

# Helping Memory-impaired Elders

**A GUIDE FOR CAREGIVERS**



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### **Acknowledgments**

Photos by Rod Schmall, West Linn, OR.

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 3 blocks from home. He felt frustrated and afraid, 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.

Getting older does not necessarily 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 more appropriate word to describe the significant

This publication is designed to give family and professional caregivers a fuller understanding of dementia in later life and ways to cope more effectively with the changes resulting from it.

In addition to general care guidelines, the publication outlines approaches for handling specific problems—driving, wandering, money management, hiding items, catastrophic reactions, hallucinations, eating, and incontinence—and how to communicate with a memory-impaired person.

progressive loss of mental abilities that some older people experience. Symptoms of dementia include impairment in thinking, learning, memory, and judgment, and changes in personality, mood, and behavior.

Dementia is the result of a disease process. It is more common with advancing age but 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 do not interfere with a person's daily functioning.

Many other factors can affect memory. These include stress, 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 been erased from the mind.

Confusion and cognitive impairment sometimes are caused by treatable illnesses, reactions to medications, drug toxicity, alcohol abuse, depression, poor nutrition, infections, and metabolic disorders such as a thyroid problem.

Any memory loss that interferes with a person's lifestyle, work or daily functioning should be evaluated. A variety of diagnostic tools can help physicians assess whether a memory problem is significant. Finding the cause of memory loss is critical to appropriate treatment.

### **Causes of dementia**

The onset and course of dementia depend on the nature of the particular disease causing it. Symptoms can vary widely, and no two afflicted persons follow precisely the same course or rate of progression.

Alzheimer's (ALZ-hy-merz) 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.

As the disease progresses, the person loses more and more of her memory and other abilities. Eventually, she is not able to function independently. The time from onset to total disability varies from 3 to 20 years.

Alzheimer's disease is diagnosed by ruling out all other causes of the symptoms. As of 2005, there was still no way to be certain of a diagnosis of Alzheimer's disease without a brain biopsy or autopsy. However, if diagnostic testing is comprehensive, one can be fairly certain that a diagnosis of probable Alzheimer's is accurate.

Currently, there is no known cure or prevention for Alzheimer's disease. Researchers, however, are making great strides in understanding the disease and in helping the afflicted person and his or her family to function better.

The second most common cause of dementia is vascular dementia. The brain's blood supply is interrupted, resulting in small strokes in the brain. The person may lose some function with a small stroke (or a series of small

strokes) and stay at that level of impairment until the next mini-stroke. He may even appear to improve slightly for a time. Symptoms depend on which area of the brain has been damaged.

Progressive dementia may also be due to Pick's disease, Creutzfeld-Jakob disease, Huntington's disease, Parkinson's disease, AIDS, or other, relatively rare, conditions.

### **The family's adjustments**

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!

It's like a funeral that never ends.

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*Dementia due to an underlying medical condition may be partly or completely reversible. Early evaluation is important, because treatable conditions may become irreversible if left untreated.*

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*Everyone who supports and cares for the impaired person benefits from information about the disease.*

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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. She may write herself “memory notes,” make light of the changes, blame others (“Who took 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 are difficult for even the professional to diagnose.

Dementia also means tasks and responsibilities gradually shift from the impaired person to the caregiver. The added responsibility can be overwhelming.

Many caregivers become socially and emotionally isolated. The 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 they find it difficult to see the deterioration in the person or to accept the behavior and personality changes. 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.

The healthy spouse also loses a companion, a sex partner, and someone with whom to share life’s joys and problems.

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. The most common reasons for placing a memory-impaired person in a care facility are that the caregiver can’t manage alone any longer, becomes ill, or dies.

## **Self-care for the caregiver**

Caregivers must take care of themselves as well as the person with dementia. Here are self-care guidelines for the caregiver.

**Learn about the disease.** Everyone who supports and cares for the impaired person benefits from information about the disease. Learning 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.

**Don't hide. This 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 the following.

- Dementia causes the brain to fail, just as heart and kidney diseases cause those organs to fail.
- The disorder is not contagious.
- People afflicted by the disease are not "insane" or "crazy."

- 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.

**Ask for and accept help.** 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. And be appreciative. Don't be a martyr—this is likely to turn off caring helpers. Realize that some people will help more than others.

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



In addition, the Alzheimer's Association has chapters in most states. 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 senior services department or the community education department of your local hospital.



**Maintain meaningful relationships.** Build and fortify your relationships early in the disease. Family and friends can be a source of great comfort, help, and pleasure.

Caregivers who take time away from their responsibilities to meet their own needs for companionship and recreation generally feel

less trapped and less isolated, and they are better able to care for the impaired person.

**Take a break from caregiving.**

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

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 and/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 or a needed vacation.

Be frank with anyone giving respite care. Family members not involved directly in care may not realize the demands of caregiving or may fear the responsibility. Give respite care providers 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 problems. Sooner or later, a substitute care provider may have to confront difficult behavior. Workbooks such as *The Carebook: A Workbook for Caregiver Peace of Mind* (see page 33) give a step-by-step guide to information that would help any substitute care provider. A brief note reminding the memory-impaired person of the caregiver's whereabouts and hour of return may reduce questioning and anxiety. This information is also important when the person is left in an unfamiliar place for a short time.

**Understand and accept feelings as normal human responses.**

Families and caregivers dealing with a dementing illness have mixed and powerful feelings—

grief, anger, sadness, embarrassment, shame, guilt. Remember that 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.

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.

No matter how much a caregiver loves the memory-impaired person, dealing with that person's behavior can be exhausting and difficult. Caregivers, too, have emotional limitations, and they need opportunities to express their anger, frustration, and hurt. They need to acknowledge their right to feel angry, and then they need to do something constructive about it. It's important to find someone who is willing to listen to and understand such feelings.

Guilt feelings are common. Caregivers may feel guilty about their anger, misdeeds of the past, wishing for the impaired person's death, or about mistakes or outbursts in dealing with the person. Caregivers must forgive themselves and consider that the impaired person has already forgotten.

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Adult sons and daughters who are caregivers commonly experience divided loyalties. Competing demands from children, spouse, other family members, and a job 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.

**Make realistic commitments.**

Nearly everyone has made an emotionally laden promise based on an unknown future. One of the most common is a promise never to place a family member in a care facility.

Unforeseen circumstances may make it impossible to keep some promises. Recognize that conditions under which such promises were made were quite different from the current situation. A realistic commitment doesn't include words such as "always," "never," or "forever." It's a pledge to do *something*, but not *everything*, regardless of what happens.

It's important not to let old promises or guilt guide decisions. They reduce objectivity and your ability to make the best choice. Consider what is best for you and

your family as well as for your memory-impaired family member. It's critical not to sacrifice your own physical and emotional health.

**Hope for the best, plan for the worst.** Caregivers need to look at a broad range of questions in planning.

- What are the legal and financial aspects of progressive mental impairment? What should be done, and when? For information, see *If You Became Incapacitated, Who Would Make Decisions for You?* (page 33).
- Where are important documents and valuables? For information, see *Where Are Your Valuable Papers?* (page 33).
- How can family, friends, and community services help with care?
- What arrangements can be made for respite?
- What should be done in an emergency?
- What community services could help the memory-impaired person or the caregiver?
- Under what conditions would a care facility be best? What does this mean financially and personally?

A time may come when placement in a care facility is best for everyone. It's often a very difficult decision. Some families hesitate to plan for the possibility

until a crisis occurs; for example, a change in the memory-impaired person's health or the caregiver's unexpected illness or death. Being informed and prepared helps avoid making unsatisfactory choices.

The Alzheimer's Association says placement 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.

**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 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.

For more information, contact the Alzheimer's Association's national office, 225 North Michigan Avenue, Floor 17, Chicago, IL 60601. A 24-hour toll-free line (1-800-272-3900) gives information and referral nationwide to local chapters. The website is <http://www.alz.org/>

The Alzheimer's Association also publishes a quarterly newsletter that reports current research about dementing illnesses and offers practical suggestions for coping.

For information about the nearest support group in Oregon, contact the Alzheimer's Association Oregon Chapter, 1311 NW 21<sup>st</sup> Ave., Portland, OR 97209. Toll-free 1-800-733-0402; Web <http://www.alz.org/oregon/>

Washington has a Western and Central Washington State Chapter at 12721 30<sup>th</sup> Ave. NE, Suite 101, Seattle, WA 98125. Toll-free 1-800-848-7097; Web

<http://www.alzwa.org/>

An Inland Northwest Chapter serves eastern Washington and northern Idaho at 601 W. Maxwell, Suite 4, Spokane, WA 99201. Toll-free 1-800-6659; Web <http://www.inwalza.org/>



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*The more secure and comfortable a person feels, the less likely she will have behavior problems.*

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In Idaho, contact the Alzheimer's Association Idaho Regional Office, 1111 S. Orchard St., Suite 200, Boise, ID 83705; 208-384-1788; toll-free 1-800-272-3900.

The Alzheimer's Disease Education and Referral Center, a service of the National Institute on Aging, provides information and publications on Alzheimer's disease. Toll-free 1-800-438-4380; Web <http://www.alzheimers.org/>

### **General guidelines for caregivers**

The amount of care, supervision, and help a memory-impaired person needs depends on the extent 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 around a lot of activity, rushed, 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.

The more secure and comfortable a person feels, the less likely she will have behavior problems. If she becomes upset or resistant, it's important to remain calm. If necessary, 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. Plan simple family events or outings after quiet days or on otherwise quiet days.

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.

Arguing and scolding usually will only cause the person to overreact. Remember: The person's behavior is a result of the *disease*, not stubbornness or willfulness.

**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 rearranging bedroom furniture.

Create a routine by doing things the same way at the same time each day. This 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, at the same time, and use the same route.

Establish a schedule of daily activities based on the impaired person's lifelong patterns, if possible. Plan more difficult tasks for the person's best time of day. Keep in mind that the memory-impaired tend to have short attention spans, 30 minutes or less.

Post the 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 you must make changes, prepare and support the person but avoid lengthy explanations. Take care when planning a trip or vacation. Some people become agitated and more confused in unfamiliar surroundings.

**Simplify tasks.** Tasks that previously were easy for the person may become too difficult. Reevaluate skills when the person becomes frustrated by a task or refuses to cooperate.

Breaking down complex tasks into simple steps and giving the person step-by-step instructions may enable her to continue to do some tasks. For example, the person may be able to help set the table as long as she can deal with items one at a time.

### **In caring for the memory-impaired...**

Keep expectations realistic.

Maintain a calm atmosphere.

Be consistent.

Simplify tasks.

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.

Treat the person as an adult.

Reassure and praise.

Maintain your sense of humor.

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*The success of memory aids depends on the severity of the disease.*

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Demonstrating each step also may help; for example, brushing your teeth at the same time as the impaired person. Occasionally, 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 perhaps even the shoes.



Think about parts of activities that the person previously enjoyed and can still do. For example, 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. The former gardener may find satisfaction in raking the yard or watering plants.

**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.

Remind with brief, simple statements; avoid lengthy explanations. 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." Give the same brief answer each time she asks the same question.

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

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

*(continued on page 14)*

## **Make the environment safe**

Caregivers continually need to be aware of sources of danger. Don't expect the person with dementia to take responsibility for his or her own safety. Even a mildly impaired person may have lost the judgment needed to avoid accidents.

Three potential dangers are smoking, cooking, and driving. Others are stairs, swimming pools, and windows from which the person could fall.

Memory-impaired people sometimes forget they are smoking or forget to put out their cigarettes. 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. Lower the temperature setting on your water heater to 120°F to prevent burns. 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 other sharp objects, razor blades, alcohol, poisons, and cleaning supplies.

The memory-impaired 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. Lock windows or limit how far they open so the person cannot climb out. Install locks on outside doors to prevent the wanderer from leaving the house unnoticed. A hard-to-reach lock on the kitchen door also may be helpful.

Awakening in the dark can be disorienting. Installing night-lights in the bedroom, hallway, and bathroom and/or a strip of glow-in-the-dark tape from bedroom to bathroom increases nighttime safety and helps orient the person.

Be sure stairs are safe. In every room, remove objects a person might trip over, such as scatter rugs, footstools, and electrical cords.

Because memory-impaired people are at greater risk for accidents, it's helpful to know first-aid procedures. Contact your local Red Cross chapter about classes.

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*Caregivers continually need to be aware of sources of danger.... Even a mildly impaired person may have lost the judgment needed to avoid accidents.*

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Signs, clocks, calendars, seasonal decorations, and a schedule of the day's activities reinforce memory.

Give cues. For example, 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 impaired 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 schedule of the day's activities. Name events, and give the names of family members and friends who visit.

When speaking to a person who has difficulty remembering you, state your name and relationship to the person; for example, "I'm Jane, your daughter. I'm here to visit you." Avoid saying "Who am I?" when the person can no longer remember who you are.

**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.

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

**Treat the person as an adult.** Include the person in adult conversations and activities. Avoid talking down to him or talking about him as if he weren't present. Don't treat him as a child because then he is more likely to respond with childlike behavior.



Maintain an attitude of respect and dignity and allow the person to be as independent as possible, even if tasks are not done as well as you would like. A person with dementia needs to feel that his dignity remains intact.

**Reassure and praise.** People with dementia also 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.

Look for 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, continue to involve the person in activities that are meaningful and enjoyable.

**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 clothing to use the toilet.



### **Responding to challenging behaviors**

Dementia can cause a person to act in different and unpredictable ways, which challenge the caregiver. In dealing with a difficult behavior, it's important to accept the behavior as a reality of the disease, try to work through it, and not take the behavior personally. There is no one "best approach" that is guaranteed to work. You may need to try several approaches. It also helps to keep the following in mind.

- Difficult behavior is not willful.
- The impaired person is always right—from his or her point of view.
- The impaired person loses the ability to learn and to record information and events.
- The past becomes more real and lovable than the present.

- Emotions and feelings remain largely intact.
- The memory-impaired person cannot change—but everyone else must.
- Connect, don't correct.
- Use distraction.

**Difficult behavior is not willful.**

Irritating, rude, stubborn, and socially inappropriate behaviors are usually beyond the control of the person with dementia. The caregiver who blames the impaired person for his behavior or views it as being done on purpose may be setting up a self-destructive pattern of anger and frustration.

Key elements in responding effectively to difficult behavior are to:

- Recognize that the person is not intentionally being difficult
- Define the behavior, not the person, as the problem
- Look at the behavior as *reflecting a need* rather than simply as a problem

Try to understand the “why” of the behavior. Behavior usually does not occur in a void. There is a reason for it. The behavior serves a purpose but is not *done* on purpose. If you can discover that purpose, you often can devise an appropriate way to meet the need, and then the behavior may lessen or stop.

**The patient is always right—from her point of view.** Try to understand the world of the person with dementia and her perceptions, thoughts, and feelings. This will help you to better develop strategies to address a difficult situation.

For example, a radio talk show playing in an adjoining room may seem as if people are 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.

**The impaired person loses the ability to learn and to record 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, dementia steals the brain's ability to record information and events. Thus, the

person can no longer remember information 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 attended and enjoyed. 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 anyway." It becomes important then to look at the joy that is created for the moment.

**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 not without feeling. They can feel love, caring, joy, embarrassment, 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 16<sup>th</sup> 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 emotional climate.

**The person cannot change. We must change *our* behavior or 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 to change are not effective strategies. The disease "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.

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*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 and convey that you are unfriendly or not to be trusted.*

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## An Alzheimer's disease Bill of Rights\*

Every person diagnosed with Alzheimer's disease or a related disorder deserves the following rights.

- 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. Baltimore: Health Professions Press, Inc. Used with permission.

**Connect. Don't 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 she says. 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 and convey that you are unfriendly or not to be trusted. Try to connect with the person as a friend (see *The Best Friends Approach to Alzheimer's Care*, page 33).

**Use distraction.** The person with dementia tends to be highly distractible. Often you can interrupt difficult behavior or avoid potential 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." Avoid saying "This is your home" because that is more likely to lead to a disagreement.

## **Approaches to specific problems**

In addition to the 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 that 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 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. A person often will stop driving on the order 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.

For more information, see *Driving Decisions in Later Life*, PNW 510 (back cover).

### **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. 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 the caregiver. This may include obtaining a durable power of attorney, conservatorship, and/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.

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*Take care of financial and legal planning early to guarantee a safe financial future for both the impaired person and the caregiver.*

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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.

For more information, see *Helping Your Older Family Member Handle Finances*, PNW 344 (back cover).

### **Repetitive questions**

Being asked the same question five times in 15 minutes can try anyone's patience. It may help to understand that each time is like the first time to the person with dementia. The person may no longer be able to remember answers—or even that she asked the question before.

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.

### **Wandering**

Individuals with dementia may become disoriented and lost in their own neighborhoods or far from home. Any person who can get around alone 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.

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



direct 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. Logic and reasoning will not be understood. 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, and telephone number and includes the phrase “memory-impaired” or “brain-impaired.” Giving the diagnosis, such as “Alzheimer’s disease” or “dementia,” may not be as helpful because others may not know what that means.

Membership in the Alzheimer’s 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.

Safeguards in the home include:

- Installing locks at the top or bottom of doors, out of the direct line of sight
- Disguising exits by painting doors the same color as the wall or covering the doors with curtains
- Installing electronic alarms or warning bells that sound when outside doors are opened
- Using dead-bolt locks that you can lock on the inside with a key

A room with a 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 the impaired person alone in a parked car. He may wander away or cause an accident by starting the car or releasing the brake. Prevent him 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

## Wandering behavior can be triggered by a variety of circumstances

These include stress, medication, fear, and failure to recognize his surroundings. Look for possible reasons for wandering behavior.

- Did the person used to enjoy walking and outdoor activity, 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 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 security.
- Is the wandering directed toward a goal? Commenting on the need to perform a task 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 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.



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 bladder before going to bed.

The quiet and darkness of a home at night may also increase restlessness. 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. Include 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

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*You often can avoid catastrophic reactions by simplifying a task, a request, or the environment.*

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mean the person can't cope with the activity any longer. Be prepared to gear down.

### **Catastrophic reactions**

Memory-impaired individuals sometimes overreact when a request, task, or situation overwhelms their thinking ability. Stubbornness, pacing, wandering, and weeping are common reactions. Rapidly changing moods, anger, and aggressive behavior also may occur. Look for clues about what may be upsetting the person. Was the reaction the result of mounting frustration? Overstimulation? Misinterpretation of requests, events, or activities? Inability to perform a task? Fatigue?

A catastrophic reaction can be triggered by being asked to think of several things at once; small mishaps; strange noises, people, and places; a confusing, unpredictable environment; and scolding and arguing. Signs of an impending outburst may be refusals, restlessness, and blushing.

You often can avoid catastrophic reactions by simplifying a task, a request, or the environment. After minor mishaps, 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.

Most memory-impaired people are easily distracted. Try to divert the person from the situation. Distract her 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 help calm her. It also may help to bring in another person to spend time with her.

Avoid explaining, arguing with, or restraining the person. Usually, these approaches will make her only more confused, angry, or combative. Recognize that feelings of distress may linger after she has forgotten the situation. And remember that the behavior is beyond her control—and can't always be prevented even by the most experienced caregiver.

Sometimes, increased agitation and irritability are the result of internal discomfort—for example, pain or constipation—and the person isn't 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.

*If you are alone and your safety is in jeopardy, don't hesitate to leave and call for help.*

Call 9-1-1 (or the emergency-services number in your area) 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 about reducing future violent episodes and about how to cope with them if they do occur. 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 kept seeing a cow on top of the neighbor's house. Another saw rats running under her bed. Such hallucinations can be disturbing and a source of intense fear, or they may be a source of laughter and 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 him fearful and resistant to all attempts at care and help.

Respond calmly to what the person is *feeling* and provide reassurance. Remember that his experiences and beliefs are based on his reality. For example, say "I don't see the cow on the roof, but it must be funny" (if the

person finds it humorous that a cow is on the roof) or "I didn't see the rats run under your bed. But don't worry, I will take care of them."

Do not argue or try to reason with the person. It usually makes matters worse. The person can't stop the hallucinations just because they're illogical or unreal to someone else, nor will he be able to remember your reasoning or rationally weigh your points.

It may help to touch the person gently and offer reassurance that you will see that things are all right. Some caregivers choose to ignore the behavior if the impaired person is not upset and has forgotten the situation. Again, it may help to distract the individual. Medication may 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 by locking closets, cupboards, and rooms the person doesn't use. Keep important and valued items locked up. Hide a spare set of household and car keys in case your set disappears.

Note where lost items are found, as a reminder of where to look 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. 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 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 the person to bathe. Avoid arguing whether he needs a bath or shower. If possible, try to maintain his lifelong routine. For example, if he took a shower before breakfast, try to follow this habit.

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, his brain may no longer process information accurately.

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.

Some families find it helpful to fill the tub with 3 to 4 inches of water before the person enters the bathroom, to use a shower chair for both baths and showers, to install grab bars, to use a shower head on a flexible hose, and to play soft music.

Bathing is a private activity, and for some people it can be embarrassing to receive assistance. Allow the person to do as much as possible for himself. However, never leave him alone in the bathtub or shower.

Simplify bathing and dressing. Encourage dressing by laying out clothes in the order in which they're put on. When necessary, show the person what to do. There are many steps in taking a bath and getting dressed. The person may no longer be able to remember these steps or do them in the correct sequence. It helps to break down a task into small steps, giving the person step-by-step instructions such as "unbutton your shirt," "take off your shirt," etc.

Provide clothes that can be put on and taken off easily and that enable the person to dress independently. You can replace

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.

Wash-and-wear clothing is easiest to care for. 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**

If you go out to eat, try to 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 order.

At home, keep menus familiar. Sometimes the impaired 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 she wants than not eat at all. However, if 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 her reach.

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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 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.

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 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 she can no longer use utensils. Serve soup in a cup if she 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.

Avoid foods the person may not chew thoroughly, such as nuts, popcorn, and raw carrots. Liquids and solids offered together may be confusing—it's hard to know whether to chew or to swallow. Serve foods and drinks lukewarm, *not hot*, because the person may have lost the ability to judge temperatures.

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 her to lie down or walk around with food in her mouth.

If you have to spoon-feed the person, it may help to talk with a nurse or speech pathologist who specializes in swallowing about the best procedure to follow. As the disease progresses, you may need to remind the person to swallow after *each* bite.

Learn the Heimlich method from a medical professional or the Red Cross. It can save the life of a choking person. Contact the doctor if the person stops eating or begins losing weight. These may be symptoms of a complicating disease.

### **Incontinence**

Caregivers report that incontinence is such a difficult problem to manage that it is often the “last straw,” prompting them to place the person in a care facility.

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 be only occasional 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.

Establishing a regular toileting routine often helps. 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. 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?”

Take the person to the toilet at the time of day he usually has a bowel movement. Observe behavior for cues. For example, sudden restlessness or picking at clothes may indicate he needs to use the toilet. Be aware that he may need some assistance to undress or to use the toilet.

Limit fluid intake after the evening meal. Getting the person up once during the night or placing a commode or urinal bottle near the bed may help prevent accidents. Using night-lights may also help the person’s orientation and ability to find the bathroom.

When a regular toileting schedule does not work, use incontinence products. Special clothing with disposable pads, absorbent undergarments (sometimes called adult diapers), protective bedding, and disposable bed pads are available from medical supply, home health, and/or drug stores. Consult the physician or a nurse for additional products available for bladder and bowel incontinence.

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*When the person no longer understands speech, touch can become the most meaningful way to communicate.*

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When a person is incontinent, it's important to keep the anal and genital area as clean and dry as possible. 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 progression 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 he cannot remember. For example, if he cannot think of the word "coffee" he may tell you "It's what I drink in the morning." If he cannot think of the word "garbage collector," he may say "The guy who empties those big cans into that big truck." Language also may be punctuated with indefinite words such as "thing," "this," "that," and "there."

As dementia progresses, communication becomes increasingly difficult. The person may have difficulty expressing himself in words, easily lose his train of thought, and lose the ability to understand what has been said. As a result, he 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 (this is not purposeful but a part of the disease process) or revert to speaking in their first language. When the memory-impaired person can no longer communicate verbally, be sensitive to nonverbal behavior—facial expressions, tone of voice, body position, and eyes.

Many people with dementia are far more sensitive to a speaker's tone of voice and body language than to the actual words spoken. Therefore, it's important to be aware of *how* you're communicating, not just *what* you're saying. Also, consider age-related changes in vision and hearing. Good lighting, a quiet environment, hearing aids, and eyeglasses may help to increase the person's understanding of what you say.

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

Kindness, patience, and respect go a long way in communicating effectively with a person who has dementia. Effective communication also takes flexibility. As the disease progresses, the person's way of communicating will





change. You will need to change your expectations and how you communicate with him.

Experts suggest the following guidelines for talking with the person who has dementia.

**Call the person by name.** Before asking a person to do something, address her by name to get her attention. In some instances, a person may better recognize a childhood nickname than 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.** Memory-impaired people 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, “Your hair looks pretty” and “Please come here.” Give instructions one step at a time. Long sentences and complex instructions are likely to overwhelm the impaired person.

**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.

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*Use positive statements. It's easier for memory-impaired people to understand what you **want** them to do than what you **don't** want them to do.*

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**Keep questions simple.** Ask one-part questions—for example, “Do you want orange juice?”—which can be answered with a yes or a no or by a gesture. Avoid open-ended questions such as “What do you want to drink?” or “What do you want to wear today?” Also avoid multiple-choice questions such as “Do you want tea or coffee, and do you want it now or with dessert?” Such questions add to confusion and stress.

Eventually, even questions requiring only a yes or no reply are difficult for some people. When this occurs, say “Here’s 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 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.” Instead of saying “I found it,” say “I found your wallet.”

**Use positive statements.** It’s easier for memory-impaired people to understand what you *want* them to do than what you *don’t want* them to do. For example, say “Please stay inside with me” rather than “Don’t go outside.” Say “Let’s go here” instead of “Don’t go there” and “Please sit in this chair” rather than “Don’t sit there.” You’re less likely to get the desired response if you use negative words such as “no” or “don’t.”

**Use nonverbal communication.** Communication is more than just words. Your nonverbal communication should reinforce your words. Gestures, pointing, demonstration, facial expressions, and visual aids help communicate to the person what you want done. Using objects such as a comb or toothbrush helps identify activities. Sometimes, pictures help convey an idea.

Be aware of your feelings and attitudes. They often are communicated, unintentionally, through tone of voice and facial expression. Also, 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. For example, if your words say something sweet, but your body language says you are irritated and upset, your body language usually is 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.

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. Sometimes a person with dementia may misinterpret the meaning of a touch. If this occurs, respond calmly.

There are special techniques for communicating with people who have specific medical conditions such as stroke, Parkinson's disease, and Alzheimer's disease. Contact the support groups and related organizations for information and materials.

## **Summary**

A time may come when the personal care and safety needs of the impaired person exceed the resources and abilities of the most dedicated in-home caregiver. Placement in a care facility may be the next logical step.

Families facing this difficult decision must realize they have not failed, broken a promise, or abandoned a loved one. They have given up only the physical chores of daily care.

As one nursing home administrator 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."

## **For more information**

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