

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:				
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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



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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.

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Taxi/Car Services:				
Mass Transit:				
Other Local Programs:				

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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?

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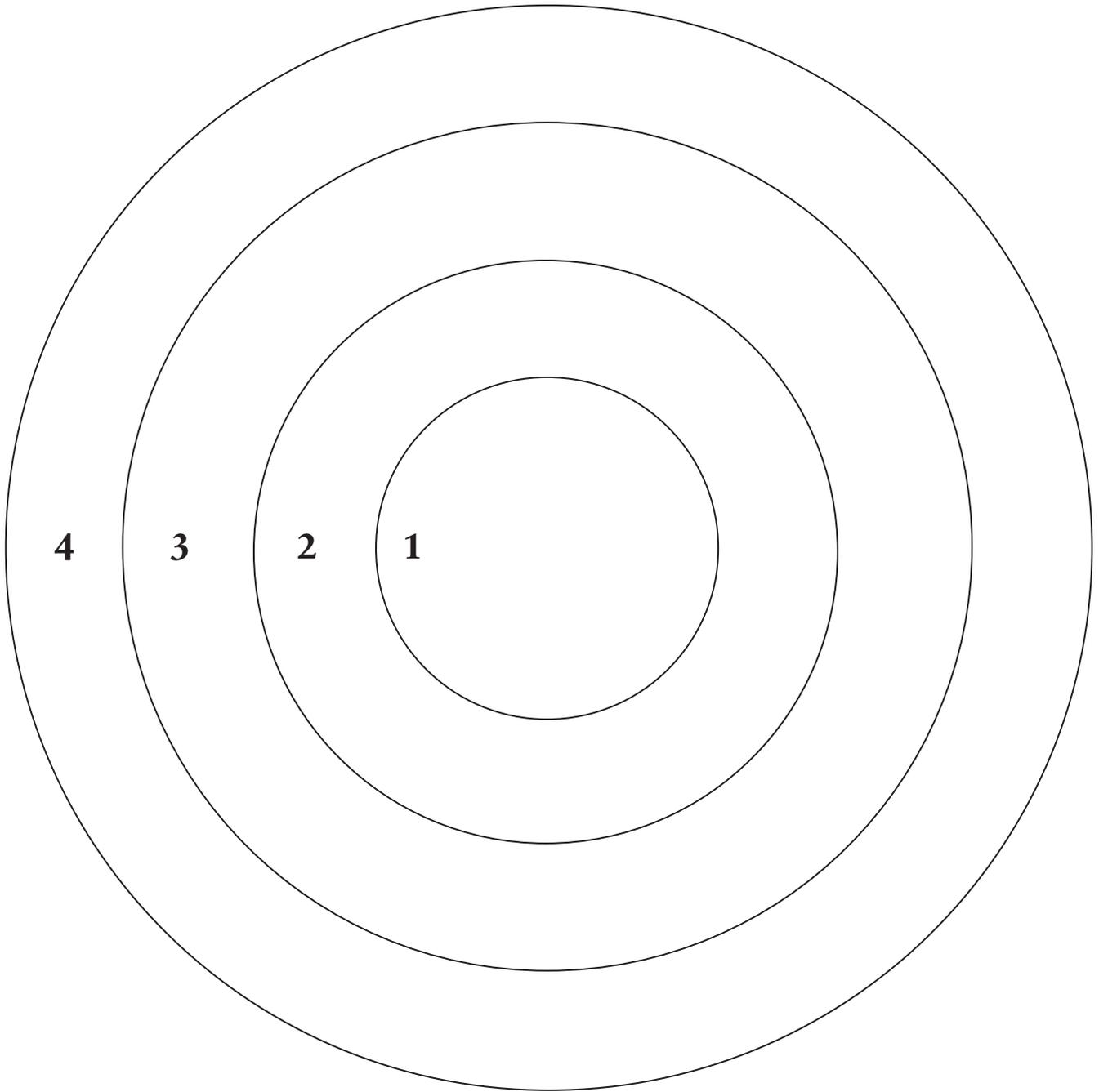
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Person	How They Help Now	Realistic Helpful Changes
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

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Circle of Support



Conversation Planner:

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- | | |
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___ 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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_____ 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?