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Rhode Island: Alzheimer's Disease and Related Disorders, 1 unit (307)

Author: Lauren Robertson, BA, MPT

Contact hour: 1

Price: \$10

Course Summary

This training is for those of you who have direct contact with patients in nursing homes, adult day care, or hospice. It is designed to increase your awareness and understanding of Alzheimer's disease and related disorders.

The first section of the course defines dementia, describes how dementia affects the brain, and discusses how the symptoms of dementia differ from normal age-related changes. The second section discusses the stages of dementia along with symptoms and behaviors you might see during the different stages. The last part of the course discusses communication challenges at the different stages of dementia, including patients with dementia who are receiving hospice, and provides tips for communicating with people at those different stages.

Criteria for Successful Completion

Study the course material, achieve a score of 80% or higher on the post test (the post test can be repeated if a learner scores less than 80%), complete the course evaluation, and pay where required. No partial credit will be awarded.

Course Objectives

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

1. Name 3 properties of dementia.
2. Name 3 differences between normal, age-related changes and the changes seen in dementia.
3. Describe the first symptom you are likely to notice in someone in the early stage of Alzheimer's disease.
4. Give one characteristic each for Alzheimer's, frontal-temporal, vascular, and Lewy body dementia.
5. Relate 1 symptom and behavioral change at each stage of Alzheimer's disease.
6. Describe 2 challenges facing caregivers at each stage of dementia.
7. Outline 3 strategies for communicating with residents at each stage of dementia.
8. Describe 4 problems faced by someone caring for a family member with dementia who is also on hospice.

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

The Rhode Island General Assembly in 2019 passed an act that established a program within the Department of health to address Alzheimer’s disease. It determined that all state-licensed physicians and nurses must complete a one-hour course of instruction . . . on the diagnosis, treatment and care of patients with cognitive impairments including, but not limited to, Alzheimer's disease and dementia.

Rhode Island General Assembly, 2019

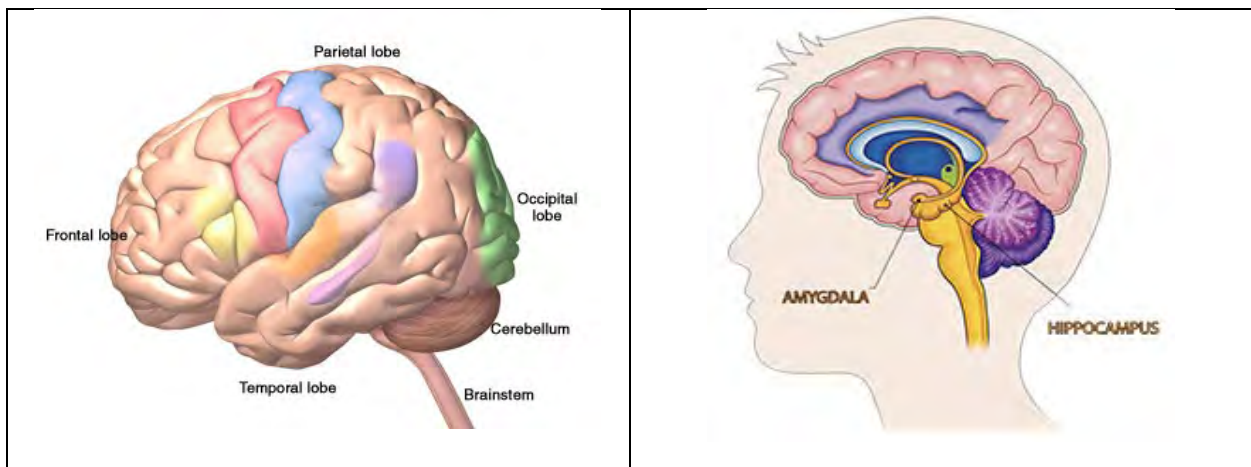
In this course we will discuss dementia. We will explain how dementia affects the brain. We will discuss how Alzheimer’s disease differs from other types of dementia. We will go over behaviors you will see every day in people with mild, moderate, and severe dementia. Finally, we will discuss communication issues you might see at different stages of dementia.

Alzheimer’s disease and other types of dementia are caused by damage to the brain. The part of the brain that is damaged in dementia is called the **cerebrum**. The cerebrum fills up most of our skull and is divided into four lobes:

- **Frontal lobes:** reasoning, judgement, motor control, planning, decision-making
- **Temporal lobes:** memory and emotion, hearing, language
- **Parietal lobes:** sensation, touch, temperature, pressure, pain
- **Occipital lobes:** visual processing, depth, distance, location of objects

The cerebrum is what makes us human—it does our thinking, remembering, talking, and understanding. It controls our emotions. It helps us reason things out and make decisions. It helps us tell right from wrong. It also controls our movements, vision, and hearing. Many of these areas of the cerebrum are damaged by dementia.

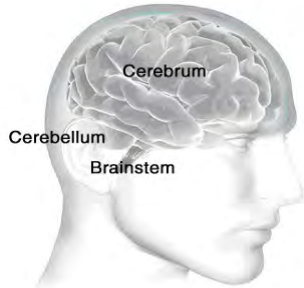
The Human Brain



Left: The four lobes of the cerebrum, plus the cerebellum and the brainstem. **Right:** The cerebellum and brainstem are at the back of your head below the cerebrum. Alzheimer’s disease starts in the temporal lobe in an area called the hippocampus. Source: Copyright, Zygot Media Group, Inc. Used with permission. Right: National Institutes of Health, Source: iStock/jambojam. Public domain.

Our brain has two other important parts: the cerebellum and the brainstem. Touch the back of your head just above your neck. The **cerebellum** is right there. It controls coordination and balance.

Cerebellum and Brainstem



The cerebellum and brainstem are at the back of your head below the cerebrum.

Now move your hand a little down and stop before you get to your spine. The brainstem is right there—at the back of the head, above your spine. It connects the brain to the spinal cord. The **brainstem** oversees automatic things like breathing, digestion, heart rate, and blood pressure. The cerebellum and the brainstem are usually not affected by dementia.

What Is Dementia?

Dementia is a brain disease. It 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.

AD begins in the area of the brain that makes new memories, called the hippocampus. The hippocampus is the memory center of the brain, responsible for forming short-term memories. That's why someone with AD forgets something that happened just a moment ago. This part of the brain also helps us associate memories with various senses, such as smell.

Other types of dementia begin in areas of the brain involved with thinking and reasoning. Although dementia can start in one part of the brain, eventually it will affect the entire brain. Emotions are also affected when someone gets dementia. That's why someone with Alzheimer's disease and other types of dementia sometimes has difficulty controlling their emotions.

When someone has dementia, their thinking becomes less clear. Decisions are more difficult and safety awareness declines. People also tire more easily. Eventually, people with dementia lose the ability to take care of themselves. In the end, they may also lose their appetite and stop eating.

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 Does Dementia Affect the Brain?

Dementia changes the entire brain. In Alzheimer's disease, nerve cells in the brain are damaged by something called **plaques** and **tangles**. As the nerve cells die, the brain gets smaller. Over time, the brain shrinks, affecting nearly all its functions.

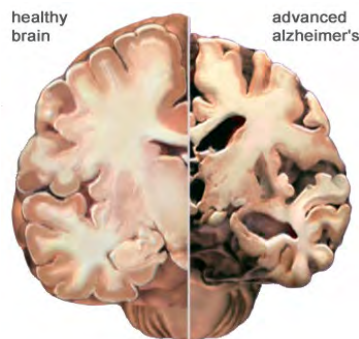
In Alzheimer's disease, damage begins in the temporal lobe, in and around the hippocampus. The hippocampus a part of the brain that is responsible for new memories, spatial awareness, and control of emotions.

Dementia affects what are called executive functions: mental skills that include memory, thinking, and self-control. We use these skills to manage daily life. Dementia causes a gradual loss of executive functions and makes it hard to plan for the future, follow complex conversations, remember new things, and control emotions.

As the disease progresses, plaques and tangles spread to the front part of the brain (the temporal and frontal lobes). These areas of the brain are involved with language, judgment, and learning. Speaking and understanding speech, the sense of where your body is in space, and executive functions such as planning and ethical thinking are affected.

In severe Alzheimer's disease, damage is spread throughout the brain. At this stage, because so many areas of the brain are affected, individuals lose the ability to communicate, to recognize family and loved ones, and to care for themselves.

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.

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.

Age-related changes don't affect a person's life very much. Someone with 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. They know how to take care of themselves. Even though they might not think or move as fast as when they were young, their thinking is normal—they do not have dementia.

The table below describes some of the differences between someone who is aging normally and someone who has some form of dementia.

Normal Aging vs. ADRD	
Normal aging	AD or other 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 night time)	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

In some older adults, memory problems are a little bit worse than normal age-related changes. This is known as **mild cognitive impairment**, also called **MCI**.

Mild cognitive impairment isn't dementia although you may see personality changes, as well as 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.

Changes in behavior can occur in older adults and may be a risk factor for dementia. This is called **mild behavioral impairment** or **MBI**. Signs of MBI are apathy, mood swings, anxiety, agitation and aggression, social withdrawal, and abnormal thoughts (Alzheimer's Association, 2021)

What Is Alzheimer's Disease?

Alzheimer's disease (AD) is the most common cause of dementia. Nearly 6 million people in the United States suffer from Alzheimer's. It is the sixth leading cause of death in the United States and affects women more than men. About two-thirds of Americans caring for someone with Alzheimer's disease are women (Alzheimer's Association, 2021).

The first thing you will notice in someone with Alzheimer's disease is that they have trouble making new memories. This is called **short-term memory loss**. This happens because the part of the brain where new memories are formed becomes damaged by dementia.

Long-ago memories are stored in a part of the brain that is not affected by Alzheimer's dementia. Especially at first, people can remember and talk about events from earlier times in their lives. As the dementia gets worse and more of the brain is affected, long ago memories might also start to fade.

Other Kinds of Dementia

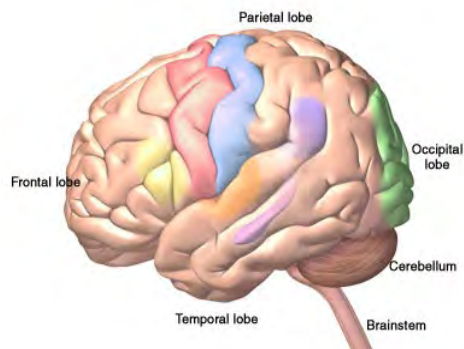
Alzheimer's disease isn't the only cause of dementia. Unfortunately, there is no way to know for sure what type of dementia a person has. There is no blood test or x-ray that can diagnose Alzheimer's or other types of dementia. The only sure way to know if someone had Alzheimer's disease is to examine their brain after they die. The symptoms are a little different in each type of dementia. It's good to know the difference to help you understand why someone is acting the way they are.

Frontal-Temporal Dementia

Look at the picture of the brain below. Put your hands on your forehead. The part of your brain just behind your forehead is called the **frontal lobe**, you have one on each side of your forehead. Now slide your fingers from the front to the side of your head (your temple). This part of the brain is called the **temporal lobe**. You have 2 temporal lobes also—one on each side.

There is a type of dementia that affects this part of the brain. It is called **frontal-temporal dementia**. It is the most common type of dementia in people under the age of 60. It's not nearly as common as Alzheimer's and it starts at a much younger age. Frontal-temporal dementia can affect one side of the brain or both.

The Lobes of the Brain



Source: Copyright, Zygotte Media Group, Inc. Used with permission.

We use the front part of our brain to make decisions, to tell right from wrong, and to control our emotions. We also use this part of the brain to plan for the future. People with dementia in this part of the brain have poor judgment and lose the ability to tell right from wrong. They also have less control over their behavior and have changes in personality.

In addition to behavioral changes, frontal-temporal dementia can affect a person's language abilities. This is called aphasia and can cause difficulty understanding what another person is saying as well as difficulty with speech. A person's speech might be hesitant, they may talk less than they did in the past, and they may have trouble naming things or understanding the meaning of words.

So, in the beginning, instead of difficulty with short-term memory like people with Alzheimer's disease, a person with frontal-temporal dementia might start doing things that are confusing to their friends and family. They might steal, even though they have never stolen in the past. They might make inappropriate sexual remarks, swear, or engage in inappropriate sexual behaviors, even though they've never done these things in the past. Eventually, people with frontal-temporal dementia will lose their short-term memory.

Vascular Dementia

Vascular dementia is caused by reduced blood flow to the brain from hardening of the arteries, small strokes, high blood pressure, infections, and certain auto-immune diseases. When blood flow is reduced, the brain is deprived of oxygen and nutrients. Generally, vascular dementia doesn't affect memory as much as Alzheimer's because damage is often spread throughout the brain. Depending on size and location, damage can be mild or severe and can affect more than one area of the brain.

Vascular dementia can cause mood swings, depression, irritability, and anxiety. It can also affect judgment—but usually not as strongly as in someone with frontal-temporal dementia. It is hard to say that vascular dementia leads to certain symptoms that are worse/or less than other types of dementia because the symptoms tend to be strongly dependent on where the strokes have occurred.

You might have cared for more than one patient with vascular dementia because many older adults have high blood pressure that isn't under good control. You may also see vascular dementia in someone who has had a stroke.

Lewy Body Dementia

Lewy body dementia is less common than Alzheimer's dementia, frontal-temporal dementia, or vascular dementia. It is responsible for a little less than 5% of all cases of dementia. People with Parkinson's disease can have this type of dementia.

In Lewy body dementia, abnormal clumps of alpha-synuclein (Lewy bodies) are scattered throughout the cortex, brainstem, and midbrain. The location of these clumps influences the symptoms, which vary from person to person.

People with Lewy body dementia may have problems with memory, which can be mistaken for Alzheimer's disease. They may have movement difficulties that are similar to Parkinson's disease (slow movement, tremors, difficulty walking). They can also have visual hallucinations, mental fluctuations (drowsiness, staring into space, long naps, disorganized speech), and sudden confusion. These symptoms can come and go throughout the day.

People with Lewy body dementia can also experience visuospatial difficulties. This is more than just *visual* difficulties—they can have problems *processing* where objects are in space, including their own arms and legs. Other visuospatial difficulties can include trouble with depth perception, judging distance, and understanding the distance between two objects. It also involves difficulties with math and reading. We use visuospatial skills to dance, make sense of the shape of numbers and letters, and to keep from bumping into someone passing us in the hallway.

Lewy body dementia can also affect a person’s sleep and cause a person to suddenly faint or pass out. This means a person with Lewy Body dementia is at high risk for unexpected falls.

Some Common Types of Dementia

Type of dementia	Characteristics and symptoms
Alzheimer’s disease (AD)	<ul style="list-style-type: none"> • Loss of short-term memory • Behavioral changes, apathy, depression, anxiety • Personality and behavior changes • Mood swings • Difficulty communicating and understanding speech
Frontal-temporal dementia	<ul style="list-style-type: none"> • Changes in behavior • Poor judgment • Loss of moral reasoning • Loss of inhibition • Changes in speech and communication
Vascular dementia	<ul style="list-style-type: none"> • Memory affected but less than in AD • Poor judgment • Mood changes—more than in AD • Apathy • Irritability
Dementia with Lewy bodies	<ul style="list-style-type: none"> • Visual hallucinations • Sleep disturbance • Motor control problems • Mental fluctuations • Visuospatial difficulties

Diagnostic Guidelines

Diagnosis of Alzheimer's disease and other types of dementia is based on symptoms; no test or technique that can diagnose dementia. To guide clinicians, in 2011 the National Institute on Aging and the Alzheimer's Association (NIA-AA) published updated diagnostic guidelines, which are intended to provide a deeper understanding Alzheimer's disease than earlier guidelines. The 2011 (latest) guidelines:

- Recognize that Alzheimer's disease progresses on a spectrum with three stages: (1) an early, preclinical stage with no symptoms; (2) a middle stage of mild cognitive impairment; and (3) a final stage marked by symptoms of dementia. Cognitive decline is gradual and progressive.
- Expand the criteria for Alzheimer's dementia beyond memory loss as the first or only major symptom and recognize that other aspects of cognition, such as word-finding ability or judgment, may become impaired first. Other cognitive changes can include changes in:
 - Episodic memory
 - Executive functioning
 - Visuospatial abilities
 - Language functions
 - Personality and/or behavior
- Reflect a better understanding of the distinctions and associations between Alzheimer's and non-Alzheimer's dementias, as well as between Alzheimer's and disorders that may influence its development, such as vascular disease, delirium, or stroke.
- Recognize the potential use of biomarkers—indicators of underlying brain disease—to diagnose Alzheimer's disease. However, the guidelines state that biomarkers are almost exclusively to be used in research rather than in a clinical setting. (NIA-AA, 2020)

Since the publication of the 2011 guidelines, researchers have increasingly come to understand that cognitive decline in AD occurs continuously over a long period, and that progression of biomarker measures* is also a continuous process that begins before symptoms are evident. The disease is now regarded as a continuum rather than three distinct clinically defined stages (Jack et al., 2018).

* β amyloid deposition, pathologic tau, and neurodegeneration / neuronal injury.

A 2018 update of the 2011 NIA-AA diagnostic guidelines added a numerical **clinical staging scheme**. This staging scheme reflects the sequential evolution of AD from an initial stage characterized by the appearance of abnormal biomarkers in asymptomatic individuals. As biomarker abnormalities progress, the earliest subtle symptoms become detectable. Further progression of biomarker abnormalities is accompanied by progressive worsening of cognitive symptoms, culminating in dementia (Jack et al., 2018).

The numerical clinical staging scheme is as follows (Jack et al., 2018):

1. Performance within expected range on objective cognitive tests.
2. Normal performance within expected range on objective cognitive tests. (Transitional cognitive decline: Decline in previous level of cognitive function, which may involve any cognitive domains.
3. Performance in the impaired/abnormal range on objective cognitive tests.
4. Mild dementia.
5. Moderate dementia.
6. Severe dementia.

In 2018 an Alzheimer’s Association workgroup lead published a report describing the need for **clinical** practice guidelines for use in primary and specialty care settings. The guidelines build on the NIA_AA guidelines but add a clinical component for the evaluation of cognitive impairment thought to be related to Alzheimer’s disease or a related type of dementia.

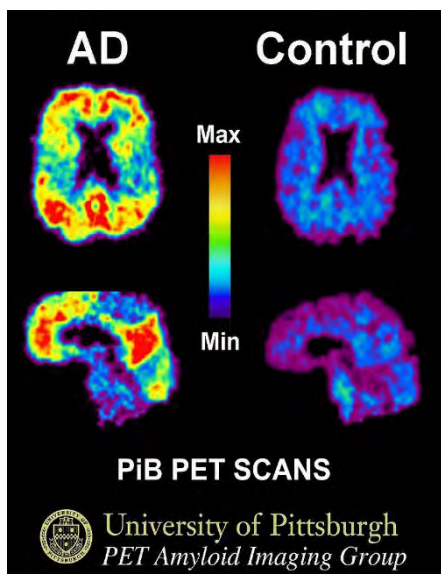
Key components include (Atri, 2019):

- Conduct an evaluation of all middle-aged or older individuals who self-report or whose care partner or clinician report cognitive, behavioral or functional changes.
- Do not dismiss concerns as “normal aging” without a proper assessment.
- Involve not only the patient and clinician but also a care partner.

Neuroimaging and CSF Biomarkers

Neuroimaging is increasingly being used to assist with early diagnosis of Alzheimer’s disease and related dementias by detecting visible, abnormal structural and functional changes in the brain. Magnetic resonance imaging (MRI) can provide information about the shape, position, and volume of the brain tissue and is being used to detect brain shrinkage, which is related to excessive nerve death. Positron emission tomography (PET) uses a radioactive dye called PiB to detect the presence of beta amyloid plaques in the brain.

PET Scans Showing PiB Uptake



A PiB-PET scan of a patient with Alzheimer's disease on the left and an elder with normal memory on the right. Areas of red and yellow show high concentrations of PiB in the brain and suggest high amounts of amyloid deposits in these areas. Source: Klunkwe, own work, CC BY-SA 3.0.

CSF biomarkers are measures of the concentrations of proteins in cerebral spinal fluid from the lumbar sac that reflect the rates of both production (protein expression or release/secretion from neurons or other brain cells) and clearance (degradation or removal) at a given point in time.

2. Characteristics of Alzheimer's Disease and Related Dementias

In the previous section, we talked about different kinds of dementia. Each one has its own set of characteristics. A **characteristic** is a feature or quality you would expect to see in a disease. You now know that one characteristic of frontal-temporal dementia is that it starts at an earlier age than Alzheimer's.

Symptoms and Behavior Changes by Stages

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. **Behavior** is how we act, move, and react to our environment. Anger and happiness are behaviors.

Symptoms and behaviors change as dementia gets worse. For some people symptoms can get worse really fast. For others symptoms may get worse gradually—over 10 to 20 years. A good way to understand symptoms and behaviors is to look at how things change in the early, middle, and late stages of dementia.

Symptoms and Behaviors in Mild Dementia

The early or mild stage of dementia begins with mild forgetfulness, especially memories of recent events. Forgetfulness might be the most obvious symptom at this stage, especially in Alzheimer's disease.


Logical thinking and judgment are mildly affected, especially in frontal-temporal dementia. At this stage, you might notice a little confusion with complex tasks that take many steps to complete. People try to cover up mild confusion so friends, coworkers, and family might not notice that something is wrong.

Even when symptoms are mild, people's behavior begins to change, especially in Alzheimer's disease. People with mild dementia know something is wrong. They may begin to worry about the future or feel stress and anxiety. They may get depressed as they struggle with changes in their thinking. Mood changes might be most obvious in a person with vascular dementia.

People with mild dementia may occasionally become angry or aggressive. They might have 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.

According to a new study, half of the people living with Alzheimer's may have mild rather than moderate or severe cases. Although there have been many studies into the prevalence of Alzheimer's, few have characterized the proportion of cases that are mild, moderate, or severe. Better understanding of these ratios could help scientists more effectively plan research and allocate future resources, particularly those targeted at various stages of disease, including mild cognitive impairment (MCI) (NIH, 2021, March 18; Yuan, 2021).

Changes in the Brain During Mild Dementia

	<p>In the earliest stages of Alzheimer’s disease, before symptoms can be detected with current tests, damage (shaded in blue) begins in the areas of the brain involved in:</p> <ul style="list-style-type: none"> • Learning and memory • Thinking and planning
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Source: Courtesy of The Alzheimer’s Association. Used with permission.

Symptoms and Behaviors in Moderate Dementia

In the moderate stage of dementia, people are more forgetful. Confusion also gets worse. Speech and communication are obviously affected. Judgment and logical thinking are much worse than in the early or mild stage.

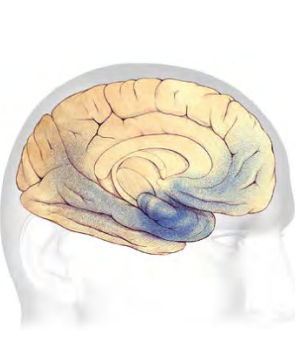
Because of memory problems and confusion, caregivers must take over tasks that the person with dementia was able to do in the past. In this stage, independent travel, work, and keeping track of personal finances are probably no longer possible.

In the moderate stage, behavior changes are much more obvious. Inappropriate behaviors such as cursing, kicking, hitting, and biting are not uncommon. Some people may repeat questions over and over, call out, or demand your attention. Sleep problems, anxiety, agitation, and suspicion can develop.

A person with moderate dementia is often still able to walk. This is because the part of the brain that controls movement is not damaged. If a person can still walk or if they can get around easily in a wheelchair, they might begin to wander. More direct monitoring is needed than during the early stage of dementia.

During this stage, people are no longer safe on their own. Caregiver responsibilities increase. This causes stress, anxiety, and worry among family members and caregivers. Surprisingly, many people with dementia may not be diagnosed until they reach this stage.

Changes in the Brain During Mild to Moderate Dementia

	<p>In mild to moderate stages, the parts of the brain involved with memory, thinking, and planning become more affected (shaded in blue).</p> <p>Work or social life becomes more difficult. Confusion increases, and many people with Alzheimer’s are first diagnosed in this stage. Damage spreads to the areas of the brain involved with:</p> <ul style="list-style-type: none"> • Speaking and understanding speech • Logical thinking • Safety awareness
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Source: Courtesy of The Alzheimer’s Association. Used with permission.

Symptoms and Behaviors in Severe Dementia

My mom is 96 years old and has pretty severe dementia. She still lives at home because we provide 24/7 care. If we put her in a nursing home I think she would go down pretty fast. Loud noises, too many people around, people that don't know her needs and habits, boredom, loneliness—all those things would drive her crazy. At this stage I think she'd be really hard to handle in a nursing home. She's kind of stubborn and independent and I'm sure she'd wander, yell, swear, shout, hit, and cry. At home she doesn't do any of these things (well, a little now and then) but we work pretty hard to keep things quiet, warm, and steady for her.

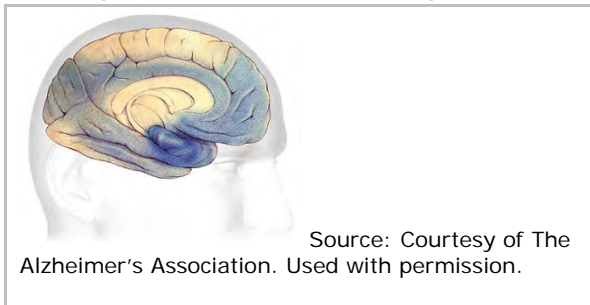
Family Caregiver, Cumberland, Rhode Island

People with severe dementia lose the ability to remember recent events although they may still remember events from long ago. They can be easily confused and indecisive. Speech, communication, and judgment are severely affected. They cannot think logically. Sleep disturbances are very common.

Challenging behaviors can include screaming, swearing, crying, shouting, loud demands for attention, negative remarks to others, and self-talk. Outbursts can be triggered by boredom, loneliness, depression, cold or heat, loud noises, and pain. Wandering, rummaging, or hoarding can occur. A person may become paranoid or have delusions or hallucinations.

In the severe stage, independence is lost, and around-the-clock care may be needed. People at this stage need assistance with eating, bathing, walking, dressing, and all other daily living activities. The illustration below shows that most of the surface of the brain is severely damaged (shaded in blue). Individuals may lose their ability to communicate and to recognize family and loved ones.

Changes in the Brain During Severe Dementia



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

Symptoms and Behaviors at the End of Life

As people with dementia approach the end of life they may lose all memory—not just memory of recent events. They are easily confused and startled by loud noises and quick movements. They can no longer communicate their needs and desires using speech. At this stage, people can develop other illnesses and infections. They may experience agitation, psychosis (loss of contact with reality), delirium (a sudden, severe confusion that can be caused by infections, medications, surgery, illness), and restlessness and depression).

At the end of life, people may be completely dependent on caregivers. They may be unable to eat, swallow fluids, or move without help. Most commonly, people with Alzheimer's disease or other types of dementia die of pneumonia or from complications of fractures, especially hips fractures.

3. Challenges for Caregivers of Patients with ADRD

I've been hired to help care for a woman with mild dementia. She has five kids—they have always come to their mother to discuss their personal problems. When they visit I noticed the mom always agrees with them but when they leave she turns around and says "I can't stand to hear all their complaints."

She gets really agitated after they visit. Sometimes she sits and cries for the rest of the day and into the evening. I can't snap her out of it. She didn't use to be like this. I get so tired it almost isn't worth it—I never get any sleep when I'm there. I finally had to cut back from 7 to 4 days—it was really difficult dealing with the family and caring for this woman.

Professional Caregiver, Newport, Rhode Island

A **caregiver** is someone who provides assistance to a person in need. Care can be physical, financial, or emotional. Each year, nearly 16 million family members and friends provide over 18.5 *billion* hours of unpaid care to those with Alzheimer's and other dementias (Alzheimer's Association, 2019).

Caregivers help with basic activities of daily living (ADLs) such as bathing, dressing, walking, and cooking. They also help with more complex tasks such as managing medications and taking care of the home. Caregivers can provide direct care or manage care from a distance. They can be a family member, a neighbor, a friend, or a medical professional.

The responsibilities of caregiving can be overwhelming. More than half of caregivers of people with Alzheimer's and dementia rate the emotional stress of caregiving as high or very high. Compared with caregivers of people **without** dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties (Alzheimer's Association, 2021).

Caregiver Challenges in Mild Dementia

In the early stage of dementia, family caregivers may not know much about dementia and may not seek help. They may be confused and frustrated when their family member "acts funny."

In the early stages, caregiving responsibilities can usually be handled by family members. In this stage, caregivers can often handle light caregiving duties. The person with dementia may only need help with complex activities such as banking, bill paying, medical appointments, and medications.

People with mild dementia may still live alone, drive, and even have a job. They can usually handle activities of daily living such as bathing, eating, and cooking.

Caregiver Challenges in Moderate Dementia

In the moderate stage, the stress of caring for a previously independent person can take a great deal of time. It can cause anxiety, sleep disruption, anger, and depression.

In this stage, more time is needed for caregiver duties. Loss of free time, work conflicts, and family issues may seem impossible to resolve. Often the responsibility of caregiving falls mostly on one person—often a woman—leading to anger and frustration with other family members.

Caregiver Challenges in Severe Dementia

I'm exhausted. I can't sleep because I have to watch out for my wife. She wanders around the house, takes out all kinds of stuff from the kitchen. I don't know what she's going to do.

Family Caregiver, West Warwick, Rhode Island

In the later stages of dementia, when fulltime care is needed, family members face difficult decisions. Should the person with dementia move in with a family member? Should a full-time caregiver be hired? Should their loved one be admitted to a long-term care facility?

Behaviors such as agitation, irritability, obscene language, tantrums, and yelling are embarrassing, tiring, and frustrating for caregivers. Caregivers can be injured if a person throws things, strikes out, or bites. Caregivers may react out of fear and strike back or yell to stop these behaviors, creating guilt and more frustration.

In this stage, safety can become a challenge for caregivers. If finances allow, a one-on-one caregiver may be needed during the day. If finances do not allow the hiring of an outside caregiver, family caregivers become exhausted tending to a person who needs constant supervision. Jobs, hobbies, friendships, travel, and exercise fall to the side. Caregivers often neglect their own health, causing more stress.

If the person with dementia is still living at home, caregivers must provide more support. Family members may find it impossible to continue to provide care and may have to move their loved one to an assisted living or skilled nursing facility.

At the end of life, care is usually carried out by a group of people who work together to care for and comfort a person prior to death. Hospice care is available under Medicare, most state Medicaid programs, and some private insurance plans. Hospice provides care for those believed to have less than six months to live.

Advance directives such as a living will and a durable power of attorney should be on file. These legal documents allow a person to communicate wishes about end-of-life care while they are still able to make these decisions.

4. Communicating with Residents

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 former President Obama—this is a new article about the weather back east.”

Caregiver, Pawtucket, Rhode Island

While memory problems are the most characteristic symptom of Alzheimer’s disease, most individuals with dementia also experience progressive problems with communication. The deterioration of a person’s ability to communicate contributes considerably to the stress and burden of caregivers and is often classified among the most serious stressors that caregivers face.

Communication changes are related to the area of the brain affected by the disease. One of the first symptoms of Alzheimer’s is loss of short-term memory. This means a person does not remember the “what, where, and when” of recent events—what they ate for breakfast, where they went yesterday, and when their daughter is returning home. Alzheimer’s also affects emotional control relatively early in the disease process, which can affect communication.

In frontotemporal dementia, because damage begins in the front part of the brain, memory is less affected, at least at first. But the front part of the brain controls judgment, moral reasoning, logical thinking, and social behavior. A person with frontotemporal dementia, because they are gradually losing some of their social control, might make inappropriate sexual comments, make socially inappropriate remarks, and be frustrated when trying to make decisions.

In vascular dementia, because damage can be widespread and not necessarily associated with a specific part of the brain, communication problems are usually less specific. There may be a slowness of thought, problems with attention and concentration, and difficulties with language. Complex, fast-paced conversations or quick changes in topic may become difficult (this is true for all types of dementia).

A person with Lewy Body dementia can experience paranoia, delusions, and hallucinations (usually visual), which are very real for the person experiencing them. Arguing, explaining, agreeing, or validating the paranoia or delusion is usually not an effective way to communicate with a person with this type of dementia. Emotional support, quiet touch, and redirection may be effective than verbal communication.

Improving Verbal Communication

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

A person with dementia has trouble with these communication skills. They have to work hard to say what they want to say. They might not remember what was said a few moments ago. They have trouble talking and doing something else at the same time. Background noise is confusing and irritating.

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

A successful conversation with a resident who has dementia begins with eye contact* and an introduction. You can put a person at ease by starting with something light and conversational such as the weather or what's happening in the news. Nonverbal gestures such as head nods, a light touch on the arm, and a warm expression create trust.

*Keep in mind that some cultures view eye contact as aggressive or rude. Also, some patients may not make eye contact with you as a sign of respect for authority.

No matter how severe the dementia, effective communication is very important. Practice these habits, even when you are busy or in a hurry:

- Approach slowly from the front. Avoid crowding the person, which may appear threatening.
- Move to the side and crouch down.
- Take a deep breath and relax.
- Greet the person by name, then introduce yourself.
- Use short, 1- or 2-part questions and wait for a reply.
- Use a calm voice, be attentive and sympathetic.
- Continue the conversation by asking a follow-up question.

General Conversations

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. You can begin a general conversation by asking for an opinion or giving an opinion. You can make a suggestion or ask for an explanation.

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? Where did they work? Where did they travel? What were their interests and hobbies?

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.

A general conversation can be about yourself, about your workday, your commute, or your family. It can include positive comments about other people you work with or other residents. If someone else is in the room include that person in the conversation.

People with dementia—especially moderate or severe 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

When you want to complete a specific task, use what is called a “closed question.” This shows interest and invites a person to respond. Say, for example, “Are you hungry?” or “Are you ready to get dressed?” Closed questions limit the conversation and keep the conversation focused on the task at hand.

Talk slowly and don’t argue. Use gentle persuasion and be positive when giving directions. Share your goals with the resident. Be respectful and relaxed. Keep in mind that the person you are caring for may not share your goal. Or 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. He is a resident in a nursing home. 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 nursing aide, 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 dining room.” 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 really busy!” Ann takes his arm and helps him stand up. George pulls away and sits back in his chair.

What Is George Thinking?

George is comfortable 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—when 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 really busy. Two nursing aides called in sick so she was assigned six additional patients. She was way behind and needed to get George to the dining room 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, 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, squatting next to him, 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.

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 verbal conversation.

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

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 can reveal calmness or impatience, affection or disapproval, confidence or fear. When you are talking, the loudness of your voice and its tone and rhythm are communicating 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 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. Some studies have shown that people say they don't like people when they see them in unattractive rooms.

Communicating When a Person Is Nonresponsive

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.

Communicating with a person who is unresponsive can be a challenge for family and caregivers. It's 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 the person 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, and 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 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.

No matter how unresponsive a resident is, practice these habits:

- Approach 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 touch to communicate your intentions.
- Avoid a condescending tone.

Communicating with a Person Receiving Hospice Care

The purpose of hospice is to ease a person's pain and reduce suffering at the end of life. However, if a person can no longer communicate due to dementia, assessing their needs can be difficult.

Although you will use many of the same communications techniques you have already learned, a person in hospice who has dementia will probably be more challenging. Non-verbal communication skills are critical—especially if the person's dementia is severe. This means you must develop good non-verbal communication skills but must also be able to understand and interpret your client's non-verbal cues. All the things we take for granted and all the things we do to keep ourselves comfortable depend on the skill and compassion of caregivers.

Pain management is an important daily consideration and involves much more than medications. All sorts of things can cause pain: heat, cold, staying in one position for too long, lack of support in bed or in a chair, constipation, pressure on skin, lack of movement, and old injuries.

People with dementia can be experiencing just as much pain at the end of life as someone with cancer. Because pain is so difficult to assess in non-communicative patients, they often receive less pain medication than they need.

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

Because it is so hard to objectively decide how much pain medication is needed, care providers must rely on their ability to read non-verbal cues such as facial expressions, withdrawal, breathing patterns, and even anger and aggressiveness. Family members can be a big help in interpreting when their loved one is in pain although they often lack information and training and fear making a wrong decision.

In a study of caregivers who were caring for a person with dementia who was also on hospice, researchers found that caregivers:

- Had difficulty communicating with patients
- Experienced a lack of consistent guidance from healthcare professionals
- Were uncertain about the cause and source of patients' pain
- Experienced a great deal of secondary suffering (Turner, n.d.)

5. Conclusion

Dementia is a disease of the brain that interferes with a person's ability to think in a normal, logical manner. Although Alzheimer's disease is the most common cause of dementia, there is more than one kind of dementia. Alzheimer's disease and other types of dementia are diseases of the brain and not a part of normal aging.

Many people with dementia have changes in their behavior. The changes are more pronounced as the dementia progresses. Despite these changes, they continue to have many of the same likes and dislikes they had earlier in life.

Caring for a person with dementia can be time-consuming and stressful. This is especially true as the dementia gets worse and the person being cared for needs more help. Caregivers are at high risk for depression. Caregivers should be encouraged to use the many resources and support services available to them both in-person and online.

Communication issues affect people with dementia. As dementia progresses, it is more difficult for people with dementia to communicate their needs. Good verbal and nonverbal communication skills are needed for caregivers to provide a high level of care.

Working with people who have dementia can be satisfying and rewarding. But it takes patience, practice, and training to learn to understand the world from that person's point of view. People with dementia can still enjoy life. They can enjoy memories, interactions with the people around them, and activities that are matched to their preferences and abilities. Your efforts to make the person comfortable and happy can make a big difference in their final years of life.

[Continue to next page for resources]

Resources

2-1-1 Information and Referral Search

For help with food, housing, employment, healthcare, counseling, and crisis intervention, and more in many counties in Rhode Island. www.211.org. Phone: 211

Alzheimer's Association

This organization provides support, education, and research. Excellent educational material, a newsletter, fundraising and volunteer opportunities, and a 24/7 helpline. www.alz.org. Phone: 800 272-3900

Alzheimer's Disease Education and Referral (ADEAR) Center

ADEAR was established by an act of Congress in 1990 and is part of the National Institutes of Health. Its mandate is to compile, archive, and disseminate information about Alzheimer's disease for health professionals, people with AD and their families, and the public. The website provides excellent educational material about Alzheimer's disease, current research initiatives, support services, and much more. <https://www.nia.nih.gov/alzheimers>. Phone: 800 438-4380

Eldercare Locator

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

Family Caregiver Alliance National Center on Caregiving

FCA is a community-based nonprofit organization that addresses the needs of families and friends providing long-term care for loved ones at home. They provide assistance, education, services, research, and advocacy. Link: <http://www.caregiver.org>. Phone: 800 445-8106

Rhode Island of Healthy Aging

Partners with organizations throughout Rhode Island to connect you with information and resources that help you age strong. And we advocate for laws, policies and investments that protect your rights and agency. In 2019, we served more than 150,000 Rhode Islanders. <http://oha.ri.gov/index.php>. Phone: 401 462-3000

Teepa Snow, Dementia Education and Training

Teepa Snow is an advocate for those living with dementia and has made it her personal mission to help families and professionals better understand how it feels to be living with the challenges and changes that accompany various forms of the condition so that life can be lived fully and well. Her company, Positive Approach, LLC was founded in 2005 and offers education to family and professional care partners all over the world. Her training is available through video, online education, and in person trainings and consulting. Link: <http://teepasnow.com/> Phone: 877 877-1671

[Continue to next page for references]

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[Continue to next page to begin post-test]

Post Test: Rhode Island ADRD (307)

1. Dementia is:
 - a. Being absent-minded or extremely forgetful.
 - b. A progressive decline in thinking that happens as we age.
 - c. A side effect of stress that occurs in older adults.
 - d. A progressive brain disease.

2. 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.

3. Alzheimer's disease is:
 - a. The gradual loss of long-term memory.
 - b. Can be treated with anti-viral medications.
 - c. The most common type of dementia.
 - d. The formal name for all types of dementia.

4. You are working with a person who is staring into space and saying things you can't understand. What type of dementia do you think this person might have?
 - a. Alzheimer's disease.
 - b. Lewy body dementia.
 - c. Frontal-temporal dementia.
 - d. Parkinson's dementia.

5. A common reaction of people in the mild stage of dementia is:
 - 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.

6. My mom 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 and is unable to handle her own finances anymore. Why does she do these things?
 - a. She is a curious person and likes getting new things.
 - b. Her judgment has been affected by her mild dementia.
 - c. She is lonely and loves to talk on the phone.
 - d. She wants to become a financially secure.

7. Providing care for a person with dementia:
 - a. Should always be overseen by a medical professional.
 - b. Can cause a great deal of emotional stress for the caregiver.
 - c. Usually gets easier as the dementia gets worse.
 - d. Is commonly shared by all members of a family.

8. A sudden change in behavior in a person with dementia:
 - a. Is very likely an age-related change.
 - b. Is related to the person's dementia getting worse.
 - c. Is probably due to a medical problem and should be reported immediately.
 - d. Should be watched closely but is usually not something to worry about.

9. Nonverbal communication is:
 - a. Using a very quiet tone of voice and speaking very slowly.
 - b. Communicating with facial expressions, hand gestures, and body language.
 - c. Speaking with affection, disapproval, confidence, or fear.
 - d. Doing your job without speaking so you don't bother the resident.

10. When communicating with someone with moderate dementia, it is best to:
 - a. Approach from behind and speak softly.
 - b. Approach slowly from the front and introduce yourself.
 - c. Talk confidently, using complex sentences.
 - d. Stand over the person with your head up and shoulders back.

11. Caregivers working with clients receiving hospice who also have dementia report which of the following:
 - a. Good communication related to pain management.
 - b. It is easy to encourage people to take their medications.
 - c. A strong desire among certain clients to use marijuana.
 - d. A lack of consistent guidance from healthcare professionals.

[Continue to next page for answer sheet]

Answer Sheet: Rhode Island ADRD (307)

Name (Please print) _____

Date _____

Passing score is 80%

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

7. _____

8. _____

9. _____

10. _____

11. _____

[Continue to next page for course evaluation]

Course Evaluation: Rhode Island ADRD (307)

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

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

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

1. Name 3 properties of dementia. 1 2 3 4 5

2. Name 3 differences between normal, age-related changes and the changes seen in dementia. 1 2 3 4 5

3. Describe the first symptom you are likely to notice in someone in the early stage of Alzheimer’s disease. 1 2 3 4 5

4. Give one characteristic each for Alzheimer’s, frontal-temporal, vascular, and Lewy body dementia. 1 2 3 4 5

5. Relate 1 symptom and behavioral change at each stage of Alzheimer’s disease. 1 2 3 4 5

6. Describe 2 challenges facing caregivers at each stage of dementia. 1 2 3 4 5

7. Outline 3 strategies for communicating with residents at each stage of dementia. 1 2 3 4 5

8. Describe 4 problems faced by someone caring for a family member with dementia who is also on hospice. 1 2 3 4 5

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

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

*Did this course contain discriminatory or prejudicial language? Yes No

*Was this course free of commercial bias and product promotion? Yes No

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

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

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

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

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

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

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

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

*Navigating the ATrain Education website was:

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

*How long did it take you to complete this course, 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
_____ Other _____

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

_____ 18 to 30 _____ 31 to 45 _____ 46+

I completed this course on:

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

Please enter your comments or suggestions here:

[Continue to next page for registration and payment]

Registration and Payment: Rhode Island ADRD (307)

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

*Name: _____

*Email: _____

*Address: _____

*City and State: _____

*Zip: _____

*Country: _____

*Phone: _____

*Professional Credentials/Designations:

*License Number and State: _____

Payment Options

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

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

1 contact hours: \$10

Credit card information

*Name: _____

Address (if different from above):

*City and State: _____

*Zip: _____

*Card type: Visa Master Card American Express Discover

*Card number: _____

*CVS#: _____ *Expiration date: _____