#### Safe Driving for a Lifetime

# AT THE CROSSROADS

Family Conversations about Alzheimer's Disease, Dementia & Driving

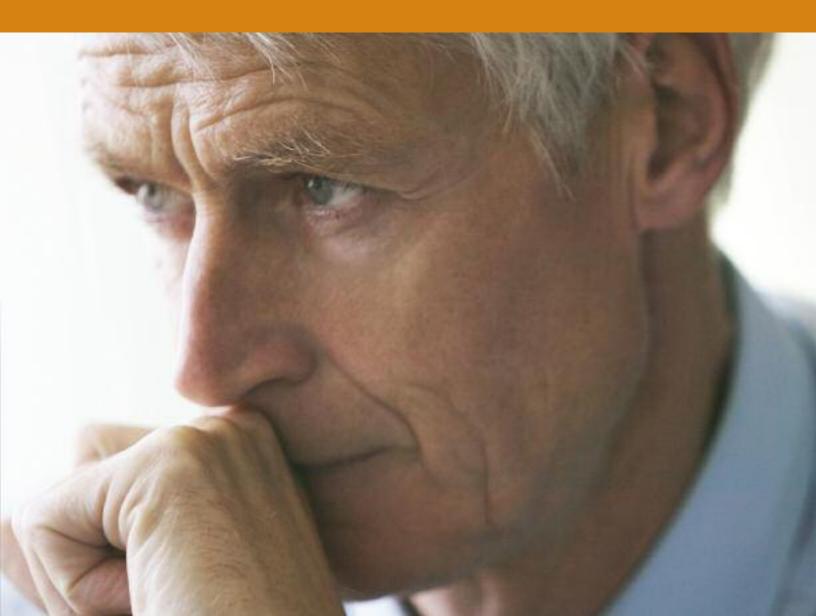
THE HARTFORD Center for Mature Market EXCELLENCE



The Hartford Center for Mature Market Excellence and the MIT AgeLab have developed this guide to help people with dementia and their families prolong independence while encouraging safe driving. The guide provides suggestions for monitoring, limiting and stopping driving. The information incorporates the experiences of family caregivers and people with dementia, as well as suggestions from experts in medicine, gerontology and transportation.

> "Our children talked to him about possibly not driving. They don't know it, but he cried that night. Driving is extremely important to him. I don't want to strip him of his dignity."

> > - Wife whose husband has mild dementia



# Balancing Independence and Safety

"My sons and daughters had a meeting without me and decided that they want me to stop driving, but they're making a big deal out of nothing. I'm very comfortable on the road. I've driven longer than they've been alive."

 Person recently diagnosed with dementia Today, more than 5 million people in the U.S. suffer from dementia, with Alzheimer's disease being the most common form. And this number is expected to grow as the population ages.

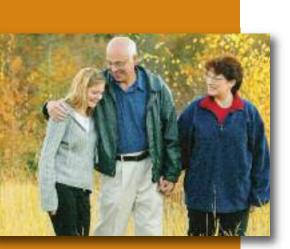


Do you have a relative with dementia who's still driving? Do you worry about him or her driving? Or are you just hoping his or her driving is "good enough?"

If you have a loved one diagnosed with dementia, you'll struggle with a number of caregiving challenges from medical and daily care to financial

and legal matters. Driving, of course, can be an immediate and life-threatening issue – making it a family priority.

It's difficult to decide when someone with dementia should stop driving, since you need to balance safety considerations with the person's sense of independence, pride and control. Most information about dementia warns against driving, but doesn't help you determine when it should stop.



"We know that stopping him from driving is the first of many indignities to come. He thinks he's not much of a man without a car. It's so difficult to know where to draw the line."

 Daughter of a person with dementia

### The Difficulties of Dementia and Driving

When you drive, different regions of your brain cooperate to receive sensory data (through sight and hearing), prioritize information, recall related past experiences, anticipate likely scenarios, analyze options, plan ahead, use proper judgment, synchronize movement responses, and juggle more than one task at a time. And, because of the nature of driving, each of these required tasks needs to be accomplished with adequate speed. Depending on the specific difficulties of the individual — and every individual with dementia may initially present with a different pattern of difficulties based on the specific areas of brain damage – one or more of these functions may be impaired. It's the specific profile of these difficulties that can pose a risk for some individuals in the early stages of dementia.

In the early stages of dementia, many people usually are still socially engaged and able to manage daily activities – including safe driving. However, all people with irreversible dementia will eventually become unsafe to drive because of the degenerative, progressive nature of the brain disease. The question is: at what point is someone unable to continue to drive safely? That nagging question surfaces early.

For most people, driving represents freedom and control. It's a way to access healthcare, to buy necessities, to be productive and to stay connected to family, friends and the community. Giving up driving can be a deeply personal and emotional issue.

If someone in your family is diagnosed with dementia, you can encourage that person to express what the loss of driving means on a personal level. Talking openly at this early stage can help smooth the transition to eventually not driving. Try to imagine what your life would be like if you couldn't drive, and encourage the person with dementia to share his or her feelings. You also might encourage that person to confide in a friend about what it means to give up driving.

#### Not Like Changes Common in Later Life

As we age, even those of us without dementia may experience physical changes that affect driving – including eyesight problems and slower reaction times. In response, most people will modify the way they drive by avoiding driving on certain roads or at night. They usually can assess and regulate their driving without family intervention and can continue to drive safely throughout their lives.

But it's different for those with Alzheimer's disease or other dementias – particularly because the condition can be gradual and unpredictable. Drivers with dementia often modify their driving by driving less at night or in unfamiliar areas, but as their abilities diminish, they lose the capacity to determine when they should stop driving. They're likely to minimize the complexity of driving and overestimate their abilities. They may lose the ability to be aware of their own neurological and thinking problems. They may make excuses or blame others for their high-risk driving behaviors, and may say things like:

- "Just because I got lost doesn't mean I can't drive."
- "I make sure I look where I'm going."
- "I've driven many, many years and haven't had an accident yet."

As the person begins to lose driving and self-assessment skills, serious risks increase and caregivers must step in.

#### Finding a Balance

The challenge with driving and dementia is to preserve a person's sense of independence for as long as possible, while simultaneously protecting the safety of that person and others.

Many times, caregivers will allow a person with dementia to continue driving even though they believe it's unsafe. They might not want to hurt that person's feelings, or they may worry about what others might think. Some want more support from family, friends or professionals before intervening, and others want to delay taking on the responsibility of providing transportation.

At the other extreme, some family members overreact to common driving errors such as failure to complete a stop at a stop sign. They may blame such errors on the disease, when, in fact, the person may have always had this bad driving habit. A single occurrence of poor driving doesn't mean the person has to stop driving. But it does signal the need for increased monitoring and assessment.

#### **Assessing Driving Abilities**

Once someone has been diagnosed with dementia, it is critically important to be on the lookout for changes in their driving skills. Family members are often in the best position to monitor changes in driving skills such as attention span, distance perception or ability to quickly process information.

You can refer to the **Warning Signs for Drivers with Dementia** on page 11 for a systematic, objective way to assess driving over time. You can refer to your notes on this worksheet when making driving-related decisions and can use them in your conversations with healthcare providers. You may also want to consider getting an independent opinion by arranging for a Comprehensive Driving Evaluation.

If you don't know what to look for, you might miss opportunities to notice driving behaviors when you ride with your relative. As a result, you might overlook subtle changes or dismiss incidents as not being cause for serious concern. The **Warning Signs** list can help you be more attentive to any decline in abilities.

- 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 do not warrant immediate or drastic action.
- Avoid an alarming reaction. Take notes and have conversations at a later, convenient time, rather than during or immediately after an incident.

Some driving errors are more serious than others. If someone gets lost while driving in a familiar area, he or she may have cognitive problems that could be caused by medication, physical illness or a disorder such as dementia. This should be brought to the attention of a doctor immediately.



"It's difficult being in the passenger seat after years of driving."

- Person with dementia

# Easing the Transition from Driver to Passenger

You can help a person with dementia limit and stop driving over time – while still preserving his or her dignity – with a progressive approach and a combination of strategies that fit your family's unique situation.

Fortunately, in many cases, older people begin limiting their driving to accommodate changes in skill, regardless of whether they have dementia. Such modifications you might notice include:

- Driving shorter distances
- Driving on familiar roads
- Avoiding difficult, unprotected left turns
- Avoiding driving at night, in heavy traffic, or during bad weather

#### Letting Others Do the Driving

Passengers often can safely help a driver by giving directions or pointing out dangers. But the situation is no longer safe if the passenger is acting as a co-pilot, regularly giving instructions as if thinking ahead for the driver. If you see this is happening, you may want to find opportunities for someone else to drive and have the person with dementia give directions.

A gradual shift in who drives can ease the transition for both family members and people with dementia. Although you may want the person with dementia to maintain control for as long as possible, it's often easier to stop driving if driving has been reduced gradually over time.

Driving even short distances in good weather can pose a risk if driving skills are impaired. Most accidents happen close to home.

When a person with dementia limits or stops driving, the responsibility for providing or finding transportation usually falls on the family. The worksheet, **Getting There: Using Alternative Transportation**, on page 13, can help you explore all transportation options – from informal arrangements with relatives and friends to formal public services.

**Public transportation** may be an option for those with mild dementia, but is often too complicated for people with more advanced dementia. People with mild dementia who live in urban areas may rely more on public transportation if they're already used to it. With some coaching and practice, people with mild dementia can learn to use senior transportation services that may be readily available.

Taxis can be a good alternative for people in middle to later stages of dementia – as long as there are no behavioral problems, the driver has explicit directions and someone is available at the beginning and end of the trip. Some companies set up accounts for family caregivers so a person with dementia has easy access to a taxi without worrying about payment.

Friends, neighbors, relatives or caregivers can offer to drive the person with dementia to appointments and social events. Other family members will be more likely to help with the driving if they're asked to pitch in at times convenient to them.

#### Reducing the Need to Drive

Resolving the driving issue involves not only substituting other drivers or modes of transportation, but also addressing why people want to go places. The worksheet, **Driving Activities: Where, When and Why?**, on page 15, helps you to consider the physical practicalities and the social benefits derived from driving. As one person reflected:

"When I went to the bank or drug store, I would stop at the local bakery for some pastries. Sometimes it would take most of the morning because I could take my time and chat with different friends along the way".

The family can then look for ways to meet those needs in other ways, such as:

- Arrange to have medications, groceries and meals delivered, reducing the need to shop
- Schedule people to visit regularly
- Arrange for friends to take the person with mild dementia on errands or to social or religious events

#### Having Positive and Productive Conversations

Asking a person to stop driving can be a delicate, highly emotional matter. Family members delay having these conversations mainly because they want to avoid conflict and hurt feelings. Some adult children don't want to challenge a parent or may already be overloaded with other responsibilities.

The worksheet, **Conversation Planner: How Can I Have Good Conversations about Not Driving?**, on page 17, can help you plan progressive and productive conversations.

It's rarely a good idea to have the conversation initiated by the person farthest away or least emotionally vested. The best choice is usually a relative who knows the driver's physical condition and driving abilities and has the person's best interests in mind.

If a relative's driving safety has been on your mind, it's time to talk about it and lay the foundation – before driving becomes a problem. Changes in medications and health status are good times for this discussion. Sometimes families wait until an accident or traffic violation happens, but then the driver may dismiss the incident as a common occurrence not related to his or her abilities.

Personalities and families vary, but it's usually better to have frequent, short conversations than a long, one-time conversation. If safety is a pressing concern, your discussions need to be more direct and specific and conducted in a calm, reasonable and informative tone. It's important for family members to know that many, if not most, individuals with dementia have difficulty learning and remembering new informa-



Take advantage of the time during the early stages to discuss options for when the person must limit and eventually stop driving. tion, even in the early stages of dementia. They may not even recall a previous conversation about driving and act as if it's the first time the topic is being raised.

#### **Building Social Support**

As a caregiver, you can reduce your stress and increase your chances for success by relying on others for emotional support, transportation assistance, financial help or to meet other needs. A grandchild or neighbor might be able to run an errand or pay a visit. A longdistance relative might be willing to pay for an occasional driver or taxi. Someone else might be able to observe your relative's driving ability and habits.

The activity, **Not Going It Alone: Who Can Offer Support?**, on page 19, can help you identify and expand your circle of support.

#### **Early Planning**

When possible, include the person with dementia in the planning process. People are better able to respond to appeals to safety during the early stages of the disease. This is a good time to discuss options for when the person must limit and eventually stop driving.

One way to initiate a conversation about driving is to use the **Agreement with My Family about Driving** on page 21. This informal agreement doesn't restrict driving at the moment of signing, but designates a person to take necessary steps to ensure safe driving in the future. It respects the individual's dignity by focusing on the disease – not the individual – as the reason for driving restrictions and cessation.

The agreement is not a legal contract, but allows families to discuss matters and agree on a course of action before a crisis occurs and while the loved one is still able to make decisions.

But keep in mind that not everyone with dementia will grant advance permission for someone to stop them from driving. The signed statement does not answer the question of when driving should stop, and it doesn't ensure that the person with dementia will comply once the disease progresses.

#### **Getting Outside Help**

In some family situations, caregivers often achieve better results and have greater success if they seek support from professionals outside the family.

#### Healthcare Professionals

Healthcare professionals may be more likely to discuss driving issues with a patient if they've met with the patient's caregivers privately to hear about the driving behavior. This input can help because doctors have no tests to determine definitively when someone should stop driving, and they may hesitate to bring up such an emotional topic for fear of jeopardizing their relationship with the patient. Doctors may ask a patient not to drive for a period of time while trying new medications. When a physician is concerned about someone's safety, he or she may address the issue by writing a "prescription" to stop driving. The physician may also be able to refer the person with dementia to a specially trained occupational therapist for a driving evaluation.

#### **Independent Driving Evaluations**

Healthcare professionals may be able to arrange for a Comprehensive Driving Evaluation through a local rehabilitation program or a specialized driving evaluation program. Driving tests aren't uniform and the types of evaluations may vary, but such tests may provide families with additional input and support. This evaluation will be conducted to determine if, or the extent to which, the person with dementia may continue driving. If the determination 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.

Another option is to have a driving test administered by your state motor vehicle authority. Unlike the Comprehensive Driving Evaluation, this exam will end in either a "pass" or "fail."

#### **Other Sources of Support**

Lawyers, financial planners and care managers – professionals who assess, coordinate and monitor

care plans – also can raise questions about driving safety. As a caregiver, you can enlist their help by asking them to mention the subject in their discussions. Alzheimer's support groups also offer opportunities for caregivers and persons with dementia to share concerns and explore options.

#### Other Opportunities to Limit Driving

With some foresight, you can create natural, nonconfrontational ways to make driving less appealing or necessary. For example, if a person with dementia is relocating, you can discuss transportation alternatives at the new location – particularly because people with dementia are more uncomfortable and at higher risk of accidents when driving in unfamiliar places.

You also could use financial issues to initiate a change, such as building a case for selling the car by itemizing the many costs of operating a car.

#### Take the Keys as a "Last Resort"

Taking away the car keys or a driver's license – or selling or disabling the car – should be a last resort. To someone in the early stages of the dementia, such actions seem abrupt, extreme, disrespectful and punitive. And people with mild dementia can ignore or get around those strategies by driving without a license, fixing the car or buying a new one. As one person with dementia noted, "If they disabled my car, I would call someone to fix it." In addition, the person with more advanced dementia may not recall that their license has been revoked or that there was an important reason for their keys to "disappear."

Once a person has stopped driving, you must decide whether taking away the keys, license and car will help the person adjust – or make it more difficult. Some caregivers remove the keys or the car from sight to avoid having the driving issue resurface. But others let people keep their keys, car and license (as photo identification) to help them maintain a sense of dignity.

"There are six of us in the family – some still deny there is a problem, some tend to panic, and the rest of us feel caught in the middle."

- Daughter of a person with dementia

## Family Relationships Affect Driving Decisions

No two families dealing with dementia resolve transportation issues in exactly the same way. Each family member plays a unique role in driving-related decisions, and individual responses may vary. For example, a caregiving spouse may try to protect the person with dementia by withholding information about driving incidents from adult children. An adult child may intervene on matters of safety,



even though this might affect the relationship with the parent. One person may avoid confronting the driving concerns, while another may take charge of the situation and act without input from others.

You need to remember that

family members follow long-established patterns for making decisions, and these patterns are unlikely to change for a difficult issue like driving safety. Family members often have different opinions on the extent of the problem, but you can work to minimize friction by listening to different opinions and appreciating what each person has to say.

Disagreements can occur when family members don't have the same opportunities to assess driving abilities. While having factual information about driving behavior doesn't guarantee consensus on when to limit driving, frequent open communication about observed behaviors and concerns may help lessen differences. Everyone involved in caring for the person with dementia can help by focusing on the key issues – the self-respect of the person with dementia and the safety of everyone on the road.

### Sound Advice from Experienced Caregivers

Caregivers who have wrestled with driving and transportation issues were asked: "If you could do it over, what would you do differently?" and "What advice would you give others who are in similar situations?" They revealed four basic principles that can help you and your loved ones manage these decisions.

#### 1. There is no easy answer, no right way.

You need to consider the personality and the abilities of the person with dementia when making decisions throughout the course of the disease. You must take into account the roles and relationships within the family that affect decisions and their outcomes. Each family must select strategies that will work within its unique situation.

# 2. Begin discussions and planning early, and involve the person with dementia.

Ideally, a person with dementia should make the transition from driver to passenger over a period of time. The Agreement with My Family about Driving can serve as the starting point for meaningful discussions about driving. Open, early and continual communication can help the person with dementia and the family to agree on a course of action before a crisis occurs.

# 3. Base decisions on driving behavior observed over a period of time.

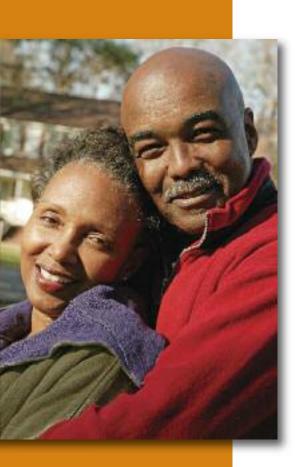
Regular monitoring and assessment of driving can help caregivers respond appropriately. A diagnosis alone may not be sufficient reason for a person to stop driving, but when it's clearly no longer safe for the person to drive, caregivers must take the necessary steps immediately. In hindsight, many caregivers regret permitting a loved one to drive longer than it was safe.

# 4. Get support when making and implementing decisions about driving.

It's not healthy for anyone when one person shoulders all of the responsibility for the decisions about driving and dementia. Caregivers can make reasonable requests of both family and non-family members and should turn to others for help in meeting the emotional, social and transportation needs of the person with dementia.

Doctors, occupational therapists, lawyers, care managers, financial planners and local Alzheimer's support groups can provide information and perspective to reinforce the family's efforts – helping to ensure that the person with dementia gets the best support.

People diagnosed with dementia rightfully want to drive for as long as it is safe. Family members must constantly weigh the need to respect a person's desire to drive with the need for safety. We hope this guide will help those at the crossroads of Alzheimer's disease, dementia and driving find the balance between maintaining independence and ensuring safety.



# Tips for Balancing Independence and Safety

#### For People with Dementia:

- Confide in a friend or family member what driving means to you. Help them understand what you have to give up when you stop driving.
- Work with your family to create a transportation plan that meets your needs.
- Consider the Agreement with My Family about Driving as a way to balance your independence and safety.
- Volunteer to be a passenger. Allow others to do the driving.

#### For Caregivers:

- Imagine for a moment your own life without driving. Allow your relative with dementia to express how he or she feels about not driving.
- Initiate conversations about driving and transportation needs early and often.
- Observe the driving of the person with mild dementia.
- Keep a written record of observed driving behavior over time.
- Share observations of unsafe driving with the person with dementia, other family members and healthcare providers.
- Create opportunities for you or others to drive the person with dementia.
- Ask professionals outside the family to raise questions about driving safety.
- Get information about driving evaluation services in your state or region.

## Warning Signs for Drivers with Dementia

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

Additional Notes:

## **Getting There: Using Alternative Transportation**

When looking for alternative transportation, you need 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 side as you explore all your transportation options.

| Transportation<br>Alternatives | Telephone | Availability, Destination<br>(day, time, route) | Cost | Notes (pros & cons) |
|--------------------------------|-----------|---|------|---------------------|
| Family Members:                |           |   |      |                     |
|                                |           |   |      |                     |
| Friends:                       |           |   |      |                     |
|                                |           |   |      |                     |
| Demand-responsive<br>Services: |           |   |      |                     |
|                                |           |   |      |                     |
| Private Program<br>Services:   |           |   |      |                     |
| Taxi/Car Services:             |           |   |      |                     |
| Mass Transit:                  |           |   |      |                     |
| Other Local<br>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 considered. 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-todoor 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 I call for a ride?
- 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?

## Driving Activities: Where, When and Why?

This worksheet can help you determine where, when and why your relative with dementia drives, and then how to reduce the need to drive without compromising the physical and social benefits of driving.

| Type of<br>Activity   | Activity or<br>Destination   | How often?<br>What day<br>and time? | Who is he/she with<br>while going to or<br>participating in activity? | What changes<br>could reduce the<br>need to drive?* |
|---|--|-------------------------------------|---|---|
| Routine:<br>Frequent trips<br>(daily or<br>weekly),<br>usually for<br>tasks (shopping,<br>exercising,<br>visiting, etc.)          | Example: To a<br>local convenience<br>store for milk,<br>bread, etc. | 2 or 3 times/week                   | Travels alone.<br>Chats with store<br>manager                         |   |
| <b>Periodic:</b><br>Regular, maybe<br>monthly (e.g.,<br>doctor's visit,<br>card games<br>with friends)                            |  |                                     |   |   |
| Occasional:<br>Special events<br>like a vacation,<br>concert, sporting<br>event, family<br>celebrations,<br>out-of-town<br>visits |  |                                     |   |   |



\* scenarios to consider on next page

Consider these possible scenarios that will allow a person to satisfy physical and social needs without driving:

- Can the person share the activity with a friend who can drive?
- Can someone take responsibility to drive to an activity on a regular basis?
- Are home-deliveries possible (e.g., prescriptions, groceries, online ordering)?
- Can someone "make a day of it," by visiting and completing errands?
- Can services be brought to the home (e.g., home hairdressing visits)?
- Can telephone or e-mail conversations occasionally substitute for personal visits?
- Is public transportation available for some trips?

#### **Additional Notes:**

### 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."
- Planning alternative transportation. "The van driver said he would make sure you got to your appointment on time."

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| <br>Potential risks to self or others. "I know you think you're okay driving. But you always said, "Better safe than sorry."  |
|---|
| <br>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."  |
| <br>Getting support from others. "I've noticed changes in his driving. Could you ride<br>with him and see what you think?" "Can we take turns taking her to the grocery store?"<br>"She needs to hear this from more than just me." |
| <br>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?

#### Additional Notes:

# 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.

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 | Uncomfortable |   |   | Comfortable |
|---------------|---------------|---|---|-------------|
| 1             | 2             | 3 | 4 | 5           |

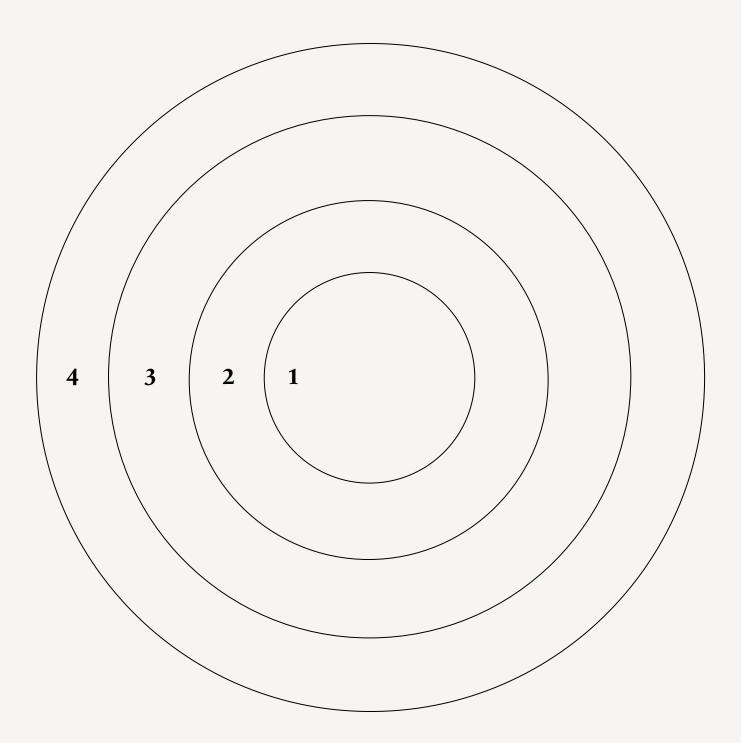
- 2. Are you using your support network to the fullest extent you need? Yes\_\_\_ No\_\_\_
- 3. If you are underutilizing your support network, what is keeping you from it? (Examples: beliefs, attitudes, concerns, relationships)
- 4. In what ways could you encourage improvement in the quantity and quality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

| Person | How They Help Now | Realistic Helpful Changes |
|--------|-------------------|---------------------------|
|        |                   |                           |
|        |                   |                           |
|        |                   |                           |
|        |                   |                           |
|        |                   |                           |
|        |                   | (continued on next page)  |
|        |                   |                           |



At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia and Driving 19





# 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.

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:



Additional Notes:

| <br> |
|------|
|      |
|      |
| <br> |
|      |
|      |
| <br> |
|      |
|      |

## **Additional Resources**

AARP

www.aarp.org

Alzheimer's Association www.alz.org

Alzheimer's Disease Education and Referral Center National Institute on Aging www.alzheimers.org

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

American Occupational Therapy Association www.aota.org

Association for Driver Rehabilitation Specialists www.aded.net

Eldercare Locator www.eldercare.gov

National Highway Traffic Safety Administration www.nhtsa.gov

## **Research Methodology**

In 1999, The Hartford Center for Mature Market Excellence, the MIT AgeLab, Connecticut Community Care, Inc., and independent researchers Donna P. Couper, Ph.D., and Cheryl M. Whitman, MSN, CMC, conducted a series of interviews with individuals with Alzheimer's and those who cared for them. The results from these interviews formed the basis for the first edition of **At the Crossroads: A Guide to Alzheimer's Disease, Dementia and Driving.** 

Expert reviewers included: Katrinka Smith Sloan (Director, Applied Gerontology Group, AARP); Richard A. Marottoli, M.D., MPH (Associate Professor of Medicine, VA Connecticut and Yale University School of Medicine; Chair, Committee on the Safe Mobility of Older Persons, Transportation Research Board); Harry E. Morgan, M.D. (The Center for Geriatric and Family Psychiatry, Inc., Glastonbury, Connecticut; Advisory Board Member, Northern Connecticut Chapter of the Alzheimer's Association); and Sue A. Smolski, A.P.R.N. (The Center for Geriatric and Family Psychiatry, Inc., Glastonbury, Connecticut).

(continued on next page)



Beginning in fall 2005, The Hartford Center for Mature Market Excellence partnered with the MIT

AgeLab and the Boston University School of Medicine's Alzheimer's Disease Clinical and Research Program to conduct a study to examine whether the materials from At the Crossroads presented in an educational seminar format helped caregivers to cope better with issues they faced around dementia and driving. More than 80 caregivers in central and eastern Massachusetts took part in the study. The results suggest that those who participated in the educational sessions: felt more certain that they would be able to handle driving-related issues; felt better prepared to address the issue with their loved one; were more likely to have made a plan to talk to their relative about limiting or stopping driving; and were more likely to have talked to their relative about his or her driving.

This revised edition, now called **At the Crossroads: Family Conversations about Alzheimer's Disease, Dementia and Driving**, incorporates new materials adapted from these educational sessions to provide caregivers with additional support and tools.

The study was funded by a grant from The Hartford Financial Services Group, Inc., and supplemental support to MIT was provided by the USDOT New England University Transportation Center.

#### The Hartford Center for Mature Market Excellence

The Hartford Center for Mature Market Excellence creates innovative business solutions for the mature market. Staffed by gerontologists, the center is uniquely positioned to apply knowledge of aging to develop one-of-a-kind products and services for The Hartford's customers, and specialized training for The Hartford's employees. The center conducts original research in partnership with academic institutions and produces public education programs on safety, mobility and independence. The Hartford has had this in-house expertise since 1984, guiding The Hartford to unparalleled success in understanding and serving the mature market.



Center for Mature Market EXCELLENCE

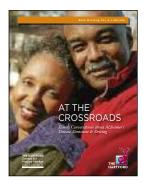
#### The Hartford/MIT AgeLab Partnership

In 1999, The Hartford became a founding sponsor of the MIT AgeLab, creating the Safe Driving for a Lifetime partnership. The MIT AgeLab and The Hartford Center for Mature Market Excellence are committed to producing original research that can expand the understanding of older drivers and their families as they deal with changes in driving abilities. Through publications, professional meetings and public education, the Hartford/ MIT AgeLab partnership has successfully reached millions of people in the U.S. and across the globe with high-quality, meaningful information to guide important decisions about safe driving.



#### You can also visit us on the Web at: www.thehartford.com/lifetime

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



This guidebook helps families determine when it's time for loved ones with dementia to stop driving and helps them cope with driving cessation.

# We Need to Talk: Family Conversations with Older Drivers



This guidebook provides families with easy-to-use, practical information to help them plan ahead and initiate productive and caring conversations with older adults about driving safely.

#### Your Road Ahead: A Guide to Comprehensive Driving Evaluations



This guidebook describes the benefits of having a comprehensive driving evaluation from an occupational therapist with specialized driver evaluation training.

# You and Your Car: A Guide to Driving Wellness



This guidebook is designed to help drivers of all ages recognize and respond to normal aging-related changes as they occur, and to make gradual adjustments to driving behavior so they can stay safe on the road.

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



This guidebook empowers widows to take control of their driving future and confidently buy, sell and maintain a car.

#### Order These Guidebooks To download or order FREE copies, visit

www.thehartford.com/lifetime.

If you do not have access to the Internet, you can order any of these guidebooks by writing to: The Hartford Publication Request 200 Hopmeadow Street Simsbury, CT 06089

Please be sure to indicate the title(s) and quantity of the guidebooks you are ordering.

This guide is intended to help readers who seek assurance about their ability to drive safely. It is not intended to be an exhaustive source or to relate to any particular driving situation. Readers are advised to consult the necessary professionals to assist them in analyzing their driving situation and to refer to the sources identified in the section entitled "Resources" for additional information. All information and representations herein are as of March 2013.



Center for Mature Market EXCELLENCE



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