Your Guide to Coping with Alzheimer’s & Dementia

Answers to the 15 Most Common Questions
About David Troxel

David Troxel is an internationally known expert in Alzheimer’s disease and memory care. He has worked for over 25 years in the Alzheimer’s care field developing and teaching care techniques as a consultant, writer and speaker. He co-authored the book The Best Friends Approach to Alzheimer’s Care, along with many other influential books and resources relating to Alzheimer’s care and training.
What is the difference between Alzheimer’s disease & dementia?

On a cold, snowy winter day, a bowl of soup sounds good.

“What’s the soup of the day?” you ask the waitress at your favorite restaurant. A few minutes later you are enjoying a steaming cup of clam chowder.

“Soup” is a general term for a category of food. Soup comes in dozens of flavors, like chicken noodle, tomato, clam chowder, or mushroom. Every can of mushroom or tomato soup is soup—but not every can of soup is mushroom or tomato.

This simple example, first used by Canadian dementia expert Carol Bowlby Sifton, is an elegant way to describe the differences between dementia and Alzheimer’s disease.

Like “soup,” the word “dementia” is an umbrella term for anything that can cause issues with brain functioning such as confusion, memory loss, or loss of problem solving ability. While Alzheimer’s disease is the most common form of dementia in older persons, there are many more varieties, including Lewy Body dementia, vascular dementia, or frontal lobe dementia.

Families often say that they struggle to understand what doctors mean by dementia. That’s why it’s important to ask the doctor what type of dementia is being diagnosed. David Troxel, a noted dementia expert who worked with Home Instead Senior Care® to develop its Alzheimer’s and Other Dementias Training Program, emphasizes that the doctor should be able to tell you the specific
diagnosis and the reason for that diagnosis, just like the waitress should be able to tell you the soup of the day and how that is different from other soups.

“It’s important to know the type of dementia being diagnosed,” Troxel said, “because different dementias have different characteristics, and family members need to know what to expect.” Persons with frontal lobe dementia, for example, often undergo profound personality changes and can get very disinhibited and outrageous. Persons with Lewy Body dementia may have profound visual hallucinations, including talking to little people in the room or seeing animals that are not really present. “It can be very helpful and reassuring for families to know that a particular behavior is part of the disease process, not just ‘bad behavior’,” Troxel noted.

In addition, different dementias may call for different medicines. Individuals with pure frontal lobe dementia often don’t do well on the typical memory medications like Aricept, Exelon & Razadyne, but they may respond to an anti-depressant. Persons with Lewy Body dementia seem to be very sensitive to mood-altering medications like anti-psychotics. In fact, an old nursing phrase says, “start low and go slow” when giving psychotropic medications to a person with Lewy Body dementia.

Finally, when the physician gives you a specific diagnosis it’s a sign that you’ve seen a medical provider who understands the contemporary best practices surrounding diagnosis. You can feel that you and your family member are in good hands.

Likewise, other professionals you may work with to care for your family member, such as professional in home caregivers, should be trained to understand the distinctions between various dementias. Paul Hogan, chairman of Home Instead Senior Care, says “Our CAREGivers are trained to understand the differences between Alzheimer’s disease and other forms of dementia. We want our clients’ families to know that we are here for them no matter which dementia diagnosis they face.”

Family caregivers can form a care team with the senior’s doctors, pharmacists, and other care providers focused on providing the best possible care and that focus needs to include an accurate understanding of the diagnosis, its symptoms, and its possible treatments. “Until we find a cure, the best approach to any of these dementias is engagement, activities, communication and loving care,” says Hogan.
What are the stages of Alzheimer’s and dementia?

“What stage is my mother in? What can we expect next?”

Alzheimer’s disease and the other dementias are usually slow and progressive illnesses. The average length of life after a diagnosis of Alzheimer’s is eight years, although many people live much longer.

While there are different theories and views of staging, many senior care professionals, including David Troxel, co-developer of the Best Friends™ Approach to Alzheimer’s care, believes that understanding three basic stages can help families prepare for the caregiving journey.

**Early dementia**

In this stage, people with Alzheimer’s retain some insight into their situation, but are getting more and more confused and forgetful. They may begin to lose language skills, have trouble handling money and paying bills, forget once-familiar tasks and have some personality changes.

One woman Troxel worked with said her mother was “fighting the battle” during this stage. She knew what was happening and fought to keep her independence.

During this stage it was tough for the family to manage issues around driving and money management, but with honest and caring communication the mother finally accepted their help.

**Middle dementia**

People in early-stage dementia can retain enough function to fool family and friends about their condition. But the game is up in stage two, marked by significant memory loss and confusion. Dad may forget or not recognize family and friends, repeat himself often, and have problems sequencing tasks like putting on clothes in the wrong order. He begins to lose independence. It is no longer safe for him to live alone and manage his own affairs.

“Dad stopped bathing, shaving and wearing clean clothes during this time,” a son remembers. “He became apathetic and seemed depressed.”
No wonder this is the point at which most families intervene and seek help for their loved one. They may arrange a power of attorney in order to manage finances, and turn to an adult day center, in home senior care provider or residential care community during this stage of dementia.

Socialization and support are important at all stages of the Alzheimer’s journey, but they are a key intervention during middle dementia. Structuring the day, arranging activities, and preventing isolation are important goals—goals that in home workers who have completed the Home Instead Senior Care® network’s Alzheimer’s and Other Dementia Program support. Besides offering daily assistance with dressing, bathing, meal preparation and other tasks, these trained CAREGivers℠ know how to plan activities they and their clients can enjoy together and how to have fun with their clients.

Late dementia

In many ways, Alzheimer’s can be considered a fatal illness. Late in the illness, the person is more prone to falls and infection. The swallowing reflex often declines, making the person vulnerable to aspiration pneumonia. While the person has experienced some incontinence, now he or she may lose full control of bladder and bowels.

Caregiving becomes quite profound and focused on physical care and well-being. Although the person may not recognize family or friends, it’s important to continue expressing love and affection. There’s still a person inside, who needs dignity and respect. Of great help during this final period are hospice services, which can provide excellent medical, spiritual and social care.

Companions along the way

“Supportive companions are important no matter where your family member is in this long journey,” says Troxel. “Building a strong network of caregivers, support groups, and friends can help a family prepare for and address needs and challenges at every stage of Alzheimer’s.” To find support groups, contact your local Alzheimer’s Association chapter. To find in home care support, contact your local Home Instead Senior Care office.
Is Alzheimer’s inherited?

The keynote speaker at a recent Alzheimer’s Association conference had just wrapped up his presentation and asked for questions when a caregiver rushed to the microphone, “Doctor, am I going to get Alzheimer’s disease too?” she asked worriedly.

For caregivers and family members, this question looms large. Forget a familiar name or appointment, make a mistake in a bank account, or burn something on the stove, and you ask yourself, “Is this it? Has my Alzheimer’s started?”

Don’t panic. While some types of Alzheimer’s may be more likely to be inherited than others, dementia expert David Troxel thinks our stress-filled, multi-tasking culture almost encourages forgetfulness: “We depend upon our smart phones to remind us of appointments, our cell phones are automatically programmed to dial a number, and our GPS systems take us where we want to go without much thinking.”

While many people are becoming a bit more forgetful because they aren’t exercising their brains, Troxel affirms that periodic memory lapses aren’t usually a sign of early Alzheimer’s, particularly in younger persons.

So, are you more likely to get Alzheimer’s if one of your parents have the disease? Here is a summary of the current thinking about the inheritability of Alzheimer’s.

**Early-onset Alzheimer’s may be more inheritable**

Alzheimer’s disease does run in some families, particularly in early onset cases in which someone gets the disease well before the age of 65. Fortunately, these devastating cases
represent less than 5 percent of all diagnoses. If you have a parent or sibling in this situation, you may want to get him or her evaluated at a university research center. You may also want to undergo genetic testing yourself to better understand your family situation.

**Later-onset Alzheimer’s is less inheritable**

If you have a relative whose Alzheimer’s disease begins well after the age of 65, you probably only have a slight increase in risk, if any. This is good news for most family members, since late-onset dementia is by far the most common form of the disease. Families will often express concern that many of their elderly relatives experienced Alzheimer’s disease. They worry that it must run in the family since “four of my five uncles had dementia.” Troxel offers some reassuring words of advice, “Remember, almost half of all elders will develop dementia. This family’s experience might just reflect the average variations in percentages that impact us all.”

**Assessing your risk**

If you still want to assess your risk, you can talk with your physician about genetic testing. The most common test looks at a gene called APOE (apolipoprotein E) found on Chromosome 29. You receive one gene from your mother and one from your father. The test reveals whether you have an APOE 2, 3 or 4 from your mother and your father. A 2/2 combination seems to actually protect the brain; an APOE 4/4 greatly increases your risk.

Most medial professionals discourage blanket genetic testing, at least in its current form. An APOE test demonstrates risk but is not definitive. It will also not tell you when you will get Alzheimer’s—at 70, 80 or 95. This makes the information hard to use on a practical basis.

**Prevention**

While the evidence is not definitive, getting plenty of exercise, not smoking, controlling weight, eating a heart-friendly diet, and staying socially and intellectually active may help delay the onset of Alzheimer’s disease, or may even prevent it. If you have experienced Alzheimer’s disease in your family, take these positive wellness steps. They cannot hurt you but may help quite a bit!
How do I talk to Dad about his diagnosis?

“However you do, don’t tell Dad about his Alzheimer’s disease.”

Doctors hear this line often. The families who say it are afraid that the truth will devastate their loved one and lead to hopelessness and depression.

Some physicians may comply, but most believe it’s a patient’s right to be fully informed about his or her situation. Even patients with dementia deserve to hear the truth. “Plain, truthful talk allows everyone to come together, be supportive, give lots of loving help, and make a game plan for care,” says Lori Hogan, co-founder of Home Instead Senior Care, an international in home care company that has helped thousands of families coping with Alzheimer’s.

Consider Margaret’s experience: Margaret’s family was so worried about her reaction to her Alzheimer’s diagnosis that they faxed the doctor and left frantic voice messages insisting he not tell Margaret anything. The doctor ignored their requests and laid it out fully for her. Her response? “I knew it! I’ve seen those ads on television about those memory pills!”

Like many people, Margaret found it comforting to finally understand the truth about her memory loss. While families dread this moment, in many cases it’s almost a non-event for the person with dementia. He or she may already know something is wrong. Others may be protected from the bad news by their forgetfulness, or not fully understand or retain the information.

Keeping a diagnosis secret makes it very hard to formulate a game plan for success. How can you get to the Alzheimer’s education workshop, support group or start using

Learn more at HelpForAlzheimersFamilies.com
helpful services if the diagnosis is not revealed? Starting your family member on a recommended memory care medication or treating depression can be extremely difficult if you’re keeping a secret.

If you’re facing the challenge of sharing a dementia diagnosis with a loved one, consider following these steps:

1. Learn all you can about Alzheimer’s and dementia so that you can speak to your family member with confidence and answer questions.

2. After the physician has explained the situation, take an upbeat approach. Tell your Mom that she is not alone, that many people have this diagnosis, and that there is a lot of life left! If you don’t want to use medical terms like Alzheimer’s disease or dementia, just remind her that the doctor says she has some “memory problems.”

3. Answer your loved one’s questions fully, but stress the positive—for example, that memory pills may help, and that research continues around the world to find a better treatment or cure.

4. Stress that you will travel the journey with your family member. Your optimism and positive tone will be comforting. Most importantly, have empathy for the person in your care, and communicate with an upbeat, positive spirit. Provide loving support and engage your loved one in meaningful activities that build their sense of purpose and self-esteem. If the journey becomes overwhelming for you, consider joining a support group, participate in family caregiver educational opportunities, and hire others to help you. You and your family member do not have to travel this path alone. Travel companions can help you make the most of every day.
How can I turn a NO into a YES?

“Whenever I ask dad if he wants to go out for a drive, go into the garden, work on some chores, or take a walk, he always declines. I get so frustrated; my new nickname for him is Dr. No!”

One of the most common frustrations among family caregivers is the propensity for people with dementia to say “No!” Loved ones can’t understand why people with dementia so often say no and refuse to do the very things they’ve done willingly and eagerly in the past.

The reasons are actually pretty straightforward. Dementia impacts memory, reasoning and language. It’s hard for the person with dementia to understand what we ask of them. When we are asked to do something we don’t understand or we feel uncomfortable with how do we respond? No!

Like the rest of us, people with dementia have the right to say no. Because of their dementia, however, they often make poor decisions. A good way for family members to approach the no’s is to ask themselves, “What would dad have done years ago? Would he have enjoyed the outing? Would he have wanted to be dressed in clean clothes? Would he have wanted me to be this stressed or would he have been willing to get some in home help so I could be sure he is safe and healthy?”

In most cases, the answer is yes. But to turn that no into a yes when dementia is present, family members and professional care givers have to become leaders and provide lots of encouragement. Home Instead Senior Care, a leading provider of Alzheimer’s in home care, trains their professional CAREGivers to try three times, in three different ways, to turn a no into a yes.
Here’s an example of how you can use that technique with your family member:

Let’s say you are trying to get Mom to sit in the garden on a beautiful day.

**One:** Ask her the way you always have. “Mom, it’s a lovely day out. Let’s go out to the garden to look at the roses.”

She declines.

**Two:** Use some information from her life story to make a more personal request. “Mom, let’s go out to the garden and see your roses. I need your advice on how to prune them properly and you are a master gardener!”

She declines.

**Three:** Take her hand into your hand and point to the garden (to give her physical cues) as you say, “Mom, it’s a lovely day out. Let’s go to the garden to look at the roses.” [Pause] “I really appreciate your help in the garden. After we’re done, let’s get some strawberry ice cream.”

This time you are giving her a physical cue to the desired response and offering your hand for support. Adding another sentence showing that you admire her willingness to help you and offering a favorite reward afterwards both increase your chances of success.

This time she says yes.

Sometimes the stakes are higher than a social visit to the rose garden. Getting Mom to agree to go to the doctor or use in-home services can be a matter of safety, security, and overall health.

David Troxel, author of *The Best Friends Approach to Alzheimer’s Care*, recommends that when you have your family member’s best interests at heart, it is sometimes easier to get forgiveness than permission. You may have to line up services that you need and start them, even without your family member’s initial consent. Once you get the ball rolling, the person with dementia often goes along.

If you face resistance when starting in home care services or starting any new routine, stress that it’s on a trial basis or mention that it’s “doctor’s orders.” Mom or Dad may be mad at you for taking him or her to the doctor, but once it’s over he or she may soon forget and move past the negative feelings. If you can get the person with dementia into a new routine centered on additional home care services, he or she may actually begin to enjoy the socialization and attention.

Remember, while it may be tough going, with patience and compassion, you can learn to turn that no into a yes.
How Can I Afford Dementia Services?

Costs for caring for a person with Alzheimer’s disease or other dementias can be high, but there are steps that families can take to use their resources wisely and identify sources of help.

Any of us who have had a family member or friend with dementia understand the enormous physical and emotional toll of caregiving. It’s very tough watching your family member or friend lose memory, skills and abilities. But there is another challenge for families that isn’t talked about as much – the enormous financial toll of caregiving for a person with dementia.

The MetLife Mature Market Institute’s 2011 Market Survey of Long-Term Care Costs revealed that:

• The national average hourly rates for home care workers is $19/hour.
• The national average daily rate for adult day services is $70.
• The national average monthly base rate in an assisted living community is $3,477.
• The national average daily rate for a private room in a nursing home is $239.

Specialized dementia services are often more expensive. The bottom line is frightening. An early study of lifetime costs by R.L. Ernst and J.W. Hay suggested that families will pay $174,000 over time providing care, a figure that has certainly risen.

What can a family do to cope with these costs? Here are some suggestions from Alzheimer’s care expert David Troxel.

• First and foremost, take stock of family resources and funds. Make sure that your family member’s legal and financial affairs are up to date, that you know where various accounts and funds are located, and that a trusted party receives a durable power of attorney to handle finances. Because persons with dementia can make bad decisions and even become victims of fraud, be vigilant in monitoring accounts and protecting remaining funds.

• Look for sources of help or untapped benefits. Individuals that are veterans may have veteran’s benefits that can be life-savers. Contact the Veteran’s Administration for help. A good source of
information regarding benefits is an online service provided by the National Council on Aging at [www.benefitscheckup.org](http://www.benefitscheckup.org). This reputable site can help with resources related to everything from medications, health care, food, utilities and more.

- **Geriatric care managers are typically nurses or social workers who charge an hourly fee to help family caregivers.** They may be able to bring their experience to the table and help you identify and become eligible for various services.

- **Call your local Alzheimer’s Association chapter to see what other programs are available to help**, for example friendly visiting programs, home delivered meals and other services.

- **Travel the continuum of care.** Community based and home services are usually cheaper than residential care. Day centers provide wonderful socialization for persons with dementia and are generally affordable. Starting out with in-home help every other day for four hours can be a life-saving way to give caregivers a break, while giving some stimulation and support to the person with dementia. When needed, an assisted living memory care program is generally much cheaper than skilled nursing.

- **Long-term care insurance is highly recommended for everyone concerned about the cost of long-term care.** Many Baby Boomers are buying policies for the future, but the policies are also available for older individuals. Unfortunately, when symptoms of dementia start it is too late to buy a policy.

What if you’ve done this and funds are not available? Unfortunately there are no easy answers, particularly since many local programs have closed in recent years with local and state government cutbacks. This may be the time for a family meeting to take stock of people resources and financial resources. When you map out a game plan, one family member may be able to contribute a monthly amount for care; another family member may be able to contribute a gift of time. Sometimes friends, neighbors, service clubs, and faith communities will rally to provide support.

Education makes a big difference and gives you greater skills to navigate this journey. A family that is proactive and educated can better manage behaviors that are challenging and may be able to keep a person at home longer.

Learn about **Dementia CARE Services** provided by the Home Instead Senior Care® network.
What are the other dementias?

The original name of the US Alzheimer’s Association was the “Alzheimer’s Disease and Related Disorder Association.” Despite that early nod to the “related” or “other” dementias, for many years almost all the public’s focus was on Alzheimer’s disease, the leading cause of dementia. Approximately 60 percent of all dementia cases are Alzheimer’s and Alzheimer’s classic symptoms affecting memory, thinking, language and judgment are well known.

So let’s take a look at the “other” dementias that affect hundreds of thousands, if not millions of persons worldwide.

Vascular dementia develops when impaired blood flow to parts of the brain deprives cells of oxygen. In one form, a series of very small strokes or “infarcts” block small blood vessels. Individually, these little strokes do not cause major symptoms, but over time their combined effect becomes noticeable, which is one reason why this type of dementia was formerly called “multi-infarct dementia.”

Most of the “memory medications” used to treat the symptoms of Alzheimer’s disease (the cholinesterase inhibitors like Aricept) have also been shown to help individuals with vascular dementia. Lifestyle changes that support good heart health and reduce stroke risk may also be helpful.

Mixed dementia is a common condition in which Alzheimer’s disease and vascular dementia occur at the same time. The treatment is similar to vascular dementia.

Lewy Body dementia is characterized by abnormal deposits of a protein called “Lewy bodies,” after the scientist who first described them.

Symptoms include memory problems, poor judgment, and confusion similar to Alzheimer’s. What is different is that persons with Lewy Body may have excessive daytime drowsiness, profound visual hallucinations, movement symptoms and a lack of facial expression.

The traditional dementia medications may be helpful; however, persons with Lewy Body dementia are often quite sensitive to psychotropic medications.
**Parkinson’s disease can sometimes be accompanied by dementia.** In fact, dementia occurs in 15-30 percent of persons with Parkinson’s disease, usually appearing in the later stages of this chronic brain and nervous system disorder. Classic symptoms of Parkinson’s include tremors and shakiness, stiffness, difficulty walking and controlling muscles, lack of facial expression and impaired speech.

Parkinson’s medications help with physical manifestations of the disease, but may have side effect of added confusion.

**Frontotemporal dementia (often called “frontal-lobe dementia”)** is a rare disorder that affects the front (frontal lobes) and the sides (temporal lobes) of the brain. Symptoms include a more rapid onset of symptoms than Alzheimer’s disease, as well as changes in personality, judgment, planning and social functioning. Individuals may make rude or off-color remarks to family or strangers. They may make unwise decisions about finances or personal matters. This is the only dementia that impacts more men than women. The peak age is 55-65.

There are no current treatments specifically for frontal-lobe dementia. The traditional memory medications, cholinesterase inhibitors such as Aricept, may make this form of dementia worse and are usually not recommended. Antidepressants may be helpful.

**Accurate diagnosis is important**

A thorough medical examination can usually identify the specific dementia diagnosis. Knowing the diagnosis can help family members better understand and cope with their situation. For example, if a person with frontal-lobe dementia makes hurtful remarks, a well-prepared family member may better take the remarks in stride. If a person with Lewy Body dementia is talking to “little people” in the room, a caregiver who understands that this is common will know not to overreact.

Staying abreast of new trends in dementia and dementia care is a priority for the Home Instead Senior Care® network, says co-founder Lori Hogan. “Knowing about these other dementias will help our wonderful CAREgiversSM come into the home with wisdom and confidence.”
Why is Mom always angry with me?

We all get angry now and then. We can be angry at a person, like a friend whose chronic tardiness makes us late for a movie. We can be angry at a thing, like an unreliable car that breaks down again and again. We can be angry at ourselves for not sticking to a diet and our resolution to lose 10 pounds “before summer!

Persons with Alzheimer’s disease and the other dementias have good days and bad days, too. Yet the memory loss and confusion associated with dementia can trigger bouts of anger that can be distressing to a family member simply trying to do his or her best.

“Some days Mom is so sweet and appreciative, but other days she is angry at me and even hits out,” says Jean P., one caregiver who feels frustrated by her mother’s dementia.

“Triggers like trying to get her into the shower are easy to understand, but sometimes her dark mood seems to come out of nowhere. Why doesn’t she know I’m doing my best?”

“Anger is a form of communication,” says Jeff Huber, President of Home Instead Senior Care®, an international provider of Alzheimer’s in home care services. “The person with dementia may not be able to tell us what they want or need. Anger is one way for them to release their frustration and emotion.”

When you’re facing a loved one who’s unexpectedly angry, try following these steps:

1. Take a break. Sometimes just pausing and coming back in 5 or 10 minutes works. Try saying, “Mom, I’m so sorry I misunderstood what you wanted for breakfast. I’ll be back in a few minutes to check in with you.”
2. Look for triggers. Think about what happened right before the outburst. Can you detect a pattern to avoid in the future? Some persons with dementia get very tired in the afternoon, for example, and may get angry if you try to engage them in activities then. Line up more activities in the morning and give them a break in the afternoon.

3. Watch for pain or illness. The person with dementia may have a toothache, arthritis pain, or simply be sick. Dementia expert David Troxel recommends watching for abrupt changes. “If a happy-go-lucky person is suddenly moody and angry, that is usually a good sign that it’s a physical health issue.”

4. Bring up a favorite subject from the person’s life story. Talking about the person’s childhood, favorite foods, or experiences can sometimes change a bad mood into a good one.

5. Apologizing is tough, but it’s sometimes the best response to anger—even if it’s not your fault! Saying, “Dad, I’m so sorry that I misunderstood you. I’ll do better next time. I love you” can turn that anger into a smile.

It’s important to share these tips with other professionals you may work with to care for your loved one, says Troxel, who helped develop a training program for Home Instead CAREGiversSM that equips them to create a positive, joyful environment through activities, loving support and good communication. “A therapeutic environment like this tends to bring out the best in persons with dementia and can reduce incidences of anger,” Troxel notes.
How do I talk to Dad about his dementia and driving?

It’s one of the most challenging problems for family caregivers. What do you do when your family member with dementia still insists upon driving his or her car?

“I was a nervous wreck about Dad’s driving,” remembers Lisa H., a family caregiver. “I confronted him, begged him, and argued with him, to no avail. The more I pushed, the more he pushed back. Because he was marginally legally competent, I couldn’t force him to stop.” Fortunately, after a couple of scary incidents, this man made the decision himself that it was time to quit driving.

Others may not be as amenable to change. “My uncle did fine for many months driving around his small town, during the daytime, on a route he knew well,” says Jenny M., another caregiver. “I hated to take away his car because it meant so much to him, but we kept an eye on the situation and talked to him about it early on.” In this case, the family eventually insisted that he only drive with a “co-pilot” who could help him navigate and provide feedback and support.

Alzheimer’s disease and the other dementias tend to be slow and progressive. Early on, the person with symptoms of dementia begins to lose skills and judgment, but might still have adequate driving skills.

As dementia progresses, driving is impaired by poor judgment (the person may drive in terrible weather), memory loss (the person may get lost), problems with reasoning and problem solving (the person may be unable to understand signage or an unfamiliar detour) and fatigue (the person may fall asleep). When these factors develop, taking the wheel...
makes a driver truly a danger to society and him or herself.

The following tips may be helpful to you when it’s time to talk to a family member about driving and dementia.

1. Explain the situation directly and share your feelings of concern and worry. Sometimes this will work.

2. Recognize that your loved one may genuinely worry about losing his or her independence and being cut off from familiar friends and activities. Offer alternatives like a senior transportation service, a taxi, or rides from another family member.

3. When choosing in-home help, look for someone with a valid driver’s license. “A well-trained and supportive caregiver becomes the life-line for a person with dementia and can take them on drives to the market, medical appointment, or social events,” says Paul Hogan, co-founder of Home Instead Senior Care®, an international in home care company that has helped thousands of Alzheimer’s families.

4. Don’t become the bad guy. Encourage the person to quit driving because it is the doctor’s order or the wishes of the family as a whole. You can also hire an expert to give an independent driving evaluation and agree to follow his or her advice. Many state motor vehicle departments provide this service or can suggest names.

5. When a person becomes quite confused or disabled, drastic steps may be required, such as hiding the keys, disabling the car, or removing the car altogether. One family simply told dad that his car was in the shop. He accepted the explanation and the problem was solved.

For additional advice on having difficult conversations such as this, take a look at Home Instead Senior Care’s 40/70 Rule™ program, which is full of helpful advice and scenarios for these challenging situations.

Most professionals support the basic privileges and rights of people with dementia, and orgetfulness alone is not a reason to strip someone of the right to drive. As a family member, you need to be supportive yet vigilant. When the ability to make good decisions vanishes, it’s time for tough love.
Do the memory drugs work?

The recommended medical treatment for Alzheimer’s disease and many of the other dementias includes a group of drugs that are often called “dementia slowing” or “memory enhancing” medications. The most prescribed include a group of drugs called cholinesterase inhibitors. These go by the trade names of Aricept, Exelon and Razadyne. These drugs do not stop the underlying progress of dementia, but they often support better thinking and memory. The drugs work by boosting a brain chemical that is essential for healthy thinking and functioning. Another drug called Namenda has different neuroprotective properties but also supports better brain functioning. Most persons on Namenda are on one of the three cholinesterase inhibitors and this combination therapy seems to work best.

These four current medications for dementia provide modest benefit. They can temporarily improve symptoms and help a person think better and remain independent longer. Conventional wisdom is that the drugs begin to lose their effectiveness over time. Side effects for these medications are modest and can include stomach/digestive (GI) problems, vivid dreams, and agitation.

One of the challenges of these drugs is that they work better for some people than others. Some people taking the medications have noticeable improvement. They might return to the golf course, gain back skills like operating the washing machine or report better memory in general. Others may be benefitting but show no noticeable effect. In these cases the drug or drugs may be helping them maintain their current levels of functioning; this is still a valuable benefit. There are some people who
seem to have no apparent benefit from these memory medications.

The British Alzheimer’s Society has a short but helpful summary on its website, “Research suggests that between 40 and 70 percent of people with Alzheimer’s disease benefit from cholinesterase inhibitor treatment, but it is not effective for everyone and may improve symptoms only temporarily, between 6 and 12 months in most cases. According to an Alzheimer’s Society survey of 4,000 people, those using these treatments often experience improvements in motivation, anxiety levels and confidence, in addition to daily living, memory and thinking.”

The US Alzheimer’s Association endorses these medications. However the Alzheimer’s Association encourages families to maintain realistic expectations, noting that the medicines don’t cure Alzheimer’s or stop it from progressing but may lessen symptoms for a limited time.

Home Instead dementia care consultant David Troxel recalls a time when there were no medications. “However modest their impact, these memory medications have given hope to millions of persons around the world. That being said we desperately need new and better medicines to help people with dementia.”

A frequently asked question at support groups and in other settings is when to stop using the medications. Many physicians will choose to keep a person with dementia on these medications for a long period of time under the theory that even modest benefits are better than nothing. Other physicians will slowly withdraw patients from these drugs if they and the families perceive that the drugs are no longer having a positive impact.

Until we find a truly effective way to prevent, treat or cure Alzheimer’s disease and other dementia David Troxel notes that the “treatment” for dementia is socialization, keeping the person active with exercise, music and creative activities. “Engaging the person in life as much as possible fights depression and keeps him or her operating at their very best.”
How are depression and dementia related?

As we work to unravel the mysteries of Alzheimer’s disease and other dementia, one of the more interesting areas of research is depression and its connection to dementia. It appears that depression impacts people with dementia in at least two different ways. First, individuals who have had significant depression in their lives may be at greater risk for developing dementia. Second, many people with dementia have depression; left untreated it makes confusion and forgetfulness worse, damaging quality of life. Let’s discuss both these aspects of depression and dementia.

A number of studies have suggested that there is a link between depression and dementia. It now appears that individuals with long histories of clinical depression (particularly depression that goes untreated) have a greater risk for developing dementia. In a 2010 study in the journal Neurology, Doctor Jane Saczynski of the University of Massachusetts, found that depression at a younger age is a significant risk factor for dementia. While the reasons are unclear, she speculated that inflammation that occurs when a person is depressed may be a contributing factor. In addition, certain proteins found in the brain increase with depression; these also may be increasing the risk of dementia.

It’s important to note that a risk factor is something that is likely to increase the chances that a particular event will occur. Having a risk factor for Alzheimer’s disease doesn’t mean that you will ever get Alzheimer’s disease; many people with histories of depression never get dementia.
What should an individual do if he or she has depression, particularly at a younger age? Common approaches include medicines and talk therapy. Many people with depression benefit from increased activity and socialization, including things like exercise, meditation, time with children and activities involving pets.

Even if we don’t fully understand the mechanisms at work within the brain, there is no doubt that a long period of depression may lead to isolation, inactivity and hopelessness. David Troxel, noted dementia care expert says that, “the brain loves company.” When you can overcome depression, it is clearly good for the brain.

How can you tell if your family member who has Alzheimer’s disease or dementia is depressed? Common signs include anxiety, sadness, lack of appetite, spending more time sleeping, weight loss and agitation. Sometimes they will express painful, upsetting thoughts or make negative comments like, “I want to die,” or “I’m so alone.” These are words that caregivers should pay attention to as they are signs of depression.

Many persons with dementia may not be able to tell you they are depressed, but actions communicate a message. For example, a person with dementia who always loved gardening will most often still respond to an activity involving flowers, for example arranging flowers in a vase or taking a walk outside to see roses in bloom. A person with dementia who is depressed, develops apathy, refusing to do the things they’ve often enjoyed in the past, even things they’ve enjoyed fairly recently.

If you suspect that your friend or family member with dementia is depressed, seek help from your physician. There are several tools that your doctor or a neuropsychologist can use to assess and treat the person. Anti-depressant medicines seem to work well. Activity is also a way to treat depression in persons with dementia. Step up your exercise to twice a day, get them outside in the sunshine, encourage attendance at a day program, or hire in-home workers who will engage them in conversation and activities.

Perhaps the answer is “hugs and drugs.” When we treat the person’s depression, we can bring the person back to a higher quality of life, for them and for all of us as well.

Resources:

Alzheimer’s Association (AD and Depression)
What are the suspected causes of Alzheimer’s and dementia?

Alzheimer’s disease is the most common dementia, impacting over 5 million Americans. Although the disease was first described by Dr. Alzheimer in the early 1900s, scientists are still trying to understand its causes. Here are some of today’s leading theories:

**Age.** In 1900, the average life expectancy in the United States was 47. Today people live well into their 80’s and 90’s. This is good news for most of us and many seniors are enjoying an active, engaged life. However, one downside of a long life is that aging increases your risk for Alzheimer’s disease - 15% of people over 65 have Alzheimer’s disease; 40% of people over 85. Despite these frightening percentages, most researchers don’t think that Alzheimer’s disease is a “normal” part of aging. Researchers remain hopeful that we will develop strategies to delay the onset of Alzheimer’s or prevent it altogether.

**Family history.** The consensus among researchers is that if you have one or more parent or close family member with Alzheimer’s disease, you are generally considered to be at greater risk for developing the disease. One gene in particular called ApoE4 increases your likelihood of getting Alzheimer’s disease. Like all risk factors, a family history may or may not lead to the development of the disease.

**Lifestyle factors.** Some lifestyles may be very unfriendly to the brain and increase the risk of Alzheimer’s disease. For example,
individuals who sustain concussions or head injury (through sports, work or accidents) have a greater risk of getting Alzheimer’s. Positive lifestyle factors that may prevent Alzheimer’s or delay the onset include exercise (break a sweat at least once a day), a healthy diet rich in antioxidants, socialization, treating depression, lifelong learning (“use it or lose it”) and avoiding tobacco use.

The Alzheimer’s Association has described the suspected links between heart health and brain health. The Association argues that “what is good for the heart is good for the head.” We may not know if a low fat, heart friendly diet will ultimately prevent Alzheimer’s, but it certainly can prevent stroke, another enemy of the brain.

**Plaques and Tangles.** Two areas of ongoing research include studying the buildup of plaques and tangles in the brain. Plaque consists of the protein beta amyloid that accumulates in the spaces between nerve cells. Tangles are the twisted fibers of another protein tau (rhymes with “how”) that accumulates inside nerve cells.

These proteins most likely block the ability of the cells to communicate, leading to cell death. This cellular death ravages the brain and causes the progressive symptoms of Alzheimer’s disease.

Much of the research to date on potential medications for Alzheimer’s has looked at ways to prevent the buildup of plaques and tangles in the brain. Unfortunately, there have been a number of very high profile failures and disappointments with promising drugs. Many scientists are now looking at other mechanisms besides attacking plaques and tangles, for example, looking at inflammation in the brain as a possible trigger for Alzheimer’s disease.

Within the field of Alzheimer’s research, there is much optimism, but also a sobering recognition that there is still much to be accomplished. The good news is that our field of knowledge about Alzheimer’s disease is expanding rapidly. New tools such as powerful scanners can look inside of the brain and now even identify amyloid plaques. There is also a world wide effort underway with significant coordination of research between scientists and universities.

The Alzheimer’s Association points out that 90% of what we’ve learned about Alzheimer’s disease has been discovered in the last 15 years. Let’s hope that the next 15 years leads to the breakthroughs we need to help Alzheimer’s disease itself become a “distant memory.”

Sources: Alzheimer’s Association and NIH National Institute on Aging
How do I deal with delusions?

It can be one of the most upsetting things about being a family caregiver. You’re always at your mom’s beck and call. You spend hours helping her, take over household chores, drive her to medical appointments, struggle with her personal care. Yet instead of thanks, you get accusations: “You’ve taken my purse! You’re stealing my money.” Then, as usual, after a few minutes’ search, the purse turns up under the pillow, where Mom hid and forgot it.

Delusions—fixed, false ideas—are quite common with Alzheimer’s disease and the other dementias. Often they can simply be caused by the very nature of the forgetfulness of these diseases: Like many seniors, Mother hid her purse “to keep it safe.” However, she forgets that she put it under the pillow so now it’s missing. You are the only person who has visited; therefore, you must be the guilty party.

Likewise, mistaken identity, another common delusion, can be caused by forgetfulness. As painful as it may be, your father may not remember what his wife, daughter, or son look like, so he no longer recognizes them. Or, forgetful and confused, he may think he is 40 years old, not 80, and so may mistake his grandson for his son.

Sometimes delusions are more mysterious. A person with dementia may decide that the neighbors have moved the fence in six feet during the night or that someone is constantly breaking into the house.

In any case, delusions can be frightening and painful for both the senior and the family.
If you are caring for someone who is experiencing delusions, consider these tips:

- Try not to overreact or get upset, even if, like the false accusation, the delusion is upsetting. Remember, a real disease or disorder is attacking the brain. It’s the disease at work, not the person.

- In cases of mistaken identity, try offering some gentle cues. “Gosh, honey, it’s me, Mary, your wife!” You can help maintain another’s dignity by saying, “You’ve got such a sense of humor” or “I know I look young enough to be your daughter.”

- Let the person know you have heard his or her concern. “Mom, I’m so sorry your purse is missing. That is upsetting. Let’s look around just in case it accidentally got misplaced.” You can then celebrate with a big smile and hug when you “find” the purse.

- “Tell me about that purse. Is it the red one or blue one?” Asking additional questions can allow the person to tell you more about worries and concerns.

- Don’t argue. You can almost never talk the person out of a belief or concern or convince him that he or she is wrong. If your family member thinks the fence has been moved, say that you will work on getting to the bottom of the situation or call the county to investigate.

- Take advantage of the passage of time. Sometimes your best efforts will fail and the person will continue to express the delusion. If you provide ongoing reassurance and take a low-key approach, these delusions will go away on their own.

Delusions can be one of the most challenging symptoms of Alzheimer’s disease and other dementias. If they become overwhelming, consider consulting a professional. Reach out to the person’s doctor, a geriatric care manager, or a professional caregiver who has received training in handling challenging behaviors like dementia.
How can I help someone in late stage dementia?

Most dementias in older persons are slow to develop. Alzheimer’s disease, the leading cause of dementia, progresses over many years.

Late-stage dementia is tough on everyone. The person with dementia may be fully incontinent, need help with eating, have difficulty walking, no longer be able to communicate, and almost certainly requires significant care. Families grieve their loss, particularly if the person no longer recognizes close friends and relatives.

How can you help someone during this part of life’s journey? Dementia expert David Troxel, who worked with the Home Instead Senior Care® network to develop its Alzheimer’s and Other Dementias Training Program, recommends these approaches:

*Always approach persons with late-stage dementia with dignity.* Never talk about them in their presence as though they aren’t there. Encourage caregivers to keep them well groomed, neatly dressed and clean.

*Provide a reassuring touch.* A gentle shoulder massage, hand rub, or friendly hug creates that needed human connection and shows the person he or she is valued.

*Enjoy music.* Music and song lyrics are in a different part of the brain than speech. Many individuals with late-stage dementia respond to beautiful music. They may even be able to sing an old, familiar song. Music brings happiness and joy.

*Manage pain.* Most persons with late-stage dementia are not able to let you know in...
words that they are in pain. If the person cries out, grimaces when touched, or shows other signs of pain, talk to your medical provider about appropriate medications. Watch for skin tears or bruises. Consult with a physical therapist about chair exercises or other simple stretches that can help keep them limber.

**Consider a visit from a friendly cat or dog.** Animals give unconditional love and the late-stage person will often take great joy from the wet nose or kiss of a dog. A cat in the lap provides an opportunity to pet the cat and enjoy its soothing purr. While it is always important to treat the person as an adult, some individuals in this stage do take comfort from holding a soft teddy bear (or substitute a baby doll).

**Go outside.** When possible, take the person outside to get some fresh air and sunshine, and to experience the beauty of nature. Use a wheelchair if needed. Going outside is sensory, spiritual and life-affirming. The person will likely enjoy feeling the sun’s warmth and seeing flowers, birds, and neighborhood children.

**Take care of yourself.** Seek out a support group or counselor to share your feelings of loss and obtain necessary support. Try to make time to exercise, eat well and spend time with family and friends.

**Take a break.** When you need a break, consider a professional caregiver who is trained in all stages of dementia care. “My goal was to get one smile an hour, but guess what? I often ended up with two or three,” Angela G., a Home Instead CAREGiverSM said about her experience with a late-stage person. “He seemed to understand some of my silly jokes. I enjoyed my time with him and I hope he enjoyed his time with me too.”

**Take advantage of hospice care.** Hospice offers wonderful services for home-bound individuals in the late stages of dementia, including assistance with nursing and medication, help with bathing, all-important respite, and spiritual support for the patient and his or her family.

Remember, the most important thing you can do during this part of life’s journey is to make sure the person with dementia knows the love and warmth of family and friends, and for you, the caregiver, to enjoy the special moments when they happen. Be sure to focus on taking care of yourself or you won’t be able to do either.
How do I manage Mom’s wandering?

“I just turned my back for a minute and mom had wandered off. She usually walks so slowly, but when she wanted to get away she became a track star!”

Why do so many people with Alzheimer’s disease or other dementias—over 60 percent—wander away from their care settings? The reasons are pretty straightforward, says the Home Instead Senior Care® network’s dementia consultant David Troxel. “Individuals with dementia get confused about time and place. They may think they are late for work and walk out the door, or get confused trying to find the bathroom and go out the wrong door.”

Fear can also be a factor. “Their dementia may cause them to become frightened or upset, and walk or run away from a safe setting.”

In most cases, the person is found quickly and safely, but sometimes the results can be tragic. No wonder wandering is such a concern!

“I’ve met families who can no longer get a good night’s sleep out of fear that the person with dementia will go out the front door in the middle of the night,” says Paul Hogan, chairman of Home Instead Senior Care. “It’s exhausting and tough to live in this state of constant worry.”

Home Instead’s Alzheimer’s and Other Dementias Training Program stresses the importance of creating a safe environment. To minimize opportunities to wander, follow these tips from Home Instead:

• Make your home safe. Put deadbolts high and out of reach. Put a sign on the bathroom door or leave the light on at night if the family member is looking for
the bathroom. Alarm doors and windows, or consider investing in an alarmed mat that goes off when someone gets out of bed.

• **Look for patterns and triggers.** A person may wander off in the morning thinking it’s time to go to work or school. Over-stimulation or worry about a friend, family member, or a pet may be a cause. Sylvia often worried about feeding her animals. When her daughter Elaine reassured her that they were being taken care of and spent a few minutes reminiscing about her mother’s life, Sylvia calmed down, and seemed to feel less of an urge to wander.

• **Carefully plan outings.** If your family member wanders, don’t go to places with large groups. Take an extra helper along if possible. Choose places with family-friendly/uni-sex bathrooms.

• **Plan for the worst.** Have extra copies of photographs of your family member to give to first responders. Keep track of the clothes he or she is wearing. Consider registering your loved one with the National Alzheimer’s Association wandering prevention program called **Medic Alert/Safe Return.**

“I’ve always been an active guy, on the go. If I had Alzheimer’s I’d probably be the first person wanting to take off,” says Hogan. “It’s a basic human desire to seek and explore.” Troxel agrees. “Ultimately, the best way to prevent wandering is to fight boredom and keep the person with dementia active and engaged. When you keep him or her busy, home becomes much more inviting!”
Where can I learn more about dementia care?

In addition to this guide, which covers the most common questions about Alzheimer’s and other dementias, Home Instead Senior Care has developed the “Helping Families Cope” guide to provide additional information about caring for someone with Alzheimer’s and the services available to help.

Helping Families Cope

A Guide for Those Caring for a Loved One with Alzheimer’s Disease or Other Dementias features the Home Instead Senior Care network’s approach to a personalized care experience for your loved one. The guide was designed for family caregivers like you to learn more about:

- Techniques for capturing life’s journey
- Keeping your loved one engaged
- Managing challenging behaviors
- Tips for taking care of yourself, the caregiver
- Finding additional resources

Wherever you are in the caregiving journey, you’ll find practical advice in this guide to ensure your loved one with Alzheimer’s or other dementias receives excellent care.

Download your copy of the Helping Families Cope (PDF) guide today.
Each Home Instead Senior Care franchise office is independently owned and operated.