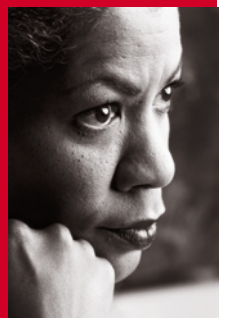


At the Crossroads

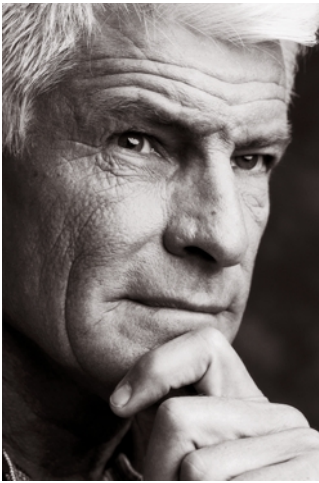
*A Guide to Alzheimer's Disease,
Dementia & Driving*



“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

Today, more than 4 million people in the U.S. are afflicted with dementia, with

Alzheimer's Disease being the most common form. And this number is expected to grow as the population ages.

“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

When a person is diagnosed with dementia, the individual and family members struggle with a number of caregiving challenges, from medical and daily care to financial and legal matters. Of these concerns, driving is one of the more immediate issues. Unsafe driving can be life threatening for both the person with dementia and countless others.

Families have difficulty deciding when a person with dementia should stop driving. Caregivers and the individual must weigh the potential safety considerations against the loved one's sense of independence, pride and control.

Abilities during the early stages of dementia may allow a person to drive safely for a time. Earlier diagnosis and better medications may help people drive longer. But until medical treatment can prevent or slow the progression of dementia, these individuals must eventually stop driving. **Most information about dementia warns against driving, but does not describe how individuals and caregivers can determine when to stop.**

The Hartford Financial Services Group, Inc., the MIT Age Lab and Connecticut Community Care, Inc., have developed this guide to help persons with dementia and their families maximize independence while minimizing driving risk. The guide provides suggestions for monitoring, limiting and stopping driving. The information is based on the experiences of family caregivers and people with dementia, and suggestions from experts in medicine, gerontology and transportation.



“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

For many adults, driving represents independence, freedom, competence and control. It is a way to access healthcare, to buy necessities, to be productive and to stay connected to family, friends and the community. Concerns about driving are likely to surface during the early stages of dementia, when individuals are still socially engaged and able to manage other daily activities. Giving up driving can be a deeply personal and emotional issue.

Once a person is diagnosed with dementia, family members can encourage the loved one to express what the loss of driving means to him or her. Open conversations at an early stage of the disease may help smooth the transition to not driving in the future. Caregivers can try to imagine what their life would be like if they could not drive and encourage the family member with dementia to share his or her feelings. It is often helpful for people with dementia to confide in a friend about what it means to give up driving.

Not Like Changes Common in Later Life

Changes common in later life, such as eyesight problems and slower reaction times, may affect the driving skills of older adults. Many individuals respond to these changes by gradually modifying the way they drive, such as avoiding driving on certain roads, at night or for long distances. Older adults who do not have dementia are often able to assess and regulate their driving without family intervention and continue to drive safely throughout their lives.

For those with Alzheimer’s Disease or other dementias, it is a different situation. The progression of Alzheimer’s Disease is usually gradual and somewhat unpredictable. It can affect cognitive functions necessary for driving, such as judgment, reaction time and the ability to solve problems. It can also cause physical and sensory problems that increase driving risk.

With dementia, an individual’s capacity to assess his or her abilities may also diminish. Although most people tend to overrate their driving skills, people with dementia are especially likely to minimize the complexity of driving and overestimate their abilities. They may make excuses or blame others for their high-risk driving behaviors. Common reasons people with dementia may use to justify their continued driving include:

- “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 driving and self-assessment skills decline, the risk of serious loss or injury increases. Caregivers often must assume most of the responsibility for monitoring and regulating the driving of the person with dementia.

Finding a Balance

Many caregivers report that they have allowed a family member with dementia to continue driving, sometimes for many months, even though they believed it was unsafe. They did so to avoid upsetting their relative, to prevent a family disagreement, or to delay taking on the responsibility of providing transportation. Others needed support from family, friends or professionals.

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 exhibited this bad driving habit long before dementia. A single occurrence of poor driving usually is not cause for a person to stop driving. It does, however, signal the need for increased monitoring and assessment.

Assessing Concerns

The following activities can help caregivers assess the driving skills of the person with dementia:

- Create opportunities to observe the person with mild dementia when driving.
- Keep a written record of observed driving behaviors over time.
- Share observations of unsafe driving with the person with dementia, other family members and healthcare providers.

Warning Signs

A diagnosis of Alzheimer’s Disease or other kinds of dementia is not automatically a reason to take away driving privileges. Unfortunately, no examination or single indicator exists to determine when a person with dementia poses a danger to himself or others. Families must determine when a person’s attention span, distance perception or ability to process information makes it difficult for him or her to respond safely in driving situations.

Caregivers can easily miss the early warning signs of driving problems:

- Incorrect signaling.
- Trouble navigating turns.
- Moving into a wrong lane.
- Confusion at exits.
- Parking inappropriately.
- Hitting curbs.
- Driving at inappropriate speeds.
- Delayed responses to unexpected situations.
- Not anticipating dangerous situations.
- Increased agitation or irritation when driving.
- Scrapes or dents on car, garage or mailbox.
- Getting lost in familiar places.
- Near misses.
- Ticketed moving violations or warnings.
- Car accident.
- Confusing brake and gas pedals.
- Stopping in traffic for no apparent reason.

Most families restrict driving after an accumulation of warning signs. Therefore, family members must frequently observe driving behaviors over time. Caregivers can note dates and incidences of good and bad driving practices on the *Warning Signs for Drivers with Dementia* worksheet on page 11.

Share observations with the person with dementia, other family members and health care providers. Families need to consider the circumstances and seriousness of unsafe driving practices to decide whether to continue monitoring, modify driving or stop driving immediately.



*“It’s difficult
being in the
passenger seat
after years
of driving.”*

– Person with dementia

Easing the Transition from Driver to Passenger

Family caregivers can help a person with dementia limit and stop driving over time, while preserving his or her dignity. The most effective approach to limit or stop driving involves progressive steps and a combination of strategies that fit the family’s unique circumstances, resources and relationships. For persons with early stages of dementia, driving is best reduced over time rather than all at once.

Fortunately, in many cases, people with dementia begin limiting where and when they drive just as many older people without dementia do to accommodate changes in skill. Caregivers can observe the person with dementia to see if he or she is modifying driving behavior in these ways:

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

Co-Piloting Is Not Recommended

In an attempt to keep a person with dementia on the road longer, some caregivers act as “co-pilots,” giving directions and instructions on how to drive. By chance, this strategy may work for a limited time. But in hazardous situations, there is rarely enough time for the passenger to foresee the danger and give instructions, and for the driver to respond quickly enough to avoid the accident. Finding opportunities for the caregiver to drive and the person with dementia to co-pilot is a safer strategy.

Letting Others Do the Driving

A gradual shift in who drives can ease the transition for both family members and people with dementia. Family members may avoid offering to drive early in the disease so the person with dementia can maintain control as long as possible or so they can delay taking on the added time commitment. However, some people with dementia are better able to adjust to not driving if others gradually assume more of the driving responsibilities. The objective is to find ways to reduce the amount of driving.

Public transportation may be an option to limit driving 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 buses or other city transportation if they are already accustomed to using these methods. 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 cost-effective transportation alternative, especially when fares are compared to the expense of gas, insurance, taxes, repairs and car payments. Taxis could be used for people in middle to later stages of dementia – if there are no behavioral problems, the driver has explicit directions and someone is available at the beginning and end of the trip. Some taxi companies set up accounts for family caregivers so a person with dementia has easy access to transportation 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 assist with the driving if caregivers make specific requests and schedule appointments at times that work for those requested to help.

Reducing the Need to Drive

Resolving the driving issue involves not only substituting other drivers or modes of transportation, but also addressing the reasons people want to go places. Caregivers can look for ways that others can help meet the physical needs of the person with dementia, such as:

- Arrange to have prescription medicines, groceries and meals delivered, reducing the need to go shopping.

- Have hairdressers make home visits.
- 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.

Balancing the Social Needs

While caregivers consider ways to reduce the need to drive, it's also important to remember the social benefits the person with dementia derives from interacting with others. 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.”

If caregivers consider the social needs that were met through driving, the transition to not driving will be more successful.

The following questions can help families and caregivers identify the social needs and develop ways to address them to ease the transition to not driving:

- Where does the person with dementia go? When and how often? (e.g., grocery store, barbershop, appointments, library or religious activities)
- What services can be brought to the home? (e.g., groceries delivered or in-home barber)
- Who can offer to provide transportation? (e.g., neighbors running errands, relatives for doctors' appointments, or a friend going to religious services)
- Can visits from family or friends include outings? (e.g., eating out or going to a park)

*Take advantage
of the time
during the early
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when the person
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eventually
stop driving.*

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 Alzheimer's Disease or other kinds of dementia. Take advantage of the time during the early stages 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 13. This informal agreement does not restrict driving at the moment of signing, but designates a person to take necessary steps to ensure driving safety 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 is a document to help plan for the future. Like plans made for medical and financial decisions, the form allows families to discuss matters and agree on a course of action before a crisis and while the loved one is capable of making decisions.

This document is a helpful tool, but it has limitations. 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 does not ensure that the person with dementia will comply once the disease progresses. However, it is a tool to help caregivers.

Getting Outside Help

Caregivers often achieve better results by seeking support from professionals outside the family.

Healthcare Professionals

Healthcare professionals may be more likely to discuss driving issues with a patient if a caregiver has met with him or her privately and shared observations of driving behavior. This input can help because physicians do not have tests to determine definitively when a person in the early stages of dementia should not drive. And some doctors may hesitate to bring up a topic as emotionally charged as not driving for fear of jeopardizing their relationship with a patient. Doctors may request that a patient not drive for a period of time while trying new medication that may produce drowsiness. When a physician is concerned about someone's driving safety, writing a prescription to stop driving may give added weight.

Independent Driving Evaluations

Healthcare professionals may know how to arrange for an independent driving evaluation. These assessments may be available through rehabilitation programs and some state 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 additional input and support.

Other Sources of Support

Lawyers, financial planners and care managers can also raise questions about driving safety. Caregivers can enlist their help by asking them to mention the subject as part of planning. Alzheimer's support groups offer opportunities for caregivers and persons with dementia to share concerns and explore options.

Other Opportunities to Limit Driving

With some foresight, caregivers can create opportunities that limit driving. For example, people with dementia sometimes consider moving to an area that has more support services. Family conversations about housing alternatives can lead to discussions about driving and transportation alternatives at the new location. People with dementia are more uncomfortable and at higher risk of accidents when driving in unfamiliar places. Caregivers can use the relocation to encourage the individual with dementia to limit or stop driving.

At times, financial issues may be used to initiate a change. Caregivers can build a case for selling a car by itemizing the cost of operating a car, including registration, insurance, maintenance, gasoline and car payments.

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 a family member in the early stages of the disease, such actions seem abrupt, extreme, disrespectful and punitive. And people with mild dementia can ignore, undo or maneuver around those strategies by driving without a license, enabling the disabled car, or buying a new car to replace the one that was sold. As one person with dementia noted, "If they disabled my car, I would call someone to fix it."

Once a person has stopped driving, caregivers must decide whether taking the keys, license and car away will help the person adjust or make it more difficult. Some caregivers remove the keys or the car from sight to avoid having driving resurface as an issue. But others allow people with dementia who have stopped driving to keep their keys, their car and their license to help them maintain a sense of dignity. Some people with dementia stop driving but carry their driver's license as photo identification.

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:



*“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. Roles and relationships within families can affect decisions about when and how a person should stop driving. Each family member plays a role in decisions about driving, even members who appear on the periphery, such as a teenage grandchild who refuses to ride with a grandparent, or an in-law who provides transportation and a sympathetic ear.

Individual responses of family members 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 of the family member, while another may take charge of the situation and act without input from others.

Caregivers need to remember that family members follow long-established patterns for making decisions. It is unrealistic to think that patterns will change when handling a difficult issue like driving safety. However, caregivers can work to minimize friction by listening to different opinions and appreciating what each person can contribute, even if it differs from their point of view.

Disagreements in families are often the result when individuals do not have the same opportunities to assess driving abilities. While having factual information about driving behavior does not guarantee family members will reach 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? What advice would you give others who are in similar situations?” They revealed four basic principles that can help caregivers and people with dementia manage driving and transportation decisions.

1. **There is no easy answer; no *right* way.**

Caregivers need to consider the personality and the abilities of the person with dementia when making decisions over the course of the disease. They 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 assessing of driving helps caregivers respond appropriately. A diagnosis alone may not be sufficient reason for a person to stop driving. However, when it clearly is no longer safe for a person to drive, caregivers must not delay in taking necessary steps.

In hindsight, many caregivers regret permitting a loved one to drive longer than it was safe. The result was prolonged anxiety for caregivers and placing others at risk.

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

It is not healthy for the caregiver, the person with dementia, or the family as a whole, when one person shoulders all of the responsibility for making and implementing decisions about driving and dementia. Caregivers can make reasonable requests of family members and those outside the family. Neighbors, friends and relatives can contribute in practical ways by providing for the emotional, social, and transportation needs of the person with dementia.

Doctors, lawyers, care managers, financial planners and local Alzheimer’s support groups offer information, guidance and perspective. People in authority outside the family can reinforce the family’s efforts to ensure the safety and dignity of a person with dementia. The more people who are asked to help, the less any one person has to do and the greater the likelihood that the person with dementia will get 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 person with mild dementia when driving.
- 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

1. Have you noticed any of the following warning signs?
2. Is there a change in frequency or severity of these warning signs?
3. Do the circumstances and seriousness of the warning signs warrant continued close monitoring, driving modification or an immediate end to driving?

<u>Warning Signs</u>	<u>Date(s) Observed</u>	<u>Notes (Severity/Frequency)</u>
Incorrect signaling.	_____	_____
Trouble navigating turns.	_____	_____
Moving into a wrong lane.	_____	_____
Confusion at exits.	_____	_____
Parking inappropriately.	_____	_____
Hitting curbs.	_____	_____
Failing to notice traffic signs.	_____	_____
Driving at inappropriate speeds.	_____	_____
Delayed responses to unexpected situations.	_____	_____
Not anticipating potential dangerous situations.	_____	_____
Increased agitation or irritation when driving.	_____	_____
Scrapes or dents on the car, garage, or mailbox.	_____	_____
Getting lost in familiar places.	_____	_____
Near misses.	_____	_____
Ticketed moving violations or warnings.	_____	_____
Car accident.	_____	_____
Confusing brake and gas pedals.	_____	_____
Stopping in traffic for no apparent reason.	_____	_____
Other signs: _____	_____	_____



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:

_____	_____
_____	_____
_____	_____
_____	_____
_____	_____



Additional Resources

AARP

601 E. St. NW
Washington, DC 20049
www.aarp.org

AARP LifeAnswers
Consultation Service
1-877-217-7800
www.aarplifeanswers.com

Alzheimer's Association

919 North Michigan Avenue, Suite 1000
Chicago, IL 60611
1-800-272-3900
www.alz.org

Alzheimer's Disease Education and Referral Center

National Institute on Aging
P.O. Box 8250
Silver Springs, MD 20907-8250
1-800-438-4380
www.alzheimers.org

Credits

The study was developed by The Hartford Financial Services Group's corporate gerontologists in cooperation with the MIT Age Lab, Connecticut Community Care, Inc., and independent researchers Donna P. Couper, Ph.D., and Cheryl M. Whitman, MSN, CMC.

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