

Florida: Alzheimer's Disease and Related Dementias, 3 units

3 contact hours: \$29

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Florida DOEA Approval: This 3-hour training program has been approved by the Department of Elder Affairs and is in compliance with 400.1755 FS and rules 58A-4.001 for Nursing Homes, Hospice, and Adult Day Care. Approval number NHAD 448.

Certified Trainers: The authors are certified as ADRD trainers by the Florida Department of Elder Affairs and are available via e-mail or by phone Monday-Friday (Pacific Time) from 9 am to 5 pm at 707 459-1315.

Course Summary: This course provides direct-care staff in nursing homes 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 June 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

See the ATrainCEU Accreditation page at <http://www.ATrainCeu.com/accreditation.php>.

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

- Understand dementia and its diagnosis, how it progresses, and differentiate it from delirium and depression.
- Describe challenging behaviors and their management during the early, middle, and late stages of dementia.
- Define physical and chemical restraints and describe alternatives to their use.
- Spell out strategies for assisting the caregiver with activities of daily living (ADLs).
- Describe the types of individual and group activities for people with dementia.
- Discuss strategies for assisting the caregiver in managing the stress associated with caregiving.
- Describe the impact of ADRD on family members, including the grief process, caregiver training, and dementia care programs.
- Relate the importance of creating a therapeutic environment that is safe, secure, and supportive 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 discuss the stages of dementia, behaviors associated with dementia, caregiver and family issues, and ethical conflicts that 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 it is easy to recognize the common characteristics of ADRD. In a busy nursing home, adult daycare center, hospice, or home setting, the ongoing challenge is how to create a safe environment that respects the independence and dignity of the person with dementia. On a practical level, the daily challenge for caregivers is what to do when people with ADRD act out, put themselves in danger, pose a threat, try to escape from the facility or home, are no longer able to walk, or engage in a host of other difficult behaviors.

To be successful working with people who have 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. Often you must do this with an inexperienced staff and inadequate resources. You must be able 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 hospice, 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.

Dementia and Its Diagnosis

Dementia is a **disease syndrome** characterized by progressive, global deterioration of the brain's executive functions. It is caused by the formation of abnormal proteins called **amyloid plaques** and **neurofibrillary tangles** and the gradual loss of neurons and atrophy of certain regions of the brain. Plaques are deposits of mostly insoluble protein fragments called beta-amyloid that collect in the spaces outside and around the nerve cells. Tangles are insoluble twisted fibers of "tau" proteins that build up inside the nerve cell.

There are several risk factors that are known to increase the likelihood of developing ADRD. Advancing age is the greatest risk factor. Alzheimer's disease (AD) develops in about 10% of people over the age of 65 and about 40% of those over the age of 80. AD is responsible for about 50% to 75% of all cases of dementia. Family history is another strong predictor for the development of ADRD. The risk increases if more than one family member had the disease.


Genetics also plays a role in the development of dementia. Specific “risk” genes such as apolipoprotein E-e4 (APOE-e4) may be a factor in 20% to 25% of Alzheimer cases. Inheriting the APOE-e4 gene from one or both parents increases the risk of developing Alzheimer’s disease but such an outcome is not a certainty (Alzheimer’s Association, 2011).

“Deterministic” genes, unlike risk genes, directly cause Alzheimer’s disease. This is sometimes referred to as **familial Alzheimer’s disease** and is responsible for less than 5% of cases. Familial AD usually occurs before the age of 60 and can begin to develop as much as 2 to 3 decades earlier than that (Alzheimer’s Association, 2011).

Other risk factors for the development of ADRD include head trauma, high blood pressure, heart disease, diabetes, and high cholesterol.

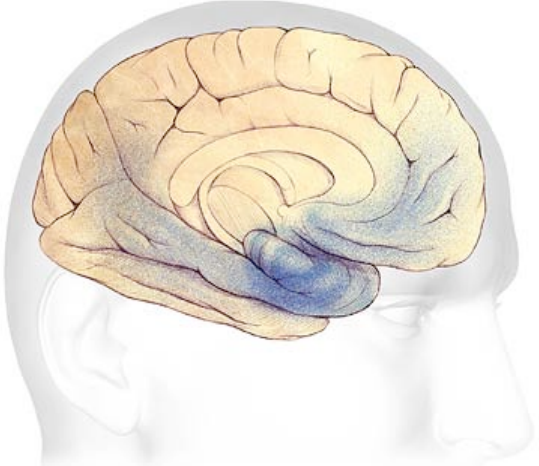
Damage typically begins in an area of the brain called the hippocampus, which is responsible for the formation of new memories. In fairly rapid succession, plaques and tangles spread forward to the temporal and frontal lobes, affecting language, judgment, learning, comprehension, orientation, and emotions. Although almost everyone with ADRD is elderly, ADRD 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.

Brain Changes in Mild Alzheimer’s Disease

	<p>In the earliest stages of Alzheimer’s disease, before symptoms can be detected, plaques and tangles (shaded in blue) form in the hippocampus, which is the area of the brain involved in:</p> <ul style="list-style-type: none"> • Learning new tasks • Short term memory • Thinking and planning
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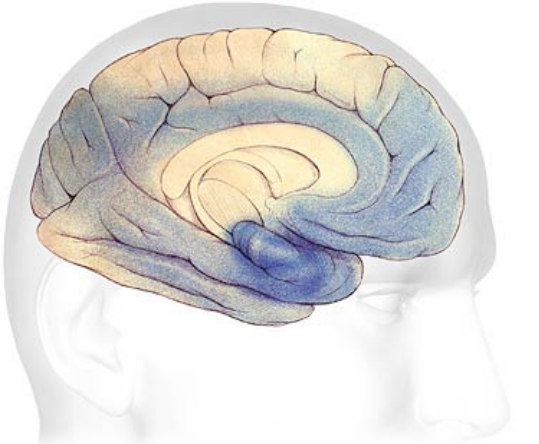
Source: Courtesy of The Alzheimer’s Association. Used with permission.

Brain Changes in Moderate Alzheimer's Disease

	<p>In mild to moderate stages, plaques and tangles (shaded in blue) 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:</p> <ul style="list-style-type: none"> • Speaking and understanding speech • The sense of where your body is in space • Executive functions such as planning, ethical thinking, judgment
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Source: Courtesy of The Alzheimer's Association. Used with permission.

Brain Changes in Severe Dementia

	<p>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.</p>
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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.

Although it accounts for the largest percentage of dementia cases, Alzheimer's disease isn't the only type of dementia. Frontal-temporal dementia—which affects mainly the frontal lobe of the brain—is the most common type of dementia in those under the age of 60. Vascular dementia and Lewy Body dementia are other common types of dementia (see table).

Types of Dementia

Types of Dementia			
Dementia subtype	Early, characteristic symptoms	Neuropathology	Proportion of dementia cases
*Alzheimer's disease (AD)	<ul style="list-style-type: none"> • Impaired memory, apathy and depression • Gradual onset • Language and visuospatial deficits 	<ul style="list-style-type: none"> • Cortical amyloid plaques • Neurofibrillary tangles 	50%–75%
*Vascular dementia (VaD)	<ul style="list-style-type: none"> • Similar to AD, but memory less affected, and mood fluctuations more prominent • Physical frailty • Stepwise onset • Patchy cognitive impairment • Often preventable 	<ul style="list-style-type: none"> • Cerebrovascular disease • Single infarcts in critical regions, or more diffuse multi-infarct disease • Group of syndromes 	20%–30%
Frontotemporal dementia (FTD)	<ul style="list-style-type: none"> • Behavioral and personality changes • Mood changes • Disinhibition • Language difficulties 	<ul style="list-style-type: none"> • No single pathology: damage limited to frontal and temporal lobes • Early onset (45 to 60 yrs of age) 	5%–10%
Dementia with Lewy Bodies (DLB)	<ul style="list-style-type: none"> • Marked fluctuation in cognitive ability • Visual hallucinations • Parkinsonism (tremor and rigidity) • Adverse reactions to antipsychotic medications 	Cortical Lewy bodies (alpha-synuclein)	<5%

*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.

The frequencies of the various dementia types are increasingly open to debate and the borders between the different types are not distinct. 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’s disease) are often misdiagnosed 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).

Diagnosis

ADRD is typically diagnosed by a neurologist, a psychiatrist, or a practitioner familiar with ADRD. Although a definitive diagnosis cannot be made until after death, a comprehensive evaluation using the process of elimination can be accurate. Assessment should include a review of the patient’s medical history, family history, medications, psychosocial history, a mental status test (such as the mini-mental state exam), and a physical exam, which should include a neurologic exam. Family members can be included to provide information about family history and information about changes in the patient’s behavior and symptoms.

Neuropsychological testing is used to assess conditions that affect thinking, emotion, and behavior. It involves a comprehensive interview that evaluates memory, language, emotional stability, planning and reasoning, and the ability to modify behavior.

Structural brain imaging technologies such as magnetic resonance imaging (MRI) and computed tomography (CT) can provide information about the size and shape of the brain and can identify brain atrophy. They are also used to rule out other causes of dementia such as tumors or stroke.

Functional brain imaging techniques such as positron emission tomography (PET) and functional MRI (fMRI) can show how well neurons are functioning by monitoring oxygen or sugar uptake in the cell. PET can help differentiate AD from other types of dementia by pinpointing differences in brain activity in various parts of the brain.

Differentiating Dementia from Other Conditions

There are a number of medical conditions with symptoms that mimic those of ADRD and must be considered when evaluating someone with 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 can be mistaken for dementia and healthcare providers and caregivers should learn to distinguish the differences.

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 was living at home with his wife, was independent in all of his ADLs, and drives a car. The day after surgery he woke up in the morning, removed his IV, got out of bed, and declared he is 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 ADRD as people become 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

Comparing Dementia, Delirium, and Depression			
	Delirium	Depression	Dementia
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.

Part I: 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 address the causes and consequences of the behavior successfully. 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 occur in other types of dementia also and some may differ depending on the type of dementia.

Individual Characteristics and Environmental Triggers

A 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:

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

Environmental Triggers

Environmental triggers are those things within the environment that may drive or cause a 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:

1. Physiologic need (such as hunger, pain, or fear)
2. Psychosocial needs (such as contact with family)
3. Environmental issues (such as a cold room or an uncomfortable chair)
4. 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 offers 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 & 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 (complaining, vocal outbursts) (Pelletier & 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, over-stimulated, or tired? What is the environment like? Is it cold, hot, noisy, or crowded? Does the agitation happen at a certain time of day? Has the person been sitting for hours without changing position? Is the person incontinent and sitting on a wet cushion? Are other people screaming and thus triggering 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.

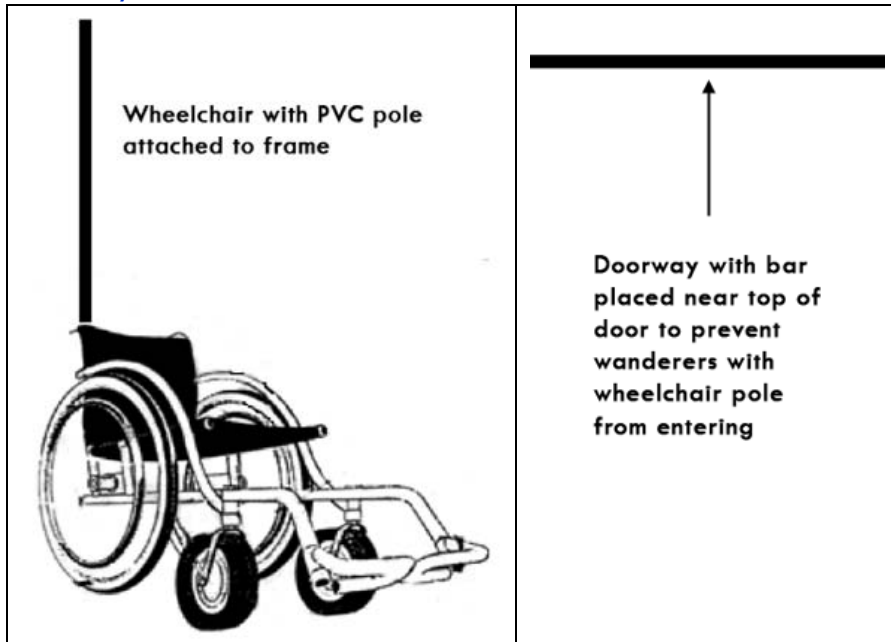
Wandering generally falls into two categories: **goal-directed**, in which residents attempt to reach an unobtainable goal (such as going home or to the store), and **non-goal-directed**, in which the resident wanders aimlessly. Wandering patterns vary and can include moving to a specific location, lapping 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, over-medicating, 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

Doorway Bar to Restrict Wheelchair Entrance



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

Florida Silver Alert

In 2008 Florida enacted a Silver Alert program, which allows the immediate broadcast of information to the public regarding missing elders with dementia or other cognitive impairment. It provides a quick and coordinated response between local and state law enforcement to broadcast important information to citizens so they can assist local law enforcement in the rescue of the endangered person and notify law enforcement with helpful information. For more information, contact the Florida Department of Law Enforcement online or by phone at 888 356-4774.

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. They maintain 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 drawer of items that the person with ADRD can pick through is a good way to redirect the behavior.

In a home setting (and even in 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. People suffering from delusions and paranoia are suspicious and experience false beliefs about caregivers or friends; they may feel 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, it is 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 relaxing music
- Cover mirrors
- Reduce glare from windows
- Ensure adequate lighting

Test your knowledge. . .

Mr. Klatu 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, 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 & McCurry, 2009), partly due to the degeneration of neurons in the part of the brain that controls circadian rhythms.

There are a number of factors besides the effects of dementia that contribute to sleep disturbances. Sleep apnea, restless leg 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 & 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. There is limited evidence to support their long-term safety in cognitively impaired older adults (Deschenes & McCurry, 2009).

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

- Light therapy (Deschenes & McCurry, 2009)
 - 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 of 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

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 dietary needs and food preferences should be considered but 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. 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 the disruption of a regular routine and the potential introduction of 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.

Edinburgh Feeding Evaluation in Dementia Questionnaire (EdFED-Q)	
Question Score answers to questions 1–10: never (0), sometimes (1), often (2)	Score
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 his head away while being fed?	
7. Does the patient refuse to open his mouth?	
8. Does the patient spit out his food?	
9. Does the patient leave his mouth open, allowing food to drop out?	
10. Does the patient refuse to swallow?	
Total Score (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 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 at <http://consultgerirn.org/resources>. 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 caused each person to behave as they did. 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?

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 towards 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 elevator. 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 ride in a car.

Case Two

Mr. Kumar lives in a board-and-care facility and was recently hospitalized for a minor surgical procedure. When he was discharged from the hospital he was transferred to a subacute rehab 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 cat where he lives and is worried about his cat.

Behavior: Mr. Kumar gets out of bed again and again, saying “I have to go home,” but he 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 to 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 her 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 butt hanging out 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 shower room, but as she turns on the shower, Mrs. Lee screams and pushes the nursing assistant away. She grabs the shower hose and sprays water all over the caregiver and into the hallway.

Consequence: The resident, staff, and the patient's daughter are all upset. The situation 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 feed back 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 half-naked down the hall. 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.

Alternatives to 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; and
- Frequently re-evaluated 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. Florida has a detailed Nursing Home Bill of Rights intended to protect residents' physical and mental well-being. The bill of rights states that a nursing home resident has:

The right to be free from mental and physical abuse, corporal punishment, extended involuntary seclusion, and from physical and chemical restraints, except those restraints authorized in writing by a physician for a specified and limited period of time or as are necessitated by an emergency. In case of an emergency, restraint may be applied only by a qualified licensed nurse who shall set forth in writing the circumstances requiring the use of restraint, and, in the case of use of a chemical restraint, a physician shall be consulted immediately thereafter. Restraints may not be used in lieu of staff supervision or merely for staff convenience, for punishment, or for reasons other than resident protection or safety (Florida Statutes, 2010).

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 reports that use of physical restraints is down to about 5% overall in the United States (Agens, 2010). A key concern of 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 PT 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 I.D. 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 intergenerational 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. They 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 always 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 five years. A controlled 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, when chemical restraints are used to subdue a patient (often as antipsychotic medications) they 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, 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 Rehab. 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 typical and atypical antipsychotics.

Medications used to treat the cognitive effects of dementia also have only a modest effect. The most commonly prescribed drugs in this category are anticholinesterase 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 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 by Food and Drug Administration (FDA) in the 1990s exclusively for the treatment of schizophrenia. 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 elders treated for dementia-related psychosis (FDA, 2009).

Because of safety considerations associated with antipsychotic medications, non-pharmacological 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 three months) and among those patients who manifest severe symptoms that may cause extreme distress and harm to themselves 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 ability to maintain a person's ability to perform daily activities and sometimes can also dampen the behavioral and psychological symptoms (although this is an off-label use).

Anticholinesterase inhibitors slow the breakdown of acetylcholine, allowing it to stay around 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.

Part II: 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 and 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), comprise 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

Symptoms, Stages, and Behavioral Symptoms

There is often no clear demarcation between the stages of ADRD, although one important consideration is that caregiver responsibilities increase and independence with ADLs decreases as dementia progresses.

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, notably 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.

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 pretty good and, if so, safety becomes a real concern for caregivers. The person may start to wander and no longer be 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 ADLs 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).

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:

- Early dementia
- Moderate dementia
- Severe dementia
- Delirium

Correct answer: A

Strategies for 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.

ADL Strategies During Stages of Dementia

When assisting someone with dressing, grooming, eating, bathing, and toileting, certain strategies will help you to complete these tasks successfully. 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"> • Generally stand-by assist. • Encourage residents to choose their own clothes. • Allow residents to do what they can even if it takes longer. • Assist as needed but allow the resident to direct the activity.
Moderate	<ul style="list-style-type: none"> • Generally moderate or close hands-on assist. • Provide comfortable, clean clothes with elastic waistbands and Velcro closures. • Select some clothes ahead of time and set them out. • Ask residents to participate in the choice of clothing. • Assist as needed but allow residents to do all they can by themselves.
Severe	<ul style="list-style-type: none"> • Generally maximum or total assist. • Select clothes and set them out, limit choices. • Choose comfortable clothing that is easy to wash. • Assist closely but encourage as much independence as possible. • Use simple, one-step commands and gestures.

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

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

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

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

Part III: Activities for Residents with AD

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 *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 who are working alone.

Appropriate Individual Activities for People Who Have ADRD			
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 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, decorating 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, eat 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.

Part IV: Stress Management for the Caregiver

A **caregiver** is someone who provides assistance to a person in need. It may be physical, financial, or emotional assistance. Caregivers can help with basic ADLs such as bathing, dressing, walking, and 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 can 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).

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. In low- and middle-income countries, while being part of a large household slightly relieved the strain on the main caregiver, traditional extended-family care networks provided little protection. Factors consistently 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"> • Female caregiver • Spousal caregivers, particularly those of younger people with dementia • Living with the care recipient • Low incomes or financial strain
Caregiver personality	<ul style="list-style-type: none"> • High level of neuroticism • High expressed emotion
Perception and experience of caregiving role	<ul style="list-style-type: none"> • A low sense of confidence by the caregiver in their role • High “role captivity”—caregivers feeling trapped in their role
Coping strategies	<ul style="list-style-type: none"> • Emotion-based or confrontive coping strategies • Dementia type • Frontotemporal dementia (FTD) • Severity of dementia • Behavioral and psychological symptoms of dementia present—particularly apathy, irritability, anxiety, depression, delusional beliefs • Cognitive impairment is not usually associated with caregiver strain
Relationship factors	<ul style="list-style-type: none"> • Intimacy—poor relationship quality • Low levels of past and current intimacy

Source: Adapted with permission from ADI, 2009.

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 regularly 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.

Part V: 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).

Early, Middle, and Late Stages

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, the caregiver is confronted with the gradual loss of companionship. If it is a parent, an adult child will gradually have to take over the care of the 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. 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 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. These may include:

- Loss of physical strength and abilities
- Increased confusion
- Loss of income and savings
- Loss of health insurance
- Changes in housing and 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 multidepartmental programs designed to meet the daily individual needs of residents. 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 [FiveStar Senior Living](#). In Florida this program is in effect at The Palms of Fort Myers (239 275 7800).

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. The next two sections list local, state, and national organizations that provide support for families and caregivers.

Local Community Resources

The Alzheimer's Project, Tallahassee (APT)

The APT is a non-profit organization located in Tallahassee. It provides comfort, support, and assistance to persons with memory disorders and their caregivers. APT serves the Big Bend community of Florida through education and training, in-home respite, support groups, counseling, referral to community resources, and proactive recovery of wanderers through the Project Lifesaver program. All services are free of charge.

- <http://www.alzheimersproject.org/>
- Phone: 850 386 2778

Area Agency on Aging for North Florida

The Area Agency on Aging for North Florida serves as the designated Aging Resource Center for the Panhandle and Big Bend areas. Consumers, families and caregivers can access the Aging Resource Center in their community by calling the Elder Helpline.

- Phone: 800 963 5337

Florida Adult Day Services Association (FADSA)

Since its inception in 1983, FADSA has provided leadership, education, planning, and development of adult day services across Florida. FADSA promotes quality day services, respite programs, adult day health centers, and education, training, and advocacy within the long-term care industry.

- <http://www.fadca.net/HomePage.html>
- Phone: 877 342 3858

Florida Council on Aging

The Florida Council on Aging serves Florida's diverse aging interests through education, information-sharing, and advocacy. Founded in 1955, it is Florida's only statewide association representing virtually all aging interests and disciplines.

- <http://www.fcoa.org/>
- Phone: 850 222 8877

Florida Department of Elder Affairs (FDEA)

The FDEA website contains a comprehensive listing of Alzheimer's and dementia care resources throughout Florida. This includes memory disorder clinics, model daycare, the Alzheimer's Rural Care Healthline, Respite Services for Caregiver Relief, and links to Alzheimer's disease information.

- <http://elderaffairs.state.fl.us/english/alz.php>
- Phone: 850 414 2000
- Email: information@elderaffairs.org

Florida Hospices and Palliative Care (FHPC)

FHPC is a not-for-profit organization representing Florida's hospice programs. Its mission is to ensure excellence and access to hospice care, and it advocates for the needs of those in the final phases of life.

- <http://www.floridahospices.org/>
- Phone: 850 878 2632

Florida Telecommunications Relay (FTRI)

FTRI is a statewide non-profit organization that administers the Specialized Telecommunications Equipment Distribution Program for citizens of Florida who are deaf, hard of hearing, deaf/blind, and speech impaired. FTRI is also responsible for the education and promotion of the Florida Relay Service.

- <http://www.ftri.org/index.cfm/go/public.view/page/1>

Memory Disorder Clinic at the Tallahassee Memorial Neuroscience Center

A team of memory disorder specialists who provide a comprehensive diagnostic evaluation for persons concerned about memory problems.

- http://www.tmh.org/neuroscience_content.cfm?id=152
- Phone: 850 431 5001

Caregiver Training and Support Services

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.

- <http://alzonline.php.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

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

Florida Elder Helpline

The Florida Elder Helpline provides information about elder services and activities, which is available through the Elder Helpline Information and Assistance service within each Florida County.

- <http://elderaffairs.state.fl.us/english/elderhelpline.php>
- Phone: 850 414 2000
- Email: Information@elderaffairs.org

Florida Respite Coalition

The Florida Respite Coalition supports caregivers and promotes quality respite care to individuals with special care needs throughout the state.

- <http://www.floridarespite.org/Default.aspx>

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
- Email: 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.

- <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.

- <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.

- <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*, chat rooms, and an online store.

- www.Caregiver.com

Part VI: Maintaining a Therapeutic Environment

Over the past 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 (Campernel & Brummett, 2010).

Philosophy of Care

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 (Campernel & 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. They assert that 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 & Brummett, 2010)

Adapting the Physical Environment

Whatever the situation, the physical environment can be adapted to meet the physiologic and social needs of those with dementia. Campernel and Brummett (2000) 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. (Campernel & Brummett, 2010)

*A Snoezelen room uses light, sound, scents, and music to initiate sensual sensations. 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 *Creating Environments of Support: A Handbook for Dementia Responsive Design*, by Sarah Campernel and William Brummett, 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"> • Paint the inner surfaces of doors so that they are not readily recognizable as an exit. • Place locks where they are not visible. • Use technology such as the Alzheimer Association's Comfort Zone.* • Provide short, looping corridors without dead ends. • Create open, common areas of interest. • Create safe, outdoor wandering areas that are accessible from indoor wandering paths.
Cooking without supervision	Fire, injury	<ul style="list-style-type: none"> • Install a shut-off valve on the stove. • Remove burner on-off handles. • Keep a working fire extinguisher. • Create a work area with an activity kitchen.
Falls	Injury	<ul style="list-style-type: none"> • Examine patient to rule out medical conditions. • Create an uncluttered environment. • Install handrails in showers and hallways. • Install carpeting to reduce injuries in the event of a fall. • Wipe up spills promptly. • Maintain physical activity. • Supervise walking and remind person to use assistive device. • Remove throw rugs. • Maintain good vision and hearing. • Provide many places to sit.
Poisoning	Sickness or death	<ul style="list-style-type: none"> • Remove toxic plants from the environment. • Lock up chemicals and medications.

*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. 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 (i.e., pain, fatigue, illness).

Caregivers are responsible for maintaining a routine schedule but must be flexible and know when to make an adjustment. For example, someone does not want to take a shower on a 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 (673 in Florida). All are required to meet minimum staffing standards to attain or maintain the highest possible physical, mental, and psychosocial wellbeing 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, large 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. Florida has the eighth highest number of beds per nursing facility at 121 beds (Harrington et al., 2010).

It is nevertheless 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 who 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.

Part VII: Ethical Issues

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. Decision-makers must put aside their own needs and desires and carry out what they believe 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. The entire text is available at <http://www.atrainceu.com/Courses.php?CourseID=46&page=0>.]

The language of biomedical ethics is applied across all practice settings, with four basic principles commonly accepted. These principles comprise (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. Such 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 & Saunders, 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** refers to the way 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 & 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 and 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 & 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, that are not automatic. We are often confronted with two equally appropriate choices—what 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, persons throughout the course of their illness, regardless of the extent of the changes in their mental abilities. (Adapted from the Nuffield Council on Bioethics)

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 RIPS model is particularly useful for the interdisciplinary team. It involves four steps (Nordrum, 2009):

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

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

Examples of Ethical Decision-Making

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 & 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 his 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 lifelong 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 15 years. She has lived in a nursing home for the past seven years. She has been fed her meals for 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. A POLST form that she completed when she was able to make her own decisions 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 & Volandes, 2008). At the very latest stages of ADRD, the natural course of the disease is that people 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. 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

<http://www.alz.org>

Family Caregiver Alliance

Information and support groups for families and caregivers.

<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 *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:

<http://www.nuffieldbioethics.org>

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

State-by-state information on POLST use

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

References

- Agens JE. (2010). Chemical and physical restraint use in the older person. *BJMP* 3(1):302. Retrieved December 17, 2010 from <http://www.bjmp.org/content/chemical-and-physical-restraint-use-older-person>.
- Algase DL, Beck C, Kolanowski A, et al. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease and Other Dementias* 11(6):10–19.
- Alzheimer's Association. (2009). 10 Symptoms of Caregiver Stress. Retrieved December 27, 2010 from http://www.alz.org/national/documents/brochure_caregiverstress.pdf.
- Alzheimer's Disease International (ADI). (2009). World Alzheimer Report. Retrieved November 19, 2009 from http://www.alz.org/national/documents/report_full_2009worldalzheimerreport.pdf.
- Amella E, Lawrence J. (2007). *Eating and Feeding Issues in Older Adults with Dementia: Part I: Assessment*. [Electronic Version]
- Barnett J, Behnke S, Rosenthal S, Koocher G. (2005). In case of ethical dilemma, break glass: Commentary on ethical decision making in practice. *Professional Psychology: Research and Practice* 38(1):7–12.
- Beauchamp TL, Childress JF. (2001). *Principles of Biomedical Ethics*, 5th ed., p. 228. New York: Oxford University Press.
- Buhr GT, Kuchibhatla M, and Clipp EC. (2006). Caregivers' Reasons for Nursing Home Placement: Clues for Improving Discussions with Families Prior to the Transition. *The Gerontologist* 46(1):52–61.
- California Advocates for Nursing Home Reform (CANHR). (2011). Dementia Care Checklist. Retrieved January 6, 2011 from http://www.canhr.org/factsheets/rcfe_fs/html/rcfe_dementia_fs.htm.
- Campernel S, Brummett W. (2010). *Creating Environments of Support: A Handbook for Dementia Responsive Design*. Available for \$10 from Alzheimer's Association at http://www.alz.org/co/in_my_community_10010.asp.
- Canadian Patient Safety Institute (CPSI). (2007). Falls in Long-Term Care: Physical Restraints. Retrieved September 20, 2009 from: <http://www.fallsinlrc.ca/physicalrestraints/restraints.htm>.
- Deschenes CL, McCurry SM. (2009, February). Current Treatments for Sleep Disturbances in Individuals with Dementia. *Current Psychiatry* 11(1): 20–26. Retrieved January 7, 2011 from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2649672/>
- Eliopoulos C. (2010) *Gerontological Nursing*, 7th ed. Wolters Kluwer Health. Lippincott, Williams, & Wilkins: Philadelphia.
- Epp TD. (2003). Person-centered Dementia Care: A Vision to be Refined. *The Canadian Alzheimer Disease Review*. Retrieved January 4, 2011 from http://www.stacomcommunications.com/customcomm/Back-issue_pages/AD_Review/adPDFs/april03e/14.pdf.
- Food and Drug Administration (FDA). (2009). Information for Healthcare Professionals: Conventional Antipsychotics. Retrieved December 16, 2010 from <http://www.fda.gov/Drugs/DrugSafety/PostmarketDrugSafetyInformationforPatientsandProviders/ucm124830.htm>.
- Folstein M, Folstein S, McHugh P. (1975). "Mini-Mental State": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* 12:189–98.
- Gabard DL, Martin MW. (2003). *Physical Therapy Ethics*. Philadelphia: F. A. Davis.
- Gillick MR, Volandes AE. (2008). The standard of caring: Why do we still use feeding tubes in patients with advanced dementia? *J Am Med Dir Assoc* 9(5), 364–67.

Harrington C, Carrillo H, Blank BW, O'Brian T. (2010). Nursing Facilities, Staffing, Residents, and Facility Deficiencies, 2004 Through 2009. Retrieved January 19, 2011 from <http://www.theconsumervoice.org/sites/default/files/advocate/action-center/OSCAR-2010.pdf>.

Inouye SK. (2006). Delirium in older persons. *N Engl J Med* 354(11):1157–65.

Illinois Foundation for Quality Health Care (IFQHC). (2006). Alternatives to Physical Restraints. Retrieved September 20, 2009 from http://www.ifqhc.org/provider/documents/alternatives_to_physical_restraints.pdf.

Kaiser Permanente Care Management Institute. (2006). Depression: Clinical Practice Guidelines. Oakland, CA: Author.

Kidder RM. (1996). How Good People Make Tough Choices: Resolving the Dilemmas of Ethical Living. New York: Wm. Morrow.

Kirsch NR. (2010). California: Ethical Decisions in Physical Therapy. Retrieved January 14, 2011 from <http://www.atrainceu.com/Courses.php?CourseID=46&page=0>.

Leperoti R, Pedone C, Corsonello A. (2008, June). Antipsychotics for the Treatment of Behavioral and Psychological Symptoms of Dementia (BPSD). *Curr Neuropsychol* 6(2): 117–24. Retrieved December 17, 2010 from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2647149>.

Mace NL, Rabins PV. (2006). The 36-Hour Day, 4th ed. Johns Hopkins University Press: Baltimore.

Manly DT, Oakley SP Jr, Bloch RM. (2000). Electroconvulsive therapy in old-old patients. *Am J Geriatr Psychiatry* 8(3):232–36.

Morrison RS, Magaziner J, Gilbert M, et al. (2003). Relationship between pain and opioid analgesics on the development of delirium following hip fracture. *J Gerontol A Biol Sci Med Sci* 58(1), 76–81.

Nordrum J. (2009). Personal communication, PT, Mayo Clinic, Rochester, MN.

Nuffield Council on Bioethics (NCB). (2009). Dementia: Ethical Issues. Retrieved November 22, 2009 from <http://www.nuffieldbioethics.org/dementia>.

Omelan C. (2006). Approach to managing behavioural disturbances in dementia. Retrieved December 8, 2010 from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1479717/>.

Pelletier IC, Landreville P. (2007). Discomfort and agitation in older adults with dementia. *BMC Geriatrics* 7:27. Retrieved December 20, 2010 from <http://www.biomedcentral.com/1471-2318/7/27>.

Phipps E, True G, Harris D, et al. (2003). Approaching the end of life: Attitudes, preferences, and behaviors of African-American and white patients and their family caregivers. *J Clin Oncol* 21(3):549–54.

Smith M, Buckwalter K. (2005). Behaviors associated with dementia. *American Journal of Nursing* 105(7):40–52.

Stokowski L. (2007) Alternatives to restraint and seclusion in mental health settings, *Medscape Nurses*. Retrieved from <http://www.medscape.com/viewarticle/555686>

Stotts N, Deitrich C, Eds. (2004–2006). A New Look at the Old. *American Journal of Nursing*.

The 2010 Florida Statutes. (2010). Nursing Home and Related Healthcare Facilities. *Residents' Rights*. Retrieved December 16, 2010 from http://www.leg.state.fl.us/statutes/index.cfm?App_mode=Display_Statute&Search_String=&URL=0400-0499/0400/Sections/0400.022.html.

Thornton M, Travis SS. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. *The Journal of Gerontology, Series B, Psychological Sciences and Social Sciences*, 58(2):S129.

Valente SM, Saunders JM. (2000). Oncology nurses' difficulties with suicide. *Med Law* 19(4): 793–814.

Veatch RM. (2003). *The Basics of Bioethics*. Upper Saddle River, NJ: Prentice-Hall.

Verbeek H, van Rossum E, Zwakhalen SMG, et al. (2009). The effects of small-scale, homelike facilities for older people with dementia on residents, family caregivers, and staff: Design of a longitudinal, quasi-experimental study. *BMC Geriatr* 9: 3. Retrieved January 19, 2011 from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2637879/>.

Verbeek H, Zwakhalen SMG, van Rossum E, et. al. (2010). Small-scale, homelike facilities versus regular psychogeriatric nursing home wards: A cross-sectional study into residents' characteristics. *BMC Health Services Research* 10:30. Retrieved January 5, 2011 from <http://www.biomedcentral.com/1472-6963/10/30>.

Watson R, MacDonald J, McReady T. (2001). The Edinburgh Feeding Evaluation in Dementia Scale #2 (EdFED #2): Inter- and intra-rater reliability. *Clinical Effectiveness in Nursing* 5(4), 184–86. Retrieved December 20, 2010 from http://consultgerirn.org/uploads/File/trythis/try_this_d11_1.pdf.

Post Test

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

1. 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.
2. 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 to eventual death.
 - d. Is characterized by a normal level of consciousness.
3. People with ADRD may engage in difficult behaviors because they:
 - a. Have been difficult people all their lives.
 - b. Are expressing unmet needs.
 - c. Have nothing better to do.
 - d. Are unhappy and want to anger relatives and caregivers.
4. 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. "That's terrible! 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."
5. People with dementia refuse food or fluids for all of the following reasons except:
 - a. Their appetite may be adversely affected by medications, oral problems, or confusion.
 - b. A neurological problem such as apraxia may affect their ability to understand how to use a utensil.
 - c. They might not like the food.
 - d. They are purposely trying to starve themselves.
6. In Florida, it is legal to use a restraint in which of the following situations?
 - a. For a specified and limited period of time or as are necessitated by an emergency.
 - b. When there is not enough staff to safely supervise a patient.
 - c. When staff are too busy to attend to the patient.
 - d. As a "time out" to address a challenging behavior.
7. Atypical antipsychotic medications are sometimes used to manage the behavioral symptoms of dementia. This is an off-label use, meaning:
 - a. The FDA has **not** approved them for treatment of BPSD.
 - b. They are prescription medications.
 - c. The medications are not effective for behavioral symptoms of dementia.
 - d. It is against the law to prescribe them for BPSD.

8. Activities of daily living (ADL) include:
 - a. Eating, bathing, and dressing.
 - b. Using the telephone, toileting, and gardening.
 - c. Using the computer, maintaining financial records.
 - d. Dressing, climbing stairs, and cooking.
9. In terms of ADLs, severe dementia can be marked by:
 - a. Getting lost while driving.
 - b. Loss of one or two ADLs.
 - c. The need for round-the-clock care.
 - d. A sudden reversal of symptoms.
10. Kalinda has moderate ADRD. She eats about a quarter of her breakfast and then stops. The best action is to:
 - a. Hold her hands down and start feeding her.
 - b. Offer her more food and assist as needed.
 - c. Take the food away—she is probably full.
 - d. Threaten to put her back to bed if she doesn't finish her meal.
11. 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:
 - a. Interview him about his experiences, hobbies, and interests.
 - b. Let him be—he probably doesn't like to participate in groups.
 - c. Create activities that men enjoy.
 - d. Tell him he must come to activities.
12. Caregivers can reduce the stress of caring for a person with ADRD by:
 - a. Getting enough training to have all the answers.
 - b. Staying away from other people who are in a similar caregiving situation.
 - c. Setting limits on caregiving time and responsibilities.
 - d. Understanding the stress will end when their loved one dies.
13. In the middle to late stage of dementia a family caregiver may decide to place their loved one in a nursing facility for a number of reasons. These may include the need for more skilled care, the caregivers' health, or the need for more assistance.
 - a. True
 - b. False
14. Person-centered care is:
 - a. A philosophical approach to dementia care that focuses on healthcare worker satisfaction.
 - b. A philosophy of care in which dementia is considered to be a biomedical problem and care is task-driven.
 - c. Encourages caregivers to use on chemical and physical control techniques to assure patient safety.
 - d. The belief that those with dementia deserve kind and supportive treatment with the rights that we reserve for any other individual.

15. In dementia care, the concept of “staff as part of the environment” means:
- Staff members are de-emphasized or even camouflaged to avoid upsetting the residents.
 - Staff members remain as much as possible at centralized nursing stations.
 - Residents are cared for by a small, fixed team of professional caregivers who are part of the household.
 - Every effort is made to keep staff members out of the residents' environment.
16. In the study of ethics, justice means:
- The decision is made by the court.
 - Being just, impartial, or fair; 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

Florida: Alzheimer's Disease and Related Dementias, 3 units

Name (Please print your name): _____

Date: _____

Passing score is 80%

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____
11. _____
12. _____
13. _____
14. _____
15. _____
16. _____

(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 how ADRD progresses, including its causes, symptoms, behaviors, and the challenges associated with each stage.
 5 4 3 2 1
 - b. Differentiate dementia from delirium and depression.
 5 4 3 2 1
 - c. Identify behaviors common to residents with ADRD.
 5 4 3 2 1
 - d. Discuss strategies for assisting the caregiver in managing the challenging behaviors associated with ADRD.
 5 4 3 2 1
 - e. Spell out strategies for assisting the caregiver with activities of daily living (ADLs).
 5 4 3 2 1
 - f. Describe the impact of ADRD on family members.
 5 4 3 2 1
 - g. Implement strategies for involving family members in the dementia care program.
 5 4 3 2 1
 - h. Demonstrate ways to create an environment that is safe, secure, and supportive 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

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

- Yes No

13. Comments or suggestions (optional): _____

(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**.

3 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!