Alzheimer’s Disease and Related Dementias, 3 units (200)

Author: Lauren Robertson, BA, MPT

Contact hours: 3

Course price: $29

Instructions

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Course Summary

This course is to provides direct-care staff with the skills, techniques, and strategies to care on a daily basis for clients who have Alzheimer’s disease or a related dementia. It includes activities that allow participants to practice the skills and strategies they have learned.

COI Support
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80% or higher on the post test, a completed evaluation form, and payment where required. No partial credit will be awarded.

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Course Objectives

When you finish this course you will be able to:

- Relate the NIA-AA diagnostic criteria for Alzheimer’s disease.
- Spell out the differences between onset, cause, and duration of dementia, delirium, and depression.
- Identify 3 common behavioral and psychological symptoms of dementia.
- Provide a definition for physical and chemical restraint.
- Describe how mild, moderate, and severe dementia affects a person’s ability to complete basic activities of daily living.
- Relate the 3 components that should be part of individual and group activities for residents with dementia.
- Describe 3 ways in which stress can affect a caregiver’s quality of life.
- Describe 3 issues family caregivers face as their loved one transitions from mild to moderate to severe dementia.
- Identify 3 philosophical concepts that are important in the design of a therapeutic environment for those with dementia.
- Identify common ethical conflicts that may arise when caring for residents with ADRD.

Causes of Alzheimer’s and Related Dementias

Although dementia has probably been around since the first humans appeared on the earth, it is only as we live longer that we have begun to see its widespread occurrence in older adults. The most common—and perhaps most familiar—type of dementia is Alzheimer's disease, but there are other types and causes of dementia. In fact, new research is suggesting that "pure" pathologies may be rare and most people likely have a mix of more than one type of dementia. Worldwide more than 35 million people live with dementia and this number is expected to double by 2030 and triple by 2050 (ADI, 2013).

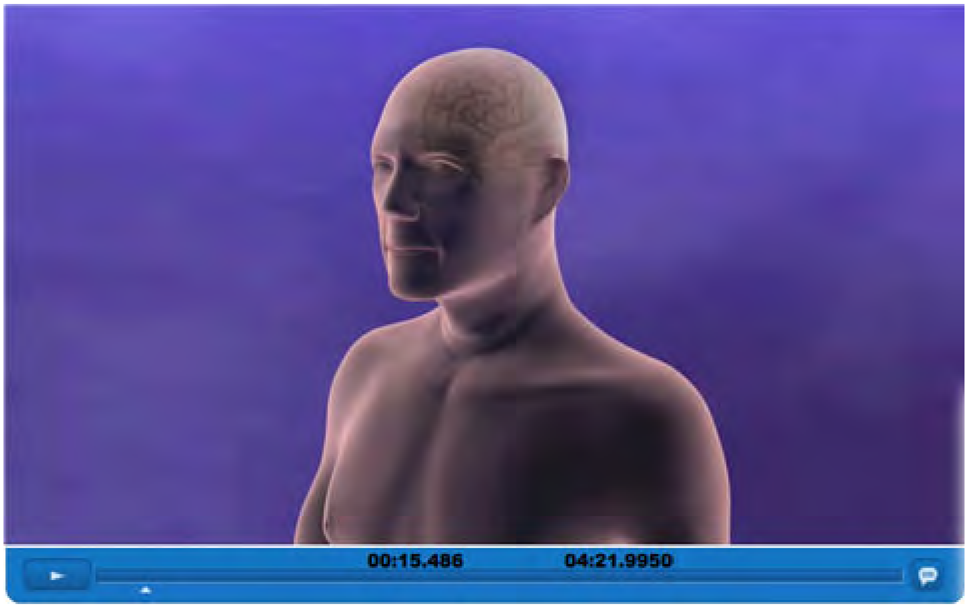
Defining Dementia

> The ugly reality is that dementia often manifests as a relentless and cruel assault on personhood, comfort, and dignity. It siphons away control over thoughts and actions, control that we take for granted every waking second of every day.
>
> Michael J. Passmore
> Geriatric Psychiatrist, University of British Columbia

Dementia is a collective name for progressive, global deterioration of the brain's executive functions. Although there are notable exceptions, dementia occurs primarily in later adulthood and represents a major cause of disability in older adults. Almost everyone with dementia is elderly but nevertheless dementia is *not* considered a normal part of aging.

Although the exact cause of dementia is still unknown, in Alzheimer's disease, and likely in other forms of dementia, damage within the brain is related to a so-called pathological triad: (1) formation of extracellular *beta-amyloid plaques*; (2) disruption of the normal function of a protein called *tau*, which leads to the development of *neurofibrillary tangles*; and (3) degeneration of cerebral neurons (Lobello et al., 2012).

Video: Inside the Brain
Unraveling the Mystery of Alzheimer's Disease (4:21)



http://www.nia.nih.gov/alzheimers/alzheimers-disease-video

In Alzheimer's disease, damage typically begins in the temporal lobe, in and around the hippocampus. The hippocampus is part of the brain's limbic system and is responsible for the formation of new memories, spatial memories and navigation, and is also involved with emotions.

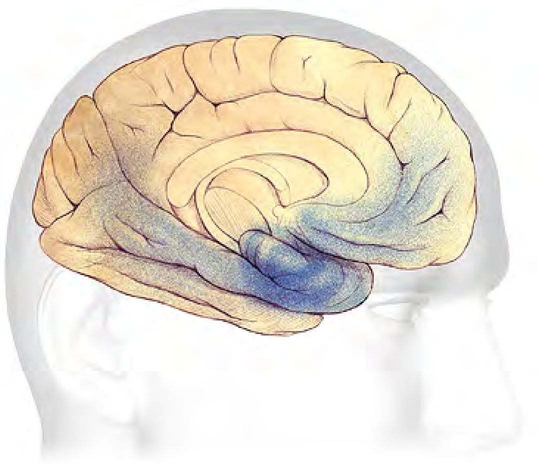
Mild Alzheimer's Disease

In the earliest stages of Alzheimer's disease, before symptoms can be detected, plaques and tangles form in and around the hippocampus (shaded in blue).

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

As the disease progresses, plaques and tangles spread forward to the temporal and frontal lobes. These areas of the brain are involved with language, judgment, and learning. Speaking and understanding speech, the sense of where your body is in space, and executive functions such as planning and ethical thinking are affected. Many people are first diagnosed with Alzheimer's disease in this stage.

Moderate Alzheimer's Disease



In mild to moderate stages, plaques and tangles (shaded in blue) spread from the hippocampus forward to the frontal lobes.

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

In severe Alzheimer's disease, damage is spread throughout the brain. Notice in the illustration below the severe damage (dark blue) in the area of the hippocampus. At this stage, because so many areas of the brain are affected, individuals lose their ability to communicate, to recognize family and loved ones, and to care for themselves.

It is now thought that the pathologic changes that underlie Alzheimer's disease begin years, or even decades, before emotional, physical, or cognitive symptoms emerge. These changes eventually reach a threshold at which the onset of a gradual and progressive decline in cognition becomes obvious (DeFina et al., 2013).

Severe Dementia

In advanced Alzheimer's, plaques and tangles (shaded in blue) have spread throughout the cerebral cortex.

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

Types of Dementia

Although the largest percentage of dementia is thought to be caused by Alzheimer’s disease, AD isn’t the only type of dementia. Frontal-temporal dementia—which is thought to begin in the frontal lobes—is a relatively 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). In all, nearly twenty different types of dementia have been identified.

Some Common Types of Dementia			
Dementia subtype	Early, characteristic symptoms	Neuropathology	% of dementia cases
*Alzheimer's disease (AD)	▪ Gradual onset ▪ Impaired memory, apathy and depression ▪ Language and visuospatial deficits	▪ Cortical amyloid plaques ▪ Neurofibrillary tangles	50–75%
Frontal-temporal dementia	▪ Early onset (45 to 60 yrs of age) ▪ Behavioral and personality changes ▪ Mood changes ▪ Disinhibition ▪ Language difficulties	▪ No single pathology: damage limited to frontal and temporal lobes ▪ Damage limited to frontal and temporal lobes	5–10%
*Vascular dementia	▪ Stepwise onset ▪ Similar to AD, but memory less affected, and mood fluctuations more prominent ▪ Physical frailty ▪ Patchy cognitive impairment ▪ Often preventable	▪ Cerebrovascular disease ▪ Single infarcts in critical regions, or more diffuse multi-infarct disease ▪ Group of syndromes	20–30%
Dementia with Lewy-bodies	▪ 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.

Diagnosing Alzheimer's Disease

Diagnosis of Alzheimer's disease and other types of dementia is based on symptoms. This generally includes a gradual decline in mental capacity, changes in behavior, and the eventual loss of the ability to live independently. As yet, there is no blood test or imaging technique that can definitively diagnose dementia.

In 2009 the National Institute on Aging and the Alzheimer's Association (NIA-AA) developed updated guidelines for the diagnosis of Alzheimer's disease. The diagnostic criteria for AD, published in 2011, are as follows:

1. A gradual, progressive decline in cognition that represents a deterioration from a previous higher level;
2. Cognitive or behavioral impairment evident in at least two of the following domains:
    a. episodic memory,
    b. executive functioning,
    c. visuospatial abilities,
    d. language functions,
    e. personality and/or behavior;
3. Significant functional impairment that affects the individual's ability to carry out daily living activities;
4. A situation in which symptoms are not better accounted for by delirium or another mental disorder, stroke, another dementing condition (i.e., vascular dementia, frontal-temporal dementia) or other neurological condition, or the effects of a medication. (DeFina et al., 2013)

The recently released Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) contains updated criteria for diagnosing Alzheimer's disease which parallel the NIA-AA diagnostic guidelines. Clinicians should familiarize themselves with these revised criteria, listed within the Neurocognitive Disorders section of the DSM-V because the criteria contained in the prior DSM-IV-TR are not reflective of the current state of the AD literature (DeFina et al., 2013).

Primary Care Barriers to Diagnosis

Primary care offices are usually responsible for medical management of most cases of dementia. However, the average primary care clinician may have difficulty providing optimal care. Clinicians face a number of barriers (Lathern et al., 2013):

- Insufficient time
- Insufficient support staff
- Difficulty accessing specialists
- Low reimbursement
- Poor connections with community social service agencies

In addition, numerous studies have found that primary care physicians may lack knowledge or skill for appropriate screening, diagnosis, and treatment of dementia. These barriers often result in delayed or overlooked dementia diagnoses and missed opportunities for treatment, care planning, and support for family members (Lathern et al., 2013).

In a retrospective study of veterans diagnosed with dementia in the Veteran's Administration (VA) New England Healthcare System, researchers found that few patients had a diagnosis of cognitive impairment prior to their first dementia diagnosis. This is despite the fact that many of them have been followed in the VA system for years. Compared to patients who see a geriatrician or neurologist, dementia patients followed up exclusively by primary care physicians are less likely to receive a specific dementia diagnosis and less likely to have their initial diagnosis change over time. They are also less likely to have neuroimaging or receive dementia medication (Cho et al., 2014).

There is a growing appreciation of the importance of early recognition of dementia. Patients with unrecognized impairment do not get tested for reversible causes of dementia, do not get counseling regarding the disease process or advanced care planning, and are not offered treatment (Cho et al., 2014).

Agreement Between Diagnosis and Pathology

A number of studies have examined the agreement between the diagnosis made while the person is alive and the pathology found in the postmortem brain. These studies 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).

In findings from the BrainNet Europe Consortium, a consortium of brain banks in Europe and the United Kingdom, upon autopsy, a little more than half of patients had mixed diagnoses among all cases of dementia. The presence of multiple brain pathologies markedly increases the odds of cognitive impairment (Herrmann et al., 2013).

In their clinical practice guideline for dementia, the National Institute for Health and Clinical Excellence noted the high prevalence of mixed pathology and suggested management according to the predominant cause. This recommendation recognizes how commonly mixed pathologies underlie dementia and gives management advice to practicing physicians (Herrmann et al., 2013).

Neuroimaging and Biomarkers

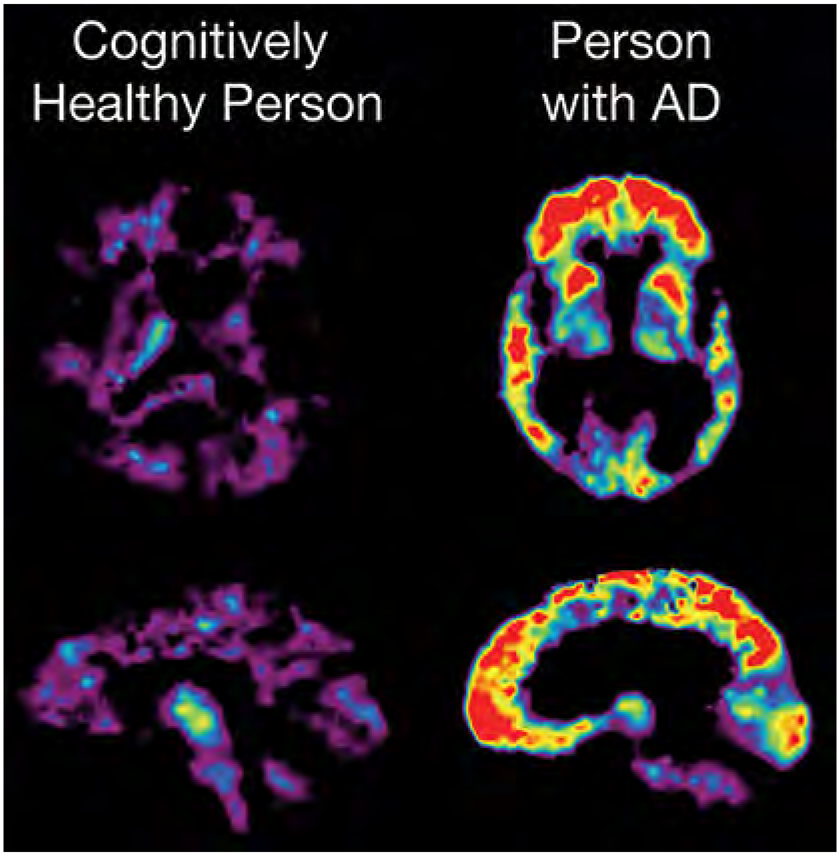
Neuroimaging—particularly magnetic resonance imaging (MRI) and positron emission tomography (PET)—is emerging as a potential diagnostic tool for dementia. These techniques may assist with early diagnosis of AD by detecting visible, abnormal structural and functional changes in the brain (Fraga et al., 2013).

Positron Emission Tomography

Positron Emission Tomography (PET) is a functional imaging technique that shows how well cells in various brain regions are working by looking at how actively the cells use sugar or oxygen. PET can also detect changes at a molecular level and may be a promising tool to detect very early changes in the brain.

Advances in PET imaging make it possible to detect beta amyloid plaques using a radiolabeled compound called Pittsburgh Compound B (PiB). This substance binds to beta amyloid plaques in the brain and can be imaged using PET scans. Initial studies have shown that people with AD take up more PiB in their brains than do cognitively healthy older people. Researchers have also found high levels of PiB in some cognitively healthy people, suggesting that the damage from beta amyloid may already be underway (NIA, 2014).

PET Scans Showing PiB Uptake



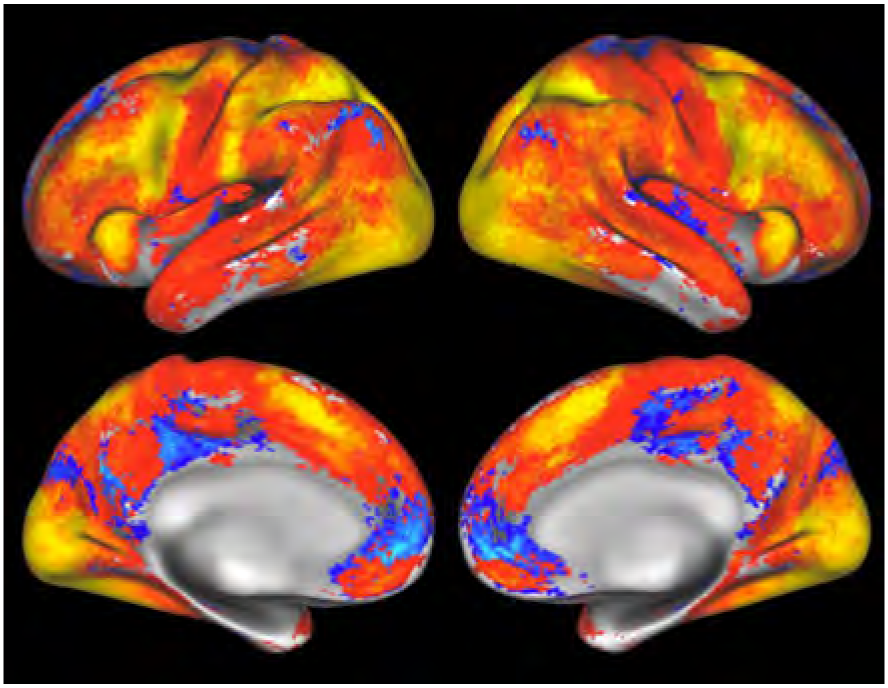
In this PET scan, the red and yellow colors indicate that PiB uptake is higher in the brain of the person with AD than in the cognitively healthy person. Source: NIA, public domain.

Magnetic Resonance Imaging

Structural imaging techniques such as magnetic resonance imaging (MRI) can provide information about the shape, position, and volume of the brain tissue. Magnetic resonance imaging is being used to detect cerebral atrophy, which is likely the result of excessive neuronal death. Atrophy correlates closely with the rate of neuropsychological decline in patients with AD.

Functional MRI, currently in the testing phase, is a technique that picks up small, MRI-measurable signals in response to increases in brain activity. It can be used to examine brain regions where activity changes when people are asked to process different kinds of information, use different types of thinking skills, or respond in different ways (Human Connectome Project, 2014).

Task Functional MRI (fMRI)



A map of overall task-fMRI brain coverage from the seven tasks used in the Human Connectome Project. Yellow and red represent regions that become more active in most participants during one or more tasks in the MR scanner; blue represents regions that become less active. Source: D.M. Barch for the WU-Minn HCP Consortium.

Biomarkers

Biomarkers are changes in sensory and cognitive abilities or substances in blood, cerebrospinal fluid, or urine. Biomarkers can indicate exposure to a substance, the presence of a disease, or disease progression over time. Elevated levels of tau protein in the cerebrospinal fluid is a mark of active neuronal degeneration, while levels of abnormally phosphorylated* tau appear to correlate with the quantity of neurofibrillary tangles in the brain (Lobello et al., 2012).

*Phosphorylation: a process that turns many protein enzymes on and off, thereby altering their function and activity. In Alzheimer's disease, tau proteins are abnormally altered by phosphorylation, which allows them to aggregate and form neurofibrillary tangles.

Conditions That Can Mimic Dementia

A number of medical conditions have symptoms that mimic those of dementia. These conditions 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 may be mistaken for dementia. Clinicians and caregivers should learn to distinguish the differences.

Delirium

Delirium (also called *acute confusion*) is a sudden, severe confusion with rapid changes in brain function and a fluctuating course. Delirium develops over hours or days and is temporary and reversible.

Delirium can cause changes in perception, mood, cognition, and attention. The most common causes of delirium, which are usually identifiable, are related to medication side effects, hypo or hyperglycemia, fecal impactions, urinary retention, electrolyte disorders and dehydration, infection, stress, metabolic changes, an unfamiliar environment, injury, or severe pain.

Video: Patient Experience of Delirium (5:51)

Source: Northumbria Healthcare Foundation Trust, England, U.K.

The prevalence of delirium is known to increase with age, and nearly 50% of patients over the age of 70 experience episodes of delirium during hospitalization. Delirium is under-diagnosed in almost two-thirds of cases or is misdiagnosed as depression or dementia. Since the most common causes of delirium are reversible, recognition enhances early intervention (Hope et al., 2014).

Early diagnosis of delirium can lead to rapid improvement. Nevertheless, diagnosis is often delayed, and problems remain with recognition and documentation of delirium by nurses and physicians. Although there are no definitive quantitative markers available to diagnose delirium, qualitative tools such as the Confusion Assessment Method (CAM) and modified Richmond Agitation and Sedation Scale have been validated. Unfortunately, the use of these tools has not generalized and nurses often simply record the patient's mental status in narrative (Hope et al., 2014).

Depression

Major depressive disorder is characterized by a combination of symptoms that interfere with a person's ability to work, sleep, study, eat, and enjoy once-pleasurable activities. Some people may experience only a single episode within their lifetime, but more often a person may have multiple episodes (NIMH, n.d.).

Dysthymic disorder, or *dysthymia*, is characterized by long-term (2 years or longer) symptoms that may not be severe enough to disable a person but can prevent normal functioning or feeling well. People with dysthymia may also experience one or more episodes of major depression during their lifetimes.

Minor depression is characterized by symptoms lasting 2 weeks or longer that do not meet full criteria for major depression. Without treatment, people with minor depression are at high risk for developing major depressive disorder (NIMH, n.d.).

Signs and symptoms of depression include:

- Persistent sad, anxious, or "empty" feelings
- Feelings of hopelessness or pessimism
- Feelings of guilt, worthlessness, or helplessness
- Irritability, restlessness
- Loss of interest in activities or hobbies once pleasurable, including sex
- Fatigue and decreased energy
- Difficulty concentrating, remembering details, and making decisions
- Insomnia, early-morning wakefulness, or excessive sleeping
- Overeating or appetite loss
- Thoughts of suicide, suicide attempts
- Aches or pains, headaches, cramps, or digestive problems that do not ease even with treatment (NIMH, n.d.)

Comorbid depression is very common among those with dementia. A review of the literature reported that almost one-third of long-term care residents have depressive symptoms, while an estimated 10% meet criteria for a current diagnosis of major depressive disorder (Jordan et al., 2014).

Despite the awareness of the high prevalence of depression in the long-term care population, there is both a high occurrence and under-treatment of depression within these settings. Depressive illness is associated with increased mortality, risk of chronic disease, and the requirement for higher levels of supported care (Jordan et al., 2014).

Long-term care staff can play a key role in the detection, assessment, management, and ongoing monitoring of mental health disorders among their care recipients; however, research suggests that these staff receive little training in mental health and commonly hold misconceptions about disorders such as depression and the behavioral and psychological symptoms of dementia. As a result, they have demonstrated poor skills in managing residents with these disorders (Jordan et al., 2014).

Comparing Dementia, Delirium, and Depression

	Delirium	Depression	Dementia
Onset	Rapid, hours to days	Rapid or slow	Progressive, develops over several years
Cause	Medications, infection, dehydration, metabolic changes, fecal impaction, urinary retention, hypo and hyperglycemia	Alteration in neurotransmitter function	Progressive brain damage
Duration	Usually less than one month but can last up to a year	Months, can be chronic	Years to decades
Course	Reversible, cause can usually be identified	Usually recover within months; can be relapsing	Not reversible, ultimately fatal
Level of consciousness	Usually changed, can be agitated, normal, or dull, hypo or hyperactive	Normal or slowed	Normal
Orientation	Impaired short-term memory, acutely confused	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.

Behavior Management

The onset of dementia and its gradual progression inevitably leads to changes in personality and behavior. Geriatrics specialists refer to these changes as *behavioral and psychological symptoms of dementia* (BPSD) or *neuropsychiatric symptoms of dementia* (NSP). It is estimated that up to 90% of patients will eventually experience challenging behaviors associated with their dementia (Passmore, 2013).

The prevalence of challenging behaviors increases demands on staff and causes job-related stress, burnout, and staff turnover. For these residents with dementia experiencing behavioral and psychological symptoms, the cost of their care is three times higher than that of other nursing home residents. About 30% of these costs are attributed to the management of disruptive behaviors (Ahn & Horgas, 2013).

Changes in personality and behavior can range from disinterest and apathy to agitation, disinhibition,* and restlessness. Behavioral interventions usually complement medication management and include creating a structured, safe, low-stress environment, promoting regular sleep and eating habits, minimizing unexpected changes, and employing redirection and distraction (DeFina et al., 2013).

*Disinhibition: a loss of inhibition, a lack of restraint, disregard for social convention, impulsiveness, poor safety awareness, an inability to stop strong responses, desires, or emotions.

In general, challenging behaviors are best managed through the use of multidisciplinary, individualized, and multifaceted care including psychosocial interventions and short-term pharmacologic treatment only when necessary (Burns et al., 2012). Prior to deciding on a course of action, a risk assessment, comprehensive assessment, and a determination of reversible cause or factors should be completed.

The Problem-Solving Approach

> My mom has dementia and my sisters and I take turns staying with her at her home. We noticed that she gets really agitated and angry in the evening—we blamed this on her dementia. We finally figured out that she gets really cold in the evening—even when it's warm outside. She doesn't tell us when she's cold but if we ask, she'll say "I'm freezing." Once we realized this, we ordered special heated slippers and also got her an electric blanket. It sounds simple but it took us a long time to figure it out because she doesn't complain. Now she's rarely agitated or angry in the evening!
>
> Caregiver, Santa Rosa, California

The *problem-solving approach* encourages caregivers to look for the root cause of a behavior and treat it—usually with environmental modification, medication management, and caregiver training. 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.

- **A**ntecedent—what precipitated or caused the behavior?
- **B**ehavior—what is the behavior?
- **C**onsequence—what are the consequences of the behavior?

The ABC approach is particularly effective when successful strategies are regularly shared by staff, caregivers, and family members and used to uncover the cause of a challenging behavior. The ABC method helps staff and caregivers understand when and how often a behavior occurs and offers the opportunity for discussion and planning.

Among many challenging behaviors associated with Alzheimer's disease and related dementias, three stand out in the current literature: aggressive behaviors, agitated behaviors, and wandering. Other challenging behaviors will arise, especially in the later stages. Rummaging and hoarding, delusions and hallucinations (psychoses), and sleep disturbances will be discussed here. This is by no means an exhaustive list and other challenging behaviors are sure to arise.

Agitation and Aggression

The terms *agitation* and *aggression* are often used in reference to behavioral symptoms associated with dementia. **Agitation** refers to observable, non-specific, restless behaviors that are excessive, inappropriate, and repetitive. This can include verbal, vocal, or motor activity (Burns et al., 2012).

Aggression is characterized by physically or verbally threatening behaviors directed at people, objects, or self. Aggressive behaviors are generally perceived as a threat to the safety of those with dementia and to those around them, which includes family caregivers, staff, and other residents. Aggression is often described by specific acts and includes:

- Verbal insults
- Shouting, screaming
- Obscene language
- Hitting, punching, kicking
- Pushing, throwing objects
- Sexual aggression (Burns et al., 2012)

Agitation and aggression occur in about 50% to 80% of nursing home residents with cognitive impairments (Ahn & Horgas, 2013). 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). Functionally impaired people are more likely to engage in verbally agitated behaviors (complaining, vocal outbursts) (Pelletier & Landreville, 2007).

Causes of Agitation and Aggression

Agitated and aggressive behaviors almost always result from loss of control, discomfort, or fear and are common ways to communicate discomfort (Pelletier & Landreville, 2007). Agitation and aggression can be a response to a violation of personal space or a perceived threat. These behaviors often occur during personal care tasks involving close caregiver-resident contact (Burns et al., 2012).

Aggression may be related to a decrease in the activity of serotonin or reduced transmission of acetylcholine in the brain. Frontal lobe dysfunction has been implicated. Aggression may also be related to underlying depression or psychotic symptoms (Burns et al., 2012).

Pain severity is positively associated with the frequency of agitated and aggressive behaviors. Nursing home residents with more severe pain are more likely to display these behaviors (Ahn & Horgas, 2013).

Management of Agitation and Aggression

To understand and prevent agitation and aggression, consider the antecedent: What precipitated the behavior? Carefully observe the person and try to determine the cause of the agitation. Look for patterns. You can use one of the following scales to assess aggressive behaviors:

- Rating scale for Aggressive behavior in the Elderly (RAGE)
- Overt Aggression Scale (OAS)
- The physically aggressive subscale of the Cohen-Mansfield Agitation Inventory (CMAI)
- Agitation/aggression subscale of the Neuropsychiatric Inventory (NPI)
- Aggression subscale of the NPI-Clinician (Burns et al., 2012)

For agitated behaviors a number of instruments can be used to assess the different aspects of agitation:

- Cohen-Mansfield Agitation Inventory

- Pittsburgh Agitation Scale
- Agitation/aggression and aberrant motor behavior subscales of the Neuropsychiatric Inventory
- NPI-Clinician
- Brief Agitation Rating Scale (Burns et al., 2012)

Psychosocial and environmental interventions can be of help in reducing or eliminating agitated or aggressive behaviors. Touch and music therapy, massage, craniosacral therapy,* therapeutic touch, acupressure, and tactile massage have been shown to be successful for treating aggression. In addition, individual behavioral therapy, bright light therapy, and Montessori activities, and individualized, person-centered care based on psychosocial management is recommended (Burns et al., 2012)

*Craniosacral therapy: a hands-on technique that uses soft touch to release restrictions in the soft tissue surrounding the central nervous system.

For people with dementia, antipsychotics may reduce aggression and psychosis, particularly among those most severely agitated. However, in older people, antipsychotics are associated with increased overall mortality, worsening cognitive impairment, hip fracture, diabetes, and stroke (Jordan et al., 2014).

Wandering

Wandering is repetitive locomotion that makes one susceptible to harm due to its incongruence with boundaries and obstacles, which may culminate in exiting, elopement,* or becoming lost (Burns et al., 2012). It is a broad term encompassing a diverse set of behaviors. It can include aimless locomotion with a repetitive pattern, hyperactivity, and excessive walking, as well as leaving a safe environment and becoming lost alone in the community (Rowe et al., 2011).

*Elopement: When a patient or resident who is cognitively, physically, mentally, emotionally, or chemically impaired wanders away, walks away, runs away, escapes, or otherwise leaves a caregiving facility or environment unsupervised, unnoticed, or prior to their scheduled discharge (The National Institute for Elopement Prevention and Resolution).

Wandering can be goal-directed, in which a person tries to reach an unobtainable goal, or nongoal-directed, in which a person wanders aimlessly. Wandering patterns can include moving to a specific location, lapping or circling along a path or track, pacing back and forth, or wandering at random.

The Alzheimer’s Association estimates that up to 60% of persons with dementia will “wander” into the community at some point during the course of their disease (Rowe et al., 2011). In nursing homes, wandering occurs in approximately 40% to 60% of residents with dementia (Ahn & Horgas, 2013).

Causes of Wandering

Those with Alzheimer's disease are more likely to wander than those diagnosed with other types of dementias. Wandering is reportedly more prevalent in men and in younger persons with dementia. Those with frontal-temporal dementia reportedly have a greater tendency to pacing and lapping behaviors whereas those with AD are more inclined to engage in random locomotion. Wandering in the form of restlessness, with a compelling need for movement or pacing, has been linked to side effects of psychotropic medications, particularly antipsychotics (Burns et al., 2012).

Wandering is likely related to boredom, pain and discomfort, disorientation, and memory problems. People may wander out of habit or because they think something from their past needs to be done, such as going home after work, walking the dog, getting exercise, or searching for something they think they have lost.

A person's pre-dementia lifestyle may be a factor in whether they are likely to wander. Studies have indicated that people with the following characteristics are more likely than others to wander:

- Those with an active physical and mental interest in music
- Those who have an extroverted personality showing warmth, positive emotion, altruism
- Those who were very involved with social activities and were active in social-seeking behaviors
- Those who were physically active
- Those who experienced stressful events throughout their life, necessitating multiple readjustments
- Those who respond to stress by engaging in motor activities (Futrell et al., 2010)

Management of Wandering

Wandering can be a beneficial activity if there are safe places to wander, in and around a facility. An assessment of the reasons for wandering should include regular review medications to make sure wandering is not the result of medication side effects, overmedicating, or drug interactions. The most important goal is to prevent a person from wandering into unsafe areas, other resident's rooms, or eloping from the facility. Wandering can be addressed by:

- Redirecting to a purposeful activity
- Providing safe, looping wandering paths with interesting rest areas

- Providing regular exercise
- Engaging the person in simple chores such as folding laundry or assisting with dinner
- Reducing excessive noise levels
- Avoiding medications that increase fall risk
- Putting up visual barriers on exit doors such as “Stop” signs
- Using electronic devices attached to the person’s ankle or wrist that alert staff or family when someone has wandered out of a designated area
- Installing alarms on entryways into unsafe areas or to the outside
- Putting up physical barriers such as yellow tape to prevent wandering into unsupervised areas

Subjective barriers such as grid patterns on the floor in front of exit doors, camouflage, and concealment of doors and doorknobs have been shown to discourage a wanderer from exiting a building.

Did You Know. . .

The Alzheimer’s Association has partnered with MedicAlert through the Alzheimer’s Association Safe Return Program 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 (Alz.org).

Rummaging and Hoarding

Rummaging and hoarding refer to behaviors in which a person gathers, hides, or puts away items in a secretive and guarded manner. These actions are considered a type of obsessive-compulsive behavior. Rummaging and hoarding are not necessarily dangerous or unsafe but they can be frustrating for caregivers and other residents.

Causes of Rummaging and Hoarding

Hoarding can arise in those with dementia due to fear of losing money or possessions, due to lack of control, need to “save for a rainy day, or simply out of confusion. Hoarding is associated with insecurity and anger and may be an attempt to hold onto possessions and memories from the past.

Cognitive changes such as memory loss, poor judgment, and confusion can contribute to the impulse to rummage and hoard. People may rummage out of boredom or to find something they think has been misplaced. They may have a fear of being robbed or feel a need to protect their own possessions. Rummaging through familiar items may create a sense of safety and security. Confusion can lead to rummaging through another person's belongings, which can be particularly frustrating for neighboring residents.

Management of Rummaging and Hoarding

To address rummaging and hoarding behaviors, try to determine what triggers or causes the behavior and look at the consequences, if any. Put yourself in the other person's head—the reason for rummaging and hoarding may not be clear to you but there may be a perfectly good reason why someone with dementia is rummaging.

Rummaging through another person's belongings can be prevented by installing locks on drawers and closets. The rummaging impulse might be satisfied by creating a rummaging room or a bag or drawer of items that the person can pick through. Restricting all rummaging and hoarding can be frustrating for a person who enjoys these activities.

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:

- Look for patterns
- 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
- Check garbage for missing items

Psychosis

Psychosis is a disturbance in the perception or appreciation of objective reality (Burns et al., 2012). Symptoms can include delusions and hallucinations, among others. A **delusion** is a false idea or belief or a misinterpretation of a situation. **Hallucinations** are sensory events in which a person hears, tastes, smells, sees, or feels something that is not there. Delusions and hallucinations can occur in people with dementia, with hallucinations particularly common in those with Parkinson's disease dementia and Lewy body dementia.

Causes of Psychosis

Delusions and hallucinations can be caused by health factors such as urinary tract infections or environmental factors such as poor lighting or sensory overload. Changes in the brain can also contribute to these behaviors, especially changes related to sensory awareness, memory, and decreased ability to communicate or be understood.

People suffering from delusions and paranoia can become suspicious of caregivers or friends; they may feel these people are stealing from them or planning them harm. Sensory deficits can contribute to delusions, and particularly hallucinations, because of the distortion of sound or sight.

Visual hallucinations can occur in the moderate to severe stages of dementia and are particularly common in those with Lewy body dementia. While atypical antipsychotics are sometimes used off-label to manage hallucinations, in a person with Lewy body dementia, antipsychotic medications can make hallucinations worse. In a person with new onset of visual hallucinations, the number one cause is medication side effects. For this reason, all medications the person is receiving should be carefully reviewed. This includes prescription and over-the-counter medications, as well as herbal supplements.

Management of Psychosis

The first step in the management of delusions and hallucinations is to rule out delirium as a cause. Another important factor is to determine if the claims by the person with dementia actually did occur (Burns et al., 2012).

Observe the behavior and listen to what the person experiencing the paranoia or delusion has to say. Is the feeling pleasant or frightening? 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?”

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. Do not agree with the person or further validate the paranoia or delusion, but respond to the person’s emotion.

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. Delusions and hallucinations can be addressed using behavioral interventions or, in some cases, antipsychotic medication. Atypical antipsychotics have largely replaced typical or traditional antipsychotics as the main treatment for psychosis, hallucinations, and delusions in those with dementia (Burns et al., 2012).

Here are some other suggestions for addressing hallucinations:

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

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.*

*Sundowning: increased confusion and restlessness in the late afternoon and early evening, possibly due to damage to the part of the brain that regulates sleep patterns.

The symptoms of sleep disruption vary according to the type of dementia and may present with the following features:

- Increased sleep latency
- Nocturnal sleep fragmentation
- Increased early-morning awakenings
- Decreased total sleep time
- Decreased sleep efficiency
- Decreased slow-wave and rapid-eye-movement (rem) sleep
- Nocturnal confusion
- Increased daytime napping and excessive daytime sleepiness
- Other behavioral and psychological symptoms such as agitation, verbally disruptive behaviors, hallucinations, and nighttime wandering (Burns et al., 2012)

Causes of Sleep Disturbances

Studies have suggested that approximately one-quarter to one-third of those with Alzheimer’s disease have problems with sleep, partly due to the degeneration of neurons in the part of the brain that controls circadian rhythms. Sleep apnea, restless leg syndrome, medical and psychiatric issues, and environmental and behavioral factors often predate the onset of dementia. Chronic pain also interferes with sleep and disturbed sleep reduces the pain threshold (Deschenes & McCurry, 2009).

Medications used to treat the psychological and 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).

Management of Sleep Disturbances

Before treating sleep disturbances look for potentially treatable causes, which can include pain, hunger and thirst, the need to urinate, infections, adverse drug reactions, and even noise. Some nonpharmacologic treatments that have been used successfully in nursing homes to treat sleep disorders include:

- Light therapy
    - High-intensity or ambient light in morning or evening
    - Full-spectrum light box
    - Melatonin with light therapy
    - Bright light exposure during the day
- Good sleep hygiene practices
    - Get up at the same time every morning and go to bed at the same time every night
    - Turn on music or radio at bedtime
    - Provide a comfortable and warm bed
    - Empty bladder before bedtime
    - Limit daytime napping
- Exercise during the day
- Individualized social activities
- Restriction or elimination of caffeine, nicotine, and alcohol
- Calm atmosphere
- Biofeedback (Deschenes & McCurry, 2009)

The Wanderer

Mrs. Winkler has moderate dementia. A nursing assistant wheels her to the activities room and leaves her there. After about 20 minutes, Mrs. Winkler decides to leave the activities room. She heads down the hall and is stopped several times by a passing staff member, all of whom turn her back toward the activities room—usually with a reprimand.

As soon as the staff member is gone, Mrs. Winkler turns around and continues down the hall. She stops near the elevator, where she sits for a while watching people come and go. Several staff members pass her and admonish her not to get on the elevator. Each time she is left in exactly the same place next to the elevator. Finally, when no one is looking Mrs. Winkler wheels into the elevator. The door closes and the elevator takes off for the ground floor.

Antecedent: Mrs. Winkler is a curious person and always liked walking around the city for exercise. She liked exploring the different neighborhoods. She was never one to sit around doing nothing. Mrs. Winkler can propel herself independently in the wheelchair but is no longer able to think logically or understand the consequences of her decisions. The elevator is interesting and looks like fun. People keep walking by and talking to her but she doesn’t understand or remember what they are saying.

Behavior: The door to the elevator is an interesting visual cue and Mrs. Winkler enjoys seeing people coming and going. When a door opens, it is a common reaction to pass through it. The opening door cues Mrs. Winkler to wheel into the elevator. When the door opens on the ground floor, she wheels herself out of the elevator without knowing 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 warnings 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. Try to determine the reason for her wandering. Review medications to make sure wandering is not the result of medication side effects, overmedicating, or drug interactions. People probably wander out of habit and because they are restless, bored, or, disoriented. Use these suggestions to keep Mrs. Winkler out of the elevator:

- Redirect her to a purposeful activity

- Provide a place where she can wander safely
- Provide her with regular exercise
- Engage her in simple, meaningful chores
- Review her medications
- Attach an electronic device to Mrs. Winkler’s ankle or wrist that alerts caregivers when she has wandered out of a designated area
- Paint a grid in front of the elevator to discourage her getting into the elevator
- Place a plastic PVC pole on the back of her wheelchair and a horizontal pole across the entrance to the elevator so that she is physically stopped from entering the elevator
- Encourage a family member to take her for a stroll outside the building or for a ride in a car

Physical and Chemical Restraints

The Omnibus Budget Reconciliation Act of 1987 (OBRA 87) established a resident’s right to be free 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 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. Many have a Nursing Home Bill of Rights intended to protect residents' physical and mental well-being. The bill of rights generally state 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. Statutes often stipulate that, in case of an emergency, a restraint may be applied only by a licensed nurse who must document the circumstances requiring the use of restraint, and, in the case of a chemical restraint, a physician must be consulted immediately. Restraints cannot be used in lieu of staff supervision or merely for staff convenience, for punishment, or for reasons other than resident protection or safety.

Physical Restraints

A **physical restraint** is any device, material, or equipment attached to or near a person's body that can neither be controlled nor easily removed by the person, and that deliberately prevents or is deliberately intended to prevent a person's free body movement to a position of choice or a person's normal access to his body (Lai et al., 2011). Restraint also includes using (or threatening) force to make a person do something that they are resisting, and restricting their movements, whether or not they resist (Nuffield Council on Bioethics, 2009). The prevalence of physical restraint varies from 5% to 56% as reported in existing literature (Lai et al., 2011).

Physical restraints include vests, straps, wrist ties, splints, mitts, belts, recliners, geri-chairs, and bedside rails, among others. Several studies have demonstrated that carefully orchestrated restraint-reduction programming can greatly reduce the use of physical restraining devices (Lai et al., 2011).

The use of physical restraints (including belts), increases the risk of death or serious injury and can increase the length of a hospital stay. The use of restraints may also indicate a failure to address the real needs of residents and patients (Gulpers et al., 2010).

Both prolonged and short periods of physical restraint use are associated with pressure sores, loss of muscle strength and endurance, joint contractures, incontinence, demoralization, humiliation, feelings of low self-worth, depression, aggression, and impaired social functioning (Gulpers et al., 2010).

The use of physical restraints creates an ethical dilemma by impinging on a person's autonomy. Their use is associated increased instances of falling, the development of hospital-associated infections, and cognitive decline. Restraints also increase dependency in activities of daily living and walking (Lai et al., 2011).

Chemical Restraints

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

In older adults with dementia, psychotropic agents such as anti-anxiety, antidepressant, and antipsychotic medications are commonly used to treat the behavioral and psychological symptoms associated with dementia. These medications, which affect mood, perception, consciousness, cognition, and behavior can become a chemical restraint if used improperly and may be overused a means of behavioral control in older adults with dementia (Peisah & Skladzien, 2014).

Attention to the misuse of antipsychotic drugs, particularly the newer atypical antipsychotic drugs, was brought to public attention by Lucette Lagnado, writing in the *Wall Street Journal* in December 2007. She reported that atypical antipsychotic drugs are used off-label in nursing facilities as a substitute for adequate staffing and to quiet residents. She described several reasons for the off-label use of antipsychotic drugs in nursing homes, including the 1987 Nursing Home Reform Law's limits on the use of physical restraints, off-label marketing of antipsychotic drugs by drug companies, and insufficient staffing in nursing facilities. Lagnado reported that the Medicaid program spent more on antipsychotic drugs than on any other class of drugs (Edelman & Lerner, 2013).

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 behavioral and psychological symptoms of dementia due to their reported advantages over conventional agents, particularly with respect to extrapyramidal symptoms such as dyskinesias (Liperoti et al., 2008).

In the elder population, the largest number of prescriptions for atypical antipsychotics is written for the neuropsychiatric symptoms of dementia, which include delusions, depression, and agitation. Neuropsychiatric symptoms affect up to 97% of people with dementia over the course of their illness. No atypical antipsychotic is FDA-approved for the treatment of any neuropsychiatric symptoms in dementia (Steinberg & Lyketsos, 2012).

Several large clinical trials have consistently demonstrated an increased risk of mortality with the use of atypical antipsychotics in dementia. All atypical antipsychotics now carry a black box warning from the FDA about this risk, and a similar warning applies to conventional antipsychotics. Atypical antipsychotics are also linked to a two- to three-fold higher risk of cerebrovascular events (Steinberg & Lyketsos, 2012).

The 2012 American Geriatric Society (AGS) Beers consensus criteria for safe medication use in elders recommend **avoiding** antipsychotics for treatment of neuropsychiatric symptoms of dementia due to the increased mortality and cerebrovascular events risk "unless nonpharmacologic options have failed and patient is threat to self or others" (Steinberg & Lyketsos, 2012).

A prescriber may choose to prescribe antipsychotic medications for behavioral and psychological symptoms associated with dementia and they may 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.

Alternatives to Restraints

Many attempts have been made to reduce restraint use in clinical practice. Most interventions have used educational approaches, aiming to improve nursing staff knowledge and confidence to avoid physical restraints and to use alternative measures that target the resident's underlying problems (Gulpers et al., 2010).

In a small Dutch study involving 30 residents, education, institutional changes, and alternative interventions resulted in a significant reduction in the use of belt restraints. Belts were replaced with resident-centered interventions such as movement and balance training, lower beds, hip protectors, extra supervision, and monitoring devices (video camera, sensor mat, and infrared alarm systems) (Gulpers et al., 2010).

Other strategies have been used as an alternative to physical restraints. Reducing clutter, keeping hallways free of equipment and obstacles, and liberal use of rails, grab bars, and transfer poles in rooms, bathrooms, hallways, and common areas is recommended. A friendly, uncluttered, home-like environment provides a safe and effective alternative to physical restraints. Other suggestions related to the environment:

- Redesign the location of nursing stations so they are part of a home-like design.
- Provide pressure-relief wheelchair and chair cushions to improve comfort.
- Lower wheelchairs to allow self-propelling with feet.

- Provide comfortable, easy-to-access alternative seating.
- Install carpeting to reduce injury from falls.

Psychosocial policies and activities can also assist in reducing or eliminating the use of restraints. Establishing a routine, including a toileting schedule, will improve comfort and reduce anxiety. Regular exercise and comfortable places to rest and nap are important. Other psychosocial suggestions:

- Assess and treat hunger, thirst, and discomfort.
- Change medications or taper medications with adverse effects.
- Treat all underlying causes, including pain.
- Assess hearing and vision.
- Establish a nap schedule.
- Relieve impaction.

Activities of Daily Living (ADLs)

> The "small things" of care are particularly important in ensuring that care is genuinely supportive of the individual, and enhances that person's autonomy and well-being. The humanity with which assistance for everyday living is offered, especially help with eating and intimate care, is crucial in helping the person retain their self-esteem and dignity, as are the manner and tone in which a person is addressed; the care taken to ensure that they participate as much as they can or wish in any decision about their day-to-day life; the trouble taken about appropriate and attractive food and environments; and access to meaningful activity.
>
> Nuffield Council on Bioethics

Activities of daily living (ADLs) are the tasks we do during our daily lives. Because ADL skills tend to worsen as dementia progresses, caregiver involvement naturally changes over time. ADLs are generally divided into two categories: basic ADLs and instrumental ADLs.

Basics ADLs are the skills needed to take care of personal needs such as:

- Eating
- Bathing or showering
- Grooming

- Walking
- Dressing and undressing
- Transfers
- Toileting

Instrumental (functional) ADLs (called IADLs) are the skills needed to function within society and within the community. As with basic ADLs, these skills decrease as dementia progresses. When a person is no longer able to perform basic math calculations, a caregiver or financial advisor must oversee finances. When insight becomes limited and memory is significantly compromised, medical decision-making and medication management will also shift to the hands of a caregiver. Pursuit of guardianship and capacity evaluations are not uncommon, especially when estate and legal issues need to be addressed (DeFina et al., 2013).

IADLs of daily living include:

- Housework
- Financial management
- Shopping
- Preparing meals
- Communicating with the outside world
- Medical management

Symptoms, Stages, and Behavioral Symptoms

Although there is often no clear demarcation between mild, moderate, and severe dementia, caregiver responsibilities increase and as independence with ADLs decrease.

Mild Dementia and ADLs

In the early stage of dementia most people are independent as to basic ADLs. Most people with mild dementia will begin to need help with some instrumental ADLs—especially complex tasks requiring multiple steps or extensive planning. Basic activities of daily living such as eating, dressing, and bathing are likely still independent.

At this stage, a person will naturally try to cover up confusion by turning to others for help with simple tasks. This is a natural response and denial, anger, and excuses are common defense mechanisms. There may be some loss of interest in hobbies and activities. Mood changes, such as depression and anxiety, can occur. Learning new tasks may be difficult and complex tasks may be left uncompleted. Faulty judgment and mild changes in personality become obvious to caregivers.

Moderate Dementia and ADLs

As dementia progresses to the moderate stage, instrumental ADLs such as work, medication management, and keeping track of personal finances become difficult or impossible. A person may begin to need help with basic daily activities. Mobility is often still good and, if so, safety becomes a concern for caregivers. Because of this, family caregiver responsibilities increase, causing stress, anxiety, and worry among family members and caregivers. In the moderate phase:

- Cooking, housework, and shopping require direct assistance
- Basic ADLs require assistance for set-up and safety
- Completing basic ADLs may be disrupted by behavioral and psychological symptoms such as anger, frustration, and difficulty communicating needs

Severe Dementia and ADLs

As dementia enters the severe stage, independence is gradually lost and caregivers must provide consistent direct care with most if not all ADLs. At this stage, a person must be directly assisted with basic ADLs such as eating, bathing, transfers, and walking. Control of bodily functions may be inconsistent, requiring direct help with bathing and toileting. 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.

Safety issues and wandering require constant monitoring. If the person with dementia is still at home, tired and overworked caregivers must provide even more support with ADLs to maintain a safe environment. If in a skilled nursing or assisted living situation, the facility must provide enough staffing and equipment to create a safe environment.

As severe dementia progresses, balance and safety awareness go from bad to worse, requiring significant direct help with transfers and mobility. 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.

Strategies for Assisting with ADLs

No matter what the level of dementia, when assisting someone with basic or instrumental activities of daily living, encourage them to express their wishes. “No, I don’t want to!” means just that, even when spoken by someone with dementia. Keep these general measures in mind when assisting someone with their ADLs:

- Make eye contact and maintain a calm demeanor and voice.
- Repeat requests in the same words if needed. Rephrasing the request is confusing.
- Engage the resident. Offer simple choices, such as “Do you want orange juice or apple juice?”
- Be empathetic. Examples of empathetic responses include “You must be cold” or “Are you uncomfortable in that chair?”
- Problem solve by asking, “What would help now?”
- Give the person physical space—do not crowd.
- Be aware of your body language and vocal tone.
- Be aware of the speed of your movements and speech.

When assisting someone with basic ADLs such as 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. Whatever the activity, move slowly, give clear, simple commands, limit choices, and allow plenty of time to complete the task.

There are times when 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.

ADL Strategies: Mild Dementia

Those with mild dementia may need very little help, if any with basic activities of daily living. Nevertheless, it is good to keep certain core principles in mind:

- Dressing
    - Encourage choice in the selection of clothes.
    - Assist as needed but allow resident to direct the activity.
- Grooming
    - Allow residents to groom themselves, provide tools if needed.

    - Monitor progress and provide assistance as needed.

- Eating
    - Ask for food preferences.
    - Ask the person to help with meal preparation and meal set-up.
    - Provide adaptive utensils if needed.
    - Provide assistance as needed.

- Bathing
    - Give choice as to when, where, and what type of bathing.
    - Assist in the decision to bathe.
    - Assist with bathing or shower as needed.
    - Monitor for safety and comfort.

- Toileting*
    - Monitor and assist as needed.
    - Encourage fluids even though more bathroom visits may be necessary.

*Be aware that some medications cause constipation while others increase or decrease the urge to urinate.

ADL Strategies: Moderate Dementia

Keeping in mind that there is no clear delineation between mild and moderate dementia, it will become clear to caregivers that a person in the moderate stage of dementia will need more help with ADLs, especially instrumental ADLs. There is variability at this stage depending on a person's physical capabilities and the type of dementia, but for some, walking, transferring, bed mobility, and basic ADLs may remain relatively independent. For others, especially those with physical limitations, more help may be required. In the moderate stage of dementia:

- Dressing
    - Provide comfortable clothes with elastic waistbands and Velcro closures.
    - Limit choices but encourage participation in the choice of clothing.
    - Assist closely but encourage independence.

- Grooming
    - Limit choices ("Would you like lipstick today?" "Would you like to brush your hair?").
    - Encourage as much independence as possible.

- Eating
    - Ask for food preferences.
    - Set up the meal before serving.
    - Open packages, uncover trays.
    - Provide adaptive equipment as needed.
    - Monitor closely.
- Bathing
    - Ask about bathing preferences.
    - Initiate and monitor the activity.
    - Provide direct assistance as needed, particularly in showers.
- Toileting
    - Ask regularly if the resident needs to eliminate.
    - Provide close assist, particularly with transfers.
    - Label bathroom door for easy identification.
    - Provide toileting on a regular schedule.

ADL Strategies: Severe Dementia

Once a person reaches the severe stage of dementia, the more complex instrumental ADLs have likely been completely taken over by a family member or caregiver. Basic ADLs will require a great deal of assistance to complete, depending on the person's physical capabilities. A person with severe dementia may still be able to walk independently. They may be independent or nearly so with bed mobility and transfers. Anything that requires planning, sequencing, or judgment will be severely impaired at this stage so close assistance will be needed for dressing, bathing, meal preparation, grooming, and toileting. If mobility is compromised, close assistance will be needed for all ADLs. In the severe stage of dementia:

- Dressing
    - Limit choices, select clothes and set them out.
    - Choose comfortable clothing that is easy to wash.
    - Use simple, one-step commands and gestures.
    - Encourage as much independence as possible.
- Grooming
    - Provide as much assistance as needed.

    - Move slowly, limit choices.
    - Use one-step commands and gestures.

- Eating
    - Ask for food preferences.
    - 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.
    - Allow plenty of time to finish eating.

- Bathing*
    - Provide complete bathing care.
    - Retain as much of resident's earlier bathing rituals as is reasonable.
    - Use resident behavior as a guide.

- Toileting**
    - Expect both bowel and bladder incontinence requiring total care.
    - Set up timed toileting schedule.

*Consider bathing habits (time of day, bath or shower); consider bed bath if more acceptable to resident.

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

Bathing

Mrs. Cavelia 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. When they leave the room and enter the hallway, Mrs. Cavelia starts to fidget. As they approach the shower room she begins to yell and protest. When she is placed in the shower she screams, grabs the door, and tries to push her caregiver away.

Antecedent: In her room, the care assistant undresses Mrs. Cavelia and wraps her in a bath blanket. Unable to find a shower chair, she helps Mrs. Cavelia into a toilet chair. Mrs. Cavelia's bottom is hanging out the hole in the chair, which embarrasses her. She tries to stop the caregiver from wheeling her out into the hallway by grabbing at the doorway as they exit. She says "No! No!" but the caregiver tells her she is dirty and needs a shower.

Behavior: By the time Mrs. Cavelia reaches the shower room she is very agitated. She slaps the nursing assistant and repeatedly grabs the shower room door. The nursing assistant manages to get Mrs. Cavelia into the shower room, but when she turns on the water, Mrs. Cavelia screams, grabs the shower hose, and pushes the nursing assistant away. She 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 and showering has become a dreaded experience for Mrs. Cavelia.

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

Mrs. Cavelia'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 Mrs. Cavelia'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.

Activities for Residents with Alzheimer's

Everyone finds enjoyment engaging in a variety of activities that they have enjoyed all 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, personal interests, and the person's physical abilities.

A number of studies have suggested that carefully designed activities can have a positive effect on depression, confusion, and challenging behaviors. Structuring a program to include activities in each of the following three categories may positively influence cognition, general functioning, and overall quality of life:

- Physical activity—aerobic exercises (walking, swimming, and cycling) and non-aerobic exercises (strength and resistance training, flexibility and balance exercises).
- Intellectual stimulation—cognitive hobbies (reading, word puzzles, and card games) and cognitive training (computer training games, memory and attention games)
- Social interaction—participation in group-related activities, such as mealtime conversations, support groups, or other forms of social engagement. (Ruthirakuhan et al., 2012)

The Montessori-based Activities for Person with Dementia has had some notable successes in the design of activity programs for people with dementia. This approach emphasizes matching a person's abilities with the activity. It 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.

Montessori-based activities promote engagement in learning by sequencing tasks from simple to complex, providing cues to successful completion, encouraging repetition, and carefully matching demands to individuals' interests and levels of competence (van der Ploeg et al., 2012).

For people with dementia, Montessori-type programs include detailed interviews with family caregivers about the resident's former interests and skills coupled with assessments of cognitive, language, and motor skills. A range of activities are then presented, tested, and refined. When dementia is advanced, the activities are simple (eg, completing a jigsaw made from a family photograph). Facilitators present tasks deliberately, demonstrating them first, and using language as appropriate. The main objective is to engage participants' interest and involvement (van der Ploeg et al., 2012).

Individual Activities

Individual activities involve a caregiver or family member and the person with dementia. Activities that stimulate the senses, such as cooking, singing, exercise, going for a drive, gardening, and aromatherapy, are encouraged at all stages of dementia. Some nursing homes allow birds, cats, and dogs in the facility. Taking care of an animal gives a sense of purpose and companionship and is a key component of person-centered care.

Successful activity programs for individuals with dementia are based on a person’s likes and interests. This means a caregiver must learn a person’s history and understand their capabilities and preferences. Determine whether a person can still read, write, or use a computer. Understand what a person is physically capable of doing. Learn about the person’s lifestyle prior to moving to a care facility.

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. Be consistent, have fun, and by all means introduce new activities. Look for signs of frustration and agitation and address these behaviors immediately.

Reality orientation is a component of cognitive stimulation and focuses on orienting the individual with AD to person, place, and time. Overall cognitive functioning was improved in AD patients receiving reality orientation and cognitive stimulation, with some studies indicating additional positive changes to social and communicative functioning and quality of life (Ruthirakuhan et al., 2012).

Individual Activities for People Who Have ADRD			
Type of activity	Mild	Moderate	Severe
Word games	▪ Word searches ▪ Crossword puzzles ▪ Card games ▪ Computer games	▪ Simple word searches ▪ Simple crossword puzzles ▪ Simple computer games	▪ Discuss a simple topic ▪ Listen to others
Letter writing	▪ Write a letter ▪ Send email ▪ Use Facebook	▪ Dictate a letter or email ▪ Use Facebook with help	▪ Listen to a letter or email being read
Art/Music	▪ Take photos ▪ Create a photo album ▪ Draw ▪ Play an instrument	▪ Take photos ▪ Maintain a photo album ▪ Draw ▪ Sing along with others	▪ View photos ▪ Listen to music ▪ Sing along to familiar songs
Woodworking	▪ Use tools ▪ Plan and complete projects with assistance	▪ Use simple tools with supervision ▪ Assist with projects	▪ Use activity board with bolts, screws, and hardware ▪ Watch projects
Sewing	▪ Use sewing machine with help ▪ Plan and complete projects with help	▪ Use simple tools with supervision ▪ Assist with projects	▪ Use sewing cards, activity blankets or aprons with buttons, snaps, ties, Velcro, and zippers ▪ Watch projects

Individual Activities for People Who Have ADRD			
Type of activity	Mild	Moderate	Severe
Gardening	▪ Garden in raised beds ▪ Help plan the garden and harvest	▪ Perform specific tasks with supervision ▪ Eat food grown in garden	▪ Sit in garden ▪ Participate in projects as able ▪ Eat 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 ▪ Help as able with shopping decisions ▪ Help put food away	▪ Go along to store ▪ Sit in car with supervision or shop with wheelchair or electric cart

Group Activities

Many people with AD sense that their cognitive impairment isolates them from other people. This leads to anxiety, depression, societal withdrawal, and decreased self-confidence. Encouraging social interaction may help those with dementia regain a sense of self-worth and have a better attitude toward life. This may improve eating and exercise habits and social interactions, which may result in improved AD prognosis (Ruthirakuhan et al., 2012).

People in the early stages of ADRD may especially enjoy working with others. As dementia 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.

Group Activities for People Who Have ADRD			
Activity	Mild	Moderate	Severe
Karaoke	▪ Sing while reading words	▪ Sing songs that are familiar	▪ Listen and sing along as able
Cooking	▪ Bake cookies ▪ Prepare a snack plate for others ▪ Clean up after cooking	▪ Participate in making cookies ▪ Assist with cleaning up	▪ Help decorate cookies that are already baked ▪ Eat the cookies
Nature	▪ Nature walks ▪ Outings to nature areas ▪ Fruit picking	▪ Shorter walks ▪ Picnicking outdoors	▪ Escorted walk or wheelchair outside the facility ▪ Attend picnic
Crafts	▪ Make ornaments ▪ Decorate room or facility for holidays	▪ Participate in making ornaments ▪ Assist with decorating for the holidays	▪ Participate in crafts ▪ Participate in decorating parties
Outings	▪ Shopping ▪ Theater and music events ▪ Museum visits ▪ Library visits ▪ Eat out ▪ Attend sporting events	▪ Same as mild with some adaptation and more supervision.	▪ Set up a store where the resident can purchase items ▪ Watch movies ▪ Outings with direct supervision

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

Stress Management for the Caregiver

> Caregiving is 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.
>
> Richard Schulz and Lynn Martire

A **caregiver** is someone who provides assistance to a person in need. It can be physical, financial, or emotional in nature. Caregivers can help with basic activities of daily living such as bathing, dressing, walking, and cooking, or with more complex tasks such as medication and home management. A caregiver may provide direct care or manage care from a distance and can be a family member, a neighbor, a friend, or a medical professional.

Caregiving is a long-term, evolving process with key transition phases. The onset of caring tends to emerge naturally from the customary family transactions, involving support given and received, that existed before the onset 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, 2013).

Causes of Stress for the Caregiver

Providing care for a person with dementia places practical, psychological, and emotional stress on caregivers. High levels of emotional stress can lead to denial, anger, and depression. The demands of caregiving can also be exhausting and contribute to social withdrawal. Caregivers overwhelmed by the demands of caring for someone with dementia can experience irritability, anxiety, and sleep disturbances. Many studies have documented a higher prevalence of depressive symptoms among caregivers, with the highest prevalence among those caring for someone with dementia (ADI, 2013).

The economic impact of caregiving is an additional stressor for caregivers. In an analysis of European and North American survey data conducted by the Organization for Economic Co-operation and Development (OECD) of caregivers of older people (not dementia caregivers specifically) a 1% increase in hours of care was associated with a reduction in the employment rate of caregivers by around 10% (ADI, 2013).

In a survey of American caregivers conducted by the Alzheimer’s Association, 13% had to go from working full- to part-time, 11% had to take a less demanding job, and 11% had to give up work entirely. Cutting back or giving up on work to care is associated with higher caregiver strain, while strain was reduced by hiring a paid caregiver, or having additional informal support (ADI, 2013). The amount of stress experienced by caregivers is associated with caregiver demographics, personality, and their perception of their role as a caregiver, their coping strategies, and relationships they have outside of their caregiving role.

Factors and Characteristics Associated with Caregiver Strain	
Factors	Characteristics associated with caregiver strain
Demography	▪ Female caregiver ▪ Spousal caregivers, particularly those of younger people with dementia ▪ Living with the care recipient ▪ Low incomes or financial strain
Caregiver personality	▪ High level of neuroticism ▪ High expressed emotion
Perception and experience of caregiving role	▪ A low sense of confidence by the caregiver in their role ▪ High "role captivity"—caregivers feeling trapped in their role
Coping strategies	▪ Emotion-based or confrontive coping strategies ▪ Dementia type ▪ Frontotemporal dementia ▪ 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	▪ Intimacy—poor relationship quality ▪ Low levels of past and current intimacy

Source: Adapted with permission from ADI, 2009.

Strategies for Managing Caregiver Stress

Reducing caregiver strain is possible when the following are provided:

- Education
- Training
- Support
- Respite

These four components have been shown to decrease caregiver stress and reduce or delay the transition from home to a care home (ADI, 2013).

Caregivers can reduce their stress by paying attention to their own health. This means getting enough sleep, eating properly, seeing their own doctors, and sharing their feelings about their caregiving duties with co-workers, family, and friends.

How to Reduce Caregiver Stress	
Things to do	Things to avoid
▪ Join a support group or see a counselor to discuss your feelings. ▪ Set limits on caregiving time and responsibility. ▪ Become an educated caregiver. ▪ Discuss your situation with your employer. ▪ Accept changes as they occur. ▪ Make legal and financial plans. ▪ Take regular breaks (respite).	▪ 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 dementia and aging.

Family Issues

All over the world, the family remains the cornerstone of care for older people who have lost the capacity for independent living. However, there has been tremendous growth in the paid direct-care worker industry, which is playing an increasingly important role in sustaining the work of family caregivers. In many developed countries, 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, 2013).

Family caregivers provide what is referred to as “informal care.” They are often cast into the role of caregiver unexpectedly and are largely unpaid or “nearly” unpaid. The need for personal care assistance among this population creates a tremendous burden on family and society. Currently, about half of people who need help with personal care have dementia (ADI, 2013).

The system of informal unpaid care provided by family members is under pressure due to declining fertility rates and fewer young people willing to care for older adults. Changing attitudes and expectations among the young as well as increased workforce mobility mean that family members are not always living nearby their older adult relatives. The education of women—the majority of informal caregivers—has led to more workforce participation and less availability for informal care (ADI, 2013).

Influence of Culture on Family Caregiving

Researchers at the University of Nevada sought to understand the influence of culture on the family caregiving experience. Feedback from 35 caregivers representing four groups (African American, Asian American, Hispanic American, and European American) uncovered some significant differences in the cultural values that shaped the caregiver experience.

Caregiving was seen as "right and correct" by all of the focus groups. However, for some of the groups, caregiving was an expected part of life that was passed down from generation to generation. In fact, caregiving was so embedded in the life experience for some of the groups that the decision to care or not to care was irrelevant; caregiving was just something that was done without question. To provide care for one's family or community was deeply rooted in the cultural subconsciousness, arising "naturally" without conscious thought. This perspective was shared by Asian American, Hispanic American, and African American focus group participants (Pharr et al., 2014).

Asian American, Hispanic American, and African American participants reported seeing many examples of caregiving, not just within their own families but throughout their communities. In fact, it was so culturally ingrained to care for family that, when the time came, care was provided without question. For Asian Americans, caregiving was described as just a normal thing to do (Pharr et al., 2014).

Family Issues by Stages

The majority of people with dementia live in the community, and for approximately 75% of these individuals, care is provided by family and friends. In 2007 approximately 10 million Americans were caring for a person with Alzheimer's disease or another dementia. The largest proportion of those caregivers was spouses, followed by children and children-in-law, mostly female. The typical profile of a dementia caregiver is a middle-aged or older female child or spouse of the person with dementia (Brodaty & Donkin, 2009).

In the United States, at least 60% of unpaid caregivers are wives, daughters, daughters-in-law, granddaughters, and other female relatives, although male caregivers are becoming more prevalent. In 2008 men made up 40% of family caregivers in the United States, an increase of 21% from a 1996 study by the Alzheimer's Association (Brodaty & Donkin, 2009).

A review of the literature on the demands of caregiving carried out by Alzheimer's Disease International found that caring for a person with dementia is time-consuming and that, on average, caregivers spend 14 hours per week assisting with basic ADLs and up to 43 hours per week when more complex assistance and supervision are needed (ADI, 2013).

In the Early Stage

In the early stage of dementia, family members are confronted with many issues, worries, and concerns and must adjust their own behavior and manage their own frustrations as they learn about the effects of dementia. They are often unaware of available dementia-care services and may find their family member's primary care physician is of little help. Spouses who care for a person with dementia may not be in good health themselves and may worry about not being able to provide good care as the dementia progresses. An adult child caregiver will be concerned about having to take over the care of the parent and assume a new role in the family.

Nevertheless, caregiver burden is usually manageable in the early stages of dementia. Direct care is generally not needed and caregivers can often leave their family member alone for periods of time.

Early, specialized training is recommended for informal caregivers. This is an essential but often neglected component of dementia care. Training can prepare family caregivers for what lies ahead and allow them to more easily partner with healthcare providers to provide competent and compassionate care.

In the Middle Stages

In the middle stages, behavioral and psychological problems will likely arise, requiring complicated decisions about behavioral interventions and, perhaps, medications. Family caregivers often have to cut back on employment as the demands of caregiving increase.

As the dementia progresses from the mild to moderate stage, caregivers begin to invest more time, energy, and money, which involve exhausting tasks leading to high levels of burnout. Depression, along with symptoms of burnout, poor self-rated health, highly perceived stress, and lower levels of life satisfaction are factors that begin to affect the caregiver's health. Family caregivers are also less likely to engage in preventive health behaviors. As a consequence, they are at risk for serious illness, increased emergency department use and hospitalization, and increased risk of mortality (Lykens et al., 2014).

Family caregivers' cumulative stress is also associated with increased nursing home placement, institutionalization, or hospitalization of the patient with dementia. Thus, caring for a patient with dementia can undermine the health and well-being of both the patient *and* the caregiver (Lykens et al., 2014).

In the Late Stages

In the late stages, as people lose the ability to talk clearly, family caregivers will struggle to find new ways to communicate when 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:

- Need for skilled care
- Family caregivers' health
- Patient's dementia-related behaviors
- Need for 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

The diagnosis of dementia may result in a personal crisis in which the person with dementia displays grief reactions related to the experience of actual or anticipated losses associated with the dementia diagnosis (Vroomen et al., 2013). Good support following the initial diagnosis helps people adapt to the diagnosis and provides opportunities to develop coping responses.

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

Losses for the person experiencing dementia 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

Losses for family members and caregivers can include:

- Loss of companionship
- Loss of income
- Loss of privacy and free time
- Changes in social roles
- Changes in routine

In the early stage, supportive interventions to address grief reactions should include counseling, assessment of co-morbid conditions, information about dementia, caregiver training, and development of a care plan.

In later stages, a person with severe dementia may need to be moved to a care home. This is a cause of grief and loss for the person with dementia and for the caregivers. People with dementia newly admitted to an institution are often disoriented and disorganized in their new environment and feel a loss of control over their lives (Vroomen et al., 2013).

When a loved one dies, family members, and especially spouses, experience a period of acute grief that generally includes intrusive thoughts,* intense emotional distress, and withdrawal from normal daily activities. This period, along with the chronic grief that follows, may vary in length and intensity from individual to individual and often resembles clinical depression (Monk et al., 2013).

*Intrusive thoughts: unwanted, involuntary thoughts, images or ideas that can be obsessive, distressing, or upsetting.

When a spouse dies, about 28% of surviving spouses experience major depression. This risk of depression appears to peak during the first six months of bereavement, although depressive symptoms can be present for up to two years. Even bereaved persons with minor depression may suffer, for they have a greater likelihood of functional impairment, poorer health, more physician visits and mental health counseling, and increased use of antidepressants than do non-bereaved individuals (Monk et al., 2013).

Family, Residents, and Dementia Care

When the person enters long-term care, family interactions and communication tend to be reduced. This is particularly the case when work pressures are present, when the family member lives a long distance from the care facility, and when family members feel they have a limited role in the provision of care. The loss of in-depth communication, as well as social conversations, can result in the person with dementia feeling socially isolated and without the opportunity to express needs (Moyle et al., 2104).

One way to alleviate this stress is to encourage family members to become involved in a facility's dementia care program. Dementia care programs are multidisciplinary and multi-departmental programs designed to meet the daily individual needs of residents. The quality and success of a dementia care program is strongly influenced by the environment of a care facility and by the facility's philosophy of care, services available, and staff experience and training. 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
- Encourages family involvement in the planning of activities
- Informs family members about changes in their loved one's condition
- Keeps a log of resident activities to share 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.

Caregiver Training and Support

> There is a . . . 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.

To be successful, caregivers must be able to differentiate dementia from other illnesses and understand how to manage the spectrum of difficult behaviors associated with the disease. Healthcare providers must be able to take a deep breath, slow down, listen, and find new and effective ways to communicate.

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 introduces caregivers to resources, support, and equipment that improve health and safety. Module 11 lists state and and national organizations that provide support for families and caregivers.

Maintaining a Therapeutic Environment

A therapeutic environment is an environment that is supportive of each individual and recognizes that people with dementia are particularly vulnerable to chaotic environmental influences. It is individualized, flexible, and designed to support differing functional levels and approaches to care (Campernel & Brummett, 2010).

Environment is, to a large extent, dictated by an organization's philosophy of care—a framework that identifies care goals and values. Philosophies of care occur along a spectrum, from less help and intervention to more technical intervention. Notably, a healthcare organization's philosophy of care may differ from that of the family.

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 need for person-centered care in dementia (also referred to as individualized, resident-centered, or patient-centered care) is now commonly accepted but **has yet to be commonly practiced.**

Implementation of person-centered care depends not only on the caregivers' acquiring skills and knowledge but also on adapting the entire care context (care practices, work organization, and physical environment) to tailor it to both residents' and caregivers' needs and preferences. This means that there must be flexibility in the organization (eg, meals, hygiene, dressing assistance, and so on). The physical environment must also be adapted to the perspective that it is both a home for the residents and a workplace for the caregivers (Desrosiers et al., 2014).

Person-centered care may reduce unwanted behaviors and improve both resident and staff outcomes. There are examples of person-centered care interventions that have lowered the rate of neuropsychiatric symptoms, falls, and the use of psychotropic drugs in nursing home residents with dementia (van de Ven et al., 2014).

Person-centered care is designed to be an alternative to or to complement pharmaceuticals in reducing problem behaviors in individuals with dementia. Person-centered care has been identified by the Committee on Quality of Health Care in America as one of the main areas that the healthcare system should address in order to improve the quality of healthcare, especially long-term care.

Person-centered care is the opposite of task-centered care. In long-term care, it involves practices aimed at helping residents establish relationships, be treated as individuals with their own life history and interests, and live in a home-like environment. This approach also provides a favorable context, particularly in terms of the organization of the nursing staff's work, and a desire to respect the values and preferences of persons when providing care (Desrosiers et al., 2014).

Dementia Care Mapping

Dementia-care mapping (DCM) is a person-centered intervention developed by the Bradford Dementia Group at the University of Bradford in the United Kingdom and is based on Kitwood's social-psychological theory of personhood in dementia. This theory states that much of the ill-being that people with dementia experience is due to negative environmental influences, including staff attitudes and care practices (van de Ven et al., 2014).

Dementia-care mapping consists of three components: (1) systematic observation, (2) feedback to the staff, and (3) action plans. The action plans are developed by the nursing staff and are based on the observation of the actual needs of the residents. This method allows for initiation of tailor-made interventions at the individual level (residents and caregivers) and the group level (nursing teams and multi-disciplinary teams), as well as at the levels of management and organization. In short, dementia-care mapping is a multi-component intervention aimed at implementing diverse interventions to improve the quality and effectiveness of care (van de Ven et al., 2014).

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, an advocacy organization based in San Francisco, recommends that family members consider each of the following questions about the organization's philosophy of care before choosing a long-term care facility:

- Is the facility's philosophy for caring consistent with your beliefs?
- Does the facility provide services to persons at all stages of dementia?
- What conditions or behaviors determine whether a facility will 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)

Design as a Therapeutic Tool

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).

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.

Sarah Campernel and William Brummett have designed or retrofitted many facilities and homes based on the idea of person-centered care. In their excellent report, *Creating Environments of Support: A Handbook for Dementia-Responsive Design* they recommend the physical environment should:

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

They recommend that anyone developing or retrofitting an environment for people with dementia and memory disorders should:

- 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 rooms, 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: Campernel & Brummett, 2010. Used with permission.

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

Snoezelen room. Source: Campernel & Brummett, 2010. Used with permission.

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

Rummage areas. Source: Campernel & 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 wandering away from home or facility. 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	Getting lost, exposure to environmental hazards	▪ 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	▪ 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	▪ Rule out medical conditions. ▪ Create an uncluttered environment. ▪ Install handrails in showers and hallways. ▪ Install carpeting to reduce injuries. ▪ 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	▪ 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. There are many proprietary companies now offering similar location services.

Schedules and Routines

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

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

Although caregivers are responsible for maintaining a routine schedule they 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 caregivers need 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 15,465 certified nursing facilities in the United States (KFF, 2011). All are required to meet minimum staffing standards to attain or maintain the highest possible physical, mental, and psychosocial well being of residents. Most facilities struggle to hire, train, and retain staff in the face of low wages, poor benefits, and risk of injury.

Proper Staffing

Proper staffing is consistently 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, home-like nursing facilities, in which staff are integrated into environment, 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 (Harrington et al., 2010).

Staff Adjusting to Resident Routines

In home-like care settings, 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 their routines to the routines of the residents.

In these settings, 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 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 home-like environment, the following practices have are recommended:

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

Ethical Issues with Dementia Patients

Those who work in dementia care settings face difficult ethical decisions each day. Caregivers must balance the needs of multiple residents while considering issues related to confidentiality, the potential for abuse, and the benefits and risks of medications and procedures. If patients are no longer able to express their own will, designated decision-makers 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.

Key Ethical Concepts

The language of biomedical ethics is applied across all practice settings, with four basic principles commonly accepted. These principles are (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 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: Kindness

Beneficence is the act of being kind. A beneficent practitioner provides care that is in the best interest of the patient. The actions of healthcare providers are intended 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.

Beneficence is closely related to the concept of nonmaleficence or “do 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.

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).

Justice: Equity and Fairness

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: Truthfulness

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: Loyalty

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.

Incorporating Ethical Principles into Care

Healthcare providers are routinely called upon to make ethical decisions. This is particularly true in the complex and ethically difficult area of dementia care. To add to the complexity, national clinical practice guidelines fail to address a full spectrum of dementia-specific ethical issues in their recommendations (Knüppel et al., 2013).

The Nuffield Council on Bioethics has published dementia-specific ethical guidelines that can guide the process of ethical decision-making in dementia care. A key principle is to understand and remember that people with dementia remain the same equally valued people throughout the course of their illness, regardless of the extent of the changes in their mental abilities (Nuffield Council on Bioethics, 2009).

Ethical Conflicts and Dilemmas

Ethical dilemmas arise when there are equally compelling reasons both for and against a particular course of action and a decision *must* be made. It is a dilemma because there is a conflict between available choices. Usually one action, though morally right, violates another ethical standard. A classic example is stealing to feed your family. Stealing is legally and ethically wrong, but if your family is starving stealing food might be morally justified (Noel-Weiss et al., 2012).

Kidder calls this 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).

Working through an ethical dilemma until a satisfactory conclusion is reached, making decisions that lead to good actions, and avoiding regrets and negative consequences are the foundational principles of ethical practice (Noel-Weiss et al., 2012).

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 fiercely independent his entire life. He is in the moderate-to-severe stage of ADRD and is unable to perform instrumental ADLs.

Mr. Corona is in the 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 et al., 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 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. Gould is 92 years old and has had Alzheimer's disease for fifteen years. She has lived in a nursing home for the past seven years. She has had help with 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. The Physician Orders for Life-Sustaining Treatment (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. Gould'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 principles 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 degenerative disease that eventually affects a person's ability to live independently. There are many types of dementia, although Alzheimer's disease is the most common type. Delirium and depression can be confused with dementia and a thorough evaluation should rule out other causes of cognitive loss prior to making a diagnosis of dementia.

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 can be 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. Physical and chemical restraints should be used only as a last resort. There are many proven alternatives to physical and chemical restraints that are the mainstays of individualized care.

Activities of daily living are disrupted in those with dementia. As the dementia gets worse, family members and caregivers must step in an assist with personal care and household management. Individual and group activities can provide a sense of accomplishment and well-being.

Caregiver training is an essential component for anyone caring for a person with dementia. 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 their family member in a care facility. In a facility, professional caregivers must be trained to view the person with ADRD in the context of a family.

Facilities built around a philosophy of person-centered care can have a profound and positive effect on challenging behaviors associated with dementia. Providing a safe, clean, home-like environment in which residents and staff work together has been shown to improve outcomes in those with dementia.

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 and References

Resources

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.

alzonline.phhp.ufl.edu/

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

www.cje.net/

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

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

www.nccdp.org

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.

sharethecare.org/

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 online community, daily inspiration, and much needed support.

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, presents Fearless Caregiver conferences, and offers a website that includes newsletters, online discussion lists, articles from *Today's Caregiver*, chat rooms, and an online store.

Caregiver.com

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Post Test ADRD 3 (200)

Use the answer sheet following the test to record your answers.

1. In Alzheimer’s, damage is thought to be related to a pathological triad. This involves:

    a. Exposure to aluminum, male gender, and inflammation within the damaged parts of the brain.

    b. The formation of beta-amyloid plaques and neurofibrillary tangles and degeneration of cerebral neurons.

    c. Inflammation that starts in the peripheral nervous system, exposure to lead, and degeneration of brainstem neurons.

    d. Female gender, old age, and loss of the sense of smell.

2. 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 with Lewy bodies.

3. Alzheimer’s disease is typically diagnosed by:

    a. A test that shows the amount of beta-amyloid plaques in the blood.

    b. Biomarkers, which show abnormal substances in urine.

    c. Symptoms, including a gradual decline in mental capacity and changes in behavior.

    d. Magnetic resonance imaging.

4. 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.

5. Depression is characterized by:

    a. Short-term memory loss and the propensity to get lost in familiar places.

    b. Permanent damage to the brain tissue, leading to an inability to concentrate.

c. Sleep disturbances lasting less than one month.

d. Distorted or pessimistic thought, sleep disturbance, and inability to concentrate.

6. The ABC approach to behaviors in ADRD includes:

a. Approach, behavior, compensate.

b. Antecedent, best option, consequence.

c. Approach, beware, consequence.

d. Antecedent, behavior, consequence.

7. Wandering can be addressed by:

a. Redirecting to a purposeful activity.

b. Verbally admonishing a person to stop or else.

c. Discussing the behavior with the doctor.

d. Restraining the person in a wheelchair.

8. Delusions and hallucinations in people with dementia can be caused by:

a. Loss of control, discomfort, or the inability to communicate discomfort.

b. Boredom, pain and discomfort, disorientation, and memory problems.

c. Degeneration of neurons in the part of the brain that controls circadian rhythms.

d. Health factors such as urinary tract infections or environmental factors such as poor lighting or sensory overload.

9. Mrs. Winkler pinches and bites her caregivers when they attempt to bathe her. The best response to this behavior would be to:

a. Ask her family to come in and bathe her.

b. Restrain her in a shower chair and bathe her anyway.

c. Don’t bathe her when her behavior is bad.

d. Observe her behavior to determine the cause of her agitation.

10. 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.

11. Basic 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

12. Instrumental activities of daily living (IADLs) include:

a. Cooking, shopping, and medical management
b. Eating, bathing, and dressing
c. Housework, bathing, and grooming
d. Transferring from bed to chair, toileting

13. In terms of ADLs, signs of moderate dementia can include:

a. Losing car keys several times a day.
b. The need for increased assistance with ADLs.
c. Compete dependence on caregivers.
d. Trying to cover up deficits by making up stories.

14. When assisting a resident who has moderate dementia with personal grooming, the best action is to:

a. Give the resident something else to do as a distraction.
b. Do it quickly so that the person does not have time to fight back.
c. Do not allow the resident to assist because it will prolong the task.
d. Make the tools available, encourage participation, and allow simple choices.

15. Your patient is in the moderate stage of dementia and has urinary incontinence. The best initial intervention is to:

a. Show her where the bathroom is and tell her to use it regularly.
b. Set up and assist her with a regular toileting schedule.
c. Use a diaper or an adult brief and encourage her to urinate in the diaper.
d. Remind her to use the bathroom as soon as she feels the urge.

16. Bathing at any stage of dementia is best managed by:

a. Proceeding with bathing as scheduled regardless of the resident's wishes.

b. Changing from a shower to a bed bath.

c. Enlisting the assistance of a co-worker to prevent injury.

d. Engaging the resident, allowing choices, and keeping the person comfortable.

17. A person who is in the moderate to severe stages of dementia might enjoy:

a. Listening to music that was popular when he was young.

b. Learning how to knit.

c. Reading books and discussing them with other residents.

d. Doing crossword puzzles if she enjoyed them earlier in life.

18. Your patient, 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. Take him to group activities even if he protests.

d. Tell him he must come to activities.

19. Ann has been her husband's sole caregiver for six years. Ann's husband has severe dementia and Ann has been reluctant to reach out for help. Friends have recently noticed that she rarely leaves the house and when one visited she noticed the house was filthy, the bed was covered with dirt from the dog, and the bathroom hadn't been cleaned in months. Ann has recently been diagnosed with mild frontal-temporal dementia. Ann and her husband are well-off, own their own home, and rent another home to a friend. What might be happening with Ann?:

a. She is certain that she cannot afford to hire a caregiver.

b. She feels it is her duty as a spouse to provide care for her husband until he dies.

c. She may have cognitive changes related to her frontal-temporal dementia and may be unable to cope with her husband's worsening dementia.

d. She has a high degree of confidence in her role as a caregiver and wants to care for her husband rather than clean the house.

20. In the early stages of dementia, it is recommended that family members:

a. Receive early, specialized training about dementia.

b. Quit their jobs and provide 24/7 care.

c. Take over as many tasks as possible so the person with dementia is well-cared for.

d. Go on with your life and ignore any changes in their loved one.

21. Grief can manifest itself in physical symptoms such as shortness of breath, headaches, fatigue, a feeling of heaviness, and a lack of energy.:

a. True

b. False

22. Person-centered care:

a. Is the same thing as task-centered care.

b. Is only used when pharmacotherapy fails.

c. Usually increases unwanted behaviors.

d. Tailors care to residents' and caregivers' needs and preferences.

23. The use of design as a therapeutic tool recognizes:

a. That there is a connection between the environment and how people behave.

b. The environment has little impact on those with dementia.

c. People with dementia can no longer rely on environmental cues to support them physically, cognitively, and emotionally.

d. That people with dementia do fairly well in unfamiliar, chaotic, or disorganized environments.

24. To encourage integration of the staff into a homelike environment:

a. Increase signage for staff and visitors.

b. Rotate staff so residents get to know everyone.

c. Eliminate institutional, centralized nursing stations.

d. Clearly mark all doors, including doors to utility areas and staff lunch room.

25. The principle of beneficence is:

a. The intention to do good.

b. Never used to make ethical decisions.

c. Not really applicable to people with ADRD.

d. Difficult to apply to ethical situations.

26. A key principle of bioethics is to understand and remember that people with dementia remain the same, equally valued, people throughout the course of their illness, regardless of the extent of the changes in their mental abilities. :

  a. True
  b. False

Answer Sheet

Alzheimer's Disease and Related Dementias, 3 units (200)

Name (Please print your name): ______________________________

Date: __________

Passing score is 80%

1. _______
2. _______
3. _______
4. _______
5. _______
6. _______
7. _______
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20. _______
21. _______

22.________

23.________

24.________

25.________

26.________

Course Evaluation ADRD 3 (200)

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

* Upon completion of the course, I was able to:

a. Relate the NIA-AA diagnostic criteria for Alzheimer’s disease.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

b. Spell out the differences between onset, cause, and duration of dementia, delirium, and depression.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

c. Identify 3 common behavioral and psychological symptoms of dementia.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

d. Provide a definition for physical and chemical restraint.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

e. Describe how mild, moderate, and severe dementia affects a person’s ability to complete basic activities of daily living.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

f. Relate the 3 components that should be part of individual and group activities for residents with dementia.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

g. Describe 3 ways in which stress can affect a caregiver’s quality of life.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

h. Describe 3 issues family caregivers face as their loved one transitions from mild to moderate to severe dementia.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

i. Identify 3 philosophical concepts that are important in the design of a therapeutic environment for those with dementia.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

j. Identify common ethical conflicts that may arise when caring for residents with ADRD.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

* The author(s) are knowledgeable about the subject matter.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

* The author(s) cited evidence that supported the material presented.

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

* This course contained no discriminatory or prejudicial language.

○ Yes ○ No

* The course was free of commercial bias and product promotion.

○ Yes ○ No

* As a result of what you have learned, do you intend to make any changes in your practice?

○ Yes ○ No

If you answered Yes above, what changes do you intend to make? If you answered No, please explain why.

* Do you intend to return to ATrain for your ongoing CE needs?

○ Yes, within the next 30 days.

○ Yes, during my next renewal cycle.

○ Maybe, not sure.

○ No, I only needed this one course.

* Would you recommend ATrain Education to a friend, co-worker, or colleague?

○ Yes, definitely.

○ Possibly.

○ No, not at this time.

* What is your overall satsfaction with this learning activity?

○ 5 ○ 4 ○ 3 ○ 2 ○ 1

* Navigating the ATrain Education website was:

○ Easy.

○ Somewhat easy.

○ Not at all easy.

* How long did it take you to complete this course, posttest, and course evaluation?

○ 60 minutes (or more) per contact hour

○ 50-59 minutes per contact hour

○ 40-49 minutes per contact hour

○ 30-39 minutes per contact hour

○ Less than 30 minutes per contact hour

I heard about ATrain Education from:

○ Government or Department of Health website.

○ State board or professional association.

○ Searching the Internet.

- ○ A friend.
- ○ An advertisement.
- ○ I am a returning customer.
- ○ My employer.
- ○ Other
- ○ Social Media (FB, Twitter, LinkedIn, etc)

Please let us know your age group to help us meet your professional needs.

- ○ 18 to 30
- ○ 31 to 45
- ○ 46+

I completed this course on:

- ○ My own or a friend's computer.
- ○ A computer at work.
- ○ A library computer.
- ○ A tablet.
- ○ A cellphone.
- ○ A paper copy of the course.

Please enter your comments or suggestions here:_______________________________________

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Registration Form ADRD 3 units (200)

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

* Name: ______________________________

* Email: ______________________________

* Address: ______________________________

* City: ______________________________ * State: ________ * Zip: ________

* Country: ______________________________

* Phone: ______________________________

* Professional Credentials/Designations:

____

Your name and credentials/designations will appear on your certificate.

* License Number and State: ______________________________

* Please email my certificate:

○ Yes ○ No

(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 ○ Master Card ○ American Express ○ Discover

* Card number: ______________________________

* CVS#: ________________

* Expiration date: ________________