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[Continue to next page to start course]

Florida: Alzheimer's Disease and Related Dementias for Adult Day Care, 3 units (370)

Contact hours: 3
Author: Lauren Robertson, BA, MPT
Price: $29

Florida DOEA Approval: ADC11410

Certified Trainer: The author is certified as an ADRD trainer by the Florida Department of Elder Affairs and is available via e-mail at Lauren@ATrainCeu.com or by phone Monday-Friday from 9 a.m. to 5 p.m. (Pacific Time) at 707 459 3475. Nursing Home Alzheimer's Disease and Related Disorders (ADRD) Training Provider Approval Number ADC11404.

Course Objectives

When you finish this course, you will be able to:

1. Describe 3 types of services offered to clients in adult day care facilities.
2. Identify 5 challenging behavioral and psychological symptoms associated with dementia.
3. Describe 3 best practices when assisting someone with activities of daily living at each stage of dementia.
4. List 4 benefits of a well-designed activities program for people living with dementia.
5. Describe 3 types of stress that are common in caregivers caring for a person living with dementia.
6. Recognize 3 issues and concerns faced by someone caring for a person living with dementia.
7. Identify 3 concepts that are important in the design of a therapeutic environment for those living with dementia.
8. Identify 4 key concepts that are part of an ethical approach to dementia care.

Course Summary

This course provides information about adult day care service centers that provide care for older adults living with cognitive changes, Alzheimer's disease, and other types of dementia. It discusses symptoms and behaviors that can arise in a person living with dementia and strategies for managing these behaviors. It describes best practices for assisting someone with activities of daily living, discusses individual and group activities, and describes how stress can affect a caregiver's life. It offers strategies for recognizing and managing caregiver stress. It concludes with a description and a therapeutic environment, safety and security, and ethical issues faced by caregivers and providers working with clients living with dementia.

Target Audience

For those of you who have direct contact with clients living with dementia who use adult day care services. It is designed to increase your awareness and understanding of Alzheimer's disease and related disorders.

[Continue to next page to start course]

Pretest

1. Adult day care services are for people who **do not** have dementia.

   a. True
   b. False

2. Forgetfulness might be the most obvious symptom in the early, mild stage of dementia.

   a. True
   b. False

3. Agitation includes irritability, confusion, making loud demands, and using obscene language.

   a. True
   b. False

4. Delusions and hallucinations in people living with dementia can be caused by urinary tract infections and dehydration.

   a. True
   b. False

5. Wandering can be addressed by using a physical restraint to keep the person from wandering.

   a. True
   b. False

6. A sign of moderate dementia can include needing more assistance with ADLs.

   a. True
   b. False

7. In the early stages of dementia, it is recommended that family members receive specialized training about dementia.

   a. True
   b. False

8. When a loved one dies, family members can experience grief that resembles clinical depression.

   a. True
   b. False

9. Integrate staff into a homelike environment by hiring staff with the emotional skills to interact with people who have memory problems.

   a. True
   b. False

10. An ethical dilemma might arise when there are good reasons both for and against a particular course of action and a decision must be made.

   a. True
   b. False

Answers: 1 and 5 are false, all others are true.

1. Adult Day Care

Adult day care centers (ADC) provide non-residential coordinated services in a community setting for less than a day. Depending on its licensing, an adult day care facility can offer social activities, medical/healthcare, or specialized services specifically intended for people living with dementia.

There are approximately 4,130 active adult day care centers in the United States with more than 250,000 participants. Users of adult day care services are medically complex, with a significant proportion living with dementia, diabetes, depression, or heart disease. They are also more racially and ethnically diverse when compared to users of other long-term care services (Sadarangani et al., 2024).

In Florida there are approximately 349 non-specialized adult day care centers providing therapeutic programs, social services, health services, and activities. Nearly half of the clients enrolled in non-specialized adult day care have Alzheimer's disease or a related disorder (FADSA, 2025).

There are also a smaller number of specialized adult day care facilities in Florida. These facilities have higher staffing levels and specialize in caring for adults living with dementia. Specialized centers enroll a higher percentage of clients with dementia than do non-specialized adult day centers and require specialized dementia training for their staff and a specialty license.

Most adult day centers in Florida also offer caregiver support programs, including educational programs (70%), caregiver support groups (58%), and individual counseling (40%). In addition, approximately 90% of centers offer cognitive stimulation programs and almost 80% provide memory training programs (FADSA, 2025).

2. Managing Challenging Behaviors

Changes in behavior occur in most people living with dementia. These changes are referred to as *behavioral and psychological symptoms of dementia* (BPSD) or *neuropsychiatric symptoms of dementia* (NSP).

Controlling and suppressing inappropriate behaviors is an important social skill that we practice every day. The loss of this ability—**disinhibition**—causes a lack of restraint, disregard for social convention, impulsiveness, poor safety awareness, and an inability to stop strong responses, desires, or emotions.

Managing difficult behaviors in a person living with dementia requires patience and compassion, and sometimes, the skill of a detective to uncover the cause of the behavior. Anyone who has worked with someone living with dementia is familiar with many of these difficult behaviors.

Although some behaviors are associated with brain changes, others are caused by frustration, loss of control, discomfort, pain, and the inability to communicate needs. In general, successfully managing challenging behaviors means:

- understanding what is causing the behavior
- creating a safe and comfortable physical environment
- learning how to divert the person's focus to an object or activity
- encouraging regular physical activity

2.1 Common Symptoms and Behaviors Associated with Each Stage

A **symptom** is an internal change in the body or the mind. Symptoms change as a person's dementia progresses and can often cause behavioral changes. For some people symptoms worsen quickly. For others, symptoms progress more slowly.

We associate certain symptoms and behaviors with stages. The type of dementia, along with a person's general physical and psychological health, can affect symptoms and behaviors as much as the stage of a person's dementia.

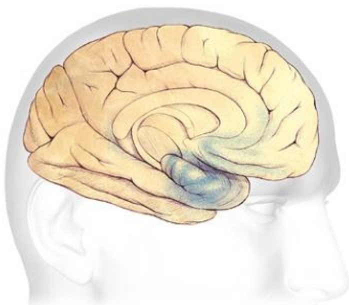
2.1.1 Mild Dementia

In early, mild Alzheimer's disease, plaques and tangles appear in the part of the brain called the hippocampus, which is responsible for memory and learning. This part of the brain helps a person form and store recent, short-term memories. The hippocampus converts short-term memories into long-term memories by organizing and retrieving memories when needed.

Location of the hippocampus. Source: Image courtesy of the National Institute on Aging/National Institutes of Health. Public domain.

The inability to recall something that just happened (short-term memory) is a common symptom in a person living with mild dementia. Spatial memory can also be affected. This means a person might get lost in a new environment, forget where they put things, and not be able to understand the layout of their surroundings. Logical thinking and judgment are often mildly affected.

Brain Changes in Mild Dementia



In early AD, often before symptoms can be detected, plaques and tangles begin to form in and around the hippocampus (shaded in blue), an area of the brain responsible for the formation of new memories. Source: The Alzheimer's Association. Used with permission.

In the early stage, a person can experience a little confusion with complex tasks. People naturally try to hide their mild confusion from friends, coworkers, and family, which can be tiring and frustrating.

Even when symptoms are mild, a person's behavior can begin to change, especially in Alzheimer's disease and some other types of dementia. People often know something is wrong, creating depression, stress, mood changes, and anxiety.

2.1.2 Moderate Dementia

As symptoms progress to the moderate stage, plaques and tangles spread forward to the areas of the brain involved with language, judgment, and learning. Many people are first diagnosed with Alzheimer's or another type of dementia during this time.

In the moderate stage, work and social life becomes more difficult and confusion may increase. Damage affects the areas of the brain involved with:

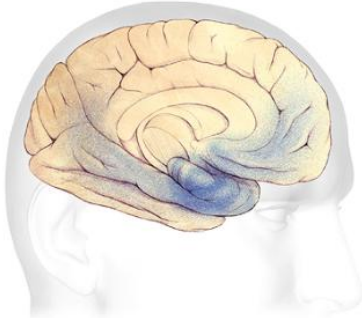
- speaking and understanding speech
- logical thinking
- safety awareness
- judgment
- planning
- ethical thinking

At this stage, because of memory problems and confusion, for the person living with dementia, travel, work, and handling personal finances may become more difficult.

Behavioral changes become more obvious to caregivers. Inappropriate behaviors such as cursing, kicking, hitting, and biting can occur. Some people may begin to repeat questions, call out, or repeatedly demand your attention. Sleep problems, anxiety, agitation, and suspicion can develop.

A person with moderate dementia is usually still able to walk. This is because the part of the brain that controls movement is not affected. Wandering can become a safety issue. More direct monitoring is needed than during the early stage of dementia. A person may no longer be safe on their own.

Brain Changes in Moderate Dementia

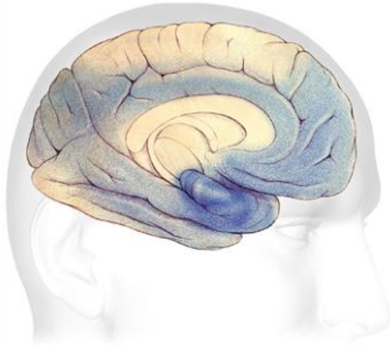


As symptoms progress from mild to moderate, plaques and tangles spread from the hippocampus (dark blue) forward to the frontal lobes (shaded in light blue). Source: The Alzheimer's Association. Used with permission.

2.1.3 Severe Dementia

In severe Alzheimer's disease, because so many areas of the brain are affected, a person's ability to communicate, recognize family members and loved ones, and care for self is severely affected. A person living with severe dementia is easily confused, indecisive, and often unable to communicate their needs clearly. Sleep disturbances, emotional outbursts, and frustration are very common.

Brain Changes in Severe Dementia



In advanced Alzheimer's, plaques and tangles have spread throughout the brain (shaded in blue). Source: The Alzheimer's Association. Used with permission.

All sorts of challenging behaviors can occur at this stage, especially if caregivers (including professional caregivers) are poorly trained, easily frustrated, or highly stressed. Bouts of paranoia, as well as delusions or hallucinations, can occur.

At this stage, a person living with severe dementia may wander, rummage, or hoard. Screaming, swearing, crying, shouting, loud demands for attention, negative remarks to others, and self-talk are common. These outbursts are usually triggered by unmet needs such as frustration, boredom, loneliness, depression, cold, heat, loud noises, or pain.

Inappropriate and impulsive behaviors are particularly common in someone with a type of dementia that affects the front part of the brain (frontotemporal dementia). For a person living with this type of dementia, socially inappropriate behaviors are common, together with *perseveration**, loss of empathy, apathy, and cognitive inflexibility.

***Perseveration**: repetition of a word, phrase, of thought. The inability to shift from one idea to another.

In the severe stage, a great deal of independence is lost, and around-the-clock care may be needed. Caregivers will likely need to oversee and directly assist with eating, bathing, walking, dressing, and other daily living activities.

2.1.4 Symptoms and Behaviors at the End of Life

At the end of life, many people living with dementia are completely dependent on caregivers. They often have trouble communicating their needs and desires using speech. They may become bedridden, or nearly bedridden.

Often there are complications such as immobility, swallowing disorders, and malnutrition. Because people at this stage are much less active than in earlier stages of dementia, there is an increased risk of developing acute conditions that can lead to illness or death. Pneumonia is a particular concern. It is the most common cause of death among older adults who have Alzheimer's or other dementias.

At the end of life, it is likely that both short- and long-term memory are affected. Sensory changes such as loss of vision and hearing mean a person can be startled by loud noises and quick movements. Depending on the type of dementia, a person may experience agitation, psychosis,* delirium,** restlessness, and depression.

***Psychosis**: loss of contact with reality.

****Delirium**: a sudden, severe confusion that can be caused by infections, a reaction to medications, surgery, or illness.

2.2 General Problem-Solving Approach to Challenging Behaviors

Problem solving is an important skill for caregivers and healthcare providers to develop when working with a person living with dementia. Practicing compassion, reassurance, and active listening can reduce or even prevent agitation and other challenging behaviors. It can also reduce the use of antipsychotics and other medications used to manage challenging behaviors.

The "ABC" model emphasizes data gathering and problem-solving. This approach helps staff and caregivers understand when and how often a particular behavior occurs. It is particularly effective when successful strategies are shared by staff, caregivers, and family members.

The ABC Approach considers:

- **A** (Antecedent) What **caused** the behavior?
- **B** (Behavior): What **is** the behavior?
- **C** (Consequence): What are the **consequences** of a behavior?

The ABC approach also encourages caregivers and healthcare providers to examine their own behaviors and responses. Understanding your own biases, frustrations, and triggers helps you to be patient and compassionate when you approach a person struggling with dementia.

2.3 Strategies for Addressing Common Challenging Behaviors

Caring for a person experiencing cognitive and sensory changes due to dementia requires training, strategies, and techniques that change as a person's dementia changes. Because dementia is progressive, strategies that work with mild dementia may not work in the later stage of a person's dementia.

Challenging behaviors can be addressed with proper staffing, pet therapy, social engagement, simplifying tasks, and good communication. Unfortunately, much of the frustration people living with dementia experience is due to negative environmental influences, including staff attitudes, behaviors, and care practices in addition to unmet needs, frustration, boredom, pain, or untreated medical or medication issues.

Although this is not all-inclusive, certain behaviors are common in people living with dementia. This can include agitation, aggression, psychosis, wandering, rummaging, hoarding, sleep disturbances, and apathy.

2.3.1 Agitation and Aggression

> Agitation, aggression, and psychosis are labels on behaviors that are often caused by environmental or personnel approaches rather than being due entirely to the person's brain changes. These reactions should be viewed as an expressive communication of a possible unmet need.
>
> Teepa Snow, STOP Treating Behaviors with Restraining Medications

Agitation and aggression are among the most common and challenging symptoms in older adults living with dementia. These behaviors worsen a client's daily functioning, increase the risk of injury, and increase the likelihood of hospitalization and long-term care placement. They also impose a significant burden on caregivers and healthcare providers (Lichwala et al., 2026).

Agitation has a range of causes. When a person is agitated, they are restless, worried, and unable to settle down.

Agitated behaviors can include:

- irritability and impatience
- pacing
- confusion
- loud demands, shouting
- using obscene language
- repetitive behaviors

Aggression involves physically or verbally threatening behaviors. Aggressive behaviors can include:

- hitting, punching, kicking, pushing
- throwing objects or using objects to hit or lash out
- engaging in inappropriate sexual advances or touching
- client-to-client aggression, verbal aggression

Left: An older woman living with dementia expresses her frustration and anger. Right: An older man living with dementia lashes out at his caregiver. Source: created by author using Midjourney AI.

Agitated and aggressive behaviors often occur during personal care tasks involving close contact. A person may feel threatened or feel their personal space is being violated. Depending on the type and severity of a person's cognitive changes, agitated and aggressive behaviors may become more pronounced as a dementia progresses.

To manage aggressive behaviors, staff and caregiver training are essential. Psychosocial and environmental interventions, and recognition of personal habits and patterns, can reduce or even eliminate agitated or aggressive behaviors.

Try the following tips to help manage these symptoms:

- Speak calmly and actively listen.
- Reassure the person that they are safe.
- Try to distract by offering an activity or chore.
- Reduce noise and clutter.
- Consider physical and medical causes.

Antipsychotic medications are often used to treat agitated and aggressive behaviors in people living with dementia. **They should be used for the shortest possible time and only as a last resort.**

2.3.2 Dementia-Related Psychosis

Dementia-related psychosis occurs when a person experiences symptoms such as delusions, paranoia, or hallucinations.

A **delusion** is a false belief or a misinterpretation of a situation. For example, a daughter might be confused with the person's mother or the person living with dementia might accuse someone of stealing something they have misplaced.

Paranoia is a type of delusion in which a person may believe—without a good reason—that others are lying to them, being unfair, or are "out to get me." A person may become suspicious, fearful, or jealous of other people. Paranoia can sometimes include caregivers, family, or friends.

Hallucinations can occur when a person hears, tastes, smells, sees, touches, or feels something that is distorted or not there. For example, they may see shadows, cats running through the room, or images of threatening people or things (Fischer, 2022).

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

*__Lewy body dementia__: a type of dementia in which a person experiences cognitive decline, "fluctuations" in alertness and attention, visual hallucinations, and slowness of movement, difficulty walking, or rigidity (stiffness).

For a person with new onset of visual hallucinations, the number one cause is medication side effects. For this reason, all medications the person is receiving should be regularly and carefully reviewed.

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

The first step in the management of delusions and hallucinations is to rule out delirium or another acute medical cause. Observing a person's behavior and listening to what they have to say often helps a caregiver address the root cause of the delusion or hallucination.

When communicating with someone who is expressing paranoia or delusions, understand that the delusion is very real for that person. Do not argue or try to correct the person. Explaining the truth of the situation does not work. Do not agree or validate the paranoia or delusion—try to respond to the person's emotion. For hallucinations, it is often helpful to decrease auditory and visual stimuli as well as evaluating the person for a visual or hearing impairment.

2.3.3 Wandering

Wandering and exploring are activities that almost everyone enjoys. But, because a person living with dementia might be at risk for falls or injury, providers and caregivers often see wandering as a problem and try to control or prevent this behavior. However, preventing a person from safely wandering creates other problems, such as boredom, loss of social interaction, stigma, loss of conditioning, pain and discomfort, and even skin breakdown.

Wandering can involve moving to a specific location, lapping, or circling along a path, pacing back and forth, or wandering at random. People may wander out of habit or because they are convinced something needs to be done. They may want to return home after work, cook dinner, walk the dog, exercise, or search for something they think they have misplaced. The most important goal is to prevent a person from wandering into unsafe areas, or *eloping** from a home or facility.

*__Eloping__: When a person wanders away or leaves a facility or home unsupervised or unnoticed.

Source: NIH, public domain.

Wandering is a common behavior seen in people living with almost all types of dementia. Nearly 60% of people living with dementia will wander during the course of their disease. Wandering can happen at home or in the community. In institutional settings, wandering occurs in about 40% of clients (Anu et al., 2024).

Wandering can be more common in someone who has experienced stressful events throughout their life or a person who responds to stress by engaging in physical activities. People with an outgoing personality, who enjoy music, and who were socially active throughout their life are more likely to wander than less active, introverted people.

Managing wandering behaviors in a person living with dementia requires a thoughtful and creative approach. Understanding the reasons for wandering should include regular review of medications to make sure wandering is not the result of medication side effects, overmedicating, or drug interactions.

Address wandering by:

- redirecting a person to a purposeful activity
- providing safe, looping wandering paths with interesting rest areas
- installing rails and grab bars for safety
- providing regular exercise
- offering to wander with the person

Engaging someone in simple chores such as folding laundry or assisting with dinner can give them a sense of purpose and fulfillment. Electronic devices attached to the person's ankle or wrist can be used to alert staff or family members when someone has wandered out of a designated area. Subjective barriers such as grid patterns on the floor in front of exit doors, camouflage, and concealment of doors and doorknobs can discourage a wanderer from exiting a building.

For a person in the later stage of dementia, especially someone who is unable to walk safely, lowering the seat on the wheelchair allows a person to wander safely by propelling the wheelchair with their feet. If the chair cannot be lowered, a "drop seat" can be installed, which has the added benefit of allowing the addition of a good-quality pressure-relief cushion. The wheelchair should be adjusted to equalize pressure wherever a person's body meets the seat, back, sides, or cushion. Daily skin monitoring is essential.

Jay adjustable solid seat insert. Only use with a pressure-relief cushion. Source: Sunrise Medical, used with permission.

Did you Know. . .

> For people who wander away from their home or care facility, the immediate action is to call 911. Florida maintains a Silver Alert program for cognitively impaired older adults who become lost while driving or walking. The Silver Alert program is activated by law enforcement and broadcasts information to the public so they can assist in the rescue of the endangered person and notify law enforcement with useful 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.

2.3.4 Rummaging and Hoarding

Rummaging and hoarding are behaviors in which a person gathers, hides, or puts away items in a secretive and guarded manner. Rummaging and hoarding are not necessarily dangerous or unsafe, but these behaviors can be frustrating for caregivers.

Hoarding is associated with insecurity, fear, and anger and may be an attempt to hold onto possessions and memories from the past. A person might hoard because they fear losing money or possessions. They may feel a lack of control or a need to "save for a rainy day."

An older woman rummaging in her closet. Created by author using Midjourney AI.

Memory loss, poor judgment, and confusion contribute to rummaging and hoarding. Rummaging through familiar items can create a sense of safety and security. Confusion can lead to rummaging through another person's belongings, which can be particularly frustrating for them.

To address rummaging and hoarding behaviors, try to determine what triggers the behavior and look at the consequences, if any. The reason for rummaging and hoarding may not be clear to you but there may be a perfectly good reason why someone living with dementia is rummaging.

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

For a person living at home, place important items such as credit cards or keys out of reach or in a locked cabinet. Consider having mail delivered to a post office box and check wastepaper baskets before disposing of trash. Look for patterns and carefully observe the person's hiding places.

In facility settings, reduce clutter and label cabinets, doors, and closets (with words or pictures). Poisonous items should be stored away from common areas in locked cabinets.

Rummaging and hoarding are obsessive/compulsive behaviors. A person who feels a strong need to rummage or hoard can be remarkably persistent, secretive, and patient, making it difficult for caregivers to address this conduct.

2.3.5 Sleep Disturbances

More than half of people living with dementia experience some sort of sleep disturbance due to comorbid medical conditions and environmental factors. Common sleep problems include insomnia, fragmented sleep, *obstructive sleep apnea,** *rapid eye movement sleep behavior disorder,*** and restless legs syndrome. Individuals may have trouble falling asleep or staying asleep due to *altered circadian rhythms**** and increased confusion during the night (Mukherjee et al., 2024).

***Obstructive sleep apnea:** a syndrome caused primarily by the collapse of the upper airway during sleep.

****Rapid eye movement sleep behavior disorder**: a sleep disorder in which individuals physically and/or vocally act out vivid, often unpleasant dreams and sudden, involuntary arm and leg movements during REM sleep.

*****Altered circadian rhythms**: disruption in the body's sleep-wake cycle.

Comorbid medical conditions that can affect sleep in older adults living with dementia include:

- cardiovascular disease
- diabetes
- depression and anxiety
- thyroid disorders (hypothyroid and hyperthyroid)
- untreated or poorly treated pain

In 2024, the Center for Medicaid and Medicare Services (CMS) published guidelines that require non-pharmacologic interventions for sleep disturbances must be tried and documented before using sedatives or psychotropic medications in a person living with dementia (CMS, 2024).

Non-pharmacologic treatments can include (Mukherjee et al., 2024; CMS, 2024):

- cognitive-behavioral therapy for insomnia
- minimizing environmental disruptions (reducing nighttime noise and excessive light).
- avoiding stimulating activities close to bedtime
- encouraging good sleep hygiene (a regular bedtime routine and a warm comfortable sleeping environment)
- restricting caffeine, nicotine, and alcohol

In addition to affecting the health and quality of life of the person living with dementia and their caregivers, sleep disturbances can contribute to some challenging behaviors. CMS requires that sleep disturbances be evaluated when a person exhibits agitation, anxiety, wandering, or changes in cognition. This includes looking for potentially treatable causes such as pain and discomfort, hunger and thirst, the need to urinate, infections, and adverse drug reactions.

Sleep disturbances can lead to "sundown syndrome," a set of symptoms or behaviors that emerge in the late afternoon or early evening. Managing sundown syndrome involves a combination of environmental, behavioral, and medical interventions. A consistent daily routine, regular physical activity, soothing and familiar activities in the late afternoon, and a calm and comfortable environment can improve sleep and decrease sundowning (Mukherjee et al., 2024).

Benzodiazepines, which have a hypnotic sedative effect are currently the most widely prescribed medications for sleep disorders in older adults. Despite their widespread use, concerns remain regarding their potential for tolerance, dependence, and adverse effects such as cognitive impairment (especially in older adults) (Chavez-Mendoza, 2025).

Benzodiazepine dependence has been associated with severe depression and anxiety and impaired cognitive and psychosocial function. In older adults, increased sensitivity to benzodiazepines can increase the risk of confusion, disorientation, and falls (Chavez-Mendoza, 2025).

Recently, non-benzodiazepine hypnotics, commonly known as Z-drugs, have been suggested as effective alternatives due to their similar mechanism of action. They may improve sleep quality, lower dependency risks, and reduce adverse effects compared to benzodiazepines (Chavez-Mendoza, 2025).

Importantly, sleep disturbances can contribute to some challenging behaviors, particularly anxiety, increased confusion, wandering, and sundowning. Sundown syndrome is the emergence or worsening of neuropsychiatric symptoms in the late afternoon or early evening. It has long been recognized as an aspect of dementia and is well known among most of healthcare providers involved in the care of persons with dementia.

Treating sleep disturbances involves looking for potentially treatable causes. This includes treating pain and discomfort, hunger and thirst, the need to urinate, infections, and adverse drug reactions.

Non-pharmacologic treatments that can improve sleep include:

- light therapy
- exercise and individualized social activities
- caffeine, nicotine, and alcohol restriction
- comfortable beds with enough pillows for back and neck support
- good temperature control in rooms
- noise reduction

2.3.6 Apathy

Apathy is a lack of interest or emotion, loss of motivation, indifference, and a blunting of emotions. It is one of the most common neuropsychiatric features of dementia, affecting 50% to 70% of people with the condition (Baber et al., 2021).

The presence of apathy in people with Alzheimer's disease is associated with increased functional impairment, a greater likelihood of rapid functional decline, and a lower self-reported quality of life. It is also associated with poorer performance in basic and instrumental activities of daily living, more rapid disease progression, and increased mortality (Dolphin et al., 2023).

Apathy is often under-recognized, under-diagnosed, and poorly managed. Caregivers often find it frustrating when it appears that a person living with dementia can do a task but simply does not bother or will only do so with strong encouragement (Baber et al., 2021).

Non-pharmacologic interventions are the first choice to treat apathy and other challenging behaviors associated with dementia. Four approaches are recommended (Oba et al., 2022):

1. Behavior-oriented approaches.
2. Emotion-oriented approaches (reminiscence therapy, validation therapy, and supportive psychotherapy).
3. Cognition-oriented approaches (reality orientation and skills training).
4. Stimulation-oriented approaches (recreational activities, group art therapies, exercise, and music therapy).

Regular one-on-one personal contact tailored to a client's particular skills or interests has also led to improvements in apathy in people with dementia (Dolphin et al., 2023).

A review on pharmacological treatments for apathy in various dementia types showed no convincing proof for the effectiveness of any drug treatment. A meta-analysis failed to find a significant treatment effect for apathy in favor of any drug (Theleritis et al., 2023).

2.4. Physical and Chemical Restraints

> When—if ever in the eternal dementia care merry-go-round of staff shortages, budget limitations, regulatory approvals, mandates, or penalties—will we focus on the people we are supposed to be serving without turning first to medications?
>
> Teepa Snow, STOP Treating Behaviors with Restraining Medications

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, 2020).

Use of restraints should be (GovTrack, 2020):

- reserved for documented indications
- time limited
- frequently re-evaluated for their indications, effectiveness, and side effects

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, a 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, 2025).

2.4.1 Physical Restraints

A **physical restraint** is any manual method, physical or mechanical device, material, or equipment attached to or adjacent to a person's body that the individual cannot remove easily and which restricts freedom of movement or normal access to one's body.

Physical restraints can include:

- chair belts, any belt restraint
- mittens, limb restraints
- soft wrist and ankle restraints
- vest and jacket restraints
- bedrails, bed sheet restraints
- geriatric chairs and recliners
- wheelchair safety bars or locked tables
- lapboards

Use of physical restraints can cause agitation, confusion, deconditioning, pressure ulcers, strangulation, suffocation, and even death. Restraints affect a person's sense of well-being, causing feelings of low self-worth, depression, withdrawal, humiliation, and anger. The use of physical restraints in older adults is considered a violation of their human rights.

Restraint can include using (or threatening) force or restricting a person's movements—even if they do not resist. Forced isolation (such as locking a person in their bedroom) is also a type of restraint.

A restraint-free environment should be the standard of care and goal for adult day care facilities. Restraint reduction programs can significantly reduce the use of restraints. Healthcare providers can lead the way by educating themselves about the dangers of restraints and sharing this knowledge with family caregivers.

Person-centered care focuses on practices that respect the dignity of each individual. Collaborating with family members and the person living with dementia allows the development of an individual care plan that addresses issues that affect a person's safety and wellbeing.

The use of physical restraints can be reduced or eliminated by creating an environment that is friendly toward older adults, embraces aging with compassion, promotes safe mobility by making the physical environment accessible to people with disabilities, and caters for the needs of older people (Atee et al., 2023).

2.4.2 Chemical Restraints

The term **chemical restraint** refers to the use of antipsychotic, antianxiety, antidepressant, or sedative medications for the purpose of controlling or restricting a person's behavior or movement. Unfortunately, a decrease in the use of physical restraints has been linked to the increased use of chemical restraints (Cain et al., 2023).

In 2023, the *American Geriatrics Society Beers Criteria for Potentially Inappropriate Medication Use in Older Adults* stressed the need to avoid antipsychotics and other medications for behavioral problems of dementia and delirium because their use is frequently associated with harm (AGS, 2023).

Between 2011 and 2019, *psychotropic drugs** were prescribed to about 80% of nursing home residents. Higher use of psychotropic drugs was associated with nursing homes with lower ratios of registered nurse staff to residents. Nursing homes with a higher percentage of low-income residents were also associated with higher use of these drugs (OIS, 2022).

***Psychotropic drugs**: antipsychotics, anticonvulsants, mood stabilizers, and central nervous system agents.

Behavioral interventions are the preferred management strategy for treatment of challenging behaviors associated with dementia. The decision to use or not use a chemical restraint should always be made in collaboration with the client and family members (AGS, 2023).

A provider may choose to prescribe an antipsychotic medication when symptoms are severe, dangerous, or cause significant distress to the client. These medications may be effective in some cases. However, the provider must disclose to the client and family that the medication is being used *off label** meaning a drug has not been approved by the Food and Drug Administration (FDA) for treatment of behavioral symptoms of dementia. The provider must obtain permission from the client or family member to use these drugs for behavioral symptoms of dementia.

***Off label**: prescribing medications for an unapproved indication, age group, dose, or form of administration.

2.4.3 Alternatives to Restraints

There are many alternatives to the use of physical and chemical restraints. Some alternatives practices enhance safety and comfort for all clients, such as increasing staffing levels, removing hazards, providing safe areas for walking, and training staff on how to identify and respond to unmet needs (CANHR, 2025).

Other alternatives include adapting and tailoring chairs to improve comfort and safety, using pads and pillows to support comfortable and safe body positions, providing therapy and restorative care to improve a resident's abilities to move safely, adjusting care and caregiver assignments to a resident's preferences, and using low beds and floor padding to safeguard against harmful falls from bed (CANHR, 2025).

Establishing a routine, including a toileting schedule, improves comfort and reduces challenging behaviors. Regular exercise, a comfortable place to rest, and establishing a schedule for napping also help. On a regular basis:

- Address hunger, thirst, and discomfort.
- Review medications for adverse effects.
- Treat all underlying causes, including pain.
- Assess hearing and vision.
- Relieve impaction.

An uncluttered, home-like environment reduces the need for physical restraints. All areas, both in the home and in a facility, should be free of equipment and obstacles. Providing wall rails, grab bars, and transfer poles in rooms, bathrooms, hallways, and common areas promotes independence and reduces caregiver stress and worry.

Transfer poles and grab bars support independence and safety. Source: Author.

3. Assistance with Activities of Daily Living (ADLs) for Persons with ADRD

> The "small things" are particularly important in ensuring that care is genuinely supportive of the individual and enhances that person's autonomy and well-being. The humanity with which assistance is offered, especially help with eating and intimate care, is crucial in helping the person retain their self-esteem and dignity.
>
> Nuffield Council on Bioethics

Activities of daily living are the personal tasks we do during our daily lives. These skills tend to decline as a person's dementia progresses.

ADLs are often divided into two categories: **basic ADLs** and **instrumental ADLs**. Basic ADLs are those skills needed to take care of personal needs. Instrumental or functional ADLs are the skills needed to function within society and within the community.

Older adults living with dementia participating in adult day programs may need less assistance with ADLs than people in long-term care settings. Nevertheless, most people living with dementia who are enrolled in an adult day program need some assistance with walking, toileting, transfers, or medication management.

For all levels of dementia, grab bars, transfer poles, assistive tableware, and other type of assistive equipment promote independence and reduce caregivers' physical strain.

Basic and Instrumental ADLs

Basics ADLs (skills needed to take care of personal needs)	Eating, bathing or showering, grooming Walking Dressing and undressing Transfers, toileting
Instrumental ADLs (skills needed to function within the community and society)	Housework Financial management Shopping, preparing meals Communicating with the outside world Medical management

3.1 General ADL Strategies

When assisting a person living with dementia with their ADLs, encourage them to express their wishes. Always try to understand why a person might be refusing help. Are they scared? Do they misunderstand what you asked them to do? Are they embarrassed? Are they cold or in pain?

If the person seems confused, repeat your request, using the same words or slightly rephrasing the question. Rephrasing the request can support understanding and reduce frustration. Offer simple choices, such as "Do you want orange juice or apple juice?" Engage the client. Be empathetic. Examples of empathetic responses include "You must be cold" or "Are you uncomfortable in that chair?" "What would help now?"

Keep these general measures in mind when assisting someone with their ADLs:

- Make eye contact (where culturally appropriate).
- Be calm.
- Do not crowd.
- Be aware of your body language and vocal tone.
- Slow the speed of your movements and speech.
- Approach from the front—don't sneak up on the person from behind.

3.2 ADL Strategies: Mild Dementia

A person with mild dementia may need very little help, if any, with basic activities of daily living. They can dress themselves, bathe, do tasks around the house and in the yard, and may still be able to shop and cook. They will likely begin to need help with complex tasks such as balancing a checkbook or paying bills.

At this stage, there may be some loss of interest in hobbies and activities. Mood changes, such as depression and anxiety, can occur. Learning new tasks, especially complex tasks, may be difficult. Faulty judgment and mild changes in personality may become obvious to family members and caregivers.

Dressing

- Encourage choice in the selection of clothes.
- Allow your client to direct the activity.

Grooming

- Encourage independent grooming, provide tools if needed.
- Monitor progress and provide help as needed.

Eating

- Ask for food preferences.
- Ask for help with meal preparation and meal set-up.
- Provide adaptive utensils if needed.
- Provide help as needed.

Bathing

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

Toileting and Incontinence*

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

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

3.3 ADL Strategies: Moderate Dementia

Often, there is often a clear delineation between mild and moderate dementia. While progression varies, the middle stage of dementia is characterized by measurable executive dysfunction, impaired sequencing, and an increased need for direct supervision and support for safety, planning, and task initiation.

Variability at this stage is seen in 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, more help may be required.

In the **moderate stage**, caregiver responsibilities increase. Cooking, housework, and shopping may require direct assistance. Basic ADLs may require assistance for set-up and safety and may be disrupted by behaviors such as anger, frustration, and denial.

Dressing

- Provide comfortable clothes with elastic waistbands and Velcro closures.
- Encourage participation in the choice of clothing but limit choices.
- Assist closely but encourage independence.
- Lay out cloths in order.
- Provide multiple pairs of favorite outfits.
- Provide adaptive equipment such as grab bars as needed.

Grooming

- Limit choices ("Would you like lipstick today?" "Would you like to brush your hair?").
- Encourage as much independence as possible.
- Provide an electric razor for safety and independence.
- Help with the application of makeup and skincare products if needed.
- Assist men with the trimming and cleansing of facial hair.
- Keep nails clean and trimmed (use a file if preferred by client).
- Assist with brushing teeth, use an electric toothbrush if needed.
- Use floss holders, oral irrigators, or interdental brushes if the client has difficulty with mouth care.
- Be aware of dry mouth, provide artificial saliva if needed.
- Visit the dentist on a regular basis.

Eating

- Ask for food preferences.
- Set up the meal before serving.
- Open packages and uncover trays.
- Provide adaptive utensils as needed.
- Monitor closely.

Bathing

- Ask about bathing preferences.
- Initiate and monitor the activity.
- Provide direct assistance as needed, particularly for showering.
- Provide adaptive equipment such as shower chairs and grab bars as needed.

Toileting and Incontinence

- Ask regularly if the bathroom is needed.
- Provide close assist, particularly with transfers.
- Label bathroom door for easy identification.
- Provide toileting on a regular schedule.
- Provide adaptive equipment such as grab bars, transfer poles, and toilet chairs as needed.

Left: An example of a complete set of assistive tableware. This tableware design applied research from Boston University. According to the study, colors help a person living with dementia to reduce visual impairment and consume 24% more food and 84% more liquid. Designed by Sha Yao, Eatwell.com. Used with permission.

3.4 ADL Strategies: Severe Dementia

Dealing with Delaying Tactics

> My mom has pretty severe dementia and needs lots of help. She goes to an adult day program three times per week. I start getting her ready at least an hour-and-a-half ahead of time. When I think we're ready to go, she insists on brushing her teeth. This takes about 15 or 20 minutes, and I must stand next to her at the sink the entire time. Yesterday, we didn't have much time, and I tried to get her to go without brushing her teeth. Big mistake! She grabbed the door to the garage, sat down on the floor, and refused to move. She only weighs 100 pounds but is surprisingly strong. She actually leaned back and put both of her feet and hands on the door opening and wedged herself in. After she brushed her teeth and was safely in the car, she yelled at me to hurry up because we were going to be late!
>
> Family Caregiver, Cottondale, Florida

In the severe stage, a great deal of independence is lost, and around-the-clock supervision may be needed. Caregivers will likely need to oversee and directly assist with eating, bathing, walking, dressing, and other daily living activities.

Difficulty swallowing (dysphagia) can develop in the later stage of dementia, leading to *aspiration** of food, fluids, or saliva into the lungs. To prevent this from happening, food choices will need to be modified by softening the texture of food and thickening liquids.

***Aspiration**: the accidental inhalation of food or liquid into the lungs.

To prevent aspiration, tuck the chin, massage the throat, or rotate the head. These practices should only be implemented under the guidance of a licensed speech-language pathologist. Other practices can include:

- Sitting in a supported, upright position.
- Using a chin-down posture.
- Adjusting the size of bites.
- Avoiding the use of sedatives and narcotics.
- Providing good oral care.

During this stage, basic ADLs require a great deal of set-up and assistance, depending on the person's physical capabilities. Complex, instrumental ADLs will be completely taken over by a family member or caregiver.

In the severe stage, individuals typically require extensive assistance with ADLs, even total care. Executive function is profoundly affected, mobility is often significantly limited, and bowel and bladder function is commonly lost.

A person with severe dementia may still be able to walk somewhat independently and may be independent, or nearly so ,with bed mobility and transfers. But anything that requires planning, sequencing, or judgment is severely impaired at this stage. Extensive close assistance will be needed for dressing, bathing, meal preparation, grooming, and toileting. If mobility is compromised, close assistance will be needed for all ADLs.

Control of bodily functions can be inconsistent, requiring direct help with bathing and toileting. Encourage family members to learn about and use assistive equipment and devices that help them and encourage independence.

Safety awareness may decline in a person with severe dementia, requiring significant direct help with transfers, gait, and mobility. To prevent injuries and falls, it may be necessary to use bed and chair alarms or provide a one-on-one caregiver, which increases the cost of care.

For caregivers, healthcare providers, direct care workers, and family members, this is the stage of dementia that requires all your patience, skills, and expertise. People still want to participate in social activities, use the bathroom without assistance, get out of bed whenever they want, and live in the way they have lived for their entire lives. These needs, desires, and habits are deeply embedded in our psyche, and it requires a great deal of patience and wisdom on the part of caregivers to understand these changes and provide support in a dignified and respectful manner.

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.
- Provide assistance but encourage independence.
- Provide assistive equipment such as transfer bars and grab bars.

Grooming

- Provide as much assistance as needed.
- Move slowly, limit choices.
- Use one-step commands and gestures.
- Provide an electric razor for safety, help if needed.
- Assist as needed with the application of makeup and skincare products.
- Assist men with the trimming and cleansing of facial hair.
- Keep nails clean and trimmed.
- Assist with brushing teeth by providing step-by-step instructions.
- Use an electric toothbrush if needed.
- Use floss holders and oral irrigators if needed.
- Be aware of dry mouth, provide artificial saliva if needed.
- Visit the dentist on a regular basis.

Eating

- Ask for food preferences and provide small amounts of food at a time.
- Let the person know what they are eating.
- Sit to the side while helping (sitting in front may be intimidating).
- Offer a bite of the meal and a bite of something sweet.
- Make sure the person has swallowed before introducing more food (food can be pocketed in the cheeks).
- Provide high-calorie, healthy foods to eat or drink (protein drinks, dietary supplements, or foods prepared with healthy fats).
- Consider a multivitamin (tablet, capsule, powder, liquid, or injection).
- Fully set up the meal before serving.
- Provide adaptive equipment as needed.
- Monitor closely and be ready to provide feeding assistance.
- Offer liquids on a regular schedule.
- Allow plenty of time to finish eating.
- Be aware of the potential for aspiration of food or fluids.

Bathing*

- Provide complete bathing care.
- Retain as much of a person's earlier bathing rituals as is reasonable.
- Use the person's behavior as a guide.
- Provide assistive equipment such as shower chairs, transfer poles, and grab bars.

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

Toileting and Incontinence*

- Expect both bowel and bladder incontinence requiring total care.
- Set up timed toileting schedule.
- Provide assistive equipment such as transfer bars and grab bars.
- Check for skin breakdown, skin rash and redness, and infections and treat promptly.
- Review medications that may contribute to incontinence.
- Restrict drinks that contain caffeine.
- Change adult diapers regularly and keep the area clean and dry.

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

Urgency, urinary frequency, lower abdominal pain or tenderness, blood in the urine, pain or burning sensation with urination, and changed mental status can be signs of a urinary tract infection, which should trigger a urinalysis and urine culture. Catheter-associated urinary tract infections are common and can occur when germs enter the urinary tract by way of the catheter. Caregivers should consistently clean their hands before touching a catheter.

4. Activities for Clients with Alzheimer's

> Carefully designed activities can have a positive effect on depression, confusion, and challenging behaviors. Activities should provide a positive experience, be meaningful, and be challenging.
>
> Telenius et al., 2022

Many adult day care centers offer a comprehensive range of activities and services that extend far beyond recreational activities, providing support that meets the needs of day care participants and their caregivers. Activities are geared toward improving cognition while supporting social interactions (Sadarangani et al., 2024).

Exercise classes support physical health and mobility. Balanced meals and snacks cater to a client's dietary needs while dining areas support conversation and allow for communal celebrations that take place around meals (Sadarangani et al., 2024).

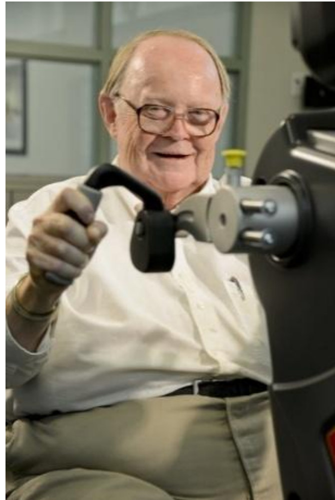
Regular health monitoring, including assessments and tracking of chronic conditions by healthcare professionals, ensures that any potential issues are identified and addressed promptly. Importantly, adult day care centers provide respite for family caregivers, allowing them to attend to their own needs and responsibilities while knowing their loved ones are in a safe and supportive environment (Sadarangani et al., 2024).

Whether individual or in groups, activities should be meaningful. Meaningful activities help people living with dementia maintain a sense of identity, autonomy, and engagement. This includes adapting tasks to match the person's current abilities, modifying the environment to reduce barriers, minimizing failure, and motivating a person to encourage involvement. Participation is not just about doing tasks—it's about being part of life in a way that has meaning for the person (Galof, 2025).

4.1 Individual Activities

Successful individual activity programs for people living with dementia are based on a person's likes, dislikes, and interests. This means learning about a person's history and understanding their capabilities and preferences.

Determine whether they can still read, write, or use a computer and what they are physically capable of doing. Individual activities that stimulate the senses, such as cooking, singing, exercise, going for a drive, gardening, and aromatherapy, are encouraged at all stages of dementia.



Left: A man using an upper extremity bike to exercise. Source: CDC.

Right: A man enjoying a familiar activity. Southeastern Veterans Center by padmva is licensed under CC BY-NC-ND 2.0.

Some organizations that serve older adults, such as the *Eden Alternative*, encourage pets in their facilities. Pets provide companionship, promote relationships, and provide meaningful activity and exercise. Taking care of an animal gives a sense of purpose and companionship and is a key component of person-centered care. Some people may refuse to participate in activities. Be on the lookout for signs of frustration and agitation and address these behaviors immediately.

Pet therapy in a nursing home. Source: CDC

Individual Activities at Different Stages of Dementia

Activity	Mild	Moderate	Severe
Word games	Word searches, crossword puzzles Card/computer games	Simple word searches, simple crossword puzzles Simple computer games	Discuss a simple topic Listen to others
Letter writing	Write a letter Send email, use Facebook, social media	Dictate a letter or email Use Facebook with help	Listen to a letter or email being read

Activity	Mild	Moderate	Severe
Art/Music	Take photos Create a photo album Draw, play an instrument	Take photos Maintain a photo album Draw, sing along with others	View photos Listen to music Sing along to familiar songs
Woodworking	Use tools Plan and complete projects with assistance	Use simple tools with supervision Assist with projects	Use activity board with bolts, screws 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	Perform specific tasks with supervision Eat food grown in garden	Sit in garden, eat food grown in garden Participate as able
Crafts	Knitting or crochet using large needles	Choose colors, roll balls of yarn	Choose colors, use the items that are created
At home activities	Help with laundry, put clothes away, assist with housekeeping	Sort and fold laundry	Fold laundry—may want to fold the same items repeatedly
Shopping	Go along to store, help with purchasing decisions Help put groceries away	Go along to store, help as able with shopping decisions Help put food away	Go along to store, sit in car with supervision or shop with wheelchair or electric cart
Meditation/religious activities Support groups Reminiscence	Attend church Pray Meditate Attend a support group Reminisce	Attend church, meditate, or attend a support group with a caregiver Participate in an online support group with caregiver assistance Reminisce	Pray or meditate at home with caregiver Participate in an online support group or religious group with caregiver assistance Reminisce

The author's mother helps with gardening in her front yard. Source: Author.

4.2 Group Activities

Cognitive impairment isolates us from other people, causing anxiety, depression, societal withdrawal, and decreased self-confidence. Meaningful social interactions help a person living with dementia regain a sense of self-worth.

Group activities may become more challenging as a person's dementia progresses, and individual activities may be preferred. Small groups of 5 to 6 people allow more personal attention, although well-planned large-group activities can also be successful.

Group Activities at different Stages of Dementia

Activity	Mild	Moderate	Severe
Singing	Choose songs Sing with others Plan singing events	Sing familiar songs Choose songs Sing with others	Listen and sing along as able Sing with encouragement with others
Cooking	Bake cookies, prepare a snack plate for others, clean up after cooking	Participate in making cookies, assist with cleaning up	Help decorate cookies that are already baked, eat the cookies
Nature	Nature walks, outings to nature areas, fruit picking	Shorter walks Picnicking outdoors	Escorted walk or wheelchair outside the facility, attend picnic
Crafts	Make ornaments Decorate room or facility for holidays	Participate in making ornaments Assist with decorating for the holidays	Participate in crafts Participate in decorating parties

Activity	Mild	Moderate	Severe
Group exercise	Choose/plan an exercise program Go to gym with caregiver Participate in Yoga, Tai Chi, Feldenkrais Participate in balance activities Participate in seated and standing group exercise	Attend organized exercise programs Participate in Yoga, Tai Chi, Feldenkrais Participate in standing and seated balance activities Participate in seated and standing group exercise	Attend organized exercise programs Participate in seated and standing group exercise as able with direct assistance Exercise and stretch in bed with direct supervision
Outings	Shopping, eat out Theater and music events, museum visits, library visits, 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

An innovative group exercise program developed at the University of California at San Francisco integrates principles from several well-established traditions including Feldenkrais Method, Rosen Method, Tai Chi, and yoga, with elements from occupational therapy, physical therapy, and dance movement therapy (Chao et al., 2021).

The program, Preventing Loss of Independence through Exercise (PLIÉ), was specifically designed to address the needs of people living with cognitive impairment using seven guiding principles (Chao et al., 2021):

1. Repetition with variation (to promote procedural learning while maintaining engagement).

2. Progressive, functional movement (to support basic functional movements such as standing safely from a seated position).

3. Slow pace and step-by-step instruction (to enable participants to participate fully, experience feelings of success, and minimize cognitive demands).

4. Participant-centered goal orientation (a goals assessment is performed at the beginning of the program, and instructors tailor content to address the personal interests and goals of participants).

5. Body awareness, mindfulness, and breathing (to bring nonjudgmental awareness to the body in the present moment).

6. Social interaction (participants sit in a circle, and many movements involve reaching across the circle to touch hands or elbows or standing in a circle holding hands and moving together to facilitate social connection).

7. Positive emotions (participants are encouraged to move in ways that feel good, personally meaningful music is incorporated, and all classes end with sharing of appreciations and things that bring joy).

4.3 Virtual Reality

A great deal of research has recently been done on the use of virtual reality (VR) programs for older adults with and without dementia. The programs are designed to reduce loneliness, improve physical activity, and engage older adults in activities such as virtual travel.

Virtual reality offers a multisensory experience that can be effective for people with Alzheimer's. It stimulates multiple senses, and may be helpful in improving memory, *dual tasking,** and visual attention. It can also provide psychological support by reducing anxiety, improving feelings of well-being, and increasing use of coping strategies (Stasolla et al., 2024).

***Dual tasking**: doing two things at once such as walking and talking or cooking dinner while watching television.

The most common reported side effects associated with virtual reality use include "cybersickness" (nausea, dizziness, disorientation, postural instability, and fatigue). Some people have reported delusions, strong negative emotional responses, upsetting memories. Adverse effects can also include vestibular-related side effects, physical experiences, and psychological impacts (Woo and Lee, 2023).

Some older virtual reality users report issues with the head-mounted device, including that it is too heavy, causes general discomfort, disorientation and imbalance, and causes feelings of being trapped, confined, afraid, or anxious (Healy et al., 2022).

For a person living with Lewy body dementia, cognition can fluctuate from day to day. A person's response to the use of a virtual reality device can be good one day and cause confusion, hallucinations, and panic the next day. To prevent *cognitive overload** and hallucinations—especially in clients with Lewy body dementia—the virtual reality experience needs to be tailored to the user's own capabilities. Keeping the programs simple and providing close monitoring can reduce or prevent these adverse reactions.

***Cognitive overload**: when the brain tries to process too much information all at once.

5. Caregiver Stress Management: Physical, Emotional, and Financial

A **caregiver** is someone who assists a person in physical, financial, or emotional need. Caregivers help with basic needs such as bathing, dressing, walking, and cooking, or with more complex tasks such as medication, financial, and home management. Caregivers can provide direct care or manage care from a distance (or a combination of both) and can be a family member, a neighbor, a friend, a paid caregiver, or a healthcare professional.

5.1 Types and Causes of Stress for the Caregiver

> When my mom still had a good appetite, could walk around the house, take care of her garden, answer the phone, and manage the TV, it was easy. As her dementia progressed, lack of sleep, family squabbles, and having to directly help with everything made things much more stressful. There were more medical appointments with a very disinterested and unhelpful doctor. I ignored my own needs (I didn't get a haircut for over a year!) because there was no one to watch her while I was gone.
>
> Family Caregiver, West Palm Beach, FL

5.1.1 Emotional Stress

Providing care for a person living with dementia can be overwhelming and stressful. There is loss of free time, isolation, feelings of stigma and, in some cases, feelings of a lack of gratitude by the person receiving the care.

More than half of people caring for a person living with dementia rate the emotional stress of caregiving as high or very high, and about 40% report symptoms of depression. One in five cut back on their own healthcare visits because of their care responsibilities (Alzheimer's Association, 2025).

A caregiver's emotional state is influenced by the severity of dementia, the perceived effectiveness of treatment, safety issues, challenging behaviors, and social support. Caring for a person living with dementia can lead to health problems such as hypertension and sleep disorders (Li et al., 2024).

High levels of caregiver anxiety, depression, stress, and distress can harm the quality of the relationship between the caregiver and the person they are caring for, sometimes leading to caregiver negligence. A caregiver's emotional stress can get worse as a person's dementia progresses, especially when a caregiver does not understand the reason behind a challenging behavior (Li et al., 2024).

5.1.2 Financial Stress

Each year more than 12 million family members and friends provide over 192 *billion* hours of unpaid care to those with Alzheimer's and other dementias, a contribution valued at nearly $413 billion (Alzheimer's Association, 2025).

The financial strain on caregivers is a well-known challenge and the vast majority experience financial difficulties. Caring for a person living with dementia is estimated to cost nearly $400,000 per person over the course of the disease, 70% of which is borne by families in the form of unpaid care and out-of-pocket expenses (Shubair, 2025).

Caregivers of older adults living with dementia report lower household incomes compared to caregivers of individuals without dementia. Limited financial resources reduce access to paid support services and increase reliance on family care, increasing the strain on caregivers. Financial stress has also been associated with adverse psychological and physical health outcomes among caregivers, further compounding the already heightened demands of dementia care (Shubair, 2025).

For families, there are many hidden costs associated with dementia-related care, including (Carlozzi et al., 2025):

- costs to caregiver physical and mental health
- lost income (for both the family members and the person living with dementia)
- impulsive spending or poor spending decisions (by the person living with dementia)
- depletion of savings

In addition, families contemplating supportive care placements for the person living with dementia (assisted living or nursing home care) must consider the economic impact on the family household. The lost income of the person living with dementia, as well as asset depletion from costs associated with assisted living, can be financially devastating, especially for lower-income families (Carlozzi et al., 2025).

For professional caregivers, understanding the strain placed on families and family caregivers is crucial. This is due to the longer clinical course of dementia, substantial informal care costs, and disease-specific financial challenges that dementia caregivers must contend with (Carlozzi et al., 2025).

5.1.3 Physical Stress

Physical stress and musculoskeletal injuries are common among family caregivers, home health aides, nurses, nursing assistants, home care providers, and physical and occupational therapists. Care settings can be unpredictable and cluttered, and many lack proper assistive equipment and help.

Assisting a person with transfers, positioning, bed mobility, bathing, toileting, and other daily activities is physically demanding. Handling equipment, lifting a person after a fall, and providing support during transfers can lead to physical strain and injury. A caregiver's physical stress is related to age, physical fitness, the amount of assistance they provide, and the amount of time spent providing care.

For a person living with dementia, maintaining as much independence as possible reduces the physical stress on caregivers. Light weight wheelchairs, transfer poles, lift chairs, grab bars, overhead bars in the bed, and other assistive equipment improve independence and reduce a caregiver's physical strain.

Factors and Characteristics Associated with Caregiver Stress

Factors	Characteristics associated with caregiver stress
Demography	Female caregiver Spousal caregivers, particularly those of younger people living with dementia Living with the care recipient, low incomes, or financial strain
Caregiver personality	Highly emotional or neurotic caregivers
Perception and experience of caregiving role	A lack of confidence by the caregiver in their role Caregivers feeling trapped in their role
Coping strategies	Emotion-based or confrontive coping strategies Type and severity of dementia Behavioral issues such as apathy, irritability, anxiety, depression, delusions
Relationship factors	Intimacy—poor relationship quality, low levels of earlier and current intimacy

Source: Adapted with permission from ADI, 2022.

5.2 Identifying and Assessing Caregiver Stress

There are dozens of tests and scales that can help identify and assess caregiver stress. Yet caregiver stress is regularly overlooked by healthcare professionals. This may be partly because caregivers minimize their stress, have guilt about feeling stress, and are reluctant to focus attention on their own problems.

Healthcare workers and providers can support caregivers by helping them understand that caregiver needs are as important as the needs of the person they are caring for. During an appointment or visit, a screening tool can assess the amount of stress the caregiver is experiencing.

Caregiver burden can be measured using the short *Zarit Burden Interview in Dementia* (ZBI) tool. It explores four items related to a caregiver's self-care, stress, and burden and is scored from 1 (never feel stress) to 5 (almost always feel stress), for a total score ranging from a minimum of 4 points to a maximum of 20 points. Caregiver burden is present when the total score is greater than or equal to 10 and absent when the score is less than 10 (García-Martín et al., 2023).

Caregiver distress can also be measured using the *Neuropsychiatric Inventory Caregiver Distress Scale* (NPI-D). This tool asks caregivers to rate their level of caregiver distress using a 0-5 scale:

- 0 = not at all distressing,
- 1 = minimally distressing,
- 2 = mildly distressing,
- 3 = moderately distressing,
- 4 = severely distressing and
- 5 = very severely or extremely distressing (García-Martín et al., 2023)

Barbara and Jim

Background: Barbara cares for her husband Jim at home and refuses any sort of help. Barbara is fairly good at the medical side of caregiving but not so good at the emotional side. She is desperately in need of education, training, and respite. Barbara is in denial of her husband's dementia, lacks dementia-specific training, and has poor coping skills. Her short temper, and her unwillingness to seek help, has created a great deal of stress and, at times, abusive behavior toward Jim.

Antecedent: Friends and family have recommended that Barbara enroll her husband in adult day care and attend a caregiver support group. She agrees to take her husband to adult day care but refuses to attend a support group. When Barbara arrives to drop Jim off, she is greeted by Sana, the center's activities director.

Sana notes that Jim is cooperative and friendly, but Barbara seems stressed out. Sana notices that Barbara seems impatient with her husband and raises her voice in frustration when he doesn't get out of the car quickly enough. As soon as Jim is in Sana's hands, Barbara hops back into her car, waves, and speeds off.

Behavior: Sana walks with Jim into the building and offers him a comfortable chair. When he sits down, he turns to Sana and says urgently, "Help me! She's trying to kill me!" This startles Sana and she's not sure what to do. He is very anxious and refuses to participate in any activities. Her first thought is that Jim has dementia and is probably just being paranoid. People with dementia have memory problems so maybe he doesn't really remember what happened five minutes ago. What should Sana do?

1. Pat Jim on the back and tell him she understands.
2. Wait until Barbara returns and tell her what Jim said.
3. Share this information with her supervisor.
4. Do nothing other than reassure Jim that he's safe and nothing bad will happen to him.

Discussion: Sana is new to the job, so she discusses the situation with her supervisor. Her supervisor is familiar with Jim's situation and tells Sana that adult protective services is already involved due to a report by Barbara's sister. When Barbara returns to pick up Jim, the supervisor encourages provides her with some online resources that might be of help. Barabara waves her off, grabs Jim, and hurries him to the car.

On the next visit, Sana's supervisor asks one of the nurses to have Barbara complete the Zarit Burden Interview in Dementia (ZBI) tool. Barbara agrees and scores 19/20, indicating she is highly stressed. Over the next couple of weeks, the staff provide both online and in-person resources and support services for Barbara. They help her find a caregiver and order a home safety assessment. Barbara says she is grateful for all the support and even agrees to attend a support group. Jim appears to be more relaxed and never repeats his fear that Barabara is trying to kill him.

5.3 Strategies for Reducing Caregiver Stress

Caregiver stress can be reduced when education, training, support, and respite are available. These four components have been shown to decrease caregiver stress and reduce or delay the transition from home to a care facility (ADI, 2022).

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

Adult day care centers offer respite and support services, provide relief for family caregivers, reduce caregiver burden, and increase caregiver motivation. A primary goal is to develop knowledge and skills in dementia care and prevent early institutional placement.

Addressing Caregiver Stress

Reducing caregiver stress	Things to avoid
• Join a support group or see a counselor to discuss your feelings. • Set limits on caregiving time and responsibility. • Become an educated caregiver. • Discuss your situation with your employer. • Accept changes as they occur. • Make legal and financial plans. • Take regular breaks (respite). • Seek out daycare services.	• Don't isolate yourself. • Don't try to be all things to all people. • Don't expect to have all the answers. • Don't deny your own fears about dementia and aging.

Take Care of Yourself as a Caregiver

Make time for a hobby you enjoy.

Go to sleep a half-hour earlier.

Take a short walk outside.

Try a yoga class.

Meet a friend for lunch.

Join a support group.

Activities like these can lower your stress, boost your mood, and help make you a better caregiver, too.

Learn more about caregiving at www.nia.nih.gov/caregiving.

NIH National Institute on Aging

5.3.1 Respite Care

Respite services support caregivers by providing time away from the person they are caring for, a chance to relax and recharge, and time for errands and other tasks. These services may be available in a person's home, an adult day care center, in the community, or in long-term care communities.

Respite care can provide relief for family caregivers. Source: NIH.

5.3.2 Positive Aspects of Caregiving

Although it is commonly believed that someone caring for a person living with dementia is under a great deal of stress (especially as the person's dementia progresses), caregivers also encounter positive experiences. These positive aspects can play an important role in the caregiver's stress and well-being (Yuan et al., 2023).

Caring for a person living with dementia can provide a sense of meaning and satisfaction, induce feelings of accomplishment, and improve the quality of relationships between family members. There can also be an increase in family cohesion and functionality with a sense of personal growth and purpose in life (Wiegelmann et al., 2021).

Nearly half of caregivers of people living with dementia indicate that providing help to someone with cognitive impairment was very rewarding. Greater satisfaction from dementia caregiving was associated with more emotional support from family members and friends (Alzheimer's Association, 2025).

5.3.3 Caregiver Bill of Rights

A caregiver bill of rights was first crafted by Jo Horne in her 1985 book *CareGiving: Helping an Aging Loved One*. Her widely adopted principles, although not legally binding, have provided a framework for additional research on the critically important role that informal, unpaid caregivers play in the care of dependent older adults.

The original caregiver bill of rights contains nine items that encourage caregivers to consider their own health and well-being and to set boundaries. Among other things, the *Caregiver Bill of Rights* states, "I have the right to":

1. Take care of myself.
2. Seek help from others.
3. Maintain facets of my life that do not include the person I care for.
4. Get angry or depressed.
5. Resist attempts by the person I am caring for to manipulate me.
6. Receive consideration, affection, forgiveness, and acceptance from the person I am caring for.
7. Take pride in what I am doing.
8. Protect my individuality.
9. Demand resources to support and aid caregivers.

6. Developing Skills for Working with Families and Caregivers

> Family is the cornerstone of care for older adults who have lost the capacity for independent living. In many *developed* countries, the vital caring role of families and their need for support is often overlooked. In *developing* countries, the reliability and availability of the family care is often overestimated. Family caregivers are often cast into the role of caregiver unexpectedly and are largely unpaid.
>
> Alzheimer's Disease International

A family caregiver and her mother. Source: CDC, public domain.

Caring for a family member is an important aspect of many cultures. When care is needed, it is often provided without thought.

Nevertheless, informal caregivers report a lack of support, insufficient knowledge about dementia, and barriers obtaining and sharing information, resulting in isolation in caregiving responsibilities. They often experience frustration, anxiety, depression, burnout, and prolonged stress (Scerbe et al., 2023).

For healthcare providers, understanding these issues and concerns is important when working with family members and caregivers. Healthcare providers also often lack dementia-specific education, training, and experience. Healthcare providers must learn how to communicate skills and techniques to sometimes-resistant family members and often-untrained paid caregivers.

6.1 Recognizing Issues and Concerns of Family Caregivers

> Taking care of my own health took a nosedive as my mom's dementia got worse. Near the end of her life, I was drained emotionally and financially. Hobbies, free time, and vacations were a distant memory, and family relationships were damaged beyond repair. Unless we get a national program to provide training and pay for family caregivers, I don't see things changing very much.
>
> Family Caregiver, Palm Beach, Florida

Family caregivers face unique challenges that differ from those of professional caregivers. Long held habits, beliefs, roles, and expectations can hurt or help familial relationships. The role of caregiver may fall on a spouse or adult children that have their own health concerns. Caregivers may live a long distance away, work fulltime, or be financially strained.

Approximately 85% of Americans living with dementia reside with family, friends, or in assisted living facilities, while 15% live in nursing facilities. In the last year of life, family caregivers of someone living with dementia are three times more likely to experience caregiver burden in their loved one's last year of life compared to caregivers of people dying from other diseases (Bigger et al., 2024).

People living with dementia and their caregivers are at higher risk for poor outcomes related to *care transitions** than people without dementia. Despite the need for flexible, tailored, and equitable services, care systems are often fragmented and difficult to navigate (Bigger et al., 2024).

***Care transitions**: movement between healthcare services or locations of care.

6.1.1 Issues and Concerns in the Early Stage

In the early stage of dementia, family members are confronted with many issues, worries, and concerns as they adjust their own behavior and manage their own frustrations while learning about the effects of dementia. They are often unaware of dementia-care services and may find their primary care physician to be of little help.

Spouses who care for a person living with dementia may not be in good health themselves and may worry about not being able to provide good care as the dementia progresses. Adult child may worry about having to take over the care of a parent and assume a new role in the family.

Early, specialized training is recommended—especially when care duties are lighter than they will be in later stages. This is an essential but often neglected part of dementia care. Training prepares family caregivers for what lies ahead and allows them to more easily partner with healthcare providers to provide competent and compassionate care.

6.1.2 Issues and Concerns in the Middle Stages

A diagnosis of dementia usually doesn't occur until the middle stage. This means family caregivers are playing catch-up, just beginning to learn about communication techniques, assistive equipment, and dementia-care services. At this stage, the person living with the effects of dementia, as well as family caregivers, have already experienced significant changes in their lives.

Caregivers can become overwhelmed as their family member's dementia progresses to the middle stage. Listening carefully to their concerns, encouraging participation in decision-making, and recommending a support group (even online) can help caregivers feel competent and valued.

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

During the middle stage, caregivers begin to invest more time, energy, and money. The increased time needed to care for a previously independent person can increase caregiver anxiety, depression, stress, and burnout. The responsibility of caregiving often falls mostly on one person, leading to anger and frustration with other family members.

6.1.3 Issues and Concerns in the Late Stages

> I'm exhausted. I can't sleep because I must watch out for my wife. She wanders around the house, takes out all kinds of stuff from the kitchen. I never know what she's going to do.
>
> Family Caregiver, Miami, FL

In the late stage of dementia, continuing to live at home or in an assisted living facility may no longer be an option. One of the most difficult issues—usually in the middle to late stages of dementia—is the decision to transfer a family member to residential care or skilled nursing. Reasons cited by caregivers for placement are:

- need for skilled care and assistance
- family caregivers' health
- patient's dementia-related behaviors

Healthcare providers can be a valuable source of support, providing information about respite care and long-term care options. Counseling and support groups allow caregivers to discuss any guilt they may be feeling and learn from other caregivers about how to navigate the medical system.

Relinquishing full-time care can cause feelings of loss, sadness, resignation, and depression for family caregivers. Paradoxically, placement of a loved one in a care facility may not lessen the stress that a caregiver experiences.

6.1.4 End of Life Issues and Concerns

The demands of caregiving intensify as the person living with dementia approaches the end of life. In the year before the person's death, more than half of caregivers feel they were "on duty" 24 hours a day, and many report caregiving during this time is extremely stressful. Many family caregivers experience relief when the person living with Alzheimer's disease or another dementia dies.

Caregiver well-being is influenced by the availability of family support, family functioning, conflict, and feelings of isolation, all of which are linked to increased depression, distress, and burden. The emotional toll of caregiving is often harder for female caregivers who take on greater responsibilities and spend more time caregiving than their male counterparts, especially during end-of-life care (Iacob et al., 2025).

Interventions, such as educational programs, can reduce caregiver burden. Family dynamics also play a crucial role in caregiver stress. Supportive families can reduce caregiver burden, while dysfunctional family dynamics increase caregiver stress. Encouraging family members to participate in therapy, support groups, and respite programs may reduce caregiver distress. Living with the care recipient can enhance caregiving but may also increase stress due to the constant demands of care (Iacob et al., 2025).

6.2 Strategies for Encouraging Family Involvement

Healthcare providers have multiple responsibilities when working with family members caring for a person living with dementia. For family members and adult day care participants, family education, training, and communication are critically important.

Family caregivers often take a step back when their relative is admitted to a care facility despite their willingness to remain actively involved. Several factors contribute to this decline in care involvement (Tasseron-Dries et al., 2023):

- caregivers not seen as partners in care
- lack of regular contact between family and staff
- family caregivers do not feel welcome

Family involvement increases the well-being of the person living with dementia by making them feel they are receiving good care and are not being abandoned in a care facility. It also increases family caregivers' satisfaction with dementia care (Tasseron-Dries et al., 2023).

Involving family members means:

- Encouraging them to choose and participate in activities.
- Helping arrange transportation if needed for regular visits.
- Encouraging them to learn about and understand the challenges associated with dementia.
- Inviting them to join multidisciplinary team meetings.
- Emphasizing their role as a partner in care for the resident.

6.2.1 Dementia Care Programs

Dementia care programs are one method for encouraging family involvement. They are designed to meet the individual needs of the person living with dementia. Their quality and success depend on the environment, philosophy of care, available services, and staff experience and training.

A well-designed dementia care program encourages the family's involvement by:

- keeping family members informed about changes in their loved one's condition
- documenting resident activities to share with the family
- encouraging clients to call and write to family members and friends
- using technology to keep families in touch with one another

6.2.2 Caregiver Training and Support

For family members and informal caregivers, training, education, and support are critical. Training introduces caregivers to resources and equipment that can improve health and safety and reduce caregiver strain.

Caregiver training and support programs provide:

- help with challenging behaviors, especially at the end of life
- help for caregivers dealing with swallowing issues and loss of appetite
- education about the dying process
- information about changing personal care needs

Family caregivers often falter in the final stage of life due to distress, increased emotional burden, and grief (Laranjeira et al., 2022). During this time, there is an increased need for good communication and consistent support. Being able to access healthcare providers via phone, text or online provides family caregivers with an opportunity to quickly receive answers to questions about medications, behavioral symptoms, and medical issues.

In addition to in-person training and support, caregivers can benefit from personalized, user-friendly online programs. Well-designed programs connect caregivers with a social network, allowing them to share ideas and practical concerns.

6.2.3 Barriers to Family Involvement

Despite the clear health and social benefits of adult day services, they are underutilized and face significant financial challenges. There is a lack of public awareness about the vital role they play in supporting older adults and their caregivers. Many people who are unfamiliar with the range of services offered may incorrectly view a facility as merely providing recreational activities rather than comprehensive health and social support (Sadarangani et al., 2024).

Access to adult day services is limited by inadequate funding and reimbursement rates. Medicaid is a primary payer, but reimbursement rates vary widely by state and are often inadequate. Services are primarily funded through a mix of public and private sources, leaving adult day care centers struggling financially, unable to hire and retain skilled staff, and forced to limit their hours and enrollment (Sadarangani et al., 2024).

For older adults who do not qualify for Medicaid, the out-of-pocket costs can be prohibitive. Many older adults and their family caregivers are unaware of the availability of adult day care services or may not meet the eligibility criteria for public funding, further limiting access (Sadarangani et al., 2024).

Changing attitudes and expectations among the young as well as increased workforce mobility mean that family members do not always live near their older adult relatives. This makes it difficult for a person living with dementia to attend an adult day program.

Family caregivers face barriers such as inadequate knowledge and skills regarding dementia, stigma, lack of knowledge and awareness in the community, limited availability of healthcare services, and healthcare professionals' lack of knowledge about dementia (Widyastuti et al., 2023).

6.3 Grief and Loss

> I'm ashamed to say that before I began taking care of my mother, I had very little understanding of the grief experienced by family members caring for someone with dementia. I only offered platitudes such as "Make sure you walk with your wife every day"—this when the husband was slumped at the kitchen table—clearly overwhelmed and severely depressed. I just didn't see it. Now I do.
>
> Home Health Physical Therapist, Tampa, Florida

A diagnosis of dementia can cause a great deal of grief for the person receiving the diagnosis, as well as family and friends. There is concern related to uncertainty about the progression of the disease and anticipated loss of independence. Grief is a response to any loss that is significant to an individual and is a process that unfolds in a non-linear manner.

The stage, age of onset, degree of insight, communication abilities, and type of dementia impact feelings of grief. A person's history, personality, coping style, gender, relationships, personal resources, and support networks are also important to consider (Waddington et al., 2023).

For family and spousal caregivers, grief is associated with changes in social roles and loss of companionship and friendship. As caregiving duties increase, caregivers will very likely experience a loss of income, loss of privacy and free time, and changes in their normal routine.

6.3.1 Five Key Dimensions of Grief

Grief can be associated with any form of loss, including loss of employment, changes in relationships, significant life changes, loss of health, and loss of the future that was hoped for and imagined (Waddington et al., 2023).

Five key dimensions of grief include (Waddington et al., 2023):

1. Grieving for the person I used to be.
2. Concern for how others see me.
3. Grieving the person I will become.
4. Grieving for those who have died.
5. Failing to know what helps me with my grief.

One of the most common grief frameworks is the "five stages of grieving" traced to Kübler-Ross's (1969) book, *On Death and Dying*. The fundamental premise is that a dying individual goes through five stages: denial, anger, bargaining, depression, and acceptance. Kübler-Ross later included anticipatory grief related to the client's family (Avis et al., 2021).

6.3.2 Anticipatory Grief

Anticipatory grief is the experience of grief before an actual loss has occurred. It is associated with severe depression and anxiety and is common among clients living with dementia, as well as their caregivers. Anticipatory grief can be an unrecognized but significant psychological burden (Wang et al., 2026).

Nearly half of clients living with a chronic illness experience anticipatory grief due to fear and uncertainty, which can significantly affect a person's quality of life. Anticipatory grief can impact health outcomes, reduce survival rates, and increase the risk of adverse events (Wang et al., 2026).

Caregivers also experience anticipatory grief due to the physical and mental burden associated with caregiving and uncertainty about the progress of the disease. This is common in informal caregivers, including spouses and family members. As caregiver stress increases, anticipatory grief can also increase, causing anxiety and depression in informal caregivers (Wang et al., 2026).

6.3.3 Physical and Psychological Symptoms of Grief

Grief can cause **physical symptoms** such as shortness of breath, headaches, fatigue, a feeling of heaviness, and a loss of physical strength and abilities. It can also cause **psychological symptoms** such as clinical depression, hypochondria, anxiety, insomnia, and the inability to get pleasure from normal daily activities.

The onset of dementia can affect other aspects of a person's life as well, including loss of income and savings, and loss of health insurance. There may be changes in housing and personal possessions, loss of pets, and loss of self-sufficiency, privacy, and self-esteem.

6.3.3 Grief in Caregivers

Caregivers of persons living with dementia experience intense feelings of grief and loss prior to the physical death of the person they are caring for. The impact of these losses can build as the disease progresses. Cognitive decline, memory loss, changes in personality, and lost and forgotten family history increase caregiver grief. A caregiver's grieving can lead to feelings of ambiguity, *disenfranchised grief*,* loss of companionship, as well as anger and guilt (Rupp et al., 2023).

*__Disenfranchised grief__: a type of grief that occurs when a person's loss is not recognized, validated, or openly acknowledged by society.

Moving from home can be the cause of grief for both the person living with dementia and their family members. It can cause a loss of connection with friends, loss of pets, and loss of control.

Worries about potential future losses can be a cause of grief. Loss of independence, loss of a driver's license, loss of communication and navigation skills, concerns about changes in personality and behavior, and fear of dying contribute to grief. There can be a general sense of the loss of the life a person had hoped for and imagined that they were no longer able to live (Waddington et al., 2023).

6.3.4 Loss of Friends and Family Members

> About two years before my mom died, I received a phone call from a cousin saying that my mom's sister had died. I hung up the phone and, not knowing how my mom would react, gently told her that her sister had died. There was a flash of recognition and grief on her face that quickly faded, and I think she almost immediately forgot what I told her. It was harder for me seeing her inability to process her sister's death than it seemed to be for her.
>
> Family Caregiver, Lauderdale Lakes, FL

Bereavement-related grief has been studied in people living with dementia, relating to the death of family members, friends, and other members of a care facility. Opinions differ on whether to inform people living with dementia of a death. Some caregivers feel that everyone had a right to be informed; others feel that telling people living with dementia can lead to unnecessary distress (Waddington et al., 2023).

Concerns about informing a person living with dementia multiple times about a death and its ongoing impact is sometimes referred to as "re-bereavement" grief. There are different views on how and who is best placed to inform, and how to best support the person living with dementia following the death of someone to whom may have been close (Waddington et al., 2023).

7. Maintaining a Therapeutic Environment

A therapeutic environment is an important factor in every person's quality of life. A thoughtfully designed environment supports the well-being of a person living with dementia and can be an effective non-pharmacological factor in reducing challenging behaviors (Siegelaar et al., 2025). It is a key component of person-centered care.

A therapeutic environment is especially important for people living with dementia because, as their cognitive skills decline, they become more dependent on the physical space. Brain changes make it harder for a person to create and retain a mental image of their physical space. A well-designed therapeutic environment can compensate for these losses (Buuren et al., 2025).

A therapeutic environment should help a person easily and safely find their way around. People living with dementia use objects and signs to find their way. Although some objects, such as a microwave or care equipment are not meant for the *wayfinding*,* people still use these objects to orient themselves to the environment (Buuren et al., 2025).

***Wayfinding**: a person's ability to navigate spaces using signs, maps, and environmental cues.

A therapeutic environment provides safe and private personal spaces as well as communal areas that encourage activities and socialization. Ample daylight, an open design for nursing stations, and placing artwork throughout the facility supports therapeutic design (Rodríguez-Labajos et al., 2024).

Certain health benefits are associated with dementia-friendly design including:

- decreased agitation
- improved well-being and affect
- improved attention
- improved quality of sleep
- decreased use of medication (Lygum et al., 2025)

7.1 Physical Environment

A supportive physical environment means treatment and care are offered in a manner that is tailored for people living with dementia (Lygum et al., 2025). A well-designed physical environment supports engagement in activities, can decrease psychotropic drug use, and improve independence (Siegelaar et al., 2025).

Interior environments that are "homelike" are associated with reduced behavioral disturbances and increase social interaction. Family-style dining in small groups can improve food and fluid intake. Good light levels during the day can reduce functional decline, while improving the circadian rhythm and quality of sleep (Siegelaar et al., 2025).

Indoor features such as bright-light therapy (1,000–2,500 Lux) have been shown to positively influence clients' agitation and disruptive behaviors and improve daytime wakefulness. In general, moderate or low levels of sensory stimulation prevent overstimulation, reducing agitation and restraint use (Siegelaar et al., 2025).

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

- private space in a person's room with a private bathroom
- public spaces that are easy to access
- rooms personalized with furniture, memorabilia, and personal possessions
- absence of smelly odors
- sunlight, ventilation, and elimination of dark nooks and crannies
- areas that cue specific behaviors (kitchen, art and music area, rummaging room, library, coffee shop, quiet areas, living room, family visiting area)

Dementia-friendly **outdoor** design should allow a person to connect with nature. An outdoor environment should (Oher et al., 2024):

- be safe and secure
- be easily accessed
- provide an identifiable entrance with a fenced space
- be familiar
- have landmarks for orientation and wayfinding
- provide options for different kinds of weather
- be calm, peaceful, and undemanding

Spending time in a garden or outdoor area can reduce agitation, aggression, drug use, and falls. Green care farms, which includes animals and gardens, provides opportunities for attractive outdoor activities and are associated with improved psychological well-being. Outdoor and garden areas and participation in outdoor activities can also reduce drug-use (Siegelaar et al., 2025).

7.2 How an Organization’s Philosophy of Care Affects the Environment

An organization’s philosophy of care is a framework that identifies its goals and values. The family, and the person receiving services, has the right to know—and should feel free to question—a center’s philosophy of care. Key questions can include (California Advocates for Nursing Home Reform, 2024):

- Is the center’s philosophy consistent with your beliefs?
- Does the center provide services to persons at all stages of dementia?
- What conditions or behaviors determine whether a center will admit or retain someone living with dementia?
- Is dementia care provided in a separate unit or as an integrated part of center’s services?
- Is the center’s philosophy and practice of handling "difficult behaviors" compatible with your views?
- What is the center’s philosophy in using physical restraints to deal with certain behaviors?
- Does the center recommend the use of psychoactive drugs to treat challenging behaviors?

Person-centered care is the philosophy of care encouraged for individuals living with ADRD. An organization’s philosophy should support a resident’s rights. People living with dementia have the right to have their own clothes and other personal items. They must have unrestricted private communication, be able to send and receive unopened correspondence, and have access to a telephone. If both spouses are residents, they have the right to share a room.

Residents have the right to visit with any person of their choice, manage their own financial affairs (if able), exercise their civil and religious liberties, and access appropriate healthcare. The living environment must be safe and clean, and residents must be free from chemical and physical restraints and free from abuse and neglect.

Dementia Friends is a global movement that is changing the way people think, act, and talk about dementia. Dementia Friends USA helps everyone in a community understand what dementia is and how it affects people. Each of us can make a difference for people touched by dementia.

Courtesy Alzheimer’s Disease International. Used with permission.

The Dementia Friends program focuses on five key messages (Dementia Friends USA, 2022):

1. Dementia is not a natural part of aging.
2. Dementia is caused by diseases of the brain.
3. It is not just about losing your memory.
4. It's possible to live well with dementia.
5. There is more to the person than the dementia.

7.3 Safety and Security

Safety is freedom from accidental or preventable injuries or harm. Security is the protection of people, organizations, and assets from harm or danger. However, changes to the physical environment intended to increase security may decrease a person's autonomy and attempts to enhance autonomy can lead to decreased security. Providing autonomy without compromising security is a considerable challenge, particularly for clients living with dementia (Sandberg et al., 2021).

7.3.1 Elements of a Safe Environment

People living with dementia need to feel safe (and be safe). A safe and secure environment includes the absence of abuse, proper assistive equipment, dementia-trained caregivers, and consistent communication with caregivers and healthcare providers. Client safety also includes infection prevention, medication safety, and personal safety awareness.

Muscle weakness, injuries from falls, hearing loss, and visual changes increase the risk of accidents and injuries. Environmental safety focuses on reducing clutter, and removing hazards such as steps, poisonous plants, household chemicals, firearms, and alcohol.

Each room must be assessed for safety—especially bedrooms, bathrooms, and kitchens. Electrical outlets should be covered, and electrical appliances placed so they cannot encounter water. Monitoring devices can be installed in each room and medications must be safely stored out of reach of the client. Alarms or locks can be helpful to prevent wandering into unsafe places.

The table below illustrates some common safety issues, consequences, and suggestions that help make the environment safe and secure. Interventions should be tailored to match the specific circumstances.

Measures to Promote Safety and Security

Safety issue	Possible consequence	Elements of a Safe Environment
Wandering	Getting lost, exposure to environmental hazards.	Use technology such as the Alzheimer Association's Comfort Zone.* Provide short, looping indoor corridors without dead ends. Create open, common areas of interest. Create safe, outdoor wandering areas that are accessible from indoor wandering paths. Paint the inner surfaces of doors so that they are not readily recognizable as an exit. Place locks where they are not visible.
Cooking without supervision	Fire, injury	Install a shut-off valve on the stove. Remove burner on-off handles. Keep a working fire extinguisher. Create a work area with an activity kitchen.

Falls	Injury	Rule out medical conditions. Create an uncluttered environment. Install handrails in showers and hallways. Wipe up spills promptly. Maintain physical activity. Supervise walking and use assistive devices. Remove throw rugs or tape edges down. Maintain good vision and hearing. Provide many places to sit.
Poisoning	Sickness or death	Remove toxic plants from the environment. Lock up chemicals and medications.

*The Alzheimer's Association has a product called Comfort Zone that uses GPS technology to locate a person who has wandered and become lost. There are many proprietary companies now offering similar location services.

7.3.2 Elements of a Secure Environment

Security includes physical security measures such as exit control, lighting and surveillance, facility and room access, and control of the facility's perimeter (fencing, gates). Security also involves staff training, emergency preparedness, and addressing resident abuse. Security measures must consider the privacy and autonomy of the resident.

For a person living with dementia who likes to wander, doors are often perceived as an attraction, inviting a person to go through. Facility exits need to be monitored or controlled to avoid a person exiting the facility (Gramegna, 2021).

Exit doors that are less visible and more camouflaged, with no obvious hardware, can reduce or even prevent a person from trying to open them. Increasing the visibility of "safe doors"—ones that encourage a resident to enter indoor safe areas of a facility—can distract them from exit doors. Alarmed exit doors should be discreet and should not disturb residents with loud sounds or strong lights. These precautions help a facility maintain a quiet atmosphere and support independence for residents (Gramegna, 2021).

7.3.2 Wandering and Safety

Although it is easy to identify the risks associated with wandering, it is often difficult to know how to allow a person to continue to wander safely. A regular review of medications ensures that wandering is not the result of medication side effects, overmedication, or drug interactions.

Despite the substantial clinical consequences of wandering, there is currently no standardized approach for assessing wandering behaviors. This has made it difficult to study the risk factors associated with wandering, its natural history and progression, and the effectiveness of interventions. Wandering behavior is typically detected by caregiver report, which may not be accurate, as it is based on the caregiver's ability to recognize and report this behavior (Kamil et al., 2021).

Address wandering by:

- Redirecting a person to a purposeful activity.
- Offering safe, looping wandering paths with interesting rest areas.
- Installing rails and grab bars.
- Providing regular exercise.

To prevent wandering into unauthorized or unsafe areas:

- Use a physical barrier (such as yellow tape).
- Put up visual barriers on exit doors such as “Stop” signs.
- Install alarms on entryways into unsafe areas or to the outside.

Engaging people in simple chores such as folding laundry or assisting with dinner can give them a sense of purpose and fulfillment. Electronic devices attached to the person’s ankle or wrist alert staff or family members when someone has wandered out of a designated area. Subjective barriers such as grid patterns on the floor in front of exit doors, camouflage, and concealment of doors and doorknobs have been shown to discourage a wanderer from exiting a building.

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

7.3.3 Technology Related to Safety

Technology and electronic devices can reduce risk and increase independence. Safety technologies include GPS trackers to monitor wandering, smart home devices like sensors and automated lighting, medication reminders, and wearable devices for fall detection and emergency calls.

Smart plugs allow caregivers to remotely monitor and control electrical appliances, such as stoves, irons, heating and cooling devices. These tools provide peace of mind for caregivers while supporting the independence of the person living with dementia by allowing for remote monitoring, automated alerts, and streamlined daily tasks.

Smart safety sensors can detect smoke, carbon monoxide, flood, and fire and send early warnings and alerts to a caregiver’s phone. Indoor cameras allow caregivers to check on their loved one remotely and communicate with them via two-way audio.

7.4 Task-Centered vs. Person-Centered Care

Many of us trained in the traditional medical model are familiar with task-centered care. In this model, we provide care to the best of our ability but generally do not consider the places we work as “homelike.” Our approach is hierarchical, and we expect a facility to be designed to help us do our jobs.

Person-centered care turns this approach on its head by putting a client living with dementia at the center of our care and planning. When done right, task-centered care recedes into the background, replaced by care and activities that focus on the needs and well-being of adult day participants. Person-centered care is encouraged for people living with ADRD.

Person-centered dementia care is built on the understanding that a sense of belonging and opportunity for meaningful engagement are critical to the success of all human communities. Key principles for successfully implementing person-centered dementia care include:

- understanding the environment of the specific care setting for residents living with dementia
- creating a clear understanding of people living with dementia as unique individuals
- promoting access to meaningful engagement tailored to suit that person (Gramegna, 2021)

The person-centered approach was developed nearly three decades ago and is now considered the gold standard in dementia care. Five essential psychological needs are emphasized (Scher et al., 2025):

1. Comfort—the feeling of trust that comes from others.
2. Attachment—security and finding familiarity in unusual places.
3. Inclusion—being involved in the lives of others.
4. Meaningful occupation—being involved in the processes of normal life.
5. Identity—what distinguishes a person from others and makes them unique.

Person-centered care can lead to positive outcomes for people living with dementia, including a reduced risk of behavioral problems, neuropsychiatric symptoms, and improved quality of life. Person-centered care can also have a positive impact on the caregivers, influencing staff behavior, job satisfaction of professional caregivers, as well as family satisfaction of informal caregivers (Wittmann et al., 2024).

7.5 Staff as Part of the Environment

> Many people living with dementia are advocating for the phasing out all institutional care, the cessation of segregation in locked dementia units, and for all healthcare staff to be fully competent in dementia as well as disability.
>
> Alzheimer's Disease International, 2019

Much of the research on the effects of staffing has been done in nursing homes. Studies indicate that nurse staffing levels are a "critical factor" in determining nursing home quality of care. Nursing homes with higher staff-to-resident ratios provide better care (White and Olsho, 2023).

Many factors make it difficult to blend staff into the environment effectively. These can include high staff turnover, insufficient education, lack of resources, heavy workload, burnout, and difficult ethical issues. Training programs that enable formal and informal caregivers to acquire knowledge, empathy, and care skills are considered crucial for treating individuals with dementia adequately and effectively (Wittmann et al., 2024).

Consistent staffing, good pay, career advancement opportunities, and education significantly reduce staff turnover and support person-centered care. Small, fixed teams of trained caregivers and activities that are organized completely, or in large part, by clients and caregivers encourage cooperation and participation.

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.
- Allow staff to control lighting and environmental levels.
- Keep staff consistent.

Whether a caregiver is hired directly by a client or is a staff member in a facility, "being part of a resident's or client's environment" means being aware of the person's routines and habits. It means respecting their needs, understanding the impact of cognitive and sensory changes (vision, hearing), and respecting cultural and language differences.

7.6 Staff Adjusting to Client Routines

> Forget dementia, remember the person!
>
> Alzheimer's Disease International

When an adult day center is organized around dementia-friendly care, staff and caregivers adjust their routines to the routines of the client, 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 are de-emphasized. Clients, staff, and family caregivers work as a consistent unit. Daily tasks, such as cooking and cleaning, can be shared and organized by clients, staff, and caregivers. Not surprisingly, this reduces staff turnover and provides more satisfaction for both staff and clients.

People living with dementia have certain rights that providers and caregivers should be aware of. They have the right to have their own clothes and other personal items. They must have unrestricted private communication, be able to send and receive unopened correspondence, and have access to a telephone.

Clients have the right to visit with any person of their choice, manage their own financial affairs, exercise of civil and religious liberties, and access appropriate healthcare. Facilities must be safe and clean, and clients must be free from chemical and physical restraints and free from abuse and neglect.

7.7 Schedules and Routines

For a person living with dementia, maintaining schedules and routines is important. A daily plan organized by the caregiver and the person they are caring for creates predictability and supports their well-being. A daily routine must be flexible, consider personal preferences, and include physical exercise and rest time.

Routine tasks such as bathing, dressing, and eating should be kept consistent each day. Keeping a to-do list with appointments, tasks, and events provides support and reminders for a person whose memory is impaired. Plan activities that the person enjoys and try to do them at the same time each day. Consider a system or reminders for helping those who must take medications regularly. Serve meals in a consistent, familiar place and give the person enough time to eat (Alzheimer's.gov, 2026).

A schedule for someone living with dementia should be carefully planned, considering the person's capabilities and preferences. A thoughtful schedule accounts for physical issues that might disrupt routines such as hunger, pain, fatigue, or illness.

Adult day facilities can be less institutional than nursing homes, allowing more personalized care. Even so, schedules and routines are often organized around the convenience of caregivers and can change dramatically from day to day. This is difficult for people living with dementia because they rely on a predictable routine to know what to expect. As a result, the person living with dementia experiences a lack of input and control.

Caregivers and healthcare workers responsible for maintaining a schedule need to be flexible while trying to maintain familiar routines. People living with dementia tend to be slow, so caregivers must allow ample time for meals and activities. Attempting to rush a person with dementia often causes aggressive behaviors that frustrate both parties.

8. Ethical Issues and Persons with AD

Healthcare workers and caregivers are often faced with difficult ethical decisions. This is particularly true in the care of people living with dementia.

Ethical issues in the care of a person living with dementia often include questions related to autonomy and consent, managing behavioral symptoms, preventing exploitation, and making decisions regarding resuscitation and end-of-life care. Navigating these issues can be challenging, often causing *moral distress** for caregivers and providers (Schou-Juul et al., 2024).

***Moral distress**: emotional discomfort that occurs when you know the ethically correct action to take but are powerless to act on it.

8.1 Key Ethical Principles

In biomedical ethics, several basic ethical principles are commonly accepted. These are (1) autonomy and well-being, (2) beneficence (kindness), and (3) justice. In addition, veracity (truthfulness) is an ethical principle that must be observed in all situations.

8.1.1 Autonomy and Well-Being

Autonomy is the right of an individual to make decisions about their own healthcare and their own life. Clients should be told the truth about their condition and informed about the risks and benefits of treatment. A person can 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.

A diagnosis of dementia does not necessarily mean a person lacks autonomy or is unable to make decisions. For a person living with dementia there can be a great deal of day-to-day variation in their ability to make decisions.

Decisions made for a person living with dementia (a *proxy decision-maker**) must consider a person's autonomy and allow healthcare providers and family members to respect and uphold a person's wishes. Decisions must be culturally relevant, respect a person's autonomy, and include the person living with dementia to engage in end-of-life planning as much as they can (Bucko et al., 2025).

***Proxy decision-maker**: a person legally designated to make decisions for someone unable, or no longer able, to make decision for themselves.

8.1.2 Beneficence (Kindness): Doing Good

Beneficence (beh-NEF-uh-suhns) is the act of doing good. A decision is beneficent or kind when the same decision is made regardless of who was making it. Beneficence is closely related to the concept of "Do No Harm." Actions or practices are beneficent if they are in the best interest of the resident and avoid negative consequences.

8.1.3 Justice: Equity and Fairness

Justice is the fair distribution of benefits, goods, and risks (Lauridsen et al., 2023). Distributive justice is the degree to which healthcare services are distributed equitably throughout society. Comparative justice refers to the way healthcare is delivered at the individual level.

Equity means clients receive fair and just treatment, without discrimination. Health inequalities are unjust barriers to receiving equitable access to care. Many factors can influence a person's health outcomes, including where they live, how they grow up, and their educational and socio-economic background (Giebel, 2024). Health equity means the absence of unfair, avoidable or remediable differences among groups of people (Goswami et al., 2025).

Equitable dementia care should consider the impact of receiving a diagnosis of dementia and information about how to live well and independently for as long as possible. There has been an increasing amount of evidence pointing to many factors leading to unequal outcomes in terms of both diagnosis and care (Giebel, 2024).

Promoting and achieving equity is a matter of fairness. Everyone should be treated with equal respect and should be able to exercise equal influence on decisions made in their name. Unfair health outcomes are nearly always caused by unfair access to opportunities and unfair inequalities in society (Fairness Foundation, 2021).

8.1.4 Veracity (Truthfulness)

Telling the truth is an important part of all human interactions. Consistently telling the truth to a person living with dementia can be complicated, especially when telling the truth causes distress, confusion, or agitation. Nevertheless, telling the truth should always be a caregiver's starting point.

There is concern among many caregivers that ,in some situations, telling the truth may cause distress, confusion, or agitation; this leads to the temptation to lie or "bend the truth" to maintain calm and well-being. It is a controversial practice when lies are told in the best interests of a person living with dementia in order to avoid distress or harm.

The difficulty is that telling the truth to clients living with dementia can cause distress or do harm. For example, when a person living with dementia asks again and again about a deceased spouse, reliving the pain of learning about the death of a loved one can cause a great deal of pain and distress. Because of this, many caregivers admit to telling lies when delivering care, even if it creates an ethical dilemma for the caregiver (Murray et al., 2025).

8.2 Incorporating Ethical Principles into Care

Caring for a person living with dementia often presents ethical challenges that require a thoughtful and compassionate approach. By integrating ethical principles such as autonomy, beneficence, and justice, caregivers and healthcare professionals can ensure that individuals living with dementia receive respectful and dignified care.

Many caregivers lack confidence in managing the challenging behaviors of people living with dementia (Schou-Juul et al., 2024). This can be overcome by training caregivers in ethical decision-making and dementia-specific challenges. Unfortunately for direct care providers, a high turnover rate, lack of support, and low pay contribute to a lack of training.

For healthcare workers and family caregivers, encouraging person-centered care, tailoring support to individual needs and preferences, and promoting advanced care planning can provide the structure and support needed when an ethical conflict arises. This can be accomplished by reviewing a resident's advance directive before making decisions about medical treatment, ensuring their previously stated preferences are honored.

To prevent harm, healthcare providers must regularly review a resident's healthcare plan (including medications) to ensure that a resident living with dementia receives appropriate pain management to alleviate discomfort without over-reliance on sedative medications that could increase fall risk.

To promote equity and fairness, a facility can offer free dementia screenings and caregiver support resources. This ensures that all individuals, regardless of financial status, have access to information about dementia resources.

8.3 Ethical Issues Related to the Use of Assistive Technology

Increasingly, smart devices are being used in long-term care environments. These "smart living" devices collect, retain, and analyze large volumes of personal data, making privacy and security major considerations. Ownership of data, technologies used to ensure encryption and regulations, and policies in place are key themes that emerge when analyzing privacy and security (Lam et al., 2022).

Assistive technologies usually involve aids that support memory, sensors to detect vitals and falls, environmental sensors to detect movement, and advanced security systems. Newer technologies include automatic pill dispensers, emotional support robots, smart home devices (smart lights, voice assistance), and GPS tracking devices.

Though smart cameras, motion detectors, and digital aides may sense trouble sooner than human helpers, their presence transforms an older adult's sense of home into a surveillance zone. Many older adults either have no idea what data is being harvested or lack the ability to adjust their settings. This generates an ethical conflict in which security is valued over a person's dignity and autonomy (Joseph, 2025).

Surveillance can be psychologically harmful. Ongoing monitoring—even aimed at protection—can produce feelings of stigma, anxiety, helplessness, or withdrawal from ordinary activities. When assistive technologies and AI tools override human judgment or fail to account for a person's comfort and consent, they risk turning care into control (Joseph, 2025).

8.4 Examples of Ethical Conflicts and Dilemmas

Ethical dementia care covers a wide range of issues and potential conflicts. Conflicts between respecting self-determination (what a person wants) while acting in their best interest are common. It is important to prioritize a person's needs while avoiding harm (Lauridsen et al., 2023).

When considering justice, equity, and fairness, conflicts arise because resources are limited. In the United States, equal access to healthcare does not exist, creating an ongoing concern about the distribution of resources, particularly as the population ages and the demand for services increases (Saccaro et al., 2025).

When considering the principle of autonomy, individuals have the right to make their own healthcare decisions. Making decisions for a person living with dementia can create significant ethical challenges and potential adverse effects. Ethically, caregivers must work to balance a client's autonomy with their duty of care (Saccaro et al., 2025).

When a person is unable to make decisions, it may be necessary to act in the person's presumed best interest. Acting for the client's well-being (beneficence) is intended to prevent harm. Striking a balance between autonomy, avoiding harm, and doing good requires careful case-by-case consideration, guided by ethical and legal frameworks designed to protect a client's well-being (Saccaro et al., 2025).

Another common dilemma in end-of-life care is how much treatment to provide and when to stop treatment for any medical issues that may occur. For example, once a person is enrolled in hospice, is it ethical to continue to go to the emergency department for IV fluids or to treat a urinary tract infection? Although this may have helped in the past, at what point should this treatment be stopped?

Ethical conflicts can arise related to a client's preferred place of death. Many people want to die at home but may end up in a hospital due to a medical emergency.

8.4.1 Maintaining Independence

Mr. Sienna is 90 years old and lives in an apartment near his daughters. He was a pilot during the Viet Nam war and has been fiercely independent his entire life. He is in the moderate-to-severe stage of dementia and is unable to independently perform many of his instrumental ADLs such as medication management, shopping, and cooking.

Mr. Sienna is in the clinic for his annual evaluation. He does not know his address, the current date, the president's name, the season, day, or time. His Mini Mental State Exam score is 11/30. When asked what he would do if his apartment caught on fire, he replied, "I would get some water and put it out."

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

Discussion: In making decisions on Mr. Sienna's behalf, his daughters are using the principles of autonomy and beneficence. Mr. Sienna'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.

Mr. Sienna agrees to attend an adult day center 3x/week, and his daughters decide to take turns sleeping at his apartment overnight and 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 apartment and that living alone is consistent with their father's life philosophy.

8.4.2 Justice, Fairness, and Equity

Alycia is a 68-year-old woman with mild dementia living independently at her home in Palm Beach. Over the past year, she has experienced increasing difficulty with her balance and has fallen several times. She is afraid to tell anyone, so she has reduced her physical activity, and stays at home most of the time.

Alycia worked her entire life as a waitress and was never able to save much money. She spent the last ten years caring for her husband. She was unable to hire a caregiver and had to cut back on her hours at work. After her husband died, Alycia became increasingly isolated and depressed.

After breaking her arm in a fall, Alycia realized she needed to do something. One of her neighbors told her she attended an adult day center during the week. Alycia was interested but learned that it would cost $50 per day. She knew she couldn't afford that, so she decided not to go.

Questions

1. Is it fair or equitable that some people can afford to pay for services while others cannot?
2. Do you think Alycia could have had a better outcome if she had enrolled in an adult day program before she dislocated her shoulder?
3. How will Alycia afford the cost of adult day services?

Discussion

The uneven distribution of care and assistance is an example of distributive justice. When supply is low or costly, many are unable to pay for help. In Florida, the average out-of-pocket cost for adult day services is more than $2,000 per month.

Alycia may be eligible for financial assistance through Medicaid, the Veterans Administration, one of the Florida PACE centers located throughout the state or from the State of Florida through the Optional State Supplements program. (FLDCA, 2025).

[Continue to next page for resources and references]

Resources

Alzheimer's Association

The Alzheimer's Association leads the way to end Alzheimer's and all other dementia—by accelerating global research, driving risk reduction and early detection, and maximizing quality care and support. Helpline: 800.272.3900 www.alz.org

Alzheimer's Disease Education and Referral (ADEAR) Center

ADEAR was established in 1990 and is part of the National Institutes of Health. It compiles, archives, and disseminates information about Alzheimer's disease for health professionals, people with AD and their families, and the public. The website provides excellent educational material about Alzheimer's disease, current research initiatives, support services, and much more. https://www.nia.nih.gov/alzheimers or call 800 438 4380.

Eldercare Locator

The Eldercare Locator, a public service of the Administration on Aging, U.S. Department of Health and Human Services, is a nationwide service that connects older Americans and their caregivers with information on senior services. https://eldercare.acl.gov/Public/Index.aspx 800 677 1116.

Family Caregiver Alliance (FCA)

A community-based nonprofit organization that addresses the needs of families and friends providing long-term care for loved ones at home. FCA provides assistance, education, services, research, and advocacy. www.caregiver.org or call 800 445 8106.

Florida Adult Day Services Association

Provides leadership, education, planning, and development of adult day services across Florida. 8175 Bird Road, Miami https://www.fadsafl.org/contact-us.

National PACE Association

PACE is a program that provides and coordinates all types of care for your loved one so you don't have to place them in a nursing home. PACE care includes medical and personal care, rehabilitation, social interaction, medications, transportation and more, all in one place so your loved one can live at home. https://www.npaonline.org/home or 703.535.1565.

Teepa Snow, Dementia Education and Training

An advocate for those living with dementia—Snow has made it her personal mission to help families and professionals better understand how it feels to live with the challenges and changes that accompany various forms of dementia. Her company, Positive Approach, offers education to family and professional care partners all over the world. Training is available through video, online, and in-person trainings and consulting. http://teepasnow.com/or call 877 877 1671.

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[Continue to next page to start quiz]

Quiz

1. Adult day care centers (ADC) provide non-residential coordinated services in a community setting for less than a day.

    a. True
    b. False

2. Although some behaviors are associated with brain changes, others are caused by frustration, loss of control, discomfort, pain, and the inability to communicate needs.

    a. True
    b. False

3. The ABC approach in dementia care encourages caregivers to understand the:

    a. Antecedent—what caused the behavior?
    b. Behavior—what is the behavior?
    c. Consequence—what are the consequences of the behavior?
    d. All of the above.

4. Agitation can include:

    a. Irritability and confusion
    b. Shouting and making loud demands
    c. Using obscene language
    d. All of the above

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

    a. The inability to communicate discomfort.
    b. Boredom.
    c. Too much sleep.
    d. Urinary tract infections and dehydration.

6. Wandering, a common activity in people living with dementia. It can be addressed by:

    a. Telling the person to stop wandering because it isn't safe.
    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 from wandering.

7. Use of restraints should be:

    a. Only for documented indications.
    b. Time limited.
    c. Frequently re-evaluated for their indications, effectiveness, and side effects in each client.
    d. All of the above.

8. Antipsychotic medications are sometimes used as a chemical restraint in people living with dementia. This is an off-label use, meaning the Food and Drug Administration (FDA) has not approved them for treatment of behavioral symptoms associated with dementia.

    a. True
    b. False

9. Assisting a person living with dementia with activities of daily living (no matter what stage of dementia) is best managed by:

a. Sticking to a schedule regardless of the person's wishes.
b. Refusing to help the person with ADLs.
c. Explaining that you're very busy and can't change the schedule.
d. Allowing choices and making sure the person is comfortable.

10. Mrs. Cortez has moderate to severe dementia. When the caregivers try to help her to the bathroom, she pinches, swears, and bites. A good way to address this behavior is:

a. Stop trying to bathe her.
b. Restrain her in a shower chair and bathe her anyway.
c. Observe her behavior, figure out why she is agitated, and adjust accordingly.
d. Stop trying to shower her and give her a bed bath instead.

11. Successful individual activity programs for people living with dementia are based on a person's likes, dislikes, and interests.

a. True
b. False

12. *Preventing Loss of Independence through Exercise* emphasizes activities that promote:

a. Body awareness, mindfulness, and breathing.
b. Slow pace and step-by-step instruction
c. Social interaction.
d. All of the above.

13. In the early stages of dementia, it is recommended that family members receive early, specialized training about dementia.

a. True
b. False

14. People caring for a person living with dementia can experience different types of stress, which can include emotional stress, financial stress, and physical stress.

a. True
b. False

15. Healthcare workers and providers can support caregivers by helping them understand that caregiver needs are as important as the needs of the person they are caring for.

a. True
b. False

16. Caregiver stress can be reduced when education, training, support, and respite are available.

a. True
b. False

17. Encouraging family involvement in care involves inviting them to choose and participate in activities. A

a. True
b. False

18. Grief can be related to loss of employment, changes in relationships, significant changes in life, loss of health, and loss of the future that was hoped for and imagined.

a. True
b. False

19. When a loved one dies, family members:

    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. Therapeutic design recognizes that there is a connection between the environment and how we behave. A

    a. True
    b. False

21. To integrate staff into a homelike environment:

    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. Keep to a rigid schedule.

22. For a person living with dementia, a safe environment should be predictable, reduce confusion, and create a sense of being at home.

    a. True
    b. False

23. The principle of beneficence (kindness) is:

    a. Unprofessional and not ethical.
    b. The act of being kind.
    c. Not an issue when caring for a person living with dementia.
    d. Impossible to keep in mind when caring for someone living with dementia.

24. An ethical dilemma might arise when:

    a. A client refuses to eat breakfast.
    b. A person living with dementia steals food from another client.
    c. There are good reasons both for and against a particular course of action and a decision must be made.
    d. A person living with dementia is no longer able to independently perform their ADLs.

[Continue to next page for answer sheet]

Answer Sheet: FL ADRD Adult Day Care (370)

Name (Please print)____

Date____

Passing score is 80%

1. _______	13. _______
2. _______	14. _______
3. _______	15. _______
4. _______	16. _______
5. _______	17. _______
6. _______	18. _______
7. _______	19. _______
8. _______	20. _______
9. _______	21. _______
10. _______	22. _______
11. _______	23. _______
12. _______	24. _______

[Continue to next page for course evaluation]

Course Evaluation: FL ADRD Adult Day Care (370)

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 3 types of services offered to clients in adult day care facilities. 1 2 3 4 5

2. Identify 5 challenging behavioral symptoms associated with dementia. 1 2 3 4 5

3. Describe 3 best practices when assisting someone with ADLs at each stage of dementia. 1 2 3 4 5

4. List 4 parts of a well-designed activities program for people living with dementia. 1 2 3 4 5

5. Describe 3 types of stress in caregivers caring for a person living with dementia. 1 2 3 4 5

6. Recognize 3 issues faced by someone caring for a person living with dementia. 1 2 3 4 5

7. Identify 3 concepts in the design of a therapeutic environment for those living with dementia. 1 2 3 4 5

8. Identify 4 key concepts that are part of an ethical approach to dementia care. 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

***From what you have learned, will you make 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:**

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

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_______30-39 minutes per contact hour

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_______A tablet.

_______A cellphone.

_______A paper copy of the course.

Please enter your comments or suggestions here:

[Continue to next page for registration and payment]

Registration: FL ADRD for Adult Day Care (370)

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

*Name: ____

*Email: ____

*Address: ____

*City and State: ____

*Zip: ____

*Country: ____

*Phone: ____

*Professional Credentials/Designations:

____

*License Number and State: ______________________________

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