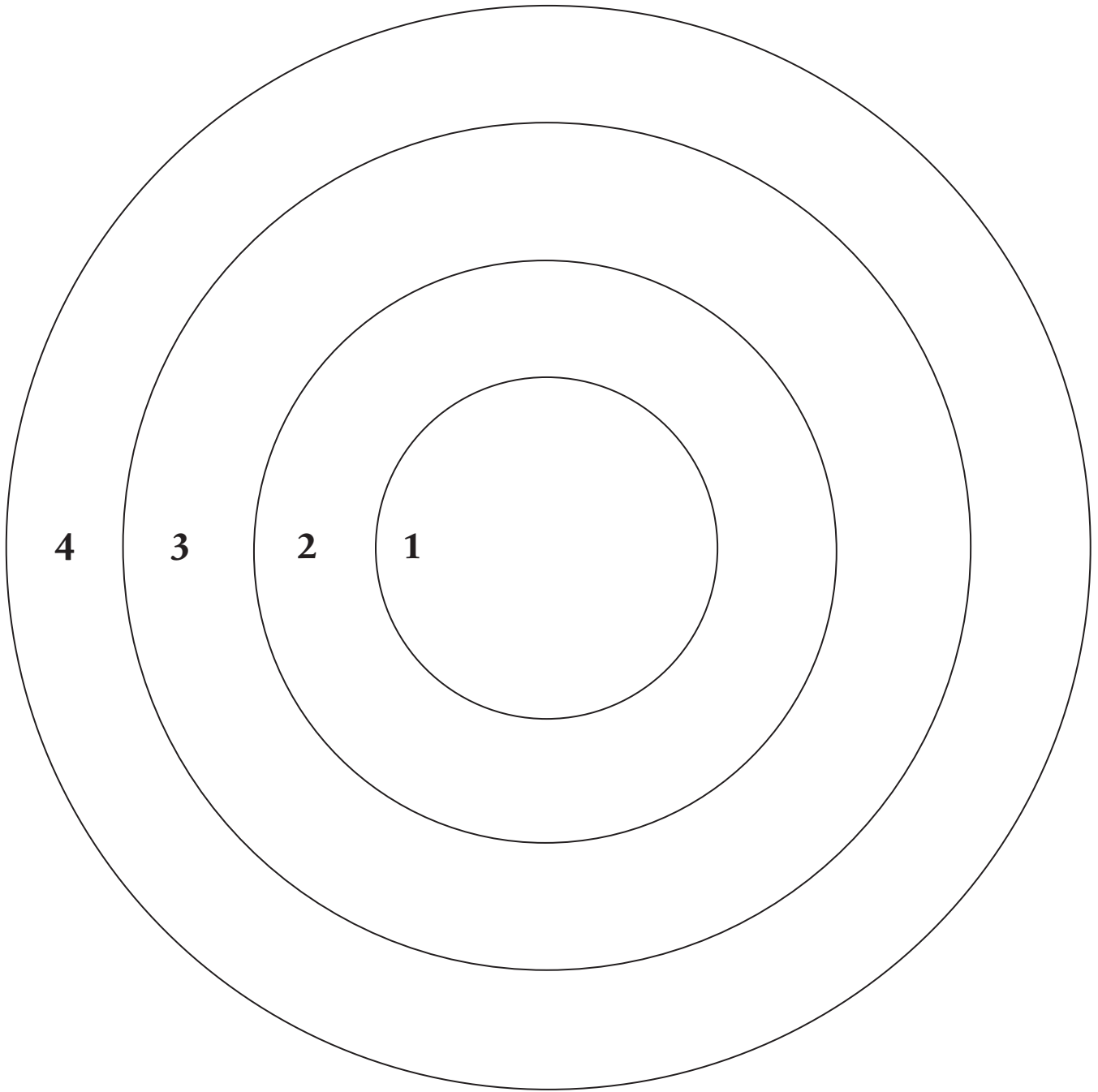
2. Are you using your support network to the fullest extent you need? Yes _____ No _____
3. If you are underutilizing your support network, what is keeping you from it?
(Examples: beliefs, attitudes, concerns, relationships)
4. In what ways could you encourage improvement in the quantity and quality of support that you and your loved one receive?

Person	How They Help Now	Realistic Helpful Changes
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

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Circle of Support



Conversation Planner:

How can I have good conversations about not driving?

You want your conversations with the person with dementia to be positive, progressive and productive. You can use these points to guide those conversations.

Who should be the messenger? The person who answers “yes” to these questions may be in the most favorable position. Is it you or someone else? If it’s not you, you may need to have a preliminary conversation with the person in the most favorable position to take action.

- | | |
|--|----------------|
| Is the driver your spouse or your parent? | Yes ___ No ___ |
| Do you have the person’s best interests in mind? | Yes ___ No ___ |
| Do you know the person’s physical and cognitive condition? | Yes ___ No ___ |
| Do you know the person’s driving abilities? | Yes ___ No ___ |
| Do you have a good relationship with the person? | Yes ___ No ___ |

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What do you want your conversation to accomplish? Keep your conversations simple, short and direct. Focus on one or two key points at a time. Here are some appropriate topics with some sample conversation starters. Which of these topics do you need to discuss?

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___ Transportation needs and alternatives. “The mall is having a sale. What if I pick you up at 10?”

___ Observations of warning signs. “How did those scrapes get on your car? They may mean that there could be a problem judging distances. What do you think?”
“We need to talk to your doctor about this.”

(continued on other side)



_____ Planning alternative transportation. “The van driver said he would make sure you got to your appointment on time.”

_____ Potential risks to self or others. “I know you think you’re okay driving. But you always said, ‘Better safe than sorry.’”

_____ Need to stop driving. “We don’t feel safe when you drive.” “I would feel awful if something terrible happened to you or someone else on the road.”

_____ Getting support from others. “I’ve noticed changes in his driving. Could you ride with him and see what you think?” “Can we take turns taking her to the grocery store?” “She needs to hear this from more than just me.”

_____ Other: _____

Personal Conversation Plan. What is your next conversation strategy? With whom will you talk? When? What do you hope to accomplish from the conversation?

Session 3

AT THE CROSSROADS

Knowing Your Options



CONTENTS

Review and Experiences

Lesson 7: Agreement with My Family

Lesson 8: The Role of
Healthcare Providers

Lesson 9: “Last Resort” Options

Comments and Questions

Closing Activity

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

www.safedrivingforalifetime.com

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

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:

_____	_____
_____	_____
_____	_____
_____	_____



Overview of Dementia*

Dementia

Dementia refers to the new onset of memory difficulties and other cognitive problems severe enough to impair daily living. Dementia is a syndrome and is not, in itself, a diagnosis. It does not refer to a specific disease or cause. There are many causes of dementia. In addition, there are reversible and irreversible causes of dementia. Reversible causes include such factors as depression, thyroid abnormalities, vitamin deficiencies, and infections. Irreversible causes of dementia include vascular disease and frontotemporal dementia, among others.

Alzheimer's Disease

Alzheimer's disease is the most common cause of dementia. It is a progressive, irreversible brain disorder. Currently, about 5.3 million people in the U.S. are living with Alzheimer's disease, and this number is projected to increase drastically as baby boomers age. More than 70 percent of people with Alzheimer's disease live at home.

Symptoms of Alzheimer's disease are memory loss (i.e., the inability to learn and recall new information), decreased judgment, mood and personality changes, and difficulty with reasoning and activities of daily living (from tasks such as making change and making telephone calls, to bathing and dressing).

The two main types of Alzheimer's disease are late-onset and a rare, early-onset form of the disease. Late-onset is by far the most common type of Alzheimer's disease, and it affects people primarily over the age of 65. The chance of an

individual developing Alzheimer's disease over 65 doubles every five years. Some estimates suggest that nearly half of those over 85 have Alzheimer's disease.

Symptoms may not be apparent in an individual until long after brain changes start. When an individual becomes symptomatic, the brain cells that play a role in storing and gathering information have begun to die. "Plaques" (caused by an over-abundance of a protein called amyloid) and "tangles" in the brain are the hallmark features of Alzheimer's disease. The plaques form outside the brain's nerve cells and the tangles are strands of protein that form in the brain cells.

Alzheimer's disease may have multiple causes. Some people may be genetically predisposed to late-onset Alzheimer's disease. A physician should conduct a thorough examination to assess any changes in memory, mood or personality. In addition, a neuropsychological evaluation, involving formal tests of memory and cognitive functioning may be ordered. The individual's family member(s) will play a key role in relaying any changes he or she sees in the person's memory or thinking abilities.

Individuals can take measures that may possibly reduce their risk or delay symptoms. These include reducing high blood pressure and cholesterol levels, maintaining a healthy weight, engaging in healthy mental and physical activities, and having a socially active lifestyle.

Facts About Older Drivers

Age alone is not a reason to stop driving. Many older adults drive safely their entire lives.

Accident Rates of Older Drivers

Older drivers (age 65-plus) represent about 14 percent of licensed drivers but only 8 percent of all crashes. In comparison, younger drivers between 16 and 29 represent about 13 percent of licensed drivers but represent 33 percent of crashes. In general, older drivers do not represent a public safety threat. Some drive safely for their entire lives.

Common Physical Changes Affecting Driving

As we age, we experience physical changes that can affect driving ability, particularly changes in vision and reflexes. Older drivers who have health conditions that cause functional limitations may be at greater risk for driving problems. Staying as healthy as possible, and maintaining flexibility and strength, can go a long way to staying on the road safely. To optimize vision for safer driving, older adults need to have regular vision checkups and proper eyeglass corrections.

Older Drivers and Self-Regulation

Most older drivers respond to physical changes by “self-regulating,” which means modifying the way they drive. They may avoid driving on certain roads or at night. Research indicates that most older drivers make modifications – or self-regulate – to stay safe on the road and prolong their driving years. Older drivers have lower crash rates in part because of their voluntary self-regulation of when and where they drive. By driving less and avoiding riskier situations – such as rush hour, inclement weather and long distances – many older adults continue to drive safely.

Research conducted by The Hartford’s Advance 50 Team and the MIT AgeLab revealed that two-thirds of older drivers voluntarily self-regulate their driving. Older drivers who are in fair to poor health self-regulate more than those in good to excellent health. In fact, an 80-year old in excellent health will self-regulate about as much as a 60-year-old in poor health.

(continued)

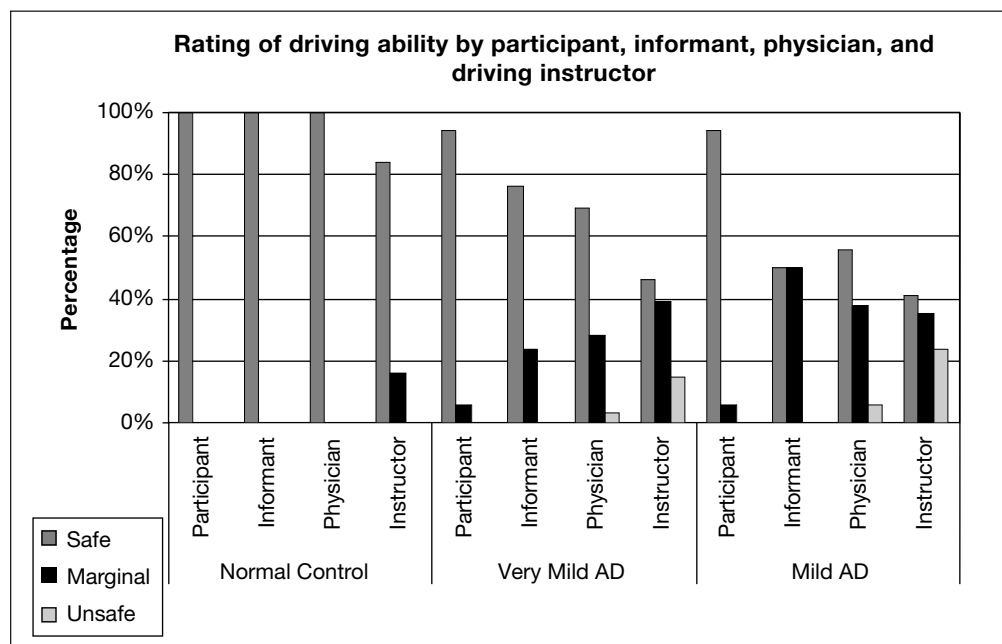
Health Problems and the Decision to Stop Driving

A diagnosis alone seldom gives enough information to make a judgment about driving safety. However, some individuals have health problems that seriously interfere with safe driving. Some of these drivers cannot continue driving safely even by limiting where and when to drive. The decision to stop driving is generally a private one, made by older drivers with the input of their families and doctors. However, not all doctors agree that they are the best source for making decisions about driving. Physicians may not be able to detect driving problems based on office visits and physical examinations alone. They can assess diminished visual, cognitive and motor skills, or refer the driver to a specially trained occupational therapist who is qualified to conduct a comprehensive driving evaluation. The difficult decision to stop driving is often based upon the individual driver's health and confidence behind the wheel and available transportation support.

Some medications – such as antidepressants, anti-anxiety, and antihistamines – can interfere with driving. Any drug that warns of decreased alertness or drowsiness may cause driving problems. Many older drivers are taking multiple medications, and little research has been done to determine the effect on their driving. When in doubt, ask your pharmacist or doctor.

Facts About Drivers with Dementia

Research shows that most people – not just those with Alzheimer’s disease (AD) – tend to overrate their driving skills. People with dementia are especially likely to minimize the complexity of driving and overestimate their abilities. As the disease progresses, the person with dementia cannot make new memories and learn new tasks. So, as their skills decrease, they cannot retain this new information about their driving skills.

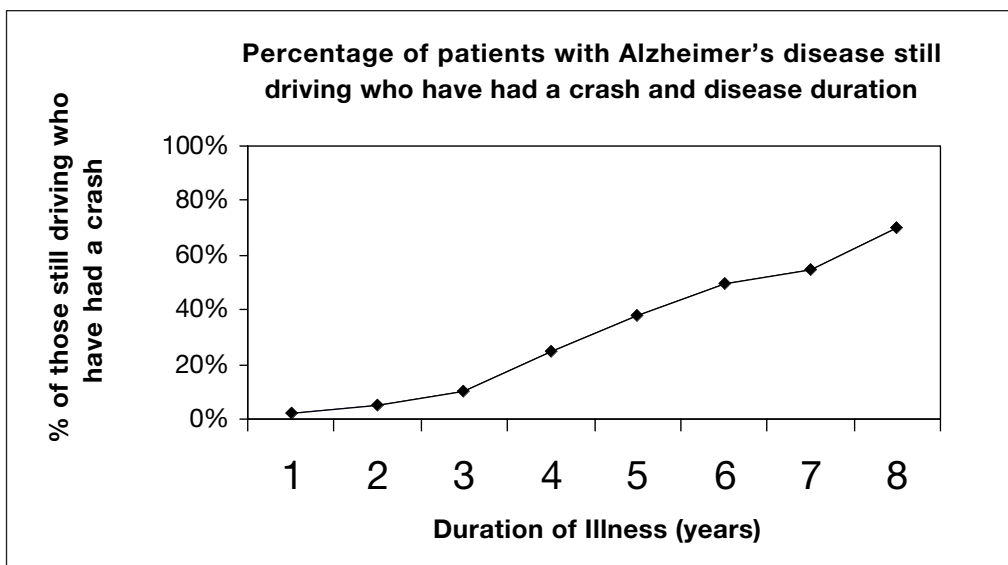
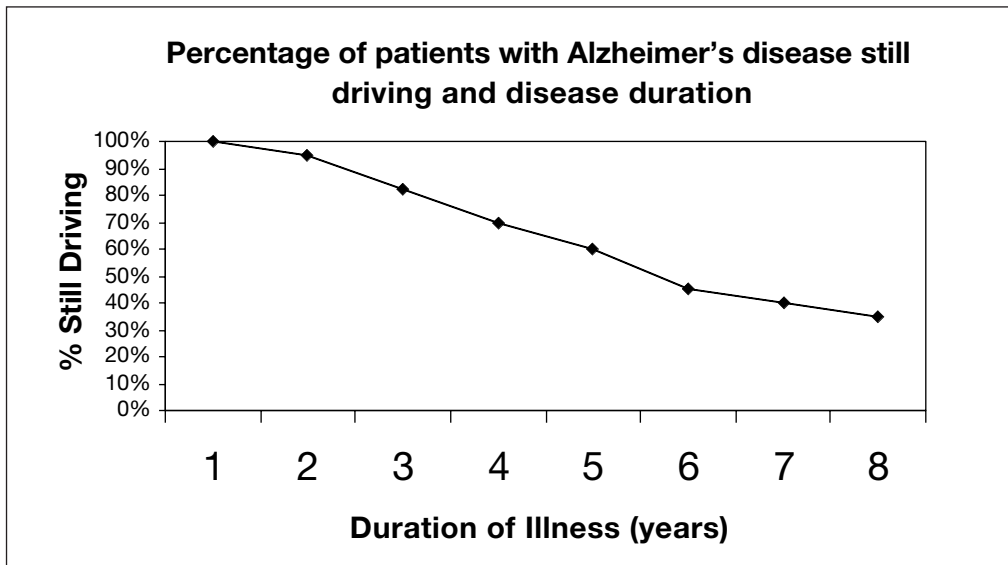


- 94% of participants with very mild or mild AD rated their driving as safe.
- Driving instructors rated less than half of the participants with very mild or mild AD driving as safe (46% of those with very mild AD were rated as safe, and 41% of those with mild AD were rated as safe).
- Neurologists rated the driving ability of 56% of the participants with mild AD safe, and 69% of those with very mild AD as safe.

Neurologists’ ratings of participants’ driving abilities – based upon clinical assessments – were significantly related to driving instructors’ ratings of on-road driving performance.

(continued)

The first of the following two charts shows that over time, people who have been diagnosed with Alzheimer's disease tend to stop driving. Even so, eight years after diagnosis, more than 30 percent of those diagnosed with Alzheimer's disease are still driving. The second chart shows that the longer a person with Alzheimer's continues to drive after diagnosis, the greater the chances of getting into an accident. On average, the chances increase most between three and four years after diagnosis. Among those who have been driving for eight years after their diagnosis, well over 60 percent have had at least one accident since their diagnosis.



Friedland, R. P. (1988). Motor vehicle crashes in dementia of the Alzheimer's type. *Annals of Neurology*, 24(6), 782-786.

Findings

From Family Conversations about Driving Study

A national survey conducted by The Hartford and the MIT AgeLab found that 50 percent of married, older drivers would prefer to hear about their driving first from their spouse. A small percentage (15 percent) said their spouse is the last person they'd like to hear deliver the message about driving. If they don't hear it from a spouse, then married older adults (14 percent) would prefer to hear from an adult child, usually a daughter, and some (27 percent) say they would listen to a physician.

Unmarried drivers say they would prefer to hear either from an adult child (31 percent) or a doctor (41 percent).

Older drivers say it is important to them that the person who talks to them about their driving needs to have their best interests at heart (51 percent), be close enough to know about the driving ability by seeing them or riding with them regularly (39 percent), and knows whether they are physically capable of being a good, safe driver (63 percent).

Of course, the last person anyone wants to hear from is a police officer or government official.

The percentage of older drivers who say these changes or events would be appropriate times to talk with them about driving are as follows:

- After a significant change in health status (74 percent)
- If they were generally concerned about my safety (71 percent)
- After some incidents of forgetfulness or getting lost while driving (70 percent)
- After a car accident (51 percent)

Opportunities such as doctor's visits or changes in medication or health are often overlooked as times to initiate meaningful conversations about driving. Sometimes families wait until there is an accident or traffic violation to have a conversation. However, older drivers may dismiss accidents or traffic violations as being common occurrences, not related to their abilities, especially if they are found to be not at fault in an accident. Drivers are less likely to think an accident alone warrants changes in driving behavior.

Comprehensive Driving Evaluations

No Reliable Test Is Available

There is no simple, accurate, readily available test to determine whether an older driver is safe to continue driving. This is especially true when the driver has cognitive problems, like dementia or Alzheimer's disease. Even existing tests (e.g., pencil and paper or vision and reaction time tests) often tend to focus only on a few of the skills important for driving. For this reason, families need to observe driving from the time of diagnosis in order to gain valuable facts about any changes in driving performance over time. This information not only helps families know whether the driver's skills are diminishing, but also can be useful to share with health professionals, such as a doctor or care manager.

Some drivers who have specific driving difficulties related to health conditions may benefit from a comprehensive driving evaluation from an occupational therapist (OT). Occupational therapists or other trained specialists can help assess driving skills and develop a plan to improve those skills. In some cases, limitations can be compensated for with exercise, special equipment and a plan for avoiding certain types of driving.

If there is a specially trained occupational therapist available in your area, a comprehensive driving evaluation may be helpful. If the older driver can drive after some rehabilitation, driving may be extended. A professional evaluation that driving is no longer safe may be convincing to an older driver.

The Occupational Therapist

While several types of practitioners can rate some aspects of driving ability, an occupational therapist with specialized training in driving evaluation has the credentials to perform a comprehensive evaluation of an individual's driving ability. These specially trained occupational therapists are qualified to offer services to evaluate driving and to involve the team of professionals required to address individual needs. They will either work with the older driver to develop a plan to continue driving or prepare him or her to transition from driver to passenger when the time comes.

A full assessment costs about \$250 to \$600 and lasts anywhere from one to four hours. Generally, Medicare and private insurers do not cover the cost of a driving evaluation, but Medicare will cover the cost for neurological screening for drivers.

Veterans may be eligible for a driving evaluation through the VA healthcare system. Eligibility is determined on a case-by-case basis. Eligible veterans may receive: a driving evaluation; patient and family education, including defensive driving techniques; behind-the-wheel instruction; and vehicle and equipment evaluation/prescription.

Driving evaluations may be available through rehabilitation programs and some motor vehicle departments. Driving tests are not uniform, and the evaluations vary depending on the extent of the tests and the evaluators' familiarity with cognitive impairments and other conditions that affect driving. Nevertheless, such tests may provide families with additional input and support.

(continued)

Components of a Driving Evaluation

What happens in a driving evaluation? Although evaluations can vary, they should include these three components:

1. Clinical Evaluation

The driver's medical and driving history should be reviewed. The OT will perform some clinical tests of the driver's performance behind the wheel, such as:

- Vision (depth perception, peripheral vision, visual spatial skills and contrast sensitivity)
- Cognition (judgment and memory, following instructions, speed with which brain reacts)
- Motor strength (also range of motion, coordination, sensation, reaction time)

2. On-The-Road Evaluation

Depending on the results of the clinical assessment, the OT will most likely watch how the driver does behind the wheel out on the road. Drivers are rated not just on how they handle the car, but also on their problem-solving ability and judgment, and how well they negotiate the traffic around them.

3. Oral Feedback and/or Written Report

Immediately after the testing or at an agreed upon time in the future, the driver will meet with the OT to discuss the clinical 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.

Note: Participants who do not do well on the clinical evaluation may still take the road test. These individuals may still demonstrate safe driving because they have “over learned” the tasks involved in driving. Also, family members may need additional information in order to accept the fact that their loved one can no longer drive.

Questions to Ask about Driving Evaluation Programs

Before pursuing a driving evaluation program, be sure to ask about:

- What makes up the evaluation?
- Who does the driving evaluation?
- How does your program work?
- How much does the evaluation cost?
- Do I need to contact my doctor for a prescription?
- Is a written report generated following the driving evaluation?

For more information about the benefits of having a comprehensive driving evaluation from an occupational therapist with specialized-driver evaluation training, download or order a free copy of *Your Road Ahead: A Guide to Comprehensive Driving Evaluations* at www.safedrivingforalifetime.com/publications.

Sample

National and Local Resources for Information on Comprehensive Driving Evaluations

National Resources

American Occupational Therapy Association
www.aota.org/olderdriver

American Medical Association
www.ama-assn.org/go/olderdrivers

Association for Driver Rehabilitation Specialists
www.aded.net

Local Resources

(Facilitator to add local resources here)

Other Valuable Resources from The Hartford

The Hartford is one of the few companies in the U.S. with in-house experts on aging. For more than 25 years, The Hartford Advance 50 Team of gerontologists has advanced the creation and delivery of research, educational guidebooks and innovative business solutions for the mature market.

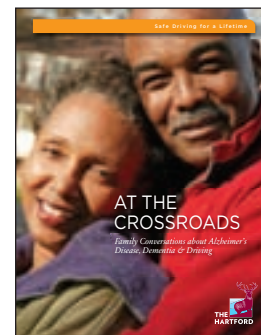
The Hartford became a founding sponsor of the MIT AgeLab in 1999. The Hartford Advance 50 Team and the MIT AgeLab are committed to producing original research to improve the quality of life for older adults and their families. Through publications, professional meetings and public education, The Hartford/MIT AgeLab partnership has reached millions of people around the globe with meaningful information to guide important decisions about safety, mobility and independence.

The following guidebooks – many of which were developed from research conducted jointly by The Hartford and the MIT AgeLab – are available free of charge. To order or download copies, visit www.safedrivingforalifetime.com/publications.

Topics of Interest to Dementia Caregivers:

At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia & Driving

- Helps families determine when it's time for loved ones with dementia to stop driving and offers strategies for coping with driving cessation.



The Calm Before the Storm: Family Conversations about Disaster Planning, Caregiving, Alzheimer's Disease and Dementia

- The first comprehensive natural disaster planning guide specifically created for caregivers, families and friends of those with memory disorders.



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Other Topics:

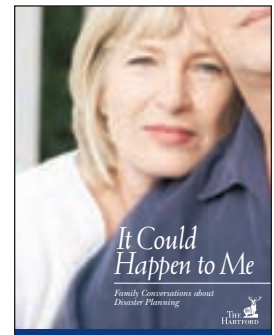
Your Road Ahead: A Guide to Comprehensive Driving Evaluations

- Describes the benefits of having a comprehensive driving evaluation from an occupational therapist with specialized driver evaluation training.



It Could Happen to Me: Family Conversations about Disaster Planning

- Based on the experiences of older adults who live in disaster-prone areas, this booklet guides readers through the disaster planning process, from assessing risk through working with a network of people to create a plan.



We Need to Talk: Family Conversations with Older Drivers

- Provides families with practical information to help them plan ahead and initiate productive and caring conversations with older adults about driving safety.



Fire Sense: A Smart Way to Prevent, Detect and Escape Home Fires

- Describes the most common causes of residential fires, offers lifestyle changes that can reduce a family's risk, and suggests what to do if fire strikes.



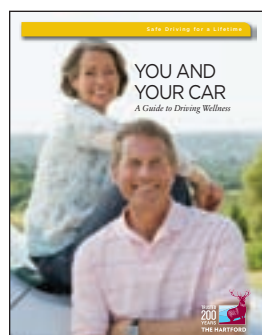
Your Road to Confidence: A Widow's Guide to Buying, Selling and Maintaining a Car

- Empowers widows to take control of their driving future and confidently buy, sell and maintain a car.



You and Your Car: A Guide to Driving Wellness

- Describes how drivers can be safe on the road for a lifetime.



Support Group Leader Feedback

We value your feedback. Please complete and mail this form to:

The Hartford Advance 50 Team
200 Hopmeadow Street C3E2
Simsbury, CT 06089

If you would prefer to receive and complete an electronic version of this form, please request a copy at safedriving@thehartford.com.

1. How many times have you facilitated the At The Crossroads support group based on the kit? _____
2. How many people attended your most recent session? _____
3. When you facilitate the ATC support group is it part of an ongoing support group for caregivers of persons with dementia? Yes No

On a scale of 1-5, where 1 is not very helpful and 5 is very helpful, how would you rate the following?

	Not Helpful				Very Helpful
	1	2	3	4	5
• Overall – the entire kit.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• At The Crossroads: The Guidebook.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Introduction Booklet.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Session 1 Guide: Assessing Driving Ability & Activity.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Session 2 Guide: Building Family Cooperation & Communication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Session 3 Guide: Knowing Your Options.....	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• Appendices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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