Instructions for Mail Order

Once you've finished studying the course material:

1. Record your test answers on the answer sheet.
2. Complete the course evaluation.
3. Complete your registration and payment*.

Mail the completed forms with your payment to:

ATrain Education, Inc

5171 Ridgewood Rd

Willits, CA 95490

*Check or money order payable to ATrain Education, Inc (or enter your credit card information on the registration form).

When we receive your order, we will grade your test, process your payment, and email a copy of your certificate to the email address you provide.

If you would like a fancy copy of your certificate (suitable for framing), please add $10.00 to your payment.

Questions? Call 707 459-3475 (Pacific Time) or email (Sharon@ATrainCeu.com).

[Continue to next page to start course]

Florida: Alzheimer's Disease and Related Dementias for Hospice, 3 units (373)

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

Florida DOEA Approval: HSP11434

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. Hospice Alzheimer's Disease and Related Disorders (ADRD) Training Provider Approval Number: HSP 11405.

Course Objectives

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

1. Describe 3 types of services offered to clients enrolled in hospice.

2. Identify 5 challenging behavioral and psychological symptoms associated with dementia.

3. Describe 3 best practices when assisting someone enrolled in hospice with activities of daily living.

4. List 4 components of a well-designed activities program for people living with dementia.

5. List 3 types of stress that are common in caregivers caring for a person living with dementia.

6. Explain 3 issues family caregivers face as their loved one transitions from mild to moderate to severe dementia to end-of-life.

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 older adults living with Alzheimer's disease and other types of dementia who are enrolled in hospice. It discusses symptoms and behaviors that can arise in a person living with dementia and strategies for managing these behaviors. It outlines strategies for assisting someone with activities of daily living and describes best practices for individual and group activities.

The course describes how stress can affect a caregiver's life, strategies for managing stress, and how healthcare providers can recognize caregiver issues and concerns. 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 utilizing hospice services. It is designed to increase your awareness and understanding of Alzheimer's disease and related disorders.

Pretest

1. Hospice services are **not** for people who have dementia.

a. True
b. False

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

a. True
b. False

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

a. True
b. False

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

a. True
b. False

5. Carefully designed activities can have a positive effect on depression, confusion, and challenging behaviors. A

a. True
b. False

6. To relieve stress, it is recommended that family members receive specialized training about dementia. A

a. True
b. False

7. In the early stage of dementia, family members are often unaware of dementia-care services.

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 are living with dementia.

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

1. Hospice

Hospice provides services for clients who have a terminal illness. It focuses on caring, not curing, addressing to the physical, spiritual, social, and psychological needs of the client and their families. In 2023, more than 1.7 million Medicare beneficiaries received hospice services, and Medicare hospice expenditures totaled about $25.7 billion (MedPAC.gov, 2025).

The hospice benefit can include visits by nurses, aides, social workers, physicians, and therapists. It also covers drugs, durable medical equipment, and supplies, short-term inpatient care and respite care, bereavement services for the family, and other services related to the terminal illness (MedPAC.gov, 2025).

To receive hospice services, a client must agree to forgo curative treatment related to the terminal diagnosis, not all medical treatment. Most commonly, hospice care is provided in a client's home, but may also be provided in nursing, assisted living, and hospice facilities, and other inpatient settings (MedPAC.gov, 2025).

Hospice is defined under Medicare Part A as a benefit that requires physician certification of a six-month terminal prognosis (if the illness runs its normal course) and election of comfort-focused care in place of curative treatment for the terminal diagnosis.

A family member usually serves as the primary caregiver. Hospice staff make regular visits to assess the client and provide additional care and support. Hospice staff are on-call 24 hours a day, seven days a week. In Florida, more than 150,000 clients are enrolled in hospice (National Alliance for Care at Home, 2024).

Originally, hospice services were designed for people with cancer. However, the number of people living with a primary diagnosis of dementia using hospice services has dramatically increased. Nationwide, about 20% of hospice clients are living with dementia (Lassell et al., 2022).

A hospice client can have an unlimited number of days in hospice, as long as they are recertified as having a six-month prognosis (after the first six months of hospice care) and each ninety-day period thereafter. People living with dementia tend to be enrolled in hospice for a longer amount of time and to have higher rates of disenrollment* from hospice before death compared with hospice clients who have other terminal illnesses (Aldridge et al., 2023).

Disenrollment: ending hospice services. The 2 most common reasons for disenrollment from hospice are 1) a person lives longer than 6 months (extended prognosis) or 2) the client or family stops hospice services.

Palliative* care is an important part of hospice, providing relief and support and managing pain and other complex symptoms as a person nears the end of their life. It focuses on symptom management and is available to anyone of any age following complex surgeries or while undergoing treatment for life-threatening conditions such as cancer. Palliative care has no prognosis requirement and may be provided alongside curative treatment at any stage of serious illness.

***Palliative**: a medicine or type of medical care that relieves symptoms without dealing with the cause of the condition.

2. Managing Challenging Behaviors

Challenging behaviors occur in the vast majority of people living with dementia. They are referred to as *behavioral and psychological symptoms of dementia* (BPSD) or *neuropsychiatric symptoms of dementia* (NSP). More than 90% of people living with dementia will eventually experience some type of challenging behavior associated with their dementia (Qi et al., 2026).

The loss of this ability to control and suppress challenging behaviors causes a lack of restraint, disregard for social convention, impulsiveness, poor safety awareness, and an inability to stop strong responses, desires, or emotions.

Although challenging behaviors are associated with brain changes, they are also caused by frustration, loss of control, discomfort, pain, and the inability to communicate needs. Challenging behaviors can also be triggered by frustrated family caregivers and poorly trained healthcare providers.

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.

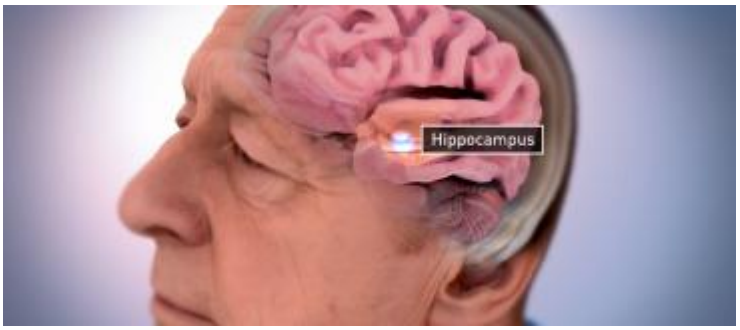
2.1 Common Challenging Symptoms and Behaviors Associated with Each Stage

A **symptom** is a 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, changes 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 affects symptoms and behaviors as much as the stage of a person's dementia.

2.1.1 Mild Dementia

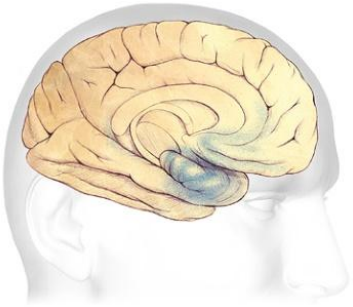
In early, mild Alzheimer's disease, plaques and tangles appear in the part of the brain called the hippocampus, which is responsible for memory and learning. This part of the brain helps a person form and store recent, short-term memories. It converts short-term memories into long-term memories by organizing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

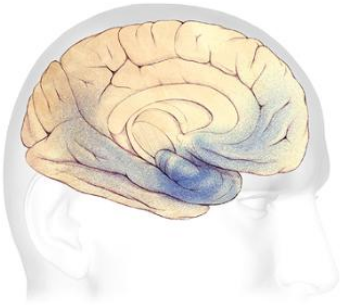
- speaking and understanding speech
- logical thinking
- safety awareness
- judgment
- planning
- ethical thinking

At this stage, because of memory problems and confusion, for a person living with dementia, travel, work, and handling personal finances *may* become more difficult, if not impossible.

Behavioral changes become more obvious to caregivers. Inappropriate behaviors such as cursing, kicking, hitting, and biting can occur. Some people repeat questions over and over, 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 and a person may no longer be safe on their own.

Brain Changes in Moderate Dementia

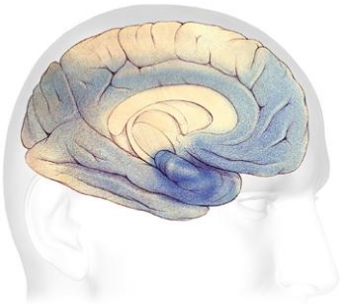


As symptoms progress from mild to moderate, plaques and tangles spread from the hippocampus (dark blue) forward to the frontal lobes (shaded in light blue). Source: The Alzheimer's Association. Used with permission.

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 themselves can be severely affected. A person living with severe dementia can be easily confused, indecisive, and often unable to clearly communicate their needs. 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 can occur as well as delusions or hallucinations.

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.

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.

For people living with severe dementia, hospice care may be needed. However, the rigidity of client admission criteria, particularly the requirement for a prognosis of 6 months or less, poses challenges for people living with dementia because prognosis can be imprecise due to the prolonged decline and sustained functional limitations related to the disease. Additionally, people living with dementia may enter hospice care after years of significant functional limitations and caregiving needs (Frank et al., 2025).

2.2 General Problem-Solving Approach to Challenging Behaviors

Problem solving is an important skill for caregivers and healthcare providers to develop. 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 approach a person struggling with dementia with patience and compassion.

Callie Disrobes at a Birthday Party

Introduction: Older adults living with dementia often exhibit unexpected, challenging behaviors that may be difficult to understand and manage. In this example, we learn about Callie, a 96-year-old woman with moderate to severe dementia who receives hospice services in her home. Her daughter has scheduled a birthday party, and the house is filled with family and friends. Callie is sitting comfortably her recliner.

Client Information: Callie lives at home with 24-hour care provided by family members and paid caregivers. She can walk with assistance but usually prefers to sit quietly by herself in the living room, listening to music. Callie smiles a lot and likes talking to her daughters. However, on occasion she has a negative reaction to large crowds or noisy environments. Family members understand this and try to remove her from these stressors.

Antecedent: On a very warm day in August, with everyone's attention focused on the celebration, no one notices that Callie had begun to remove her clothing. A caregiver turned just in time to see her take off her slacks and underpants.

Intervention: Her daughter had received dementia-specific training and knew that when something unexpected happens, the safety and dignity of her mother must come first. Rather than immediately trying to get Callie dressed, which might have caused a negative reaction, she simply asked everyone to leave the room for a few minutes. She sat next to Callie and quietly asked if she could help her get dressed. Callie responded with a definite "no" and pulled off the remainder of her clothing.

Another family member brought a sheet to cover Callie and stood by the door to maintain privacy. Callie's daughter stayed with her mom and after a few minutes asked Callie if she needed anything. Callie's response this time was that she was cold. Promising her some birthday cake if she would get dressed, the daughter was able to Callie get dressed. After Callie had moved to a quiet area (with a piece of cake), the party continued.

Discussion: Disinhibition, the loss of awareness of what is appropriate behavior, affects many individuals with dementia. If the family had gotten upset and embarrassed for her, Callie may well have reacted negatively. Temporarily removing the others from the room respected Callie's dignity and gave her a few moments to experience physical discomfort without her clothes. Once the room quieted down, she accepted assistance and a "reward" for getting dressed again.

Family members discussed the incident after the party and agreed that they had forgotten to keep an eye on Callie as the birthday party got underway. They remembered that Callie is uncomfortable with noise and lots of activity but that overall, they did a good job diffusing the situation while taking Callie's dignity and safety into account.

Client Perspective: Callie couldn't explain why she took off her clothes, but it was clear that she felt no embarrassment when she did it. In fact, when asked about the incident, she claimed she didn't remember a birthday party.

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.

Each member of the team, including the person living with dementia plays a crucial role in establishing treatment goals. Maximizing a person's function and independence, addressing challenging behaviors, and identifying and treating reversible causes of impairment is crucial.

Supportive care shifts the focus away from medications to a more comprehensive approach based on the notion of person-centered care. There is strong evidence to support the use of non-pharmacological interventions to improve cognitive functioning and reduce challenging behaviors in people living with dementia. Supportive care follows the client throughout the course of the disease by providing personalized care support to clients and families. It provides a full mixture of good quality medical care, person-centered, and psychosocial and spiritual care (Guzzon et al., 2023).

Although not a comprehensive list, 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 chance of injury, and increase the likelihood of hospitalization and long-term care placement. They also impose a significant burden on caregivers and healthcare systems (Lichwala et al., 2026).

Agitated behaviors can include:

- Irritability
- Confusion
- Making loud demands
- Using obscene language

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.

Not surprisingly, 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.

Caregiver training is essential. Psychosocial and environmental interventions, and recognition of personal habits and patterns can reduce or even eliminate agitated or aggressive behaviors. Appropriate touch*, music therapy, massage, craniosacral therapy**, acupressure, and tactile massage have been used to treat aggression. Individual behavioral therapy and individualized, person-centered care based on psychosocial management is recommended (Burns et al., 2012, latest available).

*__Appropriate touch__: when using touch as a strategy, consider permission, religious, ethnic, and personal preferences as well as professional and ethical standards.

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

Try these tips to help manage agitation and aggression:

- 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.

As a person nears the end of their life, they may experience what is sometimes referred to as terminal restlessness, terminal agitation, or end-of-life delirium. This is characterized by distress, anxiety, confusion, restlessness, hallucinations, fluctuating consciousness, and moaning or yelling.

Because of the short life expectancy, the focus of care is to relieve delirium symptoms, find a balance between communication and the need for sedation, and provide support for caregivers. Once the diagnosis of end-of-life delirium is made, it is important to educate caregivers on its irreversible nature, its symptoms, and the process of dying. Emotional support and discussions about the goals of care are essential (Hui et al., 2024).

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 person living with dementia might accuse someone of stealing something that has simply been misplaced or might confuse a caregiver with someone from their work past.

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, a person walking through the bedroom, or people or animals outside the window.

Visual hallucinations can occur in the moderate to severe stage of dementia and are particularly common in people living 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 involves 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.

Wandering is a common problem 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).

A person who was socially and physically active throughout their life, who enjoys music, or who deals with stress by engaging in physical activities is more likely to wander than others. The habits of a lifetime and the desire to be socially active remain intact.

Wandering can be a beneficial activity if there are safe places to wander, in and around a facility or home. Management of wandering should include a regular review of medications to make sure wandering is not the result of medication side effects, overmedicating, or drug interactions.

The most important goal is to prevent a person from wandering into unsafe areas or away from the home or facility by providing safe, looping wandering paths with interesting rest areas, and redirecting to a purposeful activity. Using subjective barriers such as grid patterns on the floor in front of exit doors, camouflage, and concealment of doors and doorknobs may discourage a wanderer from exiting a building.

Additional strategies to manage wandering include:

- Provide regular, meaningful exercise.
- Offer simple chores such as folding laundry or assisting with dinner.
- Reduce excessive noise.
- Attach an electronic device to the person’s ankle or wrist that alerts staff or family when someone has wandered out of a designated area.
- Install quiet alarms on entryways into unsafe areas or to the outside.
- Use physical barriers such as yellow tape or stop signs to prevent wandering into unsupervised areas.

Did you Know. . .

Florida maintains a Silver Alert program for cognitively impaired older adults who become lost while driving or walking. If a client wanders away from their home or care facility, call 911 immediately. The Silver Alert program is activated by law enforcement, which broadcasts information to the public so they can assist in the rescue of the endangered person. 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".

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 other people.

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 can 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.

To safeguard important items, place them 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.

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 client making it difficult for caregivers to address these behaviors.

2.3.5 Sleep Disturbances

Many 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.

*****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

The Center for Medicaid and Medicare Services (CMS) now requires non-pharmacologic interventions for sleep disturbances be tried and documented before using sedatives or psychotropic medications in a person living with dementia (CMS, 2024).

Non-pharmacological 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 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 a 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. These adverse effects increase the complexity of treating clients living with dementia (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).

2.3.6 Apathy

Apathy is a lack of interest or emotion, loss of motivation, indifference, and a blunting of emotions. It affects 50–70% of people living with dementia (Baber et al., 2021).

Apathy in people living 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 activities of daily living, more rapid disease progression, and increased mortality in people with Alzheimer's disease (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 is capable of doing a task but simply does not bother or will only do so with strong encouragement (Baber et al., 2021).

For healthcare providers and especially for family caregivers, keeping a person engaged in activities can break through the apathy. The efforts of caregivers to reignite this "spark" in the person they are caring for enables people living with dementia to overcome apathy through constant stimulation and encouragement (Chang et al., 2021).

Viewing apathy as simply the result of neurological changes limits successful interventions. Considering apathy as a result of environmental and social factors provides caregivers with the motivation to intervene and make a difference in the life of the person they are caring for (Chang et al., 2021).

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 clients 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

> Decades ago, there was a common misconception that restraints improve the safety of frail elders. The truth, however, is that restraints are dangerous and often cause harm to nursing home residents. Many studies document the dangers and recommend more humane methods to improve the safety of nursing home residents.
>
> CANHR, 2025

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.

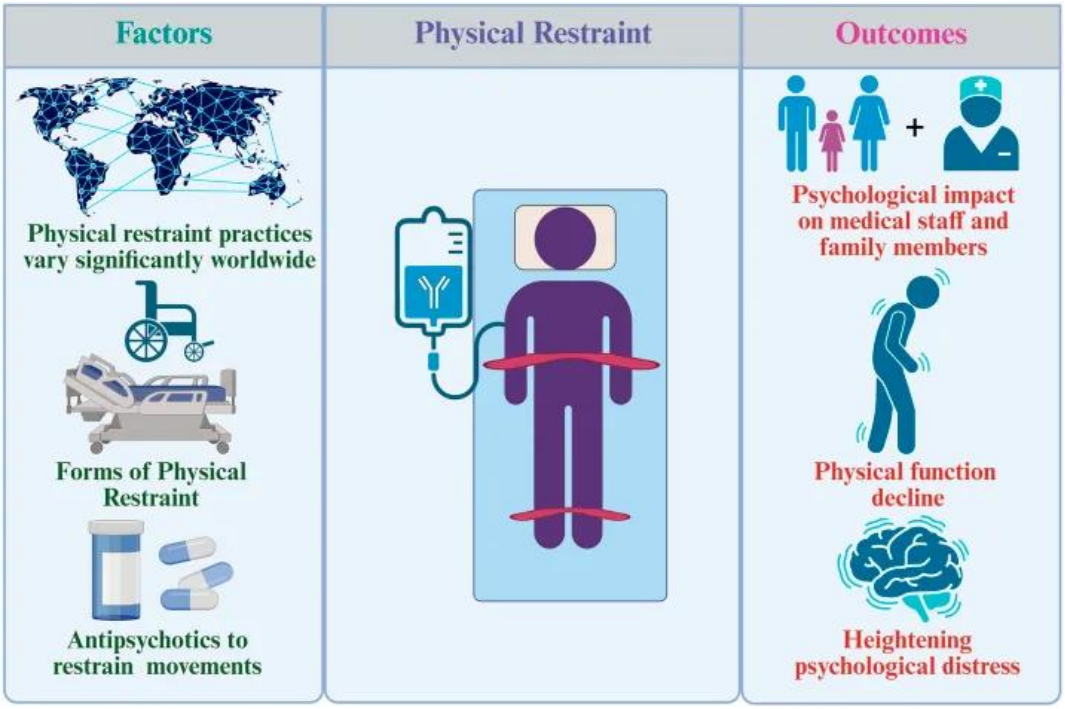
Physical restraints can include:

- belts
- mittens
- soft wrist and ankle restraints
- vest and jacket restraints
- bedrails
- geriatric chairs and recliners
- wheelchair safety bars
- lapboards

Restraints use is common yet often applied without understanding their risks. Bed rails can prevent falls but also the risk like entrapment, especially for cognitively impaired older clients. Restraint belts secure a person to a chair or bed but can cause discomfort, confusion, helplessness, agitation, and anxiety. Restraint belts can also lead to severe complications such as pressure ulcers or impaired circulation if not monitored correctly. Fixed seating devices provide support but can restrict mobility and independence (Tao et al., 2025).

Restraints affect a person's sense of well-being, causing feelings of low self-worth, depression, withdrawal, humiliation, and anger.

Restraints are not limited only to physical devices. 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.



Source: Tao, et al. Creative Commons Attribution License (CC BY).

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.

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 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. Even at the end of a person's life, encouraging independence allows people to actively manage their condition, reduce symptoms, and stay independent and socially active (WHO, 2023).

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.

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 rephrase 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

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

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. Typically, in the middle stage set up, close or direct supervision, and initial guidance or assistance are required for planning and safety due to their executive function decline.

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.

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

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 or reduce the risk 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 include:

- Sitting in a supported, upright position.
- Reducing 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 of your patience, skills, and expertise. People still want to 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 as much assistance as needed 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.

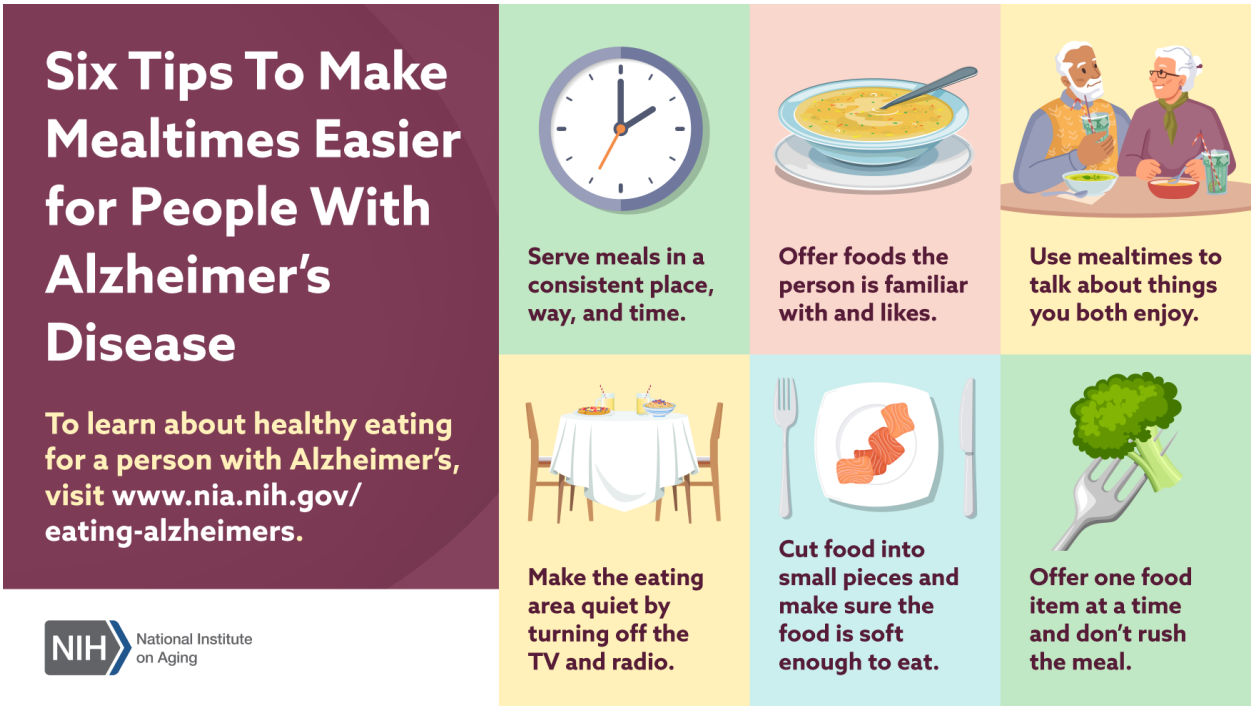
*Consider bathing habits (time of day, bath or shower); consider bed bath if more acceptable to client.

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 clients 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.



Source: NIH, 2025, public domain.

4. Activities for Patients 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

Meaningful activities are based on a person's interests, preferences, personhood, and perceived value (Yous et al., 2023). 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, 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 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	End of Life
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	Read to the person
Letter Writing (paper, email, text)	Write a letter Send an email Send email, use Facebook, social media	Dictate a letter or email Use Facebook with help	Listen to a letter or email being read by caregiver Respond to letters of email with direct supervision	Listen to an email or letter read by caregiver Dictate a letter or text with caregiver assistance
Art/Music/Reading	Take photos Create a photo album Draw, play an instrument Select and listen to books on tape Select programs to listen to on the radio or TV	Take photos with supervision Maintain a photo album Draw, sing along with others Listen to books on tape with headphones Listen to the radio with headphones Watch preferred TV programs	View photos Listen to music Sing along to familiar songs Listen to books on tape with headphones with caregiver assistance Listen to the radio with headphones caregiver assistance	Listen to music at low volume Look at photos and pictures Listen to TV, radio, or books on tape with direct assistance
Sewing	Use sewing machine with help	Use simple tools with supervision	Use sewing cards, activity blankets or	Provide simple tools and templates

Activity	Mild	Moderate	Severe	End of Life
	Plan and complete projects with assistance	Assist with projects	aprons with buttons, snaps, ties, Velcro, and zippers, watch projects	
Gardening	Garden in raised beds Help plan the garden and harvest	Garden in raised beds with assistance Perform specific gardening tasks with supervision Eat food grown in garden	Sit in garden Eat food grown in garden Participate as able	Visit garden Watch others garden Watch gardening shows
Crafts	Knit or crochet Plan and complete art, sewing, painting, or woodworking	Knitting using large needles Choose colors, roll balls of yarn Use simple tools with supervision Engage in simple art, painting, sewing or woodworking projects with setup and assistance	Use simple activity boards with bolts, screws with setup and assistance Choose colors, use the items that are created Offer templates	Provide simple tools such as dry-erase pens Provide direct setup and supervision Observe projects completed by family members or caregivers
Home Activities	Help with laundry Put clothes away Assist with housekeeping Assist with meal preparation Select TV shows Select radio shows	Sort and fold laundry Assist with meal preparation as able Assist with housekeeping as able Assist with selection of radio and TV shows	Fold laundry Assist with meal prep with close supervision Listen to quiet music	Listen to quiet music
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	Go along to the store if able

Activity	Mild	Moderate	Severe	End of Life
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	Listen to religious or spiritual music Visit with someone from their religious community Reminisce
Exercise	Walking Dancing Stretching Yoga Stationary bicycle Resistive exercise Balance exercises	Walking Stretching Seated exercises Stationary bicycle Balance exercises with assistance	Walking with assistance Seated exercises Self-propelling a wheelchair Assisted exercise in bed	Gentle bed exercises Reaching and stretching with assistance Rolling and turning in bed Gentle touch

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 and group activities 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	End of Life
Singing	Choose songs Plan singing events Sing with others	Choose songs Sing with others Sing familiar songs	Listen and sing along as able	Listen and sing along if able
Cooking	Help plan meals Bake cookies Prepare a snack plate for others Assist with cleanup after cooking	Help plan meals with assistance Participate in making cookies Assist with cleanup	Communicate food preferences Help decorate cookies that are already baked Eat the cookies	Communicate food preferences (may be nonverbal communication) Watch food preparation
Nature	Outings to parks or nature areas Group gardening Group picnics Group walks	Shorter walks Drive to parks or nature areas with caregiver supervision	Escorted walk or wheelchair outside Attend picnic with direct supervision if able	View the outside Watch nature shows on TV or computer Go outside in wheelchair if able
Outings	Group 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 Participate in group outings as able with direct supervision	May be unable but offer outings with direct supervision if able
Group Exercise	Choose/plan an exercise program Go to gym with caregiver Participate in Yoga, Tai Chi, Feldenkrais Participate in balance activities	Attend organized exercise programs Participate in Yoga, Tai Chi, Feldenkrais Participate in balance activities	Attend organized exercise programs Participate in seated and standing group exercise as able with direct assistance Exercise and stretch in bed with direct supervision	Gentle stretching and movement in bed with direct assistance Passive manual stretching Weight shifting, rolling, moving in

Activity	Mild	Moderate	Severe	End of Life
	Participate in seated and standing group exercise	Participate in seated and standing group exercise		bed with direct assistance

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 7 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 non-judgmental 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

[**Note**: ethical issues related to virtual reality and smart devices are addressed in section 8.3 LR]

A great deal of research has recently been done on the use of virtual reality (VR) 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 can provide a multisensory experience that stimulates multiple senses. It 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 2 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 study participants reported issues with the head-mounted device, including that it was too heavy, caused general discomfort, disorientation and imbalance, and caused 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

More than 80% of the assistance for older adults in the U.S. is provided by informal caregivers, who generally are family members, relatives, and friends providing unpaid care for family members with chronic diseases such as dementia (Shubair, 2025).

As a person living with dementia nears the end of their life, caregiving can become an overwhelming experience. It can lead to significant stress and burden for family caregivers who can experience high levels of emotional, physical, and financial distress and burnout. These stressors can affect a caregiver's health and the quality of care they provide (Tamer et al., 2025).

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 a lot more stressful. There were more medical appointments with a very disinterested and unhelpful doctor. I ignored my own needs because there was no one to watch her while I was gone.
>
> Family Caregiver, West Palm Beach, FL

5.1.1 Emotional Stress

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).

Caregivers can experience high levels of anxiety, depression, stress, and distress, which can harm the quality of the relationship between the caregiver and 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

> The economic impact of caring for a person living with dementia adds to a caregiver's emotional stress. A study in 2013 examining caregivers for older adults found that a 1% increase in caregiving hours corresponded to an approximately 10% decrease in the employment rate among caregivers.
>
> Alzheimer's Disease International

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. This contribution is 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).

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.

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 past 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.

The *Zarit Burden Interview in Dementia* (ZBI) tool is a quick tool for assessing caregiver stress. It explores four items related to a caregiver's self-care, stress, and burden. It 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

Barbara cares for her husband Jim at home and refuses any sort of help. Barbara is in denial of her husband's dementia. She is also in denial of her lack of knowledge, her poor coping skills, her short temper, and her unwillingness to seek help. This has created a great deal of stress and, at times, abusive behavior toward Jim.

Friends and family have recommended that Barbara enroll her husband in hospice and attend a caregiver support group. She agrees to hospice services but refuses to attend a support group.

Sana, a hospice nurse arrives at Barbara's home and notes that Jim is cooperative and friendly, but Barbara appears to be stressed out. Sana notices that Barbara seems impatient with her husband and raises her voice in frustration when he doesn't answer questions quickly enough. As soon as Jim is in Sana's hands, Barbara says she has to go grocery shopping and leaves the house.

Sana sits down next to Jim and asks him how he's doing. He turns to her and says urgently "Help me—she's trying to kill me!" This startles Sana and her first thought is that Jim has dementia and is probably just being paranoid. What should Sana do?

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 Barbara's sister has already made a report to Adult Protective Services, which is monitoring the situation.

Sana's supervisor asks one of the nurses to have Barbara complete the Zarit Burden Interview in Dementia (ZBI) tool at the next home visit. 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 addressed through the use of education, training, support, and respite care. These four components have been shown to decrease caregiver stress and reduce or delay the transition from home to a care facility (ADI, 2022).

Caregivers can reduce their stress by paying attention to their own health, getting enough sleep, eating properly, seeing their own healthcare providers. Sharing their feelings about their caregiving duties with family, and friends and attending in-person or online support groups can also reduce stress.

Adult day care centers and some skilled nursing facilities offer respite and support services, providing relief for family caregivers, reducing caregiver burden, and increasing caregiver motivation. A primary goal is to develop knowledge and skills in dementia care and prevent early placement.

Addressing Caregiver Stress

Reducing caregiver stress	Things to avoid
• Do ○ Join a support group or see a counselor. ○ 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. ○ Seek out respite services.	• Don't ○ Isolate yourself. ○ Try to be all things to all people. ○ Expect to have all the answers. ○ Deny your own fears about dementia and aging.

Source: NIH, public domain.

5.3.1 Respite Care

Respite services support caregivers by providing time away from the person they are caring for. This provides a chance to relax and recharge while making time for errands and other tasks. Respite services may be available in a person's home, an adult day care center, in the community, or in longterm care communities. Respite care is available for up to 5 days and nights and is covered by Medicare Part A.

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, create feelings of accomplishment, and improve the quality of relationships between family. There can also be 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 research on the important role that informal, unpaid caregivers play in the care of dependent older adults.

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

1. Take care of myself.
2. Seek help from others.
3. Maintain parts 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.

Family caregivers consistently report a lack of support, insufficient dementia knowledge, and barriers obtaining and sharing information. They report feeling isolated and experience feelings of frustration, anxiety, depression, burnout, and prolonged stress (Scerbe et al., 2023).

For healthcare providers, understanding these issues is important when working with family members and caregivers. And it isn't only family members who lack dementia education. Healthcare providers also often lack dementia-specific education, training, and experience. Developing skills for working with family members and caregivers means listening to and recognizing their issues, fears, and concerns. It means learning 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. Hospice helped a little but not as much as I'd hoped it would
>
> 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 compared to caregivers of people dying from other diseases (Bigger et al., 2024).

The person 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. 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 children 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—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.

For healthcare providers, listening carefully to family 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 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 cause caregiver anxiety, depression, stress, and burnout. Caregiving duties often fall mostly on one person, which can lead 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 have to 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 assisted living 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.
- Client's dementia-related behaviors.

Healthcare providers can be a valuable source of support, providing information about respite care, longterm care options, and hospice. 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 their life. In the year before the person's death, more than half of caregivers feel they are constantly on duty, and many report caregiving during this time is extremely stressful. It is not uncommon for a caregiver to feel relief when the person they are caring for 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 often 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, can reduce caregiver distress. Living with the care recipient can enhance caregiving but can also increase stress due to the constant demands of care (Iacob et al., 2025).

6.1.5 Hospice Issues and Concerns

Individuals living with dementia are the fastest growing population of patients entering hospice care in the United States. Dementia is now the leading principal diagnosis among patients enrolling in Medicare hospice services.

The decision to pursue hospice care means considering life issues, adapting to new healthcare services, and coping with a shift in goals of care from cure to comfort. However, hospice services are associated with improved symptom management, increased caregiver satisfaction, and decreased caregiver burden (Bigger et al., 2024).

Unfortunately, some hospice professionals lack dementia-specific training, and best practices are lacking. Because of this, healthcare providers may not be well-equipped to meet the needs of a person living with dementia and their caregivers. This can lead to disrupted care, burdensome transitions, financial strain, and increased stress and anxiety. These poor outcomes are especially high among Black and Latino people living with dementia (Lassell et al., 2022).

As a person nears the end of their life, they often have to rely on another person for decision-making. Proxy decision-makers* must ensure that decisions are consistent with the long-term values and beliefs of the person they are caring for. It is also important to ensure that a client's decisions are made voluntarily and without the influence of others who may try to take advantage of a vulnerable person for their own benefit (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.

Although most people receive hospice services in their home, they are more likely to die in a long-term care facility than those with any other diagnosis. A person's desire to avoid burdening their families is the main reason they choose to receive end-of-life care outside of the home (Yin et al., 2024).

6.2 Strategies for Encouraging Family Involvement

Despite their willingness to remain actively involved, family members often take a step back when their relative is enrolled in hospice. This can be because healthcare providers don't see caregivers as partners in care or due to a lack of consistent contact between family and staff. The top-down nature of healthcare services can be intimidating for family caregivers.

These issues are important for healthcare providers to keep in mind. 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. It also increases family caregivers' satisfaction with dementia care (Tasseron-Dries et al., 2023).

Strategies to increase family involvement in hospice care include:

- Encouraging them to choose and participate in activities.
- Helping them learn about and understand the challenges associated with end-of-life care.
- Helping to arrange transportation if the family member is receiving hospice services outside the home.
- Including them in team meetings.
- Emphasizing their role as a partner in care.

Advanced care planning should be discussed and encouraged as early as possible. Healthcare providers play a key role in guiding families through this process, providing resources and support. Family members may resist advanced care planning because of stigma, lack of knowledge about end-of-life concerns, complex family dynamics, or worries that end-of-life conversations will bring up uncomfortable issues (Sussman and Tétrault, 2022).

6.2.1 Caregiver Training and Support

Training, education, and support are critical for caregivers. Training introduces caregivers to resources, assistive equipment, and community services that can improve health and safety and reduce caregiver strain. This is especially important as someone approaches the end of their life.

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 distress, increased emotional burden, and grief (Laranjeira et al., 2022). During this time, there is an increased need for good communication 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.

Caregivers can also benefit from personalized, user-friendly online programs and videos. Well-designed programs connect caregivers with a social network, allowing them to share ideas and practical concerns.

6.2.2 Barriers to Family Involvement

Despite the health and social benefits of palliative care and hospice, not everyone receives these services. To qualify for hospice, a person living with dementia must have a diagnosis of severe dementia and have conditions such as aspiration pneumonia, decubitus ulcers, or constant weight loss. The lack of clarity about how long a person with dementia may live is an additional barrier to hospice entry (Oh et al., 2025).

While there are a range of programs and services that assist family caregivers, including education, respite care, and psychosocial interventions, many family caregivers underutilize these resources. Barriers such as lack of awareness, time constraints, stigma, and difficulty accessing services contribute to low use of available supports. As a result, many family caregivers manage their responsibilities with limited assistance, increasing stress and burnout (Kokorelias et al., 2025).

Overall, the treatment and care of people living with dementia at the end of life is often inadequate. On the one hand, people living with dementia are at risk of overtreatment with non-beneficial interventions, such as artificial feeding, restraints, laboratory tests, and the administration of intravenous drugs. On the other hand, some clients receive too few necessary palliative interventions, such as adequate pain management, emotional and social support, spiritual care, and support for their family caregivers (Pinkert and Holle, 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. 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.

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. Grief is a response to any loss that is significant to an individual and is a process that unfolds in a non-linear manner (Waddington et al., 2023).

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. This can 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. Not knowing 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 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, 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.

6.3.4 Caregiver Grief

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.

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).

6.3.5 Loss of Friends and Family Members

> About 2 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 is related to the death of family members, friends, and neighbors and opinions differ on whether or not 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.

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 includes:

- Private space in a person's room with a private bathroom.
- Easy-to-access public spaces.
- 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. Certain health benefits are associated with this approach:

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

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

Many people living with dementia prefer to spend their final days at home because the familiarity, stability, and predictability of the environment is important to them. As cognitive functions decline, being at home can protect them from the distress and confusion associated with environmental changes and avoid the feelings of powerlessness and displacement that arise when they are transported to a care facility (Yin et al., 2024).

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 include (CANHR, 2025):

- Is the organization's philosophy consistent with your beliefs?
- What conditions or behaviors determine whether an organization will admit or retain someone living with dementia?
- Is the organization's philosophy and practice of handling "difficult behaviors" compatible with your views?
- What is the organization's philosophy in using physical restraints to deal with certain behaviors?
- Does the organization recommend the use of psychoactive drugs to treat challenging behaviors?

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.

Dementia Friends focuses on five key messages (Dementia Friends USA):

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 is possible to live well with dementia.
5. There is more to the person than the dementia.

7.3 Safety and Security

> My mom has severe dementia. She can still walk around the house using a walker. Last month, she went into the bathroom, swung her hips around and landed heavily on the toilet. Unfortunately, when she turned, she grazed the corner of the tile sink cabinet and broke a rib. To prevent this from happening again, we installed a transfer pole next to the cabinet, which blocked the corner of the cabinet. My mom was able to grasp the pole and sit on the toilet more safely.
>
> Family Caregiver, West Palm Beach, FL

7.3.1 Elements of a Safe Environment

Safety is freedom from accidental or preventable injuries or harm. People living with dementia need to feel safe (and be safe). A safe and secure environment should include proper assistive equipment, dementia-trained caregivers, and consistent communication with healthcare providers.

For a person nearing the end of their life, muscle weakness, injuries from falls, hearing loss, and visual changes increase the risk of accidents and injuries. Safety focuses on reducing clutter, and removing hazards such as 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 come into contact with 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.

Elements related to client safety also include error reporting, infection prevention, medication safety, compliance with safety procedures, and personal safety awareness (Moran et al., 2024).

7.3.2 Elements of a Secure Environment

Physical security involves measures such as exit control, lighting and surveillance, facility and room access, and control of the facility's perimeter (fencing, gates). Security also involves caregiver and staff training, emergency preparedness, and addressing patient abuse.

On a personal level, support from healthcare providers provides a sense of security for clients and family caregivers. Family caregivers feel insecure when they don't know what to expect or have unrealistic expectations of what it means to provide care at home. A lack of information can cause caregivers to feel useless and helpless, which contributes to a sense of insecurity (Barlund et al., 2021).

The table below illustrates some common safety and security 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.

7.3.3 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 safely continue to wander. A regular review of medications ensures that wandering is not the result of medication side effects, overmedication, or drug interactions.

As a person nears the end of their life, weakness can make walking and wandering unsafe. Nevertheless, the same used in earlier stages of dementia still apply in hospice:

- Redirect to a purposeful activity.
- Provide safe places to wander.
- Install rails and grab bars.
- Encourage the use of a walker or cane.
- Provide close assistance.

Electronic devices attached to the person's ankle or wrist alert caregivers when a person has wandered out of a safe area. Subjective barriers such as grid patterns on the floor in front of exit doors, camouflage, and concealment of doors and doorknobs discourages 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).

7.3.4 Smart Technology Related to Safety and Autonomy

Smart technologies can be used to increase safety, security, and autonomy. Remotely controlled environmental monitoring systems can be used by family caregivers to regulate temperature, humidity, and air quality. Health and safety monitoring systems can detect falls and send an emergency alert. Automated lighting controls, voice-activated assistants, and GPS trackers can provide a sense of security (Hu et al., 2024).

Safety sensors can also detect carbon monoxide, flood, and fire and send early warnings and alerts to a caregiver's phone. Indoor cameras allow caregivers to remotely check on their loved one and communicate via two-way audio. These tools can provide peace of mind for caregivers and reduce risk while supporting independence.

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 person 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 hospice clients.

The person-centered approach was developed nearly 3 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, and 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

Being part of a 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.

Many factors make it difficult to effectively blend staff into the environment. 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.
- Allow staff to control lighting and environmental levels.
- Keep staff consistent.
- Encourage staff to collaborate with one another.

7.6 Staff Adjusting to Patient Routines

Forget dementia, remember the person!

Alzheimer's Disease International

At the end of life, medical aspects of care are deemphasized and the focus shifts to comfort-oriented care. Daily tasks such as bathing, grooming, and eating must consider a client's energy level and personal preferences. Caregiver tasks such as cleaning, vacuuming, and cooking must consider a client's need for rest and quiet.

For medical staff, the client's care plan must be adjusted according to the client's needs. Clients, staff, and family caregivers must work as a consistent unit. The nursing care plan must shift as needed to prioritize comfort and the client nears the end.

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 thoughtful schedule accounts for physical issues that might disrupt routines such as hunger, pain, fatigue, or illness. This is especially important for a person nearing the end of their life.

Caregivers and healthcare workers responsible for maintaining a schedule need to be flexible while helping 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.

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.

8. Ethical Issues and Persons with AD

People living with dementia and their caregivers face ethical issues every day, ranging from questions such as how to engage with a person living with dementia who is unwilling to accept that she or he has the disease or how to decide whether manipulating a person with dementia is ethically permissible if it promotes their best interest (Lauridsen et al., 2023).

Ethical issues can include questions related to autonomy (independence) 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 on it.

Prioritizing a person's needs while avoiding harm is a key issue. Respecting what a person wants while acting in their best interest can be a potential conflict (Lauridsen et al., 2023).

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 person.

There are many challenges related to autonomy. A diagnosis of dementia does not necessarily mean a person 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.

End-of-life decisions made by a proxy 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).

8.1.2 Beneficence (Kindness): Doing Good

Beneficence (buh-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 as long as they are in the best interest of the client 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 means healthcare services are distributed equitably throughout society while *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).

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).

Historically underserved populations have faced barriers to accessing palliative care services, reflecting broader structural and social inequities. Health equity means the absence of unfair, avoidable or remediable differences among groups of people (Goswami et al., 2025).

8.1.4 Veracity (Truthfulness)

Telling the truth is an important part of all human interactions. But consistently telling the truth to a person living with dementia can be difficult. Nevertheless, telling the truth should always be a caregiver's starting point.

Many caregivers are concerned that in some situations, telling the truth may cause distress, confusion, or agitation, leading to the temptation to "lie" or "bend the truth" to maintain a person's well-being. This has led to the concept of "therapeutic lying". This is a controversial practice in which lies are told in the best interests of a person living with dementia, 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 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

By integrating ethical principles such as autonomy, beneficence, and justice, caregivers and healthcare professionals ensure that individuals living with dementia receive the respectful and dignified care they deserve.

For healthcare workers and family caregivers, encouraging person-centered care, tailoring support to individual needs and preferences, and promoting advanced care planning provides the structure and support needed when an ethical conflict arises. Reviewing a client's advanced care directive before making decisions about medical treatment ensures their previously stated preferences are honored.

8.3 Ethical Issues Related to the Use of Assistive Technology

Assistive technologies include 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, and smart home devices.

Intelligent assistive technologies are being used to support individuals living with dementia. "Intelligent" means that these technologies analyze their environment using sensors and different forms of artificial intelligence. They operate somewhat independently. Examples of such devices include smart GPS tracking systems that can learn the usual routes of their users and report deviations, smart home systems that use sensors to detect falls and call for help, and (humanoid) care robots that interact with their users (Welsch and Schicktanz, 2025).

Intelligent assistive devices can increase the safety and independence of a person living with dementia (autonomy), prevent harm, and promote overall good (beneficence). Intelligent assistive devices can also relieve the physical and psychological burden of family and professional caregivers and increase the overall quality of dementia care (Welsch and Schicktanz, 2025).

Though smart cameras, motion detectors, and digital aides may sense trouble sooner than human helpers, their presence can transform an older adult's home into a surveillance zone. Many older adults either have no idea what data is being harvested, have not consented to the use of these devices, and 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).

Ongoing monitoring—even aimed at person's 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 Ethical Conflicts and Dilemmas

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

The principle of autonomy means an individual has 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).

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? 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 Mrs. Gould

Mrs. Gould is 92 years old and has severe Alzheimer's disease. She has lived in a skilled nursing facility for the past four years. She has help with her meals, but over the last month has intermittently refused food. As a result, she has lost 15% of her body weight over the past 6 weeks. She is no longer able to communicate her wishes.

A Physician Orders for Life-Sustaining Treatment (POLST) form that she completed when she was able to make her own decisions did not specifically indicate if she wanted a feeding tube inserted if she was no longer able to eat on her own. If she had specified no feeding tube, the doctor would be legally and ethically bound to honor her wishes.

Her son has medical durable power of attorney to make decisions for her when she is no longer able. He says his mother told him she would did not want to be fed through a tube and he wants to honor her wish. However, his sister is insisting that a feeding tube be inserted to keep her alive as long as possible.

Discussion: Mrs. Gould's son is acting in what he feels is in his mother's best interest, considering what he believes his mother would say if she were able. He is adhering to the principle of autonomy and is demonstrating loyalty and support of his mother's wishes (beneficence). His sister is refusing to consider her mother's wishes and is advocating for a course of action that is not in her mother's best interest (non-beneficence).

While one might think that the daughter is acting in concert with the principle of beneficence by feeding her, studies show that feeding tubes do not prolong life or improve quality of life in people in the later stages of Alzheimer's disease. At the very latest stages of Alzheimer's, the natural course of the disease is that people stop eating and drinking.

Because the brother has power of attorney, he decides to act on what his mother told him when she was able. He feels he is acting in his mother's best interest (beneficence), honoring a decision she made in the past. No feeding tube was inserted.

8.4.2 Maria Enrolls in Hospice

Background

Maria is 96 years old and lives at home with help from her daughter Alma and paid caregivers. She has severe dementia, muscle and joint stiffness, and back pain. She needs help with medications, shopping, bathing, transfers, and cooking.

Maria is in the clinic for her annual evaluation. She does not know her address, what city she lives in, the president's name, the season, day, or time. When asked what she would do if her house caught on fire, she replied, "I would call 911" even though she can no longer use a phone.

After several years of taking care of her mother, Alma is exhausted and worried about her mother's recent decline in function. She told the doctor that Maria didn't want to get out of bed in the morning, wasn't eating very much, and was sleeping a lot more than she used to. She asked the doctor about hospice, but the doctor seemed uninterested and refused to place an order. Alma returned 2 months later with another request for hospice and the doctor finally agreed.

Discussion

When the hospice nurse arrived, he brought a large bag filled with all sorts of medications that Maria didn't need, including morphine, and nausea, antianxiety, and antiseizure medications. This confused Alma but she didn't get any information from the nurse about why he brought so many medications.

Alma was also confused about whether or not she should take her mother to the hospital for a urinary tract infection or signs of dehydration. Maria's doctor didn't provide any information and although Maria received treatment for these things, the hospital personnel discouraged her from coming back for this type of care because they said she was on hospice.

Because advanced dementia can last an average of two years, healthcare providers do not always recognize when a person needs hospice care. And a person may need end-of-life support before reaching a more advanced stage of dementia. The lack of hospice services can lead to increased hospitalizations and ineffective care practices as a person nears the end of their life (Bosco et al., 2024).

Questions

1. Why did Maria receive so many medications when she enrolled in hospice?
2. Should hospice differentiate dementia from cancer or other complex medical conditions?
3. Could the doctor and hospice nurse have provided Alma and Maria with more information about medications and services?
4. What ethical issues may have been created in this situation?

Alma feels it would have been helpful if she had been told what to expect. Some kind of a very short, one page outlining the services, medications, and equipment her mother would be receiving from hospice would have helped Alma in her role as a family caregiver (Bosco et al., 2024).

From an ethical perspective, the doctor's initial refusal to order hospice failed to consider the well-being of the caregiver and the client. She failed to act with kindness (beneficence), placing a great deal of additional and unnecessary stress on Alma delayed needed services.

When the hospice nurse arrived with several potentially dangerous and unnecessary medications and failed to explain what they were for, he violated the concept of "beneficence", particularly "do no harm".

8.4.3 Fear of Discharge from Hospice

Background

Alycia is a 98-year-old woman with moderate to severe dementia receiving hospice services at her home in Palm Beach. She has congestive heart failure and arthritis and is experiencing increasing difficulty with her balance. She has fallen several times in the last year and broke her shoulder in a recent fall.

Alycia has a son and daughter who share caregiving responsibilities. Several weeks ago, Alycia got pneumonia and spent 2 weeks in the hospital. She returned home in a very weakened condition and was not expected to live much longer. Her doctor encouraged the family to enroll Alycia in hospice.

Due to the care Alycia received, she began to get stronger and was discharged from hospice after 3 months. This came as a shock to the family because they had come to rely on the services provided by hospice.

Discussion

For her daughter and son, it felt like a Catch-22 situation in which hospice came in and provided excellent care for Alycia. This provided relief and support for the family. Little by little, Alycia got stronger and was discharged from hospice. Her daughter said, "somebody's feeding her, talking with her while she's eating, and she starts to do well and then hospice leaves" (Bosco et al., 2024).

The discharge was abrupt and left the family struggling to understand what to do. "Certainly, I would have wanted a family meeting well in advance of when she was going to be discharged", said her daughter. "I would have wanted hospice to spell out their transition strategy. I happened very quickly, and I thought this should not happen this way."

Questions

1. Could hospice have communicated better with Alycia's family?
2. Would regular care meetings help?
3. Does discharge from hospice mean the caregivers become solely responsible for the care of the person with dementia?
4. What ethical issues do you think were involved?

Alycia's situation points out the difficulties associated with hospice care for older adults living with dementia. As mentioned earlier, a person living with dementia can live for a longer time that someone diagnosed with cancer. Losing hospice services means caregivers are responsible for all caregiving duties once again. Some caregivers report that it feels as if they are "going back to square one".

Alycia's family felt that her mother's discharge from hospice was unjust and unfair. Although Alycia was doing better since her discharge from the hospital, her daughter was convinced that ending hospice care was not in her mother's best interest. The lack of support caused a great deal of additional stress for the family. Within a month, Alycia fell again, broke her hip, and was re-admitted to the hospital. Alycia returned home after several weeks in a rehab facility with hospice services.

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 Agency for Health Care Administration Hospice Services

Florida Medicaid hospice services for palliative care to terminally ill recipients. https://ahca.myflorida.com/medicaid/medicaid-policy-quality-and-operations/medicaid-policy-and-quality/medicaid-policy/medical-and-behavioral-health-coverage-policy/specialized-health-services/hospice-services.

Florida Hospice and Palliative Care Association

Florida Hospice & Palliative Care Association, Inc. (FHPCA) is a not-for-profit, IRS Section 501(c)(3) organization representing Florida's hospice programs. Established in 1982, FHPCA was formed to be a unified voice for hospice programs in Florida. Hospice Helpline: (800) 282-6560 https://www.floridahospices.org/.

Hospice of Florida

Resources for patients and families who want to learn more about hospice, end of life care, as well as offer numerous clinical and government resource. (904) 789-3086 https://www.hospicefl.org/index.php.

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—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.

References

Aldridge MD, Hunt LJ, Harrison KL, McKendrick K, Li L, Morrison RS. (2023). Health Care Costs Associated with Hospice Use for People with Dementia in the US. *Health Aff* (Millwood). 2023 Sep;42(9):1250-1259. Retrieved December 23, 2025 from doi:10.1377/hlthaff.2023.00036.

Alzheimer's.gov. (2026). Tips for Caregivers and Families of People With Dementia. Retrieved March 18, 2026 from https://www.alzheimers.gov/life-with-dementia/tips-caregivers.

Alzheimer's Association. (2025). 2025 Alzheimer's Disease Facts and Figures. Retrieved September 16, 2025 from https://www.alz.org/getmedia/ef8f48f9-ad36-48ea-87f9-b74034635c1e/alzheimers-facts-and-figures.pdf.

Alzheimer's Disease International (**ADI**). (2022). Life after diagnosis: Navigating treatment, care, and support. Retrieved August 15, 2025 from https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf.

American Geriatrics Society (**AGS**). (2023). American Geriatrics Society 2023 updated AGS Beers Criteria® for potentially inappropriate medication use in older adults. *Journal of the American Geriatrics Society*. Retrieved August 15, 2025 from https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.18372.

Anu K N, Radhakrishna VC, Sojan A, et al. (2024). Association between severity of dementia, wandering behavior, and caregiver burden among caregivers of persons living with dementia. *Journal of Geriatric Mental Health* 11(1):p 22-26, Jan–Jun 2024. Retrieved March 19, 2026 from doi:10.4103/jgmh.jgmh_17_23.

Avis KA, Stroebe M, and Schut H. (2021). Stages of Grief Portrayed on the Internet: A Systematic Analysis and Critical Appraisal. *Front. Psychol*. 12:772696. Retrieved March 18, 2026 doi:10.3389/fpsyg.2021.772696.

Baber W, Chang CYM, Yates J, Dening T. (2021). The Experience of Apathy in Dementia: A Qualitative Study. *Int J Environ Res Public Health*. 2021 Mar 23;18(6):3325. Retrieved December 8, 2025 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8005167/.

Barlund AS, André B, Sand K, et al. (2021). A qualitative study of bereaved family caregivers: feeling of security, facilitators and barriers for rural home care and death for persons with advanced cancer. *BMC Palliat Care* 20, 7. Retrieved December 24, 2025 from https://doi.org/10.1186/s12904-020-00705-y.

Bosco A, Di Lorito C, Yang Y, et al. (2024). Caregiver experiences of hospice dementia care: a systematic review and meta-ethnography. *Aging & Mental Health*, 28(2), 197–206. Retrieved December 16, 2025 from https://doi.org/10.1080/13607863.2023.2241027.

Bucko P, Novack MA, Ho EH, Ece B, et al. (2025). Identification and synthesis of end-of-life decision-making measures: a scoping review. *Front. Med*. 12:1540486. Retrieved March 22, 2026 from doi:10.3389/fmed.2025.1540486.

Buuren L, Derks D, Mohammadi M and Colenbrander B. (2025). Wayfinding behavioral patterns of seniors with dementia: two exploratory case studies. *Front. Dement*. 4:1524425. Retrieved March 24, 2026 fom doi:10.3389/frdem.2025.1524425.

Cain P, Chejor P, Porock D. (2023). Chemical restraint as behavioural euthanasia: case studies from the Royal Commission into Aged Care Quality and Safety. *BMC Geriatr*. 2023 Jul 19;23(1):444. Retrieved August 18, 2025 from https://pmc.ncbi.nlm.nih.gov/articles/PMC10357622/.

California Advocates for Nursing Home Reform (**CANHR**). (2025). Restraint-Free Care. Retrieved October 10, 2025 from https://canhr.org/restraint-free-care/.

Center for Medicare and Medicaid Services (**CMS**). (2024). Center for Clinical Standards and Quality/Quality, Safety & Oversight Group. Retrieved March 12, 2026 from https://www.cms.gov/files/document/revised-long-term-care-ltc-surveyor-guidance-significant-revisions-enhance-quality-and-oversight-ltc.pdf.

Chang CYM, Baber W, Dening T, Yates J. (2021). "He Just Doesn't Want to Get Out of the Chair and Do It": The Impact of Apathy in People with Dementia on Their Carers. *Int J Environ Res Public Health*. 2021 Jun 11;18(12):6317. Retrieved December 22, 2025 from doi:10.3390/ijerph18126317.

Chavez-Mendoza LF, Vázquez-Alvarez AO, et al. (2025). Dementia and Sleep Disorders: The Effects of Drug Therapy in a Systematic Review. *International Journal of Molecular Sciences*. 2025; 26(12):5654. Retrieved March 10, 2026 from https://doi.org/10.3390/ijms26125654.

Dementia Friends USA. (2022). Join the Movement! Become a Dementia Friend. Retrieved December 8, 2025 from https://dementiafriendsusa.org/.

Dolphin H, Dyer AH, McHale C, O'Dowd S, Kennelly SP. (2023). An Update on Apathy in Alzheimer's Disease. *Geriatrics (Basel)*. 2023 Jul 14;8(4):75. Retrieved December 8, 2025 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10366907/.

Florida Statutes, The. (2025). Nursing Homes and Related Healthcare Facilities. Residents' Rights. Retrieved December 5, 2025 from https://www.leg.state.fl.us/statutes/index.cfm?App_mode=Display_Statute&Search_String=&URL=0400-0499/0400/Sections/0400.022.html.

Frank J, Huessard K, Broyles I, et al. (2025). Medicare hospice use patterns among patients with Alzheimer's disease or related dementias compared to those with other terminal diagnoses (Issue Brief). U.S. Department of Health and Human Services. Retrieved March 9, 2026 from https://aspe.hhs.gov/sites/default/files/documents/006d9e86b489c019015d7fa708a07024/HospiceAlz.pdf.

Galof K. (2025) Living with dementia in a care home: facilitating participation in activities. *Front. Sports Act*. Living 7:1563025. Retrieved March 12, 2026 doi:10.3389/fspor.2025.1563025.

García-Martín V, de Hoyos-Alonso MC, Delgado-Puebla R, et al. (2023). Burden in caregivers of primary care patients with dementia: influence of neuropsychiatric symptoms according to disease stage (NeDEM project). *BMC Geriatr* 23, 525. Retrieved September 18, 2025 from https://doi.org/10.1186/s12877-023-04234-0.

Giebel C. (2024). A new model to understand the complexity of inequalities in dementia. *Int J Equity Health* 23, 160 (2024). Retrieved March 11, 2026 from https://doi.org/10.1186/s12939-024-02245-w

Goswami R, Dalton H, Khalaf McStay C, et al. (2025). Promoting health equity in palliative care: strategies for hospital and health system leaders. *J Hosp Manag Health Policy* 2025;9:22. Retrieved March 21, 2026 from doi:10.21037/jhmhp-24-125.

GovTrack.us. (2020, latest available). H.R. 3545—100th Congress: Omnibus Budget Reconciliation Act of 1987. Retrieved August 18, 2025 from https://www.govtrack.us/congress/bills/100/hr3545.

Guzzon A, Rebba V, Paccagnella O, et al. (2023). The value of supportive care: A systematic review of cost-effectiveness of non-pharmacological interventions for dementia. *PLoS ONE* 18(5): e0285305. Retrieved March 10, 2026 from https://doi.org/10.1371/journal.pone.0285305.

Healy D, Flynn A, Conlan O, McSharry J, Walsh J. (2022). Older Adults' Experiences and Perceptions of Immersive Virtual Reality: Systematic Review and Thematic Synthesis. *JMIR Serious Games*. 2022;10(4):e35802 Retrieved March 16, 2026 from doi:10.2196/35802.

Hu M, Han S, Ghorbany S, Zhang K. (2024). Healthy Aging in Place with the Aid of Smart Technologies: A Systematic Review. *Encyclopedia*. 2024; 4(4):1918-1932. Retrieved December 17, 2025 from https://doi.org/10.3390/encyclopedia4040125.

Hui D, Cheng S-Y, Paiva CE. (2024). Pharmacologic Management of End-of-Life Delirium: Translating Evidence into Practice. *Cancers*. 2024, 16(11), 2045. Retrieved January 2, 2026 from https://doi.org/10.3390/cancers16112045.

Iacob E, Hollingshaus M, Utz RL, et al. (2025). Caregiving at end-of-life: How do family structure and dementia status impact antidepressant and anxiolytic prescriptions among families? *Alzheimers Dement*. 2025 Jun;21(6):e14590. Retrieved March 22, 2026 from doi:10.1002/alz.14590.

Joseph, J. (2025). Designing for dignity: ethics of AI surveillance in older adult care. *Front. Digit. Health*. Retrieved March 12, 2026 from doi.org/10.3389/fdgth.2025.1643238.

Kokorelias KM, Stall NM, Wasilewski M, et al. (2025). Navigating the dementia caregiving journey: A scoping review protocol of interventions and their responsiveness to caregivers' evolving needs across the illness trajectory. *PLoS One* 20(9):e0333475. Retrieved December 15, 2025 from https://doi.org/10.1371/journal.

Lam L, Fadrique L, Bin Noon G, et al. (2022). Evaluating Challenges and Adoption Factors for Active Assisted Living Smart Environments. *Front. Digit. Health*. Retrieved March 12, 2026 from https://www.frontiersin.org/journals/digital-health/articles/10.3389/fdgth.2022.891634/full.

Laranjeira C, Dixe MA, Martinho R, et al. (2022). Building Bridges for "Palliative Care-in-Place": Development of a mHealth Intervention for Informal Home Care. *Front. Psychol*. 13:862347. Retrieved January 1, 2026 from doi:10.3389/fpsyg.2022.862347.

Lassell RKF, Moreines LT, Luebke MR, et al. (2022). Hospice interventions for persons living with dementia, family members and clinicians: A systematic review. *J Am Geriatr Soc*. 2022 Jul;70(7):2134-2145. Retrieved September 19, 2025 from doi:10.1111/jgs.17802.

Lauridsen S, Schou-Juul F, Folke AP, et al. (2023). Developing the CARE intervention to enhance ethical self-efficacy in dementia care through the use of literary texts. *BMC Med Ethics* 24, 45. Retrieved August 18, 2025 from https://doi.org/10.1186/s12910-023-00926-9.

Li B, Jin H, Yan G, et al. (2024). Mental states in caregivers toward people with Alzheimer's disease at different stages. *Front. Neurol*. 14:1327487. Retrieved March 15, 2026 from doi:10.3389/fneur.2023.1327487.

Lichwala K, Szukalska S, Karczewska M, et al. (2026). Multimodal Management of Aggression in Dementia Among Geriatric Patients: A Comprehensive Overview with Particular Emphasis on Pharmacotherapy and Behavioral Interventions. *Cureus* 18(1): e101807. Retrieved March 19, 2026 from doi:10.7759/cureus.101807.

Lygum VL, Mathiasen N, and Frandsen AK. (2025). The Nature Support Model for Dementia: a conceptual idea for green nursing home environments designed to support well-being throughout the last stages of dementia. *Front. Psychol*. 16:1567619. Retrieved March 9, 2026 from doi:10.3389/fpsyg.2025.1567619.

MedPAC.gov. (2025). Hospices Services: Report to Congress, Chapter 9. Retrieved December 23, 2025 from https://www.medpac.gov/wp-content/uploads/2025/03/Mar25_Ch9_MedPAC_Report_To_Congress_SEC.pdf.

Moran S, Bailey ME, Doody O. (2024). Role and contribution of the nurse in caring for patients with palliative care needs: A scoping review. *PLoS ONE* 19(8): e0307188. Retrieved March 18, 2026 from https://doi.org/10.1371/journal.pone.0307188.

Mukherjee U, Sehar U, Brownell M, Reddy PH. (2024). Sleep deprivation in dementia comorbidities: focus on cardiovascular disease, diabetes, anxiety/depression and thyroid disorders. *Aging*. 2024 Nov 20;16(21):13409-13429. Retrieved March 10, 2026 from doi:10.18632/aging.206157.

Murray J, Thompson J, Hill M, James I. (2025). An ethnographic study to develop a taxonomy of lies for communicating with people with moderate to severe dementia. *Nurs Ethics*. 2025 Feb;32(1):272-287. Retrieved March 20, 2026 from doi:10.1177/09697330241246087.

National Alliance for Care at Home (**NACAH**). (2024). NHPCO Facts and Figures. 2024 Edition. Retrieved December 8, 2025 from https://allianceforcareathome.org/wp-content/uploads/2024/09/Facts-Figures-2024_FINAL.pdf.

Office of the Inspector General (**OIS**). (2022). Long-Term Trends of Psychotropic Drug Use in Nursing Homes. Report in Brief, November 2022. Retrieved August 18, 2025 from https://oig.hhs.gov/oei/reports/OEI-07-20-00500.pdf.

Oh O, Ulrich CM, Massimo L, Demiris G. (2025). Caregiver-reported barriers and facilitators to hospice enrollment for persons with dementia: A systematic review of qualitative evidence. *Palliat Med*. 2025 Oct;39(9):948-964. Retrieved December 8, 2025 from https://pmc.ncbi.nlm.nih.gov/articles/PMC12476476/#section23-02692163251353013.

Pinkert C and Holle B. (2023). Home-based care for people living with dementia at the end of life: the perspective of experts. *BMC Palliative Care*. 2023, 22:123. Retrieved December 29, 2025 from https://doi.org/10.1186/s12904-023-01251-z.

Qi H, Ban J, Wang N, Yao T, Li L, Tang S. (2026). Factors influencing the caregiver burden for family caregivers of people with moderate-to-severe dementia: A structural equation modeling analysis. *PLoS One* 21(2): e0341719. Retrieved March 19, 2026 from https://doi.org/10.1371/journal.pone.0341719.

Rupp L, Seidel K, Penger S, and Haberstroh J. (2023). Reducing Dementia Grief Through Psychosocial Interventions, a Systematic Review. *European Psychologist*. Volume 28, Issue 2, March 2023. Retrieved August 18, 2025 from https://econtent.hogrefe.com/doi/10.1027/1016-9040/a000501.

Saccaro LF, Privé B, D'Imperio A, et al. (2025). Ethical dilemmas in the care of patients suffering from psychotic catatonia: a case report. *Front. Psychiatry* 16:1543563. Retrieved March 19, 2026 from doi:10.3389/fpsyt.2025.1543563.

Sadowska K, Turnwald M, O'Neil T, et al. (2024). Behavioral symptoms and treatment challenges for patients living with dementia: Hospice clinician and caregiver perspectives. *J Am Geriatr Soc*. 2025 Apr;73(4):1094-1104. Retrieved November 6, 2025 from https://pmc.ncbi.nlm.nih.gov/articles/PMC11970226/.

Scerbe A, O'Connell ME, Astell A, et al. (2023). Digital tools for delivery of dementia education for caregivers of persons with dementia: A systematic review and meta-analysis of impact on caregiver distress and depressive symptoms. *PLoS ONE* 18(5): e0283600. Retrieved September 18, 2025 from https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0283600.

Scher CJ, Anderson K, Zagorski W, et al. (2025). "We feel like a family here": person-centered outcomes of adult day services use from the voices of people living with dementia and their caregivers. *BMC Health Serv* Res 25, 1188. Retrieved March 19, 2026 from https://doi.org/10.1186/s12913-025-13436-8.

Schou-Juul F, Ferm LMT, Kinch S, et al. (2024). Ethical self-efficacy among healthcare professionals caring for people with dementia: a brief pre- and post-report on the CARE intervention. *BMC Med Ethics* 25, 109. Retrieved December 5, 2025 from https://doi.org/10.1186/s12910-024-01106-z.

Shubair SA. (2025). Caregiving-related strain among informal caregivers of older adults with dementia: findings from a nationally representative study. *Front. Public Health* 13:1618379. Retrieved March 17, 2026 from doi:10.3389/fpubh.2025.1618379.

Siegelaar A, Mobach MP, Janus S, Zuidema SU. (2025). The Physical Environment and the Quality of Life and Behavior in People with Dementia: A Systematic Meta-Review. *Sage Open Aging*. 2025 Jun 13;11:30495334251345092. Retrieved March 18, 2026 from doi:10.1177/30495334251345092.

Stasolla F, Di Gioia M, Messina I, et al. (2024). Assessing and recovering Alzheimer's disease: a comparative analysis of standard neuropsychological approaches and virtual reality interventions with the use of digital storytelling. *Front Psychol*. Retrieved September 11, 2025 from https://www.frontiersin.org/journals/psychology/articles/10.3389/fpsyg.2024.1406167/full.

Sussman T and Tétrault B. (2022). "People are more afraid of a dementia diagnosis than of death": The challenges of supporting advance care planning for persons with dementia in community settings. *Front. Dement*. 1:1043661. Retrieved December 29, 2025 from doi:10.3389/frdem.2022.1043661.

Tamer E, Hoover DR, McDonald MV, et al. (2025). Feasibility, acceptability, and preliminary efficacy protocol of an intervention for caregivers of hospice patients living with dementia: A pilot randomized control trial. *PLoS One* 20(11): e0332360. Retrieved December 29, 2025 from https://doi.org/10.1371/journal.pone.0332360.

Tao S, Li H, Huang J and Li J. (2025). Research progress on risk prediction models of physical restraint in the elderly: a narrative review. *Front. Aging* 6:1650339. Retrieved March 21, 2026 from doi:10.3389/fragi.2025.1650339.

Tasseron-Dries PEM, Smaling HJA, Nakanishi M, et al. (2023). What are best practices for involving family caregivers in interventions aimed at responsive behaviour stemming from unmet needs of people with dementia in nursing homes: a scoping review. *BMJ Open*. 2023 Dec 7;13(12):e071804. Retrieved October 22, 2025 from doi:10.1136/bmjopen-2023-071804.

Telenius EW, Tangen GG, Eriksen S, et al. (2022). Fun and a meaningful routine: the experience of physical activity in people with dementia. *BMC Geriatr* 22, 500. Retrieved December 5, 2025 from https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-022-03149-6.

Waddington C, Flanagan K, Clements H, et al. (2023). Grief and loss in people living with dementia: a review and metasynthesis of qualitative studies. *Aging & Mental Health*, 28(3), 408–421. Retrieved December 5, 2025 from https://doi.org/10.1080/13607863.2023.2280925.

Wang S, Gu W, Zhang L, Liu W, et al. (2026). Patient-reported outcome measures for anticipatory grief: a systematic review. *Front Psychol*. 2026 Feb 11;17:1709822. Retrieved March 18, 2026 from doi:10.3389/fpsyg.2026.1709822.

Welsch J and Schicktanz S. (2025). Empowerment in structures. Practical-ethical considerations of the preconditions for technology-assisted dementia care in Germany based on an expert-interview study. *Front. Psychiatry* 15:1437967. Retrieved March 19, 2026 from doi:10.3389/fpsyt.2024.1437967.

Wittmann J, Bieber A, Carroll J, et al. (2024) Exploring self-experience practices in dementia care: A scoping review. *PLoS ONE* 19(5): e0302929. Retrieved March 19, 2026 from https://doi.org/10.1371/journal.pone.0302929.

Wiegelmann H, Speller S, Verhaert LM, et al. (2021). Psychosocial interventions to support the mental health of informal caregivers of persons living with dementia: A systematic literature review. *BMC Geriatr* 21(94). Retrieved December 5, 2025 from https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-021-02020-4.

Woo OKL and Lee AM. (2023). A perspective on potential psychological risks and solutions of using virtual reality in palliative care. *Front. Virtual Real*. 4:1256641. Retrieved March 16, 2026 from doi:10.3389/frvir.2023.1256641.

World Health Organization (**WHO**). (2023). Policy brief on integrating rehabilitation into palliative care services. Retrieved December 15, 2025 from https://www.who.int/europe/publications/i/item/WHO-EURO-2023-5825-45590-68173.

Yuan Q, Zhang Y, Samari E, et al. (2023). Positive aspects of caregiving among informal caregivers of persons with dementia in the Asian context: a qualitative study. *BMC Geriatr*. 2023 Jan 27;23(1):51. Retrieved March 15, 2026 from doi:10.1186/s12877-023-03767-8.

Yin G, Sivaramakrishnan D, Macaden L. (2024). Bring dying at home: What facilitates and hinders home-based end-of-life care for people living with dementia? A systematic review and meta-ethnography protocol. *PLoS ONE* 19(12):e0316446. Retrieved December 16, 2025 from https://doi.org/10.1371/journal.

Yous ML, Boamah SA, Hunter PV, et al. (2023). Exploring the factors influencing meaningful engagement of persons living with advanced dementia through the Namaste Care Program: a qualitative descriptive study. *Palliat Care Soc Pract*. 2023 Apr 1;17:26323524231165319. Retrieved March 12, 2026 from https://pmc.ncbi.nlm.nih.gov/articles/PMC10071147/.

[Continue to next page to start quiz]

Quiz: FL ADRD for Hospice (373)

Required to pass: 80%

1. Hospice services are **not** for people living with dementia.

    a. True
    b. False

2. As a person living with dementia nears the end of their life, complications such as immobility, swallowing disorders, and malnutrition can arise.

    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 and memory problems.
    c. Lack of 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. A sign of moderate dementia can include needing more assistance with ADLs.

    a. True
    b. False

9. When assisting a person who has moderate dementia with personal grooming, it is best to:

a. Distract the person while you groom them.
b. Provide appropriate tools, encourage participation, and allow simple choices.
c. Prevent the person from assisting because you can do it faster.
d. Groom them quickly so they don't have time to fight back.

10. Assisting a person living with dementia with bathing is best managed by:

a. Sticking to the bathing schedule regardless of the person's wishes.
b. Switching to bed baths only.
c. Explaining that you're very busy and can't change the schedule.
d. Allowing choices and making sure the person comfortable.

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

a. Reading books and discussing them with other clients.
b. Learning how to knit.
c. Listening to music that was popular when he was young.
d. Doing crossword puzzles.

12. Mr. Edwards has mild dementia, sits in his bedroom all day, and is refusing to participate in any activities. The best way to get him involved is to take away his T.V. until he agrees to participate in the facility's activities.

a. True
b. False

13. Caring for a person living with dementia can cause emotional, financial, and physical stress for caregivers.

a. True
b. False

14. Education, training, support, and respite have been shown to decrease caregiver stress and reduce or delay the transition from home to a care facility.

a. True
b. False

15. Lack of knowledge in one or more aspects of dementia care not only affects the mental health of caregivers, but also their caregiving abilities.

a. True
b. False

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

a. Go on with their lives and ignore changes in their loved one.
b. Quit their jobs and provide 24/7 care.
c. Take over as many tasks as possible for the person living with dementia.
d. Receive early, specialized training about dementia.

17. Strategies to increase family involvement in hospice care include:

a. Encouraging family members to choose and participate in activities.
b. Helping family members learn about the challenges associated with end-of-life care.
c. Emphasizing their role as a partner in care.
d. All of the above.

18. 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.

19. Therapeutic design recognizes:

a. There is a connection between the environment and how we behave.
b. The environment has little impact on people living with dementia.
c. People living with dementia do not understand environmental cues.
d. Unfamiliar, chaotic, or disorganized environments have very little impact on behavior.

20. Person-centered care:

a. Is the same thing as task-centered care.
b. Should only be used when antipsychotics fail to resolve behavioral problems.
c. Can increase unwanted and aggressive behaviors.
d. Has been shown to decrease unwanted, difficult behaviors.

21. To integrate staff into a homelike environment, hire staff with the emotional skills to interact with people who have memory problems.

a. True
b. False

22. 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.

23. An ethical dilemma might arise when:

a. A client refuses 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 for Hospice (373)

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. _____	

[Continue to next page for course evaluation]

Course Evaluation: FL ADRD for Hospice (373)

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 enrolled in hospice. 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 enrolled in hospice with ADLs. 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. List 3 types of stress in caregivers caring for a person living with dementia. 1 2 3 4 5
6. Explain 3 issues family caregivers face as their loved one transitions from mild to moderate to severe dementia to end-of-life. 1 2 3 4 5
7. Identify 3 concepts that are important 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

*As a result of what you have learned, will make any changes in your practice? Yes No

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

*Will you return to ATrain for your ongoing CE needs?

_____Yes, within the next 30 days. _____Yes, during my next renewal cycle.

_____Maybe, not sure. _____No, I only needed this one course.

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

_____Yes, definitely. _____Possibly. _____No, not at this time.

*What is your overall satisfaction with this learning activity? 1 2 3 4 5

*Navigating the ATrain Education website was:

_____Easy. _____Somewhat easy. _____Not at all easy.

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

_____60 minutes (or more) per contact hour _____59 minutes per contact hour

_____40-49 minutes per contact hour _____30-39 minutes per contact hour

_____Less than 30 minutes per contact hour

I heard about ATrain Education from:

_____Government or Department of Health website. _____State board or professional association.

_____Searching the Internet. _____A friend.

_____An advertisement. _____I am a returning customer.

_____My employer. _____Social Media

_____Other _____

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

_____18 to 30 _____31 to 45 _____46+

I completed this course on:

_____My own or a friend's computer. _____A computer at work.

_____A library computer. _____A tablet.

_____A cellphone. _____A paper copy of the course.

Please enter your comments or suggestions here:

[Continue to next page for registration and payment]

Registration: FL ADRD for Hospice (373)

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

*Name: _____

*Email: _____

*Address: _____

*City and State: _____

*Zip: _____

*Country: _____

*Phone: _____

*Professional Credentials/Designations:

_____

*License Number and State: _____

Payment Options

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

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

3 contact hours: $29

Credit card information

*Name: _____

Address (if different from above):

*City and State: _____

*Zip: _____

*Card type: Visa Master Card American Express Discover

*Card number: _____

*CVS#: _____ *Expiration date: _____

If you have a special code from your company, please enter it here: