

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 Assisted Living Facilities (ALF), 3 units (372)

Contact hours: 3

Author: Lauren Robertson, BA, MPT

Price: \$29

Expiration Date: May 19, 2029

Florida DOEA Approval: ALF11394

Certified Trainer: The author is certified as an ADRD trainer by the Florida Department of Elder Affairs and is available via e-mail at Lauren@ATrainCeu.com or by phone Monday-Friday from 9 a.m. to 5 p.m. (Pacific Time) at 707 459 3475. Nursing Home Alzheimer's Disease and Related Disorders (ADRD) Training Provider Approval Number 10275.

Course Objectives

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

1. State 3 reasons why an older adult may choose to live in an assisted living.
2. Identify 5 challenging behavioral and psychological symptoms associated with dementia.
3. Describe 3 best practices when assisting someone with activities of daily living at each stage of dementia.
4. Understand the basis for the design of successful individual and group activity programs for people living with dementia.
5. List 3 types of stress that are common in caregivers caring for a person living with dementia.
6. Recognize the issues and concerns faced by someone caring for a person living with dementia.
7. Identify 3 concepts that are important in the design of a therapeutic environment for those living with dementia.
8. Identify 4 key concepts that are part of an ethical approach to dementia care.

Course Summary

This Florida Department of Elder Affairs approved course is for healthcare workers and providers working in an assisted living facility. The course will increase your awareness and understanding of Alzheimer's disease and related disorders. It discusses symptoms and behaviors that can occur in a person living with dementia and strategies for managing these potentially challenging behaviors. It outlines best practices for assisting someone with activities of daily living and provides suggestions for individual and group activities. It describes how stress can affect a caregiver's life, strategies for managing stress, and recognizing issues and concerns for caregivers. The course concludes with a description and a therapeutic environment, safety and security, and ethical issues faced by caregivers, healthcare workers, and providers working with residents living with dementia.

Target Audience

For healthcare workers, providers, and caregivers employed in an assisted living facility that provides direct care for older adults living with cognitive changes, Alzheimer's disease, and other types of dementia.

Pretest

1. The more you learn about the different types of dementia and how they progress, the more success you will have when caring for someone living with dementia.

- a. True
- b. False

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

- a. True
- b. False

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

- a. True
- b. False

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

- a. True
- b. False

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

- a. True
- b. False

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

- a. True
- b. False

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

- a. True
- b. False

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

- a. True
- b. False

9. 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

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

- a. True
- b. False

Answers: 1-4, 6-10 are true, 5 is false.

1. Introduction

Assisted living facilities (ALFs) are non-medical, non-institutional care facilities also referred to as residential care, "board and care," or congregate living communities. They provide full-time living arrangements in the least restrictive and most home-like setting.

Assisted living facilities usually offer individual apartments or rooms and shared common areas. They have a range of services, including meals, personal care assistance, and help with medications, housekeeping, and laundry. Most offer 24-hour supervision, on-site staff, security and social and recreational activities (NIA, 2023, October 12).

More than 800,000 people in the United States live in assisted living facilities (Pillemer et al., 2024). In Florida, there are nearly 3,000 assisted living facilities, which range in size from a few residents to several hundred. About half of the residents in assisted living are over the age of 85 (USF, 2026).

Although assisted living was originally designed for independent older adults, more and more residents are living with complex medical needs. Nationally, about 40% of assisted living residents live with a diagnosis of dementia (Caffery et al., 2022, December).

Routine personal care services can be provided under a "Standard" license, or more specific services under a "Specialty" license. The purpose of "Specialty Licenses" is to allow individuals to "age in place" in familiar surroundings that can adequately and safely meet their continuing healthcare needs (FLAHCA, 2025).

People move into assisted living because they are no longer able to live independently in a home or apartment. They may need more help than is provided in a retirement home but do not want to live in a skilled nursing facility.

2. Managing Challenging Behaviors

For healthcare providers and family caregivers, "managing" symptoms and behaviors that arise in a person living with dementia requires patience and compassion, and sometimes, the skill of a detective. To successfully manage a challenging behavior, caregivers must try to understand what is causing the behavior. Very often, it is due to some sort of unmet need.

2.1 Symptoms and Behaviors Associated with Each Stage of Dementia

A **symptom** is a change in the body or the mind. Symptoms change as a person's dementia progresses, often leading to changes in a person's behavior. For some people symptoms associated with dementia worsen quickly while for others, symptoms progress more slowly.

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

2.1.1 Mild Dementia

In early, mild Alzheimer's disease, plaques and tangles appear in the part of the brain responsible for memory and learning. This part of the brain is called the hippocampus. It converts recent, short-term memories into long term memories by storing, organizing, and retrieving memories.



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

The inability to recall something that just happened (short-term memory) is a common symptom in the early stage of Alzheimer's disease and other types of dementia. A person can also have difficulty understanding where they are in relation to nearby objects (visual-spatial memory), have trouble finding words (verbal memory), and may not remember certain facts or experiences.

In the early stage, logical thinking, language, and judgment are often mildly affected. For example, a person may forget things more often than they did in the past or have trouble following a complex conversation.

Brain Changes in Mild Dementia



In early AD, sometimes before symptoms can be detected, plaques and tangles begin to form in and around the hippocampus (shaded in blue). Source: The Alzheimer's Association. Used with permission.

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 and may try to hide their mild confusion from friends, coworkers, and family. This can lead to depression, stress, mood changes, and anxiety.

2.1.2 Moderate Dementia

As symptoms associated with dementia 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 at this time.

During this stage, work and social life become more difficult. A person's judgement and logical thinking may be affected. Damage affects the areas of the brain involved with:

- speaking and understanding speech
- safety awareness
- planning and sequencing tasks
- ethical thinking

Because of memory problems and confusion, a person living with moderate dementia may find daily tasks more difficult and will very likely need help with personal finances, medications, and medical management.

In the moderate stage, behavioral changes become more obvious to caregivers. Some people may begin to repeat questions, call out, or repeatedly demand your attention. Sleep problems, anxiety, and agitation can develop.

A person living with moderate dementia is usually still able to walk. This is because the part of the brain that controls movement is not affected. A caregiver may need to provide more direct monitoring of daily activities and the person living with dementia 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 area of 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

Behaviors that emerged in the middle stage, when executive functioning and communication abilities typically decline, continue in the severe stage. In the severe stage, an individual living with dementia may become increasingly nonverbal, and mobility challenges can become more pronounced.

In severe Alzheimer's disease, because so many areas of the brain are affected, the ability to care for oneself is severely affected. Confusion, indecisiveness, sleep disturbances, and emotional outbursts 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. 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 often triggered by unmet needs such as frustration, boredom, loneliness, depression, cold, heat, loud noises, or pain.

A person experiencing severe dementia loses a great deal of independence, and around-the-clock care may eventually 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

As someone nears the end of their life, they may be completely dependent on caregivers. If they are unable to communicate their needs and desires using speech, caregivers must learn to recognize non-verbal cues. A person at this stage may be bedridden or nearly bedridden.

Immobility, swallowing disorders, and malnutrition can occur. 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, the most common cause of death among older adults who have Alzheimer's or another type of dementia, is a particular concern.

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

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

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

2.2 General Problem-Solving Approach to Challenging Behaviors

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

The “ABC” model emphasizes data gathering and problem-solving. This approach helps providers 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.

2.3 Strategies for Addressing Common Challenging Behaviors

Addressing common challenging behaviors in a person living with dementia requires training, strategies, and techniques that change as a person’s symptoms and behaviors change. Because dementia is progressive, strategies that work with mild dementia may not work in the later stages of dementia.

Good management means creating a safe and comfortable physical environment, learning how to divert the person’s focus to a meaningful activity, and encouraging regular physical activity and social engagement. For a person living with dementia, negative environmental influences, frustration, boredom, pain, or untreated medical or medication issues create can lead directly to challenging behaviors.

Although not a comprehensive list, certain behaviors are common in people living with dementia. This includes agitation, aggression, psychosis, wandering, rummaging, hoarding, and sleep disturbances.

2.3.1 Agitation and Aggression

Agitation, aggression, and psychosis are labels on behaviors that are often caused by environmental or personnel approaches rather than being due entirely to the person’s brain changes. These reactions should be viewed as an expressive communication of a possible unmet need.

Teepa Snow, STOP Treating Behaviors with Restraining Medications

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

Agitated behaviors can include:

- Irritability and worry
- Restlessness, unable to settle down
- Pacing
- Repetitive behaviors
- Confusion
- Loud demands
- Obscene language

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

- Hitting, punching, kicking, pushing.
- Throwing objects or using objects to hit or lash out.
- Engaging in inappropriate sexual advances or touching.
- Client-to-client aggression, verbal aggression.



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

In assisted living facilities, resident to resident aggression is not uncommon with verbal aggression being the most common type of aggressive behavior. A study of several assisted living facilities in New York found that aggressive behaviors were more common among residents of memory care units (Pillemer et al., 2024).

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 can become more pronounced as a dementia progresses.

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

When you encounter agitated and aggressive behaviors, take a deep breath, slow your movements, and be respectful of personal space. Always introduce yourself before entering a person's room. When you approach a person who is agitated:

- Speak calmly and actively listen to their complaints or frustrations.
- Reassure the person that they are safe.
- Try to distract the person by offering an activity or chore.
- Try to reduce noise and clutter.
- Consider physical and medical causes of a person's agitation.

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

Charles Lashes Out at Frances

Background: Frances, a physical therapist working in an assisted living facility, was helping Charles go from his room to the activities room. Charles, seated in his wheelchair, was quiet and relaxed as they moved down the hall.

Antecedent: In the hallway outside the activities room, Frances was stopped by two co-workers who engaged her in a conversation about another resident. All three were standing behind Charles, talking animatedly.

Behavior: Frances placed her hand on Charles's shoulder to try to include him in the conversation and he angrily pushed it away, yelling in a loud voice "Stop that!" When one of Frances's co-workers tried to calm him down, Charles yelled again and struck out at the co-worker.

Consequence: Instead of ignoring Charles and talking over him, the physical therapist should have stopped, kneeled down beside Charles, offered her upturned hand, and introduced her colleagues. She should have asked Charles if she could talk for a moment with her co-workers and included him in the conversation. Better yet, she could have asked her colleagues to wait until she and Charles finished what they were doing and continued the conversation after Charles was seated at the activities table.

Discussion: Frances and her co-workers could have avoided this incident entirely. This is a situation that didn't need to agitate Charles. If Frances and her co-workers had been respectful of Charles and validated his needs and preferences, they could have avoided upsetting him and modeled good practice for their co-workers.

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 confuse her daughter with her mother or she might accuse someone of stealing an item has simply been misplaced.

Paranoia is a type of delusion in which a person may believe—without a good reason—that someone is lying to them, being unfair, or are "out to get me." This can cause a person to become suspicious, fearful, or jealous of other people. Paranoia often includes people close to the person living with dementia (caregivers, family members, or friends).

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

Visual hallucinations can occur in the moderate to severe stage of dementia and are particularly common in people with Lewy body dementia*. For a person living with Lewy body dementia, antipsychotic medications can make hallucinations worse.

***Lewy body dementia:** a type of dementia with cognitive decline, “fluctuations” in alertness and attention, visual hallucinations, and slowness of movement, difficulty walking, or rigidity (stiffness).

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 caregivers uncover the root cause of the delusion or hallucination.

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 contribute to delusions and hallucinations. Brain changes can also contribute to hallucinations, especially changes related to sensory awareness.

When communicating with someone who is experiencing paranoia or delusions, remember 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. It is also important to evaluate the person for a visual or hearing impairment.

What Do You Think?

Consider that the claims by the person with dementia may be real. Complaints of strangers entering several resident rooms and stealing items at a Florida assisted living facility were attributed to dementia, hallucinations, and paranoia by healthcare providers (including nurses and physicians). As the complaints mounted, managers decided to install cameras in the alley next to the facility. It turned out that several of the sliding glass doors facing the alley had broken locks. The cameras showed that people were indeed entering rooms at night and rummaging through residents’ drawers and closets. There truly were people entering resident rooms and stealing items!

2.3.3 Wandering

Wandering and exploring are activities we all enjoy. It can occur at any stage of a person’s dementia. 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 is common in people living with almost all types of dementia. Nearly 60% of people living with dementia will wander during the course of their disease. Wandering can happen at home or in the community. In institutional settings, wandering occurs in about 40% of clients (Anu et al., 2024).

Wandering can involve moving to a specific location, lapping, or circling along a path, or pacing back and forth. People may wander out of habit or because they are convinced something needs to be done. They may think they need 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, other residents’ rooms, or eloping* from a facility.

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

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. Additionally, someone who experienced stressful events throughout their life or a person who responds to stress by engaging in physical activities is more likely to wander.

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

Address wandering by:

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

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

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

Did you Know. . .

For people who wander away from their home or care facility, the immediate action is to call 911. Florida maintains a Silver Alert program for cognitively impaired older adults who become lost while driving or walking. The Silver Alert program is activated by law enforcement and broadcasts information to the public so they can assist in the rescue of the endangered person and notify law enforcement with helpful information. For more information, contact the Silver Alert information line, local law enforcement, or the Florida Department of Law Enforcement either online or by phone at 888 356 4774.

The Wanderer

Mrs. Winkler lives in an assisted living facility in Miami. She is also living with moderate dementia and uses a wheelchair to get around. This morning, a caregiver asks if she would like to go to the activities room. Mrs. Winkler agrees, and the care assistant wheels her to the activities room and leaves her there. After about 20 minutes, Mrs. Winkler decides to leave the activities room. She heads down the hall and is stopped several times by staff, all of whom turn her back toward the activities room—usually with a reprimand.

As soon as the staff member is gone, Mrs. Winkler turns around and continues on her way. She stops near the elevator, where she sits for about 10 minutes watching people come and go. Several staff members pass her and sternly tell her not to get on the elevator. Each staff member leaves her in exactly the same place next to the elevator. Finally, when no one is looking Mrs. Winkler wheels into the elevator. The door closes and the elevator takes off for the ground floor.

Antecedent: Mrs. Winkler is a curious person and always liked walking around the city for exercise. She liked exploring the different neighborhoods. She was never one to sit around doing nothing. Mrs. Winkler can propel herself independently in the wheelchair but doesn't always understand the consequences of her decisions. The elevator is interesting and looks like fun. People keep walking by and talking to her although she doesn't remember what they are saying.

Behavior: The door to the elevator is an interesting visual cue and Mrs. Winkler enjoys seeing people coming and going. When a door opens, it is a common reaction to pass through it. The opening door cues Mrs. Winkler to wheel into the elevator. When the door opens on the ground floor, she wheels herself out of the elevator without knowing where it leads. Her behavior is consistent with her personality and her previous habits.

Consequence: Once she gets into the elevator, Mrs. Winkler's inability to think logically puts her at great risk. She exits the elevator next to a door that leads out of the building and wanders into the street. A concerned passerby recognizes that she needs help and takes her back to the assisted living facility.

Discussion: Mrs. Winkler doesn't understand the danger and does not remember the warnings to stay out of the elevator. One solution is to alter the environment. Move Mrs. Winkler to a place where she cannot see or hear the elevator. Try to determine the reason for her wandering. Review her medications to make sure wandering is not the result of a medication side effect, or a drug interaction. Use the following suggestions to keep Mrs. Winkler out of the elevator:

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

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. Memory loss, poor judgment, and confusion contribute to rummaging and hoarding. Rummaging and hoarding are not necessarily dangerous or unsafe, but these behaviors can be frustrating for caregivers.

Rummaging and hoarding are obsessive/compulsive behaviors. A person who feels a strong need to rummage or hoard can be remarkably persistent, secretive, and patient making it difficult for caregivers to address these behaviors. Hoarding is associated with insecurity, fear, anger, and the desire to hold onto possessions and memories from the past. A person who hoards may fear losing money or possessions. They may feel a lack of control or a need to “save for a rainy day”.



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

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. Look for patterns and carefully observe the person’s hiding places. The reason for rummaging and hoarding may not be clear to you but there may be a perfectly good reason why someone living with dementia is rummaging.

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

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

2.3.5 Sleep Disturbances

Many people living with dementia experience sleep disturbances 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).

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

Non-pharmacological treatments that can improve sleep include:

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

2.4. 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).

Florida law specifies that a facility must not use verbal, mental, sexual, or physical abuse, corporal punishment, or involuntary seclusion. A facility must ensure that the resident is free from physical or chemical restraints imposed for purposes of discipline or convenience and that are not required to treat the resident's medical symptoms. When the use of restraints is indicated, the facility must use the least restrictive alternative for the least amount of time and document ongoing re-evaluation of the need for restraints (FL Statutes, 2024).

The use of Posey restraints* is prohibited in assisted living facilities and congregate care settings in Florida. Other physical restraints may be used in accordance with agency rules when ordered by the resident's physician and consented to by the resident or the resident's representative (FL Statutes, 2024).

***Posey restraints:** soft holders attached to wrists or ankles, sleeveless vests with straps attached to the chair or bed, waist and chest belts, padded mitts, and 4 or 5 point extremity restraints.

The use of a restraint must include care planning, staff monitoring, and periodic review by a physician. The use of chemical restraints is limited to prescribed dosages of medications authorized by the resident's physician and must be consistent with the resident's diagnosis. Residents who are receiving medications that can serve as chemical restraints must be evaluated by their physician at least annually to assess (FL Statutes, 2024):

1. The continued need for the medication.
2. The level of the medication in the resident's blood.
3. The need for adjustments in the prescription.

For a given client at a particular point in time, the assessment is used to determine whether the use of less restrictive measures poses a greater risk than the risk of using a restraint (FL Statutes, 2024).

The comprehensive assessment should identify medical problems that may be causing behavior changes. For example, temperature elevations, hypoxia (low levels of oxygen), hypoglycemia (low blood sugar), electrolyte imbalances, drug interactions, and drug side effects may cause confusion, agitation, and combative behaviors. Addressing these medical issues may eliminate or minimize the need for the use of restraints or seclusion (FL Statutes, 2024).

2.4.1 Physical Restraints

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

Physical restraints can include:

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

Use of physical restraints can cause agitation, confusion, deconditioning, pressure ulcers, strangulation, and even death. Restraints affect a person's sense of well-being, causing feelings of low self-worth, depression, withdrawal, humiliation, and anger.

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

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

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

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

Restraints should **not** be considered a routine part of a falls-prevention program. There is no evidence that the use of physical restraint, (including, but not limited to, raised side rails) will prevent or reduce falls. Additionally, falls that occur while a person is physically restrained often result in more severe injuries. In fact, in some instances reducing the use of physical restraints actually decreases the risk of falling (CMS.gov, 2024).

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 enhance safety and comfort for all residents, 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 ability to move about 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, prevents mad dashes to the bathroom that increase the risk of falls. Regular exercise, a comfortable place to rest, and a schedule for napping can also help. On a regular basis:

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

An uncluttered environment can reduce the need for physical restraints. Hallways, common areas, and resident rooms 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.

Wheeled walkers with a wide base, easy-to-use brakes, and built in seats provide a safe place to rest. If a person uses a wheelchair to get around, most chairs can be lowered to a person can easily propel the chair with their feet. Wheelchair seating systems provide pressure reduction and postural support.



A seated walker with large wheels and a wide base. Source: Author.

Restraint-reduction programs can greatly reduce the use of physical restraints. As with managing challenging behaviors, the best ideas are those that are shared among staff and family.

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

Older adults living in an assisted living facility may need less assistance with ADLs than people in other longterm care settings. Nevertheless, nearly two-thirds of ALF residents require assistance with 3 or more activities of daily living (Pillemer et al., 2024).

Basic and Instrumental ADLs

Basics ADLs (skills needed to take care of personal needs)

Eating, bathing, 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 anyone with their activities of daily living, encourage them to express their wishes. If someone refuses your help, try to understand why. Are they scared? Do they misunderstand what you asked them to do? Are they embarrassed? Are they cold or in pain?

If the person seems confused, repeat your request, using the same words or slightly rephrasing the question. Rephrasing the request can support understanding and reduce frustration. Offer simple choices, such as “Would you like to shower now or after you eat?” Be calm and empathetic. Examples of empathetic responses include “You must be cold” or “Are you uncomfortable in that chair?” “What would help now?”

Best practices include:

- Make eye contact (where culturally appropriate).
- Be aware of your body language and vocal tone.
- Slow the speed of your movements and speech.
- Approach from the front.

3.2 ADL Strategies: Mild Dementia

A person living with mild dementia may need very little help, if any, with basic activities of daily living. They can get dressed, bathe, do chores 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.

In the early stage, mood changes, such as depression and anxiety can affect ADLs. 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 the resident to direct the activity.

Grooming

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

Eating

When dementia is mild, a caregiver may only need to supervise during meals and snacks. If there are no underlying medical issues, a person living with mild dementia may still be able to help with shopping, cooking, and dishwashing. In the mild stage, a person may still be able to prepare their own meals. Caregivers can supervise and provide help at a distance. Mild memory problems can lead to safety issues, such as forgetting to turn off the stove or leaving water running.

Placing food on a colored plate (for food contrast) and altering the meal schedule to suit the needs of the person living with dementia are recommended practices.

- Ask for food preferences.
- Ask for help with meal preparation and meal set-up.
- Provide adaptive utensils if needed.
- Provide help as needed.
- Provide comfortable seating and support for the feet.
- Make sure food is tasty, warm, and attractive.

Bathing

A person living with mild dementia may not need help with bathing. At this stage, the responsibility of the caregiver is to assist as needed and encourage independence. This is best accomplished by making sure the bathing area is safe, warm, and comfortable. Grab bars and non-skid mats should be available. Bathing supplies should be within reach and the water pre-heated to the proper temperature.

Although it's important to be flexible, try to set a regular time for bathing. Be gentle with fragile skin (avoid scrubbing). Practice these techniques (Alzheimer's Association, 2026a):

- Simplify the bathing process.
- Cue the person through each step, if needed.
- Use a bench or shower chair for comfort and safety.
- Assist with cleansing hard-to-reach areas, if needed.
- Offer a sponge bath in between baths or as an alternative to 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*

A person living with mild dementia may be reluctant to ask for help. They will likely be able to get to the bathroom without assistance but might have trouble managing their clothing. The Alzheimer's Society has partnered with The Able Label, an English company that offers stylish clothing for men and women designed to make dressing and "assisted dressing" easier. Clothing that is easier to manage along with assistive devices such as grab bars and safety poles improve safety and support independence.

A person living with mild dementia may try to address incontinence by cutting back on liquids to decrease the frequency of urination. This can lead to constipation and urinary tract infections, creating a difficult and vicious cycle of dehydration, infection, and incontinence. If balance is an issue, encourage men to sit to urinate rather than stand.

- 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.

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

Dressing

- Provide comfortable clothes with elastic waistbands and Velcro closures.
- Encourage participation in the choice of clothing but limit choices.
- Assist closely but encourage independence.
- Lay out cloths in order.
- Provide more than one choice of favorite outfits.
- Provide adaptive equipment such as grab bars as needed.
- Provide step-by-step cues.
- Demonstrate the task.
- Provide guided touch as support to initiate the task.

Grooming

For mouth care and other grooming tasks, provide a safe and comfortable place for these tasks, assist as needed, and offer clear instructions. For men, especially in the moderate to severe stage of dementia, an electric razor provides a safe way to shave. For both men and women, regular visits to the beauty parlor or barber shop provides social interaction and reduces caregiver burden.

- 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

As a person's dementia progresses to the moderate stage, the need for caregiver assistance increases. Swallowing difficulties may arise in the moderate stage, increasing the risk of aspiration* and choking. Preparing softer foods, cutting food into smaller pieces, and avoiding food that is hard to chew or swallow can help address this issue.

***Aspiration:** inhaling food or liquid into the lungs.

If signs of dysphagia (swallowing difficulties) are present, a speech-language pathology evaluation needs to be ordered. Any recommendations for softer food textures and thickened liquids should be guided by a speech-language pathologist, as these modifications are based on clinical assessment rather than general practice.

- Ask for food preferences.
- Set up the meal before serving.
- Open packages and uncover trays.
- Provide adaptive tableware as needed (see picture at the end of this section).
- Sit to the side while helping (sitting in front may be intimidating).
- 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.
- 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

In the moderate stage, additional safety equipment will likely be needed. This might include a shower chair, replacement of a shower door with a curtain, and a long shower hose. Depending upon a person's physical capabilities, tub bathing may no longer be safe.

Although it's important to be flexible, try to set a regular time for bathing. Be gentle with fragile skin (avoid scrubbing). Practice these techniques (Alzheimer's Association, 2026a):

- Simplify the bathing process.
- Cue the person through each step, if needed.
- Use a bench or shower chair for comfort and safety.
- Assist with cleansing hard-to-reach areas, if needed.
- Offer a sponge bath in between baths or as an alternative to bathing.
- Provide set-up assistance.
- Provide guided touch to support or help initiate a task.
- 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 (see picture at the end of this section).

Toileting and Incontinence

A person living with moderate dementia may have decreased mobility, have difficulty getting to the bathroom, and may be unable to undo clothing once in the bathroom. Men may experience problems directing their penis—especially if balance is compromised and there is nothing to hold onto. If this is the case, encourage men to sit on the toilet to urinate. Grab bars or transfer poles allow more independence with toileting.

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



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



Right: A shower chair with rail and back. Source: Author.

3.4 ADL Strategies: Severe Dementia

My mom has pretty severe dementia and needs lots of help with everything. I start getting her ready at least an hour-and-a-half ahead of appointments. When she's dressed and bathed and I think we're ready to go, she insists on brushing her teeth. Because we were already late, I tried to get her to go without brushing her teeth. Big mistake! She grabbed the door leading from the kitchen to the living room, sat down on the floor, and refused to move. She actually leaned back and put both of her feet and hands on the door opening and wedged herself in. After she brushed her teeth and was safely in the car, she yelled at me to hurry up because she said we were going to be late!

Family Caregiver, Cottondale, Florida

In the *severe stage*, a great deal of independence is lost, and around-the-clock supervision is often needed. Caregivers must 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.

To prevent this from happening, food choices need to be modified by softening the texture of food and adding a thickening agent to liquids. Tucking the chin, massaging the throat, rotating the head, sitting in a supported, upright position, and taking smaller bites of food when swallowing can also help. These practices should only be implemented under the guidance of a licensed speech-language pathologist. Avoid the use of sedatives and narcotics, which can affect swallowing.

A person with severe dementia may still be able to walk with assistance. But anything that requires planning, sequencing, or judgment is severely impaired. Close assistance will be needed for dressing, meal preparation, and grooming. Control of bodily functions can be inconsistent, requiring direct help with bathing and toileting. If mobility is compromised, close assistance will be needed for all ADLs.

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

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.

Dressing

- Limit choices, select clothes and set them out.
- Choose comfortable clothing that is easy to wash.
- Use simple, one-step commands and gestures.
- Encourage as much independence as possible.
- Provide assistive equipment such as transfer bars and grab bars.
- Provide as much assistance as needed but encourage independence.

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

In the severe stage, managing oral nutrition supplements, modifying food, and considering dysphagia (swallowing difficulties) can become a daily concern for caregivers. Proper ergonomic seating and simple swallowing techniques can be taught at this stage by a speech-language pathologist to reduce the risk of aspiration (food accidentally going into the lungs). Nevertheless, caregivers should continue to encourage independence and choice in food and drink.

Assistance, encouragement, and social support encourage eating and drinking. A person living with severe dementia may still be able to help with some parts of meal preparation—even if they only beat an egg, peel an orange, or pour juice into a cup. Remember that spilled food can always be cleaned up.

Behavioral issues can arise at this stage—refusals to eat and drink, complaints about food taste and quality, throwing food, shouting, knocking over glasses, and refusal to come to the table. Many of these things can be avoided—especially in the home setting—by adjusting to, listening to, and addressing a person's changing needs.

Assistive or adaptive tableware can be used to make meals more pleasant. Attractive assistive tableware can be used by people of all abilities, and at all stages of dementia. Color contrast helps as a visual cue—for example royal blue plates provide a contrast with a white table covering and food on a plate. A plate with a high lip and slanted bottom helps a person push the food onto the spoon and scoop it up.



The slanted bottom and lip of the plate can help users to gather food on one side without scooping. Spoon heads are designed to match the curvature of the bowls to pick up the food more easily. (Designed by Sha Yao, Eatwellset.com. Used with permission.)

The same approach can be used with cups. In the example below, a royal blue bottom and a white cover help a person with low vision or agnosia* locate the cup handle and rim. The sides of the cup are angled to reduce spillage, a large handle assures a good grip, and a wide top allows a person's nose to fit inside the cup when tipped.

***Agnosia:** a sensory disorder in which a person is unable to recognize an object by sight, touch, or hearing.



A cup with a weighted bottom is shown on the left. A cup with an easy-to-grip handle is shown on the right. (Designed by Sha Yao, Eatwell.com. Used with permission.)

Because dementia is a progressive disease, a person will gradually lose the desire to eat. This can be extremely distressing for caregivers even though it is a normal part of the disease progress. Caregivers who have worked hard to keep a person eating and drinking may struggle as it becomes harder and harder to convince the person they are caring for to eat and drink. This will be accompanied by weight loss—sometimes severe.

- 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

In the severe stage, direct help is likely needed with bathing. Shower chairs, grab bars, transfer poles, and even modifications allowing a rolling shower chair may be needed. Caregivers should expect to get wet at this stage as they assist with bathing. Continue to encourage as much independence as is safe and possible.

General considerations for 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.
- 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.
- Consider bathing habits (time of day, bath or shower).
- Consider bed bath if more acceptable to client.
- Provide guided touch to support or to help initiate a task.

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

There are times when a person may need to be bathed in bed. This is not uncommon at, or near, the end of life. Bed bathing is not as effective as showering and should only be used when there is no alternative. Cleanliness promotes skin health and supports dignity. Even at this stage, caregivers should encourage participation and consider a person's preferences for bathing.

General principles for bed bathing:

- Keep the person warm.
- Expose only the area being washed.
- Change water when dirty and after washing genital areas.
- Pat skin dry rather than rubbing.
- Talk to the person (even someone who is unconscious).

Toileting and Incontinence*

As dementia becomes more severe—and physical, sensory, and cognitive skills continue to decline—toileting becomes more difficult. A person living with severe dementia may do some things that are extremely frustrating to a caregiver. They may hide soiled underwear, hand feces to the caregiver, or wipe feces off their hands onto clothing or furniture. A person may resist help, fail to remove clothes before voiding, or void in inappropriate places.

A person living with severe dementia may or may not be able to walk without assistance but, due to sensory changes and decreased vision, may have difficulty locating or recognizing the bathroom. This probably won't stop them from trying, increasing the risk of falls. Caregivers can find this stage extremely frustrating and stressful—partly because more physical help and direct oversight are needed, and partly because more time is spent cleaning up accidents.

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

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

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

People in the last stage of dementia have the highest need for assistance from staff and caregivers and are often completely dependent on help. At the same time, they need a quiet environment. These clients tend to become overwhelmed by sensory impressions and can have a hard time interacting with other people due to intellectual and emotional impairment (Lygum et al., 2025).

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.

4. Activities for Clients with Alzheimer's

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

Telenius et al., 2022

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

We like helping one another, teaching someone a new skill, and contributing to the success of an activity. Caregivers often make the mistake of doing everything for the person they are caring for, stripping them of any meaningful way to contribute, to help, to learn, and to grow as a person.

4.1 Individual Activities

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

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



Left: A man using an upper extremity bike to exercise. Source: CDC. Right: A man enjoying a familiar activity. Southeastern Veterans Center by padmva is licensed under CC BY-NC-ND 2.0.

Some organizations that serve older adults, such as the *Eden Alternative*, encourage pets in their facilities. Pets provide companionship, promote relationships, and provide meaningful activity and exercise. Taking care of an animal gives a sense of purpose and companionship and is a key component of person-centered care. Celebrating the holidays is both an individual and group activity, which is interesting and stimulating.



Left: Pet therapy at an assisted living facility. Source: CDC **Right:** The author's mother celebrating Halloween. Source: Author.

Some people may refuse to participate in activities. Be on the lookout for signs of frustration and agitation and address these behaviors immediately.

Individual Activities at Different Stages of Dementia

Activity	Mild	Moderate	Severe
Word games	Word searches, crossword puzzles Card/computer games	Simple word searches, simple crossword puzzles Simple computer games	Discuss a simple topic Listen to others
Letter writing	Write a letter Send email, use Facebook, social media	Dictate a letter or email Use Facebook with help	Listen to a letter or email being read
Art/Music	Take photos Create a photo album Draw, play an instrument	Take photos Maintain a photo album Draw, sing along with others	View photos Listen to music Sing along to familiar songs
Woodworking	Use tools Plan and complete projects with assistance	Use simple tools with supervision Assist with projects	Use activity board with bolts, screws Watch projects
Sewing	Use sewing machine with help Plan and complete projects with help	Use simple tools with supervision Assist with projects	Use sewing cards, activity blankets or aprons with buttons, snaps, ties, Velcro, and zippers, watch projects
Gardening	Garden in raised beds Help plan the garden and harvest	Perform specific tasks with supervision Eat food grown in garden	Sit in garden, eat food grown in garden Participate as able

Activity	Mild	Moderate	Severe
Crafts	Knitting or crochet using large needles	Choose colors, roll balls of yarn	Choose colors, use the items that are created
At home activities	Help with laundry, put clothes away, assist with housekeeping	Sort and fold laundry	Fold laundry—may want to fold the same items repeatedly
Shopping	Go along to store, help with purchasing decisions Help put groceries away	Go along to store, help as able with shopping decisions Help put food away	Go along to store, sit in car with supervision or shop with wheelchair or electric cart
Pet Therapy	Go for a walk with the pet. Help groom or feed the pet.	Go along with a person taking the pet for a walk. Help groom the pet.	Hold the pet. Watch the pet play.



The author's mother helping with gardening in her front yard. Gardening is an activity she enjoyed throughout her life. Source: Author.

4.2 Group Activities

Cognitive impairment isolates us from other people, causing anxiety, depression, withdrawal, and decreased self-confidence. Meaningful group activities help all of us maintain a sense of self-worth.

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

Group Activities at different Stages of Dementia

Activity	Mild	Moderate	Severe
Karaoke	Sing while reading words	Sing familiar songs	Listen and sing along
Cooking	Bake cookies, prepare a snack plate for others, clean up after cooking	Participate in making cookies, assist with cleaning up	Help decorate cookies that are already baked, eat the cookies
Nature	Nature walks, outings to nature areas, fruit picking	Shorter walks Picnicking outdoors	Escorted walk or wheelchair outside the facility, attend picnic
Crafts	Make ornaments Decorate room or facility for holidays	Participate in making ornaments Assist with decorating for the holidays	Participate in crafts Participate in decorating parties
Outings	Shopping, eat out Theater and music events, museum visits, library visits, attend sporting events	Same as mild with some adaptation and more supervision.	Set up a store where the resident can purchase items Watch movies, outings with direct supervision

Group exercise programs such as walking, resistance training, and seated exercises that focus on improving aerobic endurance, strength, balance, and flexibility are beneficial.

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 nonjudgmental awareness to the body in the present moment).
6. Social interaction (participants sit in a circle, and many movements involve reaching across the circle to touch hands or elbows or standing in a circle holding hands and moving together to facilitate social connection).
7. Positive emotions (participants are encouraged to move in ways that feel good, personally meaningful music is incorporated, and all classes end with sharing of appreciations and things that bring joy).

4.3 Virtual Reality

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

Virtual reality offers a multisensory experience that can be attractive for people living with dementia because it stimulates multiple senses. VR may be helpful in improving memory, improving dual tasking*, and visual attention. For some people living with dementia, it can reduce anxiety, improve feelings of well-being, and increase 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

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

Caring for a person living with dementia is a huge commitment and places emotional, financial, and physical strain on family caregivers. As a person's dementia progresses, caregiving can become a fulltime, unpaid job. Good care can break down quickly if caregivers fail to get enough sleep, do not take care of their own medical needs, or do not access support and training.

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).

Caregivers of people living with dementia provide care for a longer time, on average, than caregivers of older adults with other conditions. They are more likely than caregivers of people without dementia to provide help with self-care and mobility and health or medical care. Yet half of caregivers of people living with dementia indicate they have no experience performing these tasks (Alz.org, 2025).

For professional caregivers, managing the stress associated with caring for a person living with dementia can be emotionally exhausting. Aggression (experienced or observed), repeated questions, agitation, high care needs, deaths, and the affects of illness and disease are events that activate stress in professional caregivers. Unpleasant interactions and poor treatment from residents, their families, co-workers, and supervisors are also factors that cause professional caregivers' stress (Antipas et al., 2025).

Professional caregivers have individual risk factors that may predispose them to experiencing occupational stress. For example, caregivers who speak English as a second language (when working in English-speaking facilities), have a higher level of job-related education, identify as male, and are of a younger age may experience more occupational stress. Caregivers with less than one year of experience or with limited social relationships outside of work may also be at higher risk of experiencing occupational stress (Antipas et al., 2025).

For professional caregivers, training in assessment and non-pharmacological strategies to reduce challenging behaviors in people living with dementia has a positive effect on a professional caregiver's self-efficacy, sense of personal accomplishment, and can positively influence a professional caregiver's feelings of stress (Antipas 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 much more stressful. There were more medical appointments with a very disinterested and unhelpful doctor. I ignored my own needs (I didn't get a haircut for over a year!) because there was no one to watch her while I was gone.

Family Caregiver, West Palm Beach, FL

5.1.1 Emotional Stress

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

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

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

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).

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).

5.1.2 Financial Stress

For family caregivers, the economic impact of caregiving is a stressor. A study 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, a contribution valued at nearly \$413 billion (Alzheimer's Association, 2025).

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

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

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

- Costs to caregiver physical and mental health.
- Lost income (for both the family members and the person living with dementia).
- Impulsive spending or poor spending decisions (by the person living with dementia).
- Depletion of savings.

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

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

5.1.3 Physical Stress

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

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

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

Factors and Characteristics Associated with Caregiver Stress

Factors	Characteristics associated with caregiver stress
Demography	Female caregiver Spousal caregivers, particularly those of younger people living with dementia Living with the care recipient, low incomes, or financial strain
Caregiver personality	Highly emotional or neurotic caregivers
Perception and experience of caregiving role	A lack of confidence by the caregiver in their role Caregivers feeling trapped in their role
Coping strategies	Emotion-based or confrontive coping strategies Type and severity of dementia Behavioral issues (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.

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

5.3 Strategies for Reducing Caregiver Stress

Reducing caregiver stress is possible when education, training, support, and respite are available. These four components can 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. This means getting enough sleep, eating properly, seeing their own healthcare providers, and sharing their feelings about their caregiving duties with co-workers, family, and friends. Providing caregivers with emotional, social, psychological, and technological support reduces their stress and supports them in their role as caregivers.

Interventions that are effective in supporting family caregivers include (Alz.org, 2025):

- Actively involving family caregivers in the intervention.
- Tailoring the intervention to meet the changing needs of family caregivers during the course of a relative's dementia.
- Meeting the needs of both caregivers and the person living with dementia.

Addressing Caregiver Stress

Reducing Caregiver Stress	Things to Avoid
• 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. • Use daycare services and respite care services.	• Isolating yourself. • Trying to be all things to all people. • Expecting to have all the answers. • Denying your own fears about dementia and aging.



5.3.1 Respite Care

Respite services support caregivers by providing time away, a chance to relax and recharge, and time for errands and other tasks. These services may be available in a person's home, an adult daycare center, in the community, or in longterm care communities.



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

Respite is one of the most needed and desired services for caregivers and is a good way to maintain and enhance caregiver wellbeing over time. When scheduled regularly and in sufficient doses, respite gives caregivers a temporary break to tend to their own health, maintain social and family relationships, and pursue aspects of their daily lives that they may have neglected as a result of the caregiving demands (Utz et al., 2023).

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).

Greater satisfaction was associated with more emotional support from family members and friends (Alzheimer's Association, 2025). There can also be an increase in family cohesion and functionality with a sense of personal growth and purpose in life (Wiegelmann et al., 2021).

Although caregivers report positive feelings about caregiving, such as family togetherness and the satisfaction of helping others, they also frequently report higher levels of burden and stress; depression or other adverse mental health outcomes; strain; and problems with navigating care transitions when compared with other caregivers or non-caregivers (Alz.org, 2025).

5.3.3 Caregiver Bill of Rights

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

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

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

6. Developing Skills for Working with Families and Caregivers

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

Alzheimer’s Disease International

Healthcare providers working with family members and caregivers caring for a person living with dementia must first understand their needs. Healthcare providers must learn about dementia and learn to communicate with sometimes-resistant family members and often-untrained paid caregivers. Differences in education, training, and cultural backgrounds can compound these difficulties.

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.



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

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.

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 a person 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).

Moving from home to assisted living can be extremely stressful. The person living with dementia and their caregivers are at higher risk for poor outcomes related to these care transitions* than people without dementia. Despite the need for flexible, tailored, and equitable services, care systems are often fragmented and difficult to navigate (Bigger et al., 2024).

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

6.1.1 Issues and Concerns in the Early Stage

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

Family caregivers may struggle with accepting a dementia diagnosis and may be troubled by changes they are seeing in their family member. They may have concerns about the future and how they will provide care as a family member's dementia progresses.

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

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

6.1.2 Issues and Concerns in the Middle Stages

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

Caregiving demands increase as their family member's dementia progresses to the middle stage. Behavioral and psychological problems can arise, requiring 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 increase caregiver anxiety, depression, stress, and burnout. The responsibility of caregiving often falls mostly on one person, which can lead to anger and frustration with other family members.

Listening carefully to a caregiver's concerns, encouraging participation in decision-making, and recommending a support group (even online) can help caregivers feel competent and valued.

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 in an assisted living facility may no longer be an option. One of the most difficult issues—usually in the middle to late stages of dementia—is the decision to transfer a family member to a facility with a higher level of care. 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 and longterm care options. Counseling and support groups allow caregivers to discuss any guilt they may be feeling and learn from other caregivers about how to navigate the medical system.

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

6.1.4 End of Life Issues and Concerns

The demands of caregiving intensify as the person living with dementia approaches the end of life. In the year before the person's death, more than half of caregivers feel they were "on duty" 24 hours a day, and many report caregiving during this time is extremely stressful. Many family caregivers report they experienced relief when the person with Alzheimer's disease or another type of dementia died (Alz.org, 2025).

If a family member moves to a facility with a higher level of care, healthcare providers can support family members by determining the preferences, abilities, and resources of each family member. Regular face-to-face meetings with staff will help families work through any conflicts that may arise.

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).

6.2 Strategies for Encouraging Family Involvement

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

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).

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).

Involving family members means:

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

6.2.1 Dementia Care Programs

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

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

- Keeping family members informed about changes in their loved one's condition.
- Documenting resident activities to share with the family.
- Encouraging residents to call and write to family members and friends.
- Using technology to keep families in touch with one another.

6.2.2 Caregiver Training and Support

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

Caregiver training and support programs provide:

- Help with challenging behaviors, especially at the end of life.
- Help for caregivers dealing with swallowing issues and loss of appetite.
- Education about the dying process.
- Information about changing personal care needs.

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

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

6.2.3 Barriers to Family Involvement

The system of informal, unpaid family care is under intense pressure due to declining fertility rates and fewer young people willing to care for older adults. Most family caregivers are women, and many are caring for children, working, and managing a household at the same time they are caring for a family member. In this situation, many caregivers cut back on work, which affects their finances. Hiring a caregiver is costly and may not significantly reduce the strain on family members.

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).

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

- Caregivers are not seen as partners in care.
- Regular contact between family and staff is lacking.
- Family caregivers do not feel welcome.

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 living with dementia. I only offered platitudes such as "make sure you walk with your wife every day"—this when the husband was slumped at the kitchen table—clearly overwhelmed and severely depressed. I just didn't see it. Now I do.

Home Health Physical Therapist, Tampa, Florida

A diagnosis of dementia can cause a great deal of grief for the person receiving the diagnosis, as well as family and friends. There is concern related to uncertainty about the progression of the disease and anticipated loss of independence.

The stage, age of onset, degree of insight, communication abilities, and type of dementia impact feelings of grief. A person's history, personality, coping style, gender, relationships, personal resources, and support networks are also important to consider (Waddington et al., 2023). Grief is a response to any loss that is significant to an individual and is a process that unfolds in a non-linear manner.

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

6.3.1 Dimensions of Grief

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

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

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

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

6.3.2 Anticipatory Grief

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

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

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

6.3.3 Physical and Psychological Symptoms of Grief

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

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

6.3.4 Grief in Caregivers

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

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

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

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

6.3.5 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 has been studied in people living with dementia, relating to the death of family members, friends, and other members of a care facility. Opinions differ on whether 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 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, which is the philosophy of care encouraged for individuals living with dementia.

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.

There are many health benefits associated with dementia-friendly design including:

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

Additional elements of a therapeutic environment include providing:

- Common areas such as a music room, crafts room, and garden areas.
- Links to the community.
- Areas that encourage activities and socialization.

Emphasizing the experience of living with dementia rather than focusing on symptoms and impairments enables the creation of environments that allow people living with dementia to actively participate in everyday life rather than just passively receiving care (Gramegna, 2021).

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).

The overall architecture of a care home can provide residents with a sense of freedom and mobility. For example, unique bedroom door designs with a range features, such as door knockers or letterboxes, can help residents with wayfinding and visual recognition. The building structure and floor plan can support a resident's orientation, and windows can provide views of the outdoor environment. When there are children or animals outside the window, these views can provide a sense of freedom and contribute to the quality of life of residents (Sturge et al., 2024).

Thoughtful design can reduce challenging behaviors by having clear, uncluttered pathways, place markers, safe outdoor spaces, ample lighting, and interesting destinations. A well-designed physical environment can serve as an important "non-pharmacological treatment modality" helping people compensate for sensory and cognitive changes (Gramegna, 2021).

For people living with dementia, **indoor** design should include:

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

Dementia-friendly outdoor design should allow a person to connect with nature. 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 provide 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 (Siegelhaar et al., 2025).

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

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

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

An organization's philosophy should support a resident's rights. People living with dementia have the right to have their own clothes and other personal items. They must have unrestricted private communication, be able to send and receive unopened correspondence, and have access to a telephone. If both spouses are residents, they have the right to share a room.

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

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

7.3 Safety and Security

Changes to the physical environment intended to increase security may decrease a resident's autonomy and attempts to enhance autonomy can lead to decreased security. Providing autonomy without compromising security is a considerable challenge in the care of older adults, particularly for residents who are living with dementia (Sandberg et al., 2021).

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).

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

7.3.2 Elements of a Secure Environment

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

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

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

To prevent wandering into unauthorized or unsafe areas a physical barrier (such as yellow tape or a stop sign) can be used.

Measures to Promote Resident 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. Reduce clutter. 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 facility. 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.



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

7.3.3 Technology Related to Safety

The use of technology and electronic devices can reduce risk and increase independence. Safety technologies include GPS trackers to monitor wandering, smart home devices (sensors and automated lighting), medication reminders, and wearable devices for fall detection and emergency calls.

Smart plugs allow caregivers to remotely monitor and control electrical appliances, such as stoves, irons, heating, and cooling. Smart safety sensors can detect smoke, carbon monoxide, flood, and fire and send early warnings and alerts to a caregiver's phone. Indoor cameras allow caregivers to remotely check on their loved one and communicate with them via two-way audio. These tools can provide peace of mind for caregivers while supporting the independence of the person living with dementia.

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 often 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 the person living with dementia at the center of care and planning. When done right, task-centered care recedes into the background, replaced by care that focuses on the needs and well-being of residents.

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).

Person-centered dementia care is built on the understanding that a sense of belonging and opportunity for meaningful engagement are critical to the success of all human communities. Key principles for successfully implementing person-centered dementia care in assisted living facilities include (Gramegna, 2021):

- Understanding the environment of the specific care setting for residents living with dementia.
- Creating a clear understanding of people living with dementia as unique individuals.
- Promoting access to meaningful engagement tailored to suit that person.

7.5 Staff as Part of the Environment

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

Consistent staffing, good pay, career advancement opportunities, and education can 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 residents and caregivers encourage cooperation and participation.

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 living with dementia adequately and effectively (Wittmann et al., 2024).

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

- Hire staff with the emotional skill, training, and desire to interact with people with memory problems.
- Increase pay, training, and opportunities to advance.
- Eliminate institutional, centralized nursing stations.
- Locate nursing and work areas throughout the building.
- Allow staff to control lighting and environmental levels.
- Keep staff consistent.

Being part of a resident’s environment means being aware of the person’s routines and habits. It means respecting their needs, understanding the impact of cognitive and sensory changes (vision, hearing), and respecting cultural and language differences.

7.6 Staff Adjusting to Resident Routines

Forget dementia, remember the person!

Alzheimer’s Disease International

When an assisted living facility is organized around a dementia-friendly care, resident routines are a priority. This means the medical aspects of care are deemphasized. Residents, staff, and family caregivers work as a unit and daily tasks, such as cooking and cleaning, are shared and organized by residents, staff, and caregivers.

7.7 Schedules and Routines

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

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

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

Unfortunately, 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.

Caregivers and healthcare workers responsible for maintaining a schedule need to be flexible while maintaining 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 often causes aggressive behaviors that frustrate both parties.

8. Ethical Issues and Persons with AD

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

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

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

8.1 Key Ethical Principles

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

8.1.1 Autonomy and Well-Being

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

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

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

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

8.1.2 Beneficence (Kindness): Doing Good

Beneficence (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 resident and avoid negative consequences.

8.1.3 Justice: Equity and Fairness

Justice is the fair distribution of benefits, goods, and risks (Lauridsen et al., 2023). Distributive justice 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.

There is concern among many caregivers 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 calm and 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 living with dementia asks again and again about a deceased spouse, reliving the pain of learning about the death of a loved one can cause a great deal of pain and distress. Because of this, many caregivers admit to telling lies when delivering care, even if it creates an ethical dilemma for the caregiver (Murray et al., 2025).

8.2 Incorporating Ethical Principles into Care

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

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

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

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

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

8.3 Ethical Issues Related to the Use of Assistive Technology and Artificial Intelligence

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

Assistive technologies, some using artificial intelligence (AI) involve aids that support memory, sensors to detect vitals and falls, environmental sensors to detect movement, and advanced security systems. Newer technologies include automatic pill dispensers, emotional support robots, smart home devices (smart lights, voice assistance), and GPS tracking devices. Ensuring fair access to technology and preserving the privacy of end-users and their data is often overlooked.

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

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

8.4 Examples of Ethical Conflicts and Dilemmas

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

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).

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).

A 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?

8.4.1 Maintaining Independence

Background

Mr. Sienna is 90 years old and lives in an apartment at an assisted living facility near his daughters. He was a pilot during the Viet Nam war and has been fiercely independent his entire life. He is in the moderate-to-severe stage of dementia and is unable to independently perform many of his ADLs.

Antecedent

Yesterday, he was heating up some soup and forgot to turn off the burner on the stove. The fire alarm went off when the soup started smoking, burning the bottom of the pan. Mr. Sienna ran into the kitchen, grabbed the pan, and threw it into the garbage. Fortunately, help arrived and the fire was quickly put out.

Consequence

Mr. Sienna was very upset that he wasn't able to handle this situation by himself. He burned his hand and started a small fire and said he didn't know what to do. His daughters took him to the clinic to have his hand treated. He does not know his address, the current date, the president's name, the season, day, or time. His Mini Mental State Exam score is 11/30.

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

Discussion

In making decisions on Mr. Sienna's behalf, his daughters are using the principles of autonomy and beneficence. Mr. Sienna's lifelong desire to be independent guided their decision to allow him to continue to live in his apartment. They are balancing his need for autonomy with his need for safety and protection. The three sisters decide to take turns sleeping at his apartment overnight and have agreed to stop in during the day. They accept that he is at some risk but believe that his quality of life will be better in his own apartment and that living there is consistent with their father's life philosophy.

8.4.2 Ceasing to Eat

Background

Mrs. Gould is 92 years old and has severe Alzheimer's disease. She has lived in an assisted living 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.

8.4.3 Justice, Fairness, and Equity

Background

Alycia is a 68-year-old woman who has been living independently in an assisted living facility in Florida. She has been able to pay the monthly fee for her room and board but without much left over each month. Over the past year, she experienced increasing difficulty with her balance and fell several times. She was afraid to tell anyone, so she reduced her physical activity, and limited her social participation in facility activities.

Alycia worked her entire life as a waitress and was never able to save much money. Prior to moving into assisted living, she spent more than 10 years caring for her husband. She was unable to hire a caregiver and had to cut back on her hours at work. After her husband died, Alycia sold her home in a quiet area of West Palm Beach for \$185,000. She moved to an assisted living facility, which costs her \$3,850 per month. She has calculated she could afford to live in assisted living for about 4 years before her money runs out.

Alycia did okay at first, then, after breaking her arm in a fall, she realized she was going to need help with some of her daily living tasks. She noticed that one of her neighbors had someone come in every day to help with shopping, bathing, and exercises. She was interested in hiring the helper but learned that it would cost \$15/hour. She knew she couldn't afford that, so she went without.

Alycia managed to get by for another year, not sharing her difficulties with anyone. During that time, she experienced some cognitive changes—she couldn't figure out how to work the TV and had difficulties with the phone. Normally a fastidious woman who prided herself on her appearance, she stopped bathing and stayed in bed or in her recliner most of the day.

One day she was found on the floor next to her bed, incontinent and confused. She was admitted to the hospital with a broken hip, dehydration, and delirium. After surgery and a 3-week stay in rehab, she was admitted to a local nursing home.

Questions

1. Is it fair or equitable that some people can afford private-pay help in an assisted living facility while other cannot?
2. Do you think Alycia could have had a better outcome if she had been able to afford a regular caregiver?
3. Does Florida pay for private caregivers in assisted living facilities?

Discussion

The uneven distribution of care and assistance is an example of distributive justice. When supply is low or costly, many are unable to pay for help. In Florida, the average out-of-pocket cost for a person living in an assisted living facility is more than \$4,700 per month and can be much higher.

Adverse health conditions are disproportionately associated with race, ethnicity, occupation, and socioeconomic status. A higher burden is experienced by Black Americans and other minority groups, which reflects the impacts of systemic racism and socioeconomic factors.

Alycia may be eligible for financial assistance from the State of Florida through the Optional State Supplements program. The State may supplement her income to cover room, board, and other services provided by the assisted living facility or other authorized facility. This supplementation will be combined with Alycia's SSI or disability benefits—not to exceed an amount set by the State (FLDCA, 2025).

9. 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 by an act of Congress in 1990 and is part of the National Institutes of Health. Its mandate is to compile, archive, and disseminate 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.

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.

10. References: FL ADRD for Assisted Living (372)

Alzheimer's Association (Alz.org). (2025). 2025 Alzheimer's Disease Facts and Figures. Retrieved November 18, 2025 from <https://www.alz.org/getmedia/ef8f48f9-ad36-48ea-87f9-b74034635c1e/alzheimers-facts-and-figures.pdf>.

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 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>.

American Health Care Association/ National Center for Assisted Living. (**AHCA/NCAL**). (2025). Assisted Living facts and Figures. Retrieved September 23, 2025 from <https://www.ahcancal.org/Assisted-Living/Facts-and-Figures/Pages/default.aspx>.

Antipas H, Tamplin J, Vieira Sousa T, and Baker FA. (2025). Understanding and mitigating occupational stress in professional dementia caregivers in residential aged care: a systematic review with framework synthesis. *Psychology & Health*, 1–37. Retrieved November 25, 2025 from doi.org/10.1080/08870446.2025.2527069.

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](https://doi.org/10.4103/jgmh.jgmh_17_23).

Atee M, Burley CV, Ojo VA, et al. (2023). Physical restraint in older people: an opinion from the Early Career Network of the International Psychogeriatric Association. *International Psychogeriatrics*. Volume 36, Issue 11, November 2024. Retrieved April 1, 2026 from <https://doi.org/10.1017/S1041610223000728>.

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 from [doi:10.3389/fpsyg.2021.772696](https://doi.org/10.3389/fpsyg.2021.772696).

Bigger SE, Foreman RA, Keinath C, Towsley GL. (2024). Transitions between skilled home health and hospice for persons living with dementia: a systematic review of literature. *Annals of Palliative Medicine*. Vol 13, No 3. Retrieved September 22, 2025 from <https://apm.amegroups.org/article/view/122422/html>.

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](https://doi.org/10.3389/fmed.2025.1540486).

Caffery C, Melekin A, Lu Z, Sengupta M. (2022). Variation in Residential Care Community Resident Characteristics, by Size of Community: United States, 2020. Retrieved September 23, 2025 from <https://www.cdc.gov/nchs/products/databriefs/db454.htm>.

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/>.

Carlozzi NE, Graves CM, Freeman JL, et al. (2025) Understanding financial hardship in families of people living with dementia: Protocol for a scoping review to identify subjective self-report measures that evaluate financial hardship. *PLoS One* 20(9): e0331114. Retrieved March 26, 2026 from <https://doi.org/10.1371/journal.pone.0331114>.

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>.

Center for Medicaid and Medicare Services (**CMS.gov**). (2024). Retrieved November 15, 2025 from https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap_a_hospitals.pdf.

Chao LL, Lee JA, Martinez S, et al. (2021). Preventing Loss of Independence through Exercise (PLIÉ): A Pilot Trial in Older Adults with Subjective Memory Decline and Mild Cognitive Impairment. *J Alzheimers Dis.* 2021;82(4):1543-1557. Retrieved November 18, 2025 from <https://pmc.ncbi.nlm.nih.gov/articles/PMC8461710/>.

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>.

Fischer C. (2022). Dementia-Related Psychosis. *Scientist Explain Series*. University of Toronto. Retrieved August 15, 2025 from <https://tdra.utoronto.ca/dementia-related-psychosis>.

Florida Agency for Health Care Administration (**FLAHCA**). (2025). Assisted Living Facility. Retrieved November 13, 2025 from <https://ahca.myflorida.com/health-care-policy-and-oversight/bureau-of-health-facility-regulation/assisted-living-unit/assisted-living-facility>.

Florida Department of Children and Families (**FLDCA**). (2025). Temporary Cash Assistance (TCA). Retrieved August 15, 2025 from [https://www.myflfamilies.com/services/public-assistance/temporary-cash-assistance#:~:text=The%20Optional%20State%20Supplementation%20\(OSS,mental%20health%20residential%20treatment%20facilities](https://www.myflfamilies.com/services/public-assistance/temporary-cash-assistance#:~:text=The%20Optional%20State%20Supplementation%20(OSS,mental%20health%20residential%20treatment%20facilities).

Florida Statutes. (2024). Chapter 429 (Including 2025c). Assisted Care Communities. Retrieved November 14, 2025 from <https://flsenate.gov/Laws/Statutes/2024/Chapter429/All>.

Galof K. (2025). Living with dementia in a care home: facilitating participation in activities. *Front. Sports Act. Living* 7:1563025. Retrieved March 12, 2026 from 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 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). H.R. 3545—100th Congress: Omnibus Budget Reconciliation Act of 1987. Retrieved August 18, 2025 from <https://www.govtrack.us/congress/bills/100/hr3545>.

Gramegna SM. (2021). Interior Design as a Tool for Dementia Care. Experiences and guidelines for the Therapeutic Habitat Model. *Franco Angeli Open Access*. Retrieved November 22, 2025 from <https://series.francoangeli.it/index.php/oa/catalog/book/652>.

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.

Jacob 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 November 22, 2025 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 November 21, 2025 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 Health Intervention for Informal Home Care. *Front. Psychol*. 13:862347. Retrieved January 1, 2026 from doi:10.3389/fpsyg.2022.862347.

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 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 November 22, 2025 from doi:10.3389/fpsyg.2025.1567619.

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 Institute on Aging (**NIA**). (2023, October 12). Residential Facilities, Assisted Living, and Nursing Homes. Retrieved November 13, 2025 from <https://www.nia.nih.gov/health/residential-facilities-assisted-living-and-nursing-homes>.

Office of the Inspector General (**OIG**). (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>.

Pillemer K, Teresi JA, Ramirez M, et al. (2024). Estimated Prevalence of Resident-to-Resident Aggression in Assisted Living. *JAMA Netw Open*. 2024;7(5):e249668. Retrieved November 14, 2025 from <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2818241>.

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/fpsy.2025.1543563.

Sandberg B, Hurmerinta L, Leino H M, and Menzfeld M. (2021). Autonomy or Security? Core Value Trade-Offs and Spillovers in Servicescapes for Vulnerable Customers. *Journal of Service Research*, 25(1), 9-28. Retrieved November 26, 2025 from doi.org/10.1177/10946705211012472.

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 November 24, 2025 from 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>.

Sturge J, Janus S, Zuidema S, et al. (2024). The Moral and Gender Implications of Measures Used to Modulate the Mobility of People With Dementia Living in Residential Care Environments: A Scoping Review. *Gerontologist*. 2024 Apr 1;64(4):gnad071. Retrieved November 26, 2025 from doi:10.1093/geront/gnad071.

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.

Tasserone-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 November 24, 2025 from <https://bmgeriatr.biomedcentral.com/articles/10.1186/s12877-022-03149-6>.

University of South Florida (USF). (2026). Exploring Assisted Living Communities in Florida. Retrieved April 13, 2026 from <https://www.usf.edu/cbcs/aging-studies/fpeca/research/alf.aspx>.

Utz RL, Caserta M, Iacob, et al. (2023). Maximizing the Benefit of Respite for Dementia Caregivers: A Study Protocol Describing the Development & Evaluation of the Time for Living & Caring (TLC) Intervention. *OBM Integrative and Complementary Medicine* 2023, Volume 8, Issue 4. Retrieved November 18, 2025 from <https://www.lidsen.com/journals/icm/icm-08-04-040>.

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 August 15, 2025 from 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.

White AJ and Olsho LEW. (2023). Nursing Home Staffing Study Comprehensive Report. Retrieved September 24, 2025 from <https://www.cms.gov/files/document/nursing-home-staffing-study-final-report-appendix-june-2023.pdf>.

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 August 15, 2025 from <https://bmgeriatr.biomedcentral.com/articles/10.1186/s12877-021-02020-4>.

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>.

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.

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.

[Continue to next page to start quiz]

11. Quiz: FL ADRD for Assisted Living (372)

1. Although assisted living was originally designed for independent older adults, more and more residents are living with dementia and other complex medical needs.

- a. True
- b. False

2. In the early, mild stage of dementia, especially in Alzheimer's disease, forgetfulness might be the most obvious symptom. A

- 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. 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.

5. 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.

6. 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.

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

- a. True
- b. False

16. Therapeutic design recognizes:

- a. There is a connection between the environment and how we behave.
- b. The environment has little impact on those 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.

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

- a. True
- b. False

18. To integrate staff into a homelike environment:

- a. Make sure staff members don't get too comfortable with a resident.
- b. Hire staff with the emotional skills to interact with people who have memory problems.
- c. Increase the number of centralized nursing stations.
- d. Clearly mark all doors, including doors to utility areas and staff lunchroom.

19. The principle of beneficence 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.

20. An ethical dilemma might arise when:

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

[Continue to next page for answer sheet]

Answer Sheet: FL ADRD for Assisted Living (372)

Name (Please print) _____

Date _____

Passing score is 80%

1. _____	11. _____
2. _____	12. _____
3. _____	13. _____
4. _____	14. _____
5. _____	15. _____
6. _____	16. _____
7. _____	17. _____
8. _____	18. _____
9. _____	19. _____
10. _____	20. _____

[Continue to next page for course evaluation]

Course Eval: FL ADRD for Assisted Living (372)

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

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

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

1. State 3 reasons why an older adult may choose to live in an assisted living. 1 2 3 4 5

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

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

4. Understand the basis for the design of successful individual and group activity programs for people living with dementia. 1 2 3 4 5

5. List 3 types of stress that are common in caregivers caring for a person living with dementia. 1 2 3 4 5

6. Recognize the issues and concerns faced by someone caring for a person living with dementia. 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.

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

_____ Yes, within the next 30 days. _____ Yes, during my next renewal cycle.

_____ Maybe, not sure. _____ No, I only needed this one course.

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

_____ Yes, definitely. _____ Possibly. _____ No, not at this time.

*What is your overall satisfaction with this learning activity?

1 2 3 4 5

*Navigating the ATrain Education website was:

_____ Easy. _____ Somewhat easy. _____ Not at all easy.

*How long did it take you to complete this course, 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 and Payment: FL ADRD for Assisted Living (372)

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 employer, please enter it here:**