Florida: Alzheimer’s Disease and Related Dementias for Nursing Homes, Adult Day Care, and Hospice, 3 units

Contact hours: 3
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Cost: $29
Course expires: May 30, 2026

Certified Trainer: The author is certified as ADRD trainers by the Florida Department of Elder Affairs and is available via e-mail or by phone Monday–Friday (Pacific Time) from 9 a.m. to 5 p.m. at 707 459 3475.

Florida DOEA Approval: Approved by the Florida Department of Elder Affairs for Nursing Homes (NH AD 10194), Adult Day Care (ADC AD 10195), and Hospice (HSP AD 10196). Approval through May 30, 2026.

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

Course Objectives

1. Describe the 2 pathophysiologic components thought to be part of the pathology in Alzheimer’s disease.
2. Identify 5 challenging behavioral and psychological symptoms of dementia.
3. Provide 3 best practice guidelines for the use of physical or chemical restraint.
4. Describe 3 best practices that can be broadly applied when assisting someone with activities of daily living at all stages of dementia.
5. List 4 benefits of a well-designed activities program.
6. Describe 3 ways in which caring for someone with dementia can affect a caregiver’s quality of life.
7. Explain 3 issues family caregivers face as their loved one transitions from mild to moderate to severe dementia to end-of-life.
8. Identify 3 concepts that are important in the design of a therapeutic environment for those with dementia.
9. Identify 4 key concepts that are part of an ethical approach to dementia care.

Instructions for Mail Order

Once you’ve finished studying the course material:

1. Record your test answers on the answer sheet.
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[Continue to next page to start course]

1. Causes of Alzheimer's and Related Dementias

Although dementia has probably been around since humans first appeared on earth, it is only as we live longer that we have begun to see its widespread occurrence in older adults. The most common 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 50 million people live with dementia and because people are living longer this number is expected to triple by 2050 (ADI, 2019). In Florida, there are 580,000 residents over the age of 65 currently living with Alzheimer's disease (Alzheimer's Association, 2023a) and by 2025, this number is expected to increase by more than 200,000.

In Florida, about 43% of residents in certified nursing homes have dementia and an additional 30% have some other psychological diagnosis (Harrington and Carrillo, 2018). This means understanding the issues and complexities associated with Alzheimer's disease and other types of dementia is critical for family, friends, and anyone working in a nursing home, adult day care facility, or hospice, no matter what their education, training, or background.

During the COVID-19 pandemic, the number of residents living in nursing facilities in the U.S. decreased by 13%. This data reflects longer-term trends as people increasingly opt to receive care in home and community-based settings over institutional settings. COVID-19 exacerbated that trend—in part because nursing facility residents and staff incurred so many deaths during the pandemic (Chidambaram, 2022).

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 the progressive, global deterioration of the brain's executive functions. Dementia occurs primarily in later adulthood and is a major cause of disability in older adults. Although almost everyone with dementia is elderly, dementia is *not* considered a normal part of aging.

The exact cause of dementia is still unknown. In Alzheimer's disease, and likely in other forms of dementia, damage within the brain is thought to be due to the formation of *beta-amyloid plaques*, the formation of *neurofibrillary tangles*, and degeneration neurons in the cerebrum. These processes are clearly explained in the following video.

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

https://www.youtube.com/watch?v=NjgBnx1jVIU

Source: National Institute on Aging

In Alzheimer's disease, damage 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, part of the brain's limbic system (shaded in blue).

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

As the disease progresses, plaques and tangles spread to the front part of the brain (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.

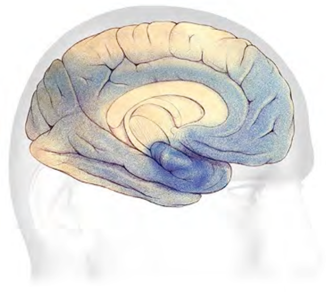
Moderate Alzheimer's Disease

	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 damage (dark blue) in the area of the hippocampus, where new, short-term memories are formed. 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.

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.

Changes in the brain may begin a decade or more before symptoms appear. During the very early stage of Alzheimer's, toxic changes are beginning to affect the brain, including abnormal buildups of proteins that form amyloid plaques and tau tangles. Previously healthy neurons damaged by these abnormalities lose connections with other neurons and eventually die. As these changes progress, cognitive changes begin to occur.

Types of Dementia

Although Alzheimer's disease is the most common cause of dementia, it isn't the only cause. Frontotemporal degeneration—which begins 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, more than twenty different types of dementia have been identified.

Some Common Types of Dementia

Dementia subtype	Characteristic symptoms	Neuropathology	% of cases
*Alzheimer's disease (AD)	• Gradual onset • Impaired memory, apathy and depression • Language and visuospatial deficits • Changes in mood, anxiety, and sleep • Later stage: impaired judgment, confusion, major behavioral changes, neuropsychiatric symptoms	• Cortical amyloid plaques • Neurofibrillary tangles	60–80%
Frontotemporal degeneration	• Early onset (45 to 60 yrs of age) • Behavioral and personality changes • Mood changes • Disinhibition, inappropriate touching, loss of social decorum • Loss of empathy • Language difficulties due to progressive aphasia • Problems with spatial orientation	• No single pathology, considered a "family" of neurodegenerative disorders • Damage initially limited to frontal and temporal lobes • 3 subtypes o Behavior variant frontotemporal dementia o Primary progressive aphasia o Disturbances of motor function	5–10%, prevalence thought to be underestimated
*Vascular dementia	• Stepwise onset • Similar to AD, but memory less affected, and mood fluctuations more prominent • Physical frailty • Patchy cognitive impairment • Often preventable	• Any dementia related to cerebrovascular disease • Most common cause is related to cerebral small vessel disease • Single infarcts in critical regions, or more diffuse multi-infarct disease • Considered a "group" of syndromes	20–30%
Dementia with Lewy bodies (closely related to Parkinson's disease dementia)	• Marked fluctuation in cognitive ability • Executive and attentional deficits • Rapid eye movement sleep behavioral disorder • Visual hallucinations • Significant visuospatial deficits • Parkinsonism (tremor and rigidity) • Adverse reactions to antipsychotic medications	• Cortical Lewy bodies (alpha-synuclein) • Autonomic dysfunction o Symptomatic orthostasis o Decreased or increased sweating o Excessive salivation o Heat intolerance o Urinary dysfunction o Impotence o Constipation	~5-10%

*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, 2019.

Diagnostic Guidelines

Diagnosis of Alzheimer's disease and other types of dementia is based primarily on clinical signs and symptoms; there is no *single* test or technique that can diagnose dementia. A combination of tools such as medical history, neurological exams, cognitive and functional assessments, brain imaging (MRI, CT, PET) and cerebrospinal fluid or blood tests are increasingly being used to make an accurate diagnosis (Alzheimer's Association, 2023b).

To guide clinicians, in 2011 the National Institute on Aging and the Alzheimer's Association (NIA-AA) published updated earlier diagnostic guidelines to provide a deeper understanding Alzheimer's disease. The 2011 guidelines:

- Recognize that Alzheimer's disease progresses on a spectrum with three stages: (1) an early, preclinical stage with no symptoms; (2) a middle stage of mild cognitive impairment; and (3) a final stage marked by symptoms of dementia. Cognitive decline is gradual and progressive.
- Expand the criteria for Alzheimer's dementia beyond memory loss as the first or only major symptom and recognize that other aspects of cognition, such as word-finding ability or judgment, may become impaired first. Other findings can include changes in:
    - episodic memory
    - executive functioning
    - visuospatial abilities
    - language functions
    - personality and/or behavior
- Reflect a better understanding of the distinctions and associations between Alzheimer's and non-Alzheimer's dementias, as well as between Alzheimer's and disorders that may influence its development, such as vascular disease, delirium, or stroke.
- Recognize the potential use of biomarkers—indicators of underlying brain disease—to diagnose Alzheimer's disease. However, the guidelines state that biomarkers are almost exclusively to be used in research rather than in a clinical setting.

National Institute on Aging, 2020

Since the publication of the 2011 guidelines, researchers have increasingly come to understand that cognitive decline in AD occurs continuously over a long period, and that progression of biomarker measures* is also a continuous process that begins before symptoms are evident. The disease is now regarded as a continuum rather than three distinct clinically defined stages (Jack et al., 2018).

*β amyloid deposition, pathologic tau, and neurodegeneration/neuronal injury.

A 2018 update of the 2011 NIA-AA diagnostic guidelines added a "numerical clinical staging scheme." This staging scheme reflects the sequential evolution of AD from an initial stage characterized by the appearance of abnormal biomarkers in asymptomatic individuals. As biomarker abnormalities progress, the earliest subtle symptoms become detectable. Further progression of biomarker abnormalities is accompanied by progressive worsening of cognitive symptoms, culminating in dementia (Jack et al., 2018).

The numerical clinical staging scheme is as follows:

1. Performance within expected range on objective cognitive tests.
2. Normal performance within expected range on objective cognitive tests. (Transitional cognitive decline: Decline in previous level of cognitive function, which may involve any cognitive domains.
3. Performance in the impaired/abnormal range on objective cognitive tests.
4. Mild dementia.

5. Moderate dementia.
6. Severe dementia.

Jack et al., 2018

An Alzheimer’s Association workgroup published a report describing the need for *clinical* practice guidelines for use in primary and specialty care settings. The guidelines build on the NIA_AA guidelines but add a clinical component for the evaluation of cognitive impairment thought to be related to Alzheimer’s disease or a related type of dementia.

Key components include:

- All middle-aged or older individuals who self-report or whose care partner or clinician report cognitive, behavioral, or functional changes should undergo a timely evaluation.
- Concerns should not be dismissed as “normal aging” without a proper assessment.
- Evaluation should involve not only the patient and clinician but, almost always, also involve a care partner (e.g., family member or confidant).

Atri, 2019

Brain Imaging

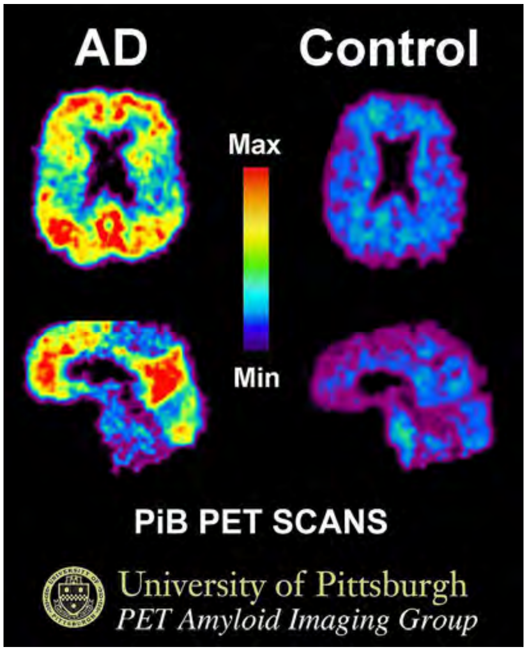
Brain imaging such as structural imaging, functional imaging, and molecular imaging, are increasingly being used to assist with the early diagnosis of Alzheimer’s disease and related dementias by detecting visible, abnormal structural, functional, or cellular changes in the brain.

Structural imaging uses magnetic resonance imaging (MRI) and computed tomography (CT) to provide information about the shape, position, and volume of the brain. It can be used to detect brain shrinkage, which is related to excessive nerve death. Structural imaging can also be used to reveal tumors, evidence of small or large strokes, damage from severe head trauma, or a buildup of fluid in the brain, as well as detect underlying conditions that may preclude an individual from certain treatments (Alzheimer’s Association, 2023b).

Functional imaging uses positron emission tomography (PET) and functional MRI (fMRI) to understand how cells in various brain regions are working by showing how actively the cells use sugar or oxygen. Studies has indicated that Alzheimer's is often associated with reduced use of glucose in areas of the brain associated with memory, learning, and problem-solving (Alzheimer’s Association, 2023b).

Molecular imaging uses PET and fMRI and targeted radiotracers to detect cellular or chemical changes linked to specific diseases. Four molecular imaging compounds have been approved for clinical use: Florbetaben, Florbetapir, and Flutemetamol have been approved for detection of beta-amyloid in the brain. Flortaucipir F18 has been approved for detection of tau in the brain (Alzheimer’s Association, 2023b).

Molecular Imaging Using a PET Scan



This PET scan shows show the uptake of a radiotracer called Pittsburg compound B (PiB). A patient with Alzheimer's disease is shown on the left and an elderly person with normal memory on the right. Areas of red and yellow show high concentrations of PiB in the brain and suggest high amounts of amyloid deposits in these areas. Source: By Klunkwe—Own work, CC BY-SA 3.0, https://commons.wikimedia.org/w/index.php?curid=5470244.

Biomarkers

Recent research has focused on discovering, evaluating, and validating biomarkers for application in clinical research. The goal is to provide evidence for earlier diagnostic and prognostic capability. Biomarkers are also employed to confirm and improve on diagnostic accuracy of dementia. In Alzheimer's disease, biomarker development and validation has focused primarily on cerebrospinal fluid (CSF), and PET to detect central nervous system amyloid beta (Aβ) or tau/tangles—the two pathological hallmarks of AD (Turner et al., 2020).

CSF biomarkers are measures of the concentrations of proteins in cerebral spinal fluid from the lumbar sac. They reflect the rates of both production (protein expression or release/secretion from neurons or other brain cells) and clearance (degradation or removal) at a given point in time.

Best practices for the use of CSF in patients with suspected dementia include: (1) determine whether CSF testing for AD biomarkers is appropriate for the patient; (2) educate the patient and family about the benefits and risks of testing, and assess their motivation and psychological readiness to learn more about their risk of AD; (3) ensure the procedure is performed with reliable assays following established guidelines; and (4) integrate the results into the evaluation and treatment plan in an in-person meeting with the patient and family (Shaw et al., 2018).

Sensory Impairment and the Changing Brain

Sensory impairments are often overlooked by caregivers and healthcare professionals when interacting with an older adult with dementia. Hearing, visual, and somatosensory impairments must be considered when assessing difficult behaviors, as well as a person's ability to complete common activities of daily living.

For a person with dementia, impairments related to hearing and vision are associated with adverse outcomes. For example, hearing impairment is associated with poor self-rated health, difficulties with basic and instrumental activities of daily living, difficulty with memory, frailty, and falls (Guthrie et al., 2018).

Similarly, visual impairment has been linked to an increased risk of mortality, difficulties with activities of daily living and mobility, and reduced social participation. Individuals with visual impairment also are more likely than those without visual impairment to require community-based supports (Guthrie et al., 2018).

Loss of cells in the part of the brain that processes vision (occipital lobe) causes a narrowing of the visual field and a loss of peripheral vision. Vision narrows and becomes binocular, and items placed on a table in front of a person (such as food) may be outside a person's visual field. Vision (especially peripheral vision) is critical for good balance and visual impairment means a person must rely heavily on touch to help with balance.

Because of damage to the visual pathways in the brain, the visual field narrows, making it difficult to see above, beside, and below. Source: National Eye Institute, National Institutes of Health. Public domain.

Macular degeneration, a common visual impairment in older adults causes loss of vision in the center of the eye, making it difficult to see something directly in front of you.

Normal vision on the left and damage cause by macular degeneration on the right. Source: National Eye Institute, National Institutes of Health. Public domain.

Conditions That Can Mimic Dementia

Medical conditions other than dementia can cause cognitive changes in older adults. Gerontology specialists speak of the "3Ds"—dementia, delirium, and depression—because these three conditions are common reasons for cognitive changes in older adults. Delirium and depression are often mistaken for dementia.

Delirium

Delirium is a sudden, severe confusion with rapid changes in brain function. Along with dementia, it is the most common cause of altered mental status in older adults (Gogia and Fang, 2023). Delirium has an abrupt onset, developing over hours or days and is typically temporary and reversible. It mainly affects attention but also is associated with changes in perception, mood, and cognition.

The most common causes of delirium in people *with* dementia are medication side effects, low or high blood sugar, fecal impactions, urinary retention, electrolyte disorders and dehydration, infection, stress, and metabolic changes. An unfamiliar environment, injury, or severe pain can also cause delirium. As a care provider with direct, daily contact with clients, your observations and feedback help other healthcare providers identify changes that may be treatable.

Delirium and dementia often co-exist although the pathophysiology remains poorly understood (Gogia and Fang, 2023). Delirium is under-diagnosed in almost two-thirds of cases and can be misdiagnosed as depression or dementia. Since the most common causes of delirium are reversible, recognition enhances early intervention. Early diagnosis can lead to rapid improvement (Hope et al., 2014).

Video: What is Delirium (2:51)

https://www.youtube.com/watch?v=ltyMJf1Z_pg

Source: Gateshead Health, National Health Service, England, U.K.

Depression

Depression is a common but serious mood disorder. **Major depressive disorder** is characterized by a combination of symptoms that interfere with a person's ability to work, sleep, study, eat, and enjoy activities. Some people may experience only a single episode within their lifetime, but more often a person may have multiple episodes (NIMH, 2023).

Persistent depressive disorder (also called dysthymia or dysthymic disorder) 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. **Depression with symptoms of psychosis** occurs when a person has severe depression, plus some form of psychosis—such as delusions or hallucinations. Psychotic symptoms typically have a depressive “theme,” such as delusions of guilt, poverty, or illness (NIMH, 2023).

Depression is very common in people with dementia. Depressive symptoms can cause distress, decrease quality of life, and exacerbate cognitive and functional impairment. It is often undiagnosed and untreated in people with dementia living in nursing homes, even though a high prevalence of depression has been reported for nursing home residents (O’Sullivan et al., 2022).

Comorbid depression in a person with dementia is associated with a profound decrease in quality of life, accelerated cognitive decline, increased mortality, and caregiver stress. The diagnosis and treatment of depression in people with dementia should be a clinical priority (O’Sullivan et al., 2022).

Even in the absence of dementia, depression can cause a person to feel hopeless, worthless, or helpless. Feelings of sadness, anxiety, or emptiness are common in addition to loss of interest in activities that were once pleasurable. Decision-making, concentration, and memory can also be affected. Because these symptoms often overlap with cognitive decline, caregivers may fail to recognize the difference between symptoms of depression and dementia and therefore offer no treatment. Other symptoms of depression can include:

- Irritability, restlessness, or having trouble sitting still.
- Moving or talking more slowly.
- Thoughts of death or suicide, or suicide attempts.
- Aches or pains, headaches, cramps, or digestive problems without a clear physical cause and/or that do not ease with treatment.

NIA, 2021

2. Behavior Management

Behavioral changes in people with dementia are generally called *behavioral and psychological symptoms of dementia* (BPSD). Anyone who has worked with someone with dementia is familiar with at least some of the difficult behaviors associated with dementia. Some behaviors are associated with brain changes while others are caused by frustration, loss of control, discomfort, pain, and the inability to communicate needs. Some are caused by poorly trained caregivers and healthcare providers.

There is no doubt that the caring for a person exhibiting a challenging behavior puts a great deal of stress on caregivers. Whether caring for someone at home, in adult day care, in a nursing home, or in hospice, difficult behaviors are emotionally and financially costly. In nursing homes, where up to 97% of residents with dementia experience at least one behavioral symptom of dementia (Scales et al., 2018), the cost of care is three times higher than that of other nursing home residents (Ahn & Horgas, 2013).

Understanding The Root Cause of Difficult Behaviors

Often behavioral symptoms of dementia can be addressed with proper staff training, environmental modifications, pet therapy, social engagement, and good communication. Unfortunately, there is strong evidence that much of the frustration that people with dementia experience is due to negative environmental influences, including staff attitudes, behaviors, and care practices.

One common-sense approach—the *problem-solving approach*—addresses challenging behaviors by looking for the root cause of a behavior. This approach encourages caregivers to get in the habit of observing the *antecedent*, *behavior*, and *consequence* (A, B, C) of a challenging behavior.

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

The problem-solving approach is very effective when insights are shared by staff, caregivers, and family members. This helps caregivers understand when (and how often) a behavior occurs and offers caregivers the opportunity for discussion and planning. To be successful, interventions and training must occur at the individual and group level, as well as at the levels of management and organization.

Common Challenging Behaviors

When considering the most common challenging behaviors seen in a person with dementia, several stand out: agitation and aggression, rummaging and hoarding, delusions and hallucinations, and sleep disturbances. Behaviors will typically change as dementia progresses although a person-centered, individual approach to management is always recommended, no matter what a person’s level of cognitive change.

Agitation and Aggression

Agitation occurs in over 40% of care home residents, 75% of older hospital patients with dementia, and as many as half of people with severe dementia. It is broadly defined as restlessness, pacing, shouting, and verbal or physical aggression. Agitation is complex, with a range of biological, psychological, and social causes. It may be a direct result of loss of cells in the area of the brain that controls behavior or an expression of pain or thirst, difficulties with communication, discomfort, and emotional distress (Sampson et al., 2019).

Sometimes agitation can result in aggression, which can be difficult, harmful, and exhausting for patients and caregivers. The impact on nursing and other healthcare providers can include burnout, sick leave, turnover, and increased economic costs. Because many people with dementia live in skilled nursing facilities, assisted living, or are seen in acute care hospitals, it is crucial to explore how staff in these settings understand and respond to agitation, particularly near the end of life (Sampson et al., 2019).

Depending on the type and severity of a person's cognitive changes, agitated and aggressive behaviors may become more pronounced as the dementia progresses. Agitated and aggressive behaviors often occur during personal care tasks involving close contact and may be related to a perceived threat or violation of personal space. In the early stages of dementia, when activities of daily living are independent (or nearly so), there is less need for direct help, less need for caregivers to be in one's personal space, and more personal control.

As dementia progresses, a person's view of the world changes: conversations are more difficult, daily tasks take longer to complete, fatigue increases, tasks that used to be done without thinking require a major effort. To make matters worse, everyone around you moves too fast. Agitation and anxiety make sense if you consider the changes that are occurring in a person's visual field, hearing, depth perception, ability to communicate, ability to walk, and independence.

Caregiver training is essential. Psychosocial and environmental interventions, recognition of personal habits and patterns can reduce or eliminate agitated or aggressive behaviors. Antipsychotics, although contraindicated in frail older adults, are sometimes used for a limited amount of time to reduce aggression (especially if related to psychosis), particularly among those most severely agitated. In frail, older adults, antipsychotics are usually contraindicated because they can increase mortality and worsen cognitive impairment.

Wandering

Wandering is a normal human activity that most people enjoy. In the early stage of dementia wandering is usually not seen as a problem. Wandering can involve moving to a specific location, lapping, or circling along a path, pacing back and forth, or wandering at random. More than half of people with dementia will wander at some point during the course of their disease.

Although wandering can appear aimless, hyperactive, and excessive—especially in the later stages of dementia, from the standpoint of the person with dementia, it is a normal activity. People wander out of habit, out of curiosity, or because they are convinced something needs to be done such as cleaning or cooking. Wandering warms a person and relieves depression, boredom, pain, and discomfort.


A woman wandering. Source: National Institute on Aging. Public domain.

Wandering is not limited to walking: people who have transitioned from walking to the use of a wheelchair also wander. There is no reason to discourage this sort of activity as long as it can be done safely. Wheelchairs can usually be lowered to allow a person to self-proper with their feet and seating systems with drop seats can be installed in wheelchairs if the chair cannot be lowered.

Wandering is thought to be most common in people with AD, and individuals who frequently wander almost always have at least moderate dementia. Wandering can also occur in people with moderate to advanced stages of frontotemporal dementia and Lewy body dementia although few studies have compared wandering rates among people with different types of dementia. The presence of comorbid neuropsychiatric symptoms such as severe depression, sleep disorders, and psychosis may increase the likelihood of wandering (Thomas and Ritter, 2022).

For safety reasons, caregivers and healthcare providers may want to control or prevent wandering. However, preventing residents from safely wandering can create other problems such as boredom, loss of social interaction, stigma, loss of conditioning, and even skin breakdown.

A person-centered, team approach involving healthcare providers, families, and even other residents can be successful in managing wandering. Facilities that provide safe, looping wandering paths with numerous rest areas, regular exercise and activities, and have measures in place to prevent a person with dementia from wandering into client rooms, have a great deal of success managing this behavior.

Easy-to-grasp rails, grab bars, transfer poles, and ballet-type bars liberally installed throughout a facility encourage safe mobility and prevent falls. Clean, clear hallways provide easy access to rails and bars.

Discrete and affordable wearable devices that have GPS tracking have significantly expanded the number of options available to address wandering and elopement*. These include GPS tagging, bed and door alarms, and surveillance systems. These devices have not been tested in controlled studies however, making it hard to make firm conclusions regarding efficacy. The ethical implications of using these technologies—including potential infringements on privacy, dignity, and autonomy of individuals—are seldom considered in clinical trials or clinical practice (Thomas and Ritter, 2022).

***Elopement**: attempting to escape or escaping a facility or home.

A Canadian study sought input about wandering from older adults with dementia living in a longterm care facility. Researchers discovered that, from the perspective of the older adults themselves, wandering was a pleasurable activity they considered healthful, purposeful, and social. Wandering was described as an expression of unmet needs, such as a desire to be with family, to relieve boredom, or to continue a lifelong habit. Residents shared six reasons why wandering or walking was important to them:

1. It is enjoyable.
2. It has health benefits.
3. It provides purpose.
4. It has been a lifelong habit.
5. It is a form of socialization.
6. It provides a chance to be with animals.

(Adekoya and Guse, 2019).

A person’s pre-dementia lifestyle is also a factor in the desire to walk or wander and certain personality traits are evident is people who wander:

- An active interest in music.
- An extroverted personality showing warmth, positive emotion, altruism.
- A history of involvement in social activities and social-seeking behaviors.
- A physically active lifestyle.
- A history of stressful events throughout their life, necessitating multiple readjustments.
- A habit of responding to stress by engaging in motor activities.

(Futrell et al., 2010).

Imagine you are working with a person whose lifestyle involved a lot of walking and exploring. They now living in an unfamiliar environment and are being prevented from moving about. Stopping the natural tendency to explore, to become familiar with a new living space, and to socialize with new people can be extremely frustrating. For some people, this can lead to depression, anger, and behavioral problems.

For people who wander away from their home or care facility, Florida maintains a *Silver Alert* program for cognitively impaired older adults who become lost while driving or walking. The *Silver Alert* program broadcasts information to the public so they can assist in the rescue of the endangered person and notify law enforcement with helpful information. For more information, contact the Silver Alert information line, local law enforcement, or the Florida Department of Law Enforcement either online or by phone at 888 356 4774.

The Wanderer

Elena is a resident in a 5-story nursing home in Miami. She has moderate dementia and although she is non-ambulatory, she is very good at propelling her wheelchair. After breakfast in her room, an aide wheels her to the activities room and leaves her alone at a table with a jigsaw puzzle. After about 15 minutes Elena gets bored with the puzzle, exits the activities room, and heads down the hall. She is stopped twice by staff members, who turn her around toward the activities room with a reprimand.

When the staff member is out of sight, Elena turns back around and continues in the direction she was headed. She stops near an elevator, where she sits for a while watching people come and go. Several more staff members pass by and gently remind her not to get on the elevator. Each time she is left in the same place next to the elevator. Finally, when no one is looking Elena wheels into the elevator.

Antecedent (what causes a certain behavior): Elena is curious and used to like walking around Miami, exploring the different neighborhoods. She was never one to sit around doing nothing. She was bored with the jigsaw puzzle and wanted to do something more interesting. She rolls out into the hallway and stops near an interesting door that opens and closes with a satisfying swoosh sound. The people going in and out of the door smile at her.

Behavior: The door to the elevator is an interesting visual cue and Elena enjoys seeing people coming and going. People talk to her—and she likes the interaction—but she doesn't understand what they are saying. She sits for a while watching people come and go and when the opportunity arises, she enters the elevator. When the door opens on the ground floor, she wheels out of the elevator, heads to the front door, and out onto the street. Her behavior is consistent with her personality and her previous habits.

Consequence: Once she gets into the elevator, Elena's inability to think logically puts her at risk. She exits the elevator next to a door that leads out of the building and wanders into the street. Fortunately, someone sees her wandering down the middle of the street and convinces her to return to the nursing home.

Discussion: Large nursing homes are busy places, often understaffed, and often poorly designed for people with dementia. Nevertheless, caregivers and healthcare providers should try to understand the reason for Elena's wandering and come up with activities that are appropriate for a person like Elena. Regular medications reviews will help staff understand if Elena's behavior is related to medication side effects, overmedicating, or drug interactions. To keep Elena out of the elevator:

- Redirect her to a *purposeful* activity.
- Provide places where she can wander safely.
- Schedule regular exercise.
- Offer simple, meaningful chores.
- Attach an electronic device that alerts caregivers when she has wandered out of a designated area.
- 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.
- Take her for regular outings outside the building.
- Allow her to keep a bird or pet in her room.
- Provide safe, meaningful outdoor activities.

Rummaging and Hoarding

Rummaging and hoarding occur when a person obsessively gathers, hides, or puts away items in a secretive and guarded manner. These behaviors are not necessarily dangerous or unsafe, but they can be frustrating for caregivers, healthcare personnel, and other residents. In a way, rummaging is similar to wandering—a desire to explore, to do something meaningful, or to complete a task.

A person **without** dementia may hoard due to fear of losing money or possessions, a lack of control, or a need to "save for a rainy day." A person with mild dementia may rummage simply out of confusion or forgetfulness. Hoarding is associated with insecurity and anger and an attempt to hold onto possessions and memories from the past. These actions can be considered a type of obsessive-compulsive behavior.

In the early stage of dementia, rummaging is likely more goal-directed than in the later stages. When activities of daily living are independent or nearly independent, rummaging and hoarding might be carefully hidden and therefore invisible to caregivers. As cognition changes and short-term memory declines, hoarding and rummaging can become more pronounced. For a caregiver, rummaging can appear completely obsessive and illogical.

As dementia progresses, 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 fear being robbed (or may actually have been robbed) and feel a need to protect their possessions. Rummaging through familiar items can create a sense of safety and security.

In the later stage, rummaging and hoarding can become a real problem for an elder-care facility. A person with significant cognitive changes might enter another person’s room and rummage through their belongings. At this stage, a person with moderate to severe dementia may not understand that certain rooms are off limits—after all, in our homes, we can go wherever we want without someone stopping us.

Rummaging in another person’s room can be prevented by installing locks on drawers and closets. The rummaging impulse can 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 the home—as well as in adult day care and nursing homes—important items such as credit cards or keys should be placed out of reach or in a locked cabinet. Caregivers may be able to identify patterns—rummaging behaviors may not be as illogical as they seem to observers. It is helpful to observe and understand a person’s favorite hiding places. Providing a place on a wheelchair or walker to store valuable items can provide a sense of control and safety for a person with dementia. Here are some safety considerations for a person who likes to rummage:

- Poisonous items such as caustic liquids should be stored in locked cabinets.
- Poisonous plants should be replaced with edible plants (or at least non-poisonous plants).
- Cabinets, doors, and closets should be labelled (with words or pictures) to help the person find what they are looking for.
- Clutter should be reduced—is visually and psychologically confusing.

Psychosis (Delusions and Hallucinations)

Psychosis is a neuropsychiatric symptom that can occur in people with dementia. Delusions, hallucinations, paranoia, euphoria, anxiety, disinhibition, or agitation are examples of psychosis. Sensory deficits such as impaired hearing or vision can contribute to psychosis because of distortions of sound or sight. For most people with dementia who experience psychosis, symptoms tend to worsen as cognition declines and dependence increases.

Although psychotic symptoms occur in AD, they are observed more frequently in other forms of dementia, such as Parkinson's disease–related dementia, Lewy body dementia, and vascular dementia. The prevalence of psychosis in other forms of dementia, such as frontotemporal dementia, tends to be quite low (Fischer et al., 2017).

Psychotic symptoms can be caused at any stage of dementia by health factors such as urinary tract infections and dehydration or environmental factors commonly found in nursing homes and day care facilities such as poor lighting, too much noise, or sensory overload. Changes in the brain contribute to these behaviors, especially changes related to sensory awareness, memory, and decreased ability to communicate or be understood.

Visual hallucinations can occur in the moderate to severe stages of dementia and are particularly common in a person with Lewy body dementia. While atypical antipsychotics are sometimes used off-label to manage hallucinations, for a person with Lewy body dementia, antipsychotic medications can make hallucinations worse.

The first step in the management of psychosis is to rule out delirium as a cause. Caregivers must also determine if the claims by the person did occur. For someone with new onset of visual hallucinations, the number one cause is medication side effects. For this reason, all medications should be carefully reviewed. This includes prescription and over-the-counter medications, as well as herbal supplements.

When communicating with someone who is expressing psychotic symptoms such as paranoia or delusions, realize that the complaint is real for that person. Do not argue; simply explaining the truth of the situation does not work. Do not agree with the person or validate the paranoia or delusion—try to respond to the person's emotion. Delusions and hallucinations are often successfully addressed using behavioral interventions. To manage hallucinations, decrease auditory and visual stimuli and evaluate for visual or hearing impairment. Other suggestions:

- Minimize violent or noisy TV.
- Remove wall hangings.
- Reduce noise, play relaxing music.
- Cover mirrors.
- Reduce glare from windows.
- Ensure adequate lighting.

Sleep Disturbances

Many older adults with dementia have sleep and circadian rhythm disturbances due to advanced age, the effects of certain chronic illnesses and medications, declining brain health, diminished mobility, and other causes. The American Geriatrics Society and the National Institute on Aging recognize a *geriatric syndrome* in which physical and mental risk factors overlap to increase risk for sleep and circadian disturbances. Numerous negative consequences are associated with sleep disturbances, including increases in cognitive decline, metabolic disease, high blood pressure, cardiovascular disease mortality, frailty, impaired quality of life, and hypersensitivity to pain (Capezuti et al., 2018).

Importantly, sleep disturbances can 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.

Sleep disruption can have the following features (Burns et al., 2012):

- Increased sleep latency
- Fragmented sleep and 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 daytime sleepiness.
- Agitation, verbally disruptive behaviors, hallucinations, and nighttime wandering.

In AD, and likely in other neurodegenerative diseases, sleep disorders appear early. Sleep disorders worsen as the disease progresses, and their progression in the late stage of the disease is a strong predictive factor for mortality (Brzecka et al., 2018).

Sleep disturbances and accompanying symptoms often lead providers to prescribe psychoactive medications, including hypnotics. About half of nursing home residents with dementia are prescribed sedative-hypnotics, especially when displaying anxiety and agitation. However, many of these medications have been associated with an increased risk of falls and fractures in older adults (Capezuti et al., 2018).

Medications used to treat behavioral symptoms of dementia, as well as those used to slow the progression of dementia, can cause daytime sleepiness and lead to sleep disturbances.
Before treating sleep disturbances, look for potentially treatable causes such as pain, hunger and thirst, the need to urinate, infections, adverse drug reactions, and even noise. Nonpharmacological treatments include:

- Light therapy
- Good sleep hygiene practices
- Exercise and individualized social activities
- Restriction of caffeine, nicotine, and alcohol
- Maintaining a calm, warm atmosphere

3. Physical and Chemical Restraints

The use of physical and chemical restraints is widespread in all settings despite evidence their use leads to functional and cognitive decline. Restraint use also contributes to loss of control, stigma, loneliness, loss of dignity, and boredom.

Despite decades of concern about their safety, effectiveness and appropriateness, physical restraints remain widely used in nursing homes—particularly for residents with poor mobility, high dependency, or dementia. Death by asphyxiation or mechanical compression is the most horrific complication of physical restraint (O'Keeffe, 2017).

The amount of restraint use in nursing homes varies, with some studies noting rates as high as 60% for certain types of restraint. It is not uncommon for a resident to be given both a chemical restraint (often atypical antipsychotics) and a physical restraint although chemical restraints are used most often. Not surprisingly, residents given both types of restraints have the worst outcomes (Foebel et al., 2016).

The Omnibus Budget Reconciliation Act of 1987 (OBRA 87) established a resident's right to be free of physical or chemical restraints in nursing homes when used for the purpose of discipline or convenience and when not required to treat the resident's medical symptoms. Uncooperativeness, restlessness, wandering, or unsociability are **not** sufficient reasons to justify the use of a restraint (GovTrack, 2023).

Use of restraints should be:

- Reserved for documented indications
- Time limited
- Frequently re-evaluated for their indications, effectiveness, and side effects in each patient

GovTrack, 2023

Florida Nursing Home Bill of Rights

In most states the use of physical and chemical restraints on nursing home patients is illegal. In Florida, the Nursing Home Bill of Rights states that a nursing home resident has

> . . . the right to be free from mental and physical abuse, corporal punishment, extended involuntary seclusion, and from physical and chemical restraints, except those restraints authorized in writing by a physician for a specified and limited period of time or as are necessitated by an emergency. In case of an emergency, restraint may be applied only by a qualified licensed nurse who shall set forth in writing the circumstances requiring the use of

> restraint, and, in the case of use of a chemical restraint, a physician shall be consulted immediately thereafter. Restraints may not be used in lieu of staff supervision or merely for staff convenience, for punishment, or for reasons other than resident protection or safety (Florida Statutes, 2020).

Physical Restraints

A **physical restraint** is any device, material, or equipment attached to or near a person's body that prevents a person from moving freely and can neither be controlled nor easily removed by the person.

Physical restraints include vests, straps, wrist ties, splints, mitts, belts, recliners, geri-chairs, and bedside rails, among others. Restraint can also include 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, latest available).

There are compelling arguments for reducing, if not eliminating, the use of physical restraints in nursing homes, and in particular among people who are in their last days of life. Physical restraints have been shown to be neither safe nor effective. They do not reduce risk of falls or injury. They can have negative physical consequences such as decubitus ulcers, urinary and fecal incontinence, and higher walking dependence. They can also cause psychological issues such as anger, anxiety, and depression and have negative social consequences for residents and family members (Pivodic et al., 2020).

Restraint use increases the risk and persistence of delirium and can lead to death. Clinical trials and non-randomized experimental studies showed that physical restraints in nursing homes can almost completely be eliminated with reasonable levels of safety (Pivodic et al., 2020).

Decision-making related to restraint use is a complex process, influenced by various factors. Research from nursing homes indicates that not only patient characteristics such as cognitive decline and poor mobility but also nonpatient-related factors such as the attitude and knowledge of healthcare providers and legislation affect decision-making about restraint use. Factors influencing restraint use include insufficient supervision, decreases in wellbeing of informal caregivers, and dissatisfaction with family support. Legislation or regulations may limit the use of restraints in some settings (Scheepmans et al., 2020).

Chemical Restraints

> Tens of thousands of nursing home residents with dementia receive powerful antipsychotic drugs that are not intended or approved for their medical conditions. Rather, the drugs are often used to sedate and control them, a terrible substitute for the individualized care they need and deserve. The U.S. Food and Drug Administration has issued its most dire warning—known as a black box warning—that antipsychotic drugs cause elders with dementia to die.
>
> California Advocates for Nursing Home Reform, 2012

A **chemical restraint** is the *intentional* use of any medications to subdue, sedate, or restrain an individual. Chemical restraints are commonly used to restrict a person's freedom of movement in acute, emergency, or psychiatric settings. Chemical restraints are often prescribed for what healthcare workers describe as dangerous, uncontrolled, aggressive, or violent behavior.

We do not usually think of a medication as having the potential to restrain a person's free movement. However, in older adults with dementia there is a long history of antipsychotic and sedative use—chemical restraints—to subdue or otherwise alter a person's behavior.

Anti-anxiety, antidepressant, and antipsychotic medications are commonly used to treat the behavioral and psychological symptoms associated with dementia. These medications affect mood, perception, consciousness, cognition, and behavior. They 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).

Antipsychotics carry a U.S. Food and Drug Administration black box warning in dementia; they must be used with extreme caution, ongoing monitoring, and only when strict conditions are met. Short-term and long-term antipsychotic use is associated with substantial risk of cognitive decline, morbidity, and mortality. The use of antipsychotics is reserved as a last resort for severe refractory behavioral disturbances without an identifiable and treatable cause or when a serious risk of immediate harm or safety exists that cannot be otherwise ameliorated (Atri, 2019).

The American Geriatric Society (AGS) Beers criteria for safe medication use in older adults list antipsychotics as potentially inappropriate medications (PIM) and recommend **avoiding** antipsychotics for treatment of behavioral symptoms or delirium in people with dementia due to the increased risk of cerebrovascular events and greater risk of cognitive decline and mortality. Further, antipsychotics should be avoided unless non-pharmacologic options have failed or are not possible and the older adult is threatening substantial harm to self or others (AGS, 2019).

Nevertheless, a prescriber may choose to prescribe antipsychotic medications for behavioral 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.

In 1987, a law signed by President Ronald Reagan banned the use of drugs in nursing homes that served the interest of staff rather than the patient, except "to ensure the physical safety of the resident or other residents." In 2012, the Centers for Medicare & Medicaid Services (CMS) began requiring nursing homes to report antipsychotic drug use data, which then became part of each nursing home's "quality of resident care" score that contributes to a facility's CMS star rating. However, nursing homes were not required to report antipsychotic prescriptions for patients who had any of three conditions: schizophrenia, Tourette's syndrome, and Huntington's disease (Advisory Board, 2023).

Medicare data shows that since then, the share of nursing home residents diagnosed with schizophrenia has risen 70%. And today, one in nine nursing home residents have been diagnosed with the disease, despite the condition affecting just around one in 150 people in the general population (Advisory Board, 2023).

Alternatives to Restraints

Many attempts have been made to reduce restraint use in clinical practice, with some notable successes. Most interventions use education and training aimed at addressing and resolving behavioral triggers.

Research into nursing homes suggests that a more favorable organizational context can lead to better person-centered care, a higher quality of care, lower rates of drug use, and less need to use restraints. Previous studies have found that nursing home facilities with more favorable organizational context, had lower rates of urinary tract infections and catheter use among older adults (Potrebny et al., 2022).

In addition, staff in favorable nursing home facilities generally reported greater job satisfaction, used best practice guidelines more often, and provided better treatment in relation to challenging behaviors related to dementia, combined with a more appropriate distribution of antipsychotic medication among older adults (Potrebny et al., 2022).

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. Changes intended to create a more dementia-friendly environment include:

- Redesigning nursing stations so they are part of a home-like design.
- Providing comfortable, easy-to-access alternative seating.
- Lowering wheelchairs to allow self-propelling with feet.
- Providing pressure-relief wheelchair and chair cushions to support comfort and reduce skin breakdown.
- Installing carpeting or rubber mats in key areas 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, improves comfort and reduces anxiety. Regular exercise and comfortable places to rest and nap are important. Other dementia-friendly psychosocial changes include:

- Assessing and treating hunger, thirst, cold, and discomfort.
- Changing medications or tapering medications with adverse effects.
- Treating all underlying causes, including pain.
- Assessing hearing and vision.
- Establishing a nap schedule.
- Relieving fecal impactions.

A nonpharmacological toolkit for reducing antipsychotic use in older adults by promoting positive behavioral health can be accessed online (www.nursinghometoolkit.com) (AGS, 2019).

> The humanity with which assistance for everyday living is offered, especially help with eating and intimate care, is crucial in helping people retain their self-esteem and dignity.
>
> 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 and increases over time.

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

- Eating and drinking
- Toileting and bathing
- Walking
- Grooming, dressing, and undressing
- Transfers

Instrumental ADLs (IADLs) are the skills needed to function within society and within the community. As with basic ADLs, these skills decrease as dementia progresses. IADLs include:

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

Direct caregivers, medical professionals, and family members, should understand and follow these best practices for all activities of daily living at all stages of dementia:

1. Engage people with dementia in interventions.
    a. Manage pain.
    b. Maintain a supportive environment.
    c. Take a holistic approach.
2. Compensate for a person's reduced abilities.
    a. Embed interventions in day-to-day life.
    b. Provide ongoing support.
    c. Involve caregivers.
3. Provide training and skills to employees working with people with dementia.
    a. Understand and know your patient.
    b. Train staff.
    c. Collaborate with other healthcare professionals and family members.

Wheatley et al., 2019

Symptoms, Stages, and Behavioral Symptoms

Caregiver responsibilities increase as dementia progresses. The ability to organize, sequence, and complete complex tasks such as shopping, cooking, and medication management begins to decline in the early stage of dementia. When a person begins to neglect these tasks, someone, often a family member or friend must step in to help. When short-term memory and logical decision-making begin to decline, caregivers must begin to oversee medical decisions, medication management, shopping, cooking, and other ADLs. The increase in caregiver responsibilities can be gradual or abrupt and may be confusing for everyone involved.

How Mild Dementia Affects ADLs

In the early stage of dementia, most people remain independent with basic ADLs. Many will begin to need help with instrumental ADLs—especially complex tasks requiring multiple steps or extensive planning. There likely will have been a gradual decline over several years, often unnoticed by family and friends. Basic activities of daily living such as eating, dressing, and bathing are likely still independent.

At this stage, a person may try to cover up any confusion by turning to others for help with simple tasks. This is a natural response to loss of cognitive abilities and may be accompanied by denial, anger, and excuses. 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 friends and family.

How Moderate Dementia Affects ADLs

As dementia progresses, instrumental ADLs such as work, medication management, and personal finances become more difficult. A person may begin to need help with some basic daily activities. Mobility is often still good and, if so, safety can become a concern. Caregiver responsibilities begin to increase, causing stress, anxiety, and worry for family members. In the moderate phase:

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

How Severe Dementia Affects ADLs

As dementia becomes more severe, independence is gradually lost and caregivers must provide close, direct care with most, if not all ADLs. At this stage, a person may require direct assistance with basic ADLs such as eating, bathing, transfers, and walking. Control of bodily functions may be inconsistent, requiring help with bathing and toileting. Family members may find it impossible to continue to provide needed care and may begin to consider an in-home caregiver, assisted living, or skilled nursing.

A person with severe dementia who still has good mobility may wander and require constant monitoring. If the person is lives at home, tired and overworked caregivers and family members must provide even more support with ADLs and to maintain a safe environment. If in a skilled nursing, adult day care, or assisted living situation, the facility must provide enough staffing and equipment to ensure a person's safety. Often, assisted living and skilled nursing facilities are understaffed and workers are untrained in dementia-friendly practices.

As severe dementia progresses, balance and safety awareness go from bad to worse, requiring significant direct help with transfers and mobility. People with dementia are much more likely to be at high risk for falls than people without dementia.

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.

End of Life / Hospice

As people near the end of life, most people will experience decreased appetite as well as difficulties swallowing food and water, which can increase the risk of aspiration pneumonia. They may be candidates for some type of artificial hydration, which can include enteral[1] or intravenous nutrition[2]. TPN is often used in the terminal state of malignancy (Takenoshita et al., 2017).

[1] **Enteral nutrition** mainly consists of nasogastric (NG) and percutaneous endoscopic gastrostomy (PEG) tube feeding.

[2] **IV nutrition** includes peripheral venous nutrition (PVN) and total parenteral nutrition (TPN).

The American Geriatrics Society has issued a position statement on tube feeding, which states that careful hand feeding is almost as good as tube feeding for the outcomes of comfort, aspiration pneumonia, functional status, and death. Hand feeding has the added benefits of being an intimate social interaction while avoiding the burdens and complications associated with tube feeding. Involving a dietician, who can offer dietary supplements in addition to the regular diets has proven effective in maintaining nutritional status in elderly people with advanced dementia (Ijaopo EO and Ijaopo RO, 2019).

In Florida, nearly 6% of residents in nursing homes receive nutrition via some sort of feeding tube (Harrington and Carrillo, 2018). The overreaching question is whether tube feeding is good for the patient or even necessary, especially those with end-stage dementia. In the latest stage of Alzheimer's, most people stop eating entirely, which is considered part of the natural course of the disease.

Strategies for Assisting with ADLs

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.

When assisting 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. For example, a caregiver in a nursing home may want to bathe a resident and get her dressed quickly because the caregiver has two more people to get dressed before breakfast. A caregiver in an adult day care facility may have multiple clients she needs to get to the lunchroom by noon but one of her clients may want to continue watching TV and want his lunch in his chair in the activities room. The resident's wishes should be respected.

ADL Strategies: Mild Dementia

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

- Dressing
    - Encourage choice
    - Allow resident or client to direct the activity
- Grooming
    - Allow residents or clients to groom themselves, provide tools as needed
    - Provide assistance only as needed
- Eating
    - Ask for food preferences, encourage choice
    - Encourage help with meal preparation and meal set-up
    - Provide adaptive utensils as needed
    - Provide assistance only as needed
- Bathing
    - Encourage choice
    - Assist with bathing or shower as needed
    - Monitor for safety and comfort
- Toileting*
    - Monitor and ask
    - 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.
**Dehydration can cause increased confusion.

ADL Strategies: Moderate Dementia

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 remain relatively independent. For others, especially those with physical limitations or underlying medical conditions, more help will be required. In the moderate stage of dementia:

- Dressing
    - Limit choices but encourage choice
    - Provide comfortable clothes with elastic waistbands and Velcro closures
    - Encourage independence
    - Provide assistance as needed
- 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, encourage independence
- 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 use the bathroom
  - 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 and may be independent or nearly so with bed mobility and transfers.

With severe dementia, anything that requires planning, sequencing, or judgment will be severely impaired, so close assistance is needed for dressing, bathing, meal preparation, grooming, and toileting. If mobility is compromised, close assistance will be needed for all ADLs. Remember to reintroduce yourself each time you meet the person you are assisting. 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 independence wherever 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 assistance
  - Offer liquids on a regular schedule

    - Allow plenty of time to finish eating
- Bathing*
    - Provide complete bathing care
    - Retain earlier bathing rituals 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.

ADL Strategies at the End of Life

End-of-life care for people with dementia can be complex for reasons other than cognitive impairment. Most people are frail and have multiple comorbidities. Near the end of life there are often complications that create dilemmas for healthcare providers and family members. A person may be agitated or experiencing difficulties with swallowing, eating, drinking, and taking oral medication and diminished immune response can cause increased susceptibility to infections (Davies et al., 2018). Loss of ability to verbally communicate, impaired hearing and vision, and the need for ever greater help with ADLs can be difficult for everyone involved.

Encouraging participation and independence in as many ADLs as possible is an important goal for caregivers. However, as the end of life approaches, comfort, companionship, skin care, and pain management become the primary focus. Active and active-assisted movement, such as reaching, rolling, standing, self-propelling a wheelchair, and participation in appropriate activities should be gently encouraged.

Bathing

Mrs. Cavalia has moderate dementia due to Alzheimer’s disease and lives in a nursing home. Tuesday is her shower day—an aide 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. Cavalia starts to fidget. As they approach the shower room she begins to yell and protest. When she is placed in the shower she screams and pushes her caregiver away.

Antecedent (what causes a certain behavior): In her room, the aide undresses Mrs. Cavalia and wraps her in a bath blanket. Unable to find a shower chair, she helps Mrs. Cavalia into a toilet chair. Mrs. Cavalia’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. Cavalia reaches the shower room she is very agitated. She slaps the aide and repeatedly grabs the shower door. The aide manages to get Mrs. Cavalia into the shower room, but when she turns on the water, Mrs. Cavalia screams, grabs the shower hose, and pushes the aide away. She sprays water all over the aide and into the hallway.

Consequence: The resident, staff, and the patient’s daughter are all upset. The situation created an unpleasant environment for everyone involved and showering has become a dreaded experience for Mrs. Cavalia.

Discussion: Find out how Mrs. Cavalia 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. Cavalia’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, hasn’t received dementia-friendly training, and hasn’t been told about Mrs. Cavalia’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.

5. Activities for Residents with Alzheimer’s

We all yearn for meaning in our lives. We like interacting with one another, teaching someone a new skill, and contributing to the success of an activity. In many institutional settings, we have stripped people of meaningful ways to contribute, to help, to learn, and to grow as a person.

Often, a person with dementia residing in a nursing home, another type of long-term care facility, or even in an adult day care facility, is not engaged in any activities. This leads to a perception of “warehousing”, the belief that moving to a facility or even participating in adult day care is nothing more than a place to be while waiting to die. Low levels of engagement and lack of stimulation are problematic because boredom and loneliness can lead to behavior challenges (Cohen-Mansfield, 2018).

The good news is that there have been some notable successes in the design of activity programs for people with dementia. A good activities program matches a person’s abilities with the activity. It encourages people with more mild cognitive changes to help and teach those with more severe dementia.

For example, Montessori-type activities 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 presented, tested, and refined. As a person’s dementia advances, activities are simplified. Facilitators present tasks deliberately, demonstrating them first, and using language as appropriate. People with mild dementia or no dementia are encouraged to help teach and demonstrate activities for people with impaired cognition (van der Ploeg et al., 2012). This allows people who can still contribute to do something meaningful.

Well-designed activities should include physical activity, which has the added health benefits of improving balance, decreasing falls, increasing strength, and improving mood. And because cognition and physical activity are linked, there is evidence that regular physical activity can favorably affect physical and cognitive function, quality of life, and activities of daily living. Lack of physical activity and a sedentary lifestyle are associated with an increased risk for cardiovascular disease, metabolic disease, and other adverse health conditions known to act as mediators in the early onset and progression of dementia (van Alphen et al., 2016).

Individual Activities

Individual activities that are carefully matched to a person’s abilities and interests are recommended at all stages of dementia. Keeping in mind that adults often have a fear of failure (especially those aware of their cognitive decline), activities must be appropriate to a person’s cognitive level, consistent, creative, and enjoyable.

Individual Activities for People with Dementia

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 or email • Use social media	• Dictate a letter or email • Use social media with help	• Listen to a letter or email being read • Listen to stories or books
Art/Music	• Take photos	• Take photos	• View photos

Individual Activities for People with Dementia

Activity	Mild	Moderate	Severe
	• Create a photo album • Draw • Play an instrument • Lead a group song	• Listen to music • Maintain a photo album • Draw • Sing along with others	• 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
Gardening	• Garden in raised beds • Help plan the garden and harvest • Assist others with gardening tasks	• Perform specific tasks with supervision • Help with simple gardening tasks such as raking, weeding, and soil turnover • Eat food grown in garden	• Sit in garden • Participate in projects as able • Eat food grown in garden
Crafts	• Knit or crochet using large needles and bulky yarn • Help with design • Create a poster • Help manage an activities board	• Choose colors, roll balls of yarn • Participate in creation of a poster • Help choose the location for posters and artwork	• Choose colors • Use the items that are created • Comment on projects • Observe the activities board
At home activities	• Help with laundry • Supervise others with laundry tasks • Put clothes away • Assist with housekeeping	• Sort and fold laundry • Help put away laundry • Help with cleaning of common areas	• Fold laundry—may want to fold the same items repeatedly • Carry laundry
Shopping	• Go with to store • Help with purchasing decisions • Choose types of food for self and family • 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 • Go into store using wheelchair or electric cart

Group Activities

Group activities and socialization are critically important for people with cognitive decline. Compared to unstructured time, well-designed group activities decrease boredom and loneliness and improve engagement and mood.

However, both the type and quality of the content matters. Because cognitive impairment isolates people from one another, activities that encourage social interaction can provide a sense of belonging and decrease feelings of anxiety and depression. Small group activities are generally preferred because they allow more activity and personal attention, although well-planned large-group activities can also be successful.

In one comprehensive review of the impact of different types of activities, the most successful group activities were games and choral singing; the least successful were storytelling and poetry, with other activities, such as exercise in between. The level of success was related to the specific activity as well as the choice of content. In the case of singing, older, familiar popular songs were more successful than newer, unfamiliar songs. Activities are less successful if they are too difficult or inappropriate for the population (Cohen-Mansfield, 2018).

Group Activities for People with Dementia			
Activity	**Mild**	**Moderate**	**Severe**
Singing	• 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
Outdoor Activities	• 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

6. Stress Management for the Caregiver

A **caregiver** is someone who provides assistance to a person in need. Care can be physical, financial, or emotional. Caregivers 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 professional.

The onset of caring tends to emerge naturally from customary family transactions that existed before the onset of dementia. The need for care escalates over time, from support for household, financial, and social activities, to personal care, to almost constant supervision and surveillance. Important transitions include the involvement of professional caregivers, institutionalization, and bereavement (ADI, 2013, latest available).

Causes of Stress for the Caregiver

Caring is an important, if often undervalued, role that comes with high levels of stress and anxiety, and much more needs to be done to make sure that caregivers are able to carry their duties without sacrificing their financial, social, and mental wellbeing. Stress is also a common factor with paid health and long-term care professionals. In an Alzheimer’s Disease International survey, almost half of respondents said they felt stressed or under pressure some of the time while 37% said they felt stressed often or all of the time (Gautier et al., 2022).

Caregivers of people with dementia invest significant time, energy, and money over a long period of time. Poor self-rated health and lower levels of life satisfaction are reported by many caregivers. Caregivers' cumulative stress is associated with increased nursing home placement of the patient with dementia (Lykens et al., 2014). On average, caregivers caring for a person with dementia spend 14 hours per week assisting with basic ADLs and up to 43 hours per week when more complex assistance and supervision are needed.

The economic impact of caregiving is an additional stressor for caregivers. For caregivers of older people (not dementia caregivers specifically) a 1% increase in hours of care is associated with a reduction in the employment rate of caregivers by around 10%. In a survey of American caregivers, 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 increases caregiver strain, while hiring a paid caregiver or having additional informal support can reduce caregiver strain (ADI, 2013).

High levels of emotional stress can lead to denial, anger, 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 depressive symptoms among caregivers, with the highest prevalence among those caring for someone with dementia (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
Relationship factors	• Intimacy—poor relationship quality • Low levels of past and current intimacy

Source: Adapted with permission from Alzheimer's Disease International.

Managing Caregiver Stress

It is possible to reduce caregiver stress with education, training, support, and respite care. These four components have been shown to decrease caregiver stress and reduce or delay the transition from home to a care home (ADI, 2013). Active training, such as engagement of caregivers in skills training, role playing, and interactive practice have been shown to be more successful in reducing caregiver burden compared with passive methods—such as providing information only (Lykens et al., 2014).

REACH-TX is a skills-training and support program for dementia caregivers. It is based on the *Resources for Enhancing Alzheimer's Caregiver Health II* intervention, which targets 5 caregiver domains (depression, burden, self-care/healthy behaviors, social support, and problem behaviors) and provides interventions to address each domain. REACH-TX provides risk assessment, education, skills training, and support for people caring for a person with dementia. The overall goal is to reduce stress and improve caregiver well-being. The program employs a trained dementia care specialist and involves 2-6 in-person contacts over a 6-month period (NCOA, 2020).

Practical guidelines for reducing caregiver stress include:

1. Relaxation: calm your mind using mediation, deep breathing exercises, journaling, aromatherapy, music, or massage.
2. Self-care: maintain a healthy diet, stay hydrated, get help, enroll your loved one in an adult daycare program, or sign up for respite care.
3. Sleep: establish a "sleep-friendly" routine, turn off devices, reduce artificial light, limit noise and heat, keep a regular bedtime routine, avoid meals and snacks before bedtime.
4. Exercise: engage in moderate aerobic exercise and strength training on a regular basis, explore exercises that promote relaxation and improve balance such as Tai Chi for Arthritis, Feldenkrais, yoga, walking, chair exercise, stretching, or swimming.
5. Education: learn about dementia by reading, joining a dementia support group, or reviewing dementia education and caregiver programs online.
6. Support: strengthen your support system by asking for support, seeking professional help, and confiding in friends.

Modified from Larkey, 2023

Pro-Social Helping

Although it is generally accepted that the accumulated financial, physical, and psychological stress of caring for a person with dementia may increase a caregiver's risk of morbidity and mortality, recent population-based studies have suggested that morbidity and mortality rates for caregivers may be *lower* than for non-caregivers. This may be due to the to the physiological benefits of prosocial helping behaviors (Roth, Brown, Rhodes, and Haley, 2018).

Tamara Sussman and Jack Lawrence provide an optimistic profile of care as they state, "While the journey of caring for a family member/friend with dementia is marked with unavoidable tribulations, it is also embedded with many rich positive experiences. Carers must adjust to the challenging behavioral changes linked to dementia, navigate complex healthcare systems, and simultaneously juggle life's other responsibilities—but they often feel a sense of purpose, pride, and gratification in fulfilling their important roles" (Gautier et al., 2022).

7. Family Issues

All over the world, the family is the cornerstone of care for older people who have lost the capacity for independent living. In Florida, more than 800,000 unpaid caregivers provide care valued at more than $23 *billion* each year (Alzheimer's Association, 2023, March 14).

About two-thirds of people with dementia live in the community, and for most of these individuals, care is provided by family, friends, or other unpaid caregivers. Nationwide, approximately 16 million Americans are caring for a person with Alzheimer's disease or another dementia. The largest proportion of those caregivers is spouses, followed by children and children-in-law, about two-thirds female. The typical profile of a dementia caregiver is a middle-aged or older female child or female spouse of the person with dementia (Alzheimer's Association, 2023, March 14).

Did You Know . . .

> 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**. Family caregivers are often cast into the role of caregiver unexpectedly and are largely unpaid or "nearly" unpaid (ADI, 2013).

Caregivers who are women may experience slightly higher levels of burden, depression, and impaired health than men. Evidence suggests that these differences arise because female caregivers tend to spend more time caregiving, take on more caregiving tasks, and are more likely to care for someone with a greater number of cognitive, functional, or behavioral problems (Alzheimer's Association, 2023, March 14).

Changing attitudes and expectations among the young, increased workforce mobility, and declining fertility rates mean that family members are less available for informal care for their older adult relatives. The education of women has led to more workforce participation. All these factors have put the system of informal, unpaid care under pressure as fewer young people are unwilling or unable to care for older adults (ADI, 2013).

For a person with dementia, caregivers provide care for a longer time, on average, than caregivers of older adults with other conditions. They are more likely than caregivers of people without dementia to provide help with self-care and mobility and health or medical care. Yet half of caregivers of people with Alzheimer's disease or another dementia indicate they have no experience performing medical or nursing tasks (Alzheimer's Association, 2023, March 14).

Caring for a person with dementia means managing symptoms that caregivers of people with other diseases may not face, such as neuropsychiatric symptoms and severe behavioral problems. Family caregivers often lack the information or resources necessary to manage the increasingly complex medication regimens for people with dementia (Alzheimer's Association, 2023, March 14).

Family caregivers often serve as proxy decision makers when a person with dementia is no longer able to contribute to care conversations. However, they may feel ill prepared and experience decision-making as challenging. This uncertainty can impact a caregivers' wellbeing and can affect the comfort of a person with advanced dementia. Helping family caregivers understand the values and preferences of the person with dementia and viewing dementia as a life-limiting condition can be helpful in addressing these issues (Bavelaar et al., 2023).

Family Issues 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 try to learn about dementia. They are often unaware of available dementia-care services and may find primary care physicians are of little help.

In this early stage, family caregivers will notice some loss of free time and some financial strain. The person experiencing cognitive changes is often aware of what they are losing, causing frustration, denial, and difficulty adapting to lifestyle changes. At this stage, periodic confusion and perceptual changes may mean the loss of a driver's license, which represents a loss of independence. Family members and spouses are more alert to safety issues, leading to a loss of privacy. Having to rely on another person for shopping, cooking, and finances means a loss of normal activities and a "normal" life.

If a spouse-caregiver is not be in good health, he or she may worry about not being able to provide good care as the disease progresses. An adult child caregiver may worry 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 often not needed, and caregivers can often leave their family member alone for periods of time.

To counteract these early difficulties, specialized training is strongly recommended for family 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.

Family Issues in the Middle Stages

In the middle stages, behavioral and psychological problems may arise, requiring decisions about behavioral interventions and, perhaps, medications. Family caregivers often 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, placing strain on their own lives and finances. Managing an additional household and the increased physical demands of assisting with transfers and other activities of daily living can increase stress. Medical care becomes more complicated, healthcare providers may provide little guidance, and care feel there is often no one to turn to for help.

Personal losses continue to accumulate for the person with dementia and for caregivers. Loss of independence becomes more severe for everyone. For the person with dementia, decisions are much more difficult and personal care often requires direct help, affecting a person's dignity. Loss of privacy, loss of independence, difficulties with mobility means the person with dementia loses the ability to live with any sort of independence.

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. Consequently, they can be at risk for serious illness, increased emergency department use, and hospitalization (Lykens et al., 2014).

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

Family Issues in the Late Stages

In the late stages, communicating with, and understanding what others are saying is severely affected. People with dementia lose the ability to make their needs clearly known. Specialized training makes helps caregivers immensely at this stage. Caregivers must learn to interpret facial expressions for sadness, anger, or frustration, as well as physical gestures such as grasping at undergarments, which may communicate the need to use the bathroom.

In the later stage, independence, privacy, and self-determination are almost completely lost. Daily care, meals, entertainment, exercise, and schedules are under the complete control of care providers. Caregivers, whether family or professional, must schedule their activities around the needs of the person they are caring for.

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

For family caregivers, relinquishing full-time care can cause feelings of loss, sadness, resignation, and depression. Although a family member might believe the care in a facility is better and more skilled than the care the person receives at home, this is often not the case. 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.

Family Issues at the End of Life

The demands of caregiving intensify as people with dementia approach the end of life. In the year before the person's death, more than half of caregivers feel they are "on duty" 24 hours a day. Many report that caregiving during this time is extremely stressful. One study of end-of-life care found that

72% of family caregivers experienced relief when the person with Alzheimer's disease or another dementia died (Alzheimer's Association, 2019).

Caring towards the end of life can be particularly challenging as medical symptoms and complications increase and the person becomes less responsive and able to communicate. Caregivers have reported a gap in support services for the challenges they face towards the end of life, such as caring at home and navigating complex care systems. The strain on health and social care services worldwide has resulted in a shift from formal care services providing care, to caregivers providing more care for longer at home (Davies et al., 2019).

Jasmine's Story

My dad died in 2007. My mom, Lucia had been experiencing very mild dementia for several years and my dad took care of most everything. When he died, me, my 3 sisters, a niece, and a nephew jumped in to help. We made a schedule, cooked, cleaned, and took care of medical care and finances. This worked pretty well for several years until my mom lost the ability to be home alone for any length of time. She was diagnosed with macular degeneration and started needing help with meal preparation, TV, and even the telephone.

Three of us, plus my nephew started staying overnight. One sister refused to stay over but helped during the day. As my mom's dementia progressed, she started getting argumentative and nasty at times. She locked my nephew out of the house, saying he was bossing her around. He stopped helping soon after.

As things progressed, my mom had trouble making decisions and her answer to anything involving money or home improvement was "no!" She absolutely refused to have any sort of hired help—not even a housecleaner.

Another year passed and my mom's dementia worsened. My niece hung in but eventually got a full-time job and had to quit helping us. We were down to the 4 sisters—one of whom refused to stay overnight and sometimes didn't show up for her shift.

By this time, my mom was almost completely blind. She was able to walk around the house, dress herself, and do most activities of daily living by herself. She still enjoyed car rides, books on tape, and TV.

Over time, as her dementia progressed, she started losing some of her independence in daily tasks such as dressing and showering. To relieve some of our caregiving duties, we finally were able to hire a caregiver. This helped a little but unfortunately, the sister in charge of my mom's money refused to pay for overnight help. We limped along like this for a couple of years until one sister quit and the other moved to Arizona. That left the 2 of us and a couple of caregivers to cover our mom's needs 24/7.

My sister cut back to 3 days at work, and I neglected my business. We split the time between the 2 of us with caregivers filling in when we weren't there.

The thing that really increased caregiving duties was when my mom could no longer safely walk by herself. That meant we had to help her every time she got up. We had to stay close by, listening carefully, and get up multiple times at night to help her to the bathroom.

During the last couple of years, we were busy from dawn to dusk—shopping, cooking, cleaning, helping her exercise, managing caregivers, taking her to medical appointments, and entertaining her. The last year was the hardest. Unfortunately, her doctor pretty much checked out well before my mom died. If it weren't for my sister's and my knowledge of the healthcare system, we would have been sunk.

My sister and I were good caregivers, but the caring last for almost 20 years. My mom died peacefully in her sleep and we're still recovering 5 years later.

The Grief Process

The diagnosis of dementia affects the person with dementia as well as family and friends. Grief is related to uncertainty about the course of the disease and anticipated loss of independence. 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 will almost certainly develop including depression, anxiety, insomnia, and loss of interest in normal hobbies and activities. These issues can lead to self-destructive behaviors, such as alcohol or drug abuse. Supportive interventions to address grief should include counseling, assessment of co-morbid conditions, education and training, and development of a care plan.

Losses for the person experiencing dementia include:

- Loss of physical strength and abilities
- Increased confusion and changes in mental abilities
- Loss of income and savings
- Changes in housing and personal possessions, including loss of pets
- Loss of self-sufficiency and privacy
- Changes in social roles, loss of friends and social networks

Losses for family members and caregivers include:

- Loss of companionship
- Loss of income
- Loss of privacy and free time
- Changes in routines and social roles
- Little time for hobbies and social activities

There may be a great deal of grief when a person with dementia moves to a care home. Nursing homes and assisted living facilities lack privacy, usually don’t allow pets, and truly represent the last stage of a person’s life. This can cause grief and depression for the person with dementia as well as family members and friends.

When a loved one dies, family members experience a period of acute grief that can include 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, a third of surviving spouses experience major depression. This risk of depression peaks during the first six months of bereavement but can last up to two years. Even bereaved persons with minor depression may suffer; 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).

Dementia Care Programs

Entering a long-term care facility is often a difficult and feared transition for an older adult. Loss of social status, stigma, isolation, and reduced contact with friends and family members can have a profound effect—especially for a person with cognitive challenges. Having to adapt to the facility’s routine, loss of privacy, and unfamiliar surroundings can leave a person feeling isolated and depressed.

To address this, friends and family members are encouraged to participate in a dementia care program—multidisciplinary programs designed to meet the individual needs of residents. The quality and success of a dementia care program is 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.
- Shares information about resident activities with the family.
- Encourages residents to call and write to family members and friends.
- Uses technology to keep families in touch with one another.
- Supports dementia-friendly activities.

Caregiver Training and Support

Education, training, and support are badly needed for caregivers, family members, and healthcare providers. The responsibilities of caregiving can be overwhelming, especially for spouses and family members. A caregiver may be in poor health and have difficulty taking on the burdens of fulltime caregiving. Even trained healthcare providers can find it difficult day-in and day-out to deal with patients (or family members) experiencing dementia.

In addition to dementia-specific education, caregivers must learn to differentiate dementia from other illnesses. This is a critical skill that allows a direct-care staff and family members to advocate for their loved one in a complicated healthcare system. Caregivers also must learn to manage difficult behaviors when they arise. This involves slowing down, listening, and finding effective ways to communicate.

With effective, dementia-based training, it is possible to get better at caring for someone with dementia. Training provides access to resources, support, and equipment that improve health and safety.

In Florida, a program funded by a grant from the National Institute on Aging provides a comprehensive listing of resources and educational materials available to caregivers. Dementia Care Central (www.dementiacarecentral.com) lists an array links and services including how to hire and pay for care, understanding Medicare benefits, in-home technology, dealing with difficult behaviors, respite services, as well as information about adult day care, assisted living, and nursing homes. In addition, Dementia Care Central provides support services for caregivers that include:

- Case management
- Specialized medical equipment and supplies
- Caregiver counseling and support groups
- Caregiver training

Supporting Caregivers of Patients with Dementia

Dementia care consultant discussing resources with family members. Source: AHRQ, 2015. Public domain.

These services are provided through the 11 Area Agencies on Aging (AAA's). For eligibility requirements and how to receive these services, you can contact your local Area Agency on Aging by calling the Elder Helpline at 1-800-96-Elder (1-800-963-5337).

8. Maintaining a Therapeutic Environment

People with dementia rely on environmental cues to support them physically, cognitively, and emotionally. Unfamiliar, chaotic, or disorganized environments—whether at home, in adult day care, or in a care facility—are stressful and can cause anxiety, disorientation, and contribute to behavioral problems.

A therapeutic environment provides support for someone with dementia and their family. It recognizes that people with dementia are influenced by their surroundings and do better with environments that are individualized, flexible, and designed to support differing functional levels and approaches to care (Campernel & Brummett, 2010). At a minimum, an organization caring for people with dementia should understand that people with dementia deserve and need kind and supportive care focused on dignity, respect, and autonomy.

Person-Centered Philosophy of Care

Person-centered care depends on a caregiver's and organization's skills, training, and knowledge. It means that care is built around both resident and caregiver needs and preferences, creating a high-quality shared environment. Person-centered care is flexible, creative, and supportive. Person-centered care is also referred to as **dementia-friendly care**, which promotes inclusion of the person living with dementia and their caregivers in care and treatment decisions, with the aim of increasing positive outcomes for both (Handley et al., 2015).

The Physical Environment

There is a connection between the environment and how people feel and behave. Homes or buildings thoughtfully designed for the care of people with dementia encourage community, maximize safety, support caregivers, cue specific behaviors and abilities, and redirect unwanted behaviors (Campernel & Brummett, 2010). Safety, security, simplicity, and familiarity are central principals for the design of dementia-friendly environments. For someone with dementia, a familiar environment is predictable, lessens confusion, and creates a sense of being at home. This supports social relationships, identity, autonomy, and privacy (Førsund et al., 2018).

A dementia-friendly facility should be of a smaller size, with an open design. This is less confusing for someone with dementia and allows staff and caregivers to easily monitor clients at a distance. Although it is important not to overwhelm residents and adult day care participants with too much information or noise, the design should provide useful stimuli such as familiar cues to bathrooms and exits to safe outside areas. Private spaces are important, allowing people to be alone or in close company of a friend (de Boer et al., 2018).

Dementia-friendly **indoor** design can include:

- Private space in a client’s room with a private bathroom and a separate bedroom or recess for sleeping.
- Public spaces with easy accessibility and places for semi-private interactions.
- Rooms personalized with furniture, memorabilia, pictures, televisions, computers, and personal possessions.
- Control/absence of smelly odors.
- Sunlight, ventilation, and elimination of dark nooks and crannies.
- Small, residential-looking nursing stations.
- Spaces that cue specific behaviors (activity kitchen, art and music therapy area, bistro/bar, rummaging room, library, coffee shop/internet café, quiet room, living room, family visiting area).

Left: Residential-looking, smaller-scaled nurses’ station. Right: a room for rummaging. Source: Campernel & Brummett, 2010. Used with permission.

Dementia-friendly **outdoor** design can include:

- Spaces that resemble a natural community.
- Continuous circulation routes with looping pathways, plenty of seating, and areas of interest.
- Residents’ inclusion in the design of new features such as walking paths and gardens.
- Safe, purposeful, and accessible outdoor areas.
- Attractive landscaping, gardens, and views to the outside.

Rijnaard et al. 2016

Left: Safe, looping wandering paths with areas of interest along the way. Right: A memory-care facility with home-like outdoor porch area for seating and reflection. Source: Campernel & Brummett, 2010. Used with permission.

Facilities using dementia-friendly design principles provide real benefits for staff, caregivers, and people with dementia. In a comparison of “regular” specialized care units and small, homelike specialized care units in the Netherlands, residents in the homelike care units needed less support with activities of daily life, were more socially engaged, showed less agitation over time, and needed less psychotropic medication and fewer physical restraints. Residents of the small, homelike units awarded higher scores to aspects of quality of life, showed less negative affect, better social relationships, and were more engaged in activities (Kok et al., 2016).

Although there is a trend toward the development of smaller, home-like nursing homes, large nursing homes are still the norm. In the U.S., there are approximately 16,000 nursing homes with an average of 100 beds per facility. In Florida, nursing homes have the eighth highest number of beds—an average of 120 beds per facility (Harrington and Carrillo, 2018).

Safety and Security

People with dementia need feel safe (and be safe) without the use of physical and chemical restraints. This means managers must create an appropriate environment, encourage safe mobility, and plan for adverse or unplanned events.

The table below illustrates some common safety hazards along with suggestions to help make the environment more safe and secure. Since every situation is different, interventions must be tailored to match the specific circumstances.

Safety and Security Issues and Interventions

Safety issue	Possible consequence	Intervention
Wandering	Getting lost, exposure to environmental hazards, injury.	• Paint the inner surfaces of doors so that they are not readily recognizable as an exit. • Place locks where they are not visible. • Use GPS tracking watches. • 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. • Provide regular exercise.
Cooking without supervision	Fire, injury	• Install a shut-off valve on the stove. • Remove burner on-off handles. • Keep a working fire extinguisher. • Create an open work area with an activities kitchen.
Falls	Injury, fear of falling, self-restriction of movement.	• Rule out medical conditions. • Keep junk (wheelchairs, medical equipment) out of hallways and walkways. • Install handrails in showers and hallways. • Install carpeting or rubber mats in key areas to reduce injuries. • Install horizontal safety poles next to beds and toilets. • Wipe up spills promptly.

		• Maintain physical activity. • Supervise walking and use assistive devices. • Remove throw rugs. • Maintain good vision and hearing. • Provide places to sit.
Poisoning	Sickness or death	• Remove toxic plants from the environment. • Lock up chemicals and medications.

Simply living in a longterm care facility or receiving care at an adult day care center can be a source of safety and security. Having regular contact with specially trained caregivers can provide comfort, predictability, and a sense of ease (Rijnaard et al., 2016).

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—schedules can change dramatically from day to day. This is difficult for people with dementia because they rely on a predictable routine for orientation.

Although caregivers and staff are responsible for maintaining a schedule, dementia-friendly facilities encourage caregivers to be flexible and adjust their schedule to benefit the person they are caring for. For example, if someone does not want to take a shower on a usual bathing day, a caregiver might help the person wash up and schedule the shower for another day. People with dementia tend to be slow, so caregivers must allow ample time when preparing for an outing or an appointment. Attempting to rush can cause aggressive behaviors and frustrate both parties.

Staff as Part of the Environment

There are approximately 687 certified nursing homes in Florida. Since 1987, the Nursing Home Reform Act has required nursing facilities to have enough nursing staff to provide nursing and related services to attain or maintain the *highest possible physical, mental, and psychosocial well-being of residents*. Facilities must have a registered nurse as a Director of Nursing for at least eight consecutive hours a day, seven days a week and licensed nurses on-site twenty-four hours a day (Harrington and Carrillo, 2018).

Staff turnover is one of the most vexing problems for nursing homes and other organizations that provide care for people with dementia. For people with dementia, this lack of consistency and staff turnover make it particularly difficult to keep staff “dementia-trained” and thus integrated into the living environment.

Did You Know . . .

> The turnover rate for registered nurses, licensed vocational nurses, and certified nursing assistants is significantly higher in nursing homes than in other healthcare settings. In Florida, from July 2014 to June 2015, the turnover rate for RNs and CNAs was approximately 40%. For LPNs the turnover rate was an eye-popping 100% (FCN, 2016, latest available).

Some organizations promote dementia-friendly care by restructuring the relationship of staff to residents. This model deemphasizes the medical model and emphasizes practices that seek to reduce loneliness, helplessness, and boredom. One example of an organization that promotes dementia-friendly care is the Eden Alternative, which focuses on what they call “elder-centered” principles of care. The Eden Alternative stresses the need to address the scourge of loneliness, boredom, helplessness, and loss of meaning. Key principles are:

- Make life worth living by creating a human habitat where life revolves around close and continuing contact with people of all ages and abilities, as well as plants and animals.
- Decrease loneliness by providing easy access to human and animal companionship.
- Address helplessness by creating opportunities to give as well as receive care.
- Address boredom by creating an environment in which unexpected and unpredictable interactions and happenings can take place.
- Develop meaningful activities. **Meaningless activity corrodes the human spirit.**
- Make medical treatment the servant of genuine human caring, never its master.
- De-emphasize top-down, bureaucratic authority, seeking instead to place the maximum possible decision-making authority into the hands of the Elders or into the hands of those closest to them.
- Make sure human growth is never be separated from human life.
- Develop wise leadership, which is the lifeblood of any struggle against loneliness, helplessness, and boredom.

(Kubsch, Tyczkowski, and Passel, 2018)

In an analysis of staffing at several Eden facilities covering a 6-year period from 1999-2005, staff turnover was reduced to approximately 10% per year (even as low as 5% in some facilities), agency staffing was eliminated, and there was a 60% decrease in absenteeism. Other positive outcomes included significant decreases in behavioral incidents, pressure ulcers, and restraint use (Buswell, 2019).

Proper Staffing

> Workforce issues are at the heart of quality care in nursing homes and are directly related to having sufficient competent staff to care for residents and meet their holistic needs.
>
> Mueller and Travers, 2023

There are multiple types of nursing home staff in nursing homes fulfilling a variety of direct and indirect care roles for nursing home residents. Some staff are required to hold a license (e.g. physical therapist, nurse) and others are not (e.g. nursing assistant, housekeeper). There are no state or federal regulations requiring that nursing home staff have specific geriatric-focused competencies. Even academic degree requirements for key staff, such as directors of nursing, administrators, and social workers, are lacking insofar as they are not specified in regulations for nursing homes (Mueller and Travers, 2023).

Proper staffing in nursing homes and other facilities providing services for older adults with dementia is consistently associated with higher quality of care. In Florida, as in many states, nursing assistants spend more than 3 times as much time with residents in nursing homes as do registered nurses (Harrington and Carrillo, 2018).

Higher education and certification for nursing home administrators (master's degrees or higher) and directors of nursing (bachelor's degrees or higher) resulted in better outcomes for selected quality measures. Research has shown that nursing home administrators with more advanced educational backgrounds were associated with better quality of care in the homes (Mueller and Travers, 2023).

Nursing homes with more RN hours per patient have been associated with positive outcomes and fewer deficiencies. The benefits of higher staffing levels, especially RNs, include lower mortality rates; improved physical functioning; less antibiotic use; fewer pressure ulcers, catheterized residents, and urinary tract infections; lower hospitalization rates; and less weight loss and dehydration (Harrington and Carrillo, 2018).

The majority of health professional education programs for licensed nursing home staff lack geriatric-focused didactic and experiential learning. Consequently, health professionals such as nurses, physicians, and social workers bring limited geriatric-focused knowledge to the care and services they provide to older persons residing in nursing homes (Mueller and Travers, 2023).

In 2022, the Committee on the Quality of Care in Nursing Homes issued a report recommending the establishment of national competency requirements for all licensed and unlicensed nursing home staff, including the medical director. Placing a priority on standards for competencies can improve quality and positively affect the recruitment and retention of nursing home staff and leaders. The full scope of competencies has not been explicitly identified for various types of nursing home staff, but training in geriatrics and principles of diversity, equity, and inclusion are strongly recommended (Mueller and Travers, 2023).

The full report: *The National Imperative to Improve Nursing Home Quality: Honoring Our Commitment to Residents, Families, and Staff* from the National Academies of Sciences, Engineering, and Medicine is available here.

Staff Adjusting to Resident Routines

When a facility is reorganized into a dementia-friendly care home, staff adjust their routines to the routines of the residents, rather than the other way around. This requires a fundamental shift in how medical professionals have been educated and trained.

In a home-like setting, the medical aspects of the facility are deemphasized. Residents, staff, and family caregivers work as a unit. To the extent possible, care team should be consistent. Daily tasks, such as cooking and cleaning, are shared and organized by residents, staff, and caregivers. Not surprisingly, this reduces staff turnover and provides more satisfaction for both staff and residents.

To encourage integration of the staff into a home-like environment:

- Hire staff with the emotional skill, training, and desire to interact with people with memory problems.
- Increase pay, training, and opportunities to advance.
- 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.

9. Ethical Issues with Dementia Patients

> Healthcare providers must learn to incorporate ethical principles into daily care, particularly in the complex and ethically difficult area of 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

Those who work in dementia care settings face difficult ethical decisions each day. Staff must balance the needs of multiple clients while considering patient confidentiality, the potential for abuse, and the benefits and risks of medications and procedures. If patients cannot express their own needs, a designated decision-maker must step in to 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.

Ethical Approaches to Care

In biomedical ethics, several basic ethical principles are commonly accepted. These are (1) autonomy and well-being, (2) beneficence, and (3) justice. Veracity or truthfulness is also an important ethical principle that must be considered.

Autonomy and Well-Being

Autonomy is the right of individuals to make decisions about their own healthcare and their own life. Patients must be told the truth about their condition and informed about the risks and benefits of treatment. Patients are permitted to refuse treatment even if the best and most reliable information indicates that treatment would be beneficial, unless this decision has a negative impact on the well-being of another individual. This sort of conflict can create an ethical dilemma.

For someone with dementia, autonomy means fostering important relationships, maintaining a sense of self, and having a way to express values. Autonomy is not simply the ability to make rational decisions. A person's well-being includes both their moment-to-moment experiences of contentment or pleasure, and more objective factors such as their level of cognitive functioning (Nuffield Council on Bioethics, 2009, latest available).

Beneficence: Kindness

Beneficence is the act of being kind. This means providing care that is in the best interest of the patient or client. A decision is beneficent or kind when the same decision would be made regardless of who was making it. Beneficence is closely related to the concept of "do no harm". Actions or practices of a healthcare provider are "right" so long as they are in the interest of the patient and avoid negative consequences.

Justice: Equity and Fairness

Justice is often defined as a fair distribution of benefits and burdens, particularly in connection with misfortunes for which we cannot be held personally responsible (Nuffield Council on Bioethics, 2009, latest available). This includes the degree to which healthcare services are distributed throughout society and the way healthcare is delivered at the individual level.

Given the vulnerability of people with dementia, it is particularly important that resources support dementia care. This is in part an issue of appropriate resources and practical support, but also requires both caregivers and care workers to be recognized and valued as people who have expertise and an important role in society. A fair distribution of benefits and burdens should promote and sustain the person with dementia throughout the course of their dementia and help them maintain their autonomy as much as possible (Nuffield Council on Bioethics, 2009, latest available).

Veracity (Truthfulness)

Veracity is telling the truth. When interacting with a person with dementia, the ethical reasoning behind most interactions is based on concern for the well-being of the person with dementia, with conflicts experienced between the desires to maintain trust while at the same time avoiding distress. Consideration for the person with dementia must coexist with beliefs about the moral importance of telling the truth and practical concerns about how to get through the day (Nuffield Council on Bioethics, 2009, latest available).

Some people argue that failing to tell the truth is a breach of trust and undermines a person's remaining grip on reality. Others point out that telling the truth in circumstances where the person with dementia will not believe it may equally undermine trust because the person will think that they are being lied to. For healthcare providers, there is the added issue of whether telling a lie undermines the integrity of professional care, and for those involved in providing care there is the concern that failing to tell the truth is detrimental to their own moral well-being (Nuffield Council on Bioethics, 2009, latest available).

Ethical Conflicts and Dilemmas

> One of the most distressing aspects of the COVID-19 pandemic for me has been the treatment of older people living in care homes—and the uncomfortable spotlight cast on the way their fundamental needs and interests are often overlooked.
>
> Katherine Wright, Recognizing the human rights of people with dementia during COVID-19

Ethical dilemmas arise when there are equally compelling reasons both for and against a specific 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 of an ethical conflict 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). This is 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 a *moral temptation* (Kidder, 1996).

During the COVID pandemic, healthcare workers experienced frequent ethical conflicts accompanied by intense concern and distress. The pandemic created difficult and ongoing ethical conflicts—for caregivers, healthcare workers, and providers. Ethical issues related to equity and fairness—especially access to healthcare services, equipment, medications, and vaccines became complex issues that affected every level of healthcare. Key considerations emerged related to nondiscrimination, fairness, and protection of vulnerable groups (Biller-Andorno and Spitale, 2022).

Examples of Ethical Decision-Making

Case 1

Mr. Corona is 88 years old and lives in a cottage on his daughter's property. He was a fighter pilot during the Korean War and has been fiercely independent his entire life. He is in the moderate-to-severe stage of dementia and is unable to perform most 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 score is 11/30. When asked what he would do if the house caught on fire, he logically 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 a concern, 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 to 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 was diagnosed with Alzheimer's disease at age 80. She has lived in a nursing home in Tampa, Florida for the past seven years. She has needed help with her meals for the last 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 principle of autonomy and is not demonstrating loyalty or support of his mother's wishes. While her son might think that he is acting out of kindness by feeding her, although feeding tubes can prolong life, they likely do not improve quality of life in people in the later stages of dementia.

10. Concluding Remarks

Dementia is a progressive, degenerative brain 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 alike, the behaviors are caused by damage to the brain and are often not intentional. Challenging behaviors can be caused by unmet needs and are often a means of communication. By carefully observing what occurs before and after a behavior, caregivers should be able to identify the underlying need and determine how to address 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 and for the shortest possible time. There are many proven alternatives to physical and chemical restraints that are the mainstays of individualized care.

Activities of daily living are disrupted in people with dementia. As the dementia progresses, caregivers must step in and assist with personal care and household management. They must also design individual and group activities that 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 dementia 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.

[Continue to next page for dementia resources]

Dementia and Aging Resources

Alzheimer's Project
The Alzheimer's Project, located in Tallahassee provides comfort, support, and assistance to persons with memory disorders and their caregivers. It serves the Big Bend community of Florida through education and training, in-home respite, support groups, counseling, referral to community resources, and recovery of wanderers through the Project Lifesaver program. Services are free of charge. www.alzheimersproject.org / 850 386 2778

Area Agency on Aging for North Florida
Serves as the designated Aging Resource Center for the Panhandle and Big Bend areas. Consumers, families and caregivers can access the Aging Resource Center in their community by calling the Elder Helpline. www.aaanf.org / 800 963 5337

Florida Adult Day Services Association (FADSA)
Provides leadership, education, planning, and development of adult day services across Florida. FADSA promotes quality day services, respite programs, adult day health centers, and education, training, and advocacy within the long-term care industry. www.fadsafl.org

Florida Council on Aging
Serves Florida's aging interests through education, information-sharing, and advocacy. Founded in 1955, it is Florida's only statewide association representing virtually all aging interests and disciplines. www.fcoa.org / 850 222 8877

Florida Department of Elder Affairs (FDEA)
A comprehensive listing of Alzheimer's and dementia care resources throughout Florida including memory disorder clinics, model daycare, the Alzheimer's Rural Care Healthline, Respite Services for Caregiver Relief, and links to Alzheimer's disease information. elderaffairs.state.fl.us/english/alz.php / 850 414 2000

Florida Hospice and Palliative Care Association (FHPC)
FHPC is a not-for-profit organization representing Florida's hospice programs. Its mission is to ensure access to hospice care, and it advocates for the needs of those in the final phases of life. www.floridahospices.org / 800 282 6560

Florida Telecommunications Relay (FTRI)
A statewide nonprofit organization that administers the Specialized Telecommunications Equipment Distribution Program for citizens of Florida who are deaf, hard of hearing, deaf/blind, and speech impaired. Responsible for the education and promotion of the Florida Relay Service. www.ftri.org / 888 554 1151

Memory Disorder Clinic at the Tallahassee Memorial Neuroscience Center
A team of memory disorder specialists who provide a comprehensive diagnostic evaluation for persons concerned about memory problems. www.tmh.org 850 431 5037

Caregiver Training and Support Services

AlzOnline: Caregiver Support Online
Part of the Center for Telehealth and Healthcare Communications at the University of Florida. Provides caregiver education, information, and support for those caring for a family member or friend with Alzheimer's disease or related dementias. alzonline.net

Family Caregiver Alliance (FCA)
Provides information, education, services, research, and advocacy for families caring for loved ones with chronic, disabling health conditions. In person and online resources listed by state. www.caregiver.org

Florida Elder Helpline
Provides information about elder services and activities, which is available through the Elder Helpline

Information and Assistance service within each Florida County.
http://elderaffairs.state.fl.us/doea/elder_helpline.php 850 955 8770

Share the Caregiving
Dedicated to educating the caregiving communities about the effectiveness of the Share the Care model. Encourages ordinary people to pool their efforts to help ease the burden on family caregivers and help those without family nearby. sharethecare.org/

Today's Caregiver
Information, support, and guidance for family and professional caregivers. 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

[Continue to next page for references]

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[Continue to next page for dementia quiz]

Quiz: FL Alzheimer's Disease for Nursing Homes, Adult Day Care, and Hospice, 3 units

1. In Alzheimer's, damage is thought to be related to: B

a. Exposure to aluminum, male gender, and brain inflammation.

b. Formation of beta-amyloid plaques and neurofibrillary tangles.

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. Although Alzheimer's disease is the most common type of dementia, new research is showing that many people with dementia have: D

a. "Pure" Alzheimer's disease.

b. "Pure" vascular dementia.

c. Alzheimer's disease with Lewy bodies.

d. A mixture of two or more types of dementia.

3. Diagnosis of Alzheimer's disease and other types of dementia is based *primarily* on: C

a. Self-report.

b. Age.

c. Clinical signs and symptoms.

d. Blood tests.

4. Delirium: A

a. Has an acute onset, a fluctuating course, and can be associated with dehydration.

b. Has a gradual onset and generally lasts several months.

c. Is usually permanent and leads to eventual dementia.

d. Has a sudden onset characterized by a normal level of consciousness.

5. Depression is characterized by: A

a. Pessimistic thoughts, sleep disturbance, and inability to concentrate.

b. An inability to concentrate due to an acute brain injury.

c. Sleep disturbances lasting less than one month.

d. Short-term memory loss and a tendency to get lost in familiar places.

6. The ABC approach to challenging behaviors in dementia encourages caregivers to: A

a. Approach cautiously, identify the behavior, and help the person compensate for bad behaviors.

b. Find out what activated the behavior, stop the behavior, and acknowledge that a person with dementia doesn't understand consequences.

c. Be cautious, be aware of any danger posed by the behavior, and determine the consequences of the behavior.

d. Figure out what caused the behavior, identify the behavior, and identify the consequences of the behavior.

7. Wandering, a common activity in people with dementia can be addressed by: B

a. Telling a person that wandering is unsafe and telling them to stop.

b. Providing a safe area to walk with looping pathways and numerous places to rest.

c. Prescribing an antipsychotic to calm the person and prevent wandering.

d. Using a physical restraint to keep the person safely in a wheelchair, recliner, or bed.

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

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

b. Boredom, disorientation, and memory problems.

c. Degeneration of neurons in the part of the brain that controls sleep patterns.

d. Urinary tract infections, dehydration, or sensory overload.

9. Antipsychotic medications are sometimes used as a chemical restraint in people with dementia. This is an off-label use, meaning: A

a. The FDA has not approved them for treatment of behavioral symptoms associated with dementia.

b. They are prescription medications approved by the FDA to be used at the discretion of practitioner.

c. They are not effective for behavioral symptoms of dementia.

d. It is against the law to prescribe them for behavioral symptoms associated with dementia.

10. Basic activities of daily living (ADL) include: A

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.

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

a. Transferring from bed to chair, toileting

b. Eating, bathing, and dressing

c. Housework, bathing, and grooming

d. Cooking, shopping, and medical management

12. In terms of ADLs, signs of moderate to severe dementia can include:

a. Losing car keys several times a day.

b. The need for increased assistance with basic ADLs.

c. Compete or nearly complete dependence on caregivers.

d. Trying to cover up deficits by making up stories.

13. 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. Make the tools available, encourage participation, and allow simple choices.

c. Do not allow the resident to assist because it will prolong the task.

d. Do it quickly so that the person does not have time to fight back.

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

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.

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

a. Reading books and discussing them with other residents.

b. Learning how to knit.

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

d. Doing crossword puzzles.

16. 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

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.

17. Bob's wife has been diagnosed with frontal-temporal dementia. Bob helps his wife when needed but otherwise doesn't pay much attention to any changes in her behavior. Friends noticed that the house hasn't been cleaned for some time, the bathroom is beyond filthy, the bed is covered with dirt from the dogs, and Bob's wife has started giving away money to anybody who asks. What might be happening with Bob and his wife? D

a. Bob and his wife have always been messy and don't notice that things have gotten worse.

b. Bob may have some cognitive changes associated with longterm marijuana and alcohol abuse.

c. Bob's wife is experiencing a gradual decline in her cognition.

d. All of the above.

18. In the early stages of dementia, it is highly recommended that family members: D

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

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. Receive early, specialized training about dementia.

19. When a loved one dies, family members: C

a. Can look forward to a period of improved health.

b. Rarely experience physical symptoms such as headaches and fatigue.

c. Can experience grief that resembles clinical depression.

d. Often feel intense relief along with an increase in energy.

20. Person-centered care: D

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

b. Should only be used when antipsychotics fail to resolve behavioral problems.

c. Can increase unwanted and aggressive behaviors.

d. Focuses care on residents' and caregivers' needs and preferences.

21. The use of design as a therapeutic tool recognizes: A

a. There is a connection between the environment and how we behave.

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

c. People with dementia do not understand environmental cues.

d. Unfamiliar, chaotic, or disorganized environments have very little impact of behavior.

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

a. Make sure staff members don't get too comfortable with a resident.

b. Hire staff with the emotional skills to interact with people who have memory problems.

c. Increase the number of centralized nursing stations.

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

23. The principle of beneficence or kindness is: B

a. Unprofessional and not ethical.

b. The act of being kind.

c. Not that much of an issue when caring for people with dementia.

d. Difficult to keep in mind when caring for someone with dementia.

24. When caring for a person with dementia, an ethical dilemma might arise when: C

a. A resident refuses to go to the dining room for breakfast.

b. A person with dementia steals food from another resident.

c. There are good reasons both for and against a particular course of action and a decision must be made.

d. A person with dementia is no longer able to independently perform their ADLs.

[Continue to next page for answer sheet]

Answer Sheet: FL Alzheimer's Disease for Nursing Homes, Adult Day Care, and Hospice, 3 units

Name (Please print) ____

Date ____

Passing score is 80%

1. ______
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[Continue to next page for course evaluation]

Course Evaluation: FL Alzheimer’s Disease for Nursing Homes, Adult Day Care, and Hospice, 3 units

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

1 = Strongly agree 2 = Agree 3 = Neutral 4 = Disagree 5 = Strongly disagree

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

1. Describe the scope of suicide in the United States. 1 2 3 4 5

2. List 3 warning signs for suicidal ideation and behaviors. 1 2 3 4 5

3. Describe 5 risk factors for suicidal ideation and behaviors. 1 2 3 4 5

4. Relate 4 job-related concerns that can lead to chronic stress among nurses. 1 2 3 4 5

5. Describe the importance of screening, assessment, and safety planning for patients as risk for suicide. 1 2 3 4 5

6. Understand the importance of evidence-based approaches and best practices in suicide care.

1 2 3 4 5

7. List four commonly accepted ethical principles. 1 2 3 4 5

*The author(s) are knowledgeable about the subject matter. 1 2 3 4 5

*The author(s) cited evidence that supported the material presented. 1 2 3 4 5

*Did this course contain discriminatory or prejudicial language? Yes No

*Was this course free of commercial bias and product promotion? Yes No

*As a result of what you have learned, will 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 satisfaction with this learning activity? 1 2 3 4 5

*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 ______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.
______Searching the Internet.
______An advertisement.
______My employer.
______Other _________________________________
______State board or professional association.
______A friend.
______I am a returning customer.
______Social Media

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 library computer.
______A cellphone.
______A computer at work.
______A tablet.
______A paper copy of the course.

Please enter your comments or suggestions here:

[Continue to next page for registration and payment]

Registration and Payment: FL Alzheimer's Disease for Nursing Homes, Adult Day Care, and Hospice, 3 units

Please answer all the following questions (* required).

*Name: ____
*Email: ____
*Address: ____
*City and State: _______________________________________
*Zip: ____
*Country: ____
*Phone: ____
*Professional Credentials/Designations:
____
*License Number and State: ____________________________

Payment Options

You may pay by credit card, check, or money order.

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 and State: ____
*Zip: ______________
*Card type: Visa Master Card American Express Discover
*Card number: ____
*CVS#: _____________ *Expiration date: ____________________