

Alzheimer's Disease: Interventions for the Caregiver

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How to Take This Course

Please take a look at the steps below; these will help you to progress through the course material, complete the course examination and receive your certificate of completion.

1. REVIEW THE OBJECTIVES

The objectives provide an overview of the entire course and identify what information will be focused on. Objectives are stated in terms of what you, the learner, will know or be able to do upon successful completion of the course. They let you know what you should expect to learn by taking a particular course and can help focus your study.

2. STUDY EACH SECTION IN ORDER

Keep your learning "programmed" by reviewing the materials in order. This will help you understand the sections that follow.

3. COMPLETE THE COURSE EXAM

After studying the course, click on the "Course Exam" option located on the course navigation toolbar. Answer each question by clicking on the button corresponding to the correct answer. All questions must be answered before the test can be graded; there is only one correct answer per question. You may refer back to the course material by minimizing the course exam window.

4. GRADE THE TEST

Next, click on "Submit Test." You will know immediately whether you passed or failed. If you do not successfully complete the exam on the first attempt, you may take the exam again. If you do not pass the exam on your second attempt, you will need to purchase the course again.

5. FILL OUT THE EVALUATION FORM

Upon passing the course exam you will be prompted to complete a course evaluation. You will have access to the certificate of completion **after you complete the evaluation**. At this point, you should print the certificate and keep it for your records.

About the Author

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Purpose Statement and Objectives

Registered nurses will examine best practices and enhance their ability to manage patients that exhibit behavioral challenges resulting from Alzheimer's disease.

At the completion of this learning activity the learner will be able to:

- Define Alzheimer's disease.
- Identify distressing behaviors that are common in patients with dementia.
- Discuss behavioral interventions that can help to ameliorate the distressing behaviors.
- Examine personal behaviors to determine how they may be contributing to the patient's distressing behaviors.

Introduction

On June 5, 2004 Ronald Reagan, the 40th President of the United States died of pneumonia, a complication from Alzheimer's disease (AD). Previous to this, he issued a widely publicized statement in November of 1994 disclosing his affliction with AD. Over the next ten years people worldwide watched the steady decline of one of America's most beloved Presidents. As people watched they saw the complications of the disease and the strain of care giving. Thus began increased research into AD: its origin, treatment, care giving, and a goal to find a vaccination or a cure. Upon Ronald Reagan's death in 2004, efforts have increased to unravel the mystery of what AD is and how the disease can be successfully prevented and cured.

AD is the most common type and leading cause of dementia. An estimated 5 to 10 percent of the U.S. adult population age 65 and older is affected by some form of dementia. The older population in the United States is increasing dramatically. As of the year 2000, an estimated 35 million people were age 65 and older. Researchers estimate that by 2050, 70 million Americans will be age 65 or older (accounting for 1 in 5 Americans), and more than 19 million Americans will be age 85 and older (U.S. Department of Health and Human Services, 2009). Its current and future impact on our society can be seen in these alarming statistics from the Department of Health and Human Services (2009):

- Scientists estimate that around 5.1 million people now have AD.
- For every 5-year age group beyond 65, the percentage of people with AD doubles.
- By 2050, 13.2 million older Americans are expected to have AD if the current numbers hold and no preventive treatments become available. This is nearly triple the current rate of AD.

A person with Alzheimer's disease will live an average of eight years and as many as twenty years or longer from the onset of symptoms. Half of all nursing home residents suffer from Alzheimer's disease (Alzheimer's Association, 2009a). This disease crosses all cultural, social and economic boundaries and impacts not only the individual, but the entire family system and communities as well.

This course will address the behavioral management of communication, catastrophic reaction, and behavioral issues such as wandering, resistance to care, sexual disinhibition, vocal disruption, and assaultive behavior.

What is Alzheimer's Disease?

Alzheimer's disease (AD) is named after Dr. Alois Alzheimer, a German doctor. In 1906, Dr. Alzheimer identified changes in the brain tissue of a woman who had died of an unusual mental illness. The brain tissue had abnormal clumps (now called amyloid plaques) and tangled bundles of fibers (now called neurofibrillary tangles). Today, these plaques and tangles in the brain are key characteristics of AD (Alzheimer's Disease Education & Referral Center [ADEAR], n.d.).

The Alzheimer's Association (2009b) identifies 10 warning signs of the disease:

1. Memory loss
2. Challenges in planning or solving problems
3. Difficulty performing familiar tasks
4. Disorientation to time and place and eventually to person
5. Trouble understanding visual and spatial relationships
6. New problems with words (in speaking or writing)
7. Misplacing things
8. Decreased judgment
9. Withdrawal from work or other activities
10. Change in mood and personality

Although these are identified as warning signs, as the disease progresses it impacts the overall functioning of the individual in relation to memory, language skills, motor coordination, judgment, orientation, abstract thinking and personality traits. Because of the degenerative nature of the disease, eventually persons with Alzheimer's disease become unable to speak, move very little, and are disoriented in all three spheres.

Many conditions can cause dementia. Cognitive impairment may be related to medication use (see Table 1), environmental toxins, infectious or metabolic illnesses such as pneumonia, urinary tract infections, diabetes, acute or chronic renal failure, thyroid disease, etc. Some of these problems may be reversible if detected early. It is important to identify the actual cause in order to receive proper treatment. There are other causes of dementia, including Creutzfeld-Jacob disease, vascular diseases, cerebral vascular accidents, head trauma, normal pressure hydrocephalus, Pick's disease, Parkinson's disease, Lewy body disease, Huntington's disease, and chronic alcohol use.

Type of Medication	Generic Name
Antiarrhythmic agents	disopyramide, quinidine, tocainide
Antibiotics	cephalexin, cephalothin, metronidazole, ciprofloxacin, ofloxacin
Anticholinergic agents	benztropine, homatropine, scopolamine, trihexyphenidyl
Antidepressants	amitriptyline, imipramine, desipramine, fluoxetine
Anticonvulsants	phenytoin, valproic acid, carbamazepine
Antiemetics	promethazine, hydroxyzine, metoclopramide, prochlorperazine
Antihypertensive agents	propranolol, metoprolol, atenolol, verapamil, methyldopa, prazosin, nifedipine
Antineoplastic agents	chlorambucil, cytarabine, interleukin-2
Antimanic agents	lithium
Anti-Parkinsonian agents	levodopa, pergolide, bromocryptine
Antihistamines/decongestants	phenylpropanolamine, diphenhydramine, chlorpheniramine, brompheniramine, pseudoephedrine
Cardiotonic agents	digoxin
Corticosteroids	hydrocortisone, prednisone
H2 receptor antagonists	cimetidine, ranitidine

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Immunosuppressive agents	cyclosporine, interferon
Narcotic analgesics	codeine, hydrocodone, oxycodone, meperidine, propoxyphene
Muscle relaxants	baclofen, cyclobenzaprine, methocarbimol
Nonsteroidal anti-inflammatory agents	aspirin, ibuprofen, indomethacin, naproxen, sulindac
Radiocontrast agents	metrizamide, iothalamate, iohexol
Sedatives	alprazolam, diazepam, lorazepam, phenobarbital, butabarbital, chloral hydrate
<p><i>Note.</i> This list is not inclusive of current medications that may contribute to cognitive impairment. Adapted from P. T. Costa, Jr., M. S. Albert, N. M. Butters, M. F. Folstein, S. Gilman, B. Gurland, ... T. F. Williams, 1996, <i>Early Identification of Alzheimer's Disease and Related Dementias. Quick Reference Guide for Clinicians Number 19</i> (AHCPR Publication No. 97-0703), Table 2. Rockville, MD: U.S. Department of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research.</p>	

Treatment of Alzheimer’s Disease

There is no current cure for AD; however, there are pharmacological and behavioral interventions that can help to manage the disease. By 2003, five medications were approved to treat AD symptoms. Of these, four are known as cholinesterase inhibitors and are prescribed to treat mild to moderate AD symptoms. Due to safety concerns the first cholinesterase inhibitor called tacrine (Cognex®) is rarely prescribed today. This medication was replaced by three newer drugs: donepezil (Aricept®), rivastigmine (Exelon®), and galantamine (Razadyne®) (U.S. Department of Health and Human Services, 2008). These newer drugs act by stopping or slowing the action of acetylcholinesterase, an enzyme that breaks down acetylcholine. Refer to Table 2 for more information on AD medications.

Acetylcholine, a neurotransmitter that is critically important in the process of forming memories, is used by many neurons in the hippocampus and cerebral cortex—regions devastated by AD. These drugs improve some patients’ abilities to carry out activities of daily living; may improve certain thinking, memory, or speaking skills; and can help with certain behavioral symptoms. Unfortunately, these drugs are time limited in that they appear to help patients only for months to a few years.

The fifth medication is memantine (Namenda®), which can be prescribed to treat moderate to severe AD symptoms. This drug appears to work by regulating excess glutamate in the brain (U.S. Department of Health and Human Services, 2008). Glutamate is another neurotransmitter involved in memory function, but high levels may damage neurons. Like the cholinesterase inhibitors, memantine will not stop or reverse AD. Studies have shown that memantine may delay loss of daily functions in patients with moderate to severe AD (Reisberg, Doody, Stoffer, Schmitt, Ferris, & Mobius, 2003; Tariot, Farlow, Grossberg, Graham, McDonald, & Gergel, 2004). The FDA has also approved Aricept for the treatment of moderate to severe AD (U.S. Department of Health and Human Services, 2008).

Because medications are limited in their ability to stop the progress of AD, it is important for caregivers to be skillful at interventions that can help to ameliorate the problematic behaviors that are often associated with AD.

Table 2. FDA Approved Medications for Symptoms of Alzheimer’s Disease			
Drug Name	Drug Type and Use	How it Works	Common Side Effects
Namenda® (memantine)	N-methyl D-aspartate (NMDA) antagonist prescribed to treat symptoms of moderate to severe AD	Blocks the toxic effects associated with excess glutamate and regulates glutamate activation	Dizziness, headache, constipation, confusion
Razadyne® (galantamine)	Cholinesterase inhibitor prescribed to treat symptoms of mild to moderate AD	Prevents the breakdown of acetylcholine and stimulates nicotinic receptors to release more acetylcholine in the brain	Nausea, vomiting, diarrhea, weight loss, loss of appetite
Exelon® (rivastigmine)	Cholinesterase inhibitor prescribed to treat symptoms of mild to moderate AD	Prevents the breakdown of acetylcholine and butyrylcholine (a brain chemical similar to acetylcholine) in the brain	Nausea, vomiting, diarrhea, weight loss, loss of appetite, muscle weakness
Aricept® (donepezil)	Cholinesterase inhibitor prescribed to treat symptoms of mild to moderate, and moderate to severe AD	Prevents the breakdown of acetylcholine in the brain	Nausea, vomiting, diarrhea
Note. Adapted from U.S. Department of Health and Human Services, 2008.			

Caregivers' Challenge

It is important to recognize that dealing with specific behavioral issues related to Alzheimer's disease and other dementias can be very challenging to the caregiver. This is true whether the caregiver is a family member in the home, or a paid professional in a long-term care setting. Nurses who care for patients with dementia must strive to gain information about the disease and its progression as well as the impact of these on the individual patient and their families. Additionally, it is important to acknowledge that caring for persons with dementia requires a tremendous amount of patience and understanding, the ability to be empathic, and provide excellent, creative care. A strong sense of caring and a strong sense of humor are critical.

This challenging illness does take its toll on caregivers as well as patients. Nurses, who are caring for patients with dementia, must make the time to express their feelings and frustrations regarding the care of these patients in an environment that is safe for expression. The nurse's own feelings need to be validated and supported; their concerns need to be addressed. Recognizing, acknowledging and mastering this challenging care are a process; proficiency requires time and practice.

Caregiver's Bill of Rights

Providing care for a person with Alzheimer's disease is often a stressful and demanding ordeal. It is important to remember that caregivers have human needs and emotions. They must care for the patient as well as themselves. The Alzheimer's Family Relief Program's "Caregiver's Bill of Rights" offers some tips for coping (American Health Assistance Foundation, n.d.):

IT IS ALL RIGHT TO:

- **BE ANGRY.** Turn this energy into positive action. Clean closets, take a walk, and talk with someone.
- **BE FRUSTRATED.** Stop the present activity, take a deep breath and begin a different activity.
- **TAKE TIME ALONE.** A favorite chair in a quiet room, a trip to the store or a few hours out with friends.
- **ASK FOR HELP.** Explore family, friends and local agencies for resource services. Most doctors' offices and clergy can make referrals.
- **TRUST YOUR JUDGEMENT.** Relax; you are doing the best you can.
- **RECOGNIZE YOUR LIMITS.** You are a valuable person. Take care of yourself, too!
- **MAKE MISTAKES.** No one is perfect. This is how we learn.
- **GRIEVE.** This is a normal response to a loss. You may be sad over the loss of the way things used to be.
- **LAUGH AND LOVE.** It may seem out of place, but your capacity to feel is not gone and can occur unexpectedly.
- **HOPE.** Tomorrow, the day may go smoother, a friend may call, and a cure may be found.

Behavioral Issues in the Management of Dementia

Overview

Managing difficult behaviors can be the greatest frustration for the caregiver. The behavior of the patient with dementia is a message – our job is to interpret the message. Staff works from logic and the patient with dementia works from emotion. So, if the caregiver becomes frustrated, the patient will become frustrated.

It is important to first rule out any physical cause for a behavior change. In Alzheimer's disease and other dementias, the patient's ability to communicate, perceive and comprehend his or her environment is impaired. They may be unable to let you know that they are experiencing a problem. Ask yourself these questions:

- Is the patient ill?
- Is there a possibility that the patient has a urinary tract infection or some other medical condition that is impacting their behavior?
- Is the patient in pain?

Remember to treat the underlying problem and comfort the patient through the process.

If no physical cause for the behavior change can be determined, further assessment is needed. Collect as much information about the behavior as you can such as: when, where, how often does this behavior occur. An important consideration regarding behavioral issues is the timing of the behavior. Has it occurred precipitously? Or, has this been the patient's usual pattern of behavior? Have there been any recent changes, such as changes in caregivers, new medications or treatments, change in visits by family and friends? Obtaining information on the pattern of the behavior may help caregivers determine the best course of behavioral interventions.

Remembering the **6 R's of Behavior Management** (The Ribbon Online, n.d.) may help you to manage a problematic situation:

- **Restrict.** First, try to get the person to stop whatever he is doing, especially when there is a danger of hurting self or others. Speak calmly and address the patient using simple commands.
- **Reassess.** Ask yourself what the cause of the behavior might be. What happened just before the behavior began? Is there a physical problem? Can the source be removed or lessened? Could it be approached in a different way?
- **Reconsider.** Try to consider the person's point of view. How must the things that are going on seem to the patient? What is she or he thinking?
- **Rechannel.** Look for a way to continue the behavior in a safe way or look for other means of using some of the energy. Redirect the person to another activity. Remember, the behavior is important to the patient in a way we cannot understand.
- **Reassure.** Take time to reassure the person that everything is okay and that you still care about him. Let him know that you are still going to care for him.
- **Review.** Afterward, think over what happened and how it was managed. What will you do if faced with this problem again? Often dealing with behavior problems is difficult because the caregiver takes the behavior personally. It is important to accept the behavior for what it is: a symptom of the disease. It is also important to acknowledge that many times behavior problems become so difficult that they require medical intervention. There are a variety of medications that have been

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effective in controlling or limiting behavior problems. The Alzheimer's Association (<http://www.alz.org/findus.asp>) has a list of healthcare providers and services that specialize in the management of behavioral problems. You can search by zip code to find support in your area.

Communication

One of the most important aspects of caring for the individual with dementia is maintaining effective communication. As the ability to **think** decreases, the response to **feelings** often increases (Feil & de Klerk-Rubin, 1992). Because their cognitive abilities have decreased, persons with dementia present with greater emotional reactions. The person with dementia expends a great deal of energy attempting to make sense of their world. This is not an easy challenge because of their declining cognitive abilities. Those with dementia are often confused by their interpretation of the environment around them. They can become anxious and fearful as they attempt to understand their world. While this presents a challenge to communicating with the person with Alzheimer's disease, it can also be used to facilitate interventions. There are some simple concepts to follow that will help.

Always approach the person in a calm, matter of fact, and friendly manner. Individuals with dementia are very sensitive to the emotional state of those around them. If you appear to be frustrated or in a rush: the patient will sense that and may become anxious or fearful. It is important to pay attention to your own body language and tone of your voice. Your body language may say you are relaxed but your tone of voice may be tense. The patient with dementia will pick up on your tension and respond with anxiety and agitation.

Identify yourself and address the person by name. This simple courtesy helps cue the patient as to who you are and who they are; it will help them focus their attention to you and the task at hand. Attempt to eliminate distractions such as background noises, including televisions, overhead pages, others' conversations and activities to avoid confusion. Make sure you have the person's attention; try to be at eye level and look directly at them. Being at eye level helps the patient feel safe. If you are standing over them, the patient with dementia may feel overpowered and helpless. This direct eye contact also helps the patient focus on what you are saying. Don't forget to have the light on your face and not at your back, which would cause your face to be in the dark. Also, remember to keep your hands away from your face while you are speaking and don't chew gum or eat while communicating with the patient, as this can be a distraction as well.

Speak slowly and distinctly. If you talk fast, slow down. If your voice has a high tonal quality, lower your voice. Many older patients lose their ability to hear higher tones as they age. Women and children tend to have higher tonal quality voice which makes it difficult for older people with hearing loss to perceive what they are saying. Shouting only raises the tonal quality of the voice; by lowering the voice the potential for hearing the conversation will be improved.

Remember that cognitive ability is impaired. Use simple, direct statements in words the patient can understand. When giving directions or asking questions, give only one at a time and allow the patient enough time to answer. If you feel the need to repeat the question or direction, use the same words. Rephrasing the question will confuse the patient and they may think you asked two separate questions.

Patients will often be disoriented to their surroundings, asking about when they will be going home, where is a particular loved one, or misidentifying a caregiver as someone they have known in the past. Feil et al. (1992) developed an approach based on Validation Therapy. The basic premise of this approach is to validate how the person *feels*, rather than focusing on the accuracy of what is being said. For example, when a patient asks what time their mother will come to pick them up, it is not helpful to reorient the patient, in other words, do not remind them that their mother is no longer living and the nursing home is now their home. Rather, focus on the patient's feelings. He or she may be missing affection and loving feelings; she may be bored and want to go home; she may be anxious and want relief. Focus on the

emotional tone) of what the patient is saying and then attempt to reassure the patient verbally or behaviorally.

Often distraction is helpful as well. Always respond to the emotional tone of the statement, regardless of whether or not what you heard the patient say is accurate, or if you don't understand what is being said. If the patient cannot finish a thought because they cannot remember the correct word, fill in the missing word for them. Provide reassurance if the patient is becoming frustrated or anxious. Make sure to allow enough time for the patient to respond before you try to answer for them.

Don't ask a lot of questions that depend on memory. Give visual cues and write things down. To simplify things, ask questions that require a "yes" or "no" response.

Don't talk about the person in front or over them. Having a conversation with another caregiver over or in front of the patient can be frightening for the patient. Even though the patient with dementia may not know what it is you are discussing, they may pick up words and feel they are going to be hurt or harmed.

Finally, if your conversation has not been successful, try again later. So many factors impact the ability of the patient with dementia to communicate. The patient with dementia may need to eat, drink, sleep, or eliminate. Dealing with these basic needs first can improve their ability to communicate, and may be what the patient is attempting to tell you.

Catastrophic Reaction

The person with dementia has an impaired ability to understand verbal communication, as is their ability to comprehend and make sense of their environment. Because of these limits in their cognitive abilities and their emotional focus, there are times the patient with dementia will feel threatened and may overreact to a situation. This exaggerated reaction to a normal situation is known as a **catastrophic reaction** and may include anger, suspicion, crying, combativeness, anxiety, and worry. There are some simple suggestions on how caregivers can stop the reaction when it does occur.

Don't try to reason with the patient or try to talk the patient out of their distress. If the patient is crying, rock, pat, or stroke the person to calm. Attempt to reassure them that you are there to help them, or have taken care of the situation. Then try to distract them with something different. Using a calming touch can often effectively eliminate anxiety and worry.

In a situation where the patient is angry or suspicious, it is most important that the caregiver stay calm. Ask the patient to help you do a job by following you out of public view. Move slowly. Talk soothingly and simply. Let the patient know what you are doing. Don't try to restrain the patient if they are agitated. If the patient becomes combative, move the person away from everyone else. Have the patient sit down and give them a soft pillow or soft rubber ball to squeeze while distracting with soothing music or with a box full of items to sort through.

Simple rules to remember to prevent a catastrophic reaction when caring for the patient with dementia include:

- Arguing with the patient only creates a bad situation.
- Do not approach from behind and touch a patient with dementia; they may not have the perceptual ability to know that someone they know may be there.
- Never take hold of a patient's body (e.g., arm) without getting eye contact first. He or she might attempt to defend him/her self if grabbed while unaware.

How effectively you, the caregiver, can communicate and maintain a calm, safe environment will determine the ease of providing care for the patient with dementia.

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Wandering

Wandering is the natural outcome of the searching process for a place of safety and familiarity. The patient has the tendency to move about in a seemingly aimless or disoriented fashion in pursuit of an indefinable or unobtainable goal. Wandering involves extended periods of movement from which the patient cannot seem to stop or rest. Management of the wandering looks at providing enough regular exercise and distraction. This may include group exercise classes or tasks that would involve physical movement such as: folding laundry, tearing up paper, moving chairs, or carts.

Many individuals with AD attend daycare centers or live in nursing homes. Among these, approximately one in five will wander outside and possibly off the grounds of the facility. In addition, 60% of AD patients overall will wander at one time or another. If not found within 24 to 48 hours, wandering people may die. According to Healthcare Review (as cited in Elderwood Senior Care, n.d.), wanderers can be found:

- In residential yards (26 percent)
- On the street (22.3 percent)
- At businesses (11.8 percent)
- In healthcare facilities (9.2 percent)

To help identify and return wanderers, the Alzheimer's Association established the **Safe Return Program**. This is the only nationwide, community based program of its kind in the United States. The program provides continuous assistance all day, every day for caregivers of enrollees. When contacted, the program will immediately fax the patient's information and photo to local law enforcement, who will forward the information to the community support network in his or her area. When found, a phone call is placed to the toll free number located on the patient's informational necklace, bracelet, or clothing patch. Safe Return will then contact the designated person(s) to convey information on location of the patient. As a nurse, you can promote this program within your healthcare facility by encouraging administration to register, or request the family to register the patient (Alzheimer's Association, n.d.).

For further information on the program and/or to register a patient(s), visit: <https://www.alz.org/Services/SafeReturn.asp>. Note: there is a registration fee per patient, and an annual fee to keep the service active.

There are generally four types of wanderers (The Ribbon Online, n.d.):

1. Exit-seekers: usually want to leave the building or house.
2. Restless wanderers: want to simply pace or roam.
3. Stimulators: looking for means of stimulation; may touch wall surfaces or curtains.
4. Imitators: wander because someone else does (generally in nursing facilities).

Aversion items and positive reinforcement can help in distracting the patient from entering other patient's rooms. Items such as a mesh barrier with a stop sign on it, or a shower curtain hanging over a room door may help keep the patient from entering. Placing a picture of the patient by the doorframe or some personal, familiar object may help the person recognize his or her own room. Also, knowing the patient's history can help eliminate the patient from continually entering another patient's room. For example, if the wandering patient is always going into the room to their left, was that their pattern at home? If so, moving the wandering patient's room to another location may eliminate the behavior. Frequent orientation to the unit and/or use of simple commands and visual cues may help this patient. Signs with a toilet on the bathroom door, pictures of food on the dining room door, etc. may help the patient identify these areas.

Be aware of barriers in the environment. Clear hallways of obstacles and pay attention to lighting. As the dementia progresses, patients' motor abilities decrease. Clear paths for walking and appropriate lighting may help to decrease the possibility of falls.

Wandering can be exhausting to the patient. Helping this patient receive appropriate food, fluids, rest, and remain safe can be a great challenge. Providing finger foods and small amounts of fluids while the patient is wandering can provide nutritional support as opposed to trying to get the patient to sit through a meal. Use of time out, beanbag chairs, rocking chairs, and recliners can provide necessary rest. Background noise can be overwhelming, but the use of “white” noise: low intensity rhythmic sound such as a fan, can increase sleep duration.

Resistance to Care

Resistance to care may be related to multiple factors, including physical causes such as urinary tract infections, constipation, hemorrhoids, etc. It may also be related to anxiety related to exposure and safety, or it can be related to issues of control and decision making. Whatever the cause, resistance to basic hygiene care can lead to skin breakdown and aversion by others because of body odor and appearance. Caregivers must learn to respond to the feelings rather than the expressed actions of the resident’s behavior.

Look at simplistic ways to avoid this problem. How is the environment impacting the patient? Be flexible! There are many ways to do routine activities of daily living. Not every patient needs to be up and dressed for breakfast. Caregivers need to examine their own feelings and responses to the patient’s behavior. Apply some basic concepts to the care of patient with dementia, such as: proceeding in a calm, quiet, patient manner; setting realistic goals for the patient and yourself when considering what must be done; being flexible and creative; avoiding confrontation and words that pose a threat, such as “undress” or “I’ll change you”. Avoid rushing, being too noisy, being frustrated, getting too close into personal space, and having too many people in the same area at the same time. Make sure to always let the patient know what care you are about to provide; enlist the patient’s assistance. Consider giving rewards, such as chocolate, when care is being given.

Bathing has its own set of issues. Many people are uncomfortable having someone see them naked. They may be used to privacy, or taking a bath in a tub as opposed to a shower. They are likely used to being in a personal bathroom not an institutional setting. There may be fear of physical harm or personal invasion, etc. To make the bathing experience more comfortable, consider the following:

- Make sure the tub/shower room does not have extra equipment.
- Play soft, quiet music in the room.
- Add pictures and decorative towels in the bathroom. Often, if the room looks more “homey”, the idea of bathing will be easier to accept.
- Bring extra towels to drape over the shoulders and over the head to retain heat.
- Offer a small piece of chocolate during the bath. It can give a sense of relaxation and enjoyment for the patient.

Ask the patient to tell you if the water temperature is comfortable, turn the water on slowly and keep the pressure at a minimum so the patient is not being hit with a hard spray. Start the water spray at the feet; this is less threatening to the patient. Give the patient a washcloth and have them wash their face, chest, arms, and any areas that they can safely reach themselves. Some patient’s may need to keep on their underwear to feel safe, they can then be removed at the end of the shower to finish and replace with dry clothing. Washing hair can be done by having the patient hold the washcloth over their face and the caregiver placing a couple of fingers over the shower head to get more focused water spray than having the water splash over the patient.

Toileting offers challenges of personal invasion of space, being exposed to another person, fear of physical harm from another person, exposing one’s private parts to someone unknown. Eliminate caffeine from the patient’s diet, as it has a diuretic effect. Clothing that is easy to remove is helpful while changing briefs or after an incontinent episode. Know the patient’s personal toileting habits, such as timing, the location of the bathroom in the home, fluid intake, bowel habits, etc. Establish a personal

toileting routine. Is the bathroom located in a direction that is familiar to the patient, i.e., if the bathroom at home was to the right of the bed, is the bathroom in the facility to the left and the patient gets confused? This helps prevent accidents. However, when accidents do occur, don't fuss; be calm and maximize the patient's dignity. Explaining to the patient what care you are providing can relieve anxiety and fear.

Changing a disposable brief can be stressful to the person with dementia because of exposure, as well as the stress of taking off shoes and pants. A new brief can be placed on the patient without removing the shoes and pants. If the patient is sitting on the toilet, remove the soiled brief and cleanse the patient. Take the new brief, place it over the shoe and through the pant leg, then open the brief across the inside of the pants and bring the other leg down through the pant and over the other shoe. The new brief is on and the pants and shoes did not need to be removed.

Dressing also offers many challenges similar to bathing and toileting, the fear of the unknown, pain, lack of control, lack of privacy, cold, and inattention to personal needs or wishes. Offering choices of clothing includes showing the clothing to the patient, not just using words. Respect the patient's privacy and focus on the person, not the task. Timing the patient's medication to be given thirty to forty five minutes prior to dressing may help alleviate pain and discomfort. Using a calm, gentle manner will assure the patient of your concern for them as does explaining, step-by-step, what you are doing.

Eating becomes a very challenging activity for many patients with dementia. This may be related to wandering or the deterioration of the patient's cognitive and motor abilities. Some are overwhelmed by the noise, the other patients, competing demands for attention, and general over stimulation in the dining areas. Simple changes can help many of these patients. If the patient is over stimulated by the noise and activity, a change in the seating arrangement may be helpful. It may require that the patient dine in a smaller room with less noise and activity, or merely be seated away from the larger group but yet be observable by the staff.

If the patient is a wanderer and is not able to sit for a meal, offer finger foods that can be eaten while traveling. Sandwiches, juice boxes, fruit slices, graham crackers, cookies, etc, can all be eaten on the move - don't forget about fluid needs. For those patients that can sit and eat, offer one or two items at a time. Space people at the table so that eating from each other's trays or plates is avoided; assist as needed - cutting up meats, offering fluids. Tolerate messy behaviors. It's more important that the patient be able to feed her or himself than to have clean clothing when finished. Direct or cue the patient to increase independence, setup the meal and go back throughout the meal to offer assistance, placing more food on the tray or plate for the patient.

Sexual Disinhibition

Disinhibited sexual behavior encompasses a variety of behaviors from making sexual comments and gestures to publicly masturbating or having sexual contact with others who may or may not be consenting to the behavior. This overt sexual talk or behavior often elicits feelings of anxiety, embarrassment or unease in the caregiver and the result is often significant disruption in continuity of care for the patient.

Human beings are sexual creatures and having sexual feelings is part of the human experience. Caregivers must recognize that despite advanced dementia, a patient may continue to have sexual feelings. Tolerance by the caregiver for appropriate sexual expression by the patient is necessary. Not taking the comments personally, offering the patient the option of having a different caregiver may alleviate some of the stress. It is important to remember that caregivers may have had experiences in their own pasts that create additional anxiety about the patient's sexual disinhibition; a change in caregivers may be needed for the caregiver's sake as well.

The underlying cause of inappropriate sexual behavior varies among patients. Careful assessment of possible etiology is the first essential step in intervening. Nursing interventions that focus on providing safe opportunities for sexual expression are encouraged. Providing privacy for a patient to masturbate

can restore the patient's sense of safeness in their environment and remove the negativity often surrounding sexual expression.

Patient's may be reacting in a sexual way to caregivers' expressions of caring. Some patient's need to be told that these feelings may be normal and understandable, but the behaviors are unacceptable. In the early stages of dementia, the patient may be responsive to verbal intervention. However, as the dementia progresses, behavioral interventions are needed. Review patients' medications: are there medications that may be contributing to their disinhibition?

Patients whose sexual disinhibition may be harmful to other residents need close supervision and a very structured environment in order to keep them occupied and focused, and to keep others safe.

Please visit http://www.alz.org/national/documents/topicsheet_sexuality.pdf for further information.

Vocally Disruptive Behavior

Vocally disruptive behavior consists of the screaming of repetitive words, shouting, or calling out. The words may be intelligible or not; it may be purposeful and goal-directed or not. The vocalization may be related to poor sleep, discomfort, or pain. It may be related to anxiety or fear. It may be a means of self-stimulation or self-soothing. Always rule out any physical causes for the behavior. Treat the underlying cause, whenever one can be identified. Focus on issues of comfort for the patient.

The repetitive nature of the vocalizing becomes frustrating for the caregiver as well as other patients. The caregiver needs to remain calm, use gentle touch, diversion, and respond to the patient. Part of the fear of the patient is that no one will be there for them when they need help.

Whenever possible, provide structure to the patient's day. Often keeping the patient focused on some activity may help to delay the vocalizing, if only minimally and temporarily. Patients may respond positively to the use of lollipops, or a soft item, such as a stuffed animal or pillow to hold and touch.

A look at Assaultiveness or Reactive Behavior

Assaultive behavior involves any activity where invasion of personal space puts the patient in a fearful or threatened position. The patient can respond with physical aggression. Many factors can lead to striking out, from drug reactions to a hurried approach by the caregiver during a bath for example. Patients with a history of previous assaultive behavior and a diagnosis of dementia or organic brain syndrome are most often associated with assaultive behavior (Somboontanont, Sloane, Floyd, Holditch-Davis, Hogue, & Mitchell, 2004).

Caregivers can decrease the risk by recognizing the potential factors that trigger assaultive or reactive behavior. As stated previously, the pattern of the patient's behavior needs to be examined. An assault is intentional, and a cognitively impaired patient may perceive fear and may be exhibiting an act of self-defense or simply a reactive behavior (Minner, 2006). When the behavior does occur, the caregiver should take a look at such factors as:

- What is the time of the day?
- Who is the target of the assault?
- Is the patient experiencing increased anxiety and restlessness, agitation and behavior due to environmental factors?
- Is it too noisy?
- Are there too many people and too many activities in the patient's space?
- Is the patient uncomfortable or in pain?

Maintaining calm, quiet environment, respecting personal space and responding to the emotional tone of the patient may prevent angry outbursts from the patient. It is often helpful to structure the patient's day with activities that the patient enjoys. Keeping the patient focused and engaged, but not too challenged may help to decrease assaultiveness.

Conclusion

As the number of elderly within our population increases, caregivers are faced with higher numbers of patients with dementia. It is important to remember that, since intellectual functioning is impaired, those with cognitive impairment often are more emotionally focused. Many of the concepts to alleviate the problems are simplistic. You, as the caregiver, set the tone for interactions with the patient. Maintaining a calm, positive attitude will help the patient feel safe and secure. Focus on the emotional tone of their words and behavior for clues to resolution. Pay close attention to the environment; over stimulation from noise, lighting or crowds can be easily resolved and eliminate or minimize some of the distressing behavior. Supporting and discussing caregiver issues and perceptions about dementia can be beneficial in alleviating frustration, preconceived notions about behavior and personal bias on the part of the caregiver.

Resources

Alzheimer's Disease Education and Referral (ADEAR) Center

P.O. Box 8250
Silver Spring, MD 20907-8250
800-438-4380
<http://www.alzheimers.org/>

Alzheimer's Association

919 North Michigan Avenue, Suite 1000
Chicago, Ill, 60611-2676
800-724-0587
www.alz.org

Alzheimer's Family Relief Program (AFRP)

To assist families with the financial strains associated with providing care for loved ones with AD a nurse can refer them to the American Health Assistance Foundation (AHAF). AHAF established the Alzheimer's Family Relief Program (AFRP) and has been providing monetary assistance to caregivers of patients with AD. The AFRP also provides informational resources to nurses and family. A frequently asked question page is available on their website (<http://www.ahaf.org/afrp/afrp.htm>) where "real life" questions can be asked of their experts and the answers are posted every other Wednesday. Application guidelines for financial assistance can be found online at: <http://www.ahaf.org/afrp/guide.htm>. As a nurse providing this information to families, you may help to lessen the stress and also help to garner quality care for the patient by assisting the family in getting the funds necessary to pay for medical care.

National Institute on Aging

31 Center Drive MSC 2292
Bethesda, MD 20894
301-496-1752
<http://www.nih.gov/nia>

Additional Reading

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Alzheimer's Disease: Interventions for the Caregiver

Course Exam

After studying the downloaded course and completing the course exam, you need to enter your answers online. **Answers cannot be graded from this downloadable version of the course.** To enter your answers online, go to e-leaRN's Web site, www.elearnonline.net and click on the Login/My Account button. As a returning student, login using the username and password you created, click on the "Go to Course" link, and proceed to the course exam.

Note: Contact hours will be awarded for this online course until March 1, 2013.

1. Alzheimer's disease:
 - a. Affects women more than men.
 - b. Is the fifth leading cause of death.
 - c. Strikes one eighth of the population.
 - d. Is the leading cause of dementia.

2. Dementia related to medications, infection, endocrine or metabolic problems may be:
 - a. Permanent
 - b. Reversible
 - c. Fluctuating
 - d. More severe

3. Communication with the patient with dementia is
 - a. No different than with another patient.
 - b. Impossible, the patient with dementia can't communicate.
 - c. Easy, the patient with dementia tells you everything.
 - d. Challenging, it requires time and patience from the staff.

4. Many patients with dementia have difficulty completing thoughts. When seeking information from this patient, it would be best to:
 - a. Ask questions that require a yes or no answer.
 - b. Have the patient write the answers down.
 - c. Talk with another caregiver.
 - d. Fill in the answers yourself.

5. Simple rules of communication will help the patient with dementia. This would include:
 - a. Shout as loud as you can, so the patient can hear you.
 - b. Keep the light in the room dim so the patient will remain calm.
 - c. Be at eye level, eliminate background noise and get the patient's attention.
 - d. Offer multiple choices when asking questions of the patient.

Mrs. H. has been on your unit for the last week. She wanders constantly and is always going into Mr. C's room to use the bathroom. Use this information to answer questions 6-8.

6. To help the wandering patient get some rest, which of the following would be useful:
 - a. A rocking chair.
 - b. Restraints.
 - c. A couch to lie on.
 - d. Insisting on afternoon naps.

7. Mr. C is very upset that Mrs. H continues to come in his room. A solution to this problem may be:
 - a. Changing Mrs. C's room to the other end of the unit.
 - b. Closing Mr. C's door.
 - c. Telling Mrs. H she is not allowed in Mr. C's room.
 - d. Assign one staff member to stay with Mrs. H at all times.

8. Mrs. H easily picks up on the emotional tone of the staff member caring for her. Keeping this in mind, the staff member should:
 - a. Have a calm tone of voice and relaxed body language.
 - b. Be upbeat and always very cheerful.
 - c. Not reflect any emotion in their voice or body language.
 - d. Say nothing at all to the patient during care.

9. A patient with dementia may find bathing very fearful related to all of the following EXCEPT:
 - a. Being naked in front of a stranger.
 - b. Lack of warmth in the bathroom.
 - c. Being cold during the shower.
 - d. Getting clean for the day.

10. Toileting issues may arise for the patient with dementia because of all the following EXCEPT:
 - a. Lack of privacy.
 - b. Fear of unknown.
 - c. Extreme trust in the staff.
 - d. Fear of physical harm.

11. Your patient with dementia is wandering and unable to sit and eat their meal. Choose the foods you would provide for the patient.
 - a. Jell-O in a dish with a spoon, and a quiet place to sit.
 - b. Popcorn in a bag and a soda in front of the TV.
 - c. Juice box and a quarter of a peanut butter sandwich.
 - d. Water popsicle in the dining room alone.

12. Catastrophic reactions can be triggered by many things. Which of the following will most likely NOT trigger a catastrophic reaction?
 - a. Calmly approaching the patient from the front with a smile and saying their name.
 - b. Coming up behind the patient and touching their shoulder.
 - c. Reaching across the patient close to their face while putting on clothing.
 - d. Telling the patient they must have a shower now.

Mr. S. is climbing into bed with a female patient who also has AD. Use this information to answer questions 13 and 14.

13. Select the best nursing intervention to use in response to Mr. S's behavior.
 - a. Call security for help.
 - b. Quietly close the door and leave them alone.
 - c. Turn on all the room lights and have another staff member help you.
 - d. Approach Mr. S and ask him to come out of the room with you.

14. While sexual activity is normal in older adults, the reason Mr. S would not be allowed to be in bed with the other resident would be:
 - a. It's against facility policy.
 - b. Mr. S is married and that's not his wife.
 - c. The female patient is not able to give consent.
 - d. It's a double room and the other patient is upset.

15. You have just started working on a unit with patients who have dementia. You are feeling very frustrated because the patients are not responding properly to you. What would be a positive direction for you to take to help deal with your frustration?
 - a. Transfer off the unit, to a unit without patients with dementia.
 - b. Talk with your coworkers about your feelings and ask for suggestions on approaches.
 - c. Realize that the patients with dementia do not like you and are trying to make you angry.
 - d. Become more authoritative with patients who have dementia so they will listen to you.