

# Alzheimer's Disease and Related Dementias, 5 units

5 contact hours: \$29

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**Course Summary:** This purpose of this course is to provide direct-care staff in nursing homes, hospice, and adult daycare with the skills, techniques, and strategies to care for residents who have Alzheimer's disease or a related dementia on a daily basis. It includes activities that allow participants to practice the skills and strategies they have learned.

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**Off-Label Use:** Any off-label medications uses described in this course have been clearly identified.

**Criteria for Successful Completion:** 80% or higher on the post test, a completed evaluation form, and payment where required. No partial credit will be awarded.

This course will be reviewed every two years. It will be updated or discontinued on August 1, 2013.

## Accreditation Information

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*Target Audience:* Occupational Therapists, OTAs

*Instructional Level:* Intermediate

*Content Focus:*

- Category 1 - Domain of OT, Client Factors

### Other Professions and Accreditations

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## Instructions

1. Read the course material and then complete the following forms:
  - A. Answer Sheet
  - B. Evaluation Learning Activity
  - C. Registration Form
2. If you are not paying by credit card, prepare a check for the amount of the course made out to: *ATrain Education, Inc.*
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## Course Objectives

- Describe the characteristics of ADRD and how it progresses.
- Differentiate Alzheimer's disease from other related dementias.
- Outline effective strategies for communicating with residents who have ADRD.
- Identify strategies for the management of the challenging behaviors associated with ADRD.
- Describe the difference between physical and chemical restraints.
- Outline strategies for assisting with activities of daily living at the various stages of dementia.
- Relate strategies for stress management for caregivers.
- Describe how to create a therapeutic environment for those with ADRD.
- Identify common ethical conflicts that may arise when caring for residents with ADRD.

## Introduction

Although dementia has probably been around since the first humans appeared on the earth, it is only as we live longer and have better healthcare that we have begun to see its widespread development in older adults. The most common—and perhaps most familiar—type of dementia is Alzheimer's disease but there are many other types and causes of dementia. Although there are notable exceptions, dementia occurs primarily in later adulthood and represents a major cause of disability in older adults.

In this course we will describe the symptoms and stages of dementia, how to address common challenging behaviors, suggest effective communication strategies, describe caregiver and family issues, outline some exciting new research on creating a therapeutic environment and discuss ethical conflicts that can arise when caring for someone with dementia. Because there is more than one type of dementia we will use the term **Alzheimer's disease and related dementias (ADRD)** to describe a set of diseases that share many common characteristics, namely progressive degeneration of specific parts of the brain that leads to disabling and irreversible cognitive and physical changes.

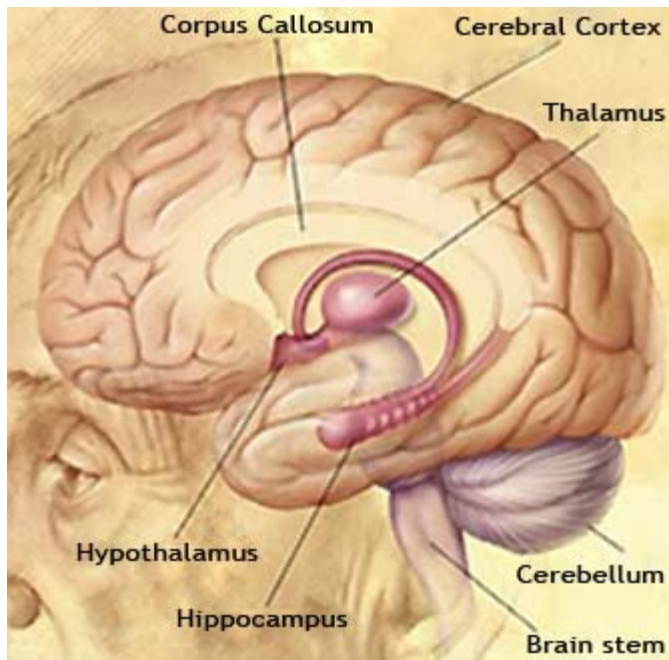
As a healthcare provider, family member, or caregiver, you may already be able to recognize the common characteristics and behaviors associated with ADRD. The ongoing challenge is how to create a safe environment that respects the independence and dignity of the person whose care is your responsibility. On a practical level, the daily challenge for caregivers is what to do when people with dementia act out, put themselves in danger, pose a threat, try to escape from a facility or home, are no longer able to walk, or engage in a host of other difficult behaviors.

To be successful working with people with dementia, caregivers must learn to recognize its signs, differentiate it from illness, depression, and delirium, and get really good at managing the spectrum of difficult behaviors that are associated with the disease. Nursing and rehabilitation managers often must do this with an inexperienced staff and inadequate resources. Caregivers must train themselves to take a deep breath, slow down, listen, and find new and effective ways to communicate. Whether you work in skilled nursing, adult daycare, or acute care, or are caring for a loved one at home, your skill, training, and knowledge will help you create the best environment possible for those suffering the effects of dementia.

## Characteristics and Stages of ADRD

The brain has three main parts: the cerebrum, cerebellum, and the brainstem. The **cerebrum** fills up most of the skull and is involved in thinking, planning, memory, problem solving, communication, emotions, and the other cognitive functions we associate with high-level cognitive function. The wrinkled outer surface of the cerebrum is a specialized layer of neural cells called the **cortex**. Specific areas of the cortex are linked to functions such as talking, understanding speech, movement, vision, hearing, and memory. Many of these areas of the cortex are damaged by dementia.

### The Human Brain

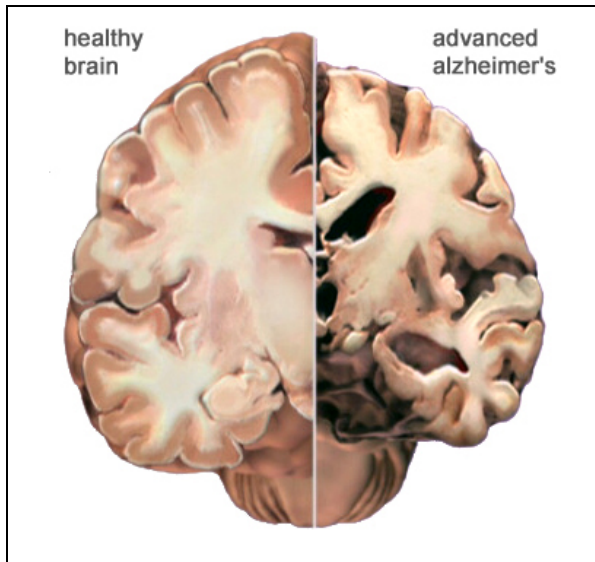


Source: Courtesy of The Alzheimer's Association. Used with permission.

The **cerebellum** is at the back of the head and controls coordination and balance. The **brain stem** is also at the back of the head above the back of your neck. It connects the brain to the spinal cord and controls automatic functions such as breathing, digestion, heart rate, and blood pressure.

Dementia changes the entire brain. In Alzheimer's disease, nerve cells in the brain die and are replaced by "plaques" and "tangles." As the nerve cells die the brain gets smaller. Over time, the brain shrinks dramatically, affecting nearly all its functions.

## Comparison of Healthy Brain and One Damaged by Alzheimer's

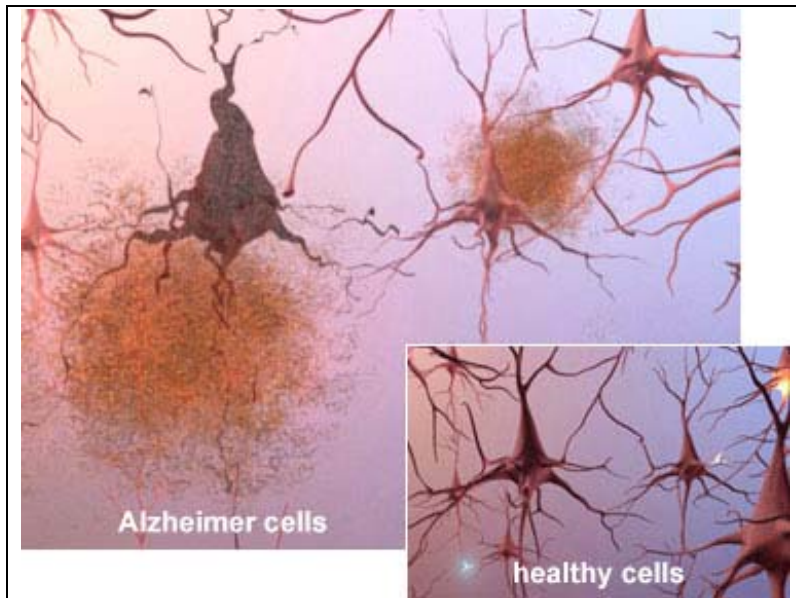


A view of how nerve cell loss changes the whole brain in advanced Alzheimer's disease. Left side: normal brain; right side, a brain damaged by advanced AD. Source: Courtesy of The Alzheimer's Association. Used with permission.

### Plaques and Tangles

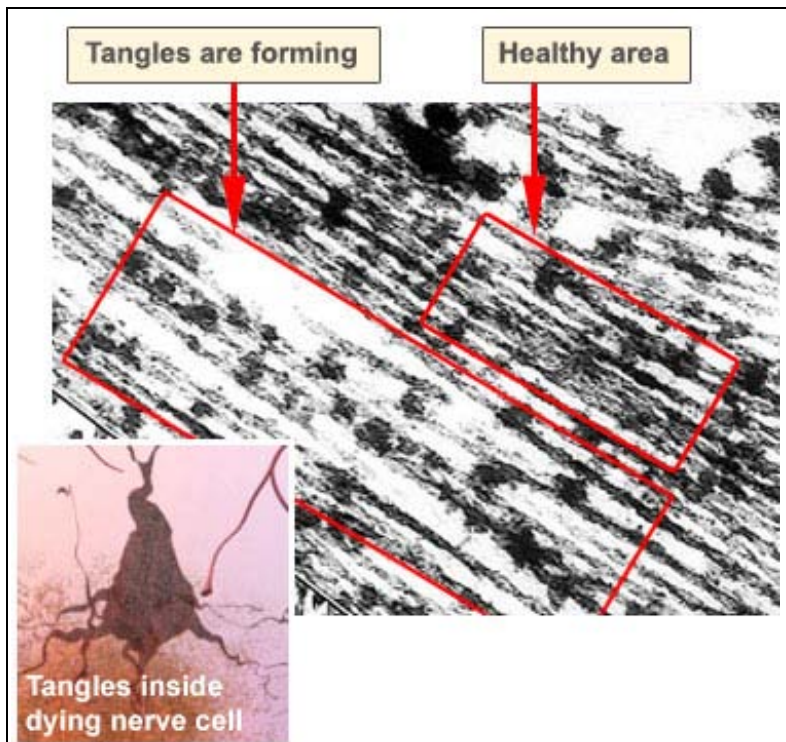
Dementia is a **disease syndrome** characterized by progressive, global deterioration of the brain's executive functions. The most common type of dementia, Alzheimer's disease (AD) is caused by the formation of abnormal proteins called **plaques** and **tangles**. Damage typically begins in an area of the cerebrum called the hippocampus, which is responsible for the formation of new memories. In fairly rapid succession, plaques and tangles spread forward to the temporal and frontal lobes, affecting language, judgment, learning, comprehension, orientation, and emotions. Although almost everyone with AD is elderly, it is not considered to be a normal part of aging. The pictures below show the formation of plaques and tangles in the early, moderate, and severe stages of Alzheimer's disease.

## Plaques



Source: The Alzheimer's Association. Used with permission.

## Tangles

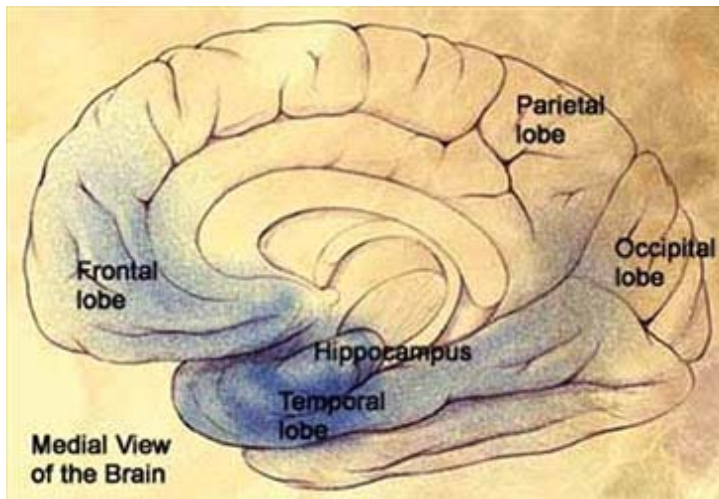


Source: The Alzheimer's Association. Used with permission.

In the earliest stages of Alzheimer's disease, before symptoms can be detected, plaques and tangles (seen below shaded in blue) form in the hippocampus, which is the area of the brain involved in learning new tasks, short term memory, thinking, and planning.

In mild to moderate stages, plaques and tangles spread from the hippocampus forward to the frontal lobes. Many people are first diagnosed with ADRD in this stage. Changes in personality and behavior occur and people begin to have trouble recognizing friends and family members. The frontal areas of the brain are involved with speaking and understanding speech, the sense of where your body is in space, and executive functions such as planning, ethical thinking, and judgment.

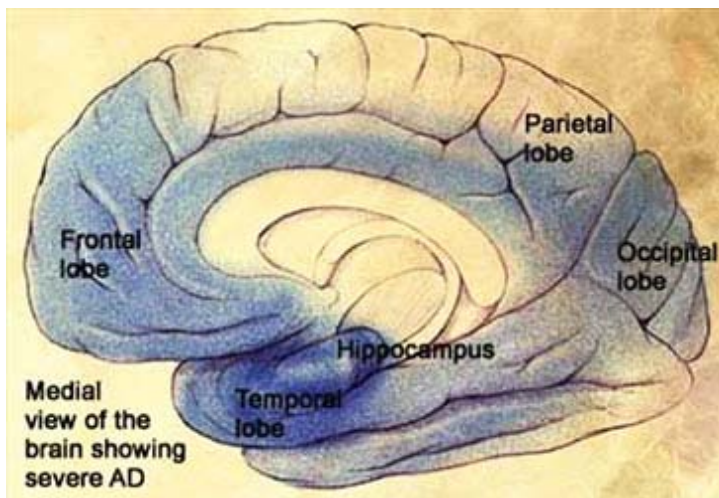
### Mild to Moderate Changes in the Brain



Source: Courtesy of The Alzheimer's Association. Used with permission.

In advanced Alzheimer's, the hippocampus is severely damaged as plaques and tangles (shaded in blue) spread throughout the cerebral cortex. Individuals lose their ability to communicate, to recognize family and loved ones, and to care for themselves. Note that the hippocampus (shaded in dark blue), which is the region of the brain responsible for the formation of new memories, is severely damaged.

### Severe Changes to the Brain



Source: Courtesy of The Alzheimer's Association. Used with permission.

Close to three-quarters of dementia cases are related to Alzheimer's disease, which affects about 7% of people over the age of 65 and about 40% of those over the age of 80 (ADI, 2009). There is no blood test or x-ray that can diagnose dementia; diagnosis is based on symptoms such as decline in mental capacity, loss of ability to live independently, and changes in behavior.

## **Types of Dementia**

Even though Alzheimer's disease is fairly common it isn't the only thing that causes dementia. The symptoms are a bit different in each type of dementia, depending upon the part of the brain that is affected. **Frontal-temporal dementia (FTD)**, which affects the front part of the brain, is the most common dementia in those under the age of 60; FTD is responsible for about 5% to 10% of all cases of dementia.

**Vascular dementia**, which is caused by small strokes, occurs in people with longstanding, inadequately controlled high blood pressure. It is responsible for about 20% to 30% of all cases of dementia. **Lewy Body dementia**, which often accompanies Parkinson's disease, can cause hallucinations and mental changes. It is responsible for a little less than 5% of all cases of dementia. Acquired immune deficiency syndrome (AIDS) can also cause a form of dementia called **AIDS-related dementia**.

Types of Dementia			
Dementia subtype	Early, characteristic symptoms	Neuropathology	Proportion of dementia cases
*Alzheimer's disease (AD)	<ul style="list-style-type: none"> <li>• Impaired short-term memory, apathy and depression</li> <li>• Gradual onset</li> <li>• Language and visuospatial deficits</li> <li>• Behavioral and personality changes</li> <li>• Rapid mood swings</li> </ul>	<ul style="list-style-type: none"> <li>• Starts in the hippocampus</li> <li>• Cortical amyloid plaques</li> <li>• Neurofibrillary tangles</li> </ul>	50%–75%
*Vascular dementia (VaD)	<ul style="list-style-type: none"> <li>• Affects frontal lobe</li> <li>• Similar to AD, but memory less affected, and mood fluctuations more prominent</li> <li>• Physical frailty</li> <li>• Stepwise onset</li> <li>• Patchy cognitive impairment</li> <li>• Often preventable</li> </ul>	<ul style="list-style-type: none"> <li>• Cerebrovascular disease</li> <li>• Single infarcts in critical regions, or more diffuse multi-infarct disease</li> <li>• Group of syndromes</li> </ul>	20%–30%
Frontotemporal dementia (FTD)	<ul style="list-style-type: none"> <li>• Behavioral and personality changes</li> <li>• Mood changes</li> <li>• Disinhibition</li> <li>• Language difficulties</li> <li>• Emotional changes</li> <li>• Poor judgment</li> <li>• Behavioral changes</li> <li>• Loss of moral reasoning</li> <li>• Loss of inhibition</li> </ul>	<ul style="list-style-type: none"> <li>• No single pathology: damage limited to frontal and temporal lobes</li> <li>• Early onset (45 to 60 yrs of age)</li> <li>• Affects frontal and temporal lobes</li> </ul>	5%–10%

Dementia with Lewy Bodies (DLB)	<ul style="list-style-type: none"> <li>• Marked fluctuation in cognitive ability</li> <li>• Visual hallucinations</li> <li>• Parkinsonism (tremor and rigidity)</li> <li>• Adverse reactions to antipsychotic medications</li> </ul>	Cortical Lewy bodies (alpha-synuclein)	<5%
AIDS-related dementia	<ul style="list-style-type: none"> <li>• Loss of judgment</li> <li>• Poor impulse control</li> <li>• Language problems</li> <li>• Motor control problems</li> </ul>	Frontal lobe	

\*Post mortem studies suggest that many people with dementia have mixed Alzheimer's disease and vascular dementia pathology and that this "mixed dementia" is underdiagnosed. Source: Adapted with permission from Alzheimer's Disease International, 2009.

### Relative Frequencies of Dementia Types

The relative frequencies of dementia types are increasingly open to debate and the borders between the different types are becoming less distinct as we learn more about dementia and brain anatomy. Studies have examined the agreement between the diagnosis made while the person was alive and the pathology found in the brain post mortem. These have suggested that mixed pathologies are more common than "pure" pathologies—meaning most people have a mixture of two or more types of dementia. This is particularly true for Alzheimer's disease and vascular dementia, and for Alzheimer's disease and dementia with Lewy Bodies (ADI, 2009).

The less common types of dementia (frontotemporal dementia, Creutzfeldt Jacob disease, and Huntington disease) are often misdiagnosed in life as Alzheimer's disease. Population-based studies have suggested that frontotemporal dementia and vascular dementia are relatively common diagnoses in men who have an early onset of dementia. Alzheimer's disease tends to predominate over vascular dementia among older people with dementia, particularly among women (ADI, 2009).

### Stages of ADRD

It may be difficult to tell the difference between dementia and normal age-related changes, especially in the early stages of dementia. It is also important to understand that delirium, depression, health problems, and medication side-effects can profoundly affect cognitive function. Even in those with ADRD, age-related changes, depression, and delirium can be a confounding presence.

### Normal Age-Related Changes

Memory does change with age, but **age-related changes** are not the same as dementia. Older people can be forgetful—for example, forgetting where they left the car keys. They may take longer to do certain mental tasks or be unable to memorize a string of words as well as a younger person. Older people may also have more difficulty doing more than one thing at a time (multi-tasking). Normally, older adults can prepare their own meals—they do not forget what a coffee pot is or how to operate a microwave. They understand when they are in danger and know that they should call for help or get out of a house if there is a fire.

**Mild cognitive impairment (MCI)** is a condition in which people have memory problems that are noticeably worse than age-related changes. However, people with MCI do not have the problems associated with dementia such as personality and cognitive changes. Some people with MCI do go on to develop AD, but not everyone does.

As opposed to age-related changes or MCI, people who have dementia don't know what to do if they are in danger. They forget how to operate a shower and how to get dressed. They may be unable to prepare meals for themselves and may forget the purpose of a coffee pot or a toaster. They slowly lose the ability to care for themselves. Some of the differences between someone who is aging normally and someone with AD or dementia are described below.

Normal Aging vs. Dementia	
Normal aging	AD or dementia
Occasionally loses keys	Cannot use a key; cannot remember what a key does
May not remember names of people they meet	Cannot remember names of spouse and children—don't remember meeting new people
May get lost driving in a new city	Get lost in own home, forget where they live
Is able to use logic (for example, if it is dark outside it is night time)	Is not logical (if it is dark outside it could be morning or evening)
Bathes, feeds, and dresses self	Cannot remember how to fasten a button, operate appliances, or cook meals
Participates in community activities such as driving, shopping, exercising, and traveling	Cannot independently participate in community activities

Dementia is usually described or defined according to its progression: as mild, moderate, or severe. This is a useful tool and although the stages and symptoms may overlap, certain symptoms and behaviors are associated with specific stages.

## Mild Dementia

The early stage of dementia usually lasts about a year or two and typically begins with mild forgetfulness. During this stage people think less clearly and can be easily confused, especially with new tasks, people, and places. Memory loss can be significant, especially for recent events. Someone might forget names or misplace possessions or get lost in familiar places. Although many older people occasionally forget words, memory problems gradually worsen, especially in those with Alzheimer's disease.

A person in the early stage of dementia may cover up their confusion by turning to others for help with simple tasks. They may have difficulty making decisions and may lose motivation and interest in hobbies and activities. They may occasionally become angry or aggressive or experience mood changes, depression, or anxiety. It may be difficult to learn new tasks, follow new rules, or successfully complete complex tasks. Faulty judgment and mild changes in personality are common.

Despite the presence of mild dementia a person may still be working, driving, and living independently. They will try their best to hide any changes from loved ones and coworkers. This can be dangerous because someone with mild dementia may make mistakes on the job, become confused while driving, and may be unsafe at home. At this stage people may shrug off the concerns of family or friends and try to go on with their lives.

Remember that although Alzheimer's disease starts with loss of short-term memory, the early symptoms of other types of dementia can be different. For example, **frontal-temporal dementia (FTD)** usually starts with changes in behavior rather than memory loss, may start at a younger age than AD—in the early to mid-fifties—often when someone is still working. In FTD, a formerly honest person might begin to shoplift or steal money from co-workers or business partners. These changes in personality are not as obvious as changes associated with AD and can be confusing to friends and family.

## Moderate Dementia

Dementia gets worse as abnormal plaques and tangles spread throughout the brain—especially to the front of the brain (frontal lobe). The frontal lobe is the part of the brain that controls judgment, safety awareness, logical thinking, and planning. Damage to the frontal lobe seen in AD is responsible for many behavioral changes such as aggression, impulsive behavior, and safety problems.

As people with dementia enter the moderate stage, they begin to lose connection with recent events. Language and reasoning deteriorates and the person can become withdrawn and less talkative. Travel, driving, work, and managing personal finances become difficult or impossible. Insomnia, anxiety, agitation, and suspicion can develop or worsen during this stage. Inappropriate behaviors such as cursing, kicking, hitting, and biting are not uncommon.

In the moderate stage, people begin to rely on others more and more for daily activities. Safety becomes a real concern for caregivers in this stage. People may start to wander and are no longer safe on their own. Because of this, family caregiver responsibilities increase, causing stress, anxiety, and worry among family members and caregivers. In the moderate stage, a person:

- May become very forgetful—especially of recent events and people's names
- Can no longer manage to live alone without problems
- Is unable to cook, clean, or shop
- May become extremely dependent on their family and caregivers
- Needs help with personal hygiene, toileting, washing, and dressing
- Has increased difficulty with speech
- Shows problems with wandering and other behavior problems such as repeated questioning and calling out, clinging, and disturbed sleeping
- Becomes lost at home as well as outside
- May have hallucinations—seeing or hearing things that aren't really there (ADI, 2009)

### **Severe Dementia**

People with severe dementia are unable to survive without assistance. Independence is gradually lost and caregivers must provide around-the-clock care. People at this stage must be assisted with eating, bathing, walking, and other daily living skills. Family members may find it impossible to continue to provide care and may have to move their loved one to an assisted living or skilled nursing facility.

Disruptive vocal outbursts are very common among people with severe dementia. These include screaming, swearing, crying, shouting, loud demands for attention, negative remarks, and self-talk. Boredom, loneliness, depression, excessive cold or heat, loud noises, and pain can trigger outbursts. Because those with severe dementia are often not able to communicate their needs, regular assessments are necessary.

Even with severe dementia people are usually still able to walk. This is because the part of the brain that controls movement is not affected until the very late stages of dementia. If the person is still in the home, tired and overworked caregivers must provide even more support to maintain a safe environment. If in a facility, healthcare workers must receive proper training and the facility must provide enough staffing and equipment to create a safe environment.

Balance and safety awareness get worse over time, and eventually walking independently is no longer safe. To prevent injuries from falls, it may be necessary to use bed and chair alarms or provide a one-on-one caregiver during the day. Caregivers and healthcare providers must make difficult decisions to prevent injury and to provide a safe environment. Restraints are not recommended and may actually increase the danger of injury.

## End of Life

Eventually dementia becomes so debilitating that patients are bedridden and are likely to develop other illnesses and infections. Most commonly, people with AD die of pneumonia. As they approach the end of life they may be unable to communicate their needs and desires. They may be unable to eat, swallow fluids, or move without help. They may become unresponsive or comatose, eventually experiencing total systems failure. The most common behavioral symptoms cited for residents with severe dementia in assisted living and nursing homes at the end of life are agitation, psychosis, delirium, restlessness, and depression (Tilly and Fok, 2007).

End-of-life care is usually carried out by a group of people who work together to care for and comfort someone as death approaches. **Hospice care** is available under Medicare, most state Medicaid programs, and some private insurance plans. Hospice provides care for those with less than six months to live.

**Advance directives** such as a living will and a durable power of attorney should be on file. These legal documents allow a person to communicate their wishes about end-of-life care while they are still able to make these decisions.

## Differentiating Dementia from Other Conditions

There are a number of medical conditions with symptoms that mimic those of dementia and must be considered when evaluating a person experiencing cognitive changes. Gerontology specialists speak of the “3Ds”—**dementia, delirium, and depression**—because these three conditions are the most prevalent reasons for cognitive impairment in older adults. Delirium and depression can cause cognitive changes that may be mistaken for dementia, and healthcare providers and caregivers should learn to distinguish among dementia and these two other conditions.

## Delirium

Delirium is a sudden, severe confusion with rapid changes in brain function. Delirium develops over hours or days and is temporary and reversible. It can occur after general anesthesia, from infections (such as a urinary infection or pneumonia), from fluid/electrolyte or acid/base disturbances, or from other conditions that deprive the brain of oxygen. Pain can also contribute to delirium, as can the medications used to treat pain. Being in an unfamiliar environment such as adult daycare or a nursing home can also contribute to delirium.

People with dementia are at increased risk of experiencing delirium and people who experience an episode of delirium are more likely to develop ADRD (Inouye, 2006). Delirium is reversible once the underlying cause is identified and treated. For example, one study showed that after hip fracture, fewer patients suffered from delirium if they were adequately treated for pain (Morrison et al., 2003).

Test your knowledge. . .

Mr. Dotson, who is 76 years old, is admitted to the hospital for repair of a fractured hip. He is living at home with his wife, is independent in all of his ADLs, and drives a car. The morning after surgery he woke up, removed his IV, got out of bed, and declared he was going home.

Mr. Dotson is likely experiencing:

- a. An episode of depression
- b. Signs of dementia
- c. An episode of delirium
- d. Homesickness

Answer: C

### Depression

Depression is caused by neurochemical imbalances in the brain. It can lead to cognitive impairment, which should improve when the depression is treated. People with depression are aware of the date and time; however, they may answer, "I don't know" to orientation questions and may not make eye contact. They may have a flat affect (show little expression) and may speak in a monotone. A smile does not rule out the presence of depression—they may smile while describing the hopelessness of life.

Irritability or verbal expression of pessimism, sadness, or hopelessness may indicate depression. Depression commonly occurs in the early stages of AD as a person becomes aware of their loss of cognitive function. The most effective treatment for depression is counseling accompanied by antidepressant medications (Kaiser, 2006).

Test your knowledge. . .

Mrs. Brown admits that she feels sad most of the time. "Why do bad things always happen to me and no one else?" she says.

She is verbalizing signs of:

- a. Depression
- b. Dementia
- c. Delirium
- d. A personality disorder

Answer: A

<b>Comparing Delirium, Depression, and Dementia</b>			
	<b>Delirium</b>	<b>Depression</b>	<b>Dementia</b>
Onset	Rapid, hours to days	Rapid or slow	Progressive, develops over several years
Cause	Medication, infection, dehydration, metabolic changes	Alteration in neurotransmitter function	Progressive brain damage
Duration	Usually less than one month	Months, can be chronic	Months to years
Course	Reversible	Usually recover within months; can be relapsing	Not reversible, ultimately fatal
Level of consciousness	Usually changed, can be agitated, normal, or dull	Normal or slowed	Normal
Orientation	Impaired short-term memory	Usually intact	Correct in mild cases; first loses orientation to time, then place and person
Thinking	Disorganized, incoherent, rambling	Distorted, pessimistic	Impaired, impoverished
Attention	Usually disturbed, hard to direct or sustain	Difficulty concentrating	Usually intact
Awareness	Can be reduced, tends to fluctuate	Diminished	Alert during the day; may be hyperalert
Sleep/waking	Usually disrupted	Hyper or hypo somnolence	Normal for age; cycle disrupted as the disease progresses

Source: Adapted from Eliopoulos, 2010.

## Communicating with Those Who Have ADRD

Because of damage to the brain, people with dementia gradually lose the ability to think logically. Something that makes perfect sense to you may not make sense to a person with dementia. They do not necessarily understand, for example, that it is nighttime if it is dark outside.

Dementia also affects a person's ability to carry on a normal conversation. It damages the parts of the brain needed for remembering, understanding, and forming new thoughts. For someone who has dementia, talking to and understanding another person takes a lot of energy and effort.

Nevertheless, communicating with others is still an important part of daily life. It creates positive relationships. It gives us an outlet for our feelings and the sense that someone cares. It gives the caregiver an opportunity to assess the behavior and well-being of the person for whom they are caring.

A person with dementia typically experience problems that affect their ability to communicate effectively:

- Trouble finding the right words and understanding their meaning
- Difficulty thinking logically or following logical discussions
- Loss of common sense
- Problems paying attention
- Loss of their train of thought
- Trouble remembering the steps in common activities, such as cooking a meal, paying bills, getting dressed, or doing laundry
- Problems blocking out background noises
- Frustration when communication isn't working
- Being very sensitive to touch, tone, and loudness of voices (ADEAR, 2011)

### Strategies to Improve Verbal Communication

In the early stages of dementia, communication problems are mild, and with a little help from caregivers and family members conversations can be successful and satisfying. A caregiver should be relaxed, friendly, and cheerful. Smile—this provides reassurance as you begin your conversation. Keep in mind that some conversations involve specific tasks while some are for the purpose of general communication. In general, you can follow these steps:

- Make eye contact, approach from the front in a relaxed manner.
- Greet people using their name.
- Be aware of your body language.
- Ask a question and wait for a reply.
- Be attentive and sympathetic.
- Continue the conversation by asking a follow-up question.
- Ask if there is anything you can do to make them more comfortable.

### Case

George has moderate dementia and is living in a board-and-care home. He is dressed and bathed and is sitting in his room. Ann, a nursing aide, enters his room without introducing herself and says, loudly and rapidly, "Come on George. Are you hungry? Did you sleep well? Time for breakfast! Stand up—let's go into the kitchen." George just sits in the chair and looks at her, so Anna continues, "Come on, George—get up. You don't want your breakfast to get cold do you? I don't think so." She places her arm around him and pulls him to his feet. George pulls away and sits back down.

#### Discussion

George is sitting in the chair and is comfortable. He's not sure what time of day it is. He's not thinking about food and isn't particularly hungry. Someone has entered his room and is saying something to him. He is still trying to figure out what she said when she says something else. Her voice is too loud, which is a little painful. He is confused and is not sure what she wants from him. When she takes his arm he supposes he should go with her but she pulls too hard and he resists.

Ann would have more success if she introduced herself and entered George's room quietly and respectfully. She should speak more slowly and pause at the end of each sentence to give George time to understand the conversation. She should use shorter sentences and wait for George's response: "Hi, George." Pause. "Time to go to breakfast." Pause. If George doesn't respond, Ann can repeat: "George, time to go to breakfast." Now George only has one simple statement to think about and he is more likely to answer or respond appropriately.

For general conversations, you may have to rely on memories of early life. Because early memories are still intact, you can have a pleasant conversation by asking about the person's early life such as where they lived as children. Ask about childhood friends, family members, and pets. If there are photos in the person's room, ask about the photos. Memory can be stimulated by touching, by fragrance such as perfume, or by using auditory cues. One-on-one singing is a great activity—it stimulates memories, improves breathing, and is a relaxing activity for everyone involved.

It is always good practice to talk slowly and avoid arguments. Use gentle persuasion and be positive when giving directions. Instead of saying "You can't go outside now," try saying "Let's sit down here, I would love to talk to you." Use hands gestures and unhurried movement to reinforce your words. You can even try silence, which is calming and reassuring. If the person does not answer right away, be patient and wait for a bit.

When starting a conversation, use short sentences without using a condescending tone of voice. If necessary, repeat what you've said in a relaxed manner. Use an adult tone of voice and choice of words—remember that you are not talking to a child. Sit on the same level as the person; do not stand over the person, which is intimidating.

It is okay to talk about yourself, about your workday, your commute, or your family, and to say good things about other workers at the facility. If another worker is in the same room, be sure to involve your coworker in the conversation, which shows friendliness. It is also okay to talk about today and what is happening now. Remember, that, for people who have dementia, especially severe dementia, you will need to start all over again tomorrow. They may not remember what you talked about yesterday but they still want to hear what you have to say, even if you are repeating something said earlier.

## Improving Nonverbal Communication

Nonverbal communication is communication without words. We all use nonverbal cues for emphasis. Humans are very good at understanding the true meaning of a discussion by reading nonverbal cues. We've all had the experience of saying one thing and meaning another.

Examples of **nonverbal communication** are facial expressions, eye movements, hand gestures, and movements of the arms and legs. How you dress, your posture, and how close you stand to another person are also examples of nonverbal communication. For example, standing above a seated person can be interpreted as dominance. Even silence is a form of nonverbal communication.

Nonverbal communication includes vocal attributes such as loudness, tone, inflection, pitch, and rhythm. How you speak is important—not just what you say. Be aware that your tone can show calmness or impatience, affection or disapproval, confidence or fear.

Touch is also a powerful form of nonverbal communication. Touch can be friendly, frightening, soothing, dominant, or supportive. Touch has different meanings depending upon your culture, gender, age, and situation.

People also communicate nonverbally through the environment. A clean, nicely decorated room with good lighting provides a supportive environment and communicates caring. It encourages people to communicate with one another. A drab room with harsh lighting and little decoration has the opposite effect—it discourages interaction. Some studies have shown that people say they don't like people when they see them in unattractive rooms and thus they don't want to return.

How you approach a person with dementia can influence the outcome. If you act hurried, frustrated, or angry, your patient will pick up on your mood or nonverbal body language more quickly than your verbal communication. If you are rushed or abrupt your patient will likely become anxious.

### Case

A nursing assistant and a physical therapy aide are walking Mr. Trudel back to his room. His walking is unstable and they are holding onto his arms and waist. They are talking loudly to one another and laughing. Mr. Trudel feels embarrassed and confused—he is getting agitated and begins to yell. Asked what's wrong, Mr. Trudel says "They're attacking me!" A dressing on his forearm has come loose and the nursing assistant is trying to replace the dressing without explaining what she is doing. Mr. Trudel starts hitting her. The physical therapy aide grabs his arm and tells him to stop. Mr. Trudel starts yelling even louder and hits the PT aide.

#### Discussion

Mr. Trudel doesn't know these people and doesn't know where they're taking him. They miss his signs of frustration and agitation because they aren't paying attention to him. They would have more success if they introduced themselves in a quiet tone of voice and explained in short sentences what they are trying to do. They should wait for Mr. Trudel to respond and look for cues to see if he understands what they are asking. If he looks or acts frightened, they should step back and observe. Finally, they should give their attention to Mr. Trudel rather than laughing and talking to each other.

It takes practice to sound relaxed when other things are on your mind. Use humor; smiling and laughing with a person can set a relaxed tone. Avoid sarcasm, which likely will not be understood and may cause anxiety.

### Communicating When a Person Is Nonresponsive

In the late stage of dementia a person may be unresponsive or only be able to utter a few incomprehensible sounds. Communicating with a person at this stage is a challenge for family and caregivers. If people are unable to speak or even use nonverbal communication, we have no way to know what they are thinking or feeling. Fortunately, many of the techniques that work in the earlier stages of dementia are useful in this stage as well. Common sense and creativity are even more important than before. Always assume that the person can hear and possibly understand even when they don't respond.

When approaching someone who is unable to communicate, move slowly and calmly, use few words, give one choice, and wait for an answer. Try to use gestures instead of words. Give the person time to understand why you are there. Keep in mind that, although they need a lot of help, they have been getting out of bed in the morning for possibly 80 or 90 years, and on some level they still understand these repetitive daily tasks. They need your patience and help. Use a calm, slow, and respectful attitude.

Providing comfort using pillows for neck, arm, and leg support, a warm blanket, or gentle repositioning will comfort a noncommunicative patient. Mild range-of-motion (ROM) exercise, gentle touching, and massage are reassuring. If the person enjoyed music earlier in life, it may still be enjoyable. Keep the environment peaceful and avoid loud or sudden noises; the person has no way to tell you when a sound is annoying. Reduce discomfort and confusion by keeping the area around the bed or chair free of clutter. Keep the walls and room clean and open.

### Communication Skills for Noncommunicative Patients

- Approach slowly and calmly, make eye contact.
- Be aware of your own movements.
- Re-introduce yourself at each encounter.
- Address the person by a preferred name or title.
- Use short, simple sentences.
- Breakdown tasks into simple steps.
- Repeat the same sentence if necessary rather than rephrasing.
- Avoid open-ended questions.
- Offer simple choices.
- Do not argue.
- Avoid a condescending tone.
- Avoid giving strict orders.

### Communicating with Family Members

By the time someone with dementia arrives at a care facility, family and friends have been involved for a long time. They have watched the steady decline of their loved one. In some cases, they have not accepted the degenerative nature of dementia. They may not understand that dementia cannot be cured and will continue to get worse.

Family and friends feel stress and anxiety about their loved one's dementia. They are losing a person who has been an important part of their family. They naturally have concerns. The cost of care and the time spent caring for and visiting their loved one is a constant worry. They may even lack confidence in the healthcare facility.

Reassure family and friends that their loved one will be treated with respect and will receive good care, proper medications, food, and cleanliness. Assure them that comfort and pain levels are continually assessed and that conversational opportunities and activities are readily available.

## Behavior Management

The onset of dementia and its gradual progression inevitably leads to changes in personality and behavior. Whether a behavior is problematic depends upon the environment and the capacity of caregivers and healthcare workers to successfully address the causes and consequences of the behavior. Properly trained caregivers and well-designed environments can have a dramatic and positive effect on challenging behaviors by identifying and addressing the cause of the behavior.

### Challenging Behaviors

Geriatrics specialists refer to the challenging behaviors seen in dementia as **behavioral and psychological symptoms of dementia** (BPSD). It is estimated that up to 90% of patients with Alzheimer's disease exhibit at least one BPSD and about one-third have severe behavioral problems (Liperoti et al., 2008). Challenging behaviors also occur in other types of dementia and some may differ depending on the type of dementia.

### Individual Characteristics and Environmental Triggers

The needs-driven behavior model suggests that disruptive, agitated, and aggressive behaviors are the result of unmet needs (Algase, 1996). In this model, behavior is related to both individual characteristics and environmental triggers.

#### Individual Characteristics

Individual characteristics are those relatively stable individual and health-related issues that predispose someone with dementia to engage in certain disruptive behaviors. With the possible exception of overall health status, caregivers have little ability to affect or change individual characteristics. Consider how these four individual and health-related characteristics might affect a person's behavior:

- Dementia-related functioning (such as language or memory impairment)
- Overall health status and level of dementia
- Demographic variables (such as marital status or number of children)
- Psychosocial variables (such as personality traits and coping mechanisms)

#### Environmental Triggers

Environmental triggers are those things within the environment that may drive or cause disruptive behavior. Healthcare provider interventions are usually directed at environmental triggers because these are things that can be changed. Consider how these four environmental triggers might cause or contribute to a challenging behavior:

- Physiologic need (such as hunger, pain, or fear)
- Psychosocial needs (such as contact with family)
- Environmental issues (such as a cold room or an uncomfortable chair)
- Social surroundings (such as too many people or too much noise)

## Problem-Solving Approach to Challenging Behaviors

A particularly effective approach to managing challenging behaviors is to identify the cause of the behavior using the problem-solving approach in which caregivers determine the root cause of a behavior and treat it—usually with environmental modification and caregiver training.

### Identification of Causes

There is no magic formula for managing difficult behaviors—interventions must be thoughtful and tailored to each person. The problem-solving approach allows caregivers and healthcare workers to identify critical points for intervention based on observing the **antecedent, behavior, and consequence (A, B, C)** of a challenging behavior.

- **Antecedent**—what precipitated or caused the behavior?
- **Behavior**—what is the behavior?
- **Consequence**—what are the consequences of the behavior?

This approach is particularly effective when successful strategies are regularly communicated to staff and caregivers and used to understand what triggers a challenging behavior. The ABC method helps staff understand when and how often a behavior occurs and gives the opportunity for discussion and planning.

### Strategies and Techniques for Dealing with Challenging Behaviors

This section describes common challenging behaviors associated with dementia. As you study each challenging behavior think how you would use the ABC approach to address the behavior. Use the case examples at the end of this section to practice what you have learned.

#### Agitation and Aggression

Agitation and aggression almost always results from loss of control, discomfort, or fear. These behaviors can take different forms: aggressive, non-aggressive, and verbally agitated behavior (Pelletier and Landreville, 2007). A person who becomes agitated or aggressive may be using these behaviors to communicate discomfort.

Men are more likely than women to engage in overtly aggressive behaviors, cognitively impaired people are more likely to engage in non-aggressive physical behaviors (such as pacing), and functionally impaired people are more likely to engage in verbally agitated behaviors (such as complaining, vocal outbursts) (Pelletier and Landreville, 2007).

Caregivers can address agitation by reassuring the patient in a quiet, calm voice. To prevent future outbursts, consider the antecedent—carefully observe the person and try to determine the cause of the agitation. Look for patterns. Is the person hungry, in pain, bored, overstimulated, or tired? What is the environment like? Is it cold, hot, noisy, or crowded? Does the agitation happen at a certain time of the day? Has the person been sitting for hours without changing position? Is the person incontinent and sitting on a wet cushion? Are several people screaming and thus encouraging the agitated behavior?

## Wandering

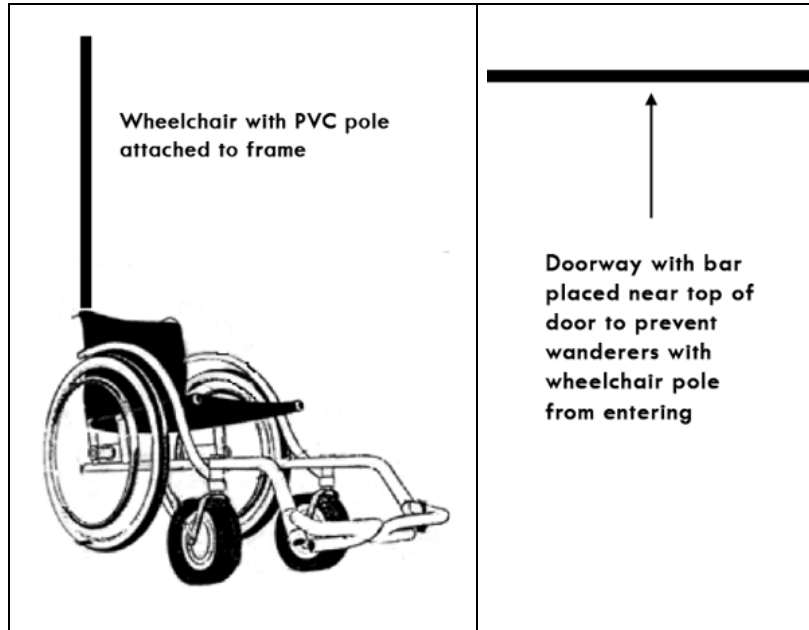
Because the motor control portion of the brain remains largely undamaged (particularly in AD and vascular dementia), people with dementia are often able to walk until the later stages of the disease. The sparing of motor function creates a safety challenge for caregivers if a resident or loved one begins to wander.

Wandering generally falls into two categories: **goal-directed**, in which residents attempt to reach an unobtainable goal (such as going home or to the store), and **non-goal-directed**, in which the resident wanders aimlessly. Wandering patterns vary and can include moving to a specific location, lapping or circling along a path or track, pacing back and forth, or wandering at random. Residents with Alzheimer's disease are more likely to wander than those diagnosed with other types of dementias.

People probably wander because they are restless, bored, or, disoriented. Using the ABC approach, try to determine the reason for the wandering. Review medications regularly to make sure wandering is not the result of medication side effects, overmedicating, or drug interactions.

Wandering can be addressed by:

- Redirecting to a purposeful activity
- Providing looping wandering paths with interesting rest areas
- Providing regular exercise
- Providing simple chores such as folding laundry or assisting with dinner
- Reducing excessive noise levels
- Avoiding medications that increase fall risk
- Putting up visual barriers such as stop signs or yellow tape to prevent wandering into unsupervised areas
- Using electronic devices that alert staff or family when someone has wandered out of a designated area
- Installing alarms that alert staff when the wanderer enters forbidden territory
- Attaching a vertical pole to the back of the wheelchair to prevent wheelchair users from wandering into off-limit rooms



A PVC pole attached to the back of a wheelchair prevents wanderers from going through any doorway with a bar. Copyright © Lauren Robertson.

### **Alzheimer's Association Safe Return Program**

The Alzheimer's Association (Alz.org) has partnered with MedicAlert to provide 24-hour assistance for those who wander. The Alzheimer's Association maintains an emergency response line and immediately activate local chapters and local law enforcement to assist with the search for someone who has wandered off. The program includes an ID bracelet and a medical alert necklace. For more information call 800 625-3780 or visit the Alzheimer's Association website.

### **Rummaging and Hiding Things**

Rummaging and hiding objects isn't necessarily a dangerous or unsafe behavior but it can be frustrating for caregivers and residents. Try to determine the reason for the behavior while addressing environmental issues that enhance safety. Locks are an effective deterrent and reduce complaints from other residents by preventing someone from rummaging in another's dresser or closet. Creating a rummaging room or a bag or a drawer of items that patients can pick through is a good way to redirect the behavior.

In a home setting or a healthcare setting, place important items such as credit cards or keys out of reach or in a locked cabinet. Consider having mail delivered to a post office box and check wastepaper baskets before disposing of trash. Other recommendations:

- Get rid of poisonous items such as caustic liquids and poisonous plants.
- Label cabinets, doors, and closets (with words or pictures) to help the person find what they are looking for.
- Reduce clutter.
- Observe carefully to learn the person's hiding places.
- Look for patterns.
- Check garbage for missing items.

## **Paranoia, Delusions, and Hallucinations**

Psychotic behaviors such as paranoia, hallucinations, and delusions can occur in those with Alzheimer's disease, vascular dementia, and Lewy Body dementia. Hallucinations tend to occur earlier in Lewy Body dementia than in AD. A person suffering from delusions and paranoia is suspicious and experiences false beliefs about caregivers or friends, feeling these people are stealing from them or planning them harm.

Careful observation is critical to determine the cause of the problem. Sensory deficits can contribute to paranoia, delusions, and particularly hallucinations because of the distortion of sound or sight. To manage hallucinations the first step is to decrease auditory and visual stimuli. The second step is to have the person evaluated for visual or hearing impairment.

When communicating with someone who is expressing paranoia or delusions, realize that even if their complaint is not true they are very real for that person. It is best not to argue; simply explaining the truth of the situation will not work. Remember that people with ADRD do not think logically. Do not agree with the person or further validate the paranoia, but respond to the person's emotion. For example, if Mrs. Xavier tells you that her roommate stole her purse and you know that is not true, respond to her in a way that validates her outrage, saying "I would be very angry if someone stole my purse!" Do not agree that the purse was stolen or try to deny that it was stolen. Think of how you would feel if you really believed that someone stole your purse. An appropriate response might be to offer to help her find it.

Delusions and hallucinations can be addressed using behavioral interventions or, in some cases, antipsychotic medication. When people with ADRD are having an auditory or a visual hallucination, observe the behavior and listen to what they have to say. Is it a pleasant hallucination or a frightening one? If the hallucination elicits a fearful or negative response, address the person's need to regain comfort. For example, you may ask "What will make you feel safe or comfortable?"

Auditory hallucinations are by far more common than visual ones. If a person has a new onset of visual hallucinations, the number one cause is medication side effect. Ask a healthcare practitioner to review all medications the person is receiving. This includes prescription and over-the-counter medications and herbal supplements.

Visual hallucinations can occur in the moderate to severe stages of ADRD and are common in those with Lewy Body dementia (DLB). While atypical antipsychotics are sometimes used off-label to manage hallucinations, in a person with DLB antipsychotic medications can make hallucinations worse.

Here are some other suggestions for addressing hallucinations:

- Reduce stimulation in the environment—minimize violent or noisy TV, remove wall hangings, reduce noise, try playing soft, relaxing music.
- Cover mirrors.
- Reduce glare from windows.
- Ensure adequate lighting.

Test your knowledge. . .

Mr. Klatz is in the moderate stage of dementia. At around 4 p.m. every afternoon he says he sees people trying to break into the house and he tries to get up out of his wheelchair to fight them off.

Your best first step is to:

- a. Put him to bed every day at 3:30 to avoid an incident.
- b. Try to distract him by having him watch a TV program.
- c. Give him a dose of sedative at 3 every day.
- d. Observe the behavior and note antecedents, decrease stimulation, and review his medications.

Answer: D

### Sleep Disturbances

Sleep disturbances are very common among older adults and are of particular concern in people with dementia. Sleep disturbances probably contribute to the onset and severity of some behavioral problems, particularly anxiety, increased confusion, wandering, and “sundowning.” Studies have suggested that approximately 24% to 35% of those with AD have problems with sleep (Deschenes and McCurry, 2009), partly due to the degeneration of neurons in the part of the brain that controls circadian rhythm.

There are a number of factors other than dementia that contribute to sleep disturbances. Sleep apnea, restless legs syndrome, medical and psychiatric issues, and environmental and behavioral factors often predate the onset of dementia. Chronic pain interferes with sleep, and disturbed sleep reduces the pain threshold (Deschenes and McCurry, 2009). Chronic disease, depression, and heart disease are linked to sleep disturbances.

Medications used to treat the behavioral symptoms of dementia as well as those used to slow the progression of dementia can negatively affect daytime alertness and can cause sleep disturbances. Short-term sleep disturbances in people with dementia are often treated with antidepressants, benzodiazepines, or non-benzodiazepines, although there is limited evidence to support their long-term safety and use with cognitively impaired older adults (Deschenes and McCurry, 2009).

Some non-pharmacologic treatments that have been used successfully in nursing homes to treat sleep disorders include:

- Light therapy
  - High-intensity or ambient light in morning or evening
  - Full-spectrum light box
  - Melatonin with light therapy
  - Bright light exposure during the day

- Good sleep hygiene practices
  - Get up at the same time every morning
  - Go to bed at the same time every night
- Exercise during the day
- Individualized social activities
- Restriction or elimination of caffeine, nicotine, and alcohol
- Limited daytime napping
- Calm atmosphere
- Music or radio at bedtime
- Comfortable and warm bed
- Biofeedback
- Empty bladder before bedtime (Deschenes and McCurry, 2009)

### **Refusing to Eat or Drink Fluids**

Appetite and fluid intake are affected by medications, dental and oral problems, nausea, confusion, muscle weakness, and swallowing problems. Many older people are not used to eating three meals a day on the rigid schedules found in many nursing homes. Special diet needs and food preferences should be considered but they are often unavailable in nursing homes and adult daycare.

Neurologic factors such as apraxia may affect a person's ability to initiate the process of eating or recognize the purpose of a utensil. Impaired communication caused by memory deficits or aphasia may make it difficult to communicate food preferences or hunger. Be aware that something as simple as not being able to get to the bathroom easily may cause a person to resist fluids.

Physical limitations often make it difficult to open a package of utensils, remove plate coverings, or retrieve something that has dropped to the floor. A new setting such as adult daycare or skilled nursing can cause confusion through disruption of a familiar routine and introduction of new and unfamiliar foods.

Determining the amount of assistance needed for eating is important. The Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q) developed by Watson and Dreary is both a caregiver report and an observational tool that can be used to identify eating and feeding difficulties. It can also be used to determine the amount of assistance or type of intervention needed.

<b>Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q)</b>	
<b>Question</b>	<b>Score</b>
Score answers to questions 1–10: never (0), sometimes (1), often (2)	
1. Does the patient require close supervision while feeding?	
2. Does the patient require physical help with feeding?	
3. Is there spillage while feeding?	
4. Does the patient tend to leave food on the plate at the end of the meal?	
5. Does the patient ever refuse to eat?	
6. Does the patient turn her head away while being fed?	
7. Does the patient refuse to open his mouth?	
8. Does the patient spit out her food?	
9. Does the patient leave his mouth open, allowing food to drop out?	
10. Does the patient refuse to swallow?	
<b>Total Score</b> (Total scores range from 0 to 20, with 20 being the most serious. Scores can be used to track change.)	
11. Indicate appropriate level of assistance required by patient: supportive-educative; partly compensatory; wholly compensatory.	

Source: Watson, 2001.

Once you have determined the level of assistance needed for eating, here are some interventions to try:

- Refer the patient to speech therapy for evaluation.
- Try different foods.
- Try different styles of communication.
- Encourage an upright position during meals.
- Create a pleasant dining environment.
- Try dining with others and dining alone.
- Try soft or pureed foods.
- Encourage family members to provide favorite foods.

- Provide a feeding assistant to sit with the resident.
- Allow plenty of time for meals.
- Provide finger foods throughout the day.

An individualized plan of care should be developed to ensure adequate food and fluid intake and to support independence. Training of caregivers, support staff, and nursing assistants may be necessary and should be documented and monitored by licensed medical staff.

For more suggestions on assessment and interventions, see the Hartford Institute for Geriatric Nursing “Try This” Series. See document D11.1, “Eating and Feeding Issues in Older Adults with Dementia: Part 1: Assessment,” and document D11.2, “Eating and Feeding Issues in Older Adults with Dementia: Part 2: Interventions.”

Test your knowledge. . .

Mrs. Ellison who has moderate dementia and has not been eating well. She joins the other residents at mealtime and begins eating but stops after about 5 minutes. She has lost 10 pounds over the past 2 months.

The best strategy to get her to eat more at mealtime is:

- a. Explain that she must eat or she will continue to lose weight.
- b. Feed her because she cannot manage feeding herself.
- c. Sit with her, offer bits of food, and attempt to keep her attention on the meal.
- d. Give her meals in her room because the dining room is too distracting for her.

Answer: C

### Challenging Behaviors: Case Examples

Using the ABC approach, analyze the following instances of challenging behaviors. In each case consider the **antecedent**—the precipitating factor that causes each person to behave as they do. Then consider the **behavior** and the **consequence**. What happens immediately after the behavior? How serious is the consequence? Where along the ABC continuum can you intervene to keep the person safe and satisfied? Decide on an intervention before reading the final section, the Discussion.

## Case One

Mrs. Winkler has moderate dementia. The staff has gotten her dressed and put her in a wheelchair in the hall next to the elevator. She has tried several times to wheel toward the elevator but is stopped each time by a passing staff member—usually with a reprimand. She is told that if she tries to get onto the elevator again she will be put back to bed. Following each reprimand she is left in exactly the same spot next to the elevator. Finally, when no one is looking, Mrs. Winkler successfully wheels into the elevator. The door closes and the elevator takes off.

### **Antecedent**

Mrs. Winkler is a curious person and always liked walking around the city for exercise. She is bored and wants to do something. She is able to propel her own wheelchair but is not able to think logically and understand the consequences of her decisions. She isn't interested in why you think she should stay away from the elevator. She has been using elevators all her life and sees no reason not to use this one. The door to the elevator is an interesting visual cue and Mrs. Winkler enjoys seeing people coming and going. She does not remember the warnings or threats she has received from healthcare workers.

### **Behavior**

The usual automatic reaction to a door opening is to pass through it. The opening door cues Mrs. Winkler to wheel into the elevator. When the door opens on another floor, she will likely wheel herself out of the elevator, no matter where it leads. Her behavior is consistent with her personality and her previous habits.

### **Consequence**

Once she gets into the elevator Mrs. Winkler's inability to think logically puts her at great risk. If she were to exit the elevator next to a door that leads out of the building, she could wander into the street. People who are not familiar with her may not know she has dementia and is unable to exercise good judgment.

### **Discussion**

Mrs. Winkler cannot understand the danger and does not remember the admonitions to stay out of the elevator. The solution is to alter the environment. Move Mrs. Winkler to a place where she cannot see or hear the elevator. Redirect her attention by getting her involved with an activity. Place an alarm on her wheelchair that warns staff when she enters the elevator. Address her curious nature by encouraging a family member to take her for a stroll outside the building or for a car ride.

## Case Two

Mr. Kumar lives in a board-and-care facility and was recently hospitalized for a minor surgical procedure. When he is discharged from the hospital he is transferred to a sub-acute rehabilitation facility for physical and occupational therapy. He has a history of mild to moderate dementia and needs assistance with many of his daily activities, including assistance with walking. In the hospital following the surgery he was very confused and repeatedly tried to leave.

### **Antecedent**

Mr. Kumar has changed environments several times and does not understand that he is in a hospital. He is hard of hearing and has lost a hearing aid. He has a pet cat where he lives and he is worried about his cat.

### **Behavior**

Mr. Kumar gets out of bed again and again, saying "I have to go home" but is unable to explain where his home is or how he will get there. He is unsafe walking without assistance but finally succeeds in leaving the facility through a back door. He is found walking unsteadily down a busy street. When he is asked to come back to the rehab facility he becomes belligerent and starts to shout and hit.

### **Consequence**

Although in this instance Mr. Kumar is uninjured, he is at great risk for harm when he wanders away from the facility. He does not have the judgment or foresight needed to avoid danger.

### **Discussion**

Assess for delirium following surgery. Check the function of his remaining hearing aid. Clean his glasses and ask him to put them on. Try to get him involved with an activity. Encourage family members to visit. Ask them to place photos of family members and familiar items around the room. Use a bed or chair alarm to alert staff if he tries to leave his room.

Through trial and error, the staff discovers that Mr. Kumar is fine when he is with someone—his attempts to leave the facility occurred when he was left alone. The staff talked about how to structure Mr. Kumar's day so that he was always with someone. They elicited the help of his family to stagger their visits so they could participate in his care. Mr. Kumar completed his rehab without further incident and was happy to return to his board-and-care home and his cat.

### Case Three

Mrs. Lee has moderate dementia due to Alzheimer's disease and lives in a nursing home. Tuesday is her shower day—a nursing assistant helps her undress in her room, covers her with a blanket, and wheels to the shower room using a rolling commode chair. As they approach the shower room Mrs. Lee starts to fidget and yell. When she is placed in the shower she starts screaming and fighting with the caregiver.

#### **Antecedent**

The assistant undresses Mrs. Lee in her room, wraps her in a bath blanket, grabs a toilet chair, and wheels Mrs. Lee down the hall with her rear end hanging out of the hole in the chair. Mrs. Lee is cold and embarrassed but when she complains the nursing assistant reminds her that she needs to bathe because she is dirty.

#### **Behavior**

By the time Mrs. Lee reaches the shower room she is already agitated. She slaps the nursing assistant and repeatedly grabs the shower room door. The nursing assistant manages to get Mrs. Lee into the room, but as she turns on the shower Mrs. Lee screams and pushes her away. Mrs. Lee manages to grab the shower hose and spray water all over the caregiver and into the hallway.

#### **Consequence**

The resident, staff, and the patient's daughter are all upset. The situation has created an unpleasant environment for everyone involved. Showering has become an unpleasant experience for Mrs. Lee.

#### **Discussion**

Find out how Mrs. Lee bathed earlier in life. Allow her to participate in her bathing even if it takes longer. Allow her to undress in the shower room rather than in her room. Talk with her during the procedure and get continual feedback from her. Ask her questions, such as "Is this too hot?" "Do you want to wash your face?" "Are you cold?"

Mrs. Lee's daughter has told the nursing staff that her mother prefers to undress in the shower room and hates being wheeled down the hall half-naked in a commode chair. The nursing assistant bathing her today is new and hasn't been told about her patient's preferences. Find a way to communicate preferences such as these. Consider whether she needs to have a shower or if there are other ways of bathing that might be more acceptable to her.

## Physical and Chemical Restraints

Imposing physical restraints is not good practice for protecting residents who are prone to falling or unsafe wandering.

Jane Tilley and Peter Reed

*Falls, Wandering, and Physical Restraints*

Because unsafe behaviors such as wandering, aggressive behaviors, and falls are so common in people with dementia, it may seem like a good idea to restrain them when you think they are in danger. But many studies have shown that restraints can actually increase the risk of falls and contribute to other negative physical and psychological outcomes such as bruises, musculoskeletal injuries, skin tears, physical deconditioning, pressure ulcers, anger, depression, and anxiety.

The Omnibus Budget Reconciliation Act of 1987 (OBRA 87) established a resident's right to be free of the use of restraints in nursing homes when used for the purpose of discipline or convenience and when not required to treat the resident's medical symptoms. Related regulations also specify that uncooperativeness, restlessness, wandering, or unsociability are not sufficient reasons to justify the use of antipsychotic medications (Agens, 2010).

Use of restraints should be:

- Reserved for documented indications
- Time limited
- Frequently reevaluated for their indications, effectiveness, and side effects in each patient (Agens, 2010)

In most states the use of physical and chemical restraints on nursing home patients is illegal.

### Physical Restraints

A physical restraint is "any manual method or physical or mechanical device, material, or equipment attached or adjacent to the patient that the individual cannot remove easily and which restricts freedom of movement or normal access to one's body" (Canadian Patient Safety Institute, 2007).

The use of physical restraints can be reduced or even eliminated using environmental, psychosocial, and physical alternatives. Since 2007, the Department of Health and Human Services (DHHS) reports that use of physical restraints is down to about 5% overall in the United States (Agens, 2010). A key concern for any healthcare facility is finding ways to address patient safety—reducing falls, wandering, and agitated behaviors without the use of restraints.

### Environmental Alternatives to Physical Restraints

**Falls** can be addressed environmentally using the following techniques:

- Complete a physical therapy evaluation.
- Keep hallways free of equipment and obstacles.
- Install rails in hallways.

- Install grab bars in bathrooms, bedrooms, and showers.
- Install floor-to-ceiling poles next to chairs and beds.
- Install half-rails on beds.
- Lower beds—place mattress on floor if necessary.
- Remove wheels from beds and chairs.
- Adapt wheelchairs to improve posture, support, and comfort.
- Provide “pressure-relief” wheelchair cushions to improve comfort.
- Lower wheelchairs to allow self-propelling with feet.
- Provide comfortable alternative seating.
- Install carpeting to reduce injury from falls.
- Use undergarments with pads over the hips to reduce injuries from falls.

**Wandering and agitated behaviors** can be addressed environmentally by:

- Creating a simple, uncluttered, home-like environment
- Locating problematic residents near nurses' station
- Placing residents' names and photos outside their rooms
- Using calming light and color on walls and floors
- Using alarm devices
- Placing large-print signs to aid way-finding
- Placing Velcro strips on the entrance to resident rooms to prevent trespassing
- Fencing property for safe outdoor walking
- Establishing wandering paths
- Bringing in pets
- Using aromatherapy and music therapy
- Providing rummage boxes or rooms
- Keeping exit doors closed and alarmed
- Avoiding mirrors and glass
- Reducing noise and environmental stimuli
- Personalizing rooms
- Providing color-coded ID bracelets
- Providing a warm, enclosed outdoor area for smoking and visiting

### **Psychosocial Alternatives to Physical Restraints**

- Provide diversionary activities.
- Use therapeutic tasks/activity boxes.
- Provide inter-generational programs.

- Provide cultural experiences.
- Distract/redirect.
- Provide gentle and calm reassurance.
- Provide counseling or psychological consultation.
- Use reminiscence/life review.

### Physical and Physiologic Alternatives to Physical Restraints

- Establish routines, including a toileting schedule.
- Assess and treat hunger, thirst, and discomfort.
- Provide daily walking/physical activity.
- Change medications or taper medications with adverse effects.
- Treat all underlying causes, including pain.
- Be attentive to positioning.
- Assess hearing and vision.
- Establish a nap schedule.
- Provide back rubs and therapeutic touch.
- Provide a warm bath.
- Give warm milk.
- Relieve impaction.

### Chemical Restraints

A chemical restraint is the use of any medications to subdue, sedate, or restrain an individual. Chemical restraints are intended to restrict the freedom of movement of a patient—usually in acute, emergency, or psychiatric settings. Chemical restraint may be prescribed for dangerous, uncontrolled, aggressive, or violent behavior, and should be used for the shortest time possible.

Chemical restraints have been used more prevalently than physical restraints—their use has been as high as 34% in long-term care facilities prior to recent regulations (Agens, 2010). As with physical restraints, there is evidence that the use of chemical restraints has also declined significantly in the last 5 years. One case-control study of more than 71,000 nursing home patients in four states showed that patients in Alzheimer special care units were no less likely to be physically restrained than those in traditional units. However, they were more likely to receive psychotropic medication (Agens, 2010).

While a physical restraint is visible, chemical restraints used to subdue a patient (often in the form of antipsychotic medications) are invisible, and abuse of chemical restraints can be difficult to detect. As with physical restraint, chemical restraint is associated with an increase in confusion, falls, pressure ulcers, and length of stay (Agens, 2010). Antipsychotics should be used only in select cases, be carefully documented, and only with informed consent.

Test your knowledge. . .

Mr. Trenton sits in a chair near the front door, as he has done every day since he moved to Lakeside Nursing and Rehabilitation. Lately he has been walking out the door and roaming the neighborhood.

One environmental adaptation you could make is:

- a. Place his chair in a location where he cannot see the door.
- b. Confine him to his bedroom.
- c. Lock all the doors.
- d. Place a "baby gate" across the front door threshold.

Correct answer: A

## Pharmacotherapy

Pharmacotherapy has only a modest effect on the behavioral and cognitive symptoms of dementia, and many medications have potentially serious side effects. The most commonly used drugs for the treatment of BPSD are the antipsychotics.

Medications used to treat the cognitive effects of dementia have only a modest effect. The most commonly prescribed drugs in this category are anti-cholinesterase inhibitors and NMDA receptor antagonists.

### Typical and Atypical Antipsychotics

**Typical** antipsychotics have been used since the 1950s for the treatment of psychosis in dementia, but they can cause irreversible physical symptoms such as Parkinsonism and tardive dyskinesia (extrapyramidal symptoms). These agents have also been systematically used for the treatment of other behavioral and psychological symptoms of dementia (besides psychosis) despite a substantial lack of scientific evidence supporting their use (Liperoti et al., 2008).

**Atypical** antipsychotics were approved exclusively for the treatment of schizophrenia by Food and Drug Administration (FDA) in the 1990s. Soon after, these medications became the new standard of care for BPSD due to their reported advantages over conventional agents, particularly with respect to extrapyramidal symptoms. In the late 1990s, atypical agents accounted for more than 80% of antipsychotic prescriptions used in dementia patients (Liperoti et al., 2008).

Over the last decade, the off-label use of atypical antipsychotics has been promoted by clinical practice guidelines although there are a limited number of clinical trials suggesting their efficacy in dementia. In 2008 the FDA issued a "drug alert" notifying prescribers that both typical and atypical antipsychotics are associated with an increased risk of mortality in elderly patients treated for dementia-related psychosis (FDA, 2009).

Because of safety considerations associated with antipsychotic medications, non-pharmacologic approaches are generally recognized as the first-line strategy for the treatment of BPSD. Antipsychotic medications are recommended only for the short-term treatment (up to 3 months) and among those patients who manifest severe symptoms that may cause extreme distress and harm to patients or others. A prescriber may still choose to prescribe antipsychotic medications for BPSD and they may indeed be effective in some cases. The prescriber must, however, disclose to the patient or family that the medication is being used off-label\* and obtain permission to use it for behavioral symptoms.

\*Off-label use is the practice of prescribing pharmaceuticals for an unapproved indication, age group, dose, or form of administration.

### **Medications Used to Treat the Cognitive Effects of Dementia**

Certain medications can be prescribed for mild to moderate ADRD to control cognitive symptoms. Two classifications of medications are approved for this purpose: anticholinesterase inhibitors and NMDA (memantine) receptor antagonists. These medications have a very slight effect on a person's ability to perform daily activities and sometimes dampen behavioral and psychological symptoms (although this is an off-label use).

Anticholinesterase inhibitors slow the breakdown of acetylcholine, allowing it to stay in the brain a little longer. Anticholinesterase inhibitors include:

- Aricept (donepezil)—all stages of AD
- Exelon (rivastigmine)—mild to moderate AD
- Razadyne (galantamine)—mild to moderate AD

Memantine (NMDA, Namenda) is approved for use in moderate to severe dementia. Memantine is a receptor antagonist that works by decreasing abnormal activity in the brain. It can help people with AD think more clearly and perform daily activities more easily, but it is not a cure and does not stop the progression of the disease. It may help patients maintain certain daily functions a little longer than they would without the medication.

## Activities of Daily Living (ADLs)

Activities of daily living (ADLs) are the self-care tasks we do during our daily lives. People with dementia gradually need more help with ADLs. Caregivers must learn how to help with ADLs without injuring themselves or their loved one. Basics ADLs include:

- Eating
- Bathing or showering
- Grooming
- Walking
- Dressing and undressing
- Transferring from bed to chair
- Using the toilet

Other ADLs, sometimes called instrumental or functional ADLs (IADLs), include activities that are necessary for us to function within our communities. These activities include:

- Housework
- Handling money and financial transactions
- Shopping
- Preparing meals
- Using the telephone
- Managing medications

### Mild Dementia and ADLs

The early stage of dementia usually lasts a year or two and most people will continue to be independent with basic ADLs at this stage. However, they begin to think less clearly and can be easily confused, especially with new tasks, people, and places. Memory loss can be significant, especially for recent events. For this reason, most will begin to need help with some IADLs—especially complex tasks requiring multiple steps or extensive planning.

A person in the early stage of dementia may cover up increasing confusion by turning to others for help with simple tasks. Denial is common, as are excuses. Those in the early stages of ADRD may be quick to anger or have difficulty making decisions. They may lose motivation and interest in hobbies and activities. Mood changes, such as depression and anxiety, are common in the early stage. Learning a new task is difficult and complex tasks may be left uncompleted. Faulty judgment and mild changes in personality are common.

Test your knowledge. . .

Mrs. Conner is an 80-year-old woman who has driven herself to church every Sunday for the last 35 years. Now, in the early stages of dementia, she cannot remember the route. She claims her trouble started when they closed the street last year to fix the potholes and insists that the road was changed and that's why she now has difficulty.

This may be a sign of:

- a. Early dementia
- b. Moderate dementia
- c. Severe dementia
- d. Delirium

Correct answer: A

### **Moderate Dementia and ADLs**

As ADRD progresses to the moderate stage, IADLs such as travel, work, and keeping track of personal finances become difficult or impossible. In this stage, a person begins to rely on others for assistance with basic daily activities such as grooming, bathing, cooking, and dressing. Mobility may still be quite good and if so, safety becomes a real concern for caregivers. The person may start to wander and is no longer safe without direct supervision. Because of this, family caregiver responsibilities increase, causing stress, anxiety, and worry among family members and caregivers. Someone in the moderate phase of ADRD:

- Is unable to cook, clean, or shop independently
- Needs help with personal hygiene, toileting, washing, and dressing
- Experiences increased difficulty with speech and communication
- Begins wandering and exhibiting other BPSDs, such as repeated questioning, calling out, and clinging
- Experiences sleep disruptions
- Becomes lost at home as well as outside
- Experiences hallucinations and paranoia (especially with Lewy Body Dementia) (ADI, 2009)

### **Severe Dementia and ADLs**

As dementia becomes more severe, independence is gradually lost and caregivers must provide around-the-clock care. A person with ADRD at this stage must be directly assisted with all basic daily living activities such as eating, bathing, transfers, and walking. They will gradually lose control of bodily functions. Family members may find it impossible to continue to provide care and may be forced to move their loved one to an assisted living or skilled nursing facility.

Poor (or non-existent) safety awareness and wandering requires constant monitoring. If the person with dementia is still at home with family, tired and overworked caregivers must provide even more support to maintain a safe environment. If in a skilled nursing facility, healthcare workers must receive proper training and the facility must provide enough staffing and equipment to create a safe environment.

As the dementia progresses, balance and safety awareness go from bad to worse and eventually walking independently is no longer safe. To prevent injuries from falls, it may be necessary to use bed and chair alarms or provide a one-on-one caregiver. Caregivers and healthcare providers must make difficult decisions to prevent injury and to provide a safe environment. In general, restraints are not recommended and may actually increase the danger of injury (Stokoski, 2007).

### **Assisting with ADLs**

In assisting residents with ADLs, it is sometimes apparent that the caregiver and the person with dementia have different goals. A caregiver in a residential care facility may want to bathe a resident and get her dressed quickly because the caregiver has two more people to get dressed before breakfast. The resident may want just to watch TV for 30 minutes before going to breakfast.

No matter what the level of dementia, when assisting someone with their basic ADLs, keep these general measures in mind:

- Maintain a calm demeanor and voice.
- Make eye contact.
- If the resident does not respond immediately, repeat the request in the same words you used the first time. Rephrasing the request is confusing.
- Engage the resident. Offer simple choices such as, "Do you want orange juice or apple juice?"
- Remember that the person **can** express his or her wishes. "No, I don't want to!" means just that, even when spoken by someone with ADRD.
- Be empathetic. Examples of empathetic responses include "You must be cold", or "Are you uncomfortable in that chair?"
- Problem solve with the person, perhaps by asking, "What would help now?"
- Give the person physical space—do not crowd.
- Be aware of your body language and vocal tone.

### **ADLs during Various Stages of Dementia**

When assisting someone with dressing, grooming, eating, bathing, and toileting certain strategies will help you to successfully complete these tasks. Use common sense, be aware of your body language, and use a quiet, confident tone of voice. What follows are some suggested interventions appropriate to the various stages of dementia. Whatever the activity, move slowly, give clear, simple commands, limit choices, and allow plenty of time to complete the task.

Dressing	
Stage of dementia	Level of assistance
Mild	<ul style="list-style-type: none"> <li>• Generally stand-by assist</li> <li>• Encourage residents to choose their own clothes</li> <li>• Allow residents to do what they can even if it takes longer</li> <li>• Assist as needed but allow the resident to direct the activity</li> </ul>
Moderate	<ul style="list-style-type: none"> <li>• Generally moderate or close, hands-on assist</li> <li>• Provide comfortable, clean clothes with elastic waistbands and Velcro closures</li> <li>• Select some clothes ahead of time and set them out</li> <li>• Ask residents to participate in the choice of clothing</li> <li>• Assist as needed but allow residents to do all they can by themselves</li> </ul>
Severe	<ul style="list-style-type: none"> <li>• Generally maximum or total assist</li> <li>• Select clothes and set them out, limit choices</li> <li>• Choose comfortable clothing that is easy to wash</li> <li>• Assist closely but encourage as much independence as possible</li> <li>• Use simple, 1-step commands and gestures</li> </ul>

<b>Grooming</b>	
Stage of dementia	Level of assistance
Mild	<ul style="list-style-type: none"> <li>• Stand-by assist</li> <li>• Provide space and materials</li> <li>• Provide bathing options</li> <li>• Provide grooming tools for people with motor control problems</li> <li>• Allow residents to groom themselves</li> <li>• Monitor their progress and provide assistance as needed</li> </ul>
Moderate	<ul style="list-style-type: none"> <li>• Moderate assist</li> <li>• Offer limited choices (“Would you like lipstick today?” “Would you like to brush your hair?”)</li> <li>• Allow the resident to do as much for themselves as possible</li> </ul>
Severe	<ul style="list-style-type: none"> <li>• Maximum assist</li> <li>• Provide as much assistance as needed</li> <li>• Move slowly, limit choices</li> <li>• Use gestures and simple, 1-step commands</li> </ul>

<b>Eating</b>	
Stage of dementia	Level of assistance
Mild	<ul style="list-style-type: none"> <li>• Stand-by assist</li> <li>• Cue meal time by encouraging the person to help with meal preparation</li> <li>• Provide adaptive utensils as needed</li> <li>• Prepare and set up meal as needed</li> <li>• Cut meat or vegetables as needed</li> <li>• Provide assistance with other tasks as needed</li> </ul>
Moderate	<ul style="list-style-type: none"> <li>• Moderate assist</li> <li>• Prepare meal for consumption before setting before resident</li> <li>• Open packages, uncover trays</li> <li>• Provide adaptive equipments as needed, such as spill proof cups and plate guard</li> <li>• Monitor the meal—resident may forget to complete the meal</li> </ul>
Severe	<ul style="list-style-type: none"> <li>• Maximum assist</li> <li>• Fully set-up meal before serving</li> <li>• Provide adaptive equipment as needed</li> <li>• Monitor closely and be ready to provide feeding assistance</li> <li>• Offer liquids on a regular schedule as the resident is unlikely to ask when thirsty</li> <li>• Discuss advance directives with family anticipating that at some point the resident will refuse to eat</li> <li>• Allow plenty of time for resident to finish eating</li> </ul>

<b>Bathing*</b>	
Stage of dementia	Level of assistance
Mild	<ul style="list-style-type: none"> <li>• Stand-by assist</li> <li>• Give resident choices as to when, where, and what type of bathing</li> <li>• Assist residents in decision to bathe—they may not initiate this activity</li> <li>• Monitor for safety and comfort</li> <li>• Assist with bathing or shower as needed</li> </ul>
Moderate	<ul style="list-style-type: none"> <li>• Moderate assist, particularly in wet showers</li> <li>• Prepare for bathing by determining resident preferences</li> <li>• Initiate and monitor the activity</li> <li>• Provide direct assistance as needed</li> </ul>
Severe**	<ul style="list-style-type: none"> <li>• Maximum assist—may be completely dependent</li> <li>• Provide complete bathing care</li> <li>• Retain as much of resident's earlier bathing rituals as is reasonable</li> <li>• Provide the bath, using resident behavior as a guide</li> </ul>

\*Consider bathing habits (time of day, bath or shower); consider bed bath if more acceptable to resident than other options). For more information see: A New Look at the Old: The Older Adult, Dementia, and Assisted Bathing (<http://www.twlk.com/healthcare/AJNwebcast424-0005.asp>).

\*\*Goal is for resident to be clean and comfortable. Shower or tub bath is not necessary—a sponge bath may suffice.

Toileting and Incontinence	
Stage of dementia	Level of assistance
Mild	<ul style="list-style-type: none"> <li>• Stand-by assist</li> <li>• Monitor and assist as needed</li> <li>• Encourage fluids but be aware that regular bathroom visits may be necessary</li> <li>• Be aware of medications that cause constipation or increase or decrease urge to urinate</li> </ul>
Moderate	<ul style="list-style-type: none"> <li>• Moderate assist, particularly with transfers</li> <li>• Label bathroom door for easy identification</li> <li>• Ask regularly if the resident needs to eliminate</li> <li>• Take the resident to the toilet on a regular schedule (i.e., every 2 hrs). Time these close enough so that the bladder does not completely fill.</li> </ul>
Severe	<ul style="list-style-type: none"> <li>• Maximum assist—may be dependent.</li> <li>• Expect both bowel and bladder incontinence requiring total care</li> <li>• Set up timed toileting schedule</li> </ul>

### Activities for Residents with ADRD

People with dementia find enjoyment engaging in a variety of activities. With a little imagination, you can adapt activities to people with different abilities. Often residents continue to do hobbies that they have enjoyed throughout their lives. An artist or musician may want to continue to paint or play an instrument. A carpenter or contractor might enjoy an activity board with nuts, bolts, screws. The type of activity depends on the level of dementia and the person's physical abilities.

There have been some notable successes in the design of activity programs for people with dementia. The Meyers Research Institute has published a book called the Montessori-Based Activities for Person with Dementia (available at Amazon.com). This approach emphasizes matching a person's abilities with the activity. It also borrows from the concept of having older children teach younger children by setting up programs in which people with mild dementia serve as group activity leaders for those with advanced dementia.

Activities that stimulate the senses such as cooking, singing, exercise, going for a drive, gardening, and aromatherapy are popular at all stages of dementia. Some nursing homes allow birds, cats, and dogs in the facility. This is a wonderful way to give someone a sense of purpose and companionship. Visit websites designed by activity directors for many more ideas.

## **Individual Activities**

To create successful individual activity programs for people with dementia find out what each person likes. Treat each resident with respect and remember that they are not babies or children. Read their history and talk to family members. Determine their capabilities—can they still read, write, play an instrument, use a computer, or paint. What are they physically capable of doing? Is their balance impaired? Do they have orthopedic problems that cause pain or limit motion? How impaired is their memory? Are they religious, political, apolitical—were they community activists, volunteers, business owners? Are they adept with electronic devices such as computers, Internet, Facebook, cell phones, Kindles, or iPads?

Adults often have a fear of failure (especially those aware of their cognitive decline) and may refuse to participate in activities because of this fear. This is rarely the case with young children. Be consistent, have fun, and by all means introduce new activities. Look for signs of frustration and agitation and address these behaviors immediately. Here are some examples of activities that are appropriate for individuals with ADRD working alone.

<b>Appropriate Individual Activities for People Who Have ADRD</b>			
Type of activity	Mild	Moderate	Severe
Word games, card games, video game	Word searches, crossword puzzles, card games, Internet games	Word searches with focus on one topic, simple computer games	Discuss a simple topic, listen to others
Letter writing	Write a letter or a card to someone special	Dictate a letter	Listen to a letter being read
Art/Music	Take photos, paste photos in an album, draw, finger paint, play an instrument	Take photos, arrange flowers, sing along with others	View photos, listen to music, sing along to familiar songs
Woodworking	Use tools with supervision	Sand, paint items	Activity board fit with bolts, screws, and other hardware that is safe to manipulate
Sewing	With stand-by assist	Supervise—give resident one task to complete at a time	Sewing cards, activity blankets or aprons with buttons, snaps, ties, Velcro, and zippers
Gardening	Garden in raised beds, can work independently, can help plan the garden and harvest	Should be supervised and given specific tasks to perform	May enjoy sitting in the garden and eating food grown in garden
Crafts	Knitting or crochet using large needles and bulky yarn	Choose colors, roll balls of yarn	Choose colors, use the items that are created
At home activities	Help with laundry with supervision, put clothes away, assist with housekeeping	Sort and fold laundry	Fold laundry—may want to fold the same items repeatedly
Shopping	Go along to store, help with purchasing decisions, help put groceries away	Go along to store, use electric cart in store	Sit in car with supervision

### Group Activities

People in the early stages of ADRD may especially enjoy working with others. As ADRD progresses, the person may be more likely to enjoy solitary activities. Small groups of about 5 to 6 people are generally preferred because they allow more activity and personal attention, although well-planned large group activities can also be successful.

Appropriate Group Activities for People Who Have ADRD			
Activity	Mild	Moderate	Severe
Karaoke	Sing while reading words.	May want to sing songs that are familiar.	Listen and sing along.
Cooking	Bake cookies, prepare a snack plate for other residents, clean up after cooking	Participate in making cookies after being given a specific task, assist with cleaning up	Help decorate cookies that are already baked, eat the cookies
Nature	Nature walks, outings to nature areas	Shorter walks; picnicking outdoors.	Escorted walk outside the facility; attending picnic.
Crafts	Make ornaments, decorate a Christmas tree, decorate a room for the holidays	Participate in making ornaments being given specific tasks, decorate the tree	Participate in the tree decorating party
Outings	Shopping, theater and music events, fruit picking, museum visits, library visits, eating in a restaurant, sporting events	Same as mild with some adaptation and more supervision.	Set up a store where the resident can purchase gifts, watch movies at home, outings with direct supervision

Whatever the stage of the dementia everyone appreciates meaningful activities. We like helping one another, teaching someone a new skill, and contributing to the success of an activity. In our institutional settings we have very nearly stripped people of any meaningful way to contribute, to help, to learn, and to grow as a person. Remember that everyone—even those with dementia yearn for meaning in their lives—a good activity program can help accomplish that goal.

## Stress Management for the Caregiver

A caregiver is someone who provides assistance to a person in need. They may provide physical, financial, or emotional assistance. They can help with basic ADLs such as bathing, dressing, walking, cooking, or more complex tasks such as medication management and home management, among other things. They may give direct care or manage care from a distance or for others. They might be a family member, a neighbor, or a medical professional.

Schulz has defined caregiving as: "...the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. It typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting" (ADI, 2009).

Caregiving is a long-term, evolving process with key transition phases. The onset of caring is often hard to define; it tends to emerge naturally from the customary family transactions, involving support given and received, that existed before the onset of dementia. The need for care may precede or post-date a formal diagnosis of dementia. Needs for care tend to escalate over time, from increased support for household, financial, and social activities, to personal care, to what for some is almost constant supervision and surveillance. Important transitions include the involvement of professional caregivers, institutionalization, and bereavement (ADI, 2009).

All people with dementia will eventually experience at least some degree of functional disability. Studies in Latin America, India, and China by the Dementia Research Group found that in most locations, between 50 and 70% of those with dementia needed some care and most needed "much care". Need for care varied by level of dementia: those with mild dementia needed care 30% of the time, those with moderate dementia 69% of the time, and those with severe dementia needed care 88% of the time (ADI, 2009).

## Challenges for Caregivers

"My mom cusses at me every day, usually in public, and usually loudly. I suppose I am beyond the point of being mortified. There's nothing to do but accept it with good humor. That did not come easily or quickly. People in the support group tell me that this period probably will not last."

ADEAR, 2011

Family caregivers—most of whom are women—must juggle child care, jobs, personal health issues, and other responsibilities while caring for family members who can no longer function on their own. The presence of other complex health problems such as heart disease and diabetes complicates care.

Professional caregivers and healthcare providers also face daunting challenges when working with dementia patients. One of the biggest struggles for any caregiver is dealing with difficult behaviors. Dressing, bathing, eating—basic activities of daily living—often become difficult to manage. Many caregivers find it helpful to use strategies for dealing with difficult behaviors and stressful situations. Each person with dementia is unique and will respond differently, and each person changes over the course of the disease.

Care provided for people with dementia includes:

- Personal activities of daily living (ADLs)—washing, dressing, grooming, toileting, eating
- Instrumental activities of daily living (IADLs)—cooking, shopping, laundry, household finances
- General supervision (ADI, 2009)

In a study of family caregivers in high-income countries, a daily average of 1.6 hours was spent assisting with personal activities, 3.7 hours was spent assisting with instrumental activities, and 7.4 hours was needed if general supervision was added to these other tasks (ADI, 2009).

The severity of the dementia determines how much care is needed, particularly for personal activities of daily living. In one study, the amount of care increased from an average of 2.3 hours per day for someone with mild dementia to 7.1 hours per day for someone with severe dementia (ADI, 2009).

*“I’m exhausted. I can’t sleep because I have to watch out for my wife. She wanders around the house, takes out all kinds of stuff from the kitchen. I don’t know what she’s going to do.”*

ADEAR, 2011

### **Causes of Stress for the Caregiver**

Caring for a person with dementia is a stressful activity and caregivers go through some of the same emotional experiences as the person with dementia. They may experience denial, anger, and depression as their loved one becomes more demented. The demands of caregiving can become exhausting and contribute to social withdrawal. Caregivers overwhelmed by the demands of caring for someone with dementia can experience irritability, anxiety, and sleep disturbances of their own.

In the United States, more than 40% of family and other unpaid caregivers of people with dementia rate the emotional stress of caregiving as high or very high. Interestingly, in low- and middle-income countries, while being part of a large household attenuated slightly the strain experienced by the main caregiver, traditional extended-family care networks provided little protection. The main factors consistently found to be associated with caregiver strain are highlighted in the following table (ADI, 2009).

Factors and Characteristics Associated with Caregiver Strain	
Factors	Characteristics associated with caregiver strain
Demography	<ul style="list-style-type: none"> <li>• Female caregiver</li> <li>• Spousal caregivers, particularly those of younger people with dementia</li> <li>• Living with the care recipient</li> <li>• Low incomes or financial strain</li> </ul>
Caregiver personality	<ul style="list-style-type: none"> <li>• High level of neuroticism</li> <li>• High expressed emotion</li> </ul>
Perception and experience of caregiving role	<ul style="list-style-type: none"> <li>• Low sense of confidence by the caregiver in their role</li> <li>• High “role captivity”—caregivers feeling trapped in their role</li> </ul>
Coping strategies	<ul style="list-style-type: none"> <li>• Emotion-based or confrontive coping strategies</li> <li>• Dementia type</li> <li>• Frontotemporal dementia (FTD)</li> <li>• Severity of dementia</li> <li>• Behavioral and psychological symptoms of dementia present—particularly apathy, irritability, anxiety, depression, delusional beliefs</li> <li>• Cognitive impairment is not usually associated with caregiver strain</li> </ul>
Relationship factors	<ul style="list-style-type: none"> <li>• Intimacy—poor relationship quality</li> <li>• Low levels of past and current intimacy</li> </ul>

Source: Adapted with permission from ADI, 2009.

Test your knowledge. . .

Tanya lives with her parents in their house. Both parents have dementia and Tanya is their primary caregiver. Her father has wandered away from home on several occasions and her mother is completely bed-bound. Tanya denies that she is stressed because, she says, "My parents deserve the best care and as their daughter I am the best person to provide this." She refuses to take time off because "I will have plenty of time to vacation when they are gone."

Your assessment of Tanya's situation is:

- a. She is a very kind person and obviously suited for caregiving.
- b. She is at very high risk for caregiver stress.
- c. She is at low risk for stress because of her close family ties.
- d. There is nothing to worry about, she is coping well.

Correct answer: A

Caregivers can use the 13-point Modified Caregiver Strain Index to assess common sources of stress. Caregivers are asked how strongly they agree with statements in the table below.

	Yes, on a regular basis = 2	Yes, sometimes = 1	No = 0
My sleep is disturbed			
Caregiving is inconvenient			
Caregiving is a physical strain			
Caregiving is confining			
There have been family adjustments			
There have been changes in personal plans			
There have been other demands on my time			
There have been emotional adjustments			
Some behavior is upsetting			
It is upsetting to find the person I care for has changed so much from his/her former self			
There have been work adjustments			
Caregiving is a financial strain			
I feel completely overwhelmed			
Total score =			

Source: Thornton and Travis, 2003. Reproduced by permission.

### Strategies and Techniques for Managing Stress

Caregivers can reduce stress by paying attention to their own health, including getting enough sleep, proper nutrition, seeing their own doctors, and sharing their feelings about their caregiving duties with co-workers, family, and friends. The Alzheimer's Association recommends ten ways to be a healthier caregiver:

1. Understand what's going on as early as possible.
2. Know what community resources are available.
3. Become an educated caregiver.
4. Get help.

5. Take care of yourself.
6. Manage your stress.
7. Accept changes as they occur.
8. Make legal and financial plans.
9. Give yourself credit, not guilt.
10. Visit your doctor regularly. (Alzheimer's Association, 2009)

### Things to Do

- Meet with a support person, group, or counselor on a regular basis to discuss your experiences and feelings.
- Set limits in caregiving time and responsibility, and stick to those limits.
- Allow yourself to have questions. Let "not knowing" be okay.
- Get the information and support you deserve and need.
- Discuss with your employer strategies for performing your job in ways that reduce stress and burnout.

### Things to Avoid

- Don't isolate yourself.
- Don't try to be all things to all people.
- Don't expect to have all the answers.
- Don't deny your own fears about Alzheimer's disease or dying.

## Family Issues

All over the world, the family remains the cornerstone of care for older people who have lost the capacity for independent living. In developed countries such as the United States, the vital caring role of families, and their need for support, is often overlooked. In developing countries, the reliability and universality of the family care system is often overestimated (ADI, 2009).

Family members are confronted with many issues, worries, and concerns and must adjust their own behavior and manage their own frustrations as the dementia progresses. If it is a spouse with dementia, caregivers are confronted with the gradual loss of companionship. If it is a parent, an adult child will have to gradually take over the care of their parent and assume a new role in the family.

In the early stage, family members should be encouraged to receive specialized training, which is an essential but often neglected component of dementia care. Trained family members are able to partner with healthcare professionals to provide competent and compassionate care. In the middle and late stages behavioral and psychological problems will likely arise, requiring complicated decisions about behavioral interventions and perhaps medications.

As people lose the ability to talk clearly, caregivers will struggle to find new ways to communicate as their loved one uses fewer and fewer words. Caregivers must learn to interpret facial expressions for sadness, anger, or frustration and physical gestures such as grasping at undergarments, which may communicate the need to use the bathroom.

One of the most difficult issues—usually in the middle to late stages of dementia—is the decision to place a family member in residential care or skilled nursing facility. There are a number of reasons cited by caregivers for placement:

- The need for more skilled care
- The caregivers' health
- The patients' dementia-related behaviors
- The need for more assistance (Buhr, 2006)

Relinquishing full-time care can cause feelings of loss, sadness, resignation, and depression for family caregivers. Paradoxically, placement of a loved one in a care facility may do little to alleviate the stress that caregivers experience.

Once a family member has moved to a care facility, family caregivers must begin the process of learning to navigate a complicated healthcare system. Healthcare workers can support family members by determining the preferences, abilities, and resources of each family member. Regular face-to-face meetings with family members and facility staff will help families work through difficult conflicts.

### **The Grief Process**

Grief is a normal reaction to the losses associated with any illness. Grief can manifest itself in physical symptoms such as shortness of breath, tension, headaches, fatigue, a feeling of heaviness, and a lack of energy. Psychological symptoms include clinical depression, hypochondria, anxiety, insomnia, and the inability to get pleasure from normal daily activities. Dealing with these issues may lead to self-destructive behaviors, such as alcohol or drug abuse.

Dementia and declining health cause multiple, ongoing losses for both the person experiencing dementia and for caregivers and family members:

- Loss of physical strength and abilities
- Increased confusion
- Loss of income and savings
- Loss of health insurance
- Changes in housing, personal possessions, including loss of pets
- Loss of self-sufficiency, privacy, and self-esteem
- Changes in social contacts and roles

### **Dementia Care Programs**

One way to alleviate the grief and stress associated with caregiving is to encourage family members to become involved in a dementia care program. Dementia care programs are multidisciplinary and multi-departmental programs that are designed to meet the individual needs of residents throughout the day. They usually include support groups for family members, friends, and caregivers.

A dementia care program:

- Allows and encourages families to visit at any time
- Plans activities that include family members, such as dinners or parties
- Determines family and encourages involvement in the planning of activities
- Asks the family how they would like to be informed about changes in condition
- Keeps a log of resident activities and shares this with the family
- Encourages residents to call and write to family members and friends
- Uses technology to keep families in touch with one another

A dementia care program should include cues and themes to help residents remain oriented to their environment, electronic door security for safety, comfortable and familiar furniture, specialized foods and beverages, and regular personalized group and individual activities.

There are many examples of good dementia care programs throughout the United States. One such program, Bridge to Rediscovery, uses a Montessori approach to help residents rediscover skills and activities that have interested them in the past. For an example of a successful program using this method see the web site for Five Star Senior Living.

### Caregiver Training

There is a general consensus that providers who care for residents with dementia need to be specifically "dementia-trained" because of the unique challenge this group presents. Training content should include knowledge of disease trajectory, symptoms, approaches to care, goals of care (cure or comfort), palliative care measures, end of life issues, signs of impending death for persons with dementia, and how to interact with residents and families.

Tilly and Fok, 2007

The responsibilities of caregiving can be overwhelming, especially for spouses, family members, and friends. A spouse (and even adult children) may be in poor health and be unable to take on the burdens of fulltime caregiving. Even trained healthcare providers can find it difficult to deal with demented patients day in and day out.

For both professional and family caregivers, training and education can be a big help. It is possible to get better at caring for someone with dementia. Training and education can help caregivers recognize signs and symptoms of injury and illness and reduce stress. Training introduces caregivers to resources, support, and equipment that improve health and safety.

## Maintaining a Therapeutic Environment

Over the last two decades there has been increasing interest in creating “therapeutic environments” for people with ADRD. A therapeutic environment is supportive of each individual and recognizes that people with dementia are particularly vulnerable to chaotic environmental influences. A therapeutic environment should be “person-centered”—individualized, flexible, and designed to support differing functional levels and approaches to care (Campenel and Brummett, 2010).

**Philosophy of care** is a framework that identifies care goals and values. Philosophies of care occur along a spectrum, for example, from less intervention to more technical intervention. A family's or an individual's philosophy of care may differ from that of a medical professional or healthcare organization.

### Person-Centered Care

Person-centered care is a philosophical approach that states that a person with dementia deserves kind and supportive treatment with the rights that we reserve for any other individual, namely dignity, respect, and autonomy. The philosophy of person-centered care (also referred to as individualized, resident-centered, or patient-centered care) is commonly accepted (although perhaps not commonly practiced) throughout the United States.

Person-centered care replaces an older philosophy of care in which dementia was considered to be a biomedical problem and care tended to be task driven. Caregivers often relied on chemical and physical control techniques and the healthcare system often devalued the individual (Epp, 2003).

Person-centered care by contrast focuses on the whole person. It places emphasis on cognitive, physical, and emotional abilities that remain—not on losses. It takes into account a person's family, marriage, culture, ethnicity, and gender and centers care within the larger society (Epp, 2003).

### Need-Driven Dementia-Compromised Behavior Model

The needs-driven model of care (discussed earlier in this course) is based on the idea that challenging behaviors are the result of unmet needs. It suggests that the loss of ability to easily communicate one's needs and desires causes a person to “communicate” through behavior. The needs-driven model emphasizes the interaction between individual characteristics and fluctuating environmental triggers that may cause stress or discomfort. In the needs-driven model, assessment is the key to accurate interventions and quality of care (Algase, 1996).

### Environment as a Therapeutic Resource

An emerging concept in dementia care is the use of design as a therapeutic tool—recognizing that there is a connection between the environment and how people behave. In this model, homes or buildings used for the care of people with memory impairment and dementia are designed or remodeled to encourage community, maximize safety, support caregivers, cue specific behaviors and abilities, and redirect unwanted behaviors (Campenel and Brummett, 2010).

## Questioning a Facility's Philosophy of Care

Family members should feel free to question a facility's philosophy of care. The California Advocates for Nursing Home Reform recommend that family members fill out an evaluation checklist that includes questions about the organization's philosophy of care:

- Is the facility's philosophy for caring for persons with dementia consistent with your beliefs?
- Does the facility provide services to persons at all stages of the disease process?
- What conditions or behaviors determine whether a facility will either admit or retain someone with dementia?
- Is dementia care provided in a separate unit or as an integrated part of facility services?
- Is the facility's philosophy and practice of handling "difficult behaviors" compatible with your views?
- What is the facility's philosophy in using physical restraints to deal with certain behaviors?
- Does the facility recommend the use of psychoactive drugs to treat behaviors? (California Advocates for Nursing Home Reform, 2011)

## Physical Environment

Maintaining a positive and healthy physical environment is an important aspect of dementia care. People with dementia rely on environmental cues to support them physically, cognitively, and emotionally. Unfamiliar, chaotic, or disorganized environments are stressful and can cause anxiety, disorientation, and other behavioral problems.

It is possible to design a supportive therapeutic environment for people with dementia—whether it is a new facility, the retrofit of an existing building, or a home modification. Sarah Campernel and William Brummett, in their excellent report, *Creating Environments of Support: A Handbook for Dementia-Responsive Design*, have designed or retrofitted many facilities and homes based on the idea of person-centered care. The physical environment should:

- Provide support for caregivers
- Ensure and maximize safety and security
- Adapt to changing needs
- Support functional abilities through meaningful activity
- Regulate and provide opportunities for positive stimulation
- Maximize awareness and orientation
- Provide opportunities for socialization
- Protect the need for privacy
- Maximize autonomy and control
- Support the continuity of the self, maintain links with their earlier life (Campernel and Brummett, 2010)

Whatever the situation, the physical environment can be adapted to meet the physiologic and social needs of those with dementia. Campenel and Brummett use these **therapeutic design** goals when developing or retrofitting an environment for people with dementia and memory disorders:

- Arrange spaces to resemble a natural community.
- Create continuous circulation routes with looping corridors and areas of interest.
- Include residents in the design of new features such as walking paths and gardens.
- Create safe, purposeful, and accessible outdoor areas.
- Replace institutional, centralized nursing stations with smaller, residential-looking stations.
- Create spaces to cue specific behaviors (activity kitchen, art and music therapy area, bistro/bar, library, coffee shop/Internet café, quiet room, living room, family visiting area).
- Create spaces to redirect unwanted behaviors (rummage areas, Snoezelen rooms,\* wandering paths)
- Create caregiver support areas throughout the building by dispersing break rooms, nursing stations, rehab room, and utility areas.
- Provide an area for privacy in each person's room.
- Create companion rooms with shared bath and entrance.
- Provide normal, dignified bathing and personal care areas. (Campenel and Brummett, 2010)

\*A Snoezelen room uses light, sound, scents, and music to arouse the senses. These have both relaxing and activating effects on the various perception areas. The specific design directs and arranges the stimuli; it creates interest, brings back memories, and guides relationships.

The following photographs from Campenel and Brummett (2010) illustrate these therapeutic design concepts.



Home-like outdoor porch area for seating and reflection. Source: Campnerl & Brummett, 2010. Used with permission.



Safe, looping wandering paths with areas of interest along the way. Source: Campnerl & Brummett, 2010. Used with permission.



Snoelezen room. Source: Campnerl & Brummett, 2010. Used with permission.



Residential-looking, smaller-scaled nurses' station. Source: Campnerl & Brummett, 2010. Used with permission.



Rummage areas. Source: Campnerl & Brummett, 2010. Used with permission.

## Safety and Security

People with ADRD need to be kept safe without the use of physical and chemical restraints. Safety includes creating an appropriate environment as well as planning for adverse events, such as **elopement** (wandering away from home or a facility). Caregivers must be alert to changes in behavior and anticipate solutions. The table below illustrates some common safety hazards and measures to help make the environment more safe and secure. Since every situation is different, interventions must be tailored to match the specific circumstances.

Measures to Promote Safety and Security		
Safety issue	Possible consequence	Intervention
Wandering	Elopement, getting lost, exposure to environmental hazards.	<ul style="list-style-type: none"> <li>• Paint the inside surface of doors so that they are not readily recognizable as an exit.</li> <li>• Place locks where they are not visible.</li> <li>• Use technology such as the Alzheimer Association's Comfort Zone.*</li> <li>• Provide short, looping corridors without dead ends.</li> <li>• Create open, common areas of interest.</li> <li>• Create safe, outdoor wandering areas that are accessible from indoor wandering paths.</li> </ul>
Cooking without supervision	Fire, injury	<ul style="list-style-type: none"> <li>• Install a shut-off valve on the stove.</li> <li>• Remove burner on-off handles.</li> <li>• Keep a working fire extinguisher.</li> <li>• Create a work area with an activity kitchen.</li> </ul>
Falls	Injury	<ul style="list-style-type: none"> <li>• Examine patient to rule out medical conditions.</li> <li>• Create an uncluttered environment.</li> <li>• Install handrails in showers and hallways.</li> <li>• Install carpeting to reduce injuries in the event of a fall.</li> <li>• Wipe up spills promptly.</li> <li>• Maintain physical activity.</li> <li>• Supervise walking and remind person to use assistive device.</li> <li>• Remove throw rugs.</li> <li>• Maintain good vision and hearing.</li> <li>• Provide many places to sit.</li> </ul>
Poisoning	Sickness or death	<ul style="list-style-type: none"> <li>• Remove toxic plants from the environment.</li> <li>• Lock up chemicals and medications.</li> </ul>

\*The Alzheimer's Association has a product called Comfort Zone that uses GPS technology to locate a person who has wandered and become lost. See: [http://www.alz.org/comfortzone/about\\_comfort\\_zone.asp](http://www.alz.org/comfortzone/about_comfort_zone.asp). There are many proprietary companies now offering similar location services.

## Schedules and Routines

In traditional nursing homes, daily life is primarily organized around the routines of the nursing home and the convenience of the staff. The schedule can change dramatically from day to day as a result. This is difficult for people with dementia because they rely on a predictable routine for orientation. A regular routine allows a person with ADRD to know what to expect. Routines also give the caregivers a benchmark for evaluating a person's behavior. When developing a schedule for someone with dementia:

- Plan the schedule carefully.
- Consider each person's capabilities and preferences.
- Try to continue familiar routines and schedules.
- Maintain mealtime routines.
- Maintain regular dental and healthcare appointments.
- Allow plenty of time.
- Note the effects of changes in routines.
- Consider issues that disrupt routines (ie, pain, fatigue, illness)

Caregivers are responsible for maintaining a routine schedule but must be flexible and know when to make an adjustment. For example, if someone does not want to take a shower on the usual bathing day, it may be best to simply help the person wash up and schedule the shower for another day.

People with ADRD tend to be slow, so the caregiver needs to allow ample time when preparing for an outing or going to an appointment. Attempting to rush can precipitate aggressive behaviors and frustrate both parties.

## Staff as Part of the Environment

There are approximately 16,500 certified nursing facilities in the United States. All are required to meet minimum staffing standards to attain or maintain the highest possible physical, mental, and psychosocial well-being of residents. Most facilities struggle to hire, train, and retain staff in the face of low wages, poor benefits, and risk of injury.

Proper staffing has consistently been associated with higher quality of care. Nursing homes with more RN hours per patient have been associated with positive outcomes. A positive relationship also exists between better staffing, improved nutrition, and fewer deficiencies. The existence of dedicated special care units (such as a dementia care unit) has been associated with higher quality of care because of higher staffing levels (Harrington et al., 2010).

Although there is a trend towards the development of smaller, homelike nursing facilities, larger nursing homes are still the norm. The number of beds per nursing home has remained largely unchanged since 2004 at an average 108 beds per facility (Harrington et al., 2010).

Nevertheless, it is instructive to examine small-scale care settings where normal daily life is emphasized and activities are centered on household tasks and activities. This type of facility requires a fundamental shift for staff, who must adjust to the routines of the residents.

In a small-scale setting, staff, residents, and family caregivers form a household together. Residents are cared for by a small, fixed team of professional caregivers, which are part of the household. Daily life is organized completely or in a large part by residents and caregivers. Staff members, residents, and family members prepare meals together and staff members are involved in multiple tasks, such as medical and personal care, domestic chores, and activities (Verbeek et al., 2009).

To encourage integration of the staff into a homelike environment, consider the following practices:

- Hire staff with the emotional skills to interact with people who have memory problems.
- Eliminate institutional, centralized nursing stations.
- Locate nursing and work areas throughout the building for staff convenience.
- Allow staff to control lighting and environmental levels.
- Emphasize signage for residents.
- Limit signage for staff and visitors.
- De-emphasize or camouflage doors to staff and utility areas.
- Keep staff consistent.

## Ethical Issues and Residents with ADRD

Those who work in dementia-care settings face difficult ethical decisions each day. They must balance a person's day-to-day autonomy and dignity against the person's need for safety. They must also balance their own needs with those of the person with dementia. Often there is no single right answer and successful strategies change as the dementia progresses.

Caregivers must balance the needs of multiple residents. They must consider issues related to confidentiality, the potential for elder abuse, and the benefits and risks of medications and procedures. When an individual is no longer able to express his or her will, a designated decision-maker must step in and make difficult decisions. The decision-maker must put aside needs and desires of the self and carry out what is believed the person with dementia would do if able.

### Incorporating Ethical Principles into Care

[This section is taken from *California: Ethical Decisions in Physical Therapy* by Nancy R. Kirsch, an ATrain course available at <http://www.atrainceu.com>.]

The language of biomedical ethics is applied across all practice settings, and four basic principles are commonly accepted as part of medical ethics. These principles include (1) autonomy, (2) beneficence, (3) nonmaleficence, and (4) justice. In health fields, veracity and fidelity are also spoken of as ethical principals.

#### Autonomy

Autonomy is an American value. We espouse great respect for individual rights and equate freedom with autonomy. Our system of law supports autonomy and upholds the right of individuals to make decisions about their own healthcare.

Respect for autonomy requires that patients be told the truth about their condition and informed about the risks and benefits of treatment. Under the law, patients are permitted to refuse treatment even if the best and most reliable information indicates that treatment would be beneficial, unless their action may have a negative impact on the well-being of another individual. These conflicts set the stage for ethical dilemmas.

#### Beneficence

Beneficence is the act of being kind. The beneficent practitioner provides care that is in the best interest of the patient. The actions of the healthcare provider are designed to bring about a positive good. Beneficence raises the question of subjective and objective determinations of benefit versus harm. A beneficent decision can only be objective if the same decision would be made regardless of who was making it. Traditionally, the decision-making process and the ultimate decision were the purview of the physician. This is no longer the case; the patient and other healthcare providers, according to their specific expertise, are central to the decision-making process (Valente, 2000).

## Nonmaleficence

**Nonmaleficence** means doing no harm. Actions or practices of a healthcare provider are “right” as long as they are in the interest of the patient and avoid negative consequences. The right of the individual to choose to “die with dignity” is the ultimate manifestation of autonomy, but it is difficult for healthcare providers to accept death when there may still be viable options. In this case, the principle of nonmaleficence conflicts with the principle of autonomy because of the healthcare provider’s desire to be beneficent or, at the least, cause no harm. The active choice to hasten death versus the seemingly passive choice of allowing death to occur requires that we provide patients with all the information necessary to make an informed choice about courses of action available to them.

A complicating factor in end-of-life decisions is patients’ concern that, even if they make their wishes clear (eg, through an advance directive), their family members or surrogates will not be able to carry out their desires and permit death to occur (Phipps et al., 2003). Treating against the wishes of the patient can potentially result in mental anguish and subsequent harm.

## Justice

Justice speaks to equity and fairness in treatment. It may be seen as having two types: distributive and comparative. **Distributive justice** addresses the degree to which healthcare services are distributed equitably throughout society. **Comparative justice** determines how healthcare is delivered at the individual level. In a society where equal access to healthcare does not exist, there is a continuing concern about the distribution of resources, particularly as the population ages and the demand for services increases.

## Veracity

**Veracity** (truthfulness) is, at its core, respect for people (Gabard and Martin, 2003). Veracity is antithetical to the concept of medical paternalism, which assumes patients need to know only what their healthcare provider chooses to reveal. There has been a dramatic change in attitudes toward veracity because it forms the basis for the autonomy expected by patients today. Informed consent, for example, is the ability to exercise autonomy with knowledge.

Decisions about withholding information involve a conflict between truthfulness and deception. There are times when the legal system and professional ethics agree that deception is legitimate and legal. Therapeutic privilege is invoked when the healthcare team makes the decision to withhold information believed to be detrimental to the patient. Such privilege is by its nature subject to challenge.

## Fidelity

**Fidelity** is loyalty. At the root of fidelity is the importance of keeping a promise, or being true to your word. It speaks to the special relationship developed between patients and their healthcare providers. Each owes the other loyalty; although the greater burden has traditionally been on the healthcare provider, increasingly the patient must assume some of the responsibility (Beauchamp and Childress, 2001). Fidelity often results in a dilemma, because a commitment made to a patient may not result in the best outcome for that patient (Veatch, 2003).

## Ethical Conflicts

Making decisions is part of everyday living. For the most part, these decisions are an automatic and unconscious process. But there are other decisions, particularly those related to professional practice, which are not automatic. We are often confronted with two equally appropriate choices, which Kidder calls a "right vs. right dilemma." When evaluating the alternatives, both courses of action have positive and negative elements. Right vs. right is an ethical dilemma, whereas right vs. wrong is identified as a moral temptation (Kidder, 1996).

All healthcare professions have established ethical decision-making standards that provide guidance in a challenging practice environment. When faced with an ethical dilemma, professional guidelines can help resolve the conflict. The Nuffield Council on Bioethics has published some ethical guidelines for healthcare providers and caregivers working with people who have dementia. When confronted with ethical conflicts:

- Compare your situation with other similar situations to find ethically relevant similarities or differences.
- Understand that dementia is caused by a brain disorder and is harmful to the individual.
- Recognize and promote the separate interests of caregivers.
- Understand that people with dementia are fellow citizens and we have a responsibility to support them, both within families and in society as a whole.
- Remember that people with dementia remain the same, equally valued, person throughout the course of their illness, regardless of the extent of the changes in their mental abilities. (Adapted from the Nuffield Council on Bioethics, 2009)

A practical guide for ethical decision making that is becoming increasingly popular in healthcare is the realm, individual process, situation (RIPS) model (Swisher et al., 2005). The steps in ethical decision making that use the RIPS model are particularly useful for the interdisciplinary team. This method involves four steps:

- Step 1: Recognize and define the ethical issues
- Step 2: Reflect
- Step 3: Decide the right thing to do
- Step 4: Implement, evaluate, reassess (Nordrum, 2009)

As someone with dementia reaches the end of their life, advance directives must guide caregivers and family members as to their wishes. Advance directives are documents that outline the person's wishes and may help caregivers resolve ethical conflicts. Many states in the United States are adopting the Physician's Order for Life Sustaining Treatment (POLST) form; found at <http://www.ohsu.edu/polst/>). This is an attempt to standardize the procedure nationally.

## Ethical Decision-Making Case Examples

### Case 1

Mr. Corona is 82 years old and lives in a cottage on his daughter's property. He was a fighter pilot during World War II and has been a fiercely independent his entire life. He is in the moderate to severe stages of ADRD and is unable to perform IADLs.

Mr. Corona is in clinic for his annual evaluation. He does not know his address, the current date, the season, day, or time. His Mini Mental State Exam (Folstein, Folstein and McHugh, 1975) score is 11/30. When asked what he would do if the house caught on fire, he replied, "I would get some water and put it out."

His three daughters discussed the situation with a social worker and with a nurse practitioner in the neurology clinic. Although Mr. Corona's safety is questionable, his daughters state that he has always been independent and does not like people taking care of him. They decide that for now they will support him living in the cottage.

#### Discussion

In making decisions on Mr. Corona's behalf, his daughters are using the principles of autonomy and beneficence. Mr. Corona's life-long desire to be independent guided their decision to allow him to continue to live alone. They are balancing his need for autonomy with his need for safety and protection. The three sisters decide take turns sleeping at his house overnight and have agreed to stop in during the day. They accept that he is at some risk living alone, but believe that his quality of life will be better in his own home and that living alone is consistent with their father's life philosophy.

### Case 2

Mrs. Grand is 92 years old and has had Alzheimer's disease for fifteen years. She has lived in a nursing home for the past seven years. She has been fed her meals for the past two years but over the last month has intermittently refused food. As a result she has lost 15% of her body weight in the past 6 weeks. She has a POLST form that she completed when she was able to make her own decisions, on which she indicated that she did not want a feeding tube if she was unable to eat on her own. Her son has durable power of attorney to make decisions for her when she is no longer able to do so. He wants her kept alive as long as possible and wants a feeding tube inserted.

#### Discussion

Mrs. Grand's son is acting from what he believes is the best course of action for her; however, he is expressing his opinion and neglecting to consider what his mother would say if she were able. He is not adhering to the principle of autonomy or fidelity. While one might think that he is acting in concert with the principle of beneficence by feeding her, studies show that feeding tubes do not prolong life or improve quality of life in people in the later stages of ADRD (Gillick and Volandes, 2008). At the very latest stages of ADRD, the natural course of the disease causes a person to stop eating and drinking.

## Conclusion

Dementia is a life-threatening degenerative disease. Although people with dementia often exhibit behaviors that are challenging for family and professional caregivers to manage, the behaviors are caused by damage to the brain and are not intentional. Challenging behaviors are often caused by unmet needs and may be a means of communication. By carefully observing what comes directly before and after a behavior, the caregiver may be able to determine the underlying need and learn how to alleviate the challenging behavior.

People with dementia need to be treated with kindness and with the knowledge that they can still enjoy life. Family caregivers play a critical and often-overlooked role in the care of loved ones with dementia—especially in the early to moderate stages. Caregivers often experience stress, which does not abate simply by placing the person with ADRD in a care facility. Caregiver training is an essential component for anyone caring for a person with dementia. Once in a facility, professional caregivers must be trained to view the person with ADRD in the context of a family.

Caregivers—both family and professional—experience many ethical conflicts when caring for a person with dementia. Education and training in ethical decision making and conflict resolution are invaluable tools to improve the experience of those with dementia.

## Resources

### **Alzheimer's Association**

Provides education and information for the public; finances research on Alzheimer's disease and related dementias.

[www.alz.org](http://www.alz.org)

### **Family Caregiver Alliance**

Information and support groups for families and caregivers.

[www.caregiver.org](http://www.caregiver.org)

### **Hartford Institute for Geriatric Nursing**

This site links to numerous resources for nursing staff, including Try This Assessment sheets, How To Try This video series and the American Journal of Nursing articles on geriatric care—A New Look at the Old.

<http://consultgerirn.org/resources>

### **Nuffield Council on Bioethics**

28 Bedford Square

London WC1B 3JS

Copies of the report are available to download from the Council's website:

[www.nuffieldbioethics.org](http://www.nuffieldbioethics.org)

### **Physician's Order for Life-sustaining Treatment (POLST)**

State-by-state information on POLST use

<http://www.ohsu.edu/polst/>

## Caregiver Training and Support Services

### **Alzheimer's Association**

The Alzheimer's Association is the leading, global voluntary health organization in Alzheimer care and support, and the largest private, nonprofit funder of Alzheimer research. They have local chapters, 24-hour helpline, support groups, and many excellent education programs.

<http://www.alz.org/index.asp>

Phone: 800 272-3900

### **AlzOnline: Caregiver Support Online**

AlzOnline is part of the Center for Telehealth and Healthcare Communications at the University of Florida. It provides caregiver education, information, and support for those caring for a family member or friend with Alzheimer's disease or related dementias.

[alzonline.phhp.ufl.edu/](http://alzonline.phhp.ufl.edu/)

### **CJE Senior Life**

CJE Senior Life provides caregivers with educational materials and resources that are applicable to many different caregiving situations. They address the risk of "caregiver burnout," by sharing expertise in dealing with the older adult population.

[www.CareGivingHelp.org](http://www.CareGivingHelp.org)

**Family Caregiver Alliance (FCA)**

FCA provides information, education, services, research, and advocacy for families caring for loved ones with chronic, disabling health conditions. They provide caregiving tips in person and online with resources listed by state.

[www.caregiver.org](http://www.caregiver.org)

**Caregiver's Marketplace**

The Caregiver's Marketplace eases some of the financial burden of caring for an ill, elderly, or disabled family member or friend. They do not sell the products directly. Instead, they offer cash back when you buy eligible products anywhere they are sold. To receive cash back on purchases print a cash-back request form, shop for eligible products, and send in the original receipts with the completed cash-back request form. Once verified, your cash-back check will arrive in the mail within 4 to 6 weeks.

<http://caregiversmarketplace.com/FrameSetup.asp>

Phone: 800 888-0889

E-mail: [contactus@caregiversmarketplace.com](mailto:contactus@caregiversmarketplace.com)

**Family Caregiving 101**

The National Family Caregivers Association (NFCA) and the National Alliance for Caregiving (NAC) are leaders in the movement to better understand and assist family caregivers. These two organizations have joined together to recognize, support, and advise family caregivers.

[www.familycaregiving101.org/index.cfm](http://www.familycaregiving101.org/index.cfm)

**National Council of Certified Dementia Trainers**

The Council was formed to promote standards of excellence in dementia education for professionals and other caregivers who provide services to dementia clients.

[www.nccdp.org/index.htm](http://www.nccdp.org/index.htm)

**Share the Caregiving**

Share the Caregiving is dedicated to educating the caregiving communities about the effectiveness of the Share the Care model. Share the Care encourages ordinary people to pool their efforts to help ease the burden on family caregivers and help those without family nearby.

<http://www.sharethecare.org/index.html>

Phone: 212 991-9688 or 212 991-9689

**Strength for Caring (SFC)**

SFC is a comprehensive website designed to provide family caregivers with a broad range of expert content and information, an emerging on-line community, daily inspiration, and much needed support.

[www.strengthforcaring.com](http://www.strengthforcaring.com)

**Today's Caregiver**

Caregiver Media Group provides information, support, and guidance for family and professional caregivers. It publishes Today's Caregiver magazine, the first national magazine dedicated to caregivers, the "Fearless Caregiver Conferences", and a website that includes newsletters, online discussion lists, articles from Today's Caregiver magazine, chat rooms, and an online store.

[www.Caregiver.com](http://www.Caregiver.com)

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## Post Test

Use the Answer Sheet following the test to record your answers.

1. Dementia changes:
  - a. A small portion of the brain.
  - b. The entire brain.
  - c. The right side of the brain.
  - d. The left side of the brain.
2. The Alzheimer's disease process:
  - a. Causes swelling of the affected part of the brain.
  - b. Produces an excess of brain cells, similar to cancer.
  - c. Smooths out the wrinkles on the brain's surface.
  - d. Replaces dead brain cells with plaques and tangles.
3. The area of the brain most affected by Alzheimer's is the:
  - a. Hippocampus.
  - b. Cerebral cortex.
  - c. Cerebellum.
  - d. Brainstem.
4. Most people with dementia have:
  - a. "Pure" Alzheimer's disease.
  - b. "Pure" vascular dementia.
  - c. A mixture of two or more types of dementia.
  - d. Alzheimer's disease and Lewy Bodies.
5. Dementia is different from normal aging in that:
  - a. Sometimes the person gets lost when driving in a new city.
  - b. There is less interest in community activities.
  - c. The person has lost the ability to think logically.
  - d. Ability to keep track of possessions is diminished.
6. A common reaction of people in the mild stage of dementia is:
  - a. Shrug off others' concerns and go on with their life.
  - b. Immediately give up driving because it could be dangerous.
  - c. Enlist the help of family and friends.
  - d. Begin to plan for a life with diminished abilities.
7. Moderate dementia is evident when:
  - a. Phone calls are brief and uncommunicative.
  - b. The person can no longer manage to live alone without problems.
  - c. Unusually chatty behavior is seen.
  - d. Personal hygiene becomes obsessive.
8. With severe dementia:
  - a. Restraints are often recommended to prevent wandering.
  - b. Patients are unable to walk in most cases.
  - c. Outbursts are rare because of generalized depression.
  - d. Safety becomes a serious concern.

9. Delirium:
  - a. Generally lasts several months.
  - b. Has a sudden onset, a fluctuating course, and can be associated with infections.
  - c. Is usually permanent and leads eventually to death.
  - d. Is experienced with a normal level of consciousness.
10. Depression is characterized by:
  - a. Short-term memory loss and the propensity to get lost in familiar places.
  - b. Permanent damage to the brain tissue.
  - c. Duration of less than one month.
  - d. Distorted or pessimistic thought, sleep disturbance, and inability to concentrate.
11. The key to communicating with those who have ADRD is:
  - a. Introducing new ideas to keep them mentally active.
  - b. Reminding them that you are only trying to help.
  - c. Making short, snappy statements to avoid confusion.
  - d. Speaking slowly and using gentle persuasion.
12. Verbal communication can be stimulated by:
  - a. Singing together.
  - b. Watching a football game on TV.
  - c. Looking at magazines.
  - d. Asking questions about their weekend.
13. When trying to communicate with a person who is nonresponsive:
  - a. Just do your job, communication is not possible.
  - b. Move slowly and calmly—give one choice and wait for an answer.
  - c. Techniques that you used for those in the earlier stages of dementia won't work.
  - d. Make sure the room is full of furniture and other items to orient the person.
14. People with ADRD may engage in difficult behaviors because they:
  - a. Have probably always been difficult people.
  - b. Have unmet needs.
  - c. Have nothing better to do.
  - d. Want to anger relatives and caregivers.
15. The problem-solving (ABC) approach to behaviors in ADRD stands for:
  - a. Approach, behavior, compensate.
  - b. Antecedent, best option, consequence.
  - c. Approach, beware, consequence.
  - d. Antecedent, behavior, consequence.
16. Mrs. Xavier, who has early to moderate ADRD, claims that someone has stolen her purse. The best response would be:
  - a. "Mrs. Xavier, you know you always leave it in your room!"
  - b. "You must be worried! Can I help you look for it?"
  - c. "Don't you remember? You gave it to your daughter for safekeeping."
  - d. "Don't worry about this now. It is time for music."

17. Mrs. Lee pinches and bites her caregivers when they bathe her. The best response to this behavior would be to:
- Ask her family to come in and bathe her.
  - Restrain her and bathe her anyway.
  - Don't bathe her when her behavior is bad.
  - Observe her behavior to determine her needs.
18. Atypical antipsychotic medications are sometimes used to manage the behavioral symptoms of dementia. This is an off-label use, meaning:
- The FDA has not approved them for treatment of BPSD.
  - They are prescription medications.
  - The medications are not effective for behavioral symptoms of dementia.
  - It is against the law to prescribe them for BPSD.
19. The medication Aricept:
- Is primarily used to treat delirium.
  - Can be used to reverse the cognitive symptoms of dementia.
  - Is used to manage the cognitive symptoms of ADRD for a limited period of time.
  - Does not work unless started when dementia is first diagnosed.
20. Activities of daily living (ADL) include:
- Eating, bathing, and dressing.
  - Using the telephone, toileting, and gardening.
  - Using the computer, maintaining financial records.
  - Dressing, climbing stairs, and cooking.
21. Instrumental activities of daily living include:
- Cooking, shopping, and managing medications.
  - Eating, bathing, and dressing.
  - Housework, bathing, and grooming.
  - Transferring from bed to chair and toileting.
22. A person with mild dementia:
- May not appear to be impaired and might continue working or driving.
  - Is likely to show signs of aggressive behavior.
  - Can be recognized by poor balance and abnormal gait.
  - Cannot perform IADLs.
23. In terms of ADLs, signs of moderate dementia can include:
- Losing car keys several times a day.
  - The need for increased assistance with ADLs.
  - Complete dependence on caregivers.
  - Trying to cover up deficits by making up stories.
24. In terms of ADLs, severe dementia can be marked by:
- Getting lost while driving.
  - Loss of one or two ADLs.
  - The need for round-the-clock care.
  - A sudden reversal of symptoms.

25. When a resident has moderate dementia, the best way to assist with personal grooming is to:
- Give the resident something else to do as a distraction.
  - Do it quickly so that the person does not have time to fight back.
  - Do not allow the resident to assist because it will prolong the task.
  - Make the tools available, encourage participation, and allow simple choices.
26. When assisting a person with mild ADRD to dress, the best action would be to:
- Choose the clothes for the person to avoid confusion.
  - Tell the person to go get their clothes.
  - Encourage the resident to choose their own clothes but assist as needed.
  - Make sure the person is dressed neatly in matching clothing.
27. Johann has moderate dementia and you are going to assist him with grooming. Your best approach would be to:
- Take control and direct his actions to save time.
  - Give detailed instructions and see how much he can do unassisted.
  - Write the instructions out or create drawings of each step.
  - Supervise the activity and offer limited choices.
28. Kalinda has moderate ADRD. She eats about a fourth of her breakfast and then stops. The best action is to:
- Hold her hands down and start feeding her.
  - Offer her more food and assist as needed.
  - Take the food away—she is probably full.
  - Threaten to put her back to bed if she doesn't finish her meal.
29. Bathing difficulties can be managed by:
- Proceeding with bathing as scheduled but explaining every step as you perform it.
  - Changing the bathing time so the resident doesn't get anxious.
  - Enlisting the assistance of a co-worker.
  - Engaging the resident, allowing choices, and keeping the person comfortable.
30. Mrs. Anuncio is in the moderate stage of ADRD and is incontinent of urine. The best initial intervention is to:
- Show her where the bathroom is and remind her to use it regularly.
  - Take her to the toilet every 2 hours.
  - Use a diaper or an adult brief and encourage her to urinate in the diaper.
  - Remind her frequently to use the bathroom as soon as she feels the urge.
31. Mr. Spando, who has mild to moderate dementia, sits in his room all day and is reluctant to participate in group activities. The best way to get him involved is:
- Interview him about his past experiences, hobbies, and interests.
  - Let him be—he probably doesn't like to participate in groups.
  - Create activities that men enjoy.
  - Tell him he must come to activities.
32. A person who is in the moderate to severe stages of dementia might enjoy:
- Listening to music that was popular when he or she was young.
  - Learning how to knit.
  - Reading books and discussing them with other residents.
  - Doing crossword puzzles if they enjoyed them earlier in life.

33. Wanda has been caring for her husband, who has ADRD, for six years in their home. Wanda formerly played bridge at the local senior center and volunteered at a local hospital. Over the past months her friends have noticed that they see her less and less. The most appropriate action for friends and family members to take would be:
- Call her and tell her how disappointed you are that she has let her activities go.
  - Realize that the caregiver is often as isolated as the person with ADRD. Offer to care for her husband so that she can get out of the house.
  - Invite her to a social activity.
  - Let her know that they miss her and recommend that she find an adult daycare program for her husband.
34. The need-driven, dementia-compromised behavior model is a theory developed to explain:
- The etiology of dementia.
  - Why people with ADRD exhibit certain behaviors.
  - Why caregiving is so stressful.
  - The differences among the types of dementia.
35. The principle of beneficence is:
- The intention to do good.
  - Never used to make ethical decisions.
  - Not really applicable to people with ADRD.
  - Difficult to apply to ethical situations.
36. In the study of ethics, justice means:
- The decision is made by the court.
  - Being just, impartial, or fair; it is the principle of right action.
  - That in an ethical dilemma, one answer is correct.
  - Balancing right and wrong.

(Answer sheet follows on next page)

## Answer Sheet

### Alzheimer's Disease and Related Dementias, 5 units

Name (Please print your name): \_\_\_\_\_

Date: \_\_\_\_\_

Passing score is 80%

- |           |           |
|-----------|-----------|
| 1. _____  | 27. _____ |
| 2. _____  | 28. _____ |
| 3. _____  | 29. _____ |
| 4. _____  | 30. _____ |
| 5. _____  | 31. _____ |
| 6. _____  | 32. _____ |
| 7. _____  | 33. _____ |
| 8. _____  | 34. _____ |
| 9. _____  | 35. _____ |
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| 22. _____ |           |
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| 25. _____ |           |
| 26. _____ |           |

(continued on next page)

## Course Evaluation

Please use this scale for your course evaluation. Items with asterisks (\*) are required.

5 = Strongly agree

4 = Agree

3 = Neutral

2 = Disagree

1 = Strongly disagree

- \*1. Upon completion of the course, I was able to:
- a. Describe the characteristics of ADRD and how it progresses.  
 5    4    3    2    1
  - b. Differentiate Alzheimer's disease from other related dementias.  
 5    4    3    2    1
  - c. Outline effective strategies for communicating with residents who have ADRD.  
 5    4    3    2    1
  - d. Identify strategies for the management of the challenging behaviors associated with ADRD.  
 5    4    3    2    1
  - e. Describe the difference between physical and chemical restraints.  
 5    4    3    2    1
  - f. Outline strategies for assisting with activities of daily living at the various stages of dementia.  
 5    4    3    2    1
  - g. Relate strategies for stress management for caregivers.  
 5    4    3    2    1
  - h. Describe how to create a therapeutic environment for those with ADRD.  
 5    4    3    2    1
  - i. Identify common ethical conflicts that may arise when caring for residents with ADRD.  
 5    4    3    2    1
- \*2. The course was written in a way that facilitated my learning.  
 5    4    3    2    1
- \*3. This course was free from commercial bias.  
 5    4    3    2    1

- \*4. The course met my continuing education needs.  
 5  4  3  2  1
- \*5. The material presented was supported by evidence.  
 5  4  3  2  1
- \*6. The author avoided the use of anecdotal information as the main source of material.  
 5  4  3  2  1
- \*7. The course was free of product promotion.  
 Yes  No\*\*  
 \*\* If you answered no, please answer #8.
8. Was product promotion the sole purpose of the presentation?  
 Yes  No\*\*
- \*9. It took me 60 minutes per contact hour to complete the course, test, and evaluation.  
 Yes  No\*\*  
 \*\* If your answer was no, how long did it take?  
 \_\_\_\_\_

10. My professional educational level is (check one):

**Nursing**

- Nurse Aide  LVN/LPN  RN (diploma)  RN (AD)  
 BSN  MSN  Nurse Practitioner/Advanced Practice Nurse  
 PhD/DNSc

**Therapy**

- OT Aide  COTA  OT  MOT  OTD  
 PT Aide  PTA  PT  MPT  MSPT  DPT  PhD

**Other** (please specify): \_\_\_\_\_

11. I heard about ATrain Education from:

- Search engine  Advertisement  
 Government or Board website  Returning customer  
 Friend  Publication (Magazine, etc.)  
 Other \_\_\_\_\_

12. I found the ATrainCEU.com website easy to use:

- Yes       No

13. Comments or suggestions (optional): \_\_\_\_\_

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(Registration on next page)

## Registration Information

Please answer all of the following questions (\*required).

\* Name: \_\_\_\_\_

\* Address: \_\_\_\_\_

\* City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

\* Phone: \_\_\_\_\_

\* Professional Designation: \_\_\_\_\_

\* License Number and State: \_\_\_\_\_

Please email my certificate:  Yes  No

Email (required if you want your certificate sent by email): \_\_\_\_\_

(If you request an email certificate we will **not** send a copy of the certificate by US Mail.)

### Payment Options

You may pay by credit card or by check.

Fill out this section only if you are **paying by credit card**.

5 contact hours: \$29

### Credit card information:

Name \_\_\_\_\_

Address (if different from above): \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Card type:  Visa  MC  American Express  Discover

Card number \_\_\_\_\_ CVS # \_\_\_\_\_

Expiration date \_\_\_\_\_

### Test Completion and Mailing Instructions

1. Complete all forms:

- Answer Sheet
- Evaluation Learning Activity
- Registration Form (this page)

2. If you are **paying by check**, prepare a check for \$29 made out to ATrain Education, Inc.

3. Mail the completed forms and your payment to:

ATrain Education, Inc  
5171 Ridgewood Rd  
Willits, CA 95490

When we receive your forms and payment, we will mail (or email, if you request it) your certificate of completion. If you have any questions or concerns, please call or contact us at Sharon@ATrainCEU.com. And thanks for taking the ATrain!