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Caregiver's Guide to Understanding Dementia Behaviors

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Introduction

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 caregiving 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, Caregiving and Controlling Frustration*).

The following is an overview of the most common dementia-associated behaviors with suggestions that may be useful in handling them. You'll find additional resources listed at the end of this Fact Sheet.

Wandering

People with dementia walk, seemingly aimlessly, for a variety of reasons, such as boredom, medication side effects or to look for "something" or someone. They also may be trying to fulfill a physical need—thirst, hunger, a need to use the toilet or exercise. Discovering the triggers for wandering are not always easy, but they can provide insights to dealing with the behavior.

- Make time for regular exercise to minimize restlessness.
- Consider installing new locks that require a key. Position locks high or low on the door; many people with dementia will not think to look beyond eye level. Keep in mind fire and safety concerns for all family members; the lock(s) must be accessible to others and not take more than a few seconds to open.
- Try a barrier like a curtain or colored streamer to mask the door. A “stop” sign or “do not enter” sign also may help.
- Place a black mat or paint a black space on your front porch; this may appear to be an impassable hole to the person with dementia.
- Add “child-safe” plastic covers to doorknobs.
- Consider installing a home security system or monitoring system designed to keep watch over someone with dementia. Also available are new digital devices that can be worn like a watch or clipped on a belt that use global positioning systems (GPS) or other technology to track a person’s whereabouts or locate him if he wanders off..
- Put away essential items such as the confused person’s coat, purse or glasses. Some individuals will not go out without certain articles.
- Have your relative wear an ID bracelet and sew ID labels in their clothes. Always have a current photo available should you need to report your loved one missing. Consider leaving a copy on file at the police department or registering the person with the Alzheimer’s Association Safe Return program (see *Resources*).
- Tell neighbors about your relative’s wandering behavior and make sure they have your phone number.

Incontinence

The loss of bladder or bowel control often occurs as dementia progresses. Sometimes accidents result from environmental factors; for example, someone can’t remember where the bathroom is located or can’t get to it in time. If an accident occurs, your understanding and reassurance will help the person maintain dignity and minimize embarrassment.

- Establish a routine for using the toilet. Try reminding the person or assisting her to the bathroom every two hours.
- Schedule fluid intake to ensure the confused person does not become dehydrated. However, avoid drinks with a diuretic effect like coffee, tea, cola, or beer. Limit fluid intake in the evening before bedtime.
- Use signs (with illustrations) to indicate which door leads to the bathroom.
- A commode, obtained at any medical supply store, can be left in the bedroom at night for easy access.
- Incontinence pads and products can be purchased at the pharmacy or supermarket. A urologist may be able to prescribe a special product or treatment.
- Use easy-to-remove clothing with elastic waistbands or Velcro[®] closures, and provide clothes that are easily washable.

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, state-ment, 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."

Sleeplessness/Sundowning

Restlessness, agitation, disorientation and other troubling behavior in people with dementia often get worse at the end of the day and sometimes continue throughout the night. Experts believe this behavior, commonly called *sundowning*, is caused by a combination of factors, such as exhaustion from the day's events and changes in the person's biological clock that confuse day and night.

- Increase daytime activities, particularly physical exercise. Discourage inactivity and napping during the day.
- Watch out for dietary culprits, such as sugar, caffeine and some types of junk food. Eliminate or restrict these types of foods and beverages to early in the day. Plan smaller meals throughout the day, including a light meal, such as half a sandwich, before bedtime.
- Plan for the afternoon and evening hours to be quiet and calm; however, *structured, quiet activity is important*. Perhaps take a stroll outdoors, play a simple card game or listen to soothing music together.
- Turning on lights well before sunset and closing the curtains at dusk will minimize shadows and may help diminish confusion. At minimum, keep a nightlight in the person's room, hallway and bathroom.
- Make sure the house is safe: block off stairs with gates, lock the kitchen door and/or put away dangerous items.
- As a last resort, consider talking to the doctor about medication to help the agitated person relax and sleep. Be aware that sleeping pills and tranquilizers may solve one problem and create another, such as sleeping at night but being more confused the next day.
- It's essential that you, the caregiver, get enough sleep. If your loved one's nighttime activity keeps you awake, consider asking a friend or relative, or hiring someone, to take a turn so that you can get a good night's sleep. Catnaps during the day also might help.

Eating/Nutrition

Ensuring that your loved one is eating enough nutritious foods and drinking enough fluids is a challenge. People with dementia literally begin to forget that they need to eat and drink. Complicating the issue may be dental problems or medications that decrease appetite or make food taste "funny." The consequences of poor nutrition are many, including weight loss, irritability, sleeplessness, bladder or bowel problems and disorientation.

- Make meal and snack times part of the daily routine and schedule them around the same time every day. Instead of three big meals, try five or six smaller ones.
- Make mealtimes a special time. Try flowers or soft music. Turn off loud radio programs and the TV.
- Eating independently should take precedence over eating neatly or with “proper” table manners. Finger foods support independence. Pre-cut and season the food. Try using a straw or a child’s “sippy cup” if holding a glass has become difficult. Provide assistance only when necessary and allow plenty of time for meals.
- Sit down and eat with your loved one. Often they will mimic your actions and it makes the meal more pleasant to share it with someone.
- Prepare foods with your loved one in mind. If they have dentures or trouble chewing or swallowing, use soft foods or cut food into bite-size pieces.
- If chewing and swallowing are an issue, try gently moving the person’s chin in a chewing motion or lightly stroking their throat to encourage them to swallow.
- If loss of weight is a problem, offer nutritious high-calorie snacks between meals. Breakfast foods high in carbohydrates are often preferred. On the other hand, if the problem is weight gain, keep high-calorie foods out of sight. Instead, keep handy fresh fruits, veggie trays and other healthy low-calorie snacks.

Bathing

People with dementia often have difficulty remembering “good” hygiene, such as brushing teeth, toileting, bathing and regularly changing their clothes. From childhood we are taught these are highly private and personal activities; to be undressed and cleaned by another can feel frightening, humiliating and embarrassing. As a result, bathing often causes distress for both caregivers and their loved ones.

- Think historically of your loved one’s hygiene routine – did she prefer baths or showers? Mornings or nights? Did she have her hair washed at the salon or do it herself? Was there a favorite scent, lotion or talcum powder she always used? Adopting—as much as possible—her past bathing routine may provide some comfort. Remember that it may not be necessary to bathe every day—sometimes twice a week is sufficient.
- If your loved one has always been modest, enhance that feeling by making sure doors and curtains are closed. Whether in the shower or the bath, keep a towel over her front, lifting to wash as needed. Have towels and a robe or her clothes ready when she gets out.
- Be mindful of the environment, such as the temperature of the room and water (older adults are more sensitive to heat and cold) and the adequacy of lighting. It’s a good idea to use safety features such as non-slip floor bath mats, grab-bars, and bath or shower seats. A hand-held shower might also be a good feature to install. Remember—people are often afraid of falling. Help them feel secure in the shower or tub.
- Never leave a person with dementia unattended in the bath or shower. Have all the bath things you need laid out beforehand. If giving a bath, draw the bath water first. Reassure the person that the water is warm—perhaps pour a cup of water over her hands before she steps in.
- If hair washing is a struggle, make it a separate activity. Or, use a dry shampoo.
- If bathing in the tub or shower is consistently traumatic, a towel bath provides a soothing alter-native. A *bed* bath has traditionally been done with only the most frail and bed-ridden patients, soaping up a bit at a time in their beds, rinsing off with a basin of water and drying with towels. A growing number of nurses in and out of facilities, however, are beginning to recognize its value and a variation—the “*towel* bath”—for others as well, including people with dementia who find bathing in the tub or shower uncomfortable or unpleasant. The towel bath uses a large bath towel and washcloths dampened in a plastic bag of warm water and no-rinse soap. Large bath-blankets are used to keep the patient covered, dry and warm while the dampened towel and washcloths are massaged over the body. For more information, see the book *Bathing Without a Battle, Bathing Without a Battle* (details in the *Recommended Reading* section below), or visit www.bathingwithoutabattle.unc.edu/.

Additional Problem Areas

- Dressing is difficult for most dementia patients. Choose loose-fitting, comfortable clothes with easy zippers or snaps and minimal buttons. Reduce the person’s choices by removing seldom-worn clothes from the closet. To facilitate dressing and support independence, lay out one article of clothing at a time, in the order it is to be worn. Remove soiled clothes from the room. Don’t argue if the person insists on wearing the same thing again.
- Hallucinations (seeing or hearing things that others don’t) and delusions (false beliefs, such as someone is trying to hurt or kill another) may occur as the dementia progresses. State simply and calmly your perception of the situation, but avoid arguing or trying to convince the person their perceptions are wrong. Keep rooms well-lit to decrease shadows, and offer reassurance and a simple explanation if the curtains move from circulating air or a loud noise such as a plane or siren is heard. Distractions may help. Depending on the severity of symptoms, you might consider medication.
- Sexually inappropriate behavior, such as masturbating or undressing in public, lewd remarks, unreasonable sexual demands, even sexually aggressive or violent behavior, may occur during the course of the illness. Remember, this behavior is caused by the disease. Talk to the doctor about possible treatment plans. Develop an action plan to follow before the behavior occurs, i.e., what you will say and do if the behavior happens at home, around other adults or children. If you can, identify what triggers the behavior.

- Verbal outbursts such as cursing, arguing and threatening often are expressions of anger or stress. React by staying calm and reassuring. Validate your loved one's feelings and then try to distract or redirect his attention to something else.
- “Shadowing” is when a person with dementia imitates and follows the caregiver, or constantly talks, asks questions and interrupts. Like sundowning, this behavior often occurs late in the day and can be irritating for caregivers. Comfort the person with verbal and physical reassurance. Distraction or redirection might also help. Giving your loved one a job such as folding laundry might help to make her feel needed and useful.
- People with dementia may become uncooperative and resistant to daily activities such as bathing, dressing and eating. Often this is a response to feeling out of control, rushed, afraid or confused by what you are asking of them. Break each task into steps and, in a reassuring voice, explain each step before you do it. Allow plenty of time. Find ways to have them assist to their ability in the process, or follow with an activity that they can perform.

Credits and Recommended Reading

Bathing Without a Battle, by Ann Louise Barrick, Joanne Rader, Beverly Hoeffler and Philip Sloane, (2002), Springer Publishing, (877) 687-7476.

36 Hour Day: Family Guide to Caregiving for People who have Alzheimer's Disease, Related Dementias and Memory Loss, (2011), Johns Hopkins Press Health Book.

Steps to enhancing communications: Interacting with persons with Alzheimer's disease. Chicago, IL: Alzheimer's Association (2012), 081312.01 770-10-0018

Communicating Effectively with a Person Who Has Alzheimer's, (2002), Mayo Clinic Staff, www.mayoclinic.com/invoke.cfm?id=AZ00004

The Validation Breakthrough: Simple Techniques for Communicating with People with “Alzheimer's-Type Dementia,” Naomi Feil, 2nd Edition 2002, Health Professions Press, Baltimore, MD, (410) 337-8539.

Understanding Difficult Behaviors: Some practical suggestions for coping with Alzheimer's disease and related illnesses, A. Robinson, B. Spencer, and L. White, (2001), Eastern Michigan University, Ypsilanti, MI, (734) 487-2335.

Resources

Family Caregiver Alliance

785 Market Street, Suite 750

San Francisco, CA 94103

(415) 434-3388

(800) 445-8106

caregiver.org

info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's and other debilitating health conditions that strike adults.

FCA Publications

FCA Fact Sheets. All Family Caregiver Alliance Fact Sheets are available free online. Printed versions are available for purchase for each title—send your requests to FCA Publications, 785 Market Street, Suite 750, San Francisco, CA 94103. For the full list, see: caregiver.org/caregiver/jsp/publications.jsp?nodeid=345

FCA Fact Sheet: *Dementia, Caregiving and Controlling Frustration*

FCA Fact Sheet: Taking Care of YOU: Self-Care for Family Caregivers

FCA Fact Sheet: Hiring In-Home Help

FCA Fact Sheet: Community Care Options

Other Web Sites

Alzheimer's Disease Education and Referral (ADEAR) Center

(800) 438-4380

www.alzheimers.org

This service of the National Institute on Aging offers information and publications on diagnosis, treatment, patient care, caregiver needs, long-term care, education and research related to Alzheimer's disease.

Eldercare Locator

(800) 677-1116

www.eldercare.gov

This service of the Administration on Aging offers information about and referrals to respite care and other home and community services offered by state and Area Agencies on Aging.

Alzheimer's Association Safe Return Program

(800) 272-3900

www.alz.org/SafeReturn

A nationwide program that identifies people with dementia who wander away and returns them to their homes. For a registration fee, families can register their loved one in a national confidential computer database. They also receive an identification bracelet or necklace and other identification and educational materials.

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.

Date:

Friday, December 31, 2004

Related Health or Illness Resources

Quality Improvement in Dementia Care

Here But Not Here—Finding Hope When a Loved One Has Memory Loss

Books to Help Children

TimeSlips

Dementia and Pain Management: A Personal Story

Guía del cuidador para entender la conducta de los pacientes con demencia (Caregiver's Guide to Understanding Dementia Behaviors)

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