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Florida Alzheimer's Disease and Related Dementias for Home Health, 2 units (376)

Contact hours: 2

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Price: \$24

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Florida DOE Approval: This course is approved by the Florida Department of Elder Affairs, curriculum approval: #HH11485

The author is certified as ADRD trainer by the Florida Department of Elder Affairs and is available via e-mail or by phone Monday–Friday (Pacific Time) from 9 a.m. to 5 p.m. at 707 459 3475. Training provider approval # HH11406.

Course Summary: This course provides home health staff with the skills, techniques, and strategies to care on a daily basis for clients with Alzheimer's disease or a related dementia. It compares Alzheimer's disease to other types of dementia, provides techniques for verbal and nonverbal communication, discusses symptoms seen at each stage of dementia, relates techniques intended to promote independence in activities of daily living (ADLs), and provides information about how to work with family members and caregivers of people with dementia.

Learning Objectives

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

1. Define dementia.
2. Describe 1 technique each for improving verbal and nonverbal communication in a person living with dementia.
3. Describe 1 symptom or behavior change you might see during each stage of dementia.
4. Relate 3 techniques for promoting independence in activities of daily living.
5. Relate 1 concern or issue you might encounter with family members and caregivers at each stage of dementia.

Pretest

1. Alzheimer's disease and most other types of dementia are *progressive*, meaning damage gets worse over time.
 - a. True
 - b. False
2. In older adults, delirium and depression are often mistaken for dementia.
 - a. True
 - b. False
3. Agitation can include irritability, confusion, making loud demands, and using obscene language.
 - a. True
 - b. False
4. Depending on the severity of the dementia, a person living with dementia might not remember what was said a few moments ago.
 - a. True
 - b. False
5. Wandering can be addressed by using a physical restraint to keep the person safe.
 - a. True
 - b. False
6. In the early stages of dementia, it is recommended that family members receive specialized training about dementia.
 - a. True
 - b. False
7. A sign of moderate dementia can include needing more assistance with ADLs.
 - a. True
 - b. False
8. According to Florida law, a restraint cannot be used for discipline or convenience. If a restraint is used, it must be the least restrictive alternative, for the least amount of time, and regularly re-evaluated.
 - a. True
 - b. False
9. Family caregivers are often isolated, may lack support, and don't know much about dementia.
 - a. True
 - b. False
10. When a loved one dies, family members can experience grief that resembles clinical depression.
 - a. True
 - b. False

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

1. Understanding Alzheimer's Disease and Related Disorders (ADRD)

Alzheimer's disease and other types of dementia cause damage to the entire brain. It affects memory, thinking, emotions, judgment, reasoning, social skills, and a person's ability to function in daily life. Dementia occurs primarily in later adulthood and is a major cause of disability in older adults. Although almost everyone living with dementia is older, dementia is not considered a normal part of aging.

1.1 Defining Dementia

Dementia is a term used to describe a group of symptoms that damage brain cells. Alzheimer's disease and most other types of dementia are *progressive*, and symptoms worsen over time as brain cells die. meaning damage gets worse over time. Dementia is a terminal illness, eventually leading to death.

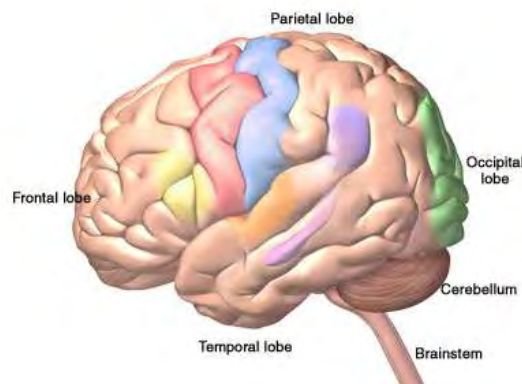
Dementia affects our *executive functions*; the skills we need to manage our daily lives. The gradual loss of executive functions makes it hard to plan for the future, follow complex conversations, remember new things, and control our emotions.

Alzheimer's disease and other types of dementia cause damage to a part of the brain called the **cerebrum**. The cerebrum fills up most of our skull and is divided into four *lobes* (or segments, one on each side of the head):

1. Frontal (right behind your forehead)
2. Temporal (on the side of your head above your ears)
3. Parietal (in the middle of your head above the temporal lobes)
4. Occipital (at the back of your head)

The cerebrum allows us to understand the world around us. It controls our memories and emotions. It helps us to reason, make decisions, and tell right from wrong. It also controls our movements, vision, and hearing. Many of these areas of the brain are damaged by dementia.

The Human Brain



The four lobes of the cerebrum, plus the cerebellum and the brainstem. Alzheimer's disease starts in the temporal lobe, an area of the brain associated with memories and emotions. (Copyright, Zygote Media Group, Inc. Used with permission.)

When someone has dementia, their thinking gradually becomes less clear. Decisions are more difficult and safety awareness declines. People also get tired more easily. People living with Alzheimer's disease and other types of dementia sometimes have difficulty controlling their emotions.

After the age of 55, the risk of developing dementia increases. Between the ages of 55 and 75, the risk is relatively low (4%). After the age of 75 the risk increases, with the highest risk occurring in people over the age of 85. Certain groups have greater risks than others. For example, women have a higher lifetime risk due to survival to older ages than men (Fang et al., 2025).

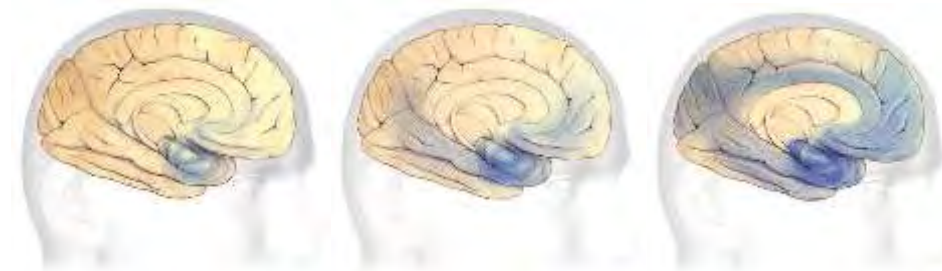
The term ADRD (Alzheimer's disease and related dementias) is a general one that refers to more than one type of dementia. While Alzheimer's disease is the most common dementia diagnosis, other types of dementia share many features with Alzheimer's. More often than not, patients with a clinical diagnosis of Alzheimer's disease have mixes of brain pathologies, complicating both diagnosis and treatment (NINDS, 2025, December 12).

1.2 Defining Alzheimer's Disease and ADRD

Alzheimer's disease (AD) is the most common kind of dementia. It typically starts in an area of the brain called the *hippocampus*. This is the part of the brain responsible for regulating emotions, forming new (short-term) memories, and converting these memories for later use (long-term memories).

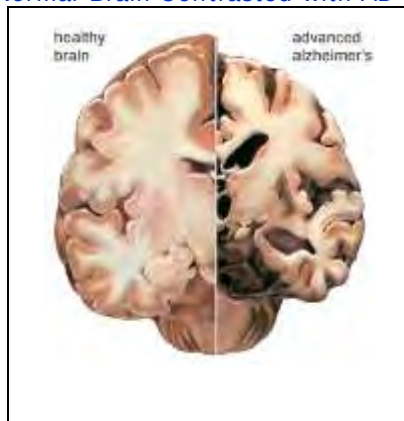
Damage to this part of the brain can cause a person to forget something that happened just a moment ago. The following pictures show how damage from Alzheimer's dementia gradually spreads throughout the brain.

Brain Changes in Mild Dementia



In the early stage of Alzheimer's disease, "plaques" and "tangles" (clumps) form in and around the hippocampus (shaded in blue). In the moderate stage, damage spreads from the hippocampus forward to the frontal lobes. In advanced Alzheimer's, plaques and tangles have spread throughout the entire brain. (Source: The Alzheimer's Association. Used with permission.)

Normal Brain Contrasted with AD Brain



A view of how Alzheimer's disease changes the whole brain. Left side: normal brain; right side, a brain damaged by advanced AD. (Courtesy of The Alzheimer's Association. Used with permission.)

1.3 Other Types of Dementia

Although Alzheimer's dementia gradually worsens over time, other types of dementia can progress differently.

1.3.1 Vascular Dementia

Vascular dementia is related to cerebrovascular disease. It can be caused by any disease or disorder that damages the vessels supplying blood to the brain. This can include hypertension, heart rhythm irregularities, diabetes, high cholesterol, smoking, sleep-disordered breathing, and a sedentary lifestyle.

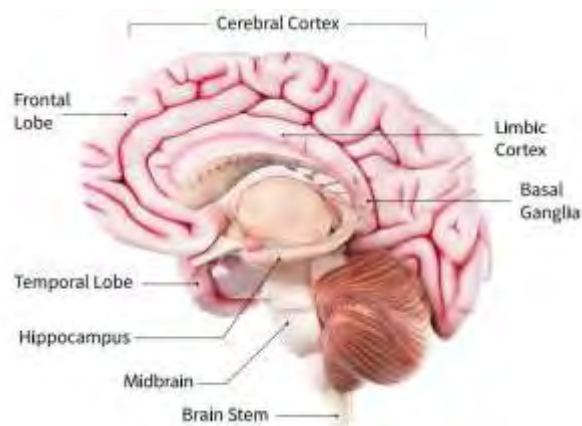
Vascular dementia usually has a *stepwise onset*, meaning symptoms can stay the same for a long period of time, then suddenly worsen. Memory may be less affected than in Alzheimer's disease, while fluctuations in mood are more common. Cognitive impairment is often "patchy" because of small vessel damage throughout the brain.

Although Alzheimer's disease is the most common cause of dementia, vascular cognitive impairment and vascular dementia represent the second leading cause, accounting for approximately 15 % to 20% of all dementia cases (Yang, 2025).

1.3.2 Lewy Body Dementia

Lewy body dementia (LBD) is progressive (symptoms start slowly and worsen over time). Early symptoms can include changes in mood, vision, sleep, and bowel movement dysfunction. Nervous system tissue outside the brain, including nerves in the intestines, heart, sex organs, and salivary glands, can be affected by LBD as well. This may lead to symptoms such as constipation, dizziness with changing position, sexual dysfunction, or drooling (NIA, 2025, January 27). Symptoms often fluctuate, even throughout the course of the day.

Lewy bodies are made of a protein called *alpha-synuclein*. In LBD, alpha-synuclein forms into clumps inside nerve cells, starting in specific regions of the brain. This process causes nerves to weaken and, eventually, to die. The result is widespread damage to certain parts of the brain and a decline in abilities controlled by the affected brain regions (NIA, 2025, January 27).



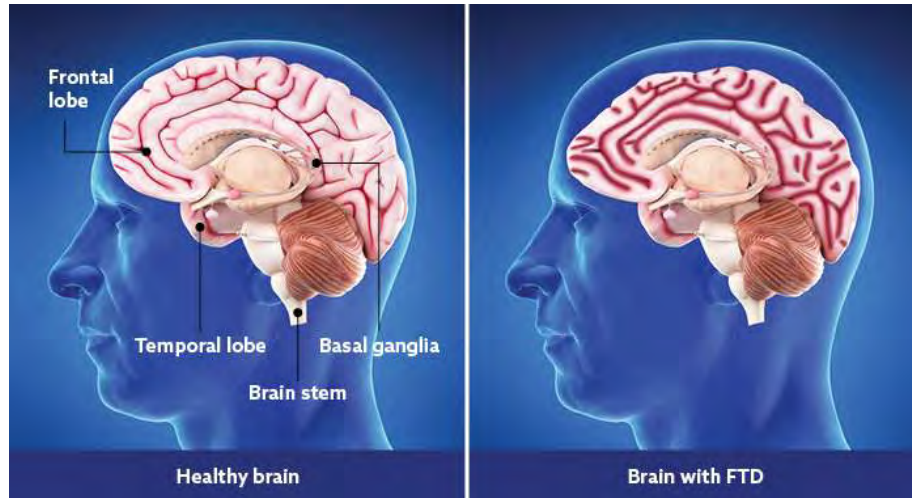
LBD dementia affects many parts of the brain including those shown above. Source: NIA, 2025, public domain.

Lewy body dementia lasts an average of 5 to 7 years from the time of diagnosis to death, but it can range from 2 to 20 years. How quickly symptoms develop varies greatly from person to person, depending on overall health, age, and severity of symptoms (NIA, 2025, January 27).

Parkinson's disease dementia is a form of LBD. People with either form of LBD eventually develop similar symptoms due to the presence of Lewy bodies in the brain. But there are some differences. For example, the symptoms of dementia with Lewy bodies may worsen more quickly than those of Parkinson's disease dementia (NIA, 2025, January 27).

1.3.3 Frontotemporal Dementia

Frontotemporal dementia (FTD) is caused by damage to nerve cells primarily in the frontal and temporal lobes of the brain. As nerve cells die in these regions, the frontal and temporal lobes atrophy, or shrink. Gradually, this damage causes difficulties in thinking and behaviors normally controlled by these parts of the brain (NIA, 2025, January 22).



An illustration showing the location of the frontal and temporal lobes of the brain. Note the shrinkage of brain tissue in the right picture. Source: NIA, 2025, public domain.

Frontal-temporal dementia usually starts at an earlier age than Alzheimer's disease. Depending on which side of the brain is affected, there are changes in personality, behavior, emotions, and judgment. There may also be early changes in language ability, including speaking, understanding, reading, and writing.

For caregivers and healthcare providers, one of the most striking and difficult aspects of frontotemporal dementia is the sometimes profound personality changes that can occur in a person experiencing the effects of damage to this part of the brain. The front part of the brain controls impulses, mood, ethical decisions, and compulsive behaviors. A person living with FTD may engage in verbal, physical, or sexual behaviors that are socially unacceptable and that never occurred prior to the onset of dementia. This is because of the loss of inhibition and emotional control due to damage to front part of the brain.

Motor (movement) decline can also occur as FTD progresses. A person may experience difficulties with movement, including the use of one or more limbs, shaking, difficulty walking, frequent falls, and poor coordination. Apathy, an unwillingness to talk, dramatic overeating, and depression are also common.

1.4 How ADRD Differs from Normal Aging

We all experience changes as we age. Some people become forgetful when they get older. They may forget names or titles. They may forget where they left their keys. They may also take longer to do certain mental tasks. They may not think as quickly as they did when they were younger. These are called **age-related changes**. This is a normal part of aging—it is not dementia.

People experiencing age-related changes can do everything in their daily lives—they can prepare their own meals, manage their finances, safely drive a car, go shopping, and use a computer. They understand when they are in danger and know how to take care of themselves. Even though they might not think or move as easily or quickly as when they were young, their thinking is normal—they do not have dementia.

In some older adults, memory problems are a bit worse than normal age-related changes. This is known as **mild cognitive disorder** (trouble thinking clearly). Mild cognitive disorder isn't dementia. You won't generally see personality changes, just a little more difficulty than is normal with thinking and memory. For some people, however, mild cognitive disorder gets worse and can develop into dementia.

Mild cognitive changes do not always develop into dementia. A person with mild cognitive impairment may remain at this level or even revert back to normal cognition under certain circumstances.

Here are some of the differences between someone who is aging normally and someone who shows the effects of dementia.

Normal Aging vs. ADRD	
Normal aging	AD or other types of dementia
Occasionally loses keys	Cannot remember what a key does
May not remember names of people they meet	Cannot remember names of spouse and children—don't remember meeting new people
May get lost driving in a new city	Get lost in own home, forget where they live
Can use logic (for example, if it is dark outside it is nighttime)	Is not logical (if it is dark outside it could be morning or evening)
Dresses, bathes, feeds self	Cannot remember how to fasten a button, operate appliances, or cook meals
Participates in community activities such as driving, shopping, exercising, and traveling	Cannot independently participate in community activities, shop, or drive

1.5 Conditions That Can Mimic Dementia

There are many conditions that can cause symptoms that look like dementia. Some conditions— infections; constipation; reactions to or interactions between medications; and abuse of alcohol, prescription medications, or recreational drugs—can be reversed with treatment.

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

1.5.1 Delirium

Delirium is sudden, severe confusion with rapid changes in brain function. Along with dementia, it is a common cause of altered (changed) mental status in older adults (Jandu et al., 2025). Delirium has an abrupt onset, developing over hours or days and is typically temporary and reversible.

Delirium and dementia can occur together. Delirium is often confused with depression or dementia. Many common causes of delirium are reversible, so recognizing signs of delirium can lead to rapid improvement.

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

1.5.2 Depression

Depression is a common but serious mood disorder. It is very common in people living with dementia and may be unseen and therefore not diagnosed or treated.

Major depressive disorder can interfere with a person's ability to sleep, eat, exercise, and participate in activities. Some people may have only a single episode within their lifetime, but more often a person may have multiple episodes (NIMH, 2024).

Persistent depressive disorder (also called dysthymia or dysthymic disorder) is long-lasting (2 years or longer). Depression with symptoms of psychosis occurs when a person has severe depression, plus some form of psychosis—such as delusions or hallucinations (NIMH, 2024).

Depression in a person living with dementia is associated with decreased quality of life, faster cognitive decline, increased mortality, and increased caregiver stress. Because of this, *the diagnosis and treatment of depression in people living with dementia should be a priority* (O'Sullivan et al., 2022).

Depression can cause a person to feel hopeless, worthless, or helpless. Because these symptoms often overlap with cognitive decline, caregivers may fail to recognize the difference between symptoms of depression and dementia and therefore offer no treatment (NIA, 2025, February 5).

1.5.3 Medical Conditions That Can Mimic Dementia

Other conditions that can look like dementia are more complicated and usually require additional evaluation and testing. This includes head injuries from falls, subdural hematomas,* nutritional or fluid deficiencies, dehydration, and malnutrition.

***Subdural hematoma:** when blood accumulates in the outer layer of the brain, usually from some sort of head injury.

Potentially treatable conditions that can affect a person's thinking include:

- metabolic, autoimmune, or endocrine abnormalities
- dehydration and malnutrition
- poisoning from exposure to lead, heavy metals, or other poisonous substances
- brain tumors, space-occupying lesions, and hydrocephalus (fluid in the brain)
- hypoxia or anoxia (not enough oxygen)
- epilepsy
- sleep apnea (NINDS, 2025, October 20)

1.6 Possible Causes of Alzheimer's Disease and Other Types of Dementia

In Alzheimer's disease, damage is thought to be caused by two *abnormal proteins*,* called tau and beta-amyloid, that accumulate in the brain. The proteins form "plaques" and "tangles" (clumps) inside the nerve cells and in the areas between the nerve cells.

***Abnormal proteins:** complex molecules that clump or fold together, disrupting normal cell function.

But abnormal proteins may not be the only factors involved in Alzheimer's. Other changes that affect the brain may also play a role:

- lack of sufficient blood and nutrients to the brain
- lack of glucose (sugar)
- chronic inflammation

Risk factors associated with the development of dementia include high blood pressure, heart disease, diabetes, stroke, and Parkinson's disease. Lifestyle risk factors include smoking, drinking large amounts of alcohol, head injuries, poor diet, and lack of exercise. Genetics also plays a role—the chance of developing a genetically linked form of dementia increases when more than one family member has the disorder (NINDS, 2025, October 20). Although genetic factors increase risk, they do not determine outcome.

2. Communicating with Clients with AD and Related Disorders

My dad gets pretty confused—especially in the early morning and late afternoon. He struggles for words—often trying to explain something by saying "You know, that *thing*" and then gets frustrated because I don't understand. When I read the newspaper to him, all the articles get jumbled up in his head and he doesn't know when one article ends and another starts. So, I just read short articles, Miss Manners, that sort of thing. I tell him, "That's the end of the article about the election—this is a new article about the weather up north."

Caregiver, West Palm Beach, Florida

2.1 How Dementia Affects Communication

Dementia affects communication in many ways. People living with dementia have to work hard to say what they want to say. Depending on how severe the dementia is, they might not remember what was said a few moments ago. They often have trouble carrying on a conversation and doing something else at the same time. Background noise is often confusing and irritating.

Communication challenges associated with dementia include reduced comprehension, reduced verbal expression, and memory problems. Cultural and language diversity adds complexity, necessitating culturally competent communication and care (Sunjaya et al., 2025).

With advancing dementia, communication difficulties can arise due to cognitive and linguistic decline, leading to potential challenges in being understood. Different challenges may be experienced depending on dementia subtype and progression. For example, difficulties in word-finding and verbal expression can lead to frustration and distress due to the inability to express thoughts and feelings (Collins et al., 2022).

Communication challenges for a person living with dementia include difficulty expressing thoughts and understanding what another person is trying to communicate. It is estimated that aphasia* is associated with 25% of all frontotemporal dementia. Most people living with dementia also demonstrate anomia** and other language deficits (Dhanda and Scaria, 2025).

***Aphasia**: a neurological language disorder caused by brain damage that impairs speaking, comprehension, reading, and writing, though intelligence remains intact.

****Anomia**: the inability to remember and retrieve words on demand.

Hearing loss is relatively common modifiable risk factor, affecting about 8% of people living with dementia. These communication impairments not only impact a person's ability to convey their needs and preferences but also contribute to frustration, social isolation, and diminished quality of life. Unmanaged hearing impairment in people living with dementia can lead to or sustain feelings of social isolation (Dhanda and Scaria, 2025).

Communication difficulties can increase the risk of individual needs not being met and so may also directly impact quality of life. Limited communication may increase depression, anxiety, and loneliness and contribute to physical and cognitive decline (Collins et al., 2022).

When a person expresses feelings of frustration and displays behaviors arising from unmet needs, others may perceive these as challenging behaviors. Although verbal expression may be more limited, nonverbal communication can convey feelings, emotions, and preferences. Nonverbal communication is often preserved in people with moderate-to-severe dementia, as is the desire and ability to communicate opinions and answer questions (Collins et al., 2022).

2.1.1 General Conversations

My mom has dementia but still listens intently to our conversations. She followed the 2024 election with a great deal of interest even though, when asked, she couldn't remember the names of the presidential candidates. When the doctor asked her "Are you a Democrat or a Republican?" she responded immediately and fiercely "I'm a Democrat!"

Family Caregiver, Pensacola, Florida

Think about the last conversation you had with a friend or family member. You said what you wanted to say. You remembered what was said and understood the conversation. You probably had the conversation while doing something else—fixing breakfast or getting ready for work. You have no trouble talking even if there is a lot of noise in the background.

General conversations are social, friendly, and informal. They are not usually related to a specific task or goal. General conversations are a way to greet people and find out how they are doing. General conversations usually begin with a greeting or a comment, suggestion, or explanation.

A general conversation with a person living with dementia is no different than a conversation you would have with a friend or coworker. You can connect with people by learning about what they liked when they were younger: What music was popular? Who was president? What major events happened in their younger years? Did they serve in the military? How many children do they have? Where did they work? Where did they travel? What were their interests and hobbies?

A person living with dementia may not remember what you talked about yesterday, but they still want to hear what you have to say, even if you are repeating something said earlier.

Avoid talking down to older adults, something that is common in hospital and care home settings. This includes using childish or pet phrases such as "Are your feeties cold?"; diminutives such as "pumpkin," "young lady," "cutie pie"; collective pronouns such as "How are we feeling today"; and belittling language such as "Let's get your leash on you." This type of verbal language is counterproductive and can increase resistance to care. Despite this, some caregivers and healthcare providers believe that people living with dementia appreciate these phrases (Sunjaya et al., 2025).

2.1.2 Conversations Related to a Task or Goal

When trying to complete a specific task, communication must be clear and direct. Conversations about a specific task are more successful when you use *closed questions*. A closed question shows your interest and invites a person to respond. For example, “Are you hungry?” or “Are you ready to get dressed?” keeps focus on the task at hand.

Task-related conversations involve gentle persuasion and positive feedback. Speak in a slow, clear voice, be respectful and relaxed, and explain the goal of the task. The person you are caring for may not share your goal or agree with what you are asking. More likely, they may not understand what you want. The following story about Randy and Ann shows this. Think about what you would do in this situation.

Randy in the Morning

Background: Randy has moderate dementia and lives at home in Sarasota with his daughter and an agency caregiver who comes in during the day to help Randy’s daughter. This morning Randy is dressed and resting in a chair next to his bed.

Antecedent: Ann, a new caregiver, enters his room and calls out to him. “Come on, sweetie. Are you hungry? Did you sleep well? Time for breakfast! Stand up. Let’s get you to the kitchen for breakfast.” Randy doesn’t move, so Ann tries again in a louder voice.

“Come on, Randy, get up! You don’t want your breakfast to get cold, do you? I don’t think so. Come on Randy, I’m kind of busy! I have to do the laundry and make your bed.” Ann takes his arm and helps him stand up.

Behavior: When Ann reaches for Randy, he shouts “no, no, no,” pulls away, and sits back in his chair. He is comfortable, warm, and a little sleepy. He’s not sure what time of day it is. He isn’t hungry. A young woman he doesn’t know has burst into his room and is saying something to him in a loud voice. He is trying to figure out what she is saying—and then she says something else. Her voice is loud, and he grimaces a little.

He is not sure what she wants. She grabs his arm, and he thinks maybe he should go with her, but she is being too pushy, and this makes him angry. So, he pulls away and sits back in his chair. He turns his head and tries to ignore her, hoping she will leave.

Consequence: Ann thinks she needs to get Randy up and fed before his daughter gets back from shopping. The regular home health aide called in sick, and Ann is covering for her today. She wants to get Randy to the kitchen for breakfast. When she enters his room, she is relieved to see that Randy is already dressed and up in a chair. She tells him it’s time for breakfast, takes his arm, and tries to help him stand up. Randy seems confused, yells at her, and pulls away. Ann repeats what she had just said, only more loudly. She reaches for him again, but he turns away, crosses his arms, and refuses to budge.

As a result, Ann is frustrated and feels Randy is being stubborn. Randy is angry and refuses to move from his chair. He shouts, “Go away! Where is my daughter?”



Source: healthypeople.org, public domain

Discussion: Ann could have avoided this disagreement by slowing down, pausing at the entrance to Randy's room, and knocking quietly on the door to get his attention. She should make eye contact and ask, "May I come in?" and await Randy's reply.

Approaching Randy more slowly to his dominant side, kneeling beside him, offering her upturned hand, and introducing herself gives Randy a chance to understand who she is.

A pause at the end of each sentence gives him time to respond.

"Hi, Randy." Pause. "How are you?" Pause. "It's 9 a.m." Pause. "Time for breakfast." Pause.

If Randy doesn't respond, Ann can repeat what she just said in a calm voice or ask another short, closed question: "Randy, are you hungry?" Pause.

Now Randy only has one simple statement to consider and is more likely to understand and respond. Ann must remember that Randy *doesn't have to do what she asks*. It's okay for Randy to have his breakfast in his room or even skip breakfast and eat when he is hungry.

2.2 Strategies and Guidelines for Verbal Communication

Verbal communication is communication *with words*. It is an important part of daily life, creating positive relationships, and letting us know that someone cares. It allows us to express our feelings and gives caregivers an opportunity to assess the well-being of the person they are caring for.

A successful conversation with a person who is living with dementia begins with eye contact (if it is OK in that person's world) and an introduction. Starting with something light and conversational, such as the weather or what's happening in the news, puts us at ease. Nonverbal gestures such as head nods, a light, *appropriate touch** on the arm, and a warm expression create trust.

***Appropriate touch:** refers to professional and ethical behavior while considering the individual's religious, cultural, and personal preferences.

Certain verbal communication techniques can enhance person-centered care. This can include greetings, rephrasing, using yes/no and open-ended questions and affirmations. Addressing a person by name and using greetings helps establish a connection and foster respect. Providing short, clear instructions and breaking down tasks into manageable steps supports comprehension and reduces anxiety and resistance (Sunjaya et al., 2025).

Successful communication also involves avoiding contradictions and using techniques like saying "I didn't realize that" to handle disagreements without escalating stress, followed by a statement that confirms the person's view. Repeating or rephrasing a statement without correcting a person can keep communication smooth and nonconfrontational. For instance, instead of correcting someone who says, "There's a dog outside my window trying to get in", a response like "There's a dog outside your window trying to get in?" maintains conversation and avoids disorientation (Sunjaya et al., 2025).

Using conversational cues encourages meaningful engagement. For example, "The weather has been really interesting lately, hasn't it?" Concluding a conversation or task is also important and helps prevent confusion. This involves making specific arrangements for what will happen next and announcing task completion, such as, "I'll see you tomorrow... That's all done, now" (Sunjaya et al., 2025).

Practice these communication techniques:

- Approach from the front and make eye contact.
- Greet the person by name, then introduce yourself.
- Kneel down to the person's right side and offer your upturned hand.
- Use short, 1- or 2-step questions and await a reply.

Be attentive and sympathetic and continue the conversation by asking a follow-up question. Take a deep breath, relax, and take a moment to look at the person. Check your body language—if you remain standing, you may appear aggressive or threatening.

Keep in mind the level of the person's dementia. Is there a hearing loss? Are there underlying conditions that affect mobility or cause pain? Are you having a social conversation or do you have a specific goal in mind?

2.3 Strategies and Guidelines for Nonverbal Communication

Nonverbal communication is communication without words. Facial expressions, eye movements, hand gestures, body language, and movements of the arms and legs are examples of nonverbal communication. Tone of voice and how well you pay attention are nonverbal skills that matter just as much as words.

Paying attention to tone, intonation, and speech rate—ensures communication is attuned to a person's emotional and cognitive needs. Showing empathy by mirroring the person's body language can deepen the connection. Gestures like pointing or demonstrating actions help direct a person's focus to specific tasks or objects, while tactile prompts, such as handing an object or guided touch,* capture attention and aid understanding (Sunjaya et al., 2025).

***Guided touch:** a technique that allows a caregiver to assist a person with tasks such as eating and grooming by placing their hand under a person's hand and providing tactile cues and gentle assistance.

Communication and emotions are related. Damage to the part of the brain that affects memory *also affects emotions*. It can affect a person's ability to read and follow nonverbal facial cues. This can affect their ability to understand when another person is frustrated, angry, or even happy.

How you dress, your posture, how you approach a person, and how close you get to a person are also examples of nonverbal communication. Even silence is a form of nonverbal communication.

Appropriate touch is a powerful form of nonverbal communication. Touch can be friendly, frightening, soothing, dominant, or supportive. Touch has different meanings depending upon your culture, gender, age, and situation.

The way you speak carries nonverbal information. Your tone reveals calmness or impatience, affection or disapproval, confidence or fear. The loudness of your voice and its tone and rhythm communicate additional information. If you are hurried, frustrated, or angry, a person will pick up on your mood and body language more quickly than your verbal communication.

How the environment (surroundings) look is a powerful form of nonverbal communication. A clean, nicely decorated room with good lighting is supportive. It encourages people to interact. A drab room with harsh lighting and little decoration has the opposite effect—it shows a lack of support and respect. Studies have shown that individuals say they don't like people when they see them in unattractive rooms.

Nonverbal communication using hand gestures and unhurried movement reinforces your words. If the person does not answer right away, be patient and wait a bit. It's OK to be silent, which is calming and reassuring—especially in social conversations.

People in the late stage of dementia may become *unresponsive*. This means they do not respond to what is happening around them. It means that they can no longer communicate their wishes. *It **does not** mean they don't feel or understand, at least on some level, what is happening around them.*

Communicating with a person who is unresponsive can be difficult for family members and caregivers because it is hard to know what the person is thinking or feeling. Fortunately, many of the techniques that work in the earlier stages of dementia are useful in this stage as well.

People may be able to hear, and possibly understand, even if they don't respond. Use gestures and facial expressions to support what you're trying to say. Give the person time to understand why you are there. Use a calm, slow manner and a respectful attitude.

You can communicate concern and caring for a person in bed or chair by providing pillows for neck, arm, and leg support; a warm blanket; and gentle repositioning. Mild range-of-motion exercises approved by a physical or occupational therapist, gentle appropriate touch, and massage are reassuring.

Keep the surroundings peaceful and avoid loud or sudden noises; the person has no way to tell you when a sound is annoying. Reduce discomfort and confusion by keeping the area around the bed or chair free of clutter.

When working with a person who is unresponsive, slow your own movements and re-introduce yourself at each encounter. Communicate using short, simple sentences. In addition :

- Approach on the person's right side in a calm and relaxed manner.
- Address the person by a preferred name or title.
- Use hand gestures and light, appropriate touch to communicate your intentions.
- Avoid a condescending tone (talking down).

Video: Gladys Wilson and Naomi Feil (5:46)

<https://www.youtube.com/watch?v=CrZXz10FcVM>

2.4 Assessing Pain in a Person with Cognitive Impairment

The assessment of pain in people living with dementia is a significant challenge. These clients tend to voice fewer pain complaints but may become agitated or exhibit unusual or sudden changes in behavior when they are in pain. Caregivers may have difficulty knowing when these clients are in pain and when they are experiencing pain relief. This makes people living with dementia vulnerable to both under-treatment and over-treatment.

Behavioral pain indicators can help with pain assessment in a person who is unable to describe or communicate their feelings of pain. The most sensitive indicators of pain in non-communicative older adults with dementia are facial expressions, vocalizations, body movements, changes in interactions with other people, difficulty with activities of daily living, and changes in mental status (Tagliafico et al., 2024).



A woman grimacing in pain. Created by author using Midjourney AI.

Uncertainty about identifying pain in a person living with dementia is a significant barrier to prompt pain management. For healthcare providers who use pain self-report tools to interpret the nonverbal indicators of pain, they may attribute these behaviors to dementia rather than pain (Tagliafico et al., 2024).

*Orofacial** pain is a common type of pain older clients living with dementia, affecting nearly half of institutionalized older adults. Impaired oral health care may be the result of cognitive dysfunction, motor apraxia, neglect, or resistance to care (Tagliafico et al., 2024).

Orofacial: relating to the mouth and face.

A Visit to the Doctor

I brought my mom to the ER because of severe back pain, confusion, and weakness. A young male doctor came into her room, identified himself, and shouted "Hello, I'm your doctor. Do you have any new or worsening pain?" He displayed a "pain scale" on his computer screen, which my mom couldn't see due to macular degeneration. I said she couldn't see that screen and he ignored me.

My mom turned towards him and smiled but didn't answer. The doctor shouted again in an even louder voice "Do you have any pain? Are you in pain?" My mother smiled but didn't answer.

She wears hearing aids, and I knew she could hear. I leaned over and asked her in a normal voice if she was in pain and she said no, meaning she was not in pain at that moment. I told the doctor that my mom is blind but has good hearing. He didn't look at me or ask me any questions. He shrugged and left the room.

The doctor returned a few minutes later with a diagnosis of agitation related to dementia and prescribed an antipsychotic, even though my mother was not showing any signs of agitation. Although a very low dose was prescribed, my mom had a very bad reaction. After we returned home, she was so disoriented and sleepy for the next 48 hours that we thought she was dying. Her pain was unaffected.

Family Caregiver, Ft Lauderdale, FL

Pain scales are tools that can be used to assess pain in a person living with dementia. Some of the most commonly used tools are (Tagliafico et al., 2024):

- **PAINAD**: the Pain Assessment in Advanced Dementia—assesses breathing, negative vocalization, facial expression, body language, and consolability.
- **PACSLAC**: Pain Assessment Checklist for Seniors with Severe Dementia—assesses facial expressions, body movements, social interaction and mood, and physiological circadian rhythms.
- **NOPPAIN**: Non-Communicative Patient's Pain Assessment—assesses activity, pain behavior presence, pain behavior intensity, and pain intensity.
- **Abbey Pain Scale**—assesses vocalization, facial expressions, change in body language, behavioral changes, and physiological and physical change.

3. Behavior Management

Alzheimer's disease, as well as other dementias, are often described as progressing in **stages**. The stages can be described as mild, moderate, and severe, or early, middle, and late. Even though disease progression differs from person to person and varies depending on the type of dementia, we nevertheless associate certain symptoms and behaviors with these stages. The type of dementia, along with a person's general health, *co-morbid conditions*,* and family support can affect how fast and how far the dementia progresses.

***Co-morbid conditions**: the presence of two or more medical conditions.

3.1 Symptoms and Behaviors Associated with Each Stage

Symptoms and behaviors are related but different. A **symptom** is a change in the body or the mind. Loss of memory is a symptom of dementia. Changes in judgment and logical thinking are also symptoms of dementia. **Behaviors** are actions—for example, biting, screaming, pacing, or hugging.

Depending on the type of dementia and underlying medical issues, symptoms and behaviors can gradually worsen over time. Behaviors can change gradually or suddenly, depending on the type of dementia, environmental factors, caregiver competence, medical issues, and the overall quality of care.

3.1.1 Symptoms and Behaviors in Mild Dementia

Mild cognitive changes, which have likely been developing for several years, affect memory, decision-making, and planning. Although a person living with mild dementia experiences forgetfulness, they can still perform all or most activities of daily (ADLs) and independent activities of daily living (IADLs). Shopping, cooking, yard work, dressing, bathing, and reading may be independent, or nearly so. These people may even continue to work but will likely begin to need help with complicated tasks such as balancing a checkbook and planning for the future.

In the early or mild stage of dementia, particularly Alzheimer's dementia, forgetfulness and mild emotional changes are the most common symptoms. Although less obvious, logical thinking and judgment are also mildly affected.

At this stage, you will notice a little confusion with multi-step tasks, increased frustration, and a loss of interest in usual activities. People living with mild dementia understandably try to hide their confusion from friends, coworkers, and family. A person may begin to repeat questions over and over due to short term memory loss.

Even when symptoms are mild, behaviors can begin to change—especially with Alzheimer’s disease. People living with mild dementia know something is wrong. They may begin to feel stress and anxiety and worry about the future. Depression can become an issue as they struggle with changes in their thinking.

People living with mild dementia can occasionally become angry or aggressive. They often have increased difficulty making decisions. They will ask for help more often. They still might be able to work, drive, and live independently, but they will begin to need more help from family or coworkers.

3.1.2 Symptoms and Behaviors in Moderate Dementia

As Alzheimer’s disease progresses from the mild to moderate stage, plaques and tangles spread to the areas of the brain involved with language, judgment, and learning. Work and social life become more tiring and challenging. Speaking and understanding speech; the sense of where your body is in space; executive functions such as planning, logical thinking, safety awareness; and ethical thinking are affected. Many people are first diagnosed with Alzheimer’s disease in this stage.

In the moderate stage of dementia, behavioral changes are more obvious to family members and caregivers. Increased forgetfulness and confusion, difficulty with communication, and impaired (weakened) judgment and reduced logical thinking are common symptoms. Cursing, arguing, yelling, or hitting can develop at this stage, often due to unmet needs. Some people may repeat questions over and over, call out, or continually demand attention. Sleep problems, anxiety, agitation, and suspicion can develop.

Because the part of the brain that controls movement is not damaged, some people living with moderate dementia might wander. More direct monitoring (watching) is needed than during the early stage of dementia and people at this stage may no longer be safe on their own. Caregiver responsibilities increase, causing stress, anxiety, and worry among family members and caregivers.

3.1.3 Symptoms and Behaviors in Severe Dementia

My mom is a 96-year-old and has pretty severe dementia. She lives at home with 24/7 care. She would hate being in a nursing home and probably wouldn’t survive there for long. Loud noises, too many people around, people who don’t know her needs and habits, boredom, loneliness—all those things would drive her crazy. She likes to walk and I’m sure she’d wander, and probably swear, hit, or cry. At home she doesn’t do any of these things very often, but we work pretty hard to keep things quiet, warm, and consistent for her.

Family Caregiver, Miami, Florida

In the late or severe stage, damage is spread throughout the brain. Because so many areas of the brain are affected, individuals may lose their ability to communicate clearly, to recognize family and loved ones, and to care for themselves.

People with severe dementia can lose all memory of recent events although they often still remember events from the past. They tire easily, are unable to make decisions, are easily confused, and cannot think logically. Speech, communication, and judgment may be severely affected. Sleep disturbances and emotional outbursts are very common.

All sorts of challenging behaviors occur at this stage. Screaming, swearing, crying, shouting, loud demands for attention, negative remarks to others, and self-talk are common. These types of behaviors are often triggered by boredom, loneliness, depression, cold or heat, loud noises, or pain, and should not be shrugged off by caregivers.

Behaviors seen in the moderate stage will likely persist and worsen in the severe stage of dementia—especially if caregivers fail to determine the cause of the unwanted behavior. Wandering, rummaging, and hoarding are common behavioral issues. Some people, particularly those with Lewy body dementia, may become paranoid or experience delusions or hallucinations.

3.1.4 Symptoms and Behaviors at End of Life

Although you will use many of the same communications techniques you have already learned, a person living with dementia nearing the end of their life will probably be more challenging. Nonverbal communication skills are critical—especially if the person’s dementia is severe. This means you need good nonverbal communication skills but must also be able to understand and interpret your client’s nonverbal cues. All the things we take for granted and all the things we do to keep ourselves comfortable depend on the skill and compassion of caregivers.

To complicate things, some people living with dementia may refuse to take medications. Some may have problems swallowing a pill. Symptoms can change from day to day and a treatment that worked one day may not work the next day.

As a person living with severe dementia nears the end of their life, they may be nonresponsive or experience significantly reduced mobility. Caregivers and healthcare providers must closely monitor nonverbal cues that indicate pain or discomfort.

At the end of life, a person living with dementia may experience agitation, *psychosis*,* *delirium*,** restlessness, and depression. Because of hearing and visual deficits, they can be startled by loud noises and quick movements. Communication may be entirely nonverbal: moaning, calling out, hitting, biting, and grabbing.

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

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

3.2 The Problem-Solving Approach

The **problem-solving approach** encourages caregivers and family members to understand and address challenging behaviors by looking for the root cause of a behavior and treating it—usually by changing the environment, managing medication, and further caregiver training. The problem-solving approach identifies critical points for intervention based on observing the *antecedent*, *behavior*, and *consequence* (A, B, C) of a challenging behavior.

- **Antecedent**—what caused the behavior?
- **Behavior**—what is the behavior?
- **Consequence**—what are the consequences (outcomes) of the behavior?

The ABC approach is very effective when successful strategies are shared by staff, caregivers, and family members. It helps caregivers understand when, and how often, a behavior occurs and offers the opportunity for discussion and planning.

The problem-solving approach is also valuable for examining your own behaviors and responses to dementia. How you react and interact with a person living with dementia can have a profound effect on that person’s behavior. Understanding your own *biases* (personal viewpoints), frustrations, and *triggers* (what makes you behave in a certain way) will help you approach a person struggling with dementia with patience and compassion. When examining the cause of a difficult behavior, consider the following:

- Does the behavior last all day?
- Has the person’s behavior recently changed?
- Has there been success dealing with the behavior in the past?
- Is the person experiencing something that is treatable?
- May the treatment or intervention affect the person’s functioning?
- Is a treatment done for the convenience of the caregivers?

3.3 Strategies and Techniques for Addressing Challenging Behaviors

Caring for a person having cognitive and sensory changes due to dementia requires strategies and techniques that need to evolve as a person's dementia changes. Family caregivers may not understand (or want to understand) that dementia is progressive (gets worse with time), and strategies and techniques that work with mild dementia may not work as the dementia progresses. Healthcare providers and care workers may fall into the same trap and must learn strategies and techniques that are effective for each person's level of dementia.

There are certain strategies and techniques that are useful, no matter the type or stage of dementia. A problem-solving approach is useful because it encourages care providers to try to understand the root cause of an unwanted behavior while also considering how their own behaviors and responses might be affecting the person they are caring for. There are some behaviors that are commonly seen in people living with dementia, although they are certainly not universal or inevitable.

3.3.1 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. Instead, these reactions should be viewed as an expressive communication of a possible unmet need.

Teepa Snow, STOP Treating Behaviors with Restraining Medications
teepasnow.com

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

Agitation is a restless behavior that is excessive, inappropriate, and repetitive. It includes a wide range of behaviors. **Aggression** involves physically or verbally threatening behaviors.

Agitated and aggressive behaviors can include:

- insulting caregivers
- shouting, screaming, and loudly demanding
- hitting, punching, kicking, pushing
- throwing objects or using objects to hit or lash out
- engaging in inappropriate sexual advances or obscene language

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

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

Try the following tips to help manage these symptoms:

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

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

Behavioral interventions, including searching for behavioral triggers (what touches off the behavior), remain the preferred management strategy for dealing with agitation and aggression (AGS, 2023). Psychosocial and environmental interventions can reduce or even end agitated or aggressive behaviors.

The use of antipsychotic medications should be a *last resort* and used only in collaboration with shared decision-making with older adults and their care partners. The 2023 updated AGS Beers Criteria for potentially inappropriate medication use in older adults stresses the need to avoid medications for behavioral problems associated with dementia and delirium because *their use is frequently associated with harm* (AGS, 2023).

3.3.2 Dementia-Related Psychosis

Psychosis is surprisingly common in Alzheimer's disease and can emerge as part of the disease process during the mild cognitive impairment (loss or weakness) stage or even earlier (Ismail et al., 2022). Dementia-related psychosis can include delusions, paranoia, and hallucinations.

A **delusion** is a false belief about reality. **Paranoia** is a type of delusion in which a person may believe that others are lying to them, being unfair, or are "out to get me." A person may become suspicious, fearful, or jealous of other people.

Hallucinations occur when a person hears, tastes, smells, sees, or feels something that is not there. A person living with dementia might see or hear something they believe is real that exists only in their mind. For example, they may see someone outside their window, bugs crawling on the wall, or images of threatening people or things. One caregiver reported that her father saw the Wells Fargo wagon with horses on the wall opposite his bed!

Visual hallucinations sometimes occur in the moderate to severe stages of dementia and are particularly common in people living with Lewy body dementia. In a person with new onset of visual hallucinations, the number one cause is medication side effects. For this reason, all medications the person is receiving should be carefully reviewed.

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

The first step in the management of delusions and hallucinations is to rule out delirium or an acute medical cause. Observing a person's behavior and listening to what they have to say can help caregivers address the cause of the delusion or hallucination.

When communicating with someone who is experiencing paranoia or delusions, know that even if their complaint is not true, *it is very real for that person*. Do not argue; simply explaining the truth of the situation does not work. Do not buy into the paranoia or delusion; instead, try to respond to the person's emotion. For hallucinations, it is often helpful to decrease auditory and visual stimuli, as well as to evaluate for visual or hearing impairment.

Case: Joining Rose in Her Own Reality

Background: Rose is an 89-year-old woman living with moderate to severe dementia. She lives at home with her daughter in South Florida. She is generally cooperative and uncomplaining.

Antecedent: Rose has suddenly become very agitated and refuses to sit in her recliner in the living room. She says she is upset at noises she hears in the ceiling. She is convinced that animals are living in the ceiling and want to hurt her.

Behavior: Because she was so frightened, she wants to stay in her bedroom. Her daughter convinces her that it is okay to at least come to the kitchen for meals. After eating, Rose insists on going back to her bedroom.

When I heard about this, I asked Rose's daughter to "put yourself in Rose's place and listen for the noise" by sitting in the living room for a little while. Surprisingly, Rose's daughter heard scratching noises from above.

Consequence: An investigation revealed that a tree branch was scraping the roof of the one-story home when it was windy. It was removed the next morning, but Rose was still frightened and would not budge from her bedroom except for meals. No amount of explanation or "reasoning" with her would help. In her mind, she was in danger from the animal in the ceiling.

Discussion: We thought about what we needed to do for Rose. Her daughter decided to "get rid of the animal." She brought in a ladder and a paper bag. Removing the ceiling tile, she climbed up and made some banging noises. Inflating the bag, and twisting the top, she came down the ladder with the "animal" in tow. Rose, who had been watching closely, was relieved, and since the noise from the branch was gone, the "animal" never came back, Rose said she felt safe and happily returned to her recliner in the living room.

There may be times when caregivers and healthcare providers attribute a person's complaints or anxiety to paranoia or delusion. But the claims by the person living with dementia may be real. For example, in a Florida nursing home, complaints of strangers entering several resident rooms and stealing items were attributed to dementia and psychosis by staff (including nurses and physicians). When the complaints increased, the facility installed cameras in the alley next to the facility. Several of the rooms facing the alley had malfunctioning locks on their sliding glass doors and the cameras showed that people were entering resident rooms at night and rummaging through residents' drawers and closets. Thieves really were entering the bedrooms of the residents and stealing items!

3.3.3 Wandering

Wandering and exploring are activities that almost everyone enjoys. But because a person living with dementia might be at risk of falls or injury, providers and caregivers often see wandering as a problem. For a variety of reasons, caregivers may want to control or prevent wandering. 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 behaviors vary depending on the person and the type and stage of dementia. It can involve repeatedly moving to a specific location, lapping or circling along a path, or pacing back and forth. Wandering is a common behavior seen in people living with almost all types of dementia. Nearly 60% of people living with dementia will wander during the course of their disease. Wandering can happen at home or in the community. In institutional settings, wandering occurs in about 40% of clients (Anu et al., 2024).

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

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

Address wandering by:

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

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

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



This person may not be able to find "home." (Source: NIA, public domain).

Case: The Wanderer

Background: Elena lives in a five-story apartment complex in Miami. She has moderate dementia and can still walk without assistance. Her daughter prepares her breakfast, then leaves to go grocery shopping. After breakfast, Elena gets bored, exits her apartment, and heads out into the hallway. She passes a few neighbors who say hello and ask how she's doing.

After the brief conversations, Elena continues in the direction she was headed. She stops near an elevator, where she sits on a small bench, watching people come and go. After a few minutes, she steps into the elevator.

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

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

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

Discussion: Large apartment buildings are busy places and not designed for people with dementia. Nevertheless, caregivers and healthcare providers should try to understand the reason for Elena's wandering and come up with activities that are appropriate for a person like Elena. Regular medications reviews will help staff understand if Elena's behavior is related to medication side effects, overmedicating, or drug interactions. To keep Elena from eloping from her apartment building:

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

Did you Know. . .

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

3.3.4 Rummaging and Hoarding

A person who *rummages and hoards* gathers, hides, or puts away items in a secretive and guarded manner. These actions are considered a type of obsessive-compulsive behavior (OCD). Rummaging and hoarding are not necessarily dangerous or unsafe, but they can be frustrating for caregivers and other residents.

Memory loss, poor judgment, and confusion can contribute to rummaging and hoarding. People may rummage because they are bored or to find something they think has been misplaced. They may have a fear of being robbed or feel a need to protect their possessions. Rummaging through familiar items can create a sense of safety and security.

To address rummaging and hoarding behaviors, try to determine what triggers (touches off) the behavior. Look at the after-effects, if any. The reason for rummaging and hoarding may not be clear to you but there may be a perfectly good reason why someone living with dementia is rummaging.

Rummaging through another person's belongings can be prevented by installing locks on drawers and closets. Caregivers who create a rummaging room, or a bag or drawer of items that the person can pick through, may find it useful. Restricting all rummaging and hoarding can be frustrating for a person who enjoys these activities.

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

Other recommendations:

- Remove or lock up poisonous items such as caustic liquids and poisonous plants.
- Label cabinets, doors, and closets with words or pictures.
- Reduce clutter.

3.3.5 Sleep Disturbances

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

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

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

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

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

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

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

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

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

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

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

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

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

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

When treating sleep disturbances, look for potentially treatable causes, such as pain, hunger and thirst, the need to urinate, infections, adverse drug reactions, and even noise. Non-drug treatments shown to improve sleep include:

- light therapy
- exposure to natural light
- 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

3.4 Alternatives to 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

A **physical restraint** is any manual, physical or mechanical device, material, or equipment attached to or next to a person's body that the individual cannot remove easily, and which restricts the person's freedom to move or reach their own body.

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

Restraints affect a person's sense of well-being. They cause feelings of low self-worth, depression, withdrawal, humiliation, and anger. They can also increase agitation and confusion, and cause deconditioning (failure to thrive), pressure ulcers, strangulation, and even death.

According to Florida law, patients must be free from physical or chemical restraints that are not required to treat a medical symptom. *A restraint cannot be used for discipline or convenience.* If a restraint is used, it must be the least restrictive alternative, for the least amount of time, and be regularly re-evaluated (FL Statutes, 2024).

Staff must complete a formal assessment on the risk of using a restraint to determine if a less restrictive method is safer. Medical problems such as temperature elevations, hypoxia (low levels of oxygen), hypoglycemia (low blood sugar), electrolyte imbalances, drug interactions, and drug side effects must be carefully considered. These issues can cause confusion, agitation, and aggressive behaviors (FL Statutes, 2024). They should be considered before resorting to restraints.

Restraints are not only limited to physical devices or chemical substances. They can include using (or threatening) force; also, restricting a person's movements—even if they do not resist (Nuffield Council on Bioethics, 2009 latest available). Forced isolation (such as locking a person in their bedroom) is also a type of restraint.

Behavioral interventions are preferred for treatment of difficult behaviors associated with dementia. The decision to use or not use a physical or chemical restraint should **always** be made while including the patient and family members (AGS, 2023).

3.4.1 Types of Physical and Chemical Restraints

Physical restraints can include:

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

Physical restraints should not be considered a routine part of a falls-prevention program. There is no evidence that the use of physical restraint (including 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 decreases the risk of falling (CMS.gov, 2024).

The use of chemical restraints is limited to prescribed dosages of medications authorized by a physician and must be consistent with the person's diagnosis. Clients who are receiving medications that can serve as chemical restraints must be evaluated by a 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.

A provider may choose to prescribe an antipsychotic medication when symptoms are severe, dangerous, or cause undue distress to the patient. These medications may be effective in some cases. However, the provider must disclose to the patient 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 patient 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.

3.4.2 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 person's ability to move about safely, adjusting care and caregiver assignments to a client'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 dashes to the bathroom that increase the risk of falls. Regular exercise, a comfortable place to rest, and a schedule for napping may 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 client 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 and reduces caregiver stress and worry.

4. Assistance with Activities of Daily Living (ADLs)

The “small things” of care are particularly important in ensuring that care is genuinely supportive of the individual and enhances that person’s autonomy and well-being. The humanity with which assistance for everyday living is offered, especially help with eating and intimate care, is crucial in helping the person retain their self-esteem and dignity.

Nuffield Council on Bioethics

Activities of daily living (ADLs) are the tasks we do during our daily lives. ADLs can be divided into *basic* ADLs and *instrumental* ADLs. **Basics ADLs** are the skills needed to take care of personal needs such as:

- eating
- bathing and showering
- grooming
- walking
- dressing and undressing
- transfers
- toileting

Instrumental ADLs (IADLs) are the skills we need to function within the community such as:

- financial management
- shopping
- preparing meals
- communicating with the outside world
- medical and medication management

Promoting independence in a person living with dementia requires patience and the ability to understand and accept that dementia changes how a person approaches an activity. Many caregivers assume a person living with dementia is child-like and no longer capable of understanding directions. Many caregivers simply take over the task. This not only robs people of their independence but also affects their self-worth.

ADL “skills training” is recommended for all caregivers—both family and professional. Emphasis is on encouraging independence in all activities while providing appropriate assistance when needed. ADL skills training can minimize caregiver stress and reduce the amount of physical labor required of a caregiver.

4.1 Strategies for Success in Various Stages

When assisting a person living with dementia with their ADLs, encourage them to say what they want. Try to understand why a person might refuse your help. Are they scared? Do they not understand what you asked them to do? Are they embarrassed? Are they cold or in pain?

If the person seems confused, repeat your request. Offer simple choices, such as “Do you want orange juice or apple juice?” Be empathetic. Examples of empathetic responses include “You must be cold” or “Are you uncomfortable in that chair?” “What would help now?”

A skilled caregiver learns to continually assess the abilities of the person they are assisting. More or less assistance may be needed depending on the task, the time of day, a person’s general health, and the level and type of dementia. For example, a person who is capable of independent self-care but has poor balance might need help setting up a place to safely brush her teeth and do other grooming.

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

- Make eye contact (where culturally appropriate).
- Do not crowd.
- Be aware of your body language and vocal tone.
- Slow the speed of your movements and speech.

Good communication is the basis for success. A calm tone and short, direct sentences build trust and encourage independence. Remember that people living with dementia often need time to complete a task. A caregiver must be patient while assessing the amount of help needed and must resist the urge to jump in to help when no help is needed.

Case Example: Lula

Lula is a 96-year-old woman with severe macular degeneration, significant hearing loss corrected with hearing aids, and moderate to severe dementia. She lives at home in Jacksonville, Florida, and is generally very cooperative and agreeable. Her daughters stay with her for 4 days each week and have hired a caregiver for the other days.

Her current caregiver has very poor English skills, does not speak Spanish, doesn't understand that Lula can't hear her, and often fails to understand what Lula is saying. Often the caregiver forgets to give Lula her hearing aids, or she puts the hearing aids in with dead batteries. She leaves the TV on when trying to talk to Lula and tends to speak in long complicated sentences. She uses phrases and words that are completely unfamiliar to Lula.

For example, when the caregiver wanted Lula to wipe herself after she finished urinating, she asked Lula to "wipe her jewel." Lula had no idea what she was talking about. Lula always tries to respond to her caregiver, even when it's clear she has no idea what she's being asked to do. Because Lula smiles and responds, the caregiver swears Lula understands her and is just being stubborn when Lula doesn't do what's asked. Lula's daughter has tried to explain this, but the caregiver ignores her.

4.1.1 ADL Strategies: Mild Dementia

A person living with mild dementia may not need any help with dressing and grooming. A caregiver can lay out a person's clothes or make suggestions, but generally a person living with mild dementia can choose what clothing they want to wear and handle grooming without much help. A caregiver may make suggestions such as using an electric razor instead of a handheld razor or provide grooming supplies. At this stage, the caregiver's role is to help as needed while promoting and encouraging independence.

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 your client 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.

4.1.2 ADL Strategies: Moderate Dementia

In the *moderate* stage, depending on a person's strength, balance, and flexibility, a caregiver will likely need to assist with at least some aspects of a person's ADLs. For example, Lula, mentioned above, has severe macular degeneration and moderate dementia. But she is very flexible and still fairly strong at the age of 95. When she's sitting in a chair with proper back support, she can easily bring her knee up to her chest. However, she can't see where her clothes are placed. It's tempting to do everything for her, but this increases caregiver burden and fails to promote Lula's independence. In this case, the caregiver can help Lula by laying out her clothes and providing verbal cues to direct the activity.

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

For some, walking, transferring, bed mobility, and basic ADLs remain relatively independent. For others, especially those with physical limitations, more help may be required.

In the moderate stage, caregiver responsibilities increase. Cooking, housework, and shopping may require direct assistance. Typically, in the middle stage, setup, close or direct supervision, and initial guidance or assistance are required for planning and safety due to decline of executive function.

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 clothes in order.
- Provide multiple pairs 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, 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.

Step-by step cues can be helpful, in addition to demonstrating the task. Aid with setup and offer guided touch for support or to initiate the task.

- 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 utensils as needed.
- Monitor closely.
- Place food on a colored plate (for food contrast).
- Alter the meal schedule to suit the needs of the person living with dementia.

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. Avoid scrubbing fragile skin. 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 setup 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.

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.

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

4.1.3 ADL Strategies: Severe Dementia

As dementia progresses to a more *severe* stage, caregivers must provide more help with ADLs. Many caregivers help too much, partly because a person living with dementia takes a long time to complete what used to be simple and automatic.

Caregivers often get impatient (even bored) with the slow pace, especially for a person with severe dementia. Slowing down, encouraging independence, and maintaining an attitude of watchful patience are critical skills for a caregiver to develop and practice.

In the severe stage, a great deal of independence is lost, and caregivers will likely need to oversee and directly assist with eating, bathing, walking, dressing, and other daily living activities.

Difficulty swallowing (dysphagia) can develop in the later stage of dementia, leading to *aspiration** of food, fluids, or saliva into the lungs. To prevent this from happening, a speech-language pathologist can help caregivers develop a plan to modify foods by softening the texture of food and thickening liquids.

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

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

- Sitting in a supported, upright position.
- Reducing the size of bites.
- Avoiding the use of sedatives and narcotics.
- Providing good oral care.

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

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

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

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

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

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

In the severe stage of dementia:

Dressing

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

Grooming

Step-by step cues can be helpful, in addition to demonstrating the task.

- 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, Eatwell.com. Used with permission. From <http://www.eatwellset.com/#!/features/cf1a>.)

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.

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



A shower chair. Source: Author.

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.

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.

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

4.1.4 Incontinence

Incontinence is the involuntary leaking of urine or feces, or both. Whatever the stage of a person's dementia, incontinence is embarrassing and stigmatizing. Incontinence adds to caregiver stress and depression and is often a factor in the decision to admit a family member to a care home. Because many caregivers believe it is normal for older adults to be incontinent, reversible causes of incontinence may not be adequately considered.

Incontinence can be related to a medical problem such as urinary tract infection, constipation, or prostate problems. It can also be associated with diabetes, stroke, Parkinson's disease, and physical disabilities that prevent the person from reaching the bathroom in time. Medications and diuretics (drugs that increase urination) can also cause incontinence. Sleeping pills and anxiety-reducing drugs that relax the bladder muscles, and drinks such as soda, coffee, and tea, can contribute to incontinence (Alzheimer's Association, 2026b).

Techniques and strategies used by caregivers to manage toileting and incontinence in a person living with dementia typically start with reminders to go to the toilet on a regular basis. As dementia progresses, other techniques may be needed such as adult diapers, bedside commodes, and direct help from the caregiver. At every stage of dementia, assistive equipment promotes independence and decreases the amount of direct caregiver assistance.

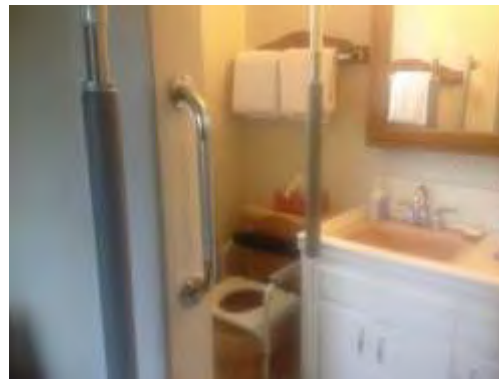
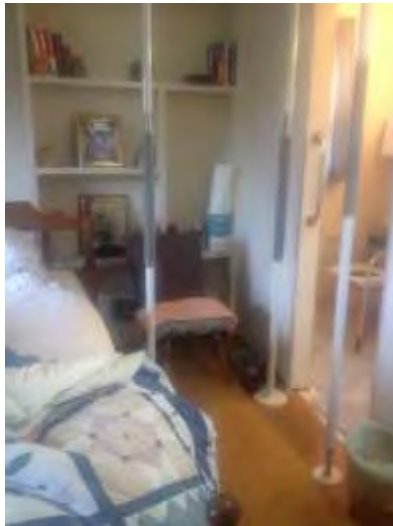
To make it easier for a person living with dementia to find and use the toilet, clear the path to the bathroom and keep the bathroom door open so the toilet is visible. Make the toilet safe and easy to use by raising the height of the toilet, installing grab bars, and using night lights to illuminate the bedroom and bath.

Additional recommendations:

- Consider a portable commode or urinal for nighttime use.
- Remove plants, wastebaskets, and other objects that could be mistaken for a toilet.
- Remove slippery throw rugs.
- Use glow-in-the-dark tape to create a clear path to the toilet.

Stress incontinence (involuntary loss of urine), can sometimes be reversed through surgical interventions. *Kegel exercise*—in which the floor of the pelvis is strengthened by regular contractions—can be of great help in this type of incontinence. Some people require a combination of treatments such as *anti-spasmodic medications** with lengthened periods between toileting to increase bladder capacity and reduce wetting episodes.

***Anti-spasmodics:** medications that relax smooth muscles and help treat overactive bladders.



An example of a bathroom with grab bars, shower chair, and floor-to-ceiling transfers poles for a woman living with moderate to severe dementia who could walk with assistance. Nearly to the end of her life she was able to safely go from her bed to the toilet without assistance. The pole next to the chair provided balance for transfers and dressing. The pole next to the sink was installed because she tended to swing onto the toilet as soon as she got close, rather than stepping and turning. Prior to installing the sink pole, she broke a lower rib when she hit the corner of the cabinet during a transfer. The bathroom door was removed for wheelchair access, allowing her to safely stand or sit at the sink for grooming. (Source: Author.)

5. Developing Skills for Working with Families and Caregivers

Family caregivers of people living with dementia are often called the invisible second patients. The effects of being a family caregiver, though sometimes positive, are generally negative, with high rates of burden and psychological morbidity as well as social isolation, physical ill-health, and financial hardship.

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Family caregivers provide the vast majority of care for older adults living with dementia. Healthcare providers must learn how to communicate skills and techniques to sometimes-resistant family members and often-untrained paid caregivers. Differences in education, training, and cultural backgrounds can make this more difficult.

In many cases, the vital caring role of families and their need for support is overlooked. Family caregivers often take on the role of caregiver unexpectedly and struggle to add caregiver duties to busy lives.

Family caregivers are often isolated, lack support, and don't know much about dementia. They must manage medications and medical care and often have trouble obtaining and sharing information. Over time, prolonged stress can cause frustration, anxiety, depression, and burnout.

Lack of knowledge not only affects the mental health of caregivers but also their caregiving abilities. Dementia education improves care management and encourages caregivers to seek counseling, join discussion forums, and attend support groups (Scerbe et al., 2023).

5.1 Recognizing Concerns and Issues of Family Members

For me, taking care of my own health and well-being took a nosedive as my mom's dementia got worse. As my sister and I neared the end of our mom's life, we were drained emotionally and financially, hobbies and vacations were a distant memory, friends had been neglected, and some family relationships were damaged beyond repair. Until we have a national program to provide training, oversight, and money for caregivers, I don't see things changing very much.

Family Caregiver, Palm Beach, Florida

Caring for a person living with dementia is a huge commitment and places both financial and physical strain on family caregivers. On average, caregivers spend 14 hours per week assisting with basic ADLs and up to 43 hours per week when more complex assistance and supervision are needed (ADI, 2013). For family caregivers, 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.

Caregivers of people living with dementia on average provide care for a longer time than caregivers of older adults with other conditions. These caregivers report providing 27 hours more care per month on average than caregivers of people without dementia. 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 medical/nursing tasks (Alz.org, 2023a).

Caring for a person living with dementia also means managing symptoms that caregivers of people with other diseases may not face, such as mental symptoms (for example, anxiety, agitation, apathy, and lack of inhibition) and other behavioral problems. Family caregivers often lack the information or resources necessary to manage the increasingly complicated medication programs for people living with dementia (Alz.org, 2023a).

Because family and unpaid caregivers provide a major societal benefit (often at considerable personal cost), there have been calls for support services that enable continued care in the home. Improving a caregiver's skills decreases burden and improves quality of life for both the caregiver and the person living with dementia. Caregiver training decreases depression, anxiety, sleep disturbance, hospital stay and mortality and reduces the risk of the patient living away from home (Nichols et al., 2017).

Providing Dementia Care in Florida

In Florida, people who are caring for a person living with dementia provide care for an average of 4 or more years—some for more than 9 years. In Florida, about 870,000 Floridians provide care for someone living with dementia (Alz.org, 2025):

- Most caregivers are unpaid.
- About 2/3 of caregivers have chronic health problems themselves.
- About 1/3 have clinical depression.

5.1.1 In the Early Stage

In the early stage of dementia, family members must manage their own frustrations as they learn about the effects of dementia. They are often unaware of available services and may find their family member's primary care physician is of little help. Nevertheless, care duties are usually manageable in the early stages of dementia when very little direct care is needed.

Early specialized training is recommended for family caregivers. This is an important but often completely overlooked part of dementia care. Training educates family caregivers about dementia and encourages them to partner with healthcare providers to provide good care.

Spouses who care for a partner living with dementia may not be in good health and may not know how to provide care as the dementia progresses. Likewise, an adult child can struggle with having to take over the care of a parent and assuming a new role in the family.

5.1.2 In the Middle Stages

As the dementia progresses from the mild to moderate stage, caregivers begin to invest more time, energy, and money, leading to high levels of burnout. Depression, poor self-health, stress, and lower levels of life satisfaction can begin to affect the caregiver. Family caregivers in particular are less likely to engage in preventive health behaviors for themselves.

In the middle stages, difficult behaviors may arise that demand complicated decisions about interventions and, perhaps, medications. In addition, family caregivers must often cut back on employment as the demands of caregiving increase.

5.1.3 In the Late Stages

Even with proper training and mentoring, it's nearly impossible to be a great caregiver all the time. It's no fun getting up in the middle of the night to clean up after an incontinent family member. It's almost impossible to be patient when your mom swears at you, screams, hits, bites, collapses during a transfer, or refuses to eat. But the dementia training and resources I found online helped a lot—it gave me strategies and techniques to use when all seemed lost and when nothing was working.

Family Caregiver, Ft. Lauderdale, Florida

Caring for a person living with severe dementia means caregivers are involved with every aspect of a person's care. During the final year, a family caregiver may be on duty throughout the day and night. Many family caregivers admit they experience relief when the person they are caring for dies.

A person living with severe dementia may no longer be able to communicate their needs clearly. This can be frustrating for caregivers, who will struggle to understand the person's needs. Caregivers must learn to interpret facial expressions for sadness, anger, or frustration, and physical gestures such as grasping at undergarments, which can communicate the need to use the bathroom.

One of the most difficult issues facing a family caregiver—usually in the middle to late stages of dementia—is the decision to place a family member in residential care or skilled nursing. Reasons cited by caregivers for placement are:

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

Turning over full-time care can cause feelings of loss, sadness, resignation, and depression for family caregivers. Unfortunately, moving to a care facility may not reduce the stress that a caregiver experiences.

If the person living with dementia moves to a care facility, family caregivers must learn to navigate a complicated healthcare system. Healthcare workers can support family members by determining the preferences, abilities, and resources of each family member. Regular face-to-face meetings with family members and facility staff will help families work through difficulties.

5.2 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

Receiving a diagnosis of dementia can cause concern and grief for everyone involved. For the person living with dementia, grief is related to changes in social roles, loss of friends, and the breakdown of social networks. There is real concern about loss of income and savings, loss of self-sufficiency and privacy, potential changes in housing and personal possessions, and loss of pets. Grief can also cause physical symptoms such as shortness of breath, headaches, fatigue, a feeling of heaviness, and a lack of energy.

For family caregivers, grief is associated with:

- loss of companionship as a person's dementia progresses
- reduced income due to caregiving responsibilities
- loss of privacy and free time
- changes in routines and social roles
- loss of time for hobbies and social activities

Moving to a nursing home can cause both grief and relief for family caregivers. Nursing homes and assisted living facilities are chronically understaffed, lack privacy, usually don't allow pets, and truly represent the last stage of a person's life. This can cause grief and depression for the person living with dementia as well as family members and friends.

Spouses often experience different grieving patterns than other family caregivers. Grief can get worse at key times such as the point of diagnosis, transition to a care facility, facing the end of life, and physical death (Rupp et al., 2023).

5.2.1 Five Key Dimensions of Grief

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

1. Grieving for the person I used to be.
2. Concern for how others see me.
3. Grieving the person I will become.
4. Grieving for those who have died.
5. Not knowing what helps me with my grief.

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

5.2.2 Anticipatory Grief

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

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

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

5.2.3 Physical and Psychological Symptoms of Grief

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

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

5.2.4 Caregiver Grief

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

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

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

5.2.5 Loss of Friends and Family Members

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

Family Caregiver, Lauderdale Lakes, FL

Bereavement-related grief is related to the death of family members, friends, and neighbors, and opinions differ on whether to inform people living with dementia of a death. Some caregivers feel that everyone had a right to be informed; others feel that telling people living with dementia can lead to unnecessary distress (Waddington et al., 2023).

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

5.3 Strategies for Encouraging Family Involvement

Encouraging family members to be involved in the care of a family member can be challenging for healthcare providers. Training, education, and support are critical. Training introduces caregivers to resources and equipment that can improve health and safety and reduce caregiver strain.

The duties associated with caring for a family member living with dementia usually develop slowly, requiring more time, knowledge, and skills over time. Encouraging family members to attend a support group or dementia care program early in the caregiving journey is strongly recommended.

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.

The system of unpaid family care is under intense pressure due to declining fertility rates and fewer young people willing to care for older adults. Many family members do not live near their older adult relatives.

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.

Family caregivers often defer to medical professionals even though they know quite a lot about the needs of the person for whom they are caring. Healthcare providers often do not see family caregivers as partners in care. Family caregivers may not know what questions to ask or how to respond to the information they receive.

[Continue to next page for references]

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[Please continue to next page to start quiz]

Quiz: FL ADRD for Home Health (376)

1. Alzheimer's disease is:
 - a. A progressive brain disease.
 - b. A change in thinking that happens to everyone as they age.
 - c. An older person's reaction to a life of stress.
 - d. Being absent-minded or forgetful.
2. In older adults, delirium and depression may often be mistaken for dementia.
 - a. True
 - b. False
3. In general, when communicating with a person with dementia, it is important to understand that:
 - a. They understand everything you're saying.
 - b. They will respond better to a loud voice.
 - c. They have to work hard to say what they want to say.
 - d. Open-ended questions work better than closed questions.
4. Effective verbal communication strategies for successfully engaging with a person living with dementia can include:
 - a. Make eye contact and introduce yourself.
 - b. Approach from the front, then kneel down on the person's right side.
 - c. Use short, 1- or 2-step questions and await a reply.
 - d. All of the above.
5. Nonverbal communication is communicating through facial expressions, hand gestures, and body language.
 - a. True
 - b. False
6. Challenging behaviors in a person living with dementia can depend on the type of dementia, environmental factors, unmet needs, caregiver competence, medical issues, and the overall quality of care.
 - a. True
 - b. False
7. The ABC approach for addressing challenging behaviors in dementia means understanding:
 - a. What caused the behavior (antecedent).
 - b. What is the behavior (behavior).
 - c. What are the consequences of the behavior (consequences).
 - d. All of the above.
8. One of your client's pinches and bites when you try to bathe her. Your best response is to:
 - a. Ask her family to come in and bathe her.
 - b. Restrain her in a shower chair and bathe her anyway.
 - c. Observe her behavior to determine the cause of her agitation.
 - d. Don't bathe her when her behavior is bad.

9. According to Florida law, a restraint cannot be used for discipline or convenience. If a restraint is used, it must be the least restrictive alternative, for the least amount of time, and regularly re-evaluated.

- a. True
- b. False

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

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

11. Encouraging independence in people with dementia:

- a. Not recommended because people with dementia have poor safety skills.
- b. Delays the progression of dementia.
- c. Involves good communication, caregiver skills training, and regular physical activity.
- d. Causes depression because it is a reminder of lost skills and abilities.

12. A person in the moderate stage of Alzheimer's disease will likely:

- a. Be able to drive safely.
- b. Have difficulty with complex tasks.
- c. Have completely lost the ability to function independently.
- d. Have a complete loss of short-term memories.

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

- a. Receive early, specialized training about dementia.
- b. Quit their jobs and provide 24/7 care.
- c. Take over as many tasks as possible so the person with dementia is well-cared for.
- d. Go on with your life and ignore any changes in their loved one.

14. One of the most difficult issues facing a family caregiver—usually in the middle to late stages of dementia—is the decision to place a family member in residential care or skilled nursing.

- a. True
- b. False

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

- a. True
- b. False

16. "Ambiguous loss" complicates grief because the person with dementia is physically present but not mentally or emotionally the same as they were before the onset of dementia.

- a. True
- b. False

[Please continue to next page for answer sheet]

Answer Sheet: FL ADRD for Home Health (376)

Name (Please print) _____

Date _____

Passing score is 80 %

1. _____
2. _____
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[Please continue to next page for course evaluation]

Course Evaluation: FL ADRD for Home Health (376)

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. Define dementia. 1 2 3 4 5

2. Describe 1 technique each for improving verbal and nonverbal communication in a person living with dementia. 1 2 3 4 5

3. Describe 1 symptom or behavior change you might see during each stage of dementia. 1 2 3 4 5

4. Relate 3 techniques for promoting independence in activities of daily living. 1 2 3 4 5

5. Relate 1 concern or issue you might encounter with family members and caregivers at each stage of dementia. 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

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 _____ Searching the Internet. _____ A friend.
 _____ An advertisement. _____ I am a returning customer.
 _____ My employer. _____ Social Media
 _____ Other _____

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

_____ 18 to 30 _____ 31 to 45 _____ 46 +

I completed this course on:

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

Please enter your comments or suggestions here:

[Continue to next page for registration and payment]

Registration: FL ADRD for Home Health (376)

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

*Name: _____

*Email: _____

*Address: _____

*City and State: _____

*Zip: _____

*Country: _____

*Phone: _____

*Professional Credentials/Designations:

*License Number and State: _____

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

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

2 contact hours: \$24

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 provided by your employer, please enter it here:**