

Helping Memory-impaired Elders

A GUIDE FOR CAREGIVERS



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Acknowledgments

Photos by Rod Schmall, West Linn, OR.

Caring for a person who is memory impaired is a difficult and stressful job. As a caregiver, you can provide the best care and survive the strains of caregiving when you:

- Understand dementia
- Attribute behavior problems to the disease and NOT to the person
- Communicate effectively with the person who is memory impaired
- Manage the environment to lessen problems
- Take care of yourself
- Seek social support and help

This publication provides up-to-date information to guide you in this difficult job. In addition to general care and management guidelines, the publication outlines approaches for self care, handling specific problems—driving, wandering, money management, hiding items, catastrophic reactions, hallucinations, eating, and incontinence—and how to communicate with a memory-impaired person as the disease progresses.

“Senility” versus “dementia”

For several years Joe had known he was having memory problems. He compensated by writing himself notes of once-familiar names, telephone numbers, and things he had to do. Sometimes he became annoyed when people tried to help by reminding him. He silently worried about becoming “senile.” He was, after all, 64 years old.

Recently, Joe encountered a detour while driving home from the neighborhood grocery store. He arrived home 2 hours late. He had become lost, but he covered up by telling his worried wife that he had run into an old friend. Joe’s work suffered. His employer suggested early retirement. Joe felt worthless. Growing old was depressing.



Joe mistakenly accepted his problems as the inevitable result of aging. He is not alone. Many people, including some health professionals, share this myth and label older adults who have memory problems as senile. Others fear that aging leads to senility or loss of memory.

Just getting older does not mean losing one’s intellectual abilities. Actually, the word *senility* has been misused. It is derived from a Latin word that means “to grow old.”

Dementia is the appropriate word to describe the significant progressive loss of mental abilities caused by damage to brain cells. The term “neurocognitive disorder,” rather than “dementia,” is the newest term being used by some professionals. Depending on the degree of cognitive decline, a neurocognitive disorder may be further labeled as mild or major.

Dementia is not a specific disease; it is an “umbrella term” describing a range of symptoms associated with impairment in thinking, learning, memory, reasoning, and judgment; communication and language; and changes in personality, mood, and behavior. These changes progress or worsen over time to the point when a person’s ability to perform everyday activities is severely impaired. Alzheimer’s disease is the most common form of dementia. Some causes of dementia-like symptoms are reversible.

Dementia is the result of a disease, not normal aging. Although dementia is more common with advancing age, it is not a normal part of growing older. Dementia is more common today than it was 100 years ago because many more people are surviving to age 85 and beyond.

Most people experience some changes in memory as they grow older. For example, information processing and recall are slower,

and it may take more time to learn new information. However, these changes, often called “age-related memory loss,” do not interfere with a person’s ability to function in everyday life. As with muscle strength, “use it or lose it” is equally important for a healthy brain, as is lifestyle, health habits, and physical activity. Activities that challenge the brain, for example brain games, may help diminish these normal declines.

Many factors can affect memory. These include stress, depression, fatigue, illness, grief, or information overload. Frequently, people don’t remember something because they didn’t concentrate in the first place, and the information wasn’t filed in the brain’s memory bank.

Adults concerned about their forgetfulness should ask themselves “*How did I know I forgot?*” The answer: “*Because I remembered later.*” In a dementing illness, these memories cannot be recalled because they have not been recorded in the brain or have been erased.

Sometimes mental confusion, severe disorientation, and other cognitive impairments are caused by treatable conditions, such as reactions to prescribed or over-the-counter medications, alcohol abuse, depression, nutritional deficiencies, infections—especially a urinary tract infection (UTI)—and metabolic disorders such as a thyroid problem. These conditions can cause *delirium*. Generally, Alzheimer’s disease and other types of dementia develop slowly over months or years. Any sudden change in a person’s cognition and functioning should be assessed by a physician. **Early medical evaluation is important because**

10 Warning signs of dementia:

The national Alzheimer’s Association has identified 10 warning signs of possible dementia. Early diagnosis is critical for treatment, support, and planning. If you see these signs, get a medical assessment now!

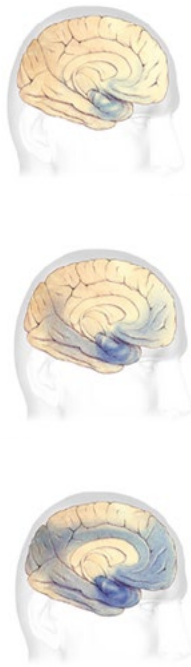
1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks at home, at work, or at leisure
4. Confusion about time (day, year), place (home, store), or person (mother, spouse, doctor, names, relationship)
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps or recall
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in typical mood and personality

For more information, go to www.alz.org or call 800.272.3900. http://www.alz.org/national/documents/checklist_10signs.pdf

treatable conditions may become irreversible if left untreated.

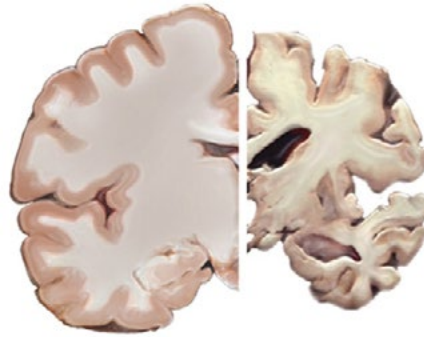
Causes of dementia

The onset and course of dementia depend on the nature of the particular disease causing it. Any memory loss that interferes with a person's lifestyle, work, or daily functioning should be evaluated. Physicians use a variety of diagnostic tools to assess whether a memory problem is significant. Finding the cause of memory loss is critical to appropriate treatment. Symptoms can vary widely, and no two afflicted persons follow precisely the same course or rate of progression. The four most



These images depict the progression of Alzheimer's disease from the earliest stages (top) to moderate severity (middle) to advanced severity (bottom). To find out more, visit the website for the [Alzheimer's Association](#).

Illustrations: Alzheimer's Disease Education and Referral Center, National Institute on Aging



The image on the left represents a healthy brain while the image on the right represents a brain with severe Alzheimer's disease. To find out more, visit the website for the [Alzheimer's Association](#).

Illustration: National Institute of Health

common types of dementia are: Alzheimer's disease, vascular dementia, motor body dementia, and frontotemporal dementia.

Alzheimer's disease is the most common cause of dementia in the United States. The disease destroys nerve cells throughout the cerebral cortex, the outer layer of the brain. Often the first symptoms include difficulty remembering recent experiences. This is because early in the disease the brain loses the ability to record new information, experiences, and events. A person will forget a conversation or instructions that were given just 5 minutes earlier.

As Alzheimer's disease progresses, affected individuals lose more and more of their memory and other abilities, including the ability to solve problems and complete everyday tasks. Tasks you consider easy to do can be difficult or impossible for people with the disease to begin or finish. Eventually, they are not able to function independently. Increasing cognitive loss leads to total disability. Alzheimer's disease is diagnosed by ruling out all other causes of the symptoms. As of 2016, there was still no way to be certain of a diagnosis of Alzheimer's disease without a brain biopsy or autopsy.

The average person lives about eight years past diagnosis; however, the time can be shortened to a few years or lengthened to as many as 20, depending on the age of the person at diagnosis and other health conditions.

Vascular dementia (previously known as multi-infarct or post-stroke dementia) is the second most common cause of dementia and accounts for 10 percent to 20 percent of

Assessment and diagnosis: *Only comprehensive diagnostic testing can determine if dementia is the likely result of Alzheimer's disease or some other cause. Early and accurate diagnosis is important!*

dementia cases. In vascular dementia, blood supply to the brain is interrupted, depriving brain cells of oxygen and nutrients. Damage can result from a series of tiny strokes, a major stroke, or chronic, untreated high blood pressure. A person may lose some function with a small stroke (or an accumulation of small strokes) and stay at that level of impairment until the next mini-stroke. The person may even appear to improve slightly for a time. Symptoms depend on which area of the brain that is damaged.

Lewy body dementia (LBD) is the third most common form of dementia, accounting for 10 percent to 15 percent of cases. LBD has been described as “a cross between Alzheimer’s disease and Parkinson’s disease.” It occurs when protein deposits called Lewy bodies (LB) accumulate in areas of the brain responsible for memory, motor control, thinking, and reasoning. When the Lewy bodies attack the brain stem first, causing rigid muscles, stiffness, and difficulty walking, Parkinson’s disease is the diagnosis. When Lewy bodies develop in the cerebral cortex of the brain, the result can be dementia. Many people with LBD eventually experience movement symptoms, and many people with Parkinson’s eventually develop problems with memory and thinking. People with LBD often experience rapid fluctuations in awareness and moods, and may have sleep disturbances, including acting out dreams at night. Visual hallucinations are common. A person with LBD may see people, animals or objects that are not there, yet they are very real to that person. Early in the disease, memory problems tend not to

be as prominent as they are in Alzheimer’s disease.

Frontotemporal dementia (FTD) refers to a group of disorders caused by progressive nerve cell loss in the brain’s frontal lobes (behind the forehead) and temporal lobes (behind the ears). Changes in behavior and personality are often the first significant symptoms. A person may suddenly become aggressive, use inappropriate language, or act out sexually. Unlike Alzheimer’s disease, memory loss isn’t significant until later in FTD, but people with FTD tend to have more difficulty speaking coherently and understanding others. FTD most commonly appears between ages 45 and 65, but can develop earlier or later.

Mixed dementia Is a condition in which more than one type of dementia occurs simultaneously. In the most common form of mixed dementia, the abnormal protein deposits associated with Alzheimer’s disease coexist with blood vessel problems linked to vascular dementia. Alzheimer’s brain changes also often coexist with Lewy bodies. In some cases, a person may have brain changes linked to all three conditions.

Other less common types of dementia include Normal Pressure Hydrocephalus, Huntington’s disease, Creutzfeldt-Jakob disease, AIDS, and long-term alcoholism. Head trauma also is increasingly linked to a higher risk of dementia.

The family’s adjustments

Whatever the underlying cause, all dementias lead to significant progressive loss of mental abilities that leave the affected person unable to function independently. Alzheimer’s disease and related

disorders (ADRD) are the major reason that families become long-term caregivers each year.

The person with dementia is not the only one affected by the disease—the person’s family is, too. Coping with the changes and problems associated with a progressive dementing illness places tremendous stress on families. The loss of the mind is difficult for everyone to accept. As dementia progresses, the affected person slowly loses insight into his or her condition. For the family, however, losing the person they have always known, though still physically present, can be very painful. Family members have said:

“It’s like looking after a 6-foot 2-year-old who is accustomed to doing what he wants to do.”

“It’s very, very hard to watch someone you love die very, very slowly. We go through many emotions—hurt, anger (at them, at ourselves), frustration, bitterness. We feel helpless!”

“Most difficult is when your family member no longer recognizes you.”

“My husband looks the same on the outside, but he is no longer the caring, loving person he once was. His disease is not only tough on him, it hurts me.”

“It’s like a funeral that never ends.”

“The disease has stolen my wife. Although physically she still looks like my wife, in every other way, she is NOT the woman I knew BEFORE this disease entered our lives.”

Denial is common early in the disease. The impaired person usually looks healthy, can talk about familiar topics, and sometimes even seems to improve.

Many changes are subtle, and early in the disease the impaired person often is adept at compensating for memory loss. The person may write “memory notes” to oneself, make light of changes, blame others (“Who stole my purse?”), or attribute memory loss to stress or other pressures.

Family members may attribute the person’s inability to carry out tasks to laziness or stubbornness, and this leads to arguments. When a disease is diagnosed, family members may have strong guilt feelings or may blame themselves for not being aware of the changes earlier. However, the subtle beginnings of dementia can be difficult for even professionals to diagnose.

Dementia also means tasks and responsibilities gradually shift from the impaired person to the caregiver. The added responsibility can be overwhelming, especially as the disease progresses and the person requires more constant supervision and help with personal care such as bathing and toileting.

Caregivers frequently become socially and emotionally isolated. A caregiver may not be able to leave the impaired person alone at home. The person may become easily upset in public, may be unable to tolerate being around people, and may lose social graces. Friends and family may stop visiting if they



do not understand the disease or if it's difficult for them to see the deterioration in the person or to accept the behavior and personality changes. The healthy spouse also loses freedom, a sex partner, and a companion with whom to share life's joys and problems. Caregivers comment:

"To go out is scary, not knowing what I'll find when I get back. My last night away was 4 years ago."

"During the 5 years of caring for my husband, I left home only to buy food and medications. I prayed nothing would happen while I was away."

"I feel like a prisoner in my

own home."

"Usually, we just stay at home because I don't know how he will act. If we have dinner with friends, he may refuse to eat and want to go home, so our social life is negligible."

"I need my friends more now than ever, but so many no longer visit or call. I know it's painful for them, too."

Caregivers must be realistic about what they can do. Eventually, the impaired person may need round-the-clock care and supervision. No caregiver can provide total care without help. Those who try usually become physically and emotionally exhausted. As the disease progresses, caregivers will likely need the support of community services, including support groups, adult day programs, respite care, and a long-term care residence. The most common reasons for moving

a memory-impaired person into a long-term care residence are that the caregiver can't manage alone any longer, becomes ill, or dies.

Self-care for the caregiver

It's critical for caregivers to take care of themselves. When a caregiver is emotionally or physically exhausted, becomes ill, or dies, remember, it also negatively impacts the person who is memory impaired. Here are some self-care guidelines for the caregiver.

Learn about the disease. If a dementing illness is diagnosed, everyone who supports and cares for the impaired person benefits from information about the disease. Learning about the disease—what can be expected as the disease progresses and how to deal with behavioral changes—enables families to better understand and accept the impaired person, to plan, and to set realistic expectations. Unrealistic expectations can compound problems by increasing anxiety and agitation in the person and stress for the caregiver.

Realize that caregiving is a marathon, not a sprint. Dementing diseases are progressive over many years. Caregiving and care plans must change as the dementia progresses. It is only possible to survive—and hopefully, thrive—as a caregiver if you sustain yourself for the long run. To learn more about caregiving, review the list of books and websites at the end of this publication.

Hope for the best, plan for the worst. Planning ahead will enable you to avoid making hasty decisions in times of crisis, such as a sudden change in your or your family member's health. Planning



does not mean endlessly worrying about things that might happen in the future. Planning means realistically considering:

- What can each family member do to best contribute to caregiving? How will roles and responsibilities change over time as the disease progresses?
- What should be done in an emergency? Who will you call in an emergency?
- What community services could help the memory-impaired person or the caregiver?
- How can I take regular breaks from caregiving? What respite care programs, if any, are available in the community?
- What legal and financial decisions need to be made? Consider wills, advance directives for health care, durable powers of attorney for finances, and estate and resource planning. There is a lot to consider, so start discussions and planning early. Review plans over time as personal situations and state laws change. Update documents as needed. For help, turn to your attorney or an attorney who specializes in elder law. For more guidance, see <https://www.nia.nih.gov/alzheimers/publication/legal-and-financial-planning-people-alzheimers-disease-fact-sheet>
- Under what conditions would another living arrangement, such as a memory care facility, be best? What would this mean financially and personally? Be open to the possibility that a time may come when a person's

dementia or your well-being necessitates a change in living arrangements.

Don't hide. Dementia is a disease, not a crime. Some families are inclined to hide their family member's illness. Explaining the disease to others may be difficult, but it helps if family, friends, and neighbors understand the impaired person's behavior and the stress of caregiving. People need to know:

- Dementia causes the brain to fail, just as heart and kidney diseases cause those organs to fail. The disease causes the mind to deteriorate gradually. Individuals are less and less able to remember, use good judgment, control their behavior, and perform seemingly simple tasks like dressing themselves.
- Dementia is not contagious.
- People afflicted by a dementia are not "insane" or "crazy."

Sometimes family and friends feel it's not worthwhile to visit or to engage the person in an activity because "it won't be remembered." Let others know that although their visit or an activity may not be remembered, **the joy they create for the moment with the person has lasting impact.** Plus, visits can give a welcome boost to the caregiver.

Ask for and accept help from others. Do not try to go it alone. Look for sources of help and information inside and outside your family. Let family and friends know how they can help.

- **Be specific with your request.** Saying nothing, yelling "*I need help!*", or thinking "*I should not have to ask for help*" are not positive ways to

It's important not to let old promises or guilt guide decisions.

get help. It is more effective to say “*I need someone to stay with Dad every Tuesday afternoon. Can you do that?*” And be appreciative. Don't be a martyr—this will likely turn off caring helpers. Realize that some people will help more than others. Be willing to negotiate times and tasks for helpers.

■ **Contact your county and state health and social service agencies** that serve older people, adult community or senior centers, local offices of Social Security and the Veterans Administration (if the impaired person served in the military). Home health and home care agencies can help with personal care and housekeeping chores. Meal delivery, transportation, and shopping services also may be available.

■ **Contact your Aging and Disabilities Resource Connection.** ADRC is a nationwide initiative that serves communities across America (ADRC). ADRC centers are staffed by local experts who help connect older adults and people with disabilities with needed services and assistance. ADRCs can be very helpful when families are providing care and support to someone in a different community. You can locate ADRCs by searching “ADRC and your state name.” For example, ADRC listings for Oregon, Washington, and Idaho are:

○ **Idaho:** <http://www.idahoaging.com/adrc/> or 800-926-2588

○ **Oregon:** <https://www.adrcoregon.org> or 855-ORE-ADRC (855-673-7332)

○ **Washington:** <https://www.dshs.wa.gov/ALISA/resources> or 360-725-2300.

■ The national **Alzheimer's Association** has chapters in all states. The Alzheimer's Association works to enhance care and support for all those affected by Alzheimer's and other dementias. Chapters offer information and support through toll-free telephone numbers, websites, and support groups. Look in the community pages of your telephone book and in your local newspaper under “Meetings;” visit the Alzheimer's Association online at <http://www.alz.org/>; or call the state or county ARDC, senior services department, or the community education department of your local hospital.

Take breaks from caregiving. Regular breaks from caregiving, also called respite, are essential. Breaks allow you to rest physically and emotionally. Breaks are as important to your health as diet and exercise—and taking breaks is NOT selfish! Breaks benefit the impaired person as well you, the caregiver.

Consider family members, friends, neighbors, fraternal and church groups to which you belong, or college and nursing students for assistance and a break from caregiving. In some communities, adult day programs or in-home respite care are available. Some care facilities also offer adult day programs and short stays for older adults, so caregivers

can take a short break during the day or week, or even a longer needed vacation.

- **When you take breaks, give clear instructions to anyone who provides respite care or other help.** Family members and others who are not involved directly in daily care may not realize the demands of caregiving or may fear the responsibility. Give respite care providers and other helpers the following information.
 - Emergency telephone numbers, including the name and number of the doctor, preferred hospital and ambulance service, nearest relative or friend to contact, local police and fire departments, or an emergency dispatch number (if there is one)
 - How to reach the caregiver
 - Estimated time of the caregiver's return
 - Special instructions for relating to and caring for the impaired person and managing difficult behavior; for example, "When Fred picks at his clothes, it may mean he needs to use the toilet."
 - List things that are stressful to the person, things to do to soothe and comfort the person (e.g., play the classical music tape, or go with Dad on a walk), and signs that trouble is brewing (e.g., Dad says "I want to go home"; Mom starts to wring her hands).
- **Be honest about any likely challenges or problems.** Sooner or later, a substitute care provider may have to confront difficult behavior. Ask each family member or other helper to read this guide and discuss the ideas that work best with your loved

one. Also suggest helpers read *Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease* by Joanne Koenig Coste.

Maintain meaningful social relationships. Family and friends can be a source of great comfort, help, and pleasure. Build and fortify your relationships early in the disease. Caregivers who take time away from their responsibilities to meet their own needs for companionship and recreation feel less trapped and less isolated, and they are better able to care for the impaired person.

Understand and accept negative feelings as normal human responses. Families and caregivers dealing with a dementing illness have mixed and powerful feelings—grief, anger, sadness, embarrassment, shame, fear, guilt. Remember, feelings are not good or bad, right or wrong. And, they are not deeds. They are responses that everyone has, especially when dealing with the stress of a chronic, progressive illness.



Find someone who is willing to listen and understands your feelings. Counselors and support group leaders and members may be especially helpful.

- **Anger is a normal response to frustration.** Caregivers often feel trapped. They may feel angry at God for what has happened, at the strange and embarrassing behaviors of the memory-impaired person, at others who offer advice but don't help. Acknowledge your right to feel angry, and then do something constructive about it. Find someone who is willing to listen and understands your feelings. Counselors and support group leaders and members may be especially helpful.
- **Guilt feelings are common.** Caregivers may feel guilty about feeling angry, misdeeds of the past, wishing for the impaired person's death, or about mistakes or outbursts in dealing with the person. It's important to forgive yourself, learn from the incidents, and move forward. Consider that the impaired person has already forgotten.
- **Caregivers commonly experience divided loyalties.** Competing demands are common when a caregiver has children, a spouse, a job, or other responsibilities. Competing demands can overwhelm the most dedicated caregiver. The caregiver's personal needs may be overlooked or ignored. If it's not possible to balance responsibilities, set priorities. Children's needs and family unity should come first. Professional help may be needed to sort through complex and emotionally charged problems and adjustments.

- **Mixed feelings are common.** Remember, it is possible to love the care recipient and hate the disease, its impact, and a caregiving task. Many caregivers feel this way.

Recognize your limits. No matter how much you love the person to whom you provide care, the needs of the person may be greater than what you can meet. Or it can be exhausting, overwhelming or unsafe to deal with the person's difficult behaviors. Like all caregivers, you have emotional and physical limitations that must be recognized and considered. If your health and well-being are being affected, it's a message that a change is needed. One older husband shared his story:

"My wife and I have been married nearly 70 years. As a result of dementia, she started beating on me because she saw me as a 'stranger in her house'. I hid the behavior from family. When my son and daughter eventually saw my bruises, they said 'this cannot continue' and expressed concern about my safety. My wife was placed in a memory care facility and it has been the best for her ... and for me. Our time together when I visit is much more positive than it was for the last few months at our home. I likely would have been dead in another couple of months if I had continued to be her daily caregiver."

Following her mother's death, a daughter said:

"I viewed it as my duty to care for my mother, so I quit work early to care for Mom in my home. However, in doing so my financial security as I grow older has been severely compromised."

Make realistic commitments and avoid promises that you

may not be able to keep. Nearly everyone has made an emotionally laden promise based on an unknown future. One of the most common is to promise to never place a family member in a care facility. You may want to say, “*I will never let you go to a nursing home.*” But you may have to make that decision if your health fails, the person’s care needs are beyond what you and in-home care services can provide, or the person becomes hostile and difficult to manage. It is better to say, “*I will be with you all the way and provide the best care possible through the illness.*”

A realistic commitment doesn’t include words such as “always,” “never,” or “forever.” A realistic commitment is a pledge to do something, but not everything, regardless of what happens. If you have already made a promise, recognize that the conditions under which you made the promise are quite different from your current situation.

Do not let old promises or guilt guide decisions. They reduce objectivity and your ability to make the best choice. You need to consider what is best for you and your family as well as for your memory-impaired family member.

Join a support group.

Family support groups can be a tremendous source of information and understanding. Sharing among people who are coping with a family member who has the same kinds of issues and concerns reduces feelings of isolation and guilt. Caregivers also learn from each other how to more effectively handle challenging behaviors, involve their family in caregiving, and make tough decisions.

In caring for the memory-impaired person,

- Keep expectations realistic
- Maintain a calm atmosphere
- Be consistent
- Simplify tasks and limit choices
- Use repetition
- Use memory aids
- Encourage recognition rather than recall
- Make the environment safe
- Use reminiscence
- Approach the person slowly and from the front
- Gently redirect a person who is moving in a dangerous manner
- Treat the person as an adult
- Reassure and praise
- Maintain your sense of humor.

Comments of support group members:

“I thought I was the only one dealing with the problems I faced with my husband and I was embarrassed to tell others about the changes in him and my struggles. In the support group I learned I was not alone, and I learned techniques for reducing difficult behaviors. Sharing in the support group also helped me to share my situation with family and friends and get their help.”

“While most support groups meet once a month, the HOPE (Vancouver, WA) support group I attend, meets weekly. These weekly meetings are invaluable. If I am dealing with an issue or am uncertain about what to do, I know I can talk about it in a few days in the support group. The group has been my life raft.”

“The support group I attend was critical to my finally taking care of myself and taking needed steps concerning my mother’s living

The tone of your voice and the feelings expressed are as important as your words. In fact, the person will tend to respond more to the tone of your message than to its content.

situation. The changes have been best for both Mom and me.”

For more information on support groups, contact the Alzheimer’s Association’s national office, 225 North Michigan Avenue, Floor 17, Chicago, IL 60601. A 24-hour toll-free line 800-272-3900 provides information and referral nationwide to local chapters. The website is <http://www.alz.org/>

- **Oregon:** Contact the Alzheimer’s Association Oregon Chapter at <http://www.alz.org/oregon/>
- **Washington:** Contact the state Alzheimer’s Association at <http://www.alzwa.org/>
- **Idaho:** Contact the Alzheimer’s Association Idaho Regional Office at <http://www.alz.org/idaho/>

To learn more about the Alzheimer’s Association and other valuable resources, see on page 34 of this publication.

Contact your local Area Agency on Aging or Aging and Disabilities Resource Connection (ADRC) for support groups that may be offered by other organizations.

General caregiving guidelines

The amount of care, supervision, and help a memory-impaired person needs depends on the extent of the disease. As the person proceeds through the progressive stages of the disease, the following guidelines will improve the quality of life for everyone.

Keep expectations realistic. Keeping expectations realistic reduces frustration. Know what you can expect from the memory-impaired person. Forcing the person to do something he cannot

do, or does not want to do, only makes the situation worse.

Neuropsychological testing may be helpful. It can identify which cognitive abilities are still intact and provide a realistic measure of what the person can do. The impaired person’s physician should be able to direct you to specialists who can administer assessment tools.

Maintain a calm atmosphere.

Being rushed, around a lot of activity, or in a chaotic environment tends to increase confusion and restlessness. Even small amounts of excitement can agitate some individuals. For example, it’s often more difficult for the person to eat a meal if the television is playing or if young children are running around.

■ **Create comfort.** The more secure and comfortable a person feels, the less likely there will be behavior problems. If the person becomes upset or resistant, it’s important that the caregiver remain calm. If necessary, calmly remove the person from the upsetting situation to a quiet, unhurried environment.

■ **Avoid confronting or overloading the individual** with stimulating experiences. Alternate activity with quiet times throughout a day and over a week. A time may come when a visit by two or more people at the same time is overwhelming to the person.

■ **Keep all activities and events simple and short.** Keep in mind that memory-impaired people tend to have short attention spans, 30 minutes or less. And every activity will

take longer than it would for a person who is not impaired.

- **Keep your voice calm and reassuring.** The tone of your voice and the feelings expressed are as important as your words. In fact, the person will tend to respond more to the tone of your message than to its content.

- **Do not argue with or scold the person.** Arguing and scolding usually causes a person to overreact and increase agitation.
Remember: The person's behavior is a result of the *disease*, not stubbornness or willfulness.

It's also important to be consistent. Avoid changes and surprises. People with a dementing illness generally do best in familiar, well-organized environments with consistent routines. Many have difficulty coping with change, even seemingly minor changes such as rearrangement of bedroom furniture. Create a consistent routine by:

- **Doing things the same way and in the same order each day.** Doing things at *exactly* the same time each day (breakfast is at 8 a.m.) is not as important as keeping routines orderly (first, we get up, go to the bathroom, have breakfast, and bathe). The same routine will make it easier to get through everyday tasks (e.g., bathing, eating, and dressing). If you go on walks, go out the same door and use the same route.
- **Establishing a schedule of daily activities based on the person's lifelong patterns, if possible.** Plan to do difficult

tasks at the person's best time of day.

- **Posting the daily schedule.** This not only helps the person who can still read, but it also makes it easier for anyone who helps in the home.

When changes must be made, prepare and support the person. However, avoid lengthy explanations. Take special care when planning a trip or vacation. Some people become agitated and more confused in unfamiliar surroundings. And, there may come a time when it is best for a person not to travel elsewhere.

Simplify tasks and limit choices. Tasks that previously were easy for the person may become too difficult. When the person becomes frustrated by a task or refuses to cooperate, a change is needed. Try these ideas:

- **Break complex tasks into simple steps and give step-by-step instructions.** This may enable the person to continue to do some tasks. For example, a person may be able to help set the table as long as he or she can deal with the items one at a time. Try drawing the location of the plate, fork, and cup on a paper place mat to give the person a visual map to follow. The individual who enjoyed cooking (but for whom cooking is now too complex) may still be able to stir batter, wash the vegetables, or tear lettuce for a salad. A former gardener may find satisfaction in raking the yard or watering plants.
- **Demonstrate each step.** For example, brush your teeth at the same time as the impaired

The success of memory aids and cues depends on the severity of the disease. In early to moderate cases of memory impairment, memory aids can help promote better orientation.

person. Sometimes, helping the person with the first step of a familiar activity enables him to complete the activity. For example, when you assist him with one sock, he might be able to put on the other sock and even the shoes.

- **Limit choices.** Limiting the choices the person has to make reduces confusion. For example, remove seldom-worn and out-of-season clothing from the closet. Limit food choices, and put out only the utensil(s) the person will need at mealtime.

Use repetition. Memory-impaired people need frequent, calm reminders. They simply may not remember what they are told because the brain no longer has the ability to retain information.

- Be prepared to repeat the same instructions daily,

sometimes several times in succession. Use brief, simple statements; avoid lengthy explanations. Give the same brief answer each time the question is asked. When repeating, do not remind the person that you said it before. Don't use phrases such as "Remember . . . I told you yesterday" or "I've already told you four times."

- The person may remember some tasks and information from repetition. Don't assume the person will forget promises you have made or places you said you would take him or her.

Use memory aids and cues.

The success of memory aids and cues depends on the severity of the disease. In early to moderate cases of memory impairment, memory aids can help promote better orientation. Signs, clocks, calendars, seasonal decorations, and a schedule of the day's activities reinforce memory.

- **Put labels on drawers, cupboards, appliances, and doors.** When the person can no longer comprehend the written word, replace word labels with pictures. Mark off days on a calendar with a large felt pen so the person will see the current date.
- **Autographed photos may help the person to remember family members and close friends.** However, expect fluctuations in the person's ability to recognize people, even close family members. Don't take it personally when you are not recognized.
- **Instruct family and friends when the person may no**



longer recognize them. Let them know that the lack of recognition is due to the disease, not to the person's feelings toward them, and that some individuals deteriorate to the point where they don't even recognize themselves in the mirror.

Encourage recognition rather than recall. It's easier to recognize than to recall information. Limit the demands for recall of facts, names, and schedules. For example, post a simple schedule of the day's activities. When speaking to a person who no longer remembers people, always give the names of family members and friends who visit. Avoid saying "Who am I?" or "Who is this?" If the person can no longer remember people, help by stating names and relationships. For example, "Clare, your sister, is here to take you out for lunch," or "I'm Jane, your daughter. I'm here to visit you."

Make the environment safe. Even a mildly impaired person may have lost the judgment needed to avoid everyday dangers and accidents. Potential dangers are everywhere: smoking, cooking, driving, swimming pools, windows and stairs from which a person could fall.

- **The person who still smokes may forget to put out his or her cigarette.** If possible, encourage the person to give up smoking. Otherwise, supervise the smoking. Keep matches, lighters, and smoking materials out of reach.
- **The person may turn on the stove and forget it, or may put flammable materials in the oven.** Removing knobs from the stove may solve the

problem. Or remove the fuse or open the circuit breaker when you're not cooking. If you have questions about how to make a stove inoperative, consult your utility company.

- **Hot tap water can be dangerous.** To prevent burns, lower the temperature setting on your water heater to 120°F. Check the temperature of bath water before the person enters.
- **Install grab bars in the bathtub and shower and by the toilet.** Use a rubber mat or no-skid decals on the tub's bottom to prevent falls. Don't use bath oils; they make the tub slippery.
- **Lock up potentially dangerous items.** These include medications, firearms, power tools, small appliances, knives and sharp objects, razor blades, alcohol, poisons, and cleaning supplies.
- **The person may not know what is edible and what isn't.** Make sure that poisonous items, such as cleaning fluids, are inaccessible. Remove items that resemble food, such as plastic fruit or rocks in a jar that might be mistaken for candy. If the person begins putting inappropriate items in her mouth, remove plants, buttons, small knickknacks, and other items that might be swallowed.
- **Remove locks on bedroom and bathroom doors to avoid accidental locking.** Installing a lock high or very low on outside doors out of a person's direct sight can help prevent a wanderer from leaving the house. A hard-to-reach lock

If the person can no longer remember people, help by stating names and relationships. For example, "This is Jane, your sister," or "I'm Jane, your daughter. I'm here to visit you."

on the kitchen door also may be helpful.

- **Install night-lights in the bedroom, hallway, and bathroom.** A strip of glow-in-the-dark tape from bedroom to bathroom increases nighttime safety and helps orient the person. Awakening in the dark can be disorienting.
- **Be sure walkways, stairs, and windows are safe.** In every room, remove objects the person might trip over, such as scatter rugs, footstools, and electrical cords. Mark the edges of stairs. Lock windows or limit how far they open so the person cannot climb out.
- **Learn basic first-aid.** Memory-impaired people are at greater risk for accidents, so it's helpful to know first-aid procedures. Contact your local Red Cross chapter about classes.

Use reminiscence. Talking about the past may help the person become involved in what she can remember. It can also build self-esteem since the past generally was a time when the person felt independent and productive. People who seem to have little memory often respond to discussions about significant personal experiences (e.g., weddings, children's births, hobbies) and unique historical events (e.g., the Great Depression). Old photographs, special holidays, and familiar songs often evoke memories and reminiscing. Most important is to "step into the person's world and timeframe." Do not try to force them into today's reality when the brain disease has stolen that ability from the person.

Identify activities that give the person a sense of accomplishment and fun. Small accomplishments are tremendous victories for people whose memories are impaired. Whether singing, dancing, gardening, or playing with a grandchild, it's important to continue to involve the person in activities that are meaningful and enjoyable. For example, one family had the person help set the table, guided by simple place mats showing the desired location of the cup, plate, spoon, and fork. Another family celebrated a birthday every Friday just so their memory-impaired grandmother could blow out the candles and sing "*Happy Birthday*."

As the disease progresses, engage with the person by sharing memories, sensory experiences, music, touch, and love. Even in advanced stages, touch, and music can soothe a person who is no longer able to speak or move independently. Musical memories are stored in several parts of the brain and these memories often outlast other memories. Many people remember tunes, and even the words to songs, long after they lose other memories. Playing familiar songs can engage and entertain the person, especially when they hum or sing along.

Approach the person slowly and from the front. Moving quickly, pushing or pulling the person, or approaching from behind or side may startle a person with dementia. It can also lead to agitation, hitting behavior, and resistance.

Treat the person as an adult. Include the person in adult conversations and activities. Avoid talking down to the person or talking about him as if he weren't

present. Don't treat the person as a child because then he is more likely to respond with childlike behavior. Allow the person to be as independent as possible, even if tasks are not done as well as you would like.

Reassure and praise. Like all of us, people with dementia need a feeling of success and self-esteem. Provide praise for tasks accomplished. Tasks such as cooking, bathing, dressing, and remembering to go to the bathroom, which are relatively easy for the healthy person, become increasingly difficult for the memory-impaired.

Maintain an attitude of respect and dignity and allow the person to do as much for himself as possible, even if tasks are not done as well as you would like or the person is not dressed perfectly! A person with dementia needs to feel that his dignity is intact.

Maintain your sense of humor. Families find a sense of humor especially helpful in dealing with trying situations—for example, discovering garden tools in the refrigerator or finding that, after spending half an hour dressing Dad, he has removed all his clothing to use the toilet. Humor does not mean making fun of the person. Rather, humor is a pleasant emotional response that reduces stressful feelings and tension. For caregivers, laughter really is good medicine.

Responding to challenging behaviors

Dementia can cause a person to act in unpredictable ways that challenge the caregiver. When difficult behaviors occur, always focus attention away from blaming



the person. Try to discover what the person may be trying to communicate through his or her behavior, or if there is an unmet need. Difficult behaviors are a result of the disease. Try to work through it and do not take the behavior personally. There is no one “best approach” that is guaranteed to work. You may need to try several approaches. It will help to keep the following ideas in mind.

Difficult behavior is not willful. Irritating, rude, stubborn, and socially inappropriate behaviors are usually beyond the control of the person with dementia. Recognize that the person is not intentionally being difficult. Define the behavior, not the person, as the problem. View the behavior as *reflecting a need* rather than simply as a problem. Work to understand the “why” of the behavior. Behavior does not occur in a void. There is a reason for it. *The behavior is not done on purpose, but it is done to meet a need.* If you can discover that need, you often can devise an appropriate way to respond that will lessen or stop the behavior. For example, if the person repeats “*Where is my*

REMEMBER: Difficult behaviors are the result of brain disease, not stubbornness.

The impaired person:

Acts to meet a need

Is always right—from his or her point of view

Is no longer able to learn or remember new information and events

Feels the past is more real and lovable than the present

Can still feel love, caring, joy, embarrassment, and other emotions

Cannot change—but you and the environment can change

Caregivers should:

- Connect, not correct
- Focus on feelings, not facts
- Use distraction to manage difficult situations

husband? When is he coming to take me home?” Try responding to the emotion by saying “You must miss him a lot. But he can’t come right now.”

The memory-impaired person is always right—from his or her point of view. Try to understand the world of the person with dementia and his or her perceptions, thoughts, and feelings. This will help you to better develop strategies to address a difficult situation. For example, to the memory-impaired person, a radio talk show playing in an adjoining room may be people in the next room. A tree branch hitting against a window when the wind blows may seem as if somebody is trying to break into the house. Ice cubes dropping into the bin of an automatic ice maker may sound like something breaking. The woman who no longer recognizes herself in the mirror may accuse her husband of having another woman in the house. A person may no longer know that shooting, violence, or other activity on television programs is not real. A daughter shares her experience:

When Dad and I visited Mom in the care facility, Mom looked very angry at me, pulled away, and called me “an old buzzard!” She thought I was Dad’s girlfriend. I knew if I tried to convince her “I’m your daughter,” it would only increase her agitation. So, I just removed myself by saying, “Please excuse me. I need to get something I forgot in the car.” I left and waited for Dad in the lobby. I smiled to myself and thought, “I, too, would NOT be happy if my husband had brought his ‘girlfriend’ with him while visiting me! Both Dad and I later enjoyed the humor of the situation. For Mom, at that visit, I was “her husband’s girlfriend.”

The impaired person loses the ability to learn and to record new information and events. It’s easy to get frustrated when a memory-impaired person says he will wait but then does not, or agrees to give up a car or to move to another home, then is adamant the next day that no such agreement was made.

Early in the disease process (especially with Alzheimer’s disease), dementia steals the brain’s ability to record new information and events. Thus, the person can no longer remember information that was just shared, instructions given, or agreements made just minutes earlier. The person may not remember your visit a few hours ago or an event that he just attended and thoroughly enjoyed. However, feelings remain even when memory does not!

The past becomes more real and lovable than the present. As dementia progresses, it increasingly erases stored memories. “Today” for the person may be what was 10, 20, or 40 years earlier. The person may talk about a family member or friend, long dead, as if she is alive. Also, the person may not recognize the people around him. For example, a man may not know his grandchild or may think that his daughter, who looks a lot like her mother, is his wife or that his nephew is his brother.

Emotions and feelings remain largely intact. People with dementia are memory impaired but still have feelings and emotions. They still can feel love, caring, joy, embarrassment, sadness, and other emotions. Sometimes a feeling will be remembered long after an event has occurred. For example:

It was Abraham Lincoln’s birthday, and the 16th U.S. president was being discussed at the

adult day program. To the surprise of staff, a male participant recited part of the Gettysburg Address. He received applause and a lot of praise. When his wife came to pick him up, he excitedly told her, "I did it, I did it." When she asked what he'd done, he couldn't remember. Yet the feeling of what had happened was still with him.

Emotions are very infectious, and people with dementia often mirror the emotions around them. If you are tense, annoyed, or angry, the memory-impaired person may show the same emotion. People with dementia lose their memory but not their sensitivity to the emotions around them.

The person cannot change. We must change *our* behavior or change the environment. An important key in meeting the challenges of caring for someone with dementia is modifying the environment or our own behavior—not trying to change the person's behavior. Trying to reason with the person or expecting him or her to change are not effective strategies. Dementia "steals" these abilities from people. It's also important to stay flexible. For example, if the person resists taking a bath in the morning, try again later.

Connect. Do not correct. If the person says something you know can't be true—for example, "*My mother is coming to see me today,*" and you know her mother died 20 years ago—don't argue about the correctness of what is said. Either let it go or look for the feeling behind the words. If the person seems pleased that her mother is going to visit, you might say something like "*Tell me about your mother.*" On the other hand, if she is upset, you might use distraction.



The goal is to create a feeling of comfort and to connect with the person in a positive way.

Focus on feelings, not facts. If you argue about the "facts" or try to convince the person she is wrong, you're likely to make the situation worse because you convey that you are unfriendly or not to be trusted. Remember, it's most likely you will not convince the person you are right and she is wrong. Try to connect with the person as a friend. *Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease* by Joanne Koenig Coste is a good source.

Use distraction and gentle redirection. The person with dementia tends to be highly distractible. Often you can interrupt difficult behavior or avoid problems by diverting the person's attention. For example, you might divert the person who wants to go home (when he's already at home) by saying "*Let's have lunch first.*" One family would say, "*Let's have a bowl of your favorite ice cream, chocolate chip, before we leave.*" Or if your father starts to walk away from the house, you could walk a short distance with him, then slowly turn in the desired

direction. You might say to him, “*I am really tired. Would you please walk me back home?*” Avoid saying “*This is your home*” because that is likely to lead to a disagreement. Avoid pulling, pushing, or physical restraint unless absolutely critical.

Approaches to specific problems

In addition to the above general care and management guidelines, the following approaches to specific problems may be helpful.

Driving

Families have a responsibility to act when the memory-impaired person no longer drives safely. The ability to make quick and reasoned decisions in traffic may be affected early in the disease. Getting lost and near-misses in traffic are clues to problems.

Don't rely on daylight hours and familiar routes to delay this difficult decision. Detours, accidents, children, and animals can surprise the driver. Remember, the impaired person generally doesn't cope well with changes.

If possible, involve the person in the decision. Be gentle but firm. Some will accept giving up driving; others will strongly resist.

Giving up driving is difficult for many people because a car represents independence and adulthood. Feelings of frustration or anger may be directed at the caregiver. Assure the person that he or she will stay mobile and that you will arrange transportation and regular outings.

The family physician can help by advising the state Department of Motor Vehicles in writing that, for reasons of health, the person should no longer be licensed to drive. Some people will stop driving on the recommendation “for health reasons” of his or her physician.

Some memory-impaired adults will not remember that they no longer have a driver's license or that they agreed to quit driving. A written prescription from the doctor stating simply “No driving” may remind the impaired person and divert blame away from the family. If necessary, hide car keys or disable the car. A car mechanic can show you how to do this.

The Alzheimer's Disease Education and Referral (ADEAR) <https://www.nia.nih.gov/alzheimer> offers several resources on driving, including an online publication entitled: *Tips for caregivers: When driving should stop* <https://www.nia.nih.gov/alzheimers/features/tips-caregivers-when-driving-should-stop>

Managing money

Problems balancing a checkbook may be an early sign of cognitive decline. Forgetting to pay bills, squandering money, or hiding cash are also early symptoms.

Alzheimer's Bill of Rights:

Every person with Alzheimer's disease or other dementia deserves

- To be informed of one's diagnosis
- To have appropriate, ongoing medical care
- To be productive in work and play for as long as possible
- To be treated as an adult, not as a child
- To have expressed feelings taken seriously
- To be free from psychotropic medications, if possible
- To live in a safe, structured, and predictable environment

- To enjoy meaningful activities that fill each day
- To be outdoors on a regular basis
- To have physical contact, including hugging, caressing, and hand-holding
- To be with individuals who know one's life story, including cultural and religious traditions
- To be cared for by individuals well trained in dementia care

From *The Best Friends Approach to Alzheimer's Care* by Virginia Bell and David Troxel. 1997.

http://www.alzsupport.org/uploads/AN_ALZHEIMER_bill_of_rights.pdf

Eventually, someone must take over the person's financial matters.

Take care of financial and legal planning *early* to guarantee a safe financial future for both the impaired person and for the caregiver. This may include obtaining a durable power of attorney, conservatorship, or guardianship.

Consult an attorney for advice. There are laws that protect the impaired, and they vary from state to state. Banks also offer services and information that may be useful.

Giving up control over money is often difficult because it means another loss of freedom and independence. The person may accuse the family of stealing. Recognize the person's sense of loss and inability to comprehend the reality of the situation. Giving the person small amounts of spending money may help.

Talk to managers of stores or restaurants the impaired person is likely to visit. Explain the nature of the person's problem. Make arrangements to pay for or return unwanted items the impaired person may have been unable to pay for or forgot to pay for.

Remember, police respond to the apparent act. They do not make judgments about intent. With information about the impaired person, store owners often are very helpful.

Repetitive questions

Being asked the same question five times in 15 minutes will try anyone's patience. In fact, for many caregivers, this is their greatest complaint.

- It may help to understand that *each time the question is*

The Alzheimer's Caregivers Bill of Rights:

As a caregiver I have the right to:

- Take care of myself so that I can better care for my loved one
- Seek help from others even though my loved ones may object; only I can recognize the limits of my endurance and strength
- Maintain aspects of my life that do not include the person I care for, just as I would if he or she were healthy. I have the right to do some things just for myself.
- Get angry, be depressed, and express other difficult feelings occasionally
- Reject any attempts by my loved one to manipulate me through guilt

- Receive consideration, affection, forgiveness, and acceptance for what I do, from my loved ones, for as long as I offer these qualities in return
- Take pride in what I am accomplishing and applaud the courage it sometimes takes me to meet the needs of my loved one
- Protect my individuality and my right to make a life for myself that will sustain me
- Expect that as strides are made in finding resources to aid physically and mentally impaired person, similar strides will be made towards supporting caregivers

http://caregiver.com/articles/print/caregiver_bill_of_rights.htm

asked is like the first time to the person with dementia. The person may no longer be able to remember answers—or even that he or she asked the question before.

- Give the same brief answer each time the same question is asked.
- Sometimes reassuring the person reduces repetitive questions. Simple written reminders also may aid a failing memory, particularly in the early stages of dementia.
- Look for a need that may underlie a repetitive question. For example, the person who continually asks “*When do we eat?*” may be asking because she is hungry. Giving a snack, even though it's an hour before dinner, may stop the repetitive question.

Some wandering behavior stems from the need to exercise. If this seems to be true, you may reduce the wandering by taking the person on frequent walks or providing other exercise such as raking leaves or sweeping the driveway.

Wandering

Individuals with dementia may become disoriented and lost in their own neighborhoods or far from home. Any person who can get outside and is mobile is at risk. Wandering is common and potentially dangerous. Traffic, weather, bodies of water, crime, missed medications, and exhaustion put the wanderer at risk. The wanderer may not realize he is lost, may not remember where home is, and may not think of (or be able to use) a telephone.

Wandering behavior can be triggered by a variety of circumstances, including stress, medication, fear, and failure to recognize his surroundings. Look for possible reasons for wandering behavior.

- Did the person previously enjoy walking and outdoor activities, or walk to reduce stress?
- Is the person bored?
- Is there somewhere the person wants to go? Is the person searching for something?
- Was the person trying to get away from someone or from an unfamiliar or uncomfortable situation?
- Did an unusual noise attract the person's attention, such as a fire truck going by, road construction, or a neighbor's remodeling project?
- Was the person overstimulated by activity, too many people, or noise in the home?
- Did the environment change at home, or is the person in a new environment?
- Does the person seem to be searching for some

satisfaction? Calling out "*I want to go home*" or "*Where is my mother?*" may indicate a search for and need for security.

- Is the wandering directed toward a goal? Commenting on the need to perform a task (I need to do the laundry) or gesturing as if performing a task may indicate a need to do something or to be busy.
- Is there a pattern to the wandering behavior? The wandering may seem to have no specific cause other than being part of the disease process.

Some wandering behavior stems from the need to exercise. If this seems to be true, you may reduce the wandering by taking the person on frequent walks or providing other exercise such as raking leaves or sweeping the driveway. Regular exercise also can relieve tension and help the person sleep better.

A high fence with locked gates may allow the person to freely wander and exercise outdoors. This may be particularly important to the person who spent considerable time outdoors before the illness.

Approach a wanderer slowly and calmly. Offer reassurance. Walk with the person a short distance in the direction he is walking. Then, gently ask him to walk you back home. Another strategy is to redirect the wanderer to a pleasant activity; for example, you might say "*We have cookies and ice cream inside.*"

Avoid moving the person hurriedly, scolding, restraining, or using physical force. These approaches generally will make the person more agitated and confused and may result in striking-out

behavior. The person will not understand logic and reasoning. Sometimes medication can lessen wandering behavior.

Alert neighbors and local merchants to the memory-impaired person's problems and ask them to contact you if they see the person leaving the area.

Have the impaired person wear an identification or medical-alert bracelet that gives his name, address, telephone number, the phrase "memory-impaired" or "brain-impaired." Giving the diagnosis, such as "Alzheimer's disease" or "dementia," may not be as helpful because some people may not know what that means.

Membership in the Alzheimer Association's program "Safe Return" provides registration in a national database and access to a nationwide alert system of law enforcement agencies, a 24-hour toll-free telephone number to contact when the person is lost, an identification bracelet or necklace, wallet cards, and clothing labels. The person who finds the wanderer can call the Safe Return number. The operator immediately calls the family members or caregivers listed.

Create safeguards against the person exiting the home and wandering. For example:

- Install locks at the top or bottom of doors where they are out of the person's direct line of sight
- Disguise exits by painting doors the same color as the wall or covering the doors with curtains
- Install electronic alarms or warning bells that sound when outside doors are opened



- Use dead-bolt locks that you can lock on the inside with a key

A room with an expansion safety gate across the open door (often used for small children) may provide an area where the person can pace and explore safely. However, if the person is a "climber," a gate could be hazardous.

Never leave a memory-impaired person alone in a parked car. He or she may wander away or cause an accident by starting the car or releasing the brake. Prevent a person from leaving a moving car by locking doors and using seat belts.

Wandering frequently occurs at night and may be the result of disorientation. Nighttime wandering also can be a sign of congestive heart failure. A medical checkup may be indicated. Wandering at night can be particularly disruptive to the caregiver's sleep—and thus to the caregiver's physical and emotional well-being. Keeping the person awake and active during the day generally promotes better sleep at night.

If medication taken during the day to control behavior is making the person sleepy, talk with the doctor. Changing the medicine or the dosage schedule may reduce daytime drowsiness and encourage sleep at night. Make sure the person empties his or her bladder before going to bed.

The quiet and darkness of a home at night may also increase restlessness for some people. Using a night-light or playing the radio softly may reduce wandering and confusion on waking.

Sundowning

Individuals with a progressive dementing illness sometimes experience more confusion and behavior problems in the late afternoon and evening. This sometimes is called *sundowning*.

The cause is unknown but may be due in part to dim light as darkness approaches, resulting in confusion. The impaired person may be tired and less able to cope with stress or, alternatively, may grow restless as activities gear down at the end of the day. Evaluate the person's daily activities. Behavior problems might be managed by:

- Lowering the noise level and decreasing activities in the evening hours
- Providing regular daily activities, such as exercise
- Restricting the person's intake of caffeine-rich liquids and foods
- Increasing lighting in the evening and using night-lights

It may help to alternate activity (including dressing and meals) with quiet time. To reduce stress for a person at the end of the day,

consider including a 30-minute rest period each morning and afternoon. Reduce all noise and distractions during this time (soft music may be the exception).

If the behavior occurs in the evening after a trip to a restaurant, a friend or family member's home, a store, or a vacation spot, it may mean the person can't cope with the activity any longer. Be prepared to gear down.

Catastrophic reactions

Memory-impaired people sometimes overreact when a request, task, or situation overwhelms their thinking ability. Try to avoid catastrophic reactions by simplifying tasks, requests, and the environment. Signs of an impending outburst may be refusals, restlessness, and blushing. Stubbornness, pacing, wandering, and weeping are common reactions. Rapidly changing moods, anger, and aggressive behavior also may occur.

■ **Pay attention to what triggers catastrophic reactions.** This information may help you avoid future catastrophic reactions. Common causes of catastrophic reactions include frustration, overstimulation, fatigue, small mishaps, inability to perform a task, strange noises, certain people, a confusing or unpredictable environment, and scolding or arguing.

■ **How you react is important.** After mishaps, remain calm and allow time for the person to calm down. It may work to ignore the behavior, leave the room, and let the person be alone if she is acting out and there is no risk of injury.

Otherwise, calmly remove her from the stressful situation.

- **Distract or redirect.** Most memory-impaired people are easily distracted. Try to divert the person from the situation. Distract with a favorite treat or activity. Do something familiar together, such as having a glass of juice or going for a walk. Soft music, holding hands, and rocking may provide calm. Sometimes bringing in another person to visit or engage in a quiet activity with the person is helpful.
- **Avoid explaining, arguing with, or restraining the person.** Usually these approaches only make a person more confused, angry, or combative. Recognize that feelings of distress may linger after the situation has been forgotten. And remember, the behavior is beyond the person's control and can't always be prevented, even by the most experienced caregiver.
- **Identify if increased agitation and irritability are the result of internal discomfort.** For example, a person who experiences pain or constipation isn't always able to put this discomfort into words. Any sudden deterioration in functioning or behavior may be a warning signal of a fall or illness. Check with the person's doctor. Correcting even minor physical and medical problems often improves the person's functioning.
- **Leave and call for help if you are alone and your safety**

is in jeopardy. Call 9-1-1 or call the police. Explain that the person cannot help his behavior but that the situation is getting out of control and you need help.

- **Seek professional help.** Get help on how to reduce and cope with catastrophic reactions. Due to the progressive nature of dementia, aggressive behaviors will lessen over time.

Hallucinations and delusions

Individuals with dementia may see or hear things that exist only in their minds. For example, one person saw a cow on top of the neighbor's house. Another saw rats running under her bed. Such hallucinations may be a source of intense fear, or they may be a source of humor for the person. The impaired person may say things have been stolen or that someone is going to harm him. These delusions can make a person fearful and resist all attempts at care and help.

- **Respond calmly to what the person is feeling and provide reassurance.** Remember, the person's experiences and beliefs are based on his or her reality. For example, if the person finds it humorous that a cow is on the roof say *"I don't see the cow on the roof, but it must be funny"* or if the person is frightened you could say, *"I didn't see the rats run under your bed. But don't worry; I will take care of them."* Reassure the person that you will see that things are all right.
- **Do not argue or try to reason with the person.** It usually only makes matters worse.



The person can't stop the hallucinations just because they're illogical or unreal to someone else, and will not be able to remember your reasoning or rationally weigh your points.

- **You will learn what works best.** Sometimes it's helpful to gently touch the person. If the person is not upset and has forgotten the situation, you might choose to ignore the behavior. Distracting the individual may be effective. Medication may also be useful to lessen the intensity, frequency, and anxiety of the hallucinations and delusions.

Hiding and losing things

Memory-impaired individuals sometimes lose things, hide objects, or put them in "safe" (and promptly forgotten) places. They may not return items to their customary places but are adamant that they always keep an object in a certain place. When the object is not in that spot, the person may accuse the caregiver or others of stealing his possessions.

- Remain calm if accusations are directed at you. Keep in mind that the person truly cannot remember that he did something with an item. Again, arguing or trying to reason with the person rarely works. It's better to remain calm and offer to look for the missing item. Look for lost items in dresser drawers, boxes, coat pockets, shoes, and wastebaskets, and under cushions and mattresses.
- **Reduce hiding places.** Lock closets, cupboards, and rooms the person doesn't use.

- **Safeguard important things.** Keep important and valued items locked up. Hide a spare set of household and car keys in case your set disappears.
- **Remember where lost items are found.** Look there the next time something is lost. Check garbage cans before emptying if these become hiding places.

Bathing and grooming

Most people feel and act better when they are well groomed. Bathing and grooming activities may be made easier for the impaired person in these ways:

- **Use cues.** Early in the disease, a checklist of activities—brush teeth, wash face, shave, comb hair, etc.—put by the bathroom mirror helps some people with grooming activities. However, as memory loss progresses, some individuals forget or resist bathing and changing clothes. Reminders about the necessity of these activities and using simple explanations may work. Bathing instructions written by a physician on a prescription pad, "bathe twice weekly," may help persuade a person to bathe. Avoid arguing about whether he or she needs a bath or shower. If possible, try to maintain a person's lifelong routine. For example, if he or she took a shower before breakfast, try to follow this habit.
- **Recognize feelings.** Bathing also may become frightening. The person may not be able to understand that someone who is undressing him is being helpful and is not trying to harm him. Water rushing out the pipe, going down the

drain, or hitting against his body may be frightening. Remember, the person's brain may no longer process information accurately.

■ **Lower your expectations.**

You may need to lower your expectations about frequency of bathing when it becomes a struggle for both you and the impaired person. A sponge bath may be the best alternative. If the bathroom is warm and the atmosphere is calm, the person may be more cooperative.

■ **Prepare the environment.**

Some families find it helps to warm the bathroom, play soft music, and fill the bath tub with 3 to 4 inches of water before the person enters the bathroom. Using a shower chair for both baths and showers, installing grab bars, and using a shower head on a flexible hose may also make bathing easier.

- **Balance independence with safety.** Bathing is a private activity, and for some people it can be embarrassing to receive assistance. Allow the person to do independently as much as possible. Try shutting a shower curtain or turning your back but stay in the room. Never leave the person alone in the bathtub or shower.

Simplify dressing

Encourage dressing by laying out clothes in the order in which they are to be put on. When necessary, show the person what to do. Just as there are many steps in bathing, there are many steps to getting dressed. The person may no longer be able to remember these steps or do them in the

correct sequence. Break down a task into small steps, giving step-by-step instructions (cues) such as “unbutton your shirt,” “take off your shirt,” etc.

- Provide clothes that can be put on and taken off easily. Consider replacing clothing that has buttons, hooks, snaps, ties, and zippers with slip-over and slip-on shirts, skirts, pants, and shoes. This also means fidgeting fingers can't unzip or unbutton clothing in public. Select nonslip shoes and slippers that close with Velcro
- Select easy care, wash-and-wear clothing.
- Support preferences. Don't argue if the person wants to wear the same clothing every day or insists on sleeping with a hat on. This is not harmful. If the person prefers to wear only one outfit, you can make life easier by buying another one just like it.

Mealtimes

As dementia progresses, some individuals forget to eat. Others forget they have eaten—and want to eat constantly. Setting out a small tray of nutritious snacks or serving less food more often is sometimes a solution. With increasing brain deterioration, people frequently lose their coordination and table manners. They may eventually lose the ability to use a knife and fork or to make proper food choices. For example, they might put gravy on salad instead of on potatoes.

- **If you go out to eat, keep it calm and simple.** Select a restaurant that is small, quiet, and familiar. Problems



are more likely to develop in large, noisy, dimly lit settings. Depending on the degree of memory loss, the person may or may not be able to read a menu or order.

- **At home, keep menus and meal routines familiar.** Sometimes a person will eat only one food several times a day or develop specific likes and dislikes. Accept the behavior if it doesn't interfere with overall nutrition and dietary restrictions. It's better for a person to eat what he or she wants than not eat at all. However, if he or she is on a restricted diet because of a condition like diabetes or high blood pressure, you may need to put restricted foods out of reach.
- **Be consistent.** Consistency at mealtimes and a calm atmosphere without distractions usually help the person to function best. Set the table in the same way, serve meals at the same time each day, and seat the person at the same place.
- **Remove unnecessary utensils, condiments, and**

foods. A person may become confused if he or she has to choose among them. Sometimes it helps to serve only one food at a time.

- **Prepare the person's plate.** Cut food into small pieces. Use finger foods when the person can no longer use utensils. Serve soup in a cup if the person has difficulty handling a spoon. Use a plastic cloth on the table, spill-proof containers, and smocks with the bottom edge turned up into a big pocket to catch crumbs.
- **Serve foods lukewarm, not hot.** The person may have lost the ability to judge food temperatures.
- **Avoid foods the person may not chew thoroughly or swallow easily.** Difficult to chew foods include nuts, popcorn, and raw carrots. Liquids and solids offered together may be confusing—the person may not know whether to chew or to swallow.
 - Foods of a soft, even consistency (like purées) are easiest to swallow. Thin liquids (water, apple juice, coffee) are the hardest to swallow.
 - A person who has difficulty swallowing should sit up straight with her head tilted forward slightly—never back—and should remain seated at least 15 minutes after eating. If she begins stuffing too much food into her mouth, remind her to swallow. Don't allow the person to lie down or walk around with food in the mouth.
 - As the disease progresses, you may need to remind the person to swallow after *each bite*.

■ **Learn about spoon feeding.**

If you have to spoon-feed the person, talk with a nurse or speech pathologist who specializes in swallowing about the best procedure to follow.

■ **Respond to choking quickly.**

Know the Heimlich maneuver. It can save the life of a choking person. This maneuver helps to pop food out of the airway by expelling air from the lungs. A medical professional or the Red Cross can teach you this technique.

■ **Contact the doctor** if the person completely stops eating or begins to steadily lose weight. These changes may be symptoms of a complicating condition.

Incontinence

Incontinence is such a difficult problem to manage that it is often the “last straw,” prompting caregivers to place the person in a long-term care residence. Incontinence has many medical causes, such as infection, that can be treated. Therefore, when incontinence begins, it’s important to get a medical evaluation. At first, loss of bladder or bowel control may only occur occasionally or during sleep. Later, the person may not be able to respond to the body’s signal to void or to remember the acceptable places and ways to eliminate bodily wastes. A man, for example, may urinate in the closet or wastebasket or on the sidewalk in town. Consider the following actions:

■ **Establish a regular toileting routine.** You may need to remind the person every 2 or 3 hours—on rising in the morning, after meals, and

before bedtime—to go to the bathroom. Take the person to the toilet at the time of day he or she usually has a bowel movement. It often works better to say *“It’s time to go to the bathroom”* than to ask *“Do you have to go to the bathroom?”*

- **Observe behavior for cues.** For example, sudden restlessness or picking at clothes may indicate the person needs to use the toilet. Be aware that he or she may need some assistance to undress or to use the toilet.



- **Take steps to help prevent accidents.** For example, limit fluid intake after the evening meal. Get the person up once during the night or place a commode or urinal bottles near the bed. Use night-lights to improve the person’s orientation and ability to find the bathroom.
- **Use incontinence products.** When a regular toileting schedule does not work, use special clothing with disposable pads, absorbent undergarments (sometimes called adult diapers), protective bedding, and disposable bed pads available from medical supply, home health, or drug stores. Consult the physician or a nurse for additional products available for bladder and bowel incontinence.
- **Keep the person clean and dry.** When a person is

Guidelines for talking with a person who has dementia

Call the person by name. Before asking a person to do something, address the person by name to get his or her attention. In some instances, a person may better recognize and respond to a childhood nickname than his or her given name. Sometimes a memory-impaired woman may not respond to her married name because she no longer remembers the name or the marriage.

Speak slowly and clearly. People who are memory-impaired need more time to comprehend a message. Allow the person time to process information and respond.

Talk about real actions and objects. People lose the ability to deal with abstract concepts such as planning and using judgment to avoid potential danger.

Keep statements short and simple. Limit statements to one idea at a time. For example, say, *"Your hair looks pretty"* and *"Please come to the table."* Give instructions one step at a time. Long sentences, complex instructions, and lengthy explanations can overwhelm people who are memory impaired.

Be specific. Statements that are specific frequently help the person grasp what you are saying. *"Pick up your glass on the table"* is preferable to *"Pick up your glass"* because it gives the person more specific information and may help to focus actions.

Keep questions simple. Ask one-part questions—for example, *"Do you want orange juice?"*—which can be answered with a "yes" or "no" response or by a gesture. Avoid open-ended questions such as *"What do you want to drink?"* or *"What do you want to eat today?"*

Avoid complicated, multiple-part questions. For example, *"Do you want tea or coffee, and do you want it now or with dessert?"* To answer such a question the person has to think about what (tea or coffee) and when (now or later). Such questions add to confusion and stress.

Provide solutions rather than ask a question. Eventually, even questions requiring only a yes or no response are difficult for some people. When this occurs, say *"Here is your orange juice"* rather than ask *"Do you want orange juice?"* It's less confusing to provide the solution than to ask a question.

Avoid quizzing the person. For example, *"Do you know my name?"* *"What is this I am holding?"* *"What day is today?"* *"Do you remember when...?"* Such questions can frustrate and agitate the person who can no longer remember and answer.

Use names or nouns, not pronouns. For example, instead of saying *"Your best friend is coming to see you. She wants to make cookies with you,"* it is better to say *"Your friend, Cynthia, is coming to see you. Cynthia wants to make cookies with you."*

Make positive statements. It's easier for people who are memory impaired to understand what you want them to do than what you don't want them to do. Use clear, positive statements and avoid negative words such as "no" and "don't". Saying *"Please sit in this chair"* is more likely to get the desired response than saying *"Don't sit there."*

Use positive nonverbal communication. Many people with dementia are far more sensitive to a speaker's tone of voice and body language than the actual words spoken. Therefore, it's important to be aware of how you are communicating with tone of voice, facial expressions, and gestures. Be sure your words and body language are consistent. If they contradict each other, the person is more likely to respond to your body language. If your words say something kind but your body language is saying you are irritated and upset, your body language usually carries the stronger message.

Use the person's vocabulary. For example, if the person uses the word "potty" for toileting activities, then use that word, too.

Use touch. When a person no longer understands speech, touch can become the most meaningful way to communicate. Tender hugs, holding hands, gently combing the hair, and giving a massage can communicate acceptance, love, and caring. Touch is also soothing and can reduce feelings of isolation. However, the need for touch must be met on an individual basis. Each person has a different level of comfort with touch and some people are not comfortable with touch. Sometimes a person with dementia may also misinterpret the meaning of a touch. If this occurs, respond calmly.

incontinent, it's important to keep the anal and genital area as clean and dry as possible. This will help reduce Urinary Tract Infections (UTIs). Also, watch for redness and other signs of skin irritation.

Communicating with the memory-impaired person

The effects of dementia on communication vary with each person and the stage of the illness. Early in the disease, communicating isn't too difficult, although the person may have problems finding the correct word, especially nouns. The person may substitute phrases for words. For example, if a person cannot think of the word "coffee," he or she may tell you *"It's what I drink in the morning."* Language also may include indefinite words such as "thing," "this," "that," and "there."

If the person cannot take telephone messages, disconnect the telephone when you're unable to answer it. Install an answering machine, use voicemail, or subscribe to an answering service.

As dementia progresses, the person may have difficulty expressing ideas and easily lose his or her train of thought. As a result, he or she may not be able to understand instructions or to report physical needs, discomfort, or pain to caregivers. Late in the disease, a person's vocabulary may be reduced to a few words. Some individuals use curse words often or revert to speaking in their first language. When the memory-impaired person can no longer communicate verbally, be sensitive to facial expressions, tone of voice, body position, and eyes.

Kindness, patience, respect and flexibility are essential to

communication. As the disease progresses, the person's way of communicating will change. You will need to change your expectations and how you communicate. **For guidelines on communication, see page 32.**

When it is time to move on from full-time family care

When living at home is no longer safe, the personal care and safety needs of the impaired person exceed the resources and abilities of the home caregiver, or caregiving threatens the safety and health of the caregiver, moving the impaired person to a long-term care residence is often the best option. The Alzheimer Association also says a long-term care residence may be desirable if the impaired person wanders, is a danger to self or others, is unable to care for himself in the most basic ways, or frequently interrupts another's sleep.

While moving a person to a long-term care residence is often a difficult decision, it's important to realize you have not failed, broken a promise, or abandoned a loved one. You only give up the physical chores of daily care.

Unfortunately, too many families hesitate to plan for, or even consider, the possibility of a move until a crisis occurs (for example, a sudden change in the memory-impaired person's health, functioning, or behavior, or the caregiver's unexpected illness or death). Plan ahead! It will help you make the best possible decisions.

■ **Be informed and prepared.**

Before a crisis occurs, discuss with your family and medical providers the conditions under which a long-term care residence might be the

best option. What would such care mean financially and personally? Explore the resources—including personal finances, long-term care insurance, Medicare, Medicaid—that may help with costs.

Meeting with an attorney who specializes in elder law can help protect resources for spouses. Visit some residences or facilities, especially those that specialize in dementia or “memory care.”

Recognize it takes time for a person to adjust to a move. Following a move to a long-term care residence, it is often best to keep visits short so the person gets into the new routine of “their new home” and involved in activities. A few treasured items from home can help make the person’s room feel more familiar and comfortable. Ask the staff for advice on how to make the transition as smooth as possible for your family member. They have been through this many times and will have good ideas on adjustment.

- **Expect improved relationships.** Most families find that after a period of adjustment, relationships improve. Families can focus on being supportive and meeting the person’s emotional and social needs rather than focusing on caregiving tasks. As one administrator of a care facility said, “Anyone can give a bed bath or help a person to dress, but only a family member

knows the favorite treats, events, and memories that are meaningful to the person.”

As you choose a long-term care residence, look for one that offers a friendly, supportive, community atmosphere, and has staff trained in dementia care and residents who are engaged in activities that match their abilities. For more specific information about long-term care options, refer to PNW 563 *Making Decisions About Long-term Care (LTC) Options*.

Additional resources

For further information on caring for a memory-impaired person, contact:

The Alzheimer’s Association
www.alz.org

The Alzheimer’s Association works on a global, national, and local level to enhance care and support for all those affected by Alzheimer’s and other dementias. The association offers:

- Local chapters across the nation, providing services within each community, including education and support groups. You can locate a chapter near you at www.alz.org
- A professionally staffed 24/7 Helpline (800-272-3900) and translation services in more than 200 languages.
- An online message board, ALZConnected, to answer questions and provide support.
- A free online tool, Alzheimer’s Navigator, helps determine and develop an action plan.
- A free online Community Resource Finder database of

programs, housing and care services, and legal experts

- Alzheimer's and Dementia Caregiver Center features information on caregiving as dementia progresses through early, middle, and late stages.
- Safety services, including Comfort Zone, MedicAlert, and Alzheimer Safe Return, provide location management for people with Alzheimer's who wander.
- A free matching service (TrialMatch) that connects individuals with Alzheimer's, caregivers, volunteers, and physicians with current clinical studies
- The nation's largest library and resource center on Alzheimer's disease and related dementias, and the annual Walk to End Alzheimer's is the world's largest event to raise awareness and funds for Alzheimer's care and support.

Alzheimer's Disease Education and Referral Center (ADEAR)

<https://www.nia.nih.gov/alzheimers>

Call 800-438-4380, Mon.-Fri., 8:30 a.m.-5. p.m. Eastern Time

ADEAR, a service of the National Institute on Aging (NIA), offers information and current research on Alzheimer's and other dementias. Many practical resources are available to assist patients, caregivers, and health care professionals. Some ADEAR

resources are available in Spanish. Of special interest to caregivers are:

- *Caring for a Person with Alzheimer's Disease: Your Easy-to-Use Guide*
- *Understanding Alzheimer's Disease*
- *Alzheimer's Disease Medications Fact Sheet*
- *Home Safety*
- *Long Distance Caregiving*
- *Helping the Memory Impaired Stay Physically Active*

Useful books for family caregiving

How to Care for Aging Parents, 3rd Edition: A One-Stop Resource for All Your Medical, Financial, Housing, and Emotional Issues. Virginia Morris. 2014.

The Emotional Survival Guide for Caregivers: Looking After Yourself and Your Family While Helping an Aging Parent. Barry J. Jacob. 2007.

AARP Meditations for Caregivers: Practical, Emotional, and Spiritual Support for You and Your Family. Barry J. Jacobs & Julia L. Mayer. 2016.

The Complete Eldercare Planner, Revised and Updated Edition: Where to Start, Which Questions to Ask, and How to Find Help. Joy Loverde. 2009.

The Caregiver's Toolbox: Checklists, Forms, Resources, Mobile Apps, and Straight Talk to Help You Provide Compassionate Care. Carolyn P. Hartley and Peter Wong. 2015.

Useful books specifically related to Alzheimer's disease and related dementia:

The Best Friends Approach to Alzheimer's Care. Bell, Virginia and David Troxel. 1997

The Alzheimer's and Dementia Caregiver's Helpbook: 101 Tips, How-to's & Great Ideas to Help a Mildly Impaired Loved One Live 'Independently' Longer. Jessica Hatchigan. 2013.

Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease. Joanne Koenig Coste. 2004.

The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer Disease, Related Dementias, and Memory Loss. Peter

V. Rabins and Nancy L. Mace. 2008.

Creating Moments of Joy for the Person with Alzheimer's or Dementia: A Journal for Caregivers, Fourth Edition 4th Edition. Jolene Brackey, 2015.

OSU Extension Service publications

Coping with Caregiving: How to Manage Stress When Caring for Elderly Relatives (PNW 315).

Making Decisions about Long-term Care (LTC) (PNW 563).

Loss and Grief in Later Life (PNW 439)

Aging Parents: Helping When Health Fails (PNW 246)

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