

Fact Sheet : Caregiver's Guide to Understanding Dementia Behaviors

Caring for a loved one with dementia poses many challenges for families and caregivers. People with dementia from conditions such as Alzheimer's and related diseases have a progressive *brain* disorder that makes it more and more difficult for them to remember things, think clearly, communicate with others, or take care of themselves. In addition, dementia can cause mood swings and even change a person's personality and behavior. This Fact Sheet provides some practical strategies for dealing with the troubling behavior problems and communication difficulties often encountered when caring for a person with dementia.

Ten Tips for Communicating with a Person with Dementia

We aren't born knowing how to communicate with a person with dementia—but we can learn. Improving your communication skills will help make care giving less stressful and will likely improve the quality of your relationship with your loved one. Good communication skills will also enhance your ability to handle the difficult behavior you may encounter as you care for a person with a dementing illness.

- 1. Set a positive mood for interaction.** Your attitude and body language communicate your feelings and thoughts stronger than your words. Set a positive mood by speaking to your loved one in a pleasant and respectful manner. Use facial expressions, tone of voice and physical touch to help convey your message and show your feelings of affection.
- 2. Get the person's attention.** Limit distractions and noise—turn off the radio or TV, close the curtains or shut the door, or move to quieter surroundings. Before speaking, make sure you have her attention; address her by name, identify yourself by name and relation, and use nonverbal cues and touch to help keep her focused. If she is seated, get down to her level and maintain eye contact.
- 3. State your message clearly.** Use simple words and sentences. Speak slowly, distinctly and in a reassuring tone. Refrain from raising your voice higher or louder; instead, pitch your voice lower. If she doesn't understand the first time, use the same wording to repeat your message or question. If she still doesn't understand, wait a few minutes and rephrase the question. Use the names of people and places instead of pronouns or abbreviations.
- 4. Ask simple, answerable questions.** Ask one question at a time; those with yes or no answers work best. Refrain from asking open-ended questions or giving too many choices. For example, ask, "*Would you like to wear your white shirt or your blue shirt?*" Better still, show her the choices—visual prompts and cues also help clarify your question and can guide her response.
- 5. Listen with your ears, eyes and heart.** Be patient in waiting for your loved one's reply. If she is struggling for an answer, it's okay to suggest words. Watch for nonverbal cues and body language, and respond appropriately. *Always strive to listen for the meaning and feelings that underlie the words.*
- 6. Break down activities into a series of steps.** This makes many tasks much more manageable. You can encourage your loved one to do what he can, gently remind him of steps he tends to forget, and assist with steps he's no longer able to accomplish on his own. Using visual cues, such as showing him with your hand where to place the dinner plate, can be very helpful.

7. When the going gets tough, distract and redirect. When your loved one becomes upset, try changing the subject or the environment. For example, ask him for help or suggest going for a walk. *It is important to connect with the person on a feeling level, before you redirect.* You might say, “I see you’re feeling sad—I’m sorry you’re upset. Let’s go get something to eat.”

8. Respond with affection and reassurance. People with dementia often feel confused, anxious and unsure of themselves. Further, they often get reality confused and may recall things that never really occurred. *Avoid trying to convince them they are wrong.* Stay focused on the feelings they are demonstrating (which are real) and respond with verbal and physical expressions of comfort, support and reassurance. Sometimes holding hands, touching, hugging and praise will get the person to respond when all else fails.

9. Remember the good old days. Remembering the past is often a soothing and affirming activity. Many people with dementia may not remember what happened 45 minutes ago, but they can clearly recall their lives 45 years earlier. Therefore, *avoid asking questions that rely on short-term memory*, such as asking the person what they had for lunch. Instead, try asking general questions about the person’s distant past—this information is more likely to be retained.

10. Maintain your sense of humor. *Use humor whenever possible, though not at the person's expense.* People with dementia tend to retain their social skills and are usually delighted to laugh along with you.

Handling Troubling Behavior

Some of the greatest challenges of caring for a loved one with dementia are the personality and behavior changes that often occur. You can best meet these challenges by using creativity, flexibility, patience and compassion. It also helps to not take things personally and maintain your sense of humor.

To start, consider these ground rules:

We cannot change the person. The person you are caring for has a brain disorder that shapes who he has become. When you try to control or change his behavior, you’ll most likely be unsuccessful or be met with resistance. It’s important to:

- *Try to accommodate the behavior, not control the behavior.* For example, if the person insists on sleeping on the floor, place a mattress on the floor to make him more comfortable.
- *Remember that we **can** change our behavior or the physical environment.* Changing our own behavior will often result in a change in our loved one’s behavior.

Check with the doctor first. Behavioral problems may have an underlying medical reason: perhaps the person is in pain or experiencing an adverse side effect from medications. In some cases, like incontinence or hallucinations, there may be some medication or treatment that can assist in managing the problem.

Behavior has a purpose. People with dementia typically cannot tell us what they want or need. They might do something, like take all the clothes out of the closet on a daily basis, and we wonder why. It is very likely that the person is fulfilling a need to be busy and productive. *Always consider what need the person might be trying to meet with their behavior—and, when possible, try to accommodate them.*

Behavior is triggered. It is important to understand that all behavior is triggered—it doesn't occur out of the blue. It might be something a person did or said that triggered a behavior or it could be a change in the physical environment. *The root to changing behavior is disrupting the patterns that we create.* Try a different approach, or try a different consequence.

What works today, may not tomorrow. The multiple factors that influence troubling behaviors and the natural progression of the disease process means that solutions that are effective today may need to be modified tomorrow—or may no longer work at all. The key to managing difficult behaviors is being creative and flexible in your strategies to address a given issue.

Get support from others. You are not alone—there are many others caring for someone with dementia. Call your local Area Agency on Aging, the local chapter of the Alzheimer's Association, a [Caregiver Resource Center](#) or one of the groups listed below in *Resources* to find support groups, organizations and services that can help you. Expect that, like the loved one you are caring for, you will have good days and bad days. Develop strategies for coping with the bad days (see the FCA Fact Sheet, *Dementia, Care giving and Controlling Frustration*).

Agitation

Agitation refers to a range of behaviors associated with dementia, including irritability, sleeplessness, and verbal or physical aggression. Often these types of behavior problems progress with the stages of dementia, from mild to more severe. Agitation may be triggered by a variety of things, including environmental factors, fear and fatigue. Most often, agitation is triggered when the person experiences “control” being taken from him.

- Reduce caffeine intake, sugar and junk food.
- Reduce noise, clutter or the number of persons in the room.
- Maintain structure by keeping the same routines. Keep household objects and furniture in the same places. Familiar objects and photographs offer a sense of security and can suggest pleasant memories.
- Try gentle touch, soothing music, reading or walks to quell agitation. Speak in a reassuring voice. Do not try to restrain the person during a period of agitation.
- Keep dangerous objects out of reach.
- Allow the person to do as much for himself as possible—support his independence and ability to care for himself.
- Acknowledge the confused person's anger over the loss of control in his life. Tell him you understand his frustration.
- Distract the person with a snack or an activity. Allow him to forget the troubling incident. Confronting a confused person may increase anxiety.

Repetitive speech or actions (perseveration)

People with dementia will often repeat a word, statement, question or activity over and over. While this type of behavior is usually harmless for the person with dementia, it can be annoying and stressful to caregivers. Sometimes the behavior is triggered by anxiety, boredom, fear or environmental factors.

- Provide plenty of reassurance and comfort, both in words and in touch.
- Try distracting with a snack or activity.
- Avoid reminding them that they just asked the same question. Try ignoring the behavior or question and distract the person into an activity.
- Don't discuss plans with a confused person until immediately prior to an event.
- You may want to try placing a sign on the kitchen table, such as, "Dinner is at 6:30" or "Lois comes home at 5:00" to remove anxiety and uncertainty about anticipated events.
- Learn to recognize certain behaviors. An agitated state or pulling at clothing, for example, could indicate a need to use the bathroom.

Paranoia

Seeing a loved one suddenly become suspicious, jealous or accusatory is unsettling. Remember, what the person is experiencing is very real to them. It is best not to argue or disagree. This, too, is part of the dementia—try not to take it personally.

- If the confused person suspects money is "missing," allow her to keep small amounts of money in a pocket or handbag for easy inspection.
- Help them look for the object and then distract them into another activity. Try to learn where the confused person's favorite hiding places are for storing objects, which are frequently assumed to be "lost." Avoid arguing.
- Take time to explain to other family members and home-helpers that suspicious accusations are a part of the dementing illness.
- Try nonverbal reassurances like a gentle touch or hug. Respond to the feeling behind the accusation and then reassure the person. You might try saying, "I see this frightens you; stay with me, I won't let anything happen to you."

This fact sheet was prepared by Family Caregiver Alliance in cooperation with California's statewide system of Caregiver Resource Centers. Reviewed by Beth Logan, M.S.W., Education and Training Consultant and Specialist in Dementia Care. Funded by the California Department of Mental Health. © 2004 Family Caregiver Alliance. All rights reserved. FS-CGTU20050610.

