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Florida Alzheimer's Disease and Related Dementias for Home Health

Contact hours: 2

Course Price: $19

Author: Lauren Robertson, BA, MPT

FL DOEA Approval: This course is approved by the FL Department of Elder Affairs, curriculum approval #HH AD 9534 through June 6, 2023.

The author is certified as ADRD trainers by the FL 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 1315.

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 non-verbal communication, discusses symptoms seen at each stage of dementia, relates techniques intended to promote independence in activities of daily living, 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. State 3 differences between dementia and age-related changes in cognition.
2. Describe one technique each for improving verbal, non-verbal, and non-responsive communication in those with dementia.
3. Describe one 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. For each stage of dementia, relate one concern or issue you might encounter with family members and caregivers.

Understanding Alzheimer's Disease and Related Disorders (ADRD)

In this course we explain how dementia affects the brain and how Alzheimer's disease differs from other types of dementia. We review behaviors you might see in people with mild, moderate, and severe dementia and describe communication issues you will encounter at different stages. We offer techniques to address behavioral issues, and tools to promote independence in all activities. Finally, we will discuss how to work with family members and caregivers who are caring for a person with dementia.

What Is Dementia?

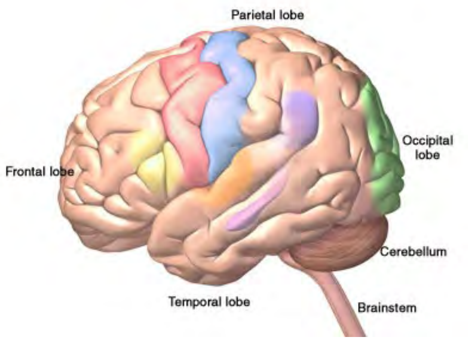
Dementia is a collective name for the progressive, global deterioration of the brain's executive functions. Dementia occurs primarily in later adulthood and is a major cause of disability in older adults. Although almost everyone with dementia is elderly, dementia is not considered a normal part of aging.

Dementia is caused by damage to a part of the brain called the **cerebrum**. The cerebrum fills up most of our skull and is divided into four lobes (one on each side of the head):

- Frontal
- Temporal
- Parietal
- Occipital

The cerebrum is what makes us human—it allows us to think, make plans, talk, and understand. It controls our memories and emotions. It helps us reason, make decisions, and tell right from wrong. It also controls our movements, vision, and hearing. Many of these areas of the cerebrum 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.

Dementia is a group of symptoms impacting cognitive functions such as memory, judgment, reasoning, and social skills as well as interfering with the ability to function in daily life. Dementia is *progressive*, meaning it gets worse over time. It is a terminal illness, meaning it will eventually lead to death. Alzheimer's disease (AD) is the most common kind of dementia.

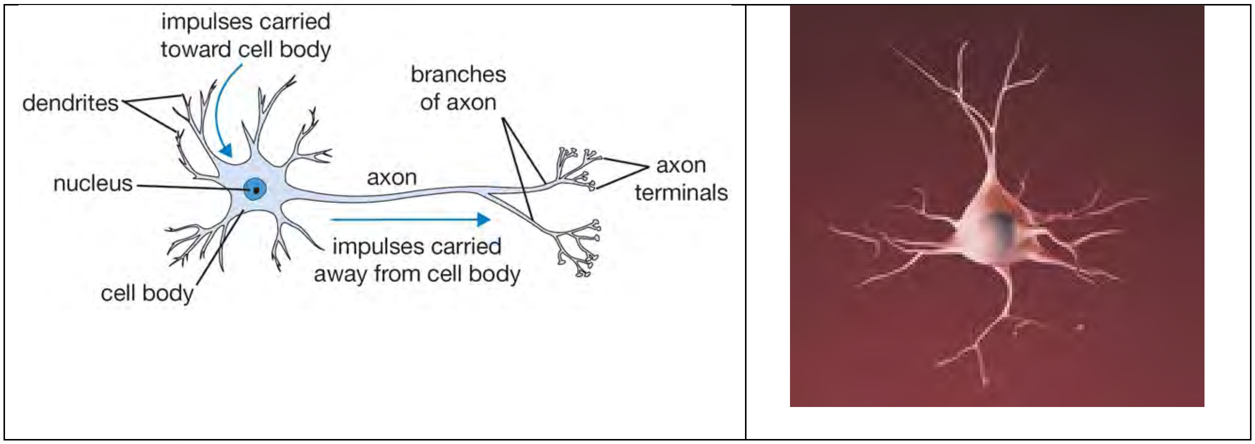
When someone has dementia their thinking becomes less clear. Decisions are more difficult and safety awareness declines. People also get tired more easily. Emotions are also affected—that's why people with Alzheimer's disease and other types of dementia sometimes have difficulty controlling their emotions.

For people between the ages of 65 and 75, only about 5% will get any sort of dementia. For people over the age of 85, about 40% will experience some form of dementia. Even so, dementia is *not* considered a normal part of aging.

How the Brain Works

The brain is the most complex organ in the human body. This three-pound mass of gray matter contains more than 90 billion nerve cells with about 150 *trillion* connections. The brain is at the center of all human activity—it regulates the body's basic functions, allows us to interpret and respond to everything we experience, and shapes our thoughts, emotions, and behaviors (NIDA, 2018).

A nerve call (neuron) has three major parts: (1) the cell body—the part of the nerve cell that contains the nucleus and other organelles, (2) the axon—an elongated process that carries the nerve impulse *away* from the cell body, and (3) dendrites—which *receive* nerve impulses from neighboring nerves and transmit them to the cell body.



Left: An illustration of a healthy neuron showing the nucleus, cell body, dendrites, and axons. Source: WPClipArt.com. Used with permission. From https://www.wpclipart.com/medical/anatomy/nervous_system/neuron/neuron.png.html. Right: A healthy nerve cell. Source: ADEAR, 2014. Public domain.

Left illustration is from
https://www.wpclipart.com/medical/anatomy/nervous_system/neuron/neuron.png.html

In healthy people, all sensations, movements, thoughts, memories, and feelings are the result of signals that pass through billions of nerve cells, or neurons, in the brain. Neurons constantly communicate with each other through electrical charges that travel down axons, causing the release of chemicals across tiny gaps to neighboring neurons. Other cells in the brain, such as astrocytes and microglia, clear away debris and help keep neurons healthy (NIA, 2017).

Most neurons in the human brain are *myelinated*. Myelin, also called white matter, is a fatty substance that surrounds the axon and increases the speed and efficiency of the nerve impulse. Myelin insulates the axon, preventing leakage of the electrical impulse into the surrounding fluid as well as providing structural support for the axon.

How Does Dementia Affect the Brain?

In a person with Alzheimer's disease, the most basic form of dementia, toxic changes in the brain destroy healthy tissue. These changes may occur years, even decades, before the first signs of dementia. This process involves two proteins called beta-amyloid and tau, which somehow become toxic to the brain.

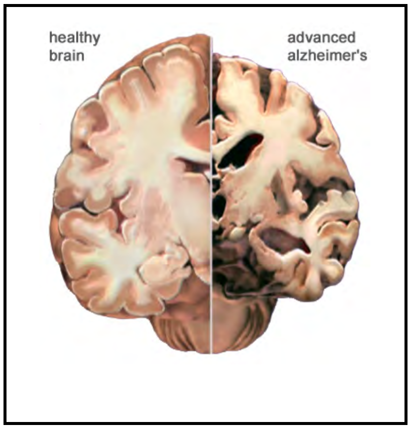
It appears that abnormal tau accumulates, eventually forming tangles inside neurons. The beta-amyloid form plaques, which slowly build up between neurons. As the level of amyloid reaches a tipping point, there is a rapid spread of tau throughout the brain.

But tau and beta-amyloid may not be the only factors involved in Alzheimer's. Other changes that affect the brain may also play a role over time.

- The vascular system may fail to deliver sufficient blood and nutrients to the brain.
- The brain may lack the glucose needed to power its activity.
- Chronic inflammation sets in as microglial cells fail to clear away debris, and astrocytes react to distressed microglia.

Eventually, neurons lose their ability to communicate. As neurons die, the brain shrinks, beginning in the hippocampus, a part of the brain important to learning and memory. People may begin to experience memory loss, impaired decision-making, and language problems. As more neurons die throughout the brain, a person with Alzheimer's gradually loses the ability to think, remember, make decisions, and function independently (NIA, 2017).

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

Because dementia causes damage to the part of the brain that process visual input, is can affect visual acuity, the size of a person's visual field, and visual-spatial perception, the ability to see objects and the distance between those objects. It also impairs *working memory*, a type of memory that promotes active short-term maintenance of information for later access and use. The decline in working memory also affects language comprehension and visuospatial reasoning (Kirova et al., 2015).

Normal Age-Related Changes

We all experience changes as we age. Some people become forgetful when they get older. 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 not dementia.

People experiencing age-related changes can easily 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 little bit worse than normal age-related changes. This is known as **mild cognitive disorder**. 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, mild cognitive impairment gets worse and develops into dementia, but this doesn't happen with everyone.

The table below describes some of the differences between someone who is aging normally and someone who is experiencing 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

Stages of Alzheimer's Disease and Other Types of Dementia

Alzheimer's disease typically starts in an area of the brain called the *hippocampus*—the part of the brain responsible for new, short-term memories. This can cause a person with dementia, particularly someone with Alzheimer's disease, to forget something that happened just a moment ago. Although most types of dementia start in one part of the brain, eventually the entire brain will be affected.

It is common to describe Alzheimer's disease, as well as other dementias, 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.

Did You Know . . .

The National Institute on Aging and the Alzheimer's Association have published guidelines aimed at improving current diagnosis, strengthening autopsy reporting of Alzheimer's brain changes, and promoting research into the earlier detection of Alzheimer's disease. These guidelines describe three stages of AD: (1) preclinical AD, (2) mild cognitive impairment, and (3) dementia due to Alzheimer's disease:

1. **Preclinical AD**: the stage in which changes have begun to appear in the brain but no cognitive or emotional symptoms are present.
2. **Mild cognitive impairment (MCI)**: a decline in cognitive function that falls between the changes associated with typical aging and changes associated with dementia.
3. **Dementia due to Alzheimer's disease**: a period in which symptoms become more obvious and independent living becomes more difficult.

Alzheimer's Association, 2019

Mild Dementia

In the early, mild stage of dementia due to Alzheimer's disease, plaques and tangles begin to cause damage within the temporal lobes, in and around the hippocampus. The hippocampus is part of the brain's limbic system and is responsible for the formation of new memories, spatial memories and navigation, and is also involved with emotions.

Brain Changes in Mild Dementia

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

Mild cognitive changes, which have likely been developing for several years, affect memory, decision-making, and complex planning. A person with mild dementia can still perform all or most activities of daily living such as shopping, cooking, yardwork, dressing, bathing, and reading. They may even continue to work, but will likely begin to need help with complex tasks such as balancing a checkbook and planning for the future.

Trouble remembering recent events is a common symptom of mild Alzheimer's disease. Source: NIA. Public domain.

Moderate Dementia

As Alzheimer's disease progresses from the mild to moderate stage, plaques and tangles spread forward to the areas of the brain involved with language, judgment, and learning. Work and social life can 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.

Brain Changes in Moderate Dementia

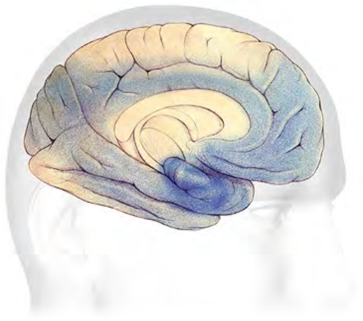
In mild to moderate stages, plaques and tangles (shaded in blue) spread from the hippocampus forward to the frontal lobes. Source: The Alzheimer's Association. Used with permission.

Severe Dementia

In the later 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 are easily confused, tire easily, are unable to make decisions, and cannot think logically. Speech, communication, and judgment are severely affected. Sleep disturbances and emotional outbursts are very common.

Brain Changes in Severe Dementia



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

Stages of Other Types of Dementia

Although Alzheimer's dementia worsens steadily over time, other types of dementia may progress differently. Because **vascular dementia** is caused by a stroke or series of small strokes, dementia may worsen suddenly and then stay steady for a long period of time–especially if the underlying cardiovascular causes are addressed.

In **Lewy body dementia**, which is often associated with Parkinson's disease, symptoms—including cognitive abilities—can fluctuate drastically, even throughout the course of a day. Nevertheless, the dementia is progressive and worsens over time. In the later stages, progression is similar to Alzheimer's disease.

Frontal-temporal dementia generally starts at an earlier age than Alzheimer's disease. In the early stage—depending on which lobe 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. Motor decline can also occur as the disease progresses. This is characterized by difficulties with movement, including the use of one or more limbs, shaking, difficulty walking, frequent falls, and poor coordination.

Communicating with Clients with AD and Related Disorders

> My mom gets pretty confused—especially in the early morning and late evening. She 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 her, all the articles get jumbled up in her head and she doesn't know when one article ends and another starts. So I just read short articles, Miss Manners, that sort of thing. I tell her "that's the end of the article about the election—this is a new article about the weather back east."
>
> Caregiver, West Palm Beach, Florida

How Dementia Affects Communication

Think about the last conversation you had a with 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 was a lot of noise in the background.

People with dementia have difficulty initiating and understanding communication. They have to work hard to say what they want to say. Depending on the severity of the dementia, they might not remember what was said a few moments ago. They will often have trouble carrying on a conversation and doing something else at the same time. Background noise is often confusing and irritating.

General Conversations

> My mom has dementia but still listens intently to our conversations. She followed the 2016 election with a great deal of interest even though when asked, she couldn't remember the names of the presidential candidates. When we said to her "are you are Democrat or a Republican" she responds immediately and fiercely "I'm a Democrat!"
>
> Family Caregiver, Pensacola, Florida

General conversations are friendly and informal. They are not usually related to a specific task or goal. General conversations are social, 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 can be about yourself, your hobbies, your workday, your commute, or your family. It can include positive comments about other people you work with or other residents. General conversations can include other people who are close by.

A general conversation with a person 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 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.

Conversations Related to a Task or Goal

Dementia affects goal-directed conversations just as much as it affects general conversations, maybe more. However, when trying to complete a specific task, communication must be more direct. Conversations about a specific task are more successful when "closed questions" are used. A closed question shows interest and invites a person to respond. For example, "Are you hungry?" or "Are you ready to get dressed?" limits the scope of the conversation and keeps the person with dementia focused 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 at hand. The person you are caring for may not share your goal or agree with what you are asking. Or, more likely, they may not understand what you want. The following story featuring George and Ann illustrates this point. Think about what you would do in this situation.

George in the Morning

George has moderate dementia and lives at home in Sarasota with his daughter and an agency caregiver. He can still get up and dress himself without help. This morning George got dressed and is resting in a chair next to his bed. Ann, a new caregiver, enters his room and calls out to him, “Come on George. Are you hungry? Did you sleep well? Time for breakfast! Stand up. Let’s get you to the kitchen for breakfast.” George doesn’t move, so Ann tries again, “Come on, George, get up! You don’t want your breakfast to get cold, do you? I don’t think so. Come on George, I’m kind of busy! I have to do the laundry and make your bed.” Ann takes his arm and helps him stand up. George pulls away and sits back in his chair.

From https://www.healthypeople.gov/2020/topics-objectives/topic/older-adults

What Is George Thinking?

George 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 barged 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 supposes he should go with her but she is being too pushy and this makes him mad. So he pulls away and sits back in his chair. He turns his head and tries to ignore her, hoping she will go away.

What Is Ann Thinking?

Ann is a new caregiver and needs to get George 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 George to the kitchen for breakfast. When she enters his room she is relieved to see that George 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. George seems confused and he 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.

What Could Ann Have Done?

Ann should enter George’s room quietly and respectfully after knocking on the door to get George’s attention. She should ask “May I come in?” and wait for George’s reply. Approaching George more slowly to his right side, squatting beside him, offering her upturned hand, and introducing herself gives George a chance to understand who she is. A pause at the end of each sentence gives George time to respond. “Hi, George.” Pause. “How are you?” Pause. “It’s 9 a.m.” Pause. “Time for breakfast.” Pause. If George doesn’t respond, Ann can repeat what she just said in a calm voice or ask another short, closed question: “George, are you hungry?” Pause. Now George only has one simple statement to think about and he is more likely to understand and respond. Ann must remember that George doesn’t have to do what she asks. It’s okay for George to have his breakfast in his room or even skip breakfast and eat when he is hungry.

Strategies and Guidelines for Verbal and Nonverbal Communication

When communicating with a person with dementia, there are several things to keep in mind. What is 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?

Improving Verbal Communication

Verbal communication is communication *with words*. It is an important part of daily life, creates positive relationships, and lets 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 has dementia begins with eye contact and an introduction. Starting with something light and conversational, such as the weather or what's happening in the news, will put the person 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.

When communicating with a person with dementia, practice these habits:

- Approach from the front, then kneel down to the person's right side
- Take a deep breath, relax, and take a moment to look at the person
- Offer your upturned hand
- Greet the person using their name, then introduce yourself
- Check your body language—if you remain standing, you may appear aggressive or threatening
- Use short, 1- or 2-step questions and await a reply
- Be attentive and sympathetic
- Continue the conversation by asking a follow-up question

Improving 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 listen and pay attention are nonverbal skills that matter just as much as words.

How you dress, your posture, how you approach a person with dementia, 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 looks 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 participants 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 okay to be silent, which is calming and reassuring—especially in social conversations.

Communicating When a Person Is Not Responsive

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 a challenge for family members and caregivers. It is difficult 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.

Assume that people can 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 by using pillows for neck, arm, and leg support, a warm blanket, and gentle repositioning. Mild range-of-motion exercises, gentle, appropriate touching, and massage are reassuring.

Keep the environment 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, practice these habits:

- Approach on the person's right side in a calm and relaxed manner
- Slow your own movements
- Re-introduce yourself at each encounter
- Address the person by a preferred name or title
- Use short, simple sentences
- Use hand gestures and light, appropriate touch to communicate your intentions
- Avoid a condescending tone

Detecting and Assessing Pain

It is important to recognize when a person who is has impaired communication is experiencing pain. There is good agreement in both large and small studies that about 50% of the people with dementia regularly experience pain (van Kooten et al., 2015).

Healthcare providers and caregivers are often uncertain about identifying and assessing pain in clients with dementia, especially if the client is unable to communicate when they are in pain. Clients, especially those with advanced dementia will not be able to respond to pain scales, so careful observation and proxy reports will be needed in up to about half of clients. Many clients (>50%) with advanced dementia experience pain in the last week of life that is not satisfactorily managed (Volicer and van der Steen, 2014).

Both physiologic and behavioral responses can indicate the presence of pain. *Physiologic* responses include tachycardia, increased respiratory rate, and hypertension. *Behavioral* responses include splinting, grimacing, moaning or grunting, distorted posture, and reluctance to move. A lack of physiologic responses or an absence of behaviors indicating pain does not mean there is an absence of pain.

Observational pain assessment tools have been published by the American Geriatrics Society, which describes six domains for pain assessment in older adults:

1. Facial expression
2. Negative vocalization
3. Body language
4. Changes in activity patterns
5. Changes in interpersonal interactions
6. Mental status changes (Lichtner et al., 2014)

For non-communicative patients, the Pain Assessment in Advanced Dementia (PAINAD) is a commonly used observational scale. This tool, developed by a team of clinicians at the E.N. Rogers Memorial VA Hospital in Bedford, Massachusetts, assesses breathing, negative vocalization, facial expression, body language, and consolability.

Pain Assessment in Advanced Dementia (PAINAD)

	0	1	2	Score*
Breathing	Normal	• Occasional labored breathing • Short period of hyperventilation	• Noisy labored breathing • Long period of hyperventilation • Cheyne-Stokes respirations	
Negative vocalization	None	• Occasional moan/groan • Low level speech with a negative or disapproving quality	• Repeated, troubled calling out • Loud moaning or groaning • Crying	
Facial expression	Smiling or inexpressive	• Sad • Frightened • Frown	Facial grimacing	
Body language	Relaxed	• Tense • Distressed • Pacing • Fidgeting	• Rigid • Fists clenched • Knees pulled up • Pulling/pushing away • Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract, or reassure	
PAINAD Scoring: 1-3 = Mild; 4-6 = Moderate; 7-10 = Severe *Some institutions have developed policies in which a PAINAD score of four or greater must be addressed in the nursing care plan. Public domain.				Total:

Behavior Management

Behavior is how we act, move, and react to our environment. Behaviors tend to change as dementia progresses. Some behaviors are related to changes in the brain, some to personality, and some to physiological symptoms. Memory loss and changes in the ability to think logically, as well as loss of judgment, certainly affect behavior.

Symptoms and Behavior Change 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 generally worsen gradually—over 10 to 20 years. Behaviors can change gradually or suddenly, depending on the type of dementia, environmental factors, caregiver competence, medical issues, and the overall quality of care.

Mild Dementia

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 complex, multi-step tasks, increased frustration, and a loss of interest in usual activities. People with mild dementia understandably try to hide their confusion from friends, coworkers, and family.

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

People 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.

Moderate Dementia

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 judgment and logical thinking are common symptoms. Cursing, arguing, yelling, or hitting can develop at this stage. 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 with moderate dementia might wander. More direct monitoring 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. Surprisingly, many people with dementia may not be diagnosed until they reach this stage.

Severe Dementia

> My mom is a 96-year-old retired nurse with pretty severe dementia. She still lives at home with 24/7 care. She would never survive in a nursing home. 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 maybe swear, hit, or cry. At home she doesn’t do any of these things, but we work pretty hard to keep things quiet, warm, and consistent for her.
>
> Family Caregiver, Miami, Florida

People with severe dementia lose all memory of recent events. They are easily confused and are unable to make decisions. Speech, communication, and judgment are severely affected. They cannot think logically. Sleep disturbances 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 can be triggered by boredom, loneliness, depression, cold or heat, loud noises, and pain and should not be shrugged off by caregivers because they are likely related to unmet needs.

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.

End of Life

As people with dementia approach the end of life they may lose all memory—not just memory of recent events. The damage to their brains is so severe that they are in a constant state of confusion. At this stage, people can develop other illnesses and infections.

At the end of life, a person with dementia may experience agitation, psychosis*, delirium**, restlessness, and depression. Because of hearing and visual deficits, they are startled by loud noises and quick movements. They are often unable to communicate their needs and desires using speech. Communication may be entirely nonverbal: moaning, calling out, hitting, biting, and grabbing.

***Psychosis**: loss of contact with reality.
****Delirium**: a sudden, severe confusion that can be caused by infections, a reaction to medications, surgery, or illness.

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 with environmental modification, medication management, and 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.

- **A**ntecedent—what caused the behavior?
- **B**ehavior—what is the behavior?
- **C**onsequence—what are the consequences 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 invaluable for examining your own behaviors and responses to dementia. How you react and interact with a person with dementia can have a profound effect on a person's behavior. Understanding your own biases, frustrations, and triggers will help you approach a person struggling with dementia with patience and compassion.

Strategies and Techniques

As a caregiver, family member, or healthcare provider, how you interact with a person with dementia requires different strategies and techniques depending on the stage of a person's dementia. Family caregivers, interacting with only one or two people, may still find it difficult to identify when a new strategy or technique is needed. Healthcare providers, because they interact with many different people in varying stages of dementia, must have strategies and techniques that they can call on throughout the day.

Nevertheless, there are certain foundational strategies and techniques that are useful when interacting with someone with dementia, no matter the type or stage. Using a technique such as the problem-solving approach is recommended anytime you encounter an unwanted behavior.

Agitation and Aggression

Agitation is non-specific, restless behaviors that are excessive, inappropriate, and repetitive. **Aggression** involves physically or verbally threatening behaviors.

Aggressive behaviors can be a threat to the safety of the person with dementia and to those around them. These behaviors are particularly difficult to manage because they are confusing and sometimes unexpected, causing caregivers a great deal of stress.

Agitated and aggressive behaviors can include:

- Verbal insults
- Shouting, screaming, loudly demanding something
- Hitting, punching, kicking, pushing
- Throwing objects or using objects to hit or lash out
- Inappropriate sexual advances or obscene language

Agitation and aggression occur in about 50% to 80% of nursing home residents with dementia. These behaviors can be related to loss of control, discomfort, fear, or be a response to a perceived threat or violation of personal space. Agitation and aggression often occur during personal care tasks involving close contact. Pain is also associated with agitated and aggressive behaviors and nursing home residents with severe pain are more likely to display these behaviors (Ahn & Horgas, 2013).

Psychosocial and environmental interventions can reduce or eliminate agitated or aggressive behaviors. Music therapy, craniosacral therapy*, therapeutic touch, acupressure, and tactile massage have been shown to be successful for treating aggression. In addition, individual behavioral therapy, bright light therapy, Montessori activities, and individualized, person-centered care based on psychosocial management is recommended (Burns et al., 2012).

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

For people with dementia, antipsychotics may reduce aggression and psychosis, particularly among those most severely agitated. However, in older adults, antipsychotics are associated with increased overall mortality, worsening cognitive impairment, hip fracture, diabetes, and stroke (Jordan et al., 2014). It is recommended that antipsychotics be used only as a last resort.

Wandering

Wandering is a normal human activity that we all enjoy. But, because a person with dementia is at increased risk for falls, wandering into restricted areas of a facility, or getting lost in the community, healthcare providers and caregivers often see it as a problem and disruptive to their care duties. For a variety of reasons, caregivers may want to control or prevent the behavior. However, preventing residents from safely wandering can create a whole other set of problems such as boredom, loss of social interaction, stigma, loss of conditioning, and even skin breakdown.

Although wandering can appear aimless, hyperactive, and excessive, look at it from the standpoint of the person with dementia. People may wander out of habit or because they are convinced something needs to be done, such as going home after work, walking the dog, getting exercise, or searching for something they think they have lost. Wandering may relieve depression, boredom, or pain and discomfort.

Wandering can involve moving to a specific location, lapping or circling along a path, pacing back and forth, or wandering at random. More than half of people with dementia will wander at some point during the course of their disease. Wandering can cause harm if a person with dementia exits the home or facility, elopes*, or becomes lost (Burns et al., 2012).

***Elopement**: When a patient or resident who is cognitively, physically, mentally, emotionally, or chemically impaired wanders away, walks away, runs away, escapes, or otherwise leaves a caregiving facility or environment unsupervised, unnoticed, or prior to their scheduled discharge (The National Institute for Elopement Prevention and Resolution).

People with Alzheimer's disease are more likely to wander randomly than those diagnosed with other types of dementias. People with frontal-temporal dementia tend to pace and lap. Restlessness, with a compelling need for movement or pacing has been linked to side effects of psychotropic medications, particularly antipsychotics (Burns et al., 2012).

Wandering can be beneficial if there are safe places to wander. The most important goal is to prevent a person from wandering into unsafe areas, other resident's rooms, or eloping from the facility. Wandering can be addressed or even encouraged by providing safe, looping wandering paths with interesting rest areas and providing regular exercise.

A person's pre-dementia lifestyle may be a factor in whether they are likely to wander. Studies have indicated that people with the following characteristics are more likely than others to wander:

- People with an active interest in music
- Those who have an extroverted personality showing warmth, positive emotion, altruism
- Those who were very involved with social activities and were active in social-seeking behaviors
- People who were physically active
- Those who experienced stressful events throughout their life, necessitating multiple readjustments
- People who respond to stress by engaging in motor activities (Futrell et al., 2014)

Imagine if a person whose pre-dementia lifestyle involved a lot of walking is now living in an unfamiliar environment and is being prevented from moving about. Stopping the natural tendency to explore, to become familiar with a new living space, and to socialize with new people can be extremely frustrating. It is no wonder that this can lead to depression, anger, and behavioral problems.

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.

Since the Silver Alert program started in Florida in 2008 there have been 2,243 Silver Alerts enacted. The highest number was issued in Palm Beach County (14%). More than three-quarters of the reports were issued for men. A little more than half of the reports were issued for people between 80 and 89 years of age.

Rummaging and Hoarding

Rummaging and hoarding refer to behaviors in which a person gathers, hides, or puts away items in a secretive and guarded manner. These actions are considered a type of obsessive-compulsive behavior. Rummaging and hoarding are not necessarily dangerous or unsafe but they can be frustrating for caregivers and other residents.

Hoarding can arise in those with dementia due to fear of losing money or possessions, due to lack of control, need to "save for a rainy day", or simply out of confusion. Hoarding is associated with insecurity and anger and may be an attempt to hold onto possessions and memories from the past.

Cognitive changes such as memory loss, poor judgment, and confusion can contribute to the impulse to rummage and hoard. People may rummage out of boredom or to find something they think has been misplaced. They may have a fear of being robbed or feel a need to protect their possessions. Rummaging through familiar items may create a sense of safety and security. Confusion can lead to rummaging through another person's belongings, which can be particularly frustrating for neighboring residents.

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

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

In 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. Other recommendations:

- Look for patterns
- Get rid of poisonous items such as caustic liquids and poisonous plants
- Label cabinets, doors, and closets (with words or pictures) to help the person find what they are looking for
- Reduce clutter
- Observe carefully to learn the person's hiding places
- Check garbage for missing items

Psychosis

Psychosis is a disturbance in the perception or appreciation of objective reality (Burns et al., 2012). Symptoms can include delusions, hallucinations, and paranoia. A **delusion** is a false idea or belief or a misinterpretation of a situation. **Hallucinations** are sensory events in which a person hears, tastes, smells, sees, or feels something that is not there.

People suffering from paranoia can become suspicious of caregivers or friends; they may feel these people are stealing from them or planning them harm. Sensory deficits can contribute to delusions, and particularly hallucinations, because of the distortion of sound or sight.

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

Visual hallucinations can occur in the moderate to severe stages of dementia and are particularly common in those with Lewy body dementia. While atypical antipsychotics are sometimes used off-label to manage hallucinations, in a person with Lewy body dementia, antipsychotic medications can make hallucinations worse. 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. This includes prescription and over-the-counter medications, as well as herbal supplements.

Management of delusions and hallucinations involves ruling out delirium as a cause. Observe the behavior and listen to what the person experiencing the paranoia or delusion has to say. Is the feeling pleasant or frightening? If the hallucination elicits a fearful or negative response, address the person's need to regain comfort. For example, you may ask "What will make you feel safe or comfortable?"

When communicating with someone who is expressing paranoia or delusions, realize that even if their complaint is not true, it is very real for that person. Do not to argue; simply explaining the truth of the situation will not work. Do not agree or further validate the paranoia or delusion—try to respond to the person's emotion. For hallucinations, it is often helpful to decrease auditory and visual stimuli as well as evaluating for visual or hearing impairment. Behavioral interventions are also useful.

Caregivers must also consider that the claims by the person with dementia may be real. For example, complaints of strangers entering several resident rooms and stealing items in a California nursing home were attributed to dementia and psychosis by healthcare providers (including physicians). When the complaints mounted, the facility installed cameras in the alley next to the facility. Several of the rooms facing the alley had malfunctioning locks on the sliding glass doors leading to the alley. The cameras showed that people were indeed entering rooms at night and rummaging through residents' drawers and closets. There truly were people entering resident rooms and stealing items!

Sleep Disturbances

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

Importantly, sleep disturbances can contribute to the onset and severity of some behavioral problems, particularly anxiety, increased confusion, wandering, and sundowning*.

*Sundowning: increased confusion and restlessness in the late afternoon and early evening, possibly due to damage to the part of the brain that regulates sleep patterns.

The symptoms of sleep disruption vary according to the type of dementia:

- Increased sleep latency
- Nocturnal sleep fragmentation
- Increased early-morning awakenings
- Decreased total sleep time and decreased sleep efficiency
- Decreased slow-wave and rapid-eye-movement (rem) sleep
- Nocturnal confusion
- Increased daytime napping and excessive daytime sleepiness
- Agitation, verbally disruptive behaviors, hallucinations, and nighttime wandering (Burns et al., 2012)

Studies have suggested that approximately one-quarter to one-third of those with Alzheimer's disease have problems with sleep, partly due to the degeneration of neurons in the part of the brain that controls circadian rhythms. Sleep apnea, restless leg syndrome, medical and psychiatric issues, and environmental and behavioral factors often predate the onset of dementia. Chronic pain also interferes with sleep and disturbed sleep reduces the pain threshold (Deschenes & McCurry, 2009).

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

Before treating sleep disturbances look for potentially treatable causes, which can include pain, hunger and thirst, the need to urinate, infections, adverse drug reactions, and even noise. Non-pharmacologic treatments include:

- Light therapy
- Good sleep hygiene practices
- Exercise and individualized social activities
- Restriction caffeine, nicotine, and alcohol
- Maintaining a calm, warm atmosphere
- Comfortable beds with enough pillows for back and neck support
- Good temperature control in rooms

Promoting Independence Through 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, as are the manner and tone in which a person is addressed; the care taken to ensure that they participate as much as they can or wish in any decision about their day-to-day life; the trouble taken about appropriate and attractive food and environments; and access to meaningful activity.
>
> Nuffield Council on Bioethics

Activities of daily living (ADLs) are the tasks we do during our daily lives. Because ADL skills decline as dementia progresses, caregiver involvement naturally changes over time. Caregivers often help more than is needed and research suggests that people with dementia—even those with advanced dementia—can do more than caregivers allow them to do.

Promoting independence requires good communication, patience, and the ability to understand and accept that dementia changes how a person approaches an activity. Many caregivers assume someone with dementia is child-like and no longer capable of understanding how to complete an activity. Many caregivers, family members, and healthcare providers simply take over the task. This not only robs people of their independence; it affects their self-worth.

ADLs are generally divided into *basic* ADLs and *instrumental* ADLs. **Basics ADLs** are the skills needed to take care of personal needs such as:

- Eating
- Bathing or showering
- Grooming
- Walking
- Dressing and undressing
- Transfers
- Toileting

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

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

As a direct caregiver, medical professional or family member, the following best principles should be understood and applied to all activities of daily living at all stages of dementia:

1. Engage people with dementia in interventions and solutions
   a. Manage pain
   b. Maintain a supportive environment
   c. Take a holistic approach

2. Compensate for a person’s reduced abilities
    a. Embed interventions in day-to-day life
    b. Provide ongoing support
    c. Involve caregivers
3. Get dementia-friendly training and develop skills for working with people with dementia
    a. Understand and know your patient
    b. Train caregivers
    c. Collaborate with healthcare professionals and family members

(Wheatley et al., 2019)

General Strategies for Promoting Independence in ADLs in Various 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 I found online and the support from hospice helped a lot—it gave me strategies and techniques to use when all seemed lost and when nothing was working.
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> Family Caregiver, Ft. Lauderdale, Florida

Good Communication is the Basis for Success

Good communication starts with patience and thoughtfulness. Good communication builds trust, encourages independence, and leads to better outcomes. Caregivers must learn and *believe* that consistently trying to understand the needs of the person they are caring for will make their job easier. Good communication takes into account a person's ability to comprehend, their sensory abilities, and their culture.

In the home setting, communication may be easier because the environment is familiar with fewer distractions although caregivers are often alone and cannot turn to a co-worker for help. No matter what setting, a calm tone, short direct sentences, a slow rate of speech, and patience encourages independence in people with dementia.

Case Example

Clara is a 96-year old, Caucasian 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 a thick accent and poor English skills and doesn’t understand that Clara can’t hear her and often doesn’t understand what she’s saying. The caregiver sometimes forgets to give Clara her hearing aids, sometimes puts the hearing aids in with dead batteries, leaves the TV on when trying to talk to Clara, and speaks in long, complicated, thickly accented sentences. She uses phrases and words that are completely unfamiliar to Clara.

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

ADL Skill Training

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 promotes involvement in self-care, minimizes caregiver stress, and reduces the amount of physical labor required of a caregiver.

A skilled caregiver learns to continually assess the strengths, comprehension, and capabilities of the person they are caring for. More or less assistance may be needed depending on the task, the time of day, co-morbidities, and level and type of dementia. For example, a person who is otherwise capable of independent self-care tasks but has poor balance might need help setting up a place to safely brush her teeth and do other grooming. If forced to stand during these activities, the person may need more help from the caregiver than is needed if a suitable sitting area is arranged.

Caregiver skills training provides caregivers with information, strategies, and tools to develop an individualized program that provides just the right amount of assistance. This might involve gestures, verbal and visual cues, assistive devices, planning and problem solving, and physical assistance.

Planning Activities

Planning an activity for someone with dementia must account for a person's abilities and interests, which promotes success and leads to a wider range of activities. Well-planned activities will naturally arise from a careful assessment of a person's lifestyle, occupation, interests, and preferences. For example, a person who loved to go for hikes but can no longer walk will still enjoy going for a drive or visiting a park with paths that accommodate wheelchairs. That same person may not enjoy sitting in front of a television tuned to a game show.

Assistive Technologies

Assistive technologies—devices designed to enable people with a disability to function more independently—have been developed to support people with dementia and their caregivers. Assistive technologies focus on safety and social participation. They are different than assistive devices, which aid with mobility and physical activities of daily living.

Assistive technologies:

- Provide the caregiver with a way to make sure the person they are caring for is safe.
- Provide help with memory and recall.
- Improve a person's confidence and independence.
- Keep people with dementia socially connected.

Examples of assistive technologies include:

- Face-to-face communication with family members and friends using tablets or computers.
- Tracking devices, that allow a person to walk independently within a safe area.
- Electronic prompts and medication reminders.
- Medical check-ups via telephone or video conferencing.
- Automated lights.
- Automated shut-off sensors that prevent flooding or turn off devices that have been left on.
- Communication aids such as adapted telephones with pre-set numbers.
- Cameras mounted throughout the home.

Assistive technologies can reduce the cost of care, decrease caregiver burden, promote independence and autonomy, and increase quality life for people with dementia. They may also promote aging in place, delay transfer into a care facility, and help people with dementia maintain independence (Czarnuch et al., 2016).

Adaptive Aids

Adaptive aids are devices and equipment designed to assist a person with daily activities such as mobility, transfers, dressing and grooming, bathing, and eating. They can help individuals with disabilities compensate for lost functions, increase their independence, and develop their potential (Yeung et al., 2016). The selection of an adaptive aid or device depends on the person's level of dementia, preferences and lifestyle, and physical abilities.

Adaptive aids include:

- Safety devices such as grab bars, transfer poles, handrails, and non-skid mats.
- Assistive devices such as walkers, wheelchairs, braces, height-adjustable chairs and beds, pulleys and slings, ramps, and lifts.
- Devices to assist with eating and drinking such as non-tip cups, assistive tableware, non-spill cups, adjustable-height tables, and easy-grip silverware.
- Devices for washing and bathing such as commodes, shower chairs, transfer benches, and walk-in or roll-in showers.
- Devices for household tasks such as adjustable-height cupboards, reachers, grip extensions for appliance controls, and pull-out shelves or pull-down shelves.

Preventing Loss of Independence through Exercise

Conventional exercise programs such as walking, resistance training, and seated exercises that focus on improving aerobic endurance, strength, balance, and flexibility have beneficial effects on physical function in individuals with dementia. Exercise improves the ability to perform basic activities of daily living such as eating, dressing, bathing, using the toilet, and transferring from bed to chair (Barnes et al., 2015). Homes that are dementia-friendly (and safe) promote independence and physical activity. This means they are safe for walking, easy to navigate, and have plenty of places to sit and rest.

Care Techniques

Care techniques are the skills needed by the caregiver for monitoring, assisting, and providing total care in dressing, grooming, eating, bathing, or toileting and incontinence. As dementia progresses, the amount of care a person with dementia requires understandably changes.

Dressing and Grooming

As with other activities of daily living, people with dementia often need time to dress and groom. The caregiver must assess the person they are caring for to determine the amount of help needed, must be patient, and must resist jumping in to help if no help is needed. Depending on the severity of the dementia and co-morbidities such as visual and perceptual changes, balance, and strength—even the time of day—caregivers must train themselves to encourage as much independence as possible.

A person with *mild* dementia may not need any help with dressing and grooming. These are habits and activities that a person has developed and practiced over a lifetime; habits that rely on parts of the brain, including motor control, not generally affected in the early stages of dementia. A caregiver may need to lay out a person's clothes or make suggestions, but generally a person with mild dementia can choose what clothing they want to wear and handle grooming without help. A caregiver may suggest using an electric razor, lay out grooming supplies, or provide tools to assist with dressing and grooming. At this stage, the caregiver's role is to help as needed while promoting and encouraging independence.

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 dressing and grooming. For example, Clara, mentioned earlier in this section 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 to place her leg when she tries to put on her pants and 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 Clara's independence. In this case, the caregiver must be patient—help Clara lay out her clothes and provide verbal and appropriate touch cues to direct the activity.

The same is true for grooming. For mouth care and other grooming tasks, caregivers must provide a safe and comfortable place for these tasks, assist as needed, and provide clear, step-by-step instruction and help. For men, especially in the moderate to severe stage of dementia, the use of an electric razor provides a safe way to shave, and for both men and women, regular visits to the beauty or barber shop provides social interaction and reduces caregiver burden.

As dementia progresses to a more *severe* stage, caregivers must provide more help with dressing and grooming. Many caregivers tend to overhelp, partly because the person with dementia takes a long time to complete what used to be simple and automatic tasks. In the home setting, schedules and routines for activities of daily living are more flexible than in a nursing home. Nevertheless, caregivers often get impatient (even bored) with the slow pace of dressing and grooming. Slowing down, encouraging independence, and maintaining an attitude of watchful patience are critical skills for a caregiver to develop and practice.

Eating and Hydration

Interventions to support older people with eating and drinking vary depending on the stage of a person's dementia. There are certain general strategies that can be undertaken in the early stage and continued as a person's dementia progresses. This includes assisting with the setup of a meal, providing a supportive seating arrangement, providing support for the feet, and making sure food is tasty, warm, and attractive. Other recommended practices include changing the color of a plate (for food contrast), encouraging daily exercise, and altering the meal schedule to suit the needs of the person with dementia.

When dementia is *mild*, a caregiver may only need to supervise. A person with mild dementia, depending on other underlying medical issues, will likely be able to help with shopping, cooking, and dishwashing. In the mild stage, a person might be able to prepare their own meals. A caregiver will likely need to supervise and help at a distance while assuring the person with dementia is safe. Mild memory problems can lead to safety issues such as forgetting to turn off the stove, leaving water running, or forgetting to eat or drink. A person with mild dementia may feel they are safe to drive—this is when a caregiver must step in address this issue.

As a person's dementia progresses to the *moderate* stage, the need for caregiver assistance increases and safety issues arise. As balance and strength decline, the risk for falls increases and all activities of daily living, including eating and hydration are affected.

Mild swallowing difficulties may arise in the moderate stage, increasing the risk of aspiration and choking. This can be addressed by preparing softer foods, cutting food into smaller pieces, and avoiding food that is hard to chew or hard to swallow. Proper ergonomic seating and simple swallowing techniques can be taught at this stage to reduce the risk of aspiration. Caregivers should always encourage independence, encourage choice in food and drink, and allow the person they are assisting to do as much as they can on their own.

In the later stage, oral nutrition supplementation, food modification, and dysphagia management are a daily concern for caregivers. Eating assistance, encouragement, and social support have been shown to increase the amount a person with severe dementia eats and drinks. Eating can be an automatic behavior—we often eat when we see other people eating or when we smell something delicious cooking. A person with severe dementia can still help with meal preparation—even if they only beat an egg, peel an orange, or pour juice into a cup (with assistance). Remember that, especially in the home, spilled food can always be cleaned up.

Caregiver education and training is critical (and often lacking) throughout every stage of a person's dementia but becomes particularly important as a person nears the end of their life. Behavioral issues may arise—refusal to eat and drink, blunt 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, and listening to, a person's changing needs.

Assistive Tableware

Assistive or adaptive tableware has been a mainstay in nursing homes and assisted living facilities for many years and is recommended for use in the home as well. Unfortunately, a lot of assistive tableware lacks aesthetic appeal. In a group setting (and even at home), users of assistive table settings may feel stigmatized because assistive tableware stands. In the home, a person may feel less stigma, but introducing tableware that significantly differs from the tableware someone has been using their entire adult life may be an issue for some people.

As eating difficulties develop and appetite decreases, meals must be simplified by providing just a plate and spoon with pureed or diced food. 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 hip 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 easier. Designed by Sha Yao, Eatwell.com. Used with permission. From http://www.eatwellset.com/#!features/cf1a

Well-designed assistive tableware can be used by people of all abilities, and at all stages of dementia. Color contrasts should feature prominently to provide contrast and visual cues—for example royal blue plates provide a contrast both with a white table covering and food on a plate.

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

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.

Remember that dementia is a progressive disease, and 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 progression. Caregivers who have worked hard to keep a person eating and drinking may be alarmed 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.

Interventions that improve nutrition among people with dementia include, eating meals with caregivers, family style meals, soothing mealtime music, accessible snacks, longer mealtimes, education and support for formal and informal caregivers, facilitated breakfast clubs, and regular exercise (Bunn et al, 2016).

Other recommendations:

- Provide food that a person likes.
- Involve the person in food preparation.
- Give small portions.
- Experiment with different consistencies (milkshakes, smoothies).
- Use more flavoring.
- Provide food when a person is awake—even if that's in the middle of the night.
- Be patient and use common sense.

Bathing

Throughout our lives, bathing is a private, independent, and personal experience. For someone with dementia, having another person help with bathing can be uncomfortable and even threatening. It is a caregiver's responsibility to help the person they are caring for feel a sense of control and independence. This is accomplished by including the person is the bathing decision, encouraging independence, protecting the person's privacy and dignity, and practicing flexibility.

During bathing, techniques that comfort and reassure a person during all stages of dementia include:

- Set a regular time for bathing
- Be gentle with fragile skin, avoid scrubbing
- Simplify the bathing process, use assistive devices
- Coach or cue the person through each step, if needed
- Offer a bench or shower chair for comfort and safety
- Assist with cleansing of hard-to-reach areas, if needed
- Use a sponge bath in between baths or as an alternative to bathing (Alzheimer's Association, 2020a)

A person 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, if needed.

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.

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

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

Incontinence is the involuntary leaking of urine or feces or both. No matter where a person lives, and how far their dementia has progressed, incontinence can be embarrassing and stigmatizing. Incontinence adds to caregiver stress and depression and is a factor in the decision to admit a family member to a care home.

There are a number of issues related to toileting and incontinence in people with dementia. Some are the result of the loss of cognition and memory, some from behavioral and psychological symptoms, and some from the interplay of these with other comorbidities. Over-medicating with laxatives (sometimes without the knowledge of the caregiver) can be a problem. For this reason, medications should be reviewed on a regular basis—especially when a medication is changed.

Many care providers believe that it is normal for older adults to be incontinent and as a result, reversible causes of incontinence are not adequately addressed. This may be because the person with dementia is too embarrassed to mention it, or the caregiver is not overly concerned.

Stress incontinence, which causes 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. An overactive bladder during a urinary tract infection may cause urinary retention as well as incontinence.

Some people require a combination of treatments such as anti-spasmodic medications with lengthened periods between toileting to increase bladder capacity to reduce wetting episodes.

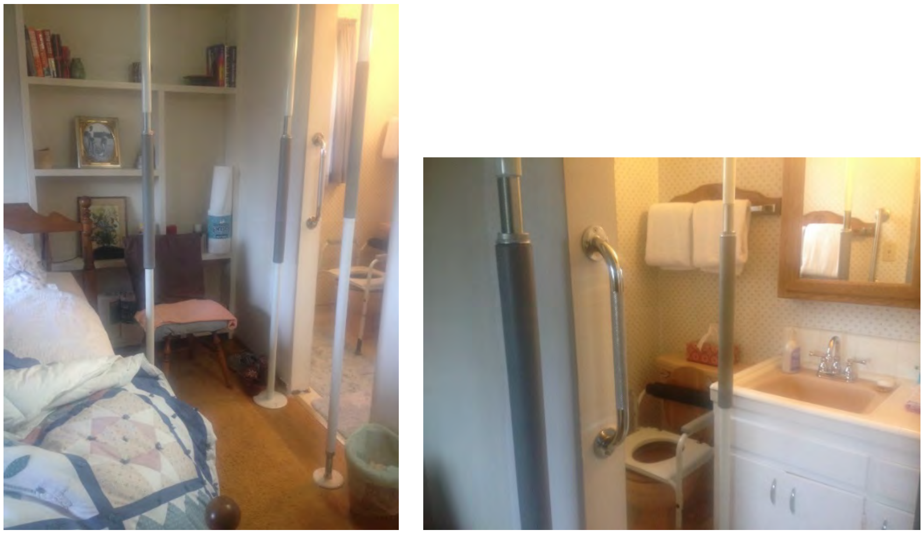
A person with *mild* dementia (as well as those in the later stages), may be physically unable to get to the bathroom in time to void. They may hide this problem out of embarrassment or ignore the problem. They may have difficulty with cleansing and personal hygiene.

A person 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. Lack of grab bars or transfer poles are a problem of cleansing as well.

As dementia becomes more *severe* and physical, sensory, and cognitive skills continue to decline, it is not uncommon for a person to hide soiled underwear, hand feces to the caregiver, or wipe feces off hands onto clothing or furniture. A person may resist help entirely, fail to remove clothes before voiding, void in inappropriate places (the garden, next to the bed at night, in waste bins) (Drennan et al., 2011). Often the person with dementia will try to stop drinking 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.

In the severe stage, a person 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 a person from trying, increasing the risk of falls. Caregivers can find this stage extremely frustrating and stressful—partly because more physical help is required and more direct oversight is needed, and partly because more time is spent cleaning up accidents.

Techniques and strategies used by caregivers to manage toileting and incontinence in a person with dementia typically start with reminders to go to the toilet on a regular basis. As dementia progresses, other techniques are needed such as adult diapers, bedside commodes, and direct help from the caregiver. Assistive equipment is critical to promote independence and to decrease the amount of lifting for the caregiver.



An example of a small bathroom with grab bars, shower chair, and floor-to-ceiling transfers poles used for a woman with moderate to severe dementia who could still walk with assistance, nearly to the end of her life, but had poor balance. She was able to safely go from her bed to the toilet without assistance until the last month of her life. The pole next to the sink was installed because she had a tendency to swing onto the toilet as soon as she got close, rather than stepping and turning. Prior to installing the pole next to the sink cabinet, she turned too soon and broke a lower rib when she hit the corner of the cabinet. She held on to the pole next to the chair for balance as she got dressed. The door was also removed from the bathroom to allow wheelchair access so she could safely stand or sit at the sink for grooming. Source: Author.

To make it easier for a person with dementia to find and use the toilet:

- Clear the path to the bathroom by moving furniture.
- Keep the bathroom door open so the toilet is visible.
- Put colored rugs on the bathroom floor or put a picture of a toilet on the bathroom door.
- Make the toilet safe and easy to use. Raise the toilet seat, install grab bars on both sides, and use nightlights to illuminate the bedroom and bath.
- Consider a portable commode or urinal for the bedroom for nighttime use.
- Remove plants, wastebaskets, and other objects that could be mistaken for a toilet.
- Remove throw rugs that may cause a person to trip and fall.
- Consider using glow-in-the-dark tape to create a direct line or path to the toilet (Alzheimer's Association, 2020b).

Keep in mind that incontinence can be related to a medical problem such as urinary tract infection, constipation or prostate problems. Incontinence is also 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. This includes sleeping pills, anxiety-reducing drugs that may relax the bladder muscles, and drinks such as cola, coffee and tea (Alzheimer's Association, 2020b).

Developing Skills for Working with Families and Caregivers

> Family caregivers of people 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.
>
> Henry Brodaty and Marika Donkin, Prince of Wales Hospital, Sydney, Australia

All over the world, the family is the cornerstone of care for older people who have lost the capacity for independent living. More than 80% of the care provided to older adults in the United States is provided by family, friends, or other unpaid caregivers. People with dementia who live in the community are more likely than older adults without dementia to rely on multiple unpaid caregivers (often family) (Alzheimer's Association, 2019).

In many developed countries, the vital caring role of families and their need for support is often overlooked. In developing countries, the reliability and universality of the family care system is often overestimated. Family caregivers are often cast into the role of caregiver unexpectedly and are largely unpaid or "nearly" unpaid. Currently, about half of people who need help with personal care have dementia (ADI, 2013).

Working with family members and caregivers caring for a person with dementia takes a great deal of understanding, training, and patience on the part of a healthcare provider. Not only must a healthcare provider learn skills for working with a person with dementia he or she must learn how to communicate these skills and techniques to sometimes resistant family members and often untrained hired caregivers. Differences in education, training, and cultural backgrounds can compound the difficulties.

At the time of diagnosis with Alzheimer's disease or other forms of dementia, the family caregiver is faced with new challenges in identifying as a caregiver, developing self-confidence in this role, including the mastery of specific skills to manage the new situations, knowledge about relevant services, and connecting with an informal support network (White et al., 2018).

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 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.

Not surprisingly, caregivers of people with dementia provide care for a longer time, on average, than caregivers of older adults with other conditions. They are more likely than caregivers of people without dementia to provide help with self-care and mobility and health or medical care. Yet half of caregivers of people with dementia indicate they have no experience performing medical/nursing tasks (Alzheimer's Association, 2019).

Caring for a person with dementia also means managing symptoms that caregivers of people with other diseases may not face, such as neuropsychiatric symptoms (for example, anxiety, apathy and lack of inhibition) and severe behavioral problems. Family caregivers often lack the information or resources necessary to manage the increasingly complex medication regimens for people with dementia (Alzheimer's Association, 2019).

Because family and unpaid caregivers provide major societal benefit at minimal cost to the healthcare system, often at considerable personal cost, there have been repeated calls for support services that enable continued provision of care in the home. Interventions that enhance caregiver coping skills and management of difficult behaviors have been shown to decrease caregiver burden and improve caregiving skills and quality of life for both caregiver and person with dementia. Caregiver behavioral interventions have been shown to decrease physical and psychological consequences such as depression, anxiety, sleep disturbance, hospitalization and mortality, and increased risk of patient institutionalization (Nichols et al., 2017).

A survey of more than 1,000 caregivers in Florida who are caring for a person with dementia had these key findings:

- More than half of caregivers have been providing care for four or more years, and nearly 17% have been providing care for nine years or more;
- The average caregiver provides 78 hours of care per week; 23% provide around-the-clock care;
- About a quarter of caregivers work full-time and 10% work part-time; 94% of caregivers are not paid for the assistance they provide;
- About a third of caregivers have a health problem, physical condition, or disability that affects the type or amount of care that they can provide, while more than half are experiencing stress or mental health problems that affect the type or amount of care they can provide;
- About 41% of caregivers do not have any plans for how to secure their loved one with ADRD in the event of a disaster; and 59% report that respite is the most needed service to continue providing care, especially for those who wish to continue working in their careers without interruptions.

FL Department of Elder Affairs, 2016

In the Early Stage

In the early stage of dementia, family members are confronted with many issues, worries, and concerns and must adjust their own behavior and manage their own frustrations as they learn about the effects of dementia. They are often unaware of available dementia-care services and may find their family member's primary care physician is of little help.

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

Nevertheless, caregiver burden is usually manageable in the early stages of dementia. Direct care may not be needed and caregivers can often leave their family member alone for periods of time.

Early, specialized training is recommended for informal caregivers. This is an essential but often completely neglected component of dementia care. Training prepares family caregivers for what lies ahead and allows them to more easily partner with healthcare providers to provide competent and compassionate care.

In the Middle Stages

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

As the dementia progresses from the mild to moderate stage, caregivers begin to invest more time, energy, and money, which involve exhausting tasks leading to high levels of burnout. Depression, along with symptoms of burnout, poor self-rated health, highly perceived stress, and lower levels of life satisfaction are factors that begin to affect the caregiver's health. Family caregivers are also less likely to engage in preventive health behaviors. As a consequence, they are at risk for serious illness, increased emergency department use and hospitalization, and increased risk of mortality (Lykens et al., 2014).

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

In the Late Stages

In the late stages, as people lose the ability to communicate clearly, family caregivers will struggle to find new ways to understand as their loved one uses fewer and fewer words. Caregivers must learn to interpret facial expressions for sadness, anger, or frustration, and physical gestures such as grasping at undergarments, which may communicate the need to use the bathroom.

The demands of caregiving intensify as people with dementia approach the end of life. In the year before the person's death, 59% of caregivers feel they were "on duty" 24 hours a day, and many report caregiving during this time is extremely stressful. One study of end-of-life care found that 72% of family caregivers experienced relief when the person with Alzheimer's disease or another dementia died (Alzheimer's Association, 2019).

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

- Need for skilled care and assistance
- Family caregivers' health
- Patient's dementia-related behaviors

Relinquishing full-time care can cause feelings of loss, sadness, resignation, and depression for family caregivers. Paradoxically, placement of a loved one in a care facility may do little to alleviate the stress that caregivers experience.

Once a family member has moved to a care facility, family caregivers must begin learning to navigate a complicated healthcare system. Healthcare workers can support family members by determining the preferences, abilities, and resources of each family member. Regular face-to-face meetings with family members and facility staff will help families work through difficult conflicts.

The Grief Process

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

The diagnosis of dementia difficult for the person receiving a diagnosis of dementia as well as family and friends. There is concern related to uncertainty about the course of the disease and anticipated loss of independence. Grief can manifest in physical symptoms such as shortness of breath, headaches, fatigue, a feeling of heaviness, and a lack of energy. Psychological symptoms such as depression, anxiety, insomnia, and loss of interest in normal hobbies and activities will almost certainly develop. These issues can lead to self-destructive behaviors, such as alcohol or drug abuse. Supportive interventions to address grief and loss include counseling, assessment of co-morbid conditions, education and training, and development of a care plan.

Losses for the person experiencing dementia include:

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

Losses for family members and caregivers include:

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

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

When a loved one dies, family members (especially spouses) experience a period of acute grief that can include intrusive thoughts*, intense emotional distress, and withdrawal from normal daily activities. This period, along with the chronic grief that follows, may vary in length and intensity from individual to individual and often resembles clinical depression (Monk et al., 2013).

***Intrusive thoughts**: unwanted, involuntary thoughts, images or ideas that can be obsessive, distressing, or upsetting.

When a spouse dies, a third of surviving spouses will experience major depression. This risk of depression peaks during the first six months of bereavement but can last up to two years. Even bereaved persons with minor depression may suffer; they have a greater likelihood of functional impairment, poorer health, more physician visits and mental health counseling, and increased use of antidepressants than do non-bereaved individuals (Monk et al., 2013).

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Post Test

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 extremely forgetful.

2. Mild cognitive impairment:

a. Is not common in older adults.

b. Will eventually progress to Alzheimer's disease.

c. Does not necessarily indicate the presence of Alzheimer's disease.

d. Compromises a person's ability to function independently.

3. How is dementia different from normal aging?

a. Age-related changes and dementia are the same thing.

b. A person with dementia does not get lost when driving in a new city.

c. In dementia, a person gradually loses the ability to think logically.

d. A person with normal age-related changes cannot live independently.

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

a. Still be able to work, but will need help from coworkers with complex tasks.

b. First be diagnosed at this stage of the disease.

c. Have completely lost the ability to function independently.

d. Have a complete loss of immediate recall.

5. In general, when communicating with a person with dementia, it is important to understand:

a. Although people with dementia can't speak very well, they understand everything you're saying.

b. People with dementia will respond better to a loud voice.

c. It takes a lot of energy for a person with dementia to communicate with another person.

d. Open-ended questions work better than closed questions.

6. Nonverbal communication is:

a. Using a very quiet tone of voice and repeating what you just said.

b. Communicating through facial expressions, hand gestures, and body language.

c. Speaking calmly, or speaking with affection, disapproval, confidence, or fear.

d. Doing your job without speaking so you don't bother the resident.

7. When communicating with someone who is not responsive, it is best to:

a. Approach from behind and speak loudly.

b. Talk normally, using complex sentences.

c. Slow your movements and re-introduce yourself at each encounter.

d. Complete your duties quietly and try not to disturb the person.

8. A common coping strategy of people in the mild stage of dementia is to:

a. Shrug off others' concerns and go on with their life.

b. Immediately give up driving because it could be dangerous.

c. Enlist the help of family and friends.

d. Begin to plan for a life with diminished abilities.

9. My mom, retired nurse, has moderate dementia. She answers the phone and talks to whoever is on the other end of the line. Last month she bought $600 worth of financial books and audiotapes even though she can't see the print and doesn't handle her own finances anymore. When I tried to stop her from ordering the books she got really mad and screamed at me. Why does she do these things? B

a. She just likes getting new things.

b. Her judgment has been affected by dementia.

c. She loves to talk on the phone.

d. She wants to become a financially secure.

10. The ABC approach to behaviors in dementia refers to:

a. Approach, behavior, compensate.

b. Antecedent, best option, consequence.

c. Approach, beware, consequence.

d. Antecedent, behavior, consequence.

11. Wandering can be addressed by:

a. Providing a safe area to walk.

b. Verbally admonishing a person to stop or else.

c. Discussing the behavior with the doctor.

d. Restraining the person in a wheelchair.

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

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

b. Boredom, pain and discomfort, disorientation, and memory problems.

c. Degeneration of neurons in the part of the brain that controls circadian rhythms.

d. Health factors such as urinary tract infections or environmental factors such as poor lighting or sensory overload.

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

a. Cooking, shopping, and medical management

b. Eating, bathing, and dressing

c. Housework, bathing, and grooming

d. Transferring from bed to chair, toileting

14. 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.

15. One of your client's pinches and bites her caregivers when they attempt to bathe her. The best response to this behavior would be 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.

16. 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.

17. 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

Answer Sheet

Name (Please print your name)____

Date____

Passing score is 80%

1. ______
2. ______
3. ______
4. ______
5. ______
6. ______
7. ______
8. ______
9. ______
10. ______
11. ______
12. ______
13. ______
14. ______
15. ______
16. ______
17. ______

Course Evaluation

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

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

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

1. State 3 differences between dementia and age-related changes in cognition. 5 4 3 2 1

2. Describe one technique each for improving verbal, non-verbal, and non-responsive communication in those with dementia. 5 4 3 2 1

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

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

5. For each stage of dementia, relate one concern or issue you might encounter with family members and caregivers. 5 4 3 2 1

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

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

*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, do you intend to 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? 5 4 3 2 1

*Navigating the ATrain Education website was:

______Easy. ______Somewhat easy. ______Not at all easy.

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

______60 minutes (or more) per contact hour ______59 minutes per contact hour

______40-49 minutes per contact hour ______30-39 minutes per contact hour

______Less than 30 minutes per contact hour

I heard about ATrain Education from:

______Government or Department of Health website. ______State board or professional association.

______Searching the Internet. ______A friend.

______An advertisement. ______I am a returning customer.

______My employer. ______Social Media (FB, Twitter, LinkedIn, etc)

______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:

Registration and Payment Form

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

*Name: ____

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*Zip: ____

*Country: ____

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____

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*Name and credentials as you want them to appear on your certificate.

____

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*Zip: ______________

*Card type: Visa Master Card American Express Discover

*Card number: ____

*CVS#: _____________ *Expiration date: ____________________