

## Module 5– Driving and Safety

**Purpose: To provide caregivers and people with dementia information about the ever-increasing risks faced when driving and common safety issues they might face.**

**Intended use: People in stages 3-6 of dementia**

### Driving

Driving is one activity that requires immediate attention once a person has a recognizable memory loss and regular scrutiny as long as the person drives. Driving is a complex activity that begins to decline very early in the dementing process in the following ways:

- The brain's ability to "see" or perceive changes. Basically, "the eyes take the picture but the brain does not develop the film correctly." This means there are changes in the following areas:
  - Depth perception (the ability to judge distances)- Good examples of this include following too closely or too far, having dents in the car from sideswiping the garage or things in the garage, mishaps with distance, and rear-end collisions.
  - Ability to see moving objects (the person does not see things moving across the horizon or towards them) – Examples include not seeing oncoming traffic, cars at intersections, trains, or children darting across a road.
  - The ability to recognize familiar places - This may occur spontaneously while driving or when a mildly unexpected event occurs. Examples include asking directions in familiar places, making wrong turns, having difficulty following directions from a passenger/copilot, getting lost in places that were once were familiar, or getting lost after a relatively minor event.
- The ability to remember. The person does not remember where they came from, why they are in the car, how to get to where they were planning to go. Later in the illness they forget how to operate the car as evidenced by hitting the gas instead of the brake pedal.
- The ability to change body posture quickly – When the person turns a corner, how long does it take to regain an upright position? For that period of time the car is essentially out of control.
- The ability to make good judgments quickly – The person must be able to respond quickly and appropriately when the unexpected occurs:
  - How will he/she respond if cut off by another driver? Will he/she try to retaliate? Become confused? Cry?
  - How will the person respond in traffic?
  - What would he/she do if someone rear-ended them?
  - What would happen at a train crossing?
  - Would the person try to make a "left on red?"
  - If the person had an accident would he/she know it? Leave the scene?
  - Would the person try to pass slower vehicles into oncoming cars or in a no-passing lane?

- The ability to react quickly and appropriately – The person with dementia has slowing of brain processes and is not able to respond as quickly to things as in the past.
  - If a child ran in front of the car, would the person be able to stop quickly?
  - Would the person respond appropriately to emergency vehicles?
  - Would the person be able to manage “near miss” situations?
  - Can the person manage the speeds on the highways? Higher limit city streets?
  - Does the person drive erratically? Stop suddenly at inappropriate places?
  - Does the person become “befuddled” in situations that are “beyond the norm?”

### **Why is driving such a difficult issue?**

In America there are few privileges more cherished than driving. Teenagers obsess on the day they get their learners permits and then licenses. Buying a car is a major life event. Driving often has little to do with the actual need for transportation. It is a reflection on a person’s ability to be independent and autonomous. Additionally for many people driving is a status symbol. When the ability to drive is taken away many people become angry, depressed, and may become socially isolated. The availability of public transportation does not make this any easier. Driving is an extremely emotional issue and one where families often strongly disagree on management.

Research shows that the incidence of accidents both had and caused by people with dementia rises sharply – even very early in the disease. While the person with dementia may deny the risk, the reality is that they will experience difficulty. In one state, people with dementia must be reported to the Department of Transportation as soon as diagnosed, however most professionals agree this serves as a disincentive to go to the doctor. Moreover, many people with dementia continue to drive even after their license is revoked. In all other states it is generally up to the family to monitor and stop the person from driving when the risks of the disease pose danger to the public and the family member.

### **The Elephant in the Living Room: Approaching the decision not to drive**

- When do we start talking about driving?
  - You want to start discussing driving as soon as the disease is diagnosed, or even earlier if problems are noticed.
    - The first discussions should center on the person’s illness: “Mr. Jones (Dad), you know you have an illness called dementia. This means the day is coming when you will have to give up driving. You may not know when you are unsafe, so someone will have to tell you. Who will you trust to tell you to tell you when you need to stop?” This discussion informs the person that giving up driving is inevitable and brings the person into the decision-making process. They actually decide who will be the “the decider.” Then let the decider know and ask them to observe the person driving on a regular basis: monthly of the person is mildly

impaired; weekly if the person's impairment is obvious. As many of the family as possible should witness this discussion in order to develop agreement among members.

- The person with early dementia who continues to drive should have a Medic-Alert Bracelet in case of being stopped by police. This helps to assure the person will not be arrested for DUI if mildly confused.
  - It may help the person to remember about the “decider” monitoring their driving if the health provider writes it on a prescription for the person and family to use as a prompt
  - The health provider should also mention their obligation under state law to report unsafe drivers
- Whenever the person visits a health-care provider the driving issue must be revisited. This helps the person to understand that the day to stop driving is coming.
  - Whenever you see the person driving unsafely, mention it and remind them of the agreement to stop driving when the “decider” says.
  - When the person agrees to stop driving provide lots and lots of positive feedback.
  - Some people with dementia will give up driving voluntarily, but unfortunately this is not always the case. If the person does not voluntarily relinquish driving there are several options:
    - Discuss it with the person. Expect the person to become angry. After all, wouldn't you be angry if someone took your driving privileges? Re-emphasize that it is the disease that is causing the problem, so the person stays angry at the disease. Understand that the person's anger is really grief at the unfairness of having dementia and so agree with them. Apologize that they are upset, but remain steadfast that they can not drive.
    - Let the person know they could be sued if they have an accident and their diagnosis may be disclosed during the course of the lawsuit. This would have very negative outcomes and would probably mean either being dropped by insurance or having financial losses.
    - Remember that stopping driving includes the automobile, truck, snow mobile, tractor, and boat.
    - The doctor or an anonymous citizen can report the person to the Department of Transportation (DOT). Unless you live in a very small town, the local police will not come and take the car.
      - If the DOT requires a test, do not fight it. Do what you can to make sure the person will falter. Take them out to dinner the night before so they may be tired. Schedule the test for either late in the day or the person's worst time of day. If the test is in the afternoon take them to lunch prior to the exam. Your goal is to have the person perform at their worst.

- Remember many people with dementia who have lost their license continue to drive
  - Some families will try to break the car by removing the distributor cap or spark plug. Sometimes this works, but often results with the person making repeated calls to the repair shop. Some people with dementia remain quite adept at auto repair
  - Some families try to hide or take the car. This may result in the person calling the police to report it stolen. It may also result in a family member being arrested for auto theft.
  - Some people have gotten keys that don't fit. Unfortunately, one person with dementia got into the wrong car and his key fit, prompting an arrest for auto theft
  - A better approach is to take the keys surreptitiously and file the bumps off. Return the keys to the person's key ring without mentioning the filing. Many people with dementia become embarrassed when they can't make something work, and give it up voluntarily.
  - Reward any movement towards driving cessation. Do not get into arguments about "I've been driving for 55 years and never had an accident." The disease changes everything.

**Driving assessments** - For those people who either insist they are still safe to drive, refuse to give up driving, or the physician or family is unsure about safety, the Occupational Therapy Program at the Banner Rehabilitation Institute offers driving assessments. This service tests the individual and makes recommendations to the person with dementia, their attending family, and the physician. Ask your physician for a referral.

**Clues to know when the person is no longer safe to drive** (This is, by no means a complete list)

- Fender benders and mishaps, unexplained dents and scrapes
- Hitting parked cars and trees (common when backing up)
- Missed signals such as running a stop sign or red light
- Gross errors in judgment such as thinking the train should stop, making a left turn on red, or turns from the wrong lane
- Getting angry with other drivers
- Becoming lost
- Slowing down or speeding up
- Driving erratically
- Tailgating
- Needing directions in familiar places
- Missing an exit and backing up
- Getting onto the wrong freeway ramp
- Making unsafe U-turns
- Going the wrong way on a one-way street
- Driving on the sidewalk

- Backing out of the garage with the door closed or through the front of the garage
- Falling asleep or having spells
- Needing a “co-pilot in the car

**Things that can lead to disaster**

- Having the person with dementia follow another car – The person will forget that they are following
- Having the person drive only during the daylight and only in town – Where are there most likely to be children out and when?
- Refusing to let the grandchildren in the car, fearing for their safety – We must be concerned with EVERYONE’S safety
- Co-piloting – Telling the person when to stop and go will eventually lead to mixing up the gas and brake pedals
- Sticking your head in the sand and expecting others to do something – It won’t happen

**NOTES:**

Key Points for Driving and Dementia
<ol style="list-style-type: none"> <li>1. The day will come when the person with dementia will not be able to drive</li> <li>2. The best way to stop the person from driving is to approach it early and often allowing the person to decide who will regularly evaluate and make the decision</li> <li>3. When the patient begins to make mistakes driving it is time for the family to take the keys</li> <li>4. Anger is a normal and desirable reaction to involuntary surrender of driving, but make sure the disease is the villain, not the caregiver</li> <li>5. A good way to get the keys from a person who is resistant is to file the “bumps” from the keys without the person’s knowledge.</li> <li>6. The Department of Transportation can be notified by the doctor or anonymously be family or neighbors to remove the license, but many people drive without a license.</li> <li>7. Driving is a dangerous activity and can cost the person with dementia, their family, and the public their lives. It is the family responsibility to remove privileges before accidents happen</li> </ol>

## **Worrying About Safety:**

People with memory loss lose their sense of “danger” quite early in the disease. Early in the disease we begin to see accidents or unintended outcomes with power tools, lawnmowers, snow blowers, cars, medications, propane tanks, gas grills, guns, and almost anything else that involves a degree of complexity. If the person is in a rural area we see problems with farm chemicals and tractors. Even worse, people in early stages of the disease are vulnerable to unscrupulous individuals and scams very early in the disease. And, research shows that early in the disease they are not able to use the phone reliably to call for help in an emergency.

In mid-disease we see additional problems with cigarettes, candles, using the stove, adjusting the thermostat and taking medications. As the disease progresses, one must consider protecting the person as if they were a child, including watching water temperature when bathing, removing hazardous chemicals, and hiding medications. Caregivers often need to hide knives and watch the person when using glass and eating utensils. Stairs must be gated and if the person wanders, slide bolts placed at the base of exterior doors.

Reminding the patient that something is unsafe is the most unreliable method for insuring safety because the patient will forget and is unable to stop themselves when presented with an appealing idea. While you can not protect the patient from all possible harm, you can decrease the potential for harm by recognizing and preventing the possibilities.

- Hire someone to mow the grass and shovel or blow the snow. Contact your nearest Area Office on Aging in the blue government pages of your phone book to locate chore services. Chore services can help with these services.
- Turn the water heater to about 110 degrees.
- Remove power tools
- Recognize that telephone solicitors target people with mild memory loss and plan to stop “junk” mail. This may mean renting a post-office box without the patient’s knowledge.
- Supervise or administer all medications early in the disease -- particularly insulin, Coumadin (blood thinner), and other potentially toxic medications. Do not expect the person to be able to understand diabetic testing and coordinating insulin dosage.
- Avoid having the person change the propane tank -- especially if he/she smokes.
- No guns, ammunition, or hunting knives in the house, please
- Pull the knobs off of the stove when it is not in use.
- Put away knives, the blender, mixer, toaster, food processor, and hot appliances when not in use.
- Store medications and liquor in either a locked cupboard or a place where the patient will not find them.
- Have the patient smoke in a single area, preferably the kitchen. Avoid having cigarettes near upholstery. If you see upholstery smoking, do not try to extinguish it. If possible, move the piece outside. Call the fire department. If the piece of furniture can not be moved, leave the house immediately.
- “Safety-Proof the house as if you had a visiting toddler, evaluating every possible thing that pose safety hazards.
- Recognize that the patient loses their sense of danger very early in the disease. Simply telling them to be careful will not be effective, as the patient is unable to use reasoning.

## NOTES:

### Key Points for Maintaining Safety

1. People with dementia lose their sense of risk or danger early in the disease
2. Thus they begin to make “careless” errors or errors in judgment early in the disease
3. This can involve the car, power tools, medications, and finances and almost anything you can imagine with potentially disastrous results
4. The family must think creatively about what hazards may be present and take steps to limit the person’s exposure, almost as one might do for a child
5. Denial of the risks is dangerous!
6. Simply telling the person not to do something will be forgotten as often the patient can not stop themselves from acting