



alzheimer's  association®

FAMILY CARE GUIDE

No one should face Alzheimer's alone. In this guide, you will find helpful information and resources for those living with or caring for someone with Alzheimer's or other dementias.

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CHAPTER 1

WHAT IS DEMENTIA?

Dementia is an overall term for diseases and conditions characterized by a decline in memory, language, problem-solving and other thinking skills that affect a person's ability to perform everyday activities. Memory loss is an example. Alzheimer's is the most common cause of dementia.

ABOUT DEMENTIA

Dementia is not a single disease; it's an overall term — like heart disease — that covers a wide range of specific medical conditions, including Alzheimer's disease. Disorders grouped under the general term "dementia" are caused by abnormal brain changes. These changes trigger a decline in thinking skills, also known as cognitive abilities, severe enough to impair daily life and independent function. They also affect behavior, feelings and relationships.

Alzheimer's disease accounts for 60 to 80 percent of cases. Vascular dementia, which occurs because of microscopic bleeding and blood vessel blockage in the brain, is the second most common cause of dementia. But there are many other conditions that can cause symptoms of dementia, including some that are reversible, such as thyroid problems and vitamin deficiencies.

Dementia is often incorrectly referred to as "senility" or "senile dementia," which reflects the formerly widespread but incorrect belief that serious mental decline is a normal part of aging.

ABOUT ALZHEIMER'S DISEASE

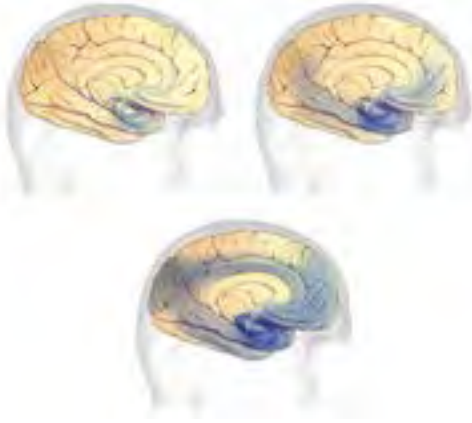
Alzheimer's is a degenerative brain disease that is caused by complex brain changes following cell damage. It leads to dementia symptoms that gradually worsen over time. The most common early symptom of Alzheimer's is trouble remembering new information because the disease typically impacts the part of the brain associated with learning first.

As Alzheimer's advances, symptoms get more severe and include disorientation, confusion and behavior changes. Eventually, speaking, swallowing and walking become difficult. There is no way to prevent, cure or even slow Alzheimer's disease.

Though the greatest known risk factor for Alzheimer's is increasing age, the disease is not a normal part of aging. And though most people with Alzheimer's are 65 and older, approximately 200,000 Americans under 65 have younger-onset Alzheimer's disease.

STAGES OF ALZHEIMER'S DISEASE

Alzheimer's disease typically progresses slowly in three general stages — mild (early stage), moderate (middle stage), and severe (late stage). Since Alzheimer's affects people in different ways, the timing and severity of dementia symptoms varies as each person progresses through the stages of Alzheimer's differently.



OVERVIEW OF DISEASE PROGRESSION

The symptoms of Alzheimer's disease worsen over time, although the rate at which the disease progresses varies. On average, a person with Alzheimer's lives four to eight years after diagnosis, but can live as long as 20 years, depending on other factors.

Changes in the brain related to Alzheimer's begin years before any signs of the disease. This time period, which can last for years, is referred to as preclinical Alzheimer's disease.

MILD ALZHEIMER'S DISEASE (EARLY STAGE)

In the early stage of Alzheimer's, a person may function independently. He or she may still drive, work and be part of social activities. Despite this, the person may feel as if he or she is having memory lapses, such as forgetting familiar words or the location of everyday objects.

Friends, family or others close to the individual begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration. Common difficulties include:

- Problems coming up with the right word or name
- Trouble remembering names when introduced to new people
- Challenges performing tasks in social or work settings.
- Forgetting material that one has just read
- Losing or misplacing a valuable object
- Increasing trouble with planning or organizing

MODERATE ALZHEIMER'S DISEASE (MIDDLE STAGE)

Moderate Alzheimer's is typically the longest stage and can last for many years. As the disease progresses, the person with Alzheimer's will require a greater level of care.

During the moderate stage of Alzheimer's, the dementia symptoms are more pronounced. A person may have greater difficulty performing tasks, such as paying bills, but they may still remember significant details about their life.

You may notice the person with Alzheimer's confusing words, getting frustrated or angry, or acting in unexpected ways, such as refusing to bathe. Damage to nerve cells in the brain can make it difficult to express thoughts and perform routine tasks.

At this point, symptoms will be noticeable to others and may include:

- Forgetfulness of events or about one's own personal history
- Feeling moody or withdrawn, especially in socially or mentally challenging situations
- Being unable to recall their own address or telephone number or the high school or college from which they graduated
- Confusion about where they are or what day it is
- The need for help choosing proper clothing for the season or the occasion
- Trouble controlling bladder and bowels in some individuals
- Changes in sleep patterns, such as sleeping during the day and becoming restless at night
- An increased risk of wandering and becoming lost
- Personality and behavioral changes, including suspiciousness and delusions or compulsive, repetitive behavior like hand-wringing or tissue shredding

SEVERE ALZHEIMER'S DISEASE (LATE STAGE)

In the final stage of this disease, dementia symptoms are severe. Individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement. They may still say words or phrases, but communicating pain becomes difficult. As memory and cognitive skills continue to worsen, significant personality changes may take place and individuals need extensive help with daily activities.

- Need round-the-clock assistance with daily activities and personal care
- Lose awareness of recent experiences as well as of their surroundings
- Experience changes in physical abilities, including the ability to walk, sit and, eventually, swallow
- Have increasing difficulty communicating
- Become vulnerable to infections, especially pneumonia

CAUSES AND RISK FACTORS

Researchers believe there is not a single cause of Alzheimer's disease. The disease likely develops from multiple factors, such as genetics, lifestyle and environment. Scientists have identified factors that increase the risk of Alzheimer's. While some risk factors — age, family history and heredity — can't be changed, emerging evidence suggests there may be other factors we can influence.

AGE

The greatest known risk factor for Alzheimer's is increasing age, but Alzheimer's is not a normal part of aging. While age increases risk, it is not a direct cause of Alzheimer's.

Most individuals with the disease are 65 and older. After age 65, the risk of Alzheimer's doubles every five years. After age 85, the risk reaches nearly one-third.

FAMILY HISTORY

Another strong risk factor is family history. Those who have a parent, brother or sister with Alzheimer's are more likely to develop the disease. The risk increases if more than one family member has the illness. When diseases tend to run in families, either heredity (genetics), environmental factors, or both, may play a role.

GENETICS (HEREDITY)

Scientists know genes are involved in Alzheimer's. Two categories of genes influence whether a person develops a disease: risk genes and deterministic genes. Alzheimer's genes have been found in both categories. It is estimated that less than 1 percent of Alzheimer's cases are caused by deterministic genes (genes that cause a disease, rather than increase the risk of developing a disease).

OTHER RISK FACTORS YOU MAY BE ABLE TO INFLUENCE

While age, family history and heredity are all risk factors we can't change, research is beginning to reveal clues about other risk factors we may be able to influence through general lifestyle and wellness choices and effective management of other health conditions.

Head injury: There is a link between head injury and future risk of dementia. Protect your brain by buckling your seat belt, wearing your helmet when participating in sports, and "fall-proofing" your home.

Heart-head connection: Some of the strongest evidence links brain health to heart health. This connection makes sense, because the brain is nourished by one of the body's richest networks of blood vessels, and the heart is responsible for pumping blood through these blood vessels to the brain.

The risk of developing Alzheimer's or vascular dementia appears to be increased by many conditions that damage the heart and blood vessels. These include heart disease, diabetes, stroke, high blood pressure and high cholesterol. Work with your doctor to monitor your heart health and treat any problems that arise.

Studies of donated brain tissue provide additional evidence for the heart-head connection. These studies suggest that plaques and tangles are more likely to cause Alzheimer's symptoms if strokes or damage to the brain's blood vessels are also present.

CAUSES

Dementia is caused by damage to brain cells. This damage interferes with the ability of brain cells to communicate with each other. When brain cells cannot communicate normally, thinking, behavior and feelings can be affected.

The brain has many distinct regions, each of which is responsible for different functions (for example, memory, judgment and movement). When cells in a particular region are damaged, that region cannot carry out its functions normally.

Different types of dementia are associated with particular types of brain cell damage in particular regions of the brain. For example, in Alzheimer's disease, high levels of certain proteins inside and outside brain cells make it hard for brain cells to stay healthy and to communicate with each other. The brain region called the hippocampus is the center of learning and memory in the brain, and the brain cells in this region

are often the first to be damaged. That's why memory loss is often one of the earliest symptoms of Alzheimer's.

While most changes in the brain that cause dementia are permanent and worsen over time, thinking and memory problems caused by the following conditions may improve when the condition is treated or addressed:

- Depression
- Medication side effects
- Excess use of alcohol
- Thyroid problems
- Vitamin deficiencies

DIAGNOSIS OF DEMENTIA

There is no one test to determine if someone has dementia. Doctors diagnose Alzheimer's and other types of dementia based on a careful medical history, a physical examination, laboratory tests, and the characteristic changes in thinking, day-to-day function and behavior associated with each type. Doctors can determine that a person has dementia with a high level of certainty. But it's harder to determine the exact type of dementia because the symptoms and brain changes of different dementias can overlap. In some cases, a doctor may diagnose "dementia" and not specify a type. If this occurs it may be necessary to see a specialist such as a neurologist or geriatric psychiatrist.

DEMENTIA TREATMENT AND CARE

Treatment of dementia depends on its cause. In the case of most progressive dementias, including Alzheimer's disease, there is no cure and no treatment that slows or stops its progression. But there are drug treatments that may temporarily improve symptoms. The same medications used to treat Alzheimer's are among the drugs sometimes prescribed to help with symptoms of other types of dementias. Non-drug therapies can also alleviate some symptoms of dementia.

DEMENTIA RISK AND PREVENTION

Some risk factors for dementia, such as age and genetics, cannot be changed. But researchers continue to explore the impact of other risk factors on brain health and prevention of dementia.

Research reported at the 2019 Alzheimer's Association International Conference[®] suggests that adopting multiple healthy lifestyle choices, including healthy diet, not smoking, regular exercise and cognitive stimulation, may decrease the risk of cognitive decline and dementia.



CHAPTER 2

COMMUNICATION

Alzheimer's disease and other dementias gradually diminish a person's ability to communicate. Communication with a person with Alzheimer's requires patience, understanding and good listening skills. The strategies below can help both you and the person with dementia understand each other better.

CHANGES IN COMMUNICATION:

Changes in the ability to communicate can vary, and are based on the person and where he or she is in the disease process. Problems you can expect to see throughout the progression of the disease include:

- Difficulty finding the right words
- Using familiar words repeatedly
- Describing familiar objects rather than calling them by name
- Easily losing a train of thought
- Difficulty organizing words logically
- Reverting to speaking a native language
- Speaking less often
- Relying on gestures more than speaking

COMMUNICATION IN THE EARLY STAGE:

In the early stage of Alzheimer's disease, sometimes referred to as mild Alzheimer's in a medical context, an individual is still able to participate in meaningful conversation and engage in social activities.

However, he or she may repeat stories, feel overwhelmed by excessive stimulation or have difficulty finding the right word. Tips for successful communication:

- Don't make assumptions about a person's ability to communicate because of an Alzheimer's diagnosis. The disease affects each person differently.
- Don't exclude the person with the disease from conversations.
- Speak directly to the person rather than to his or her caregiver or companion.
- Take time to listen to the person express his or her thoughts, feelings and needs.
- Give the person time to respond. Don't interrupt unless help is requested.
- Ask what the person is still comfortable doing and what he or she may need help with.
- Discuss which method of communication is most comfortable. This could include face-to-face conversation, email or phone calls.
- It's OK to laugh. Sometimes humor lightens the mood and makes communication easier.
- Don't pull away; your honesty, friendship and support are important to the person.

COMMUNICATION IN THE MIDDLE STAGE

The middle stage of Alzheimer's, sometimes referred to as moderate Alzheimer's, is typically the longest and can last for many years. As the disease progresses, the person will have greater difficulty communicating and will require more direct care. Tips for successful communication:

- Engage the person in one-on-one conversation in a quiet space that has minimal distractions.
- Speak slowly and clearly.
- Maintain eye contact. It shows you care about what he or she is saying.
- Give the person plenty of time to respond so he or she can think about what to say.
- Be patient and offer reassurance. It may encourage the person to explain his or her thoughts.
- Ask one question at a time.
- Ask yes or no questions. For example, "Would you like some coffee?" rather than "What would you like to drink?"
- Avoid criticizing or correcting. Instead, listen and try to find the meaning in what the person says. Repeat what was said to clarify.
- Avoid arguing. If the person says something you don't agree with, let it be.
- Offer clear, step-by-step instructions for tasks. Lengthy requests may be overwhelming.
- Give visual cues. Demonstrate a task to encourage participation.
- Written notes can be helpful when spoken words seem confusing.

COMMUNICATION IN THE LATE STAGE

The late stage of Alzheimer's disease, sometimes referred to as severe Alzheimer's, may last from several weeks to several years. As the disease advances, the person with Alzheimer's may rely on nonverbal communication, such as facial expressions or vocal sounds. Around-the-clock care is usually required in this stage. Tips for successful communication:

- Approach the person from the front and identify yourself.
- Encourage nonverbal communication. If you don't understand what the person is trying to say, ask him or her to point or gesture.
- Use touch, sights, sounds, smells and tastes as a form of communication with the person.
- Consider the feelings behind words or sounds. Sometimes the emotions being expressed are more important than what's being said.
- Treat the person with dignity and respect. Avoid talking down to the person or as if he or she isn't there.
- It's OK if you don't know what to say; your presence and friendship are most important.



CHAPTER 3

DAILY CARE

A person living with dementia will eventually need assistance with daily living. By using creativity and caregiving skills, you can adapt routines and activities as needs change. Use our resources to get ideas and connect with other caregivers.

ACTIVITIES

A person living with Alzheimer's or other dementia doesn't have to give up the activities that he or she loves. Many activities can be modified to the person's ability. In addition to enhancing quality of life, activities can reduce behaviors like wandering or agitation.

CHOOSING ACTIVITIES

In the early stages of dementia, the person may withdraw from activities he or she previously enjoyed. It is important to help the person remain engaged. Having an open discussion around any concerns and making slight adjustments can make a difference. For example, a large social gathering may be overwhelming, but the person may be able to interact more successfully in smaller groups.

As Alzheimer's progresses, you may need to make other adjustments to the activity. Use the following tips:

- Keep the person's skills and abilities in mind. Stick with activities the person has always enjoyed and adjust, as needed, to match the person's current abilities.
- Pay special attention to what the person enjoys. Take note when the person seems happy, anxious, distracted or irritable. Some people enjoy watching sports, while others may be frightened by the pace or noise.
- Consider if the person begins activities without direction. Does he or she set the table before dinner or sweep the kitchen floor mid-morning? If so, you may wish to plan these activities as part of the daily routine.
- Be aware of physical problems. Does he or she get tired quickly or have difficulty seeing, hearing or performing simple movements?
- Focus on enjoyment, not achievement. Find activities that build on remaining skills and talents.
- Encourage involvement in daily life. Activities that help the individual feel like a valued part of the household — like setting the table — can provide a sense of success and accomplishment.
- Relate activity to work life. A former office worker might enjoy activities that involve organizing, like putting coins in a holder, helping to assemble a mailing or making a to-do list.
- Look for favorites. The person who always enjoyed drinking coffee and reading the newspaper may still find these activities enjoyable, even if he or she is not able to completely understand what the newspaper says.

- Consider time of day. Caregivers may find they have more success with certain activities at specific times of day, such as bathing and dressing in the morning.
- Adjust activities to disease stages. As the disease progresses, you may want to introduce more repetitive tasks. Be prepared for the person to eventually take a less active role in activities.



YOUR APPROACH

If you notice a person's attention span waning or frustration level increasing, it's likely time to end or modify the activity. Help get the activity started. Most people with dementia still have the energy and desire to do things but may lack the ability to organize, plan, initiate and successfully complete the task.

- Offer support and supervision. You may need to show the person how to perform the activity and provide simple, easy-to-follow steps.
- Concentrate on the process, not the result. Does it matter if the towels are folded properly? Not really. What matters is that you were able to spend time together, and that the person feels as if he or she has done something useful.
- Be flexible. When the person insists that he or she doesn't want to do something, it may be because he or she can't do it or fears doing it. Don't force it.
- Break activities into simple, easy-to-follow steps. Focus on one task at a time. Too many directions at once can be overwhelming.
- Assist with difficult parts of the task. If you're cooking, and the person can't measure the ingredients, finish the measuring and say, "Would you please stir this for me?"
- Let the individual know he or she is needed. Ask, "Could you please help me?" Be careful, however, not to place too many demands upon the person.
- Don't criticize or correct the person. If the person enjoys a harmless activity, even if it seems insignificant or meaningless to you, encourage the person to continue.
- Encourage self expression. Include activities that allow the person a chance for expression. These types of activities could include painting, drawing, music or conversation.
- Substitute an activity for a behavior. If a person with dementia rubs his or her hand on a table, provide a cloth and encourage the person to wipe the table. Or, if the person is moving his or her feet on the floor, play some music so the person can tap to the beat.
- Try again later. If something isn't working, it may just be the wrong time of day or the activity may be too complicated. Try again later, or adapt the activity.

FOOD AND EATING

Regular, nutritious meals may become a challenge for people with dementia. As a person's cognitive function declines, he or she may become overwhelmed with too many food choices, forget to eat or have difficulty with eating utensils.

NUTRITION TIPS

Proper nutrition is important to keep the body strong and healthy. For a person with Alzheimer's or dementia, poor nutrition may increase behavioral symptoms and cause weight loss. The basic nutrition tips below can help boost the person with dementia's health and your health as a caregiver, too.

- Provide a balanced diet with a variety of foods. Offer vegetables, fruits, whole grains, low-fat dairy products and lean protein foods.
- Limit foods with high saturated fat and cholesterol. Some fat is essential for health — but not all fats are equal.
- Cut down on refined sugars.
- Limit foods with high sodium and use less salt as it can affect blood pressure. Cut down by using spices or herbs to season food as an alternative.

As the disease progresses, loss of appetite and weight loss may become concerns. In such cases, the doctor may suggest supplements between meals to add calories.

Staying hydrated may be a problem as well. Encourage fluids by offering small cups of water or other liquids throughout the day or foods with high water content, such as fruit, soups, milkshakes and smoothies.

POSSIBLE CAUSES OF POOR APPETITE

- Not recognizing food.
- Poor fitting dentures. Eating may be painful, but the person may not be able to tell you this. Make sure dentures fit and visit the dentist regularly.
- Medications. New medications or a dosage change may affect appetite. If you notice a change, call the doctor.
- Not enough exercise. Lack of physical activity will decrease appetite.
- Decreased sense of smell and taste.



MAKE MEALTIMES EASIER

During the middle and late stages of Alzheimer's, distractions, too many choices, and changes in perception, taste and smell can make eating more difficult. The following tips can help:

- Limit distractions by serving meals in quiet surroundings.
- Keep the table setting simple and use only the utensils needed.
- Distinguish food from the plate. It can help to use white plates or bowls with a simple, solid colored but contrasting place mat.
- Check the food temperature. A person with dementia might not be able to tell if something is too hot to eat or drink.
- Serve only one or two foods at a time so as not to overwhelm.
- Be flexible to food preferences. Keep long-standing personal preferences in mind but be aware preferences might change.
- Eat together and don't rush. Research suggests that people eat better when they are in the company of others.
- Keep in mind the person may not remember when or if he or she ate.

ENCOURAGE INDEPENDENCE

During the middle and late stages of Alzheimer's, allow the person with dementia to be as independent as possible during meals. Be ready to help, when needed.

- Adapt serving dishes and utensils to make eating easier. You might serve food in a bowl instead of on a plate, or try using a plate with rims or protective edges. A spoon with a large handle may be easier to handle than a fork.
- Serve finger foods. Try bite-sized foods that are easy to pick up, such as chicken nuggets, fish sticks, steamed broccoli or a sandwich.
- Use a "watch me" technique to show the person how to eat.
- Don't worry about neatness and let the person feed themselves as much as possible.



BATHING

Bathing is often the most difficult personal care activity that caregivers face. Because it is such an intimate experience, people with Alzheimer's and other dementias may perceive it as unpleasant or intrusive.

BEHAVIORS DURING BATHING

People with dementia may become resistant to bathing. Such behavior often occurs because the person doesn't remember what bathing is for or doesn't have the patience to endure lack of modesty, being cold or other discomforts. Loss of independence and privacy can be very difficult for the person with dementia. The disease also may increase sensitivity to water temperature or pressure.



BEFORE YOU BEGIN

When bathing a person with dementia, allow the person to do as much as possible. Be ready to assist when needed, but try to offer only the level of help necessary. In the earlier stages, the person may only need a reminder to bathe. As the disease progresses, he or she will require more assistance.

Prepare the bathroom in advance by:

- Gathering bathing supplies. Have large towels, shampoo and soap ready before you tell the person that it's time to bathe.
- Making the room comfortable. Pad the shower seat and other cold or uncomfortable surfaces with towels. Keep the room warm.
- Monitoring water temperature. The person may not sense when the water is dangerously hot or may resist bathing if the water is too cool.

MAKING THE BATHROOM SAFE

It's important to make the bathroom as safe and comfortable as possible. Install grab bars, place non-skid mats on floors, use a tub bench or bath chair that can be adjusted to different heights, watch for puddles and lower the thermostat on your hot-water heater to prevent scalding injuries. Also, take care to never leave the person with dementia alone in the bathroom, use products made of non-breakable materials, and keep sharp objects (i.e. tweezers, scissors) out of reach.



ADAPTING THE BATHING PROCESS

- Set a regular time for bathing. If the person usually bathes in the morning, it may confuse him or her to bathe at night. Determine what time of day is best for the person with dementia. Then set a routine.
- Be gentle. The person's skin may be very sensitive. Avoid scrubbing. Check the spray on the shower head to make sure the water pressure isn't too intense.
- Coach the person through each step. For example: "Put your feet in the tub." "Sit down." "Here is the soap." "Wash your arm."
- Use other cues to remind the person what to do. Try using a "watch me" technique or lead by example.
- Use a tub bench or bath chair. Having the person sit while showering may be easier and safer.
- Be sure to cleanse hard-to-reach areas.
- Sponge bathe as an alternative. Don't worry about the frequency of bathing. Sponge baths with a washcloth can be effective between showers.

INCONTINENCE

Many people will experience incontinence (a loss of bladder or bowel control) in the later stages of Alzheimer's and other dementias. There are many causes, as well as ways to help manage incontinence. How you respond can help the person with dementia retain a sense of dignity.

CAUSES OF INCONTINENCE

Incontinence can be caused by many factors, including an inability to recognize the need to use the restroom, forgetting where the bathroom is located, medications, stress, certain physical conditions, clothing that is difficult to remove, and constipation.

If a person with Alzheimer's or other dementia has recently started to lose control of his or her bladder and bowels, the first and most important step is to determine possible causes. If incontinence is a new problem, consult with the doctor to rule out potential causes such as a urinary tract infection, weak pelvic muscles or medications.

Consider medical conditions, medication side effects and obstacles that may be causing or contributing to the problem:

Medical conditions that can cause incontinence:

- Urinary tract infection, constipation or prostate problem
- Diabetes, stroke or a muscular disorder such as Parkinson's disease
- Physical disabilities that prevent the person from reaching the bathroom in time

Medications and diuretics that can cause incontinence:

- Sleeping pills and anxiety-reducing drugs that may relax the bladder muscles
- Drinks such as cola, coffee and tea, which can act as diuretics; a diuretic increases urination

Environment and clothing obstacles that can contribute to incontinence:

- Not being able to find the bathroom
- Obstacles on the way to the bathroom, such as furniture or clutter
- Clothing that is difficult to remove

HOW TO RESPOND

Be supportive

- Reassure the person to reduce feelings of embarrassment. Find ways to preserve dignity. For example say, “Anyone can have an accident” instead of saying, “You wet yourself.”
- Be matter-of-fact; don't scold or make the person feel guilty.
- Respect the need for privacy as much as possible.
- Do not withhold fluids. This can cause dehydration, which can lead to a urinary tract infection, increased incontinence and agitated behavior. You may, however, want to limit fluids before bed.

Communicate

- Encourage the person to tell you when he or she needs to use the toilet.
- Watch for nonverbal cues, such as restlessness, making unusual sounds or faces, pacing, sudden silence or hiding in corners.
- Use adult words rather than baby talk to refer to using the toilet.
- Learn the person's trigger words or phrases for needing to use the toilet. The person may use words that have nothing to do with toileting.
- Some people do well when they are reminded to go to the bathroom on a regular schedule, perhaps every two hours.

Make it easy to find and use the toilet

- Clear the path to the bathroom by moving furniture.
- Keep the bathroom door open so the toilet is visible.
- Make the bathroom standout. For example, place colored rugs on the bathroom floor and lid covers or post a sign of a toilet on the door.
- Make the toilet safe and easy to use. Raise the toilet seat, install grab bars on both sides, and use nightlights.
- Consider a portable commode or urinal for the bedroom
- Remove plants, wastebaskets and other objects that could be mistaken for a toilet.
- Remove throw rugs that may cause a person to trip and fall.
- Choose clothing that is easy to remove and clean.
- Consider using incontinence products, such as waterproof mattress covers, incontinence pads on the person's bed, padded undergarments or adult briefs.

DRESSING AND GROOMING

Helping a person with dementia maintain his or her appearance can promote positive self-esteem. While these tasks may become challenging for a person with Alzheimer's in the later stages of the disease, the tips below can help simplify the process.

DRESSING

- Simplify choices. Keep the closets free of excess clothing and try offering just two choices.
- Organize the process. Lay out clothing in the order that each item should be put on. Hand the person one item at a time while giving simple, direct instructions.
- Pick comfortable and simple clothing. Choose tops that button in front, bottoms that have elastic and comfortable, non-slip shoes.
- Be flexible. If the individual wants to wear the same outfit repeatedly, buy duplicates or have similar options available.

GROOMING

- Continue grooming routines. If the person has always gone to the beauty shop or a barber, continue this activity.
- Perform tasks alongside the person.
- Use safer, simpler grooming tools. Cardboard nail files and electric shavers can be less threatening than clippers and razors.

SLEEP ISSUES

Discuss sleep disturbances with the doctor to help identify causes and possible solutions. Physical ailments, such as urinary tract infections or incontinence problems, restless leg syndrome or sleep apnea (an abnormal breathing pattern in which people briefly stop breathing many times a night) can cause or worsen sleep problems. For sleep issues due primarily to Alzheimer's disease, most experts encourage the use of non-drug measures, rather than medication. In some cases when non-drug approaches fail, medication may be prescribed for agitation during the late afternoon and evening hours. Work with the doctor to learn both the risks and benefits of medication before making a decision.

FACTORS THAT MAY CONTRIBUTE TO SUNDOWNING AND SLEEP DISTURBANCES INCLUDE:

- End-of-day exhaustion (both mental and physical)
- An upset in the "internal body clock," causing a biological mix-up between day and night
- Reduced lighting and increased shadows causing people with Alzheimer's to misinterpret what they see, and become confused and afraid
- Reactions to nonverbal cues of frustration from caregivers who are exhausted from their day
- Disorientation due to the inability to separate dreams from reality when sleeping
- Less need for sleep, which is common among older adults

COPING STRATEGIES FOR SLEEP ISSUES AND SUNDOWNING

- Keep the home well lit in the evening. Adequate lighting may reduce the agitation that occurs when surroundings are dark or unfamiliar.
- Make a comfortable and safe sleep environment. The person's sleeping area should be at a comfortable temperature. Provide nightlights and other ways to keep the person safe, such as appropriate door and window locks. Door sensors and motion detectors can be used to alert family members when a person is wandering.
- Maintain a schedule. As much as possible, encourage the person with dementia to adhere to a regular routine of meals, waking up and going to bed. This will allow for more restful sleep at night.
- Avoid stimulants. Reduce or avoid alcohol, caffeine and nicotine, which can all affect ability to sleep. Discourage watching television during periods of wakefulness at night, as it can be stimulating.
- Plan more active days. A person who rests most of the day is likely to be awake at night. Discourage afternoon napping and plan more challenging activities such as doctor appointments, trips and bathing in the morning or early afternoon. Encourage regular daily exercise.

IF THE PERSON IS AWAKE AND UPSET:

- Approach him or her in a calm manner.
- Find out if there is something he or she needs.
- Gently remind him or her of the time.
- Avoid arguing.
- Offer reassurance that everything is all right.
- Don't use physical restraint. If the person needs to pace, allow this to continue under your supervision.

PARTNERING WITH THE DOCTOR

Good health care requires a partnership between the patient, family and physician. Plan ahead to get the most out of medical appointments, and be open and honest when discussing care.

GETTING READY FOR YOUR VISIT

Plan ahead. Many people report forgetting to ask their doctor all of their questions. Whether you are the patient or the caregiver, avoid this problem by writing down questions and concerns beforehand. Bring the list to your appointment. If you get home and realize you still have questions, call the doctor to discuss them.

Give details. Make notes about changes in behaviors, routines or eating habits. Be as specific as you can. When does it happen? How often? Does something seem to trigger it?

Bring medications. People with Alzheimer's or dementia may be under the care of more than one doctor and may be taking medications for multiple health conditions. It is important that everyone on the health care team knows about all prescription and over-the-counter medications, including any vitamins or herbal supplements being taken. Bring medication containers or a complete list (including dosages) with you to each appointment.



CHAPTER 4

UNDERSTANDING BEHAVIORS

As Alzheimer's and other dementias progress, behaviors change—as does your role as caregiver. While changes in behavior can be challenging, we have resources to help you through each stage of the disease.

Alzheimer's and other dementias can cause people to act in different and unpredictable ways. Some individuals become anxious or aggressive. Others repeat certain questions or gestures. Many misinterpret what they hear.

These types of reactions can lead to misunderstanding, frustration and tension, particularly between the person living with dementia and his or her caregiver. It's important to understand that the person is not trying to be difficult and the behavior can be a form of communication.

The following three-step approach can help you identify and respond to common dementia-related behaviors and their causes.

1. Examine the behavior

- What was the behavior? Was it harmful?
- Did something trigger it?
- What happened immediately after?
- Could something be causing the person pain?
- Could this be related to medications or illness? Consult a physician to be sure.

2. Explore potential solutions

- Are the person's needs being met?
- Can adapting the surroundings comfort the person?
- How can you change your reaction or approach?

3. Try different responses

- Did your new response help?
- Do you need to explore other potential solutions? If so, what can you do differently?

Anyone experiencing behavioral symptoms should receive a thorough medical checkup, especially when symptoms appear suddenly. Treatment depends on a careful diagnosis, determining possible causes and the types of behavior the person is experiencing. With proper treatment and intervention, symptoms of behavior challenges can be greatly reduced.

ANXIETY AND AGITATION

A person with Alzheimer's may feel anxious or agitated. He or she may become restless, causing a need to move around or pace, or become upset in certain places or when focused on specific details.

POSSIBLE CAUSES OF AGITATION

Anxiety and agitation may be caused by a number of different medical conditions, medication interactions or by any circumstances that worsen the person's ability to think. Ultimately, the person with dementia is biologically experiencing a profound loss of their ability to negotiate new information and stimulus. It is a direct result of the disease.

Situations that may lead to agitation include:

- Moving to a new residence or nursing home
- Changes in environment, such as travel or hospitalization
- Changes in caregiver arrangements
- Misperceived threats
- Fear and fatigue

HOW TO RESPOND

Check for Pain

Pain can often trigger anxiety or agitation. Sources include being in an uncomfortable situation, injury, reaction to medication or a urinary tract infection.



Listen to the Frustration

Find out what may be causing the anxiety and try to understand.

Provide Reassurance

Speak in calming tones and phrases. Let the individual know you're there for support.

Involve the Person in Activities

Engage the person in art, music or other activities to promote relaxation.

Modify the Environment

Decrease noise and distractions or relocate the person.

Find Outlets for Energy

The person may be looking for something to do. Take a walk or go for a car ride.

AGGRESSION AND ANGER

Aggressive behaviors may be verbal or physical. They can occur suddenly, with no apparent reason, or result from a frustrating situation. While aggression can be hard to cope with, understanding that the person with Alzheimer's or dementia is not acting this way on purpose can help.

POSSIBLE CAUSES OF AGGRESSION AND ANGER

Aggression can be caused by many factors including physical discomfort, environmental factors and poor communication. If the person with Alzheimer's is aggressive, consider what might be contributing to the change in behavior.

HOW TO RESPOND

Rule Out Pain as the Cause of the Behavior

Pain can trigger aggressive behavior for a person living with dementia.

Try to Identify the Immediate Cause

Think about what happened right before and whether it may have triggered the behavior.

Focus on Feelings, Not Facts

Look for the feelings behind the words or actions.

Try Not to Get Upset

Be positive and reassuring. Speak slowly in a soft tone.

Limit Distractions

Examine the person's surroundings and adapt them to avoid other similar situations.

Try a Relaxing Activity

Use music, massage or exercise to help soothe the person.

Shift the Focus to Another Activity

If a situation or activity causes an aggressive response, try something different.

Speak Calmly

Using a calm tone, try to reassure the person.

Take a Break

If the person is in a safe environment and you are able, walk away and take a moment for yourself.

Ensure Safety

Make sure you and the person are safe. If he or she is unable to calm down, seek assistance from others. Always call 911 in emergency situations. If you do call 911, make sure to tell responders the person is living with dementia, which may cause them to act aggressively.

SUSPICIONS AND DELUSIONS

A person with Alzheimer's may become suspicious of those around them, even accusing others of theft, infidelity or other improper behavior. While accusations can be hurtful, remember that the disease is causing these behaviors and try not to take offense.

POSSIBLE CAUSES

Delusions (firmly held beliefs in things that are not real) may occur in the middle-to late-stage Alzheimer's. Confusion and memory loss can contribute to these untrue beliefs. Although not grounded in reality, the situation is very real to the person with dementia. Keep in mind that a person with dementia is trying to make sense of his or her own world with declining cognitive function.

HOW TO RESPOND

- Don't take offense
- Don't argue or try to convince
- Offer a simple answer
- Switch the focus to another activity
- Duplicate any lost items

REPETITION

A person with dementia may do or say something over and over--like repeating a word or question or activity--or undo something that was just finished. In most cases, he or she is probably looking for comfort, security and familiarity.

POSSIBLE CAUSES

In the case of repetition, the person may not remember that she or he has just asked a question or completed a task. Environmental influences also can cause symptoms or make them worse. People with dementia who ask questions repeatedly may be trying to express a specific concern, ask for help, or cope with frustration, anxiety or insecurity.

HOW TO RESPOND

- Look for a reason
- Focus on the emotion rather than reacting to the words or actions
- Turn the action into an activity
- Stay calm and patient
- Provide an answer
- Engage the person in activity
- Use memory aids like notes, photos and calendars

HALLUCINATIONS

Hallucinations are false perceptions of objects or events involving the senses. When a person with Alzheimer's or other dementia hallucinates, he or she may see, hear, smell, taste or feel something that isn't there. Some hallucinations may be frightening, while others may involve ordinary visions of people, situations or objects from the past.

POSSIBLE CAUSES

These false perceptions are caused by changes within the brain that result from Alzheimer's, usually in the later stages of the disease.

Alzheimer's and other dementias are not the only cause of hallucinations. Other causes include:

- Schizophrenia
- Physical problems, such as kidney or bladder infections, dehydration, intense pain, or alcohol or drug abuse
- Eyesight or hearing problems
- Medications

If a person with Alzheimer's begins hallucinating, it is important to see a doctor to rule out other possible causes and determine if medications are necessary. The first line of treatment for behavioral symptoms for Alzheimer's is non-drug approaches, but if these strategies fail, medication may be appropriate.

HOW TO RESPOND

Offer Reassurance

- Respond in a calm, supportive manner. You may want to respond with, "Don't worry. I'm here. I'll protect you. I'll take care of you."
- Gentle patting may turn the person's attention toward you and reduce the hallucination.
- Acknowledge the feelings behind the hallucination and try to find out what the hallucination means to the individual. You might want to say, "It sounds as if you're worried" or "I know this is frightening for you."

Use Distractions

- Suggest a walk or move to another room. Frightening hallucinations often subside in well-lit areas where other people are present.
- Try to turn the person's attention to music, conversation or activities you enjoy together.

Respond Honestly

- If the person asks you about a hallucination or delusion, be honest. For example, if he or she asks, "Do you see him?" you may want to answer with, "I know you see something, but I don't see it." This way, you're not denying what the person sees or hears, but you avoid an argument.

Modify the Environment

- Check for sounds that might be misinterpreted, such as noise from a television or an air conditioner.
- Look for lighting that casts shadows, reflections or distortions on the surfaces of floors, walls and furniture. Turn on lights to reduce shadows.
- Cover mirrors with a cloth or remove them if the person thinks that he or she is looking at a stranger.

DEPRESSION

Depression is very common among people with Alzheimer's, especially during the early and middle stages. Experts estimate that up to 40 percent of people with Alzheimer's disease suffer from significant depression. Treatment is available and can make a significant difference in quality of life.

SYMPTOMS OF DEPRESSION

Identifying depression in someone with Alzheimer's can be difficult, since dementia can cause some of the same symptoms. Examples of symptoms common to both depression and dementia include:

- Apathy
- Loss of interest in activities and hobbies
- Social withdrawal
- Isolation
- Trouble concentrating
- Impaired thinking

In addition, the cognitive impairment experienced by people with Alzheimer's often makes it difficult for them to articulate their sadness, hopelessness, guilt and other feelings associated with depression.

Depression in Alzheimer's doesn't always look like depression in people without Alzheimer's. Here are some ways that depression in a person with Alzheimer's may be different:

- May be less severe
- May not last as long and symptoms may come and go
- The person with Alzheimer's may be less likely to talk about or attempt suicide

As a caregiver, if you see signs of depression, discuss them with the primary doctor of the person with dementia. Proper diagnosis and treatment can improve sense of well-being and function.

DIAGNOSING DEPRESSION WITH ALZHEIMER'S DISEASE

There is no single test or questionnaire to detect depression. Diagnosis requires a thorough evaluation by a medical professional, especially since side effects of medications and some medical conditions can produce similar symptoms.

An evaluation for depression will include:

- A review of the person's medical history
- A physical and mental examination
- Interviews with family members who know the person well

Because of the complexities involved in diagnosing depression in someone with Alzheimer's, it may be helpful to consult a geriatric psychiatrist who specializes in recognizing and treating depression in older adults. Ask your doctor for a referral.



TREATING DEPRESSION

The most common treatment for depression in Alzheimer's involves a combination of medicine, counseling, and gradual reconnection to activities and people that bring happiness.

Non-drug approaches

- Support groups can be very helpful, particularly an early-stage group for people with Alzheimer's who are aware of their diagnosis
- Make a list of activities, people or places that the person enjoys and schedule these things more frequently
- Help the person exercise regularly, particularly in the morning
- Acknowledge the person's frustration or sadness
- Celebrate small successes and occasions
- Find ways that the person can contribute to family life and be sure to recognize his or her contributions
- Reassure the person that he or she will not be abandoned

Medication to treat depression in Alzheimer's

There are several types of antidepressants available to treat depression. Antidepressants called Selective Serotonin Reuptake Inhibitors (SSRIs) are often used for people with Alzheimer's and depression because they have a lower risk than some other antidepressants of causing interactions with other medications.

As with any medication, make sure to ask about risks and benefits, as well as what type of monitoring and follow-up will be needed.

CHAPTER 5

SAFETY

Safety is important for everyone, but the need for a comprehensive safety plan becomes vital as dementia progresses. Taking measures to improve safety can prevent injuries and help the person with Alzheimer's feel more relaxed, less overwhelmed and maintain his or her independence longer.

WANDERING

Six in 10 people with dementia will wander. A person with Alzheimer's may not remember his or her name or address, and can become disoriented, even in familiar places. Wandering among people with dementia is dangerous, but there are strategies and services to help prevent it.

WHO IS AT RISK OF WANDERING?

Anyone who has memory problems and is able to walk is at risk for wandering. Even in the early stages of dementia, a person can become disoriented or confused for a period of time. It's important to plan ahead for this type of situation. Be on the lookout for the following warning signs:

- Returns from a regular walk or drive later than usual
- Forgets how to get to familiar places.
- Talks about fulfilling former obligations, such as going to work
- Tries or wants to "go home," even when at home
- Is restless, paces or makes repetitive movements
- Has difficulty locating familiar places like the bathroom, bedroom or dining room
- Asks the whereabouts of past friends and family
- Acts as if doing a hobby or chore, but nothing gets done (e.g., moves around pots and dirt without actually planting anything)
- Acts nervous or anxious in crowded areas, such as shopping malls or restaurants.



TIPS TO PREVENT WANDERING

Wandering can happen, even if you are the most diligent of caregivers. Use the following strategies to help lower the chances:

- Identify the most likely times of day that wandering may occur. Plan activities at that time. Activities and exercise can reduce anxiety, agitation and restlessness.
- Reassure the person if he or she feels lost, abandoned or disoriented. If the person with dementia wants to leave to "go home" or "go to work," use communication focused on exploration and validation. Refrain from correcting the person. For example, "We are staying here tonight. We are safe and I'll be with you. We can go home in the morning after a good night's rest."
- Ensure all basic needs are met. Has the person gone to the bathroom? Is he or she thirsty or hungry?
- Avoid busy places that are confusing and can cause disorientation. This could be a shopping malls, grocery stores or other busy venues.
- Place locks out of the line of sight. Install either high or low on exterior doors, and consider placing slide bolts at the top or bottom.
- Use devices that signal when a door or window is opened. This can be as simple as a bell placed above a door or as sophisticated as an electronic home alarm.
- Provide supervision. Do not leave someone with dementia unsupervised in new or changed surroundings. Never lock a person in at home or leave him or her in a car alone.
- Keep car keys out of sight. If the person is no longer driving, remove access to car keys — a person with dementia may not just wander by foot. The person may forget that he or she can no longer drive. If the person is still able to drive, consider using a GPS device to help if they get lost.



MAKE A PLAN

The stress experienced by families and caregivers when a person with dementia wanders and becomes lost is significant. Have a plan in place beforehand, so you know what to do in case of an emergency:

- Keep a list of people to call on for help. Have telephone numbers easily accessible.
- Ask neighbors, friends and family to call if they see the person alone.
- Keep a recent, close-up photo and updated medical information on hand to give to police.
- Keep a list of places where the person may wander. This could include past jobs, former homes, places of worship or a restaurant.
- If the person does wander, search the immediate area for no more than 15 minutes. If the person is not found within 15 minutes, call 911 to file a missing person's report. Inform the authorities that the person has dementia.
- Consider enrolling the person living with dementia in a wandering response service.

24/7 WANDERING SUPPORT FOR A SAFE RETURN

Our nationwide emergency response service facilitates the safe return of individuals living with Alzheimer's disease or another dementia who wander or have a medical emergency. The Alzheimer's Association, in collaboration with MedicAlert® Foundation, provides membership plans with 24/7 Wandering Support.

To learn more about and purchase a MedicAlert membership plan and ID products:

- Online: Go to medicalert.org/alz and use the promo code ALZ.
- Phone: Call MedicAlert's Member Services line 800.ID.ALERT (800.432.5378) and use the promo code ALZ.

MEDICATION SAFETY

Individuals living with Alzheimer's may take medications to help ease the symptoms of the disease and to address depression, sleeplessness, anxiety or challenging behavior changes. Additional measures may be needed to ensure individuals living with dementia take medications as directed. A plan to safely manage prescription and over-the-counter medications is critical to avoid medication-related problems.

WORKING WITH THE DOCTOR AND PHARMACIST

Coordinate with all care providers. A person with Alzheimer's may be under the care of more than one doctor. Make sure all health care team members know about any prescription and over-the-counter medications, including herbal or vitamin supplements. Each time you go to an appointment, take a list of current medications and dosages.

- Ask your doctor or pharmacist to check for possible drug interactions. Also, remind the health care team of any allergies to medications or side effects that have occurred in the past.
- Get details. Find out as much as possible about every medication, including name, purpose, dosage, frequency and possible side effects. If troubling side effects occur, report them to the doctor.
- Take as directed. Do not ever change dosages without first consulting the doctor who prescribed the medication.
- Maintain medication records. Keep a written record of all current medications, including the name, dosage and starting date.

GIVING MEDICATION TO SOMEONE WITH ALZHEIMER'S

In the early stages of Alzheimer's, the person with dementia may need help remembering to take medications. As a caregiver, you may find it helpful to:

- Use a pill box organizer. Using a pill box or keeping a daily list or calendar can help ensure medication is taken as prescribed.
- Develop a routine for giving the medication such as taking medications with meals or before bed.

As the disease progresses, you'll need to provide a greater level of care. In addition to using a pill box organizer and keeping a daily routine, try these tips:

- Use simple language and clear instructions. For example, say "Here's the pill for your high blood pressure. Put it in your mouth and drink some water."
- If the person refuses to take the medication, stop and try again later.
- Make changes for safety. Be sure to place medications in a locked drawer or cabinet to avoid accidental overdose, and throw out medications that are no longer being used or that have expired.
- Have emergency numbers easily accessible. Keep the number of your local poison control center or emergency room handy.

HOME SAFETY

People with Alzheimer's can live in their homes, as long as safety measures are in place. As Alzheimer's progresses, a person's abilities change. With creativity and flexibility, you can create a home that is both safe and supportive of the person's needs for social interaction and meaningful activity.

HOME SAFETY TIPS

Evaluate your environment. A person with dementia may be at risk in certain areas of the home or outdoors. Pay special attention to garages, work rooms, basements and outside areas where there are more likely to be tools, chemicals, cleaning supplies and other items that may require supervision.

Avoid safety hazards in the kitchen. Install a hidden gas valve or circuit breaker on the stove so a person with dementia cannot turn it on. Consider removing the knobs. Use appliances that have an auto shut-off feature. Keep them away from water sources such as sinks.

Make sure safety devices are in working order. Have working fire extinguishers, smoke detectors and carbon monoxide detectors.

Install locks out of sight. Place deadbolts either high or low on exterior doors to make it difficult for the person to wander out of the house. Keep an extra set of keys hidden near the door for easy access. Remove locks in bathrooms or bedrooms so the person cannot get locked inside.

Keep walkways well-lit. Add extra lights to entries, doorways, stairways, areas between rooms, and bathrooms.

Use night lights in hallways, bedrooms and bathrooms to prevent accidents and reduce disorientation.

Remove and disable guns or other weapons. The presence of a weapon in the home of a person with dementia may lead to unexpected danger.

Remove tripping hazards. Keep floors and other surfaces clutter-free. Remove objects such as magazine racks, coffee tables and floor lamps.

Watch the temperature of water and food. It may be difficult for the person with dementia to tell the difference between hot and cold. Consider installing an automatic thermometer for water temperature.

Avoid injury in the bathroom. Install walk-in showers. Add grab bars to the shower or tub and at the edge of the vanity to allow for independent, safe movement. Add textured stickers to slippery surfaces. Apply adhesives to keep throw rugs and carpeting in place, or remove rugs completely.

Assess safety hazards in the garage and/or basement. Secure hand and power tools including equipment such as lawn mowers and weed trimmers. Keep poisonous chemicals such as gasoline, spray paint and paint thinner out of reach. Install a garage door safety sensor.

Support the person's needs. Try not to create a home that feels too restrictive. The home should encourage independence and social interaction. Clear areas for activities.

DEMENTIA AND DRIVING

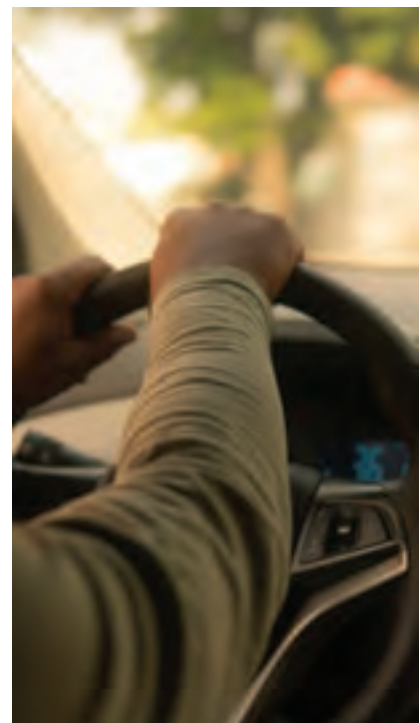
Driving requires the ability to react quickly to a variety of circumstances. Because of this, a person living with Alzheimer's will, at some point, be unable to drive. Planning ahead can help ease the transition.

HAVING THE CONVERSATION

Plan to discuss how retirement from driving will be handled before it becomes an issue. Be sympathetic as you address the topic because retiring from driving and the perceived loss of independence is difficult for many. It is important to acknowledge a person's feelings and preserve his or her independence, while ensuring the person's safety and the safety of others.

Starting the conversation:

- Initiate a dialogue to express your concerns. Stress the positive and offer alternatives.
- Address resistance while reaffirming your unconditional love and support.
- Appeal to the person's sense of responsibility.
- Ask your physician to advise the person not to drive. Involving your physician in a family conference on driving may be more effective than trying to persuade the person not to drive by yourself. Ask the physician to write a letter or prescription stating that the person with Alzheimer's must not drive. You can then use the document to remind your family member what's been decided.
- Consider an evaluation by an objective third party.
- Understand that this may be the first of many conversations about driving.



When the conversation does not go well:

Some people give up driving easily, but for others this transition can be very difficult. Be prepared for the person to become angry with you, due to the memory and insight issues that are part of Alzheimer's.

- Be patient and firm. Demonstrate understanding and empathy.
- Acknowledge the pain of this change and appeal to the person's desire to act responsibly.
- Ask a respected family authority figure or your attorney to reinforce the message about not driving.
- As a last resort, take away the car keys, disable the car or consider selling the car. When you do any of these things, be sure to provide safe, reliable alternative transportation.

Transportation Options:

Driving is not the only transportation option available. There are many options people can explore that will allow them to continue to travel independently and remain in control of their mobility.

- Transition driving responsibilities to others. Arrange for family members and friends to provide transportation.
- Arrange a taxi service.
- Use special transportation services for older adults.
- Reduce the need to drive by having prescription medicines, groceries or meals delivered.

SIGNS OF UNSAFE DRIVING

Determining when someone can no longer safely drive requires careful observation by family and caregivers. The following list provides warning signs that it's time to stop driving:

- Forgetting how to locate familiar places
- Failing to observe traffic signs
- Making slow or poor decisions in traffic
- Driving at an inappropriate speed
- Becoming angry or confused while driving
- Hitting curbs
- Using poor lane control
- Making errors at intersections
- Confusing the brake and gas pedals
- Returning from a routine drive later than usual
- Forgetting the destination you are driving to during the trip

CHAPTER 6

PLANNING AHEAD

LEGAL CONSIDERATIONS

While it's important for everyone to plan for the future, legal plans are especially vital for a person diagnosed with dementia. The sooner these plans are put in place, the more likely it is that the person living with dementia will be able to participate in the process.

WHY PLAN AHEAD?

Making legal plans in advance is important for several reasons: Early planning allows the person with dementia to be involved and express his or her wishes for future care and decisions. This eliminates guesswork for families, and allows for the person with dementia to designate decision makers on his or her behalf. Early planning also allows time to work through the complex legal and financial issues that are involved in long-term care.

Legal planning should include:

- Preparing for long-term care and health care needs.
- Making arrangements for finances and property.
- Naming another person to make decisions on behalf of the person with dementia.

MEETING WITH A LAWYER

You can complete certain legal documents without a lawyer, but getting legal advice and services from an attorney who specializes in elder law can be especially helpful.

If you already have a lawyer, he or she may be able to refer you to an attorney that specializes in elder law. Otherwise, there are several resources available to help you locate elder law services in your community.

If you meet with a lawyer, be sure to discuss these key issues and any other concerns you may have:

- Options for health care and long-term care decision-making for the person living with dementia.
- Options for managing the individual's personal care and property.
- Possible coverage of long-term care services, including what is provided by Medicare, Medicaid, veterans benefits and other long-term care insurance.

Gather all documents relating to the assets of the person with dementia ahead of time so you can bring them to your appointment.

PLANNING FOR CARE COSTS

To plan for financial needs during the course of Alzheimer's disease, you'll need to consider all the costs you might face now and in the future. Keep in mind that Alzheimer's is a progressive disease and the person's needs will change over time. While medical or other forms of insurance may cover some of these costs, they may not cover all.

COMMON CARE COSTS INCLUDE

- Ongoing medical treatment for Alzheimer's-related symptoms, diagnosis and follow-up visits
- Treatment or medical equipment for other medical conditions
- Safety-related expenses, such as home safety modifications or safety services for a person who wanders
- Prescription drugs
- Personal care supplies
- Adult day care services
- In-home care services
- Full-time residential care services

DOCUMENTS YOU'LL NEED

Gather and organize financial documents in one place. Then, carefully review all the documents, even if you're already familiar with them.

Financial documents include:

- Bank and brokerage account information
- Deeds, mortgage papers or ownership statements
- Insurance policies
- Medical and durable powers of attorney
- Monthly or outstanding bills
- Pension and other retirement benefit summaries (including VA benefits, if applicable)
- Rental income paperwork
- Social Security payment information
- Stock and bond certificates
- Wills

At this point, it may also be helpful to identify which necessary documents are not in place. Professional financial and legal advisors can assist you with this task. You'll also need to learn about the legal documents needed to plan for long-term care.

DETERMINE NEEDS AND GOALS

Bring family together to talk about putting financial and care plans in place. Discussing financial needs and goals early on enables the person with dementia to still understand the issues and to talk about his or her wishes. If others are available to help, encourage the sharing of caregiving duties. And discuss how finances might be pooled to provide necessary care.

In addition to planning for the cost of care, there are many ongoing financial duties to discuss, including:

- Paying bills
- Arranging for benefit claims
- Making investment decisions
- Preparing tax returns

CONSIDER YOUR RESOURCES

Consider all the private and government financial resources that are available to you when planning for care costs.

These may include:

- Insurance, including government insurance programs
 - > Medicare or a supplemental insurance policy
 - > Disability insurance from an employer-paid plan or personal policy
 - > Group employee plan or retiree medical coverage
 - > Life insurance and long-term care insurance, which is usually not available for purchase after symptoms of Alzheimer's appear
- Government help
 - > Social Security Disability Income (SSDI) for workers under age 65
 - > Supplemental Security Income (SSI)
 - > Medicaid
 - > Veterans' benefits
 - > Tax deductions and credits, such as the Household and Dependent Care Credit
- Community support, including low- or no-cost support services, respite care, support groups, transportation and meal delivery
- Retirement benefits
- Personal savings and assets



GET PROFESSIONAL ASSISTANCE

Financial advisors, such as financial planners and estate planning attorneys, are valuable sources of information and assistance. They can help you:

- Identify potential financial resources
- Identify tax deductions
- Analyze your investment portfolio with long-term care needs in mind

Make sure to ask the financial advisor if they are familiar with elder care or long-term care planning.

CHAPTER 7

CAREGIVER HEALTH

As a caregiver, you may find yourself with so many responsibilities that you neglect taking good care of yourself. But the best thing you can do for the person you are caring for is stay physically and emotionally strong. Support groups are a great opportunity for caregivers to receive peer support, dementia education, and problem-solving assistance. Support groups can be found by calling the 24/7 Helpline at 800.272.3900.

SEE THE DOCTOR

Be sure to visit your physician regularly (at least annually), and listen to what your body is telling you. Any exhaustion, stress, sleeplessness, or changes in appetite or behavior should be taken seriously. Ignoring these symptoms can cause your physical and mental health to decline.

If you are caring for someone in the late-stages of Alzheimer's, talk to your health care provider about the seasonal flu shot. Being vaccinated protects both you and the person you are caring for.

If you experience any of these signs of stress on a regular basis, make time to talk to your doctor.

GET MOVING

No doubt you know that exercise is an important part of staying healthy — it can help relieve stress, prevent disease and make you feel good. But finding the time to exercise is another story.

Use these tips:

- Take friends and family members up on their offers to help.
- You can get in a good workout in a short amount of time — even a 30 minute break. Help coordinate a schedule where you have breaks to exercise and take care of your health.
- Start small.
- While it is recommended that you get 30 minutes of physical activity at least five days a week, even 10 minutes a day can help. Fit in what you can, and work toward a goal.
- Exercise at home.
- When the person with dementia naps, pull out a yoga mat and stretch, set up a stationary bike, or try exercise tapes.
- Find something you love.
- If you enjoy the activity, it will be easier to make it a habit.

There also are many ways you can be active with the person with dementia. Here are a few ideas:

- Take a walk together outside to enjoy the fresh air
- Go to the mall and take a stroll indoors
- Do seated exercises at home
- Dance together to favorite music
- Garden or do other routine activities that you both enjoy

EAT WELL

Heart-healthy eating patterns, such as the Mediterranean diet, are good for overall health and may help protect the brain. A Mediterranean diet includes relatively little red meat and emphasizes whole grains, fruits, vegetables, fish, nuts, olive oil and other healthy fats. Try new recipes and involve the person with dementia.

RESPIRE CARE

Everyone needs a break. Respite care provides caregivers a temporary rest from caregiving, while the person with Alzheimer's continues to receive care in a safe environment. Using respite services can support and strengthen your ability to be a caregiver. Respite care can be provided at home — by a friend, other family member, volunteer or paid service — or in a care setting, such as adult day care or residential facility. The next chapter provides information on care options that can provide respite care.

FIVE TIPS TO HELP YOU COPE

- **Manage your level of stress.** Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, change in appetite). Note your symptoms and discuss with a doctor, as needed. Try to find relaxation techniques that work for you.
- **Be realistic.** The care you give does make a difference, but many behaviors can't be controlled. Grieve the losses, focus on positive times as they arise, and enjoy good memories.
- **Know you're doing your best.** Remember that the care you provide makes a difference and that you are doing the best you can. You may feel guilty because you can't do more, but individual care needs change as Alzheimer's progresses. You can't promise how care will be delivered, but you can make sure that the person with the disease is well cared for and safe.
- **Take a break.** It's normal to need a break from caregiving duties. No one can do it all by themselves. Look into respite care to allow time to take care of yourself.
- **Accept changes as they occur.** People with Alzheimer's disease change over time and so do their needs. They may require care beyond what you can provide on your own. Becoming aware of community resources and care options — from home care services to residential care — can make the transition easier. So will the support and assistance of those around you.

10 SYMPTOMS OF CAREGIVER STRESS

Alzheimer's caregivers frequently report experiencing high levels of stress. It can be overwhelming to take care of a loved one with Alzheimer's or other dementia, but too much stress can be harmful to both of you. Read on to learn symptoms and ways to avoid burnout.

- 1. Denial** about the disease and its effect on the person who has been diagnosed.
- 2. Anger** at the person with Alzheimer's or frustration that he or she can't do the things they used to be able to do.
- 3. Social withdrawal** from friends and activities that used to make you feel good.
- 4. Anxiety** about the future and facing another day.
- 5. Depression** that breaks your spirit and affects your ability to cope.
- 6. Exhaustion** that makes it nearly impossible to complete necessary daily tasks.
- 7. Sleeplessness** caused by a never-ending list of concerns.
- 8. Irritability** that leads to moodiness and triggers negative responses and actions.
- 9. Lack of concentration** that makes it difficult to perform familiar tasks.
- 10. Health problems** that begin to take a mental and physical toll.



CHAPTER 8

CARE OPTIONS

There is no one-size-fits all formula when it comes to Alzheimer's care. Needs change at different stages of the disease and each family's situation is unique. Deciding on care can be a tough decision. Our 24/7 Helpline 800.272.3900 is here to help you.

COMMUNITY SERVICES

Community Services: Many communities offer low cost or free-of-charge services to seniors and disabled people through senior centers, Area Agencies on Aging and municipal government. The type and cost of services, as well as eligibility for services, varies from location to location.

Community-based services can include:

- Meals on Wheels
- Transportation
- Personal care
- Chore services
- Legal aid services
- Home repair
- Social activities



IN-HOME CARE

In-home care includes a wide range of services provided in the home, rather than in a hospital or care facility. It can allow a person with Alzheimer's or other dementia to stay in his or her own home. It also can provide respite for caregivers.

Common types of in-home services:

- **Companion services:** Help with supervision, recreational activities or visiting.
- **Personal care services:** Help with bathing, dressing, toileting, eating, exercising or other personal care.
- **Homemaker services:** Help with housekeeping, shopping or meal preparation.
- **Skilled care:** Help with wound care, injections, physical therapy and other medical needs by a licensed health professional. Oftentimes, a home health care agency coordinates these types of skilled care services once they have been ordered by a physician.

ADULT DAY CENTERS

Adult day centers offer people with Alzheimer's and other dementias the opportunity to be social and to participate in activities in a safe environment.

The services provided vary depending upon the center. Common types of services include:

- **Counseling:** The center may provide support services for people with dementia and their families.
- **Health services:** If the person with Alzheimer's requires medical services (i.e., insulin shots, help with medication, etc.) be sure to ask if staff provides medical assistance.
- **Nutrition:** Does the center provide nutritious meals and snacks? If needed, ask if the center can accommodate a special diet or provide a culturally specific menu.
- **Personal care:** Centers may provide help with hairstyling, toileting, eating, showering and other personal care tasks.
- **Activities:** Daily activities may include music, art, recreation, discussion and support groups.
- **Behavior management:** Find out if the center is prepared to deal with behaviors associated with dementia. These many include wandering, incontinence, hallucinations, sexually inappropriate behavior or speech difficulties.
- **Therapy:** Some centers help arrange for needed physical, occupational or speech therapy.
- **Special needs:** Make sure the center can accommodate any special needs. For example, is the center equipped to deal with someone who uses a wheelchair, who is hearing or visually impaired, or who is handicapped in another way? Knowing about any service restrictions before using a center may help prevent problems.



RESIDENTIAL CARE

If the person with Alzheimer's or other dementia prefers a communal living environment or needs more care than can be provided at home, a residential facility may be the best option. Different types of facilities provide different levels of care, depending on the person's needs.

1. RETIREMENT HOUSING

Retirement housing may be appropriate for individuals with early-stage Alzheimer's who are still able to care for themselves independently. A person may be able to live alone safely, but has difficulty managing an entire house. Generally, this type of senior housing provides limited supervision and may offer opportunities for social activities, transportation and other amenities.

2. ASSISTED LIVING

(Also called board and care, adult living, supported care)

Assisted living bridges the gap between living independently and living in a nursing home. It typically offers a combination of housing, meals, supportive services and health care. Assisted living is not regulated by the federal government and its definitions vary from state to state. Not all assisted living facilities offer services specifically designed for people with dementia, so it is important to ask.



3. NURSING HOMES

(Also called skilled nursing facility, long-term care facility, custodial care)

Nursing homes provide round-the-clock care and long-term medical treatment. Most nursing homes have services and staff to address issues such as nutrition, care planning, recreation, spirituality and medical care. Different nursing homes have different staff-to-resident ratios. Also, the staff at one nursing home may have more experience or training with dementia than the staff at another. Nursing homes are usually licensed by the state and regulated by the federal government.

4. ALZHEIMER'S SPECIAL CARE UNITS (SCUs)

SCUs are designed to meet the specific needs of individuals with Alzheimer's and other dementias. SCUs can take many forms and exist within various types of residential care, and they may or may not be locked or secure units. Because requirements for SCUs vary from state to state and type of facility, it is important to ask specific questions about what type of care is provided to ensure that the level of care is appropriate for the person.

5. CONTINUING CARE RETIREMENT COMMUNITIES (CCRC)

CCRCs provide different levels of care (independent, assisted living and nursing home) based on individual needs. A resident is able to move throughout the different levels of care within the community if his or her needs change. Payment for these types of facilities can include an initial entry fee with subsequent monthly fees or payment may be based solely on monthly fees.

HOSPICE CARE

Hospice is a special way of caring for people who are terminally ill — and for providing support to their family. The primary purpose of hospice care is to manage pain and other symptoms during the last six months of life where treatments focus on comfort rather than curing the underlying disease. Hospice providers with expertise in dementia can help families understand what to expect in the final stages of Alzheimer's and provide support throughout the end-of-life process. Hospice care is provided by a team of specially trained providers, including doctors, nurses, home health aides, social workers, counselors, clergy and volunteers.

CHOOSING PROVIDERS

Good care includes ensuring safety and meeting basic needs; it also means finding care providers that treat the whole person and providing an environment that allows the person to feel independent and safe.

The first step in choosing the right care provider is determining the needs of the person with dementia at this point in time. Whenever possible, involve the person with dementia in care decisions. Important factors to consider include safety, health, amount and type of care needed (i.e. specific tasks), and need for social engagement.

Once you have a clear idea of what care is needed, you can find referrals for providers from:

- Your local Alzheimer's Association or our online Community Resource Finder (www.communityresourcefinder.org)
- The doctor
- Your local senior center or Area Agency on Aging
- Other caregivers who have used providers in the past

You will need to screen potential providers by phone and through on-site visits to identify the best option.

COSTS OF CARE

Costs for care vary depending on many factors, including what services are being provided, where you live, whether the expenses qualify for Medicare or private insurance coverage and if the person receives Medicaid or Veteran's benefits. Families should consult with an elder law attorney or Area Agency on Aging (www.n4a.org) about the costs of care.

MORE ONLINE AT
ALZ.ORG/HELP-SUPPORT/CAREGIVING/CARE-OPTIONS



Changing Care Providers



Working with Care Providers



Creating Your Care Team



Respite Care



Hospital Care



Choosing Care Providers



The Alzheimer's Association is the leading voluntary health organization in Alzheimer's research, care and support. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health. Our vision is a world without Alzheimer's®.

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