



CARING FOR THE PERSON
WITH ALZHEIMER'S AND
OTHER DEMENTIA DISEASES
(1-HOUR SELF-LEARNING MODULE)

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PURPOSE

The purpose of this self-learning module is to provide the healthcare professional with the knowledge, skills and attitudes to care for and assist patients and caregivers affected by Alzheimer's disease and related disorders.

OBJECTIVES

Upon completion of this self-learning module, the learner will be able to:

1. distinguish between symptoms of normal aging and symptoms of Alzheimer's disease and other dementia diseases.
2. identify the physical and behavioral symptoms of Alzheimer's disease and other dementia diseases.
3. identify the characteristics and symptoms of the various stages of Alzheimer's disease and other dementia diseases.
4. communicate effectively with patients who have Alzheimer's disease and similar dementia disorders.

***Read the content and complete the learning activities in the module.
When you have completed this self-learning module, take the post-test.
Check your answers with the module answer sheet. If you have at least
70% right (14 correct answers), you have successfully completed this
module.***

FORWARD

Most people have experienced being distracted while driving and somehow forgotten to make the turn onto a familiar street. Most of us have misplaced our wallet or had to ask, “What date is it?” But we count on these reliable intellectual abilities to return as soon as we slow down and take time to think. However, the loss of memory and concentration associated with Alzheimer’s disease and many other similar dementia disorders does not improve.

Patients with advanced dementia diseases are often not able to tell their caregivers what they want or need. They are unable to make decisions or take actions necessary for independent daily living. Professional and informal caregivers must be alert to the cues, both subtle and obvious that the dementia patient provides to give them care that is appropriate and dignified. Providing quality of life to a patient, even when they are no longer able to communicate what that means to them, remains the foundation of hospice care. A person who can’t recall their past, who is confused and bewildered, may seem to others as though they have no awareness. But dementia patients are aware of their immediate feelings and experiences; and their interactions with others is the bases for their quality of life. Providing responsive and appropriate care to the dementia patient requires that health care professionals and volunteers be informed and educated in dementia disease. Making a difference in the life of the dementia patient and their caregivers is worth the effort.

Dementia is not a disease in itself but is a symptom of other disorders of which Alzheimer’s disease is one type. Having dementia does not always mean that a person has Alzheimer’s disease. Having Alzheimer’s disease does mean, however, that eventually the person will experience dementia.

The 2013 update to the DSM-5 (the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders) organized dementia into two diagnostic categories: major and mild neurocognitive disorders. For both major and mild neurocognitive disorders physicians are to specify whether the condition is due to Alzheimer’s disease or another condition such as Lewy body disease or stroke.

Diagnosis of major neurocognitive disorder

The person must have evidence of significant cognitive decline (such as in memory, language or learning) and the cognitive decline must interfere with independence in everyday activities (such as managing medications or paying bills).

Diagnosis of minor neurocognitive disorder

The person has evidence of modest cognitive decline, but it does not interfere with everyday activities such as paying bills, but the activities require greater effort.

According to data released from the Alzheimer’s Association, an estimated 5.8 million Americans of all ages have Alzheimer’s disease in 2020. Alzheimer’s disease is the most common cause of dementia.

- One in ten people 65 and older (10%) has Alzheimer’s disease.
- About 1/3 of people age 85 and older (32%) has Alzheimer’s disease.
- Of those with Alzheimer’s disease 80% are age 75 or older.

The number of Americans with Alzheimer's disease and other dementia disease will grow each year as the size and proportion of the U.S. population of people age 65 and older continues grow.

- By 2050, the number of people age 65 and older with Alzheimer's disease may nearly triple to a projected 13.8 million.

This health issue has staggering global implications as well with estimates that someone in the U.S. someone develops Alzheimer's disease every minute. The World Health Organization (WHO) has identified Alzheimer's and dementia as a global health threat. Researchers are working to find more effective treatments since the overall societal, emotional, and financial impact are so significant.

INTRODUCTION

Both men and women are affected by Alzheimer's disease, but women have a higher risk of getting the disease than men. The "lifetime risk" of a disease or condition is the likelihood that a person will develop that disease or condition at any time in his or her life. Almost two-thirds of Americans with Alzheimer's are women. Of the 5.8 million people aged 65 and older with Alzheimer's, 3.6 million are women and 2.2 million are men. That more

women than men have Alzheimer's disease and other dementias is primarily explained by the fact that women live longer on average than men do, and age is the greatest risk factor (from Alzheimer's Association, 2020 Alzheimer's Disease Facts and Figures).

People with Alzheimer's disease and other dementias require complex health care and long-term care services and will ultimately need end-of-life care. The cost in 2019 dollars for all individuals with dementia diseases is estimated at \$244 billion and will continue to rise. The total lifetime cost of care for someone with dementia was estimated at \$357,297 in 2019 dollars. Seventy percent of the lifetime cost of care is borne by family caregivers in the forms of unpaid caregiving and out-of-pocket expenses for items ranging from medications to food for the person with dementia. Current estimates of the lifetime costs of care may underestimate the impact of a relative's dementia on family caregivers' health and workplace productivity.

Alzheimer's disease passed diabetes to become the sixth leading cause of death in the United States in 2014 when an estimated 93,541 Americans died of the disease. (CDC, 2015) Between 2000 and 2014, deaths from Alzheimer's disease increased 89%.

The hospice average length of stay for patients with a diagnosis of Alzheimer's disease and senile dementia decreased 1 and 2 % respectively from 1998 to 2000 but increased 50% from 2000 to 2005 for Alzheimer's disease and 49% for senile dementia (www.cms.hhs.gov). The CDC considers a person to have died from Alzheimer's disease only if the death certificate lists Alzheimer's disease as the cause of death. However, many death certificates list acute condition such as pneumonia or failure to thrive from complications such as swallowing disorders contributing to malnutrition rather than Alzheimer's disease.

Alzheimer's disease and other related dementias affect the patient's emotional, behavioral, and spiritual life as well as their physical condition. Emotional experiences of fear, frustration, anger, and guilt can overwhelm patients, families, and caregivers. A vital aspect of providing care is in offering support to patients and their caregivers in recognizing and coping with the losses that occur in independence,

memory and communication. Patients with dementia illnesses and their caregivers suffer from loss and grief as memory and forgetfulness cause relationships to end before a person’s life is over. It is important for anyone having direct contact with patients and their caregivers to have a general understanding of the Alzheimer’s disease and basic knowledge of other similar dementia disorders to help meet physical and emotional care needs.

NORMAL AGING VERSUS DEMENTIA

Minor memory loss is a natural part of aging and while frustrating, this common experience is usually not so progressive or serious that it impairs the ability to function productively in daily life. As people get older, they may use notes and lists to help them remember details or need time to recall someone’s name. Periods of stress can also cause episodes of memory loss and cloud thinking. Forgetfulness due to aging or increased stress is not dementia. In Alzheimer’s or other dementia diseases using notes as reminders will eventually fail and the ability to recall a name will be lost.

NORMAL AGING VERSUS ALZHEIMER’S DISEASE & DEMENTIA

Normal Aging	Alzheimer’s Disease & Dementia
Forgets part of an experience	Forgets whole experiences
Often remembers the experience later	Rarely remembers the experience later
Usually able to follow written or spoken directions	Gradually unable to follow written or spoken directions
Usually able to use notes as reminders	Gradually unable to use notes as reminders
Usually able to care for oneself	Gradually unable to care for oneself

MILD COGNITIVE IMPAIRMENT

The minor memory loss that many aging people experience may sometimes be a sign that worsening memory loss will occur. In the last few years, there has been a substantial increase in the clinical research being done on the common experience of memory loss and what it may mean in terms of worsening into a dementia disease.

The syndrome of subjective (what the person reports that they experience) memory problems has come to be called “Mild Cognitive Impairment” (MCI). The person with MCI complains of difficulty remembering the names of people, trouble staying attuned to the flow of a conversation (What were we just talking about?), and an increased tendency to misplace things. An increased reliance on notes and list making will generally help compensate for these tendencies. MCI means that while a person has

some memory difficulties, they can still function independently and do not rely on others to assist them in their basic daily activities. They may, however, begin to have difficulties learning new activities, have difficulty completing complex activities or planning complex tasks. They may notice that interest in and ability to plan time for hobbies or leisure activities is diminished.

Several studies have indicated that these minor cognitive difficulties may be associated with a higher-than-average risk of developing dementia in the future. Most commonly, the type of dementia that patients with MCI are at risk to develop is Alzheimer's disease. Certain features are associated with the highest likelihood of progression. These include:

- Confirmation from a reliable friend or relative that memory loss is occurring (such as difficulty in name recall or difficulty with complex activities that the person was able to perform before)
- Impairment in executive function (the ability to execute things that require planning and sequencing such as balancing the checkbook, handling emergencies, managing routine household chores)
- Poor performance on objective memory testing

The general recommendation for those concerned about their memory is to discuss these concerns with their significant family and friends, as well as their physician. The medical evaluation of MCI is essentially the same as for the investigation of any dementia. Many people with MCI do not progress to dementia. However, the early recognition of an increased risk for developing dementia allows for evaluating future support systems (family, living arrangements, medical care) and making financial preparation for the possibility that cognition may deteriorate in the future (<https://memory.ucsf.edu/dementia/mild-cognitive-impairment>).

PRECLINICAL ALZHEIMER'S DISEASE

Recent research has revealed that the brain changes of Alzheimer's may begin 20 or more years before the onset of any symptoms. In the response to these findings, the National Institution on Aging (AoA) and the Alzheimer's Association have proposed revised criteria and guidelines that identifies this asymptomatic period as preclinical Alzheimer's disease.

In this stage, individuals have measurable changes in the brain, cerebrospinal fluid and/or blood (known as biomarkers) that indicate the earliest signs of disease, but the person does not yet have symptoms such as memory loss. However, currently there is no diagnostic criterion recommended for doctors to use. Additional research on biomarker tests is needed before this stage of Alzheimer's disease can be diagnosed.

DEMENTIA

When memory loss has progressed to the point that normal independent function is impossible, for instance, if one can no longer prepare their own meals or reliably be able to handle day to day financial transactions, then this degree of cognitive impairment is referred to as dementia. Dementia is the progressive decline in intellectual function due to disease or damage to the brain. Memory loss is the most common recognizable feature of cognitive impairment, but dementia also affects:

- judgment and decision making

- learning
- language
- attention
- problem solving
- orientation (disorientation to person, place and/or time)

Changes in mood and behavior, including agitation, delusions, paranoia, withdrawal and loss of inhibitions also may occur. Dementia is caused by the permanent damage or death of brain neurons. According to the Alzheimer's Association, for a cognitive disorder to be classified as dementia, the syndrome must include a loss or decline in memory and must be severe enough to interfere with daily life and have a loss in at least one of the following:

- ability to write or speak or the ability to understand written or spoken words
- difficulty finding words when speaking
- trouble in writing complete sentences
- difficulty in reading comprehension
- ability to recognize and identify familiar objects
- confusion about the use of everyday objects
- inability to correctly name a familiar object

Ability in motor abilities

- loss of balance, change in gait
- change in handwriting
- loss of dexterity
- ability to reason, plan and solve problems and make sound judgments and/or focus on a task
- struggling to complete a familiar task such as following a recipe
- difficulty balancing checkbook or complete a household project
- learning new information or change routines
- making bad decisions, loss of impulse control

The symptoms and progression of dementia depend on the type of disease causing it and the location and number of damaged brain cells. Some types progress slowly over years, while others (such as a major stroke or head injury) may result in sudden loss of intellectual function. Alzheimer's disease is the most common form of untreatable, irreversible dementia.

Each type of dementia can be differentiated by different changes or abnormalities in the brain. Different types of dementia have different symptom and progression patterns. Just as jaw pain is a symptom that might be a symptom of a decayed tooth or a symptom of a heart attack, making the correct symptom diagnosis leads to the correct treatment. To determine whether a patient has Alzheimer's disease or a different kind of dementia the physician will complete a medical history, conduct diagnostic tests and perform physical examinations. For instance, vascular dementia (VaD) which is the second most commonly occurring type of dementia occurs when blood flow is blocked to parts of the brain, depriving cells of food and oxygen. VaD also called multi-infarct dementia can occur after a major stroke or after a series of very small strokes (mini-strokes) cause damage to the brain. In vascular dementia, memory loss

may not be the most noticeable symptom depending on what part of the brain is damaged by lack of blood flow.

Some other conditions may look like dementia and can cause confusion, memory loss and change in level of consciousness. Depression, nutritional deficiencies, infections, electrolyte imbalances and medication reactions can cause dementia-like symptoms and might potentially be treatable and sometimes even reversible.

DIAGNOSING ALZHEIMER'S DISEASE AND OTHER DEMENTIAS

Clinicians can now diagnose Alzheimer's disease with up to 90% accuracy. But it can only be confirmed by an autopsy, or examination of the brain after death. Currently, there is no single blood test, x-ray, scan or other procedure or test that can diagnose Alzheimer's disease. Dementia is not always due to Alzheimer's. Memory loss, confusion and other symptoms of cognitive impairment may be caused by another disease or a potentially treatable condition. A thorough medical evaluation may uncover another likely cause of the dementia.

Diagnosing Alzheimer's disease or a related dementia disorder requires that the physician, with the assistance of the patient, family, and other healthcare professionals, does a complete medical workup. To determine the cause of dementia a comprehensive health assessment will include:

- Health history
- Physical examination
- Brain imaging (or scans)
- Mental status assessment

Currently, the PET scan is used primarily in research studies in hopes of gaining knowledge in diagnosing Alzheimer's disease and monitoring progression. Medicare will cover the PET scan only to help differentiate (distinguish) the disease from frontotemporal dementia (a rare related dementia disorder). Another promising area of brain imaging research is working to develop tracer compounds that can be used to tag abnormal brain deposits. In late stages of Alzheimer's disease, the MRI may show a decrease in the size of certain areas of the brain.

While the scans cannot confirm the diagnosis of AD, they can exclude other causes of dementia (such as stroke or tumor).

Commonly, the diagnosis of Alzheimer's disease is made by first ruling out other conditions that may be causing the symptoms of dementia. Other diseases which can cause symptoms of dementia include:

VASCULAR DEMENTIA

Vascular dementia, also known as Multi-infarct or post-stroke dementia is caused by problems in the blood vessels in the brain, resulting in destruction of brain tissue (stroke).

- Less common as a sole cause of dementia than is Alzheimer's disease

- Impaired judgment or ability to make plan is more likely to be the initial symptom, as opposed to memory loss associated with Alzheimer's

MIXED DEMENTIA

Mixed dementia is the description used when Alzheimer's disease and vascular dementia (VaD) occur together.

STROKE

A stroke occurs when the blood supply to a part of the brain is suddenly blocked by a clot or embolus (ischemic) or when a blood vessel in the brain bursts (hemorrhagic) and the cells of the brain are thereby deprived of oxygen, are damaged and die.

DEMENTIA WITH LEWY-BODIES (DLB)

Dementia with Lewy-Bodies can occur alone or simultaneously with Alzheimer's or Parkinson's disease. It is a neurodegenerative disorder associated with deposits of abnormal proteins (Lewy-bodies) found in the nerve cells of the affected brain. These patients are more likely to have initial symptoms such as sleep disturbances, well- formed hallucinations, and muscle rigidity or other parkinsonian movement symptoms.

PARKINSON'S DISEASE

Some patients with Alzheimer's disease show symptoms of Parkinson's disease (PD), and some patients with Parkinson's disease show signs of Alzheimer's disease. PD is a progressive, debilitating disease that affects the central nervous system. Problems with movement are a common symptom early in the disease. Parkinson's disease occurs about 1/10 as often as Alzheimer's disease.

HUNTINGTON'S DISEASE

Huntington's disease is a fatal disease that is most often characterized by involuntary movements (chorea) and cognitive decline (dementia). It is predominantly (50%) genetic and affects structures deep within the brain (basal ganglia) which are responsible for such functions as movement and coordination.

FRONTOTEMPORAL DEMENTIA (FTSD) OR PICK'S DISEASE

Frontotemporal dementia (FTD) is a rare progressive disorder that affects the temporal and frontal lobes of the brain. Abnormal "Pick's" bodies in the nerve cells of these lobes cause symptoms similar to Alzheimer's disease including loss of language abilities (aphasia), decreased ability to recognize familiar people and things (amnesia), and loss of movement (apraxia) and personality changes.

SECONDARY DEMENTIA CAUSES

Dementia-like symptoms can also develop as the result of other medical conditions. If the underlying condition can be diagnosed and treated, it is possible the dementia symptom may stabilize, improve, or even resolve. Nutritional deficiencies, alcohol and substance abuse, metabolic disorders such as diabetes or kidney failure, delirium and infections can all cause dementia-like symptoms.

Urinary tract infections, upper and lower respiratory tract infections and pneumonia can affect the central nervous system and cause dementia symptoms. Symptoms of confusion are often the hallmark of an infection, especially in the elderly, where dehydration also causes delirium symptoms. Prompt recognition and treatment of viral and bacterial infections may reverse dementia-like symptoms.

Delirium is often mistaken for dementia or part of old age (think of the number of patients who are elderly who become confused in the hospital). It occurs more commonly in elderly people who already have compromised mental status. Delirium is extremely common among nursing home residents.

LEARNING ACTIVITY

Please read the scenario below to see if you recall any patient you have observed experiencing similar symptoms. Mrs. Taylor lives in the memory unit of an assisted living residence (ALR) and is diagnosed with probable Alzheimer's disease. She is always alert, smiles and laughs appropriately and is generally calm and content. Although she is usually unable to correctly recall the names of her caregivers, she greets them with a wave and hello and remembers the routine of most of the activities they regularly do together. She needs help initiating her ADL's and is becoming incontinent, but she knows the location of her room, and other frequented activity areas.

One day she is found in another resident's room and keeps repeating that she saw a tiger in her room; she is very agitated and seems to recognize no one. Later, she strikes out at the aide who tries to help her with personal care. The next morning, she is listless and can't get up from bed. She is tested for a urinary tract infection (UTI) and given an antibiotic when the UTI is confirmed. Within the week, Mrs. Taylor's acute confusion and agitation is resolved, and her alert and happy state is restored.

EMOTIONAL PAIN

Emotional pain, including depression, anxiety, and grief, can mimic signs of dementia by causing memory loss, forgetfulness, and withdrawal, lack of motivation and other behavior changes. It is important to remember that as dementia-related, life-limiting diseases progress the patient will experience multiple physical and emotional losses. Loss and grief are normal reactions, but they can worsen the symptoms of dementia. Treating the depression symptoms with medications is often effective in relieving dementia symptoms, and even in diagnosed primary dementia disorders treatment can improve dementia symptoms that are exacerbated by depression.

PHYSICAL PAIN

Physical pain can be all consuming and can cause dementia-like symptoms or increase symptoms in patients with Alzheimer's disease. Mood swings, irritability, aggressiveness, confusion, disorientation, and an array of other behaviors can signal physical or emotional pain and suffering. Pain is difficult to assess in the elderly and even more difficult to determine in the cognitively impaired. As such, it is extremely important to do a thorough assessment for physical and emotional pain. Involving the physician, nurse, social worker, chaplain, family, and patient as able in the assessment process can result in a plan of care that meets the specific needs of the patient.

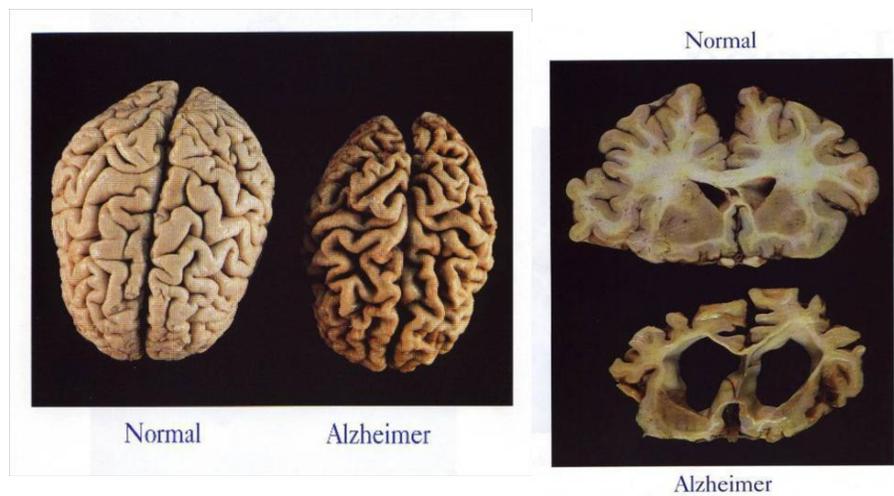
ALZHEIMER'S DISEASE

Alzheimer's disease was first identified in 1906 by a German neurologist, Alois Alzheimer. Like many illnesses characterized by mental or behavioral changes, the disease was first thought to be psychological in nature.

Alzheimer's disease, however, was soon recognized to be a progressive, degenerative, irreversible disease that leads eventually to death.

In Alzheimer's disease, as in other types of dementia, brain cells deteriorate and die. Billions of brain cells (called neurons) connect with each other and communicate by sending chemical messages. The points where neurons connect are known as synapses and in Alzheimer's disease information transfer at the synapse progressively fails. These neurons communicate thoughts, store memories, and form the basis of all intellectual function and skills. In Alzheimer's disease the protein beta-amyloid accumulates OUTSIDE the neuron (called beta-amyloid plaques) and an abnormal form of the protein tau collects INSIDE the neurons (called tau tangles). These changes contribute to the cause of the brain changes in Alzheimer's disease. Over the course of the disease the number of synapses decline, and nerve cells eventually die. In a brain affected by advanced Alzheimer's disease, the brain literally shrinks because of this cell loss.

The following illustration shows the difference between a normal brain and a brain affected by Alzheimer's disease. Source: Dementia Education and Training Program (<http://alzbrain.org/>). Alzheimer's: A Broken Brain.



Some of the symptoms caused by the destruction of brain cells include:

- Gradual memory loss
- Loss of ability to concentrate
- Decreased ability to perform routine tasks like bathing and dressing
- Disorientation (loss of orientation to person, place, time) Loss of language skills
- Impaired judgment
- Personality changes

The symptoms of dementia caused by Alzheimer's disease are progressive, but there can be great variation in the rate of change from one person to another. Some persons may retain the ability to speak intelligibly late in the disease, while another may have great difficulty retaining communication skills. It depends on what area and to what extent the disease destroys the brain cells.

The exact cause of AD is unknown; it may be sporadic or passed through the genetic makeup. Prior theories that attributed the buildup of aluminum, lead, mercury or other brain toxins have been disproved. Although Alzheimer's disease is not a normal part of aging, the risk of developing the illness rises with aging. The National Institute on Aging estimates that the probability of developing Alzheimer's disease doubles every 5 years beyond age 65. (alzfdn.org).

Other risk factors can include:

- Family history of dementia
- Longstanding high blood pressure, diabetes and cardiovascular disease
- History of head trauma or brain injury
- Female gender – because women statistically live longer than men, they are more likely to develop AD

The patient's life expectancy from the time of onset of symptoms is approximately 8 - 10 years. However, each patient is unique and may have as little as 2 years or as long as 20 years to live with Alzheimer's disease. The course of the illness and the symptoms experienced over time vary in each individual, but the symptoms always progress. Since the brain controls all bodily functions, the person will eventually be unable to walk, stand, control elimination, sit up or even swallow. This physical decline leaves the person susceptible to infections such as pneumonia, which is the primary complication that leads to death from the disease. In the final stages a person will require complete care leading to complete dependence on others for care.

STAGES OF ALZHEIMER'S DISEASE

Alzheimer's disease and other similar dementias are progressive diseases, and although each dementia experience is unique, those affected eventually will be dependent on other for care in all aspects of daily life. Stages often overlap and progress at no predictable rate. Each person affected with Alzheimer's disease progresses through these stages differently.

EARLY STAGES

In the early stages of Alzheimer's disease, the symptoms are subtle and may resemble signs easily attributable to "normal aging." Small changes in language and memory are easy to dismiss or excuse at this stage which may last from 2 to 10 years or longer. Some or all of the following symptoms may occur, although they are generally mild, becoming worse with fatigue or stress and decline generally over the years.

- Forgetfulness and memory loss, sometimes need reminders to complete everyday tasks
- Trouble completing everyday routine activities, may start one project, then shift to another and not complete
- Loss of initiative
- Anomia (unable to come up with a person's name or the name of a familiar item)
- Apraxia (difficulty remembering how to use familiar tools or equipment)
- Disorientation of time or place

- Impaired judgment
- Problems with abstract thinking (understanding new complicated concepts or organizing future events)
- Changes in mood or behavior (anxiety, fear, depression)
- Loss of initiative

For example, the person in this stage will usually have difficulty remembering names, especially new names or names from the past. They may be unable to quickly recall the name of familiar objects. Social graces and politeness begin to break down. A thought might occur to the person, but as soon as they begin to act on it, they forget what they intended to do. They will probably be able to live independently but may need assistance with complex tasks or have difficulty with finding their way in familiar places, balancing the checkbook, or preparing meals on their own.

Remember that many people at stressful times in their lives experience many of these symptoms. These symptoms usually decrease when stress decreases and life stabilizes. With the beginning of Alzheimer's disease, the person experiences many of these symptoms and they do not resolve, but gradually progress in frequency and severity.

Overall, experiencing many of these symptoms may be an indication that a person should seek medical attention.

MIDDLE STAGES

The middle stages of Alzheimer's disease can last up to ten years or more and can be an extremely difficult time for patients and caregivers. Due to the progression, severity or frequency of symptoms, the middle stages are often the time when a physician is consulted to diagnose the problem. There is often a particular significant event that helps the family (and the patient) recognize that there is something wrong. Signs and symptoms associated with these stages of the disease include:

- Poor short-term memory
- Forgetting details about current events
- Wandering or getting lost in familiar places
- Increased language difficulty (difficulty word finding, naming) Increased disorientation and confusion
- May need reminders or supervision with bathing, grooming, may need assistance in dressing appropriately
- More spontaneity, decreased inhibitions
- Inability to think abstractly
- Repetitive actions and speech (fidgeting, rummaging) Suspiciousness, paranoia
- Sleep changes, may sleep more during day, be wakeful during night
- Hoarding and "hiding" objects
- Depression, anxiety, social withdrawal

This stage is typified by the loss of the ability to reliably attend to the activities of daily living (preparing meals, bathing, grooming, dressing etc.). Business and financial affairs must be managed by another.

Time disorientation is a common indicator; the person is often wakeful at night and sleepy during the day and will awake after napping and be confused about the time of day or date and place. The ability to remember public figures such as who is president, or identify seasonal holidays is lost. Appointments are forgotten; personal possessions are lost or sometimes hoarded and hidden in bizarre places. Simple tasks like hair washing, brushing their teeth, or making a bed require prompting or assistance from others.

LATE STAGES

The later stages of Alzheimer's disease are usually shorter than the other stages, lasting up to a year or more. During these stages, patients will require 24-hour supervision and total care. Sleep becomes impaired, with confusion often worse upon awakening and at bedtime.

Behavior tends to deteriorate with agitation and wandering or bewilderment occurring. The person is easily frightened and is often anxious. New experiences and familiar ones may seem completely overwhelming resulting in aggression and combative behavior as the person has lost control of their world. Symptoms of the latter stages of the disease include:

- Profound memory loss with confusion about past and present events
- May misidentify people previously familiar to them or even not recognize themselves in a mirror
- Fine motor skills (such as writing, using utensils) decline
- May have repetitive aphasia (ask the same question repeatedly or repeat the same name again and again) or cannot speak
- Difficulty understanding what is spoken to them
- May exhibit a compulsive need to touch things or examine all objects
- May put inappropriate things in their mouth or pica (eating non-edible objects)
- May exhibit wandering, pacing
- May exhibit inappropriate behavior, aggression, combative behavior or sexual impropriety, inappropriate verbal outbursts
- Change in dietary habits, may have little appetite or binge eat
- May experience hallucinations or illusions and paranoia
- Incontinence
- Total dependence on ADLs

Even at this stage, patients may still be able to engage in and enjoy physical activities such as walking, group activities and will still enjoy music and the company of others, especially those familiar to them.

TERMINAL OR END STAGES

The length of the terminal stage is most influenced by the patient's will and ability to eat and drink. If a patient has a living will and has chosen no artificial feeding, this stage may be short. During the terminal stage, intensive comfort care is important.

During the terminal stage, symptoms include:

- Usually unable to respond to name
- No intelligible language - muteness or garbled noises

- Inability to walk, progressing to inability to hold their head erect, or purposefully move
- Difficulty swallowing and inability to eat
- Little or no response to environment

Note that all of these stages can continue for long periods of time. There may even be times when the patient's condition seems to plateau, only to decline a short time later. In addition, when the person's quality of life increases with care and attention, the person may seem to get better when their symptoms and behaviors are only being better managed. In any event, the Alzheimer's disease will eventually continue to progress.

Keep in mind that in all the stages, the person is capable of feeling emotion including anger, sadness, fear, and happiness even though he/she lacks the ability to verbalize the emotion. As such, it is important to anticipate the patient's needs and continue to communicate with Alzheimer's patients even though they cannot communicate reliably with you.

CARING FOR PATIENTS WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS

Today about 5.8 million Americans are living with Alzheimer's disease or other similar dementias. More than two-thirds are at home in the community, being cared for by family and friends. Their illness has an immense impact on their families.

More than 16 million Americans provide unpaid care for people with Alzheimer's disease and other dementias. 55% of these caregivers are caring for a parent. Unpaid caregivers are usually immediate family members, but they also may be other relatives and friends. In 2013, 85% of help provided to all older adults in the U.S. is from family members. 25% of Alzheimer's disease and dementia caregiver have children under 18 year's old living with them.

Because of the unique demands of caring for both aging parents and dependent children, this "sandwich generation" caregivers face unique and increased demands. They may experience higher rates of anxiety and depression.

The demands of caregiving will intensify as people with dementia approach the end of life. In last year of their life, 59% of caregivers report that they felt "on duty" 24 hours a day, and many felt caregiving during this time was extremely stressful.

The stress of the caregiver takes a toll on the emotional, physical, and spiritual functioning of the caregiver. 72% of family caregivers said they experienced relief when the person with Alzheimer's disease or another dementia died (Peacock SC, in Palliative Supportive Care 2013).

In the early stages of Alzheimer's and other dementia diseases, caregivers are often finding their footing in this new role. Anxiety from uncertainty and what the future holds is a normal part of the process for all family members and loved ones, though the caregiver may be especially affected by the expectations of their role now, and in the future.

Challenges for the caregiver at this stage include knowing when to offer assistance and give support. The person with early-stage Alzheimer's and other dementia is primarily independent with dressing, walking, bathing, and may still even work and drive themselves. For the caregiver, finding balance between offering independence and offering assistance can be a struggle. Additionally, the emotional toll from diagnosis and this new reality of the early stages can be its own challenge.

In the middle stages, the caregiver may notice more symptoms of the person with Alzheimer's or dementia diseases such as having trouble dressing, jumbling words, and acting out in various and unexpected ways, sometimes in frustration and anger. Caregivers will have challenges managing these new symptoms and finding strategies that work both for them and for the person in their care. Adapting these strategies over time will be important, and thus flexibility and patience are important during this stage. The caregiver can struggle with the change in their relationship to the person with dementia, and over time the demands of caregiving and maintaining their emotional wellbeing can be overwhelming. A challenge many caregivers experience involve knowing when to take care of themselves, including when to take breaks, learn what respite services are available, and finding community support resources and groups.

As Alzheimer's and other dementia diseases progress to the most advanced stages, family members often need to consider moving the patient to another care setting such as a long-term care facility or assisted living facility. There are various reasons for placement. The caregiver may be fatigued or frail, the care may be too intense, or the patient may be at risk for injury due to wandering or decreased ability to ambulate safely. In addition, mood swings, memory loss and aggressive behavior may be difficult to manage at home. Many long-term care facilities now have specialized units for Alzheimer's and other dementia patients with staff who have expertise in working with these patients. Fifty to seventy percent of residents in a nursing facility have some form of dementia.

For the person suffering from dementia, the move to a caregiving facility is difficult. Already confused, they become more bewildered as they must find their way in a strange environment without the comfort of what had been familiar to them. Most of all, they are giving up their independence.

In hospice, we support the patient's and family's decisions regarding placement and work to provide compassionate assistance in all aspects of care.

LEARNING ACTIVITY

Read the following story, putting yourself in the place of a caregiver of an Alzheimer's patient. After you have read the story, answer the questions at the end.

You are 78 years old. You have been caring for your spouse, who has Alzheimer's disease, for the past 8 years. You have arthritis which is painful.

Your spouse seldom sleeps all night. Recently she/he has removed the lock on the door twice. Once your spouse was found near a pond down the street, and another time went wandering in traffic on a busy cross street.

You are currently bathing and dressing her/him every morning as she/he is no longer able to accomplish these activities without reminders, prompting or supervision. Your spouse is often incontinent of urine and occasionally incontinent of stool.

You have put her/him in adult diapers, but during the day she/he is able to remove them and soils their clothes on a regular basis. You end up re-dressing your spouse about three times a day and do two loads of laundry a day.

Some days during morning grooming she/he is happy, and sometimes becomes angry at you for no reason. She/he chokes on pills for a heart condition or spits them out. It takes you two hours to feed your spouse a meal, due to his/her difficulty swallowing. She/he has put the cat in the dryer and the ice cream in the oven. Over the past year, your spouse has lost the ability to recognize you or close friends. Your spouse has a living will stating that she/he does not want any artificial feeding. When younger and healthy, both you and your spouse decided you would never want to have to go to a nursing home.

You are tired, frail and in physical pain from the arthritis almost every day. You have not had a solid 8 hours of sleep in two years. You are afraid to close your eyes at night for fear that your spouse will get out of the house and get hurt. You barely have time for a quick bath at night. You have had little time to be with friends due to your spouse's care needs and feel isolated from the outside world. You love your spouse dearly, but she/he no longer seems to be the person with whom you have spent the last 25 years.

Think about this situation as though you are the caregiver. Would you consider placing the patient in a nursing facility? Why or why not? What kind of emotions would you feel while making such a decision?

COMMUNICATION TECHNIQUES

Learning ways to have caring and effective communication is tremendously important. The person with dementia will have increasing difficulty expressing what they need or want. They will have difficulty speaking and difficulty understanding language. They will however still be able to have feelings of love, rejection, hope, fear, sadness, and happiness. They may not be able to communicate these feelings. They may not be able to understand the meaning in your words, but they will be able to understand the meaning in your touch, your voice, and your attitude. Being able to connect and communicate with a patient with dementia requires having realistic and reasonable expectations of what the patient can understand.

In hospice, you may encounter persons with dementia on a regular basis. You might be providing direct care, assisting them in their daily activities or taking them for a wheelchair ride. In all these situations, you will need to know how to communicate with them verbally and non-verbally. You may also have the opportunity to interact with and help their family and other caregivers. When the patient no longer remembers their relationship or becomes angry and says hurtful things to their caregivers, it can be painful. The breakdown in communication can lead to guilt, exhaustion, and hopelessness.

At some point, communicating with a person with dementia is almost always frustrating. Both the patient and their caregivers find the changes in understanding and communicating emotionally difficult. Feeling frustrated is a normal response. When possible, learning to use the feeling of frustration as a challenge to discover a more productive and satisfactory way to communicate is a good strategy. Above all, it takes patience and practice to develop good communication skills. The following general

guidelines, as well as more specific guidelines based on the stages of the Alzheimer's disease, are provided to assist you in communicating effectively with a patient with dementia.

NON-VERBAL LANGUAGE

Non-verbal language is also called body language. For example, putting your hands on your hips may communicate "I mean business," or "I'm aggravated with you" depending on your facial expressions and tone of voice. Persons with Alzheimer's disease may no longer understand spoken words, so it is especially important to be aware of our body language and the message it sends. Remember that eye contact, a smile and gentle tone of voice is reassuring to the dementia patient long after their ability to use and understand language is gone.

Nonverbal (body language) is communicated through:

- Gestures and movements
- Facial expressions (including eye contact)
- Touch
- Tone and speed of words

Tips for Non-verbal communication

- Use all your senses to understand what the patient is trying to communicate
- Be aware of and sensitive to nonverbal messages you receive
- Be aware of your own nonverbal messages and use them to reassure, calm and encourage others
- Be sure your nonverbal messages match your words. Smile when you meet someone.

Always try to have positive, compassionate, and pleasant nonverbal messages. Remember that your tone of voice communicates frustration and impatience stronger than your words. When you speak sharply or feel irritated, a person will react to your emotional message.

VERBAL COMMUNICATION

Effective communication involves both speaking and being heard. Listen to the patient, even when what they try to say is difficult to understand, to show that you care about them as a person.

Acknowledge the person by calling him/her by name. Find out the name they most prefer to be called and use it often. Be sensitive to cultural and regional differences. Some people may not feel respected if you call them by their first name.

Identify yourself when approaching the person with dementia and acknowledge them by calling him/her them by name. Don't approach them suddenly from behind, this can be startling. Use eye contact.

Use eye contact and approach the patient slowly. If they are seated or lying down, get down on their level instead of looking down on them. Maintain a non-threatening distance so as not to encroach on their personal space.

- Avoid touching the person without his/her permission. If they enjoy affection, then holding their hand or taking their arm when you walk together can be very comforting.

- Speak softly and at a normal pace. Keep your tone warm and empathetic. Be willing to rephrase and repeat what is not understood.
- Show acceptance. Our goal is to communicate in a way that works best for the Alzheimer's patient, not have the patient adapt to our communication style.
- Be patient and offer reassurance. If the patient becomes confused, frustrated or upset because they are having difficulty understanding you or communicating something to you, be patient and calm. Remember that at some point, logical explanations and "common sense" will be meaningless and will only lead to frustration. Use humor to distract when you can.
- Listen actively. You show respect and can connect to someone on a personal level by listening.
- Use non-verbal communication as needed. Even after the Alzheimer's patient has lost the ability to speak, he/she may still be able to understand non-verbal communications. Your non-verbal communication in the form of body position, tone of voice, gestures, facial expressions, touch and eye contact can convey an array of emotions and acceptance or non-acceptance.

EARLY STAGES OF ALZHEIMER'S DISEASE COMMUNICATION

When symptoms of Alzheimer's first occur, the patient has a tendency to speak more in an attempt to cover up for their confusion. They may not be able to talk about one subject for very long or forget what they were saying before finishing one thought and move on to another. As this stage progresses and the patient's ability to communicate changes, he/she may gradually speak less. Change how you talk to match what he/she understands.

In the early stages, the patient may:

- have difficulty finding the right words
- repeat himself/herself, may not remember
- ask the same question again and again
- not remember what you just told them
- create new words or substitute phrases like "thing-a-mido"
- have difficulty organizing his/her thoughts and sentences in a logical manner
- revert to a native language
- use words he/she never used before, such as curse words
- To communicate effectively in the early stages of the disease, you can:
- Use simple words, short sentences. Be especially aware of the need to use familiar, lay terms and not medical terms. Don't talk to them in a child-like voice or talk down to them. For example, don't say "Well, sweetie, are we feeling a little cranky today?"
- When giving directions, give one step at a time. Wait for the patient to accomplish that step before you
- give another step. Keep directions as simple and as uncomplicated as possible. Don't tell them more than they need to know at any one time.
- Avoid using pronouns such as 'he or she' when referring to another person. Instead, refer to other people by name. For example, refer to their roommate as Mr. Jones instead of "he" or

their nurse as Nurse Laura instead of “she.” When referring to objects, avoid using the word “it.” For example, instead of pointing to the water pitcher and saying, “Do you want me to fill it?” you should say, “Would you like me to fill your water pitcher?”

- If the patient is having difficulty finding the right word, and if you can, offer a guess. If this is upsetting to the person, give them time to come up with it on their own.
- Give them plenty of time to respond to a question and don’t butt in. If they lose their train of thought, ask them again.
- Because short-term memory is most affected at this stage, try to focus the conversation away from short-term events and onto events that require long-term memory. Helping them to reminisce about happy memories is comforting and safe.
- Remember that people with dementia cannot store new memory. No matter how many times you repeat something to them, they will forget it a moment later. Be prepared to offer frequent, gentle reminders and explanations.
- Turn off the radio or TV before you try to communicate. Reduce any obvious distracting noises or move to a quieter place if possible.
- Don’t try to force or pressure the person into conversation. If the person has difficulty speaking or understanding, they will react to you by becoming anxious or agitated.
- Be patient and calm.

MIDDLE STAGES ALZHEIMER’S DISEASE COMMUNICATION

In the middle and later stages of the disease, communication with a patient with Alzheimer’s disease becomes more challenging. Memory loss has deteriorated and will continue to worsen until the person has no memory at all. The person will still know who they are but may not always know who you are or where they live. They may think they are back in their childhood home. Correcting them usually only causes them to be upset. To improve communication as much as possible, try the following techniques:

- Tell the patient who you are before conversing or doing any kind of care. Treat them with dignity and respect.
- Use the person’s name when addressing them. Acknowledge their presence.
- Speak slowly and clearly in short, simple sentences. Use ordinary words.
- Avoid asking questions. Turn questions into instructions. Instead of saying, “Do you want to go outside?” Say, “Let’s go outside.”
- Don’t say “I will do that for you,” say, “Do as much as you can, and I will help you.”
- Singing, playing music or reading to a patient and simply being with them are all forms of communication and may be comforting. Even advanced dementia patients retain memory of music and often the ability to sing or play an instrument long after they are unable to speak.
- Frequently repeat simple instructions or any information you are trying to convey to the patient.
- Use touch as appropriate and if comfortable for the patient.
- Avoid arguing with or correcting the patient. This will only aggravate behavioral symptoms.
- Don’t try to reason with them, this will only frustrate you both.
- Change what you’re talking about, use distraction.

- Don't correct them for something they get wrong or remember incorrectly. Remind yourself that it doesn't really matter and will only make them feel bad.
- Don't ask them to "remember" things that happened in the past; at this stage this may be difficult and cause unnecessary anxiety. Instead, ask family members and friends to tell them stories that they remember.

LATE-STAGE ALZHEIMER'S DISEASE COMMUNICATION

By the late or terminal stages of dementia diseases the patient will no longer be able to tell you what they need or if they have pain or hunger. You will have to learn by studying their nonverbal communications. They no longer have any meaningful speech ability. They can still cry or laugh.

You can still touch them or hold their hand if this is comforting to them. You can talk to them, sing to them or offer comforting rituals appropriate to their faith tradition. You can offer reassurance and keep them comfortable. (Alzheimer's Association and Coach Broyles Playbook).

COMMUNICATING IN CHALLENGING SITUATIONS

Patients with dementia may become aggressive and disruptive. They may scream, swear, shout and/or make negative comments to family members, friends, and professional staff. They may also strike out at others.

Aggressive and disruptive behaviors can be caused by an increased sensitivity to the environment (noise, crowding), changes in routines or their room, changes in their eating patterns, and demands placed on them to bathe, dress or attend activities. Sometimes aggressive behavior may have no known trigger other than the disease itself. Keep in mind that the behavior is often beyond the control of the patient and not a personal affront to the family, caregiver or professional staff.

Dealing with aggressive behaviors appropriately helps maintain the patient's dignity. When a patient becomes disruptive, keep communication simple and direct. Do not confront the patient as he/she has no ability to respond to confrontational situations. Keep your tone of voice calm, quiet and pleasant and use a coaxing approach without touching the patient. Seek the assistance and skills from other members of the interdisciplinary team to help deal with aggressive and disruptive behavior.

CONCLUSION

Each patient with AD and other dementia disorders is an individual with unique presentation of symptoms and care needs. Each caregiver will have specialized needs as well. We can help patients by caring for them with respect and dignity, by communicating effectively with them, and by anticipating their needs. We can help caregivers by encouraging verbalization of their feelings, by actively listening to their concerns, and by encouraging them to seek assistance from family, friends, and healthcare professionals such as the nurse, psychosocial professional, chaplain, physician, nursing assistant, and volunteers. Verifying the important and meaningful work they do is also essential in providing compassionate care to those affected by Alzheimer's disease and other similar dementia disorders.

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CARING FOR THE PERSON WITH ALZHEIMER'S AND OTHER DEMENTIA DISEASES - 1HR | POST-TEST

1	T	F	There is a cure for Alzheimer's disease.
2	T	F	Alzheimer's disease is the most common form of dementia.
3	T	F	Patients with Alzheimer's disease and their family members experience feelings of loss and grief.
4	A C	B D	The syndrome of subjective memory problems has come to be called: A. Mild Cognitive Impairment B. Source Amnesia C. Misattributed Familiarity D. None of the above
5	A C	B D	Fill in the blank. The following symptoms are signs of _____-stage Alzheimer's Disease: <ul style="list-style-type: none"> ▪ difficulty swallowing ▪ little/no response to environment ▪ usually unable to respond to name ▪ inability to eat ▪ inability to walk A. Early B. Middle C. Late D. Terminal/End
6	T	F	A patient with dementia can always control his/her aggressive behavior.
7	A C	B D	Alzheimer's Disease can only be confirmed by: A. X-ray B. Autopsy C. Brain scans D. Blood test
8	T	F	Dementia is not a disease in itself but is a symptom of other disorders of which Alzheimer's disease is one type.
9	T	F	Patients with Alzheimer's disease and related disorders may be able to feel emotion throughout all stages of the disease process and even when they cannot express or show emotion.
10	T	F	Correcting, arguing with and constantly reorienting a patient with Alzheimer's disease will help decrease their memory loss.
11	T	F	Encouraging the caregiver to share their feelings with a psychosocial professional, friends, and spiritual care provider or in a support group may help them feel as though they are not alone.
12	T	F	Often much of the financial burden of caring for a patient with Alzheimer's disease falls on the patient and family.
13	T	F	Alzheimer's disease is reversible.
14	T	F	When communicating with someone with Alzheimer's disease or another similar dementia you should be willing to rephrase and repeat what is not understood.
15	T	F	We can help caregivers by encouraging verbalization of their feelings, by actively listening to their concerns, and by encouraging them to seek assistance from family, friends, and healthcare professionals.

