Chapter 4

Dealing with Challenging Behaviors

We all have behaviors. Behaviors are demonstrations of who we are and how we communicate our response to daily living.[1]

Five General Principles About Behavior

1. **Behavior varies from person to person.** While it is possible to list behaviors that are common to dementia, it is not possible to predict which, if any, behavior a particular resident will display in the course of his or her illness. Some people display traits that are exaggerated versions of their former personality (e.g., a former boxer who becomes more aggressive) while others do things that seem entirely out of character (e.g., the minister's wife who is swearing like a pirate). People have good days and bad days and behaviors will fluctuate accordingly. Behaviors will also change as the disease progresses.

2. **Loss of control is not deliberate.** People with Alzheimer's disease are capable of a full range of behaviors — positive to negative— just as we all are. Due to the damage to their brains, however, they do not have the same ability to plan, initiate, and control the behaviors that they display. People with Alzheimer's are not being deliberately difficult or manipulative, and they are not trying to drive you crazy! These residents are simply reacting in the moment to their feelings and to the world around them. They are doing the best they can with a disabling disease.

3. **Behavior does not occur in a vacuum.** Behaviors displayed by residents with dementia are related to the loss of cognitive capacities and are often triggered by internal distress or something in the environment that is causing fear, confusion or frustration.

4. **Behavior is communication.** As verbal skills diminish, behavior becomes the resident's primary mode of communication. Therefore, always ask: "What is the behavior saying about the resident's thoughts, feelings, and perceptions that he or she cannot express in words?" Is she in pain? Frightened? Confused? Is there an unmet need? For example, pacing or anxious, repetitive speech may mean that the resident is hungry or needs to go to the bathroom.

Continued

5. **Positive approaches work best.** Use a friendly, reassuring, helpful approach that respects the resident with dementia as an adult. Negative approaches such as demands, threats or scolding will not be effective and may provoke a catastrophic reaction, making a difficult situation even worse.

Behaviors Common to Dementia

- Repetitive speech or actions
- Neglect of personal hygiene and grooming
- Swearing or tactlessness
- Wandering
- Sundowning (increased restlessness or agitation at the end of the day)
- Shadowing (following others)
- Apathy or withdrawal
- Hostility or aggression
- Hoarding
- Sleep disturbances
- Paranoia and suspiciousness (e.g., false accusations about people stealing from them)
- Delusions (beliefs that are contrary to fact)
- Hallucinations (false perceptions of something that is not really there)
- Decreased awareness of personal safety
- Forgetting what is private behavior (e.g., urinating in a plant pot, cleaning dentures at the table, disrobing or masturbating in public)
- Catastrophic reactions (extreme emotional responses such as yelling, crying or striking out that seem out of proportion to the actual event)

Source: Alzheimer's Disease and Related Disorders Association, Inc. 1999

Possible Causes of Challenging Behaviors[2]

Physical Causes
- Effects of medication
- Impaired vision or hearing
- Acute illness (e.g., urinary or respiratory infection)
- Chronic illness
- Pain or physical discomfort
- Constipation
- Dehydration
- Fatigue .

Emotional Causes
- Depression
- Fear
- Frustration
- Embarrassment
- Unable to communicate needs or articulate feelings.

Environmental Causes
- Environment too large
- Too much clutter
- Excessive stimulation (too loud, bright, everyone talking at once)
- Too little stimulation (bored, lonely)
- No orientation information or cues (e.g., all doors look the same on the hallway)
- Too many choices or ideas at once
- Unstructured or unfamiliar environment

Task-Related Causes
- Too complicated
- Too many steps combined
- Task unfamiliar; requires new learning

Responses To How Individual Is Approached Or Treated
- Hurrying or rushing
- Impatience
- Being preoccupied; not focusing on the resident
- Quizzing with memory questions
- Commands
- Talking loudly
- Negative demands (“No,” “Don’t,” “Can’t,” “Should”)
- Criticizing, scolding, shaming
- Trying to argue or convince
- Long explanations
- Reality orientation

- Talking down to the resident or talking about them as if they were not there.

The Parable of the Lighthouse

Collision: A True Log

Signalman Alpha: This is Signalman Alpha. Please divert your course fifteen degrees to port to avoid imminent collision….

Signalman Bravo: This is Signalman Bravo. Recommend you come right fifteen degrees to avoid imminent collision….

Signalman Alpha: This is Signalman Alpha. We are a large naval vessel. I say again, change course to avoid collision…

Signalman Bravo: This is Signalman Bravo. I repeat, change course to starboard immediately.

Signalman Alpha: This is the Captain of the aircraft carrier USS Enterprise, a 75,000-ton United States Naval warship. Get out of the way, now!

Signalman Bravo: This is a lighthouse keeper. Your call.

Author Unknown

Problem Solving Strategies

Ask questions
- What exactly is the behavior?
- What was happening just before the behavior occurred?
- When does it happen? Early morning? Late afternoon?
- How often has it happened?
- Where does it happen? In the lobby? The hallway? The lounge?
- Why is the behavior a problem? For whom?
- How was the behavior handled? Did it work?Keep a Log

Keep a log
- Document the behavior responding to the questions above.
- See if you can determine a pattern.

Look for triggers
- the resident's physical condition
- the resident's emotional condition
- the environment
- the task
- the way the resident was approached by others.

Step into the resident's shoes
- Try to see the situation from the resident's perspective.

Pay attention to nonverbal cues
- Be sensitive to the resident's mood, facial expression, tone of voice and body language.

Explore potential solutions
- Alert the Resident Service Coordinator or Property manager to the situation.

- Talk to the resident.

- Use good communication skills when approaching the resident [see Chapter 3].

- Try to get the resident to agree to a medical evaluation or a home nursing visit to determine the cause of the dementia and to rule out physical or medical problems that may be creating an excess disability.

- Proceed with steps for emergency and non-emergency situations as outlined in Chapter 6.

- Consider modifying the resident's environment to make it easier for him or her to manage (e.g., an automatic shut-off for the stove or a dark-colored toilet seat).

- Sponsor an education session about memory loss and dementia for the whole building in order to foster a more tolerant community.

- Call the Maine Alzheimer's Association's Helpline (1-800-660-2871) for help in brainstorming possible solutions and referral sources.

- Refer the resident to appropriate supportive services.

- Involve Adult Protective Services if the resident is at risk due to abuse, exploitation or self-neglect.

- Begin to explore alternative living arrangements if the resident's needs can no longer be met in independent housing.

Tips For Responding To The Resident With Dementia

- ➡ Stay calm and be understanding. Remember: the resident will mirror your mood.
- ➡ Acknowledge feelings. *"You seem upset about . . . " "You're thinking about . . . " or "You're missing your mother . . . your home,"* etc. Then encourage venting or reminiscing.
- ➡ Reassure: *"It's okay. I'll help you."*
- ➡ If the resident begins to get upset, change the subject and distract his/her attention to something else. (e.g, *"What beautiful flowers. You must have a green thumb.")*
- ➡ Ask the resident to help you.
- ➡ Look for reasons for the behavior [see page 53].
- ➡ Accept the behavior as a reality of the disease and try to work through it.
- ➡ Explore various solutions.
- ➡ Be patient and flexible.
- ➡ Acknowledge requests and respond to them.
- ➡ Find other outlets for the behavior.
- ➡ Encourage the use of memory aides (notes, reminders, calendars) whenever feasible.
- ➡ Do not argue or try to convince.
- ➡ Do not take behaviors personally.
- ➡ If the resident accuses you of stealing, don't argue and don't take the behavior personally. False accusations are not uncommon because people with dementia can't remember where they leave their belongings and may misinterpret the statements and actions of those around them. Be calm and reassuring. Respond to the feelings behind the statement and offer to help look for the item. "*You must be very upset. Let's look for your purse.*" Take another person along whenever you enter the resident's apartment.

Strategies For Specific Behaviors

The suggested coping strategies in the Appendices that follow have been compiled from a number of sources, including Alzheimer's Association brochures and training materials, newsletters, books and articles. For the most part, these strategies are geared for family caregivers, or for professionals staff providing direct care. Housing staff may want to bear in mind the following:

- When it comes to challenging behaviors, there is no cookbook or magic formula. Finding a solution that works for a particular individual in a particular situation is largely a matter of trial and error.

- Even when a solution is found it may not work every time. And, in any event, adjustments will need to be made as the disease progresses and new behaviors present themselves.

- While housing staff are not family, neither are they direct-care providers. However, these strategies represent accepted practice in the dementia care community. These are approaches that accept the reality of the disease rather than attempting to change the resident. They seek to prevent or minimize problems while respecting the resident and supporting his or her remaining strengths. We invite and encourage housing staff to review these suggestions and adapt and apply them in ways that are consistent with the regulations governing your own setting and job description.

Sources

1. *Alzheimer's Disease: Activity-Focused Care* (Second Edition), by Carly R. Hellen, Butterworth-Heinemann, Boston, 1998. Page 295.

2. *Understanding Difficult Behaviors,* by Anne Robinson, et. al., Geriatric Education Center of Michigan, Eastern Michigan University, 1996.

3. Adapted from: *Steps to Understanding Challenging Behaviors,* Alzheimer's Disease and Related Disorders, Association, Inc., 1996.

Resources And Further Reading

1. *"Home Is Where I Remember Things:"A Curriculum for Home and Community Alzheimer Care, Home and Community Alzheimer Care*, by Lisa P. Gwyther, Duke University Medical Center, Durham, North Carolina, 1997. To order, contact the Maine Alzheimer's Association toll-free at 1-800-660-2871 or visit the web site at www.mainealz.org

2. *The 36-Hour Day* (Third Edition), by Nancy L. Mace and Peter V. Rabins, The Johns Hopkins University Press, Baltimore, 1999. To order, contact the Maine Alzheimer's Association toll-free at 1-800-660-2871, or visit the web site at www.mainealz.org

3. *Understanding Difficult Behavior: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses,* by Anne Robinson, et al., Geriatric Education Center of Michigan, Eastern Michigan University, 1989. To order, contact the Maine Alzheimer's Association toll-free at 1-800-660-2871, or visit the web site at www.alz.org

4. *Caregiving at a Glance: Fingertip Help for Families Taking Care of People With Alzheimer's Type Illnesses*, (Second Edition), by Lin E. Noyes, Family Respite Center, Falls Church, Virginia, 2000. To order, contact the Maine Alzheimer's Association toll-free at 1-800-660-2871, or visit the web site at www.alz.org

5. *Caring for People With Dementia: A Training Guide,* published by The Training Collaborative, a joint project of the Alzheimer's Association, Maine Chapter; the Alzheimer's Care Center, Gardiner; Muskie School of Public Service at the University of Southern Maine; and the Maine Alzheimer's Project, April 1998. For more information, contact the Maine Alzheimer's Association toll-free at 1-800-660-2871.

6. Alzheimer's Awareness Training Packet, developed by Evelyne Tunley-Daymude, Ph.D., Director of Education, Alzheimer's Association Alaska Chapter. For more information, call 1-800-478-1080.

7. *Alzheimer's Disease: Activity-Focused Care* (Second Edition), by Carly R. Hellen, Butterworth-Heinemann, Boston, 1998. To order, contact the Maine Alzheimer's Association toll-free at 1-800-660-2871, or visit the web site at www.alz.org

8. *Behaviors in Dementia: Best Practices for Successful Management,* edited by Mary Kaplan and Stephanie B. Hoffman, Health Professions Press, Baltimore, 1998.

➡ You can also order the following brochure by calling the Maine Alzheimer's Association at 1-800-660-2871.

    - *Steps to Understanding Challenging Behaviors*

Appendix 4.1

Bathing:
Tips for Families and Direct Care Providers

Keeping the Alzheimer’s resident clean and well groomed can be a challenge. A depressed resident might have lost her desire to bathe while another resident might feel embarrassed about getting undressed or might become frightened by running water or mirrors.

For the resident with Alzheimer’s, it’s easy to feel confused and overwhelmed by simple daily routines such as bathing and grooming. If the resident seems afraid, stressed or resistant to bathing, try to determine the reasons why by asking the following questions:

Physical/Psychological Factors

- Does the resident seem depressed?
- Is there a physical illness or infection?
- Does the resident seem overly sensitive to water or changes in water temperature?

Environmental Factors

- Is the resident sensitive about having someone else in the bathroom?
- Is the resident able to find the bathroom and see clearly once he or she enters it?
- Is the room temperature too cold?
- Is the water temperature too hot or cold? Or is the water pressure too intense? Is the water in the tub too deep?

Special Concerns

- Is the resident afraid of falling, running water or soap?
- Or is the resident confused over such tasks as turning on the water or filling the sink?

Once you've determined the answers to these questions, you'll be in a better position to manage the bathing routine.

Action Steps

➡ Have reasonable expectations
Keep in mind that frequency of washing and bathing is a personal preference. Some people may not feel the need to shower and/or wash their hair every day. In these cases you might want to alternate a sponge bath with a more complete bath or shower.

Continued

➡ Adapt to the resident's needs, routines, and preferences

If the resident is used to taking a shower in the morning or a bath at night, try to maintain that routine. Changing from day to night might distress the resident. Also keep in mind that a resident may refuse to take a bath for an unfamiliar caregiver of the opposite sex.

➡ Prepare the bathroom in advance

- Have the towels ready.
- Draw the water in the bathtub and test the temperature.
- Pre-measure the shampoo.
- Develop a soap pocket in the washcloth so that the resident can wash him or herself.
- Keep the bathroom warm and comfortable.

➡ Gently prepare the resident for the bath

Be directive at bath time by using such phrases as, "Your bath is ready." In this way, the resident will focus on each step of the task instead of whether or not she needs or wants a bath. If the individual continues to resist the idea of bathing, distract her for a few moments and then try again.

➡ Make the bathroom safe

- Always check the temperature of the water. Keep in mind that the resident may not be able to judge temperature.
- Avoid using bubble bath or bath and shower oils that would make the tub or shower stall slippery.
- Keep in mind that to people with Alzheimer’s disease, showers are often more dangerous and frightening than baths. If you must use a shower, install grab-bars and use a tub seat.
- Never leave a resident alone in the bath or shower.
- Consider using a hand-held shower.
- Use only two to three inches of water in the tub and make sure there are rubber mats or decals on the tub's bottom.
- Use a non-slip bath mat and make sure that the bathroom floor is free from puddles. Some caregivers install carpeting in the bathroom.

➡ Take care in giving the bath

- Gently coach the resident during each step of the bath, reminding her of the areas that need washing. Keep in mind that you may need to complete part of the bath or shower yourself.
- Plan to do a project such as hair washing in the morning when the resident is well rested. Get the individual to participate as much as possible.
- Avoid using harsh deodorant soaps unless there's a serious problem with incontinence, in which case there are special soaps available.

Continued

- Make sure that the resident washes the genital area, especially if incontinence is a problem. Also make sure that the resident washes within folds of flesh and under the breasts.
- After the bath or shower is completed, check to see that the resident is completely dry.
- Check the resident for red areas of skin, rashes and sores. If the problem is serious, consult a physician. Keep in mind that pressure sores and skin ulcers can develop quickly on people who sit or lie down much of the time.
- Use a body powder, cornstarch or baby powder under the breasts or in creases or folds of the skin, and use a lotion to keep skin soft and flexible. If the individual resists deodorant, try baking soda.

Appendix 4.2

Combativeness:
Tips for Families and Direct Care Providers

When an Alzheimer's resident becomes combative, angry or agitated, it may be because of frustration. The resident may feel that he or she is being pushed to do something that simply can't be done. Consider the following factors as possible sources of frustration:

Dressing

- The resident who can't get an arm through a sweater may grow increasingly upset and start to thrash around.

Bathing

- The resident who's frightened by running water in the bathtub may push away a caregiver who is trying to give him or her a bath.

Eating

- The resident who doesn't like a certain type of food may refuse to eat it.

Keep in mind that combativeness takes many forms. Sometimes the resident may simply try to push your hand away, while at other times the resident may resist or strike you. Deal with combativeness by trying to examine the underlying causes. Consider the following issues:

Physical Causes

Is the resident tired because of' inadequate rest or sleep? Are medications such as sedatives and tranquilizers creating side effects? Is the resident unable to express the fact that he or she is in pain?

Environmental Causes

Is the resident overstimulated by loud noises, people or physical clutter? Is the environment unfamiliar? Does the resident feel lost or abandoned by the caregiver?

Poor Communication

Are you asking too many questions or making too many statements at once? Are your instructions simple and easy to understand? Is the resident picking up on your own stress and irritability? Are you making the resident more frustrated by being overly negative or critical?

Continued

Action Steps

➡ Be on the lookout for frustration
Look for early signs of frustration in such activities as bathing, dressing or eating, and respond in a calm and reassuring tone.

➡ Don't take aggression and combativeness personally
Keep in mind that the resident isn't necessarily angry at you. Instead, he or she may misunderstand the situation or be frustrated with his or her own disabilities.

➡ Avoid teaching
Offer encouragement, but keep in mind the resident’s capabilities and don't expect more than he or she can do. Avoid elaborate explanations or arguments.

➡ Use distraction
Don't persist in making the resident perform a particular task, especially if he or she has repeatedly been unsuccessful. If you see the resident getting frustrated with buttoning a shirt, try to distract her with another activity such as putting on a pair of pants. After a time, you can return to the shirt. Or take the resident to a quiet room, have a cup of tea or go for a walk.

➡ Communicate directly with the resident
Avoid expressing anger or impatience in your voice or physical actions. Instead use positive, accepting expressions such as “please,” “thank you,” and “don't worry, everything's going to be fine.” In addition, use touch to reassure and comfort the resident. For example, you might want to put your arm around the resident or give him or her a kiss. In addition, follow these tips:

- Speak slowly and clearly.
- Use short, simple sentences.
- Approach the resident slowly and from the front.
- Use repetition and frequent reminders.

➡ Decrease your level of danger
Assess the level of danger, both for yourself and for the resident. In other words, if the resident becomes combative, ask this question: "How much trouble am I in--and what can I realistically do about it?" Often you can avoid harm by simply taking five steps back and standing away from the resident for a short period of time. On the other hand, if the person is headed out of the house and onto a busy street, you need to be more aggressive.

Continued

➡ Be conservative in using restraint or force

Unless the situation is serious, try to avoid physically holding or restraining the resident. By fighting with the individual, you'll probably make him even more frustrated and anxious.

➡ Experiment with objects that have a soothing effect

Some caregivers believe that stuffed animals have a soothing effect on the resident, while others find that pets—from cats and dogs, to birds or goldfish—have a calming effect.

➡ Learn from previous experiences

Try to avoid situations or experiences that make the resident combative. For example, if the resident tires easily when he or she visits with family members, you might want to limit the length of these visits. Try to identify early signs of agitation. For example, outbursts are sometimes preceded by restlessness, frustration, fidgeting, or blushing.

➡ Restructure tasks and the resident's environment

- Simplify tasks or plan more difficult tasks for the time of the day when the resident is at his best.
- Give the resident adequate time to respond to your directions or requests.
- Allow the resident to make some choices, but limit the total number of choices. Having too many decisions to make about what to eat or wear might be confusing or overwhelming.
- Break down each task into small steps and allow the resident to complete one step at a time.
- Keep the environment calm, quiet and clutter free.

Appendix 4.3

Hallucinations:
Tips for Families and Direct Care Providers

Understanding the difference between hallucinations and delusions is important. A delusion is defined as a false idea, sometimes originating in a misinterpretation of a situation. For example, an elderly resident with a delusion may think that family members are stealing from her or that she's in another place when she's actually still in her own home.

A hallucination, in contrast, is a false perception of objects or events, and is sensory in nature. When a resident with Alzheimer's has a hallucination, he or she can see, hear, smell, taste, or even feel something that isn't really there.

Hallucinations are caused by changes within the brain that result from Alzheimer's disease. Hallucinations are visual and auditory. For example, a resident may see the face of a former friend in a curtain or see insects crawling on his hand. In other cases, he may hear someone talking and may even talk back to the imagined person.

Hallucinations can be frightening to the resident and the caregiver. On some occasions, the resident may see threatening images or just ordinary images of people, situations or objects from the past. Although you can create an environment to manage wandering, you won't be able to control the resident's hallucinations or prevent them from occurring. Some ideas to follow for handling a resident with hallucinations are:

Action Steps

➡ Obtain medical guidance

- Ask a physician to evaluate the resident to determine if medication is needed or might be causing the hallucinations. In some cases, hallucinations are caused by schizophrenia, a disease different from Alzheimer's.

- Have the resident's eyesight or hearing checked or make sure that the resident wears her glasses or hearing aid on a regular basis.

- The physician can look for physical disorders such as kidney or bladder infections, dehydration, intense pain, or alcohol or drug abuse. These are conditions that might cause hallucinations. If the physician prescribes a medication, watch for symptoms such as over-sedation, increased confusion, tremors or tics.

Continued

➡ Assess and evaluate

Assess the situation and determine whether or not the hallucination is a problem for you or for the individual. Is the hallucination upsetting to the resident? Is it leading him or her to do something dangerous? Does the sight of an unfamiliar face cause the resident to become frightened? If so, react calmly and quickly with reassuring words and comforting touch.

➡ Respond with caution

Be cautious and conservative in responding to the resident's hallucinations. If the hallucination doesn’t cause problems for you, the resident or other family members, you may want to ignore it. Don't argue with the resident about what she sees or hears. Unless her behavior becomes dangerous, you might not need to intervene.

➡ Offer reassurance

Reassure the resident with kind words and a gentle touch. For example, you might want to say: "Don't worry. I'm here. I'll protect you. I'll take care of you," or "I know you're worried. Would you like me to hold your hand and walk with you for awhile"

- Gentle patting may turn the resident's attention toward you and reduce the hallucination.

- Look for the reasons or feelings behind the hallucination and try to find out what the hallucination means to the individual. For example, you might want to respond with words such as these: "It sounds as if you're worried" or "I know this is frightening for you."

➡ Use distraction

Suggest that the resident come with you on a walk or sit next to you in another room. Frightening hallucinations often subside in well-lit areas where other people are present.

- You might also try to turn the resident's attention to other features of the room. Other distractions include music, conversation, drawing, looking at photos or pictures, or counting coins.

➡ Respond honestly

Keep in mind that the resident may sometimes ask you about the hallucination. For example, "Do you see him?" or "Can you hear the children laughing?" You may want to answer with words such as these: "I know that you see something, but I don't see it." In this way, you're not denying what the resident sees or hears or getting involved in an argument.

Continued

➡ Check out the reality of the situation
Ask the resident to point to the area where he sees or hears something. Glare from a window may look like snow to the resident and dark squares on a tiled floor may look like dangerous holes.

➡ Modify the environment
If the resident looks at the kitchen curtains and sees a face, you may be able to remove, change or close the curtains.

- Check the environment for noises that might be misinterpreted, for lighting that casts shadows, or for glare, reflections or distortions from the surfaces of floors, walls, and furniture.
- If the resident insists that he or she sees a strange person in the mirror, you may want to cover up the mirror or take it down. It's also possible that the resident doesn't recognize himself or herself.
- On other occasions, you may want to turn on more lights and make the room brighter.

You can ease the fears of the resident with Alzheimer's disease by using words that are calm, gentle and reassuring. Remember that the hallucination is very real to the individual with the disease. Your goal is to support the resident's feelings without agreeing with the hallucination.

Appendix 4.4

Coping with Suspicion and Paranoia:
Tips for Families and Direct Care Providers

"You stole my purse! It was right here! Get away from me! Leave me alone! I hate you!" These words may be all too familiar to caregivers, families and friends of individuals with Alzheimer's disease or related disorders. Suspiciousness is very common in people who suffer from dementia. Some even project their own feeling of frustration and hostility onto another person, something known as "paranoia." The uncertainty, loss of control and confusion experienced by those with dementia contributes to this most upsetting type of behavior.

What Causes It?

Think about it . . . if you had difficulty recognizing people, you might approach them cautiously. If you were self-absorbed, you might assume that conversations you overheard were about you. When you have difficulty understanding things, it is easy to become worried, scared and suspicious.

These tendencies often lead to accusations, angry outbursts, and even delusions (thoughts that are contrary to reality) or hallucinations (seeing, hearing, or sensing things that are not really there).

Suspiciousness and paranoia may be some of the most difficult behaviors to witness in a loved one.

Check Potential Causes

- Visual problems or hearing loss may result in hearing or seeing things.

- Insufficient lighting may play tricks.

- Unfamiliar noises or changes in the surrounding may account for fear.

- Physical illnesses, infections, medication or dehydration may be to blame. Watch for any signs of pain. Increase your vigilance to be sure that your loved one is not eating or imbibing anything inappropriate.

- The source of suspicion may be real! Check it out first.

- Memory loss may lead to the sensation that something is wrong, leading to frustration when the resident cannot explain or name the difficulty.

Continued

- Assess the problem. What happened right before the resident became suspicious? Has something like this happened before? Was it in the same room or at the same time of day?

Action Steps

- Reassure and comfort with a gentle touch by holding and by using calming words and gestures. For example, “Don’t worry. I’ll help you find it. It’s all right to feel that way.”

- Focus on and acknowledge the feelings surrounding the situation rather than arguing or reasoning. “You’re feeling afraid (angry). I understand how upsetting this is. This is very frightening for you, isn’t it?”

- Take the resident’s mind off the problem by using familiar distractions. Take a walk; turn on some music; bring out a favorite activity, photo album or game.

- Accept the resident’s belief that this is happening rather than arguing or challenging. “I see that your glasses are not right here. Let’s look for them.”

- When you have identified possible environmental causes, change the surroundings.

- Cover mirrors if they cause confusion. Many people with dementia do not recognize their own images.

- Brighten the room.

- Restore furniture to its original placement if it has been moved.

When There Are Accusations Of Stealing . . .

- Help the resident look for lost objects rather than scolding.

- Keep a spare set of frequently lost items.

- Identify places where valuables are stored and keep track of favorite hiding places.

What About Medications?

Obtain advice about medication from a physician.

Appendix 4.5

Incontinence
Tips for Families and Direct Care Providers

Incontinence, which includes loss of bladder and/or bowel control and bedwetting, is a difficult problem if you're caring for an Alzheimer patient. Incontinence is common among Alzheimer patients--especially those in the latter stages of the disease.

Although you can manage incontinence by changing the patient's routine, clothing or environment, at some point you'll need to accept incontinence as a permanent condition of the disease.

If incontinence is a new behavior, your first and most important step is to identify the possible reasons for this loss of control. Ask yourself the following questions:

Medical Conditions

Could the reason be medical? For example, could the resident have a urinary tract infection, constipation, or a prostate problem? Or is there an illness such as diabetes, stroke, or Parkinson's disease? Do movement difficulties make it hard for the resident to get to the bathroom in time? If the answer to any of these questions is "yes," you may want to consult with his or her physician.

Stress

Is the incontinence caused by stress or movement? For example, does the resident release urine with a sneeze, cough or laugh? Does fear of an embarrassing accident make the resident want to continually visit the bathroom? Keep in mind weak pelvic muscles in a woman could cause uncontrollable loss of urine.

Medication

Is the resident on medication that might intensify the behavior? Is it possible that tranquilizers, sedatives, or diuretics contribute to incontinence? Keep in mind, for example, that some tranquilizers can relax the bladder muscles. Medications used to treat incontinence can cause such side effects as dry mouth and eye problems.

Dehydration

Did anyone withhold fluids when the resident started to lose bladder control? If so, the resident might become dehydrated. Dehydration can, in turn, create a urinary tract infection, which can lead to incontinence.

Continued

Diuretics
Are you giving the resident fluids that might produce a diuretic effect (increased urinating)? Beverages such as coffee, colas, and tea might contribute to incontinence.

Environment
Are there problems in the environment? Is it possible that the resident can't find the bathroom? Does the resident have too far to travel to reach the bathroom in time? Is the resident afraid of falling? Are there obstacles in the path such as chairs or throw rugs? Is the path well lighted?

Clothing
Does the resident have problems undressing in the bathroom? Are the zippers and buttons on clothing causing problems?

ACTION STEPS

➡ **Innovate**
Be willing to experiment with new concepts and ideas. Keep in mind that every person is different. What works for one person may not work for another.

➡ **Understand**
Remember that accidents are embarrassing. Be matter-of-fact and understanding and avoid blaming or scolding the individual. When the resident is successful, use praise, encouragement and reassurance.

➡ **Communicate**
Encourage the resident to tell you when she thinks she needs to use the bathroom. The resident may not be able to say, "I need to use the bathroom. "Watch for visible cues that the resident needs to use the bathroom. For example, the resident may get restless, make unusual sounds or faces, or pace around the room.

➡ **Plan ahead**
Train yourself to respond to the resident's routine and schedule. Identify when accidents occur and plan ahead. If an accident happens every two hours, you'll need to get the resident to the bathroom before that time. You might also find it helpful to keep a notebook or log that notes when the person uses the bathroom.

Continued

➡ Change and adjust

Be patient and allow the resident adequate time in the bathroom. In addition, rearrange the environment to make it easier for the resident to use the bathroom. For example, leave on a nightlight in the bathroom and bedroom. Put a picture of a toilet on the bathroom door, or paint the bathroom door a color different than the wall. If accidents occur at night, consider a portable commode or urinal near the bed.

➡ Simplify clothing

Keep the resident's dress simple and practical. Instead of choosing clothing with zippers and buttons, choose easy-to-remove and easy-to-clean styles such as sweat pants with elastic waistbands. Consider using such products as pads or protective bedding, adult diapers, or panty liners for female patients.

➡ Follow-up

Make sure the resident uses the bathroom. You may need to assist in removing clothes, wiping or flushing. You might also want to stimulate urination by giving the resident a drink of water or running water in the sink. Keep sensitive skin areas clean with regular washing and application of a powder or ointment.

➡ Control

To help control night incontinence, limit the resident's intake of liquids after dinner and in the evening and cut down on drinks such as cola, coffee, tea, and grapefruit juice. Encourage the resident to drink at least one-and-a-half quarts (six cups) of fluids daily. For variety, you might want to introduce decaffeinated herbal teas, decaffeinated coffee, jello, or fruit juice.

Help the resident with Alzheimer's retain a sense of dignity despite the problems with incontinence. Reassuring and non-judgmental statements will help lessen feelings of embarrassment.

Appendix 4.6

Sundowning and Shadowing
Tips for Families and Direct Care Providers

Sundowning
People with diseases such as Alzheimer's often have behavior problems in the late afternoon and evening. They may become demanding, suspicious, upset or disoriented, see or hear things that are not there and believe things that aren't true. Or they may pace or wander around the house.

While experts are unsure how or why this behavior occurs, they suspect that the problem of late afternoon confusion, which is sometimes called "sundowning," or "sundown syndrome," may be due to these factors:

- The resident with Alzheimer's can't see well in dim light and becomes confused.
- The impaired resident may have a hormone imbalance or a disturbance in his/her "biological clock."
- The resident with Alzheimer's tires at the end of the day and is less able to cope with stress.
- The resident is involved in activities all day long and grows restless if there's nothing to do in the late afternoon or evening.
- The caregiver communicates fatigue and stress to the resident with Alzheimer's and the resident becomes anxious.

ACTION STEPS

➡ **Try these ways to lesson the behaviors of "sundowning":**

- Make afternoon and evening hours less hectic. Schedule appointments, trips, and activities such as baths or showers early in the day.

- Help the resident to use up extra energy through exercise. For the resident who tends to pace or wander in the evening, you may want to arrange at least one or two brisk walks during the day.

- Control the resident's diet. Reduce foods and beverages with caffeine (chocolate, coffee, tea, and soda) or restrict them to the morning hours to reduce agitation and sleeplessness.

Continued

- An early dinner or late afternoon snack may also help.

- It's important to provide regular activities and you may want to discourage napping during the day if nighttime sleeplessness is a problem.

- You may want to reduce the level of noise from radios, televisions or stereos, control the number of people who visit in the evening hours, or confine noisier family activities to another area of the house.

- Consult with your physician. Your physician may be able prescribe medication to encourage sleep. At the same time, your physician can check for signs of depression, or for physical problems, such as prostate difficulties that might lead to frequent urination. This condition can cause pain and make sleep uncomfortable.

- Make it easy for the resident to use the bathroom. Consider a bedside urinal or commode. Or encourage the resident to use the bathroom before going to bed.

- Keep rooms adequately lit. Good lighting may reduce the resident's confusion. A night-light may prevent the resident from becoming agitated in unfamiliar surroundings.

➨ **Remain flexible and consider the resident's needs.**

- While people with Alzheimer's may find it difficult to sleep in their beds, they may fall asleep more easily on the living room couch or in a reclining chair.

- Reassure and comfort the resident. Tell the resident experiencing sundowning what time it is and what's going on in the house. Let the resident know you're there and will remain there. Then try to involve the resident in a meaningful activity such as setting the table, folding towels, doing dishes, or sweeping the floor.

- Avoid arguing or asking for explanations. The resident may not know what's wrong or be able to tell you if he does. Keep in mind that the resident with Alzheimer's has no control over annoying, repetitive behavior. Confusion and restlessness occur because the brain can no longer sort out cues in the environment.

➨ **Remember to care for yourself.**

- Make sure you get adequate rest. Just because the resident with Alzheimer's can't sleep at night doesn't mean you should go without sleep. Arrange for another family member to supervise the resident at night. Or arrange the room so that it is safe enough (and has locked doors) to let the resident stay awake and pace there while you nap or sleep in another room.

Continued

Shadowing

"Sundowning" is often accompanied by "shadowing," where the resident with Alzheimer's follows or mimics the caregiver, or talks, interrupts, and ask questions repeatedly. At times, the resident may become upset if the caregiver wants to be alone. While shadowing and other forms of agitation vary from resident to resident, you may be able to manage the behavior by following these steps:

ACTION STEPS

➡ Examine factors that encourage agitation. Consider these questions:

- How long does the behavior last?
- At what time of day does it occur?
- Is the behavior triggered by certain people or surroundings?
- What seems to calm the impaired resident?

Once you develop answers to these questions, you may be able to avoid the situations that bring about agitation and introduce activities that help calm the resident with Alzheimer's.

✓ Protect your privacy. You may want to install a childproof doorknob on the bathroom door or use a timer and reassure the resident by saying, "I'll be back when the timer goes off."

✓ Try to keep the resident occupied. Find simple, repetitious activities to occupy the resident even if you could do them better on your own. Possibilities include folding the wash, dusting, stacking 'papers or magazines, stuffing envelopes, or winding a ball of yarn. Or provide the resident with Alzheimer's with headphones for listening to calming music.

✓ Consider "gum therapy" or "cereal therapy." If the resident with Alzheimer's is able to chew and swallow easily, you may want to give him/her sugarless gum. Or consider providing the resident with a non-breakable bowl of high-fiber, low-sugar cereal. By having something to snack on, the resident may be less inclined to talk or ask questions.

✓ Rely on the ideas of support groups. Caregivers are always discovering new ways to deal with behaviors such as shadowing and sundowning and are happy to share them.

A better understanding of the feelings of the resident with Alzheimer's disease, such as fear, frustration, and anger, may help you accept the resulting behaviors. Providing reassurance and helping your loved one respond to his or her changing environment can help you manage the resident's behavior.