ALZHEIMER’S DISEASE

INTRODUCTION

Alzheimer’s disease is a chronic, incurable, disease that causes devastating damage to the brain and nervous system. Nerve cells in the brain become dysfunctional and die. Normal functioning becomes very, very difficult and eventually, impossible.

People suffering from Alzheimer’s disease (the disease was named after the physician who first identified the condition) have difficulty with memory, language, and abstract thinking. They are often confused and disoriented, even in familiar situations and even among people they know. The disease is progressive; once someone develops Alzheimer’s disease mental functioning inevitably deteriorates, some times rapidly and some times slowly. No one knows what causes Alzheimer’s and there is no cure. Eventually, someone with Alzheimer’s will need to be cared for completely.

Caring for a patient with Alzheimer’s can be one of the biggest challenges you will ever face in your career as a Certified Nursing Assistant (CNA). And without your assistance, many patients with Alzheimer’s would be basically helpless.

But although it can be a tremendous challenge to provide care for a patient with Alzheimer’s, it can be very rewarding. Also, there is a lot of experience that caregivers of all professions have accumulated while working with patient’s with Alzheimer’s disease. This experience can be invaluable, and you can draw on it to help you manage. With a sound basis of knowledge about the disease and with this advice and support, you will be able to make the experience a good one for you and your patient.

OBJECTIVES

When the student has finished this module, he/she will demonstrate familiarity with:

1. Alzheimer’s Disease or Related Disorders
2. Characteristics of Alzheimer’s Disease or Related Disorders
3. Communicating with Residents with Alzheimer’s Disease or Related Disorders

ALZHEIMER’S DISEASE: THE SCOPE OF THE PROBLEM

Alzheimer’s disease is very common; in fact it is the most common cause of dementia (the term dementia will be explained later). Over 5 million people in the United States now suffer from Alzheimer’s disease and by the year 2030, the number of people aged 65 years and older who have Alzheimer’s is expected to grow to almost 8 million. More than 14% of all American adults over the age of 65 have Alzheimer’s disease, and it is considered to be a leading cause of death. Women are at greater risk: this may be because the amount of estrogen they produce after menopause decreases significantly and this may predispose them for the development of the disease. It was thought for many years that the African American population has a higher incidence of Alzheimer’s disease, but this is no longer thought to be the case.
THE BRAIN, THE NERVOUS SYSTEM, AND ALZHEIMER’S DISEASE

Alzheimer’s is a disease that affects the nervous system and the brain, so to understand Alzheimer’s disease you must understand the purpose of the nervous system and the brain, how they are organized, and how they work.

Learning Break: The brain and the nervous system are considered here separately because the brain is a distinct organ. However, many times the term nervous system is used to refer to the brain, the spinal cord, and the nerves themselves.

• Purpose of the nervous system and the brain: The basic purpose of the nervous system and the brain is to initiate and control our involuntary behaviors such as breathing, circulation, and digestion, and to initiate and control our voluntary behaviors such as abstract thinking, memory, planning, solving problems, etc. Everything we do essentially starts and is controlled by the nervous system and the brain. It is helpful to think of the brain as the “command center” and the nervous system as

• Organization of the nervous system: The nervous system is basically comprised of the brain, the spinal cord, and the nerve fibers. In one sense the brain could be considered the power plant or command center, and the spinal cord and the nerve fibers are the wiring that carry the energy and the messages generated by the brain to the different parts of the body. The nerve fibers and the spinal cord also carry information and messages back to the brain, as well.

• How the nervous system works: The brain system initiates and controls behavior by receiving and sending information. For example, when someone is standing in front of you, the image of that person is transmitted through the nerve fibers in your eyes to an area of the brain called the cortex that stores information - your memory center. When the image reaches the cortex, you search your memory, recognize (or not recognize) that person and depending on who they are you respond in a particular way. In this situation, the visual image is carried to the brain by the nerve fibers and the spinal cord to the brain, the brain receives this information and after searching the memory, the brain sends a message to the body through the spinal cord and the nerve fibers for you to speak, or ask a question, etc. The information our nervous system sends and receives is carried by tiny electrical impulses and chemicals called neurotransmitters. The brain is the “command center” and the spinal cord, the nerve cells, and the nerve fibers are the “wiring” that carry information to and from the brain. However, there are short breaks in the connections (the wiring) between the nerve fibers, the nerve cells, the spinal cord, and the brain. These breaks are called synapses and when an electrical impulse reaches a synapse, a neurotransmitter chemical is released and carries the impulse across the synapse to the next part of the nervous system.
Learning Break: The drugs that are used to treat patients who have Alzheimer’s disease work by affecting the neurotransmitters that carry the electrical impulses across the synapses.

The nervous system initiates and controls involuntary and voluntary behavior, and different areas of the brain are responsible for specific behaviors. The example given above is voluntary behavior, but the brain also has many specific areas that control involuntary behavior such as breathing, circulation, and digestion.

WHAT DOES ALZHEIMER’S DISEASE DO TO THE BRAIN?

Alzheimer’s disease causes damage to the cortex, the part of the brain that is responsible for memory, problem solving, language and speech, and abstract thinking - the things that we typically refer to as the higher mental activities. When the brain of someone who has Alzheimer’s disease is examined, the most striking finding is the presence of what are called plaques and tangles in the cortex. The plaques and tangles are clumps of abnormal tissue - they are almost like scar tissue - that form inside the cells of the cortex and in the synapses. The plaques and tangles cause irreversible damage to the nerve and brain cells, and they interrupt normal nervous system functioning. Initially the body tries to repair this damage by an immune system response, but eventually this stops being helpful and actually increases the damage and deterioration.

At some point, the cortex can no longer function and the transmission of information to and from the brain is abnormal and disrupted. When that “tipping point” is reached, the person with Alzheimer’s disease cannot perform the mental activities that allow us to function and survive. In some case the progression of damage and the signs of Alzheimer’s disease are slow and subtle, but in some cases the damage happens very quickly.

WHAT CAUSES ALZHEIMER’S DISEASE?

There has been a tremendous amount of research directed towards discovering the causes, or causes of Alzheimer’s disease, but at this point no one can say with certainty why it happens or what causes Alzheimer’s disease. Some cases appear to have a genetic component and the risk for developing Alzheimer’s disease may be, in part, inherited: for example, if someone in your family has developed Alzheimer’s disease, your risk for developing the disease will be higher. However, genetics seems to account for only a very small number of all cases of the disease, but it does seem to be responsible for the cases of Alzheimer’s that are called “early-onset” in which the signs of the disease develop when in people who are their 40s or slightly younger. There are probably many causes for Alzheimer’s disease, and factors such as a traumatic brain injury, obesity, advanced age, high blood pressure, and metabolic problems could all possibly contribute to the development of the disease. However, at this point, no one knows how, why, or to whom Alzheimer’s disease will happen.

People with Alzheimer’s disease live an average of eight years after the diagnosis is confirmed, but some people may survive up to 20 years. Life expectancy and the speed with which the disease progresses depends on the general health of the individual and
how early in life they develop Alzheimer’s: if you get Alzheimer’s early, the outlook is generally poor. Some people have a slow, almost imperceptible progression of the signs and symptoms; other people become debilitated very rapidly and dramatically.

Learning Break: If there are defective genes that can cause Alzheimer’s disease, should people be tested to see if they have these genes? This is a difficult question to answer. Although there are defective genes that can definitely cause Alzheimer’s disease, these only account for a tiny minority of all cases of the disease. There is a gene that, if it is defective, may increase the risk for developing the more common type of Alzheimer’s, the late-onset form of the disease. However, some people who have this defective gene do not develop Alzheimer’s and some people who do not have the defective gene do.

MYTHS ABOUT ALZHEIMER’S DISEASE

Although Alzheimer’s is a very common disease, there are many misconceptions and myths about the disease:

- **Only older people develop Alzheimer’s disease:** Alzheimer’s disease is more common among people aged 65 years and older, but people in their 30s and 40s can develop Alzheimer’s disease.

- **Alzheimer’s disease is very debilitating but it is not fatal:** Alzheimer’s is one of the leading causes of death.

- **Using aluminum cookware or being exposed to aluminum in deodorants can cause Alzheimer’s:** There is no evidence that being exposed to aluminum by using pots and pans made of aluminum, or using deodorants that contain aluminum causes Alzheimer’s disease.

- **The memory loss of Alzheimer’s disease is a normal part of aging:** There is still no definite evidence that memory loss is inevitable as we age. And the memory loss that is part of Alzheimer’s disease is definitely not normal. It is very severe and prevents normal functioning.

- **People with Alzheimer’s disease are not aware that they are forgetful:** Some people in the early stages of Alzheimer’s disease are aware that their mental faculties are getting worse. Knowing that your mental capacity is diminished is very frightening and it can worsen the behavior of many people who have Alzheimer’s disease.

- **Alzheimer’s disease has been linked with certain foods, the flu vaccine, and dental fillings:** There have been rumors that certain foods, the flu vaccine, and dental fillings with mercury can cause Alzheimer’s disease, but these rumors have been disproved.

HOW IS ALZHEIMER’S DISEASE DIAGNOSED?
Alzheimer’s disease is diagnosed using a computerized tomography (CT) scan or a magnetic resonance (MR) scan of the brain that can detect the physical damage to the brain and by a physician’s exam. There are no laboratory tests that can be used to confirm a diagnosis of Alzheimer’s disease. The exam by the physician should look for:

- Multiple deficits in mental and physical functioning such as: impaired memory; the inability to recognize familiar objects despite normally functioning senses; an inability to speak or an inability to speak clearly and coherently; an inability to perform simple manual tasks despite normally functioning motor capacity; and an inability to perform higher mental activities.

- These deficits should be causing serious difficulties in day-to-day living.

- The deficits should start gradually and get worse over time.

- Other causes of the deficit such as a brain tumor, medication side effect, and infection, etc. have been investigated and ruled out.

- The patient’s mental and physical deficits do not occur during a period of delirium; they are consistently present.

An initial screening test that is often used to assess people who may have Alzheimer’s disease is the Mini-mental state exam (MMSE), and you may see a physician or other health care professional use this test. This is a quick test the physician or a mental health professional can administer if they suspect a patient may have Alzheimer’s disease. Examples of question from the test include:

- Ask the patient to state the year, the season, the day of the week, and the month.

- Ask the patient to count backwards from 100 using intervals of 7.

- Name two familiar objects in the room such as a lamp or a chair when the examiner points to them.

- Say out loud a short list of simple objects, wait a few minutes, then ask the patient to repeat the list.

- Say a short, common phrase, wait a few minutes, then ask the patient to repeat the phrase.

Some of us might have difficulty performing all of these tasks perfectly if we were tired, anxious, etc., yet we would get most of them right. But for the patient with Alzheimer’s disease, these memory/mental challenges would be far too difficult and confusing.
Learning Break: The MMSE is not a test that can be used to definitively make a diagnosis of Alzheimer’s disease. It is a screening tool and if someone has abnormal results other tests must be done before it can be determined that that person has Alzheimer’s disease.

SIGNS AND SYMPTOMS OF ALZHEIMER’S DISEASE

Alzheimer’s disease is a progressive condition, and patients who have Alzheimer’s typically move through stages of impairment as they get older.

- Stage 1: The patient has Alzheimer’s but she/he does not yet have any signs or symptoms of the disease. The disease is starting and it cannot be detected by family/friends or an exam by a physician.

- Stage 2: Very mild decline: The patient has some mild signs and symptoms. The patient may occasionally forget a name or a familiar word, but there are no signs or symptoms of Alzheimer’s disease that are very obvious or that can be detected by a medical professional.

- Stage 3: Mild decline: In this stage of Alzheimer’s disease, the patient’s family and friends may notice that the patient is having difficulties with memory, concentration, etc., and with an examination a physician may be able to find some mental deficits that are consistent with Alzheimer’s disease. At this stage, the patient with Alzheimer’s disease may easily lose an important object such as house keys, may have difficulty functioning socially or at work, may not be able to remember important words, may not be able to plan or organize very well and these problems are happening frequently.

- Stage 4: Moderate decline: Patients with Alzheimer’s disease who are in Stage 4 will have many of the same problems listed in the description of Stage 3, but he/she will also begin to experience mood swings and may become inappropriate and withdrawn in social situations. Complex intellectual tasks such as mental arithmetic - counting backward from 100 to 1 - become very hard to complete, and the patient has great difficulty in planning activities and managing multiple and/or complex tasks. At this stage, a physician should be able to make a diagnosis of Alzheimer’s disease.

- Stage 5: Moderately severe decline: The patient’s mental faculties and ability to function worsen. At this stage, the patient will need help with day-to-day activities because she/he will not be able to remember a home address, a home telephone number, and may become confused and uncertain about what day it is and where they are. However, the patient should not require assistance to eat and use the toilet.

- Stage 6: Severe cognitive decline: Memory and higher mental faculties continue to decline, and the patient may now need help with dressing, eating, and toilet
activities. Sleep disorders become common (sleeping during the day and staying awake at night), bladder and bowel incontinence may happen, and the patient may have significant mood swings and personality changes.

- **Stage 7:** Very severe decline: At this stage of the disease, the patient is severely impaired. The patient cannot converse, cannot control movement, has no bladder or bowel control, and cannot eat, dress, etc, independently.

There are many causes of decreased mental function in the elderly and not all people who are over the age of 65 and have memory lapses or confusion have Alzheimer’s. The earliest evidence of Alzheimer’s disease is often a slow, progressive memory loss, but there are other neurological signs and symptoms that can be warning signs of Alzheimer’s. Specific examples of the signs and symptoms of Alzheimer’s disease may include:

- Asking for the same information again and again, forgetting important names, dates, and events.

- Difficulty in balancing a checkbook, following a simple set of instructions such as a recipe, adjusting a thermostat, using a microwave oven, or finding the way to store. Also, the person with Alzheimer’s disease may understand something while it is being explained or while being supervised (e.g., how to use a microwave oven) but that person will need to re-learn the task each time.

- Trouble with vision and depth perception while driving or walking.

- Constantly misplacing things.

- Social withdrawal: People with Alzheimer’s will frequently begin to interact less and less and avoid people and places they used to frequent.

- Changes in mood and personality: Confusion, depression, anger, and suspicion that are intense and unusual may be a sign of Alzheimer’s.

One thing that is obvious from this list is that some of these behaviors, at least initially and when they are mild, can’t be easily measured and seen. They can also be overlooked or misunderstood. Many people, young and old, have mood swings, forget where they put their glasses, and/or need occasional reminders to help them through the day, but these people do not have Alzheimer’s disease. So what is the difference? Where is the dividing line between occasional memory lapses and behavior changes and Alzheimer’s? The difference is that for people with Alzheimer’s, the behaviors listed above will be persistent, unusual for them, very dramatic, will get worse over time. Also, these behaviors will seriously interfere with their ability to safely and competently care for themselves.
WHAT ARE THE DIFFERENCES BETWEEN ALZHEIMER’S DISEASE, DEMENTIA, AND THE NORMAL AGING PROCESS?

The terms dementia and Alzheimer’s are often used as if they were one and the same. Many people are confused about the differences and definitions of Alzheimer’s disease and dementia, and many people are confused about the differences between the signs and symptoms of the normal aging process and the signs and symptoms of Alzheimer’s disease. Dementia is simply a word that means a loss of mental ability. It refers to a group of neurological signs and symptoms, and many of these are seen in patients who have Alzheimer’s disease. However, there are lots of causes of dementia such as Parkinson’s disease, dementia associated with HIV/AIDS, dementia caused by abnormal blood vessels in the brain, and dementia caused by infections, traumatic brain injury, stroke, and metabolic problems. Alzheimer’s disease is simply one cause of dementia.

When it comes to the differences between memory loss and changes in mental functioning that happen as we age and the changes that are seen in Alzheimer’s disease, these differences can be easily summed up:

1) The mental deficits that are seen in a patient with Alzheimer’s are much more serious and are not part of the aging process.

2) The mental deficits cannot be easily corrected.

3) They seriously interfere with activities of daily living and with someone’s ability to safely care for herself/himself.

4) They get worse over time.

For example, someone who is elderly may forget what day it is or have a hard time learning something new. However, with a little help that person will quickly remember the day or be able to learn the new task. But if someone has Alzheimer’s disease that person may forget what day it is but also the year and the time of day, and no amount of reminding will help. The person with Alzheimer’s disease will not be able to learn something new, regardless of how much help is given.

TREATMENT FOR ALZHEIMER’S

Currently, there is no cure for Alzheimer’s disease. The treatment focuses on two areas of care: 1) using medications that can help the signs and symptoms caused by the disease, and; 2) providing a safe and supportive environment for the patient.

Medications such as Aricept® and Namenda® can help by affecting the levels of neurotransmitters in the brain. Also, antipsychotic drugs, antidepressants, and sedatives can be helpful in treating the mood swings and erratic behavior of Alzheimer’s patients. Encouraging social activity and mentally challenging activities that are within the patient’s capabilities and with good support may be helpful. Physical exercise that is within the patient’s capability can also be helpful.
WORKING WITH THE ALZHEIMER’S DISEASE PATIENT

Working with a patient who has Alzheimer’s disease can be very difficult. The patient’s ability to understand the world is severely compromised. The ability to communicate is also deeply damaged. Because of these problems, the patient simply does not have the tools needed to function normally and as a result, the behaviors of a patient with Alzheimer’s can be frightening and/or harmful to the patient and the caregiver. Some of these behaviors may include:

- Aggression
- Anxiety
- Agitation
- Confusion
- Repetition
- Suspicion
- Wandering

What is difficult for the caregiver of a patient with Alzheimer’s disease is that these behaviors are often very extreme, they are unpredictable and they happen without warning: from the standpoint of a family member or a caretaker, there is no apparent cause for the patient to act out. However, if you look carefully at what the patient is doing and what happened immediately before the behavior started, you can often determine why the patient is acting out in a particular way.

The key is to remember that the patient with Alzheimer’s disease has very diminished mental capacity and many times the patient with Alzheimer’s will act out because she/he cannot cope with stress: stress is the basic cause for many of the disturbing behaviors that can be seen in patients with Alzheimer’s disease. Stress is a normal part of life, but because these patients have such diminished mental capacities, even simple, non-threatening situations are beyond their abilities to deal with. Situations that most of us would easily understand and problems that most of us would easily solve are overwhelming for the patient with Alzheimer’s disease. That means stress, and the patient with Alzheimer’s disease has a limited ability to cope with stress. Specifically, these patients can be disturbed by:

- Physical discomfort: The Alzheimer’s patient may be uncomfortable or in pain, but will be unable to identify this fact, be unable to tell someone, or be unable to help themselves.
• Over-stimulation: Loud noises or an exceptionally active environment, or an environment that changes too quickly can confuse and frighten the patient with Alzheimer’s disease.

• Unfamiliar surroundings: If the surroundings are unfamiliar, this too can cause fear, anxiety, and confusion.

• Complicated tasks: A patient with Alzheimer’s is often unable to perform complicated tasks. They can be easily frustrated by this and then act out.

• Complex interpersonal interactions: A patient with Alzheimer’s disease can get overwhelmed by long conversations and complex social situations are incomprehensible and stressful.

We all experience these types of situations from time to time. We are physically uncomfortable, we are over-stimulated, or we are involved in complex personal interactions. Most of the time we have the abilities and experience to cope, but everyone can remember a situation that seemed too challenging, a situation that made us confused, anxious, frightened, etc. What did you do in that situation? Were you at your best? Probably not.

When that is considered, the reactions of an Alzheimer’s patient to stress - aggression, anxiety, agitation, confusion, wandering, repetition, and suspicion - begin to make sense. When you are in a new, unfamiliar situation, it is normal to feel anxious and confused. And if you are frightened, you may even feel and act a little aggressively. However, most of us can assess a new situation and plan an appropriate behavior that will help us cope. But the patient with Alzheimer’s disease simply has a much, much lower level of tolerance for these stressors and an extremely diminished ability to adjust to them. The result? They act out, and they act out in ways that seem inappropriate.

However, with patience and planning, you can successfully manage situations in which the Alzheimer’s patient is agitated, confused, or suspicious. You can also adjust the environment so that these patients do not become emotionally upset or act out physically.

The Alzheimer’s Association (www.alz.org) recommends this step by step approach:

• Identify and examine the behavior: First, identify the behavior and determine whether or not it may be harmful to the patient or others. If it may be harmful or put someone at risk, take decisive steps to stop the behavior. Have a plan. Don’t react; act. Use physical restraints only as a last resort and only if a supervisor or a physician has ordered their use. A patient with Alzheimer’s may behave in a way that is dangerous to themselves and others. There are situations in which physical restraint is necessary to stop this behavior, but using physical restraint can be very risky for the patient and the staff. Where ever you work, there should be some clear-cut policies and procedures that explain when and how to use physical restraint. Read them and understand them.

• Try and identify the cause: Look for the “trigger” that might have caused the behavior. Remember, for the patient with Alzheimer’s disease, small changes or
disruptions in the environment or the daily routine can be disorienting and upsetting. Identifying the trigger can help in removing/changing the stimulus for the behavior and also help in managing stress in the future.

- Look for solutions: This can be challenging, because it is difficult to put yourself on the place of a patient with Alzheimer’s. But be flexible; look for new ways to solve the problem and defuse the situation.

The Alzheimer’s Association also recommends some specific approaches to the difficult behaviors such as suspicion and aggression that can be seen with these patients.

1) In a general sense, it is always best to remain flexible, patient, and calm.

2) Do not get angry or confrontational. This will only increase the tension of the situation.

3) Do not use threats. For example, do not say to the patient who is acting out “If you don’t stop behaving this way, I will have to take you back to your room.” This will not work for several reasons. First, the patient with Alzheimer’s may not understand - even if it is pointed out – what he/she is doing or why it is wrong. Second, a threat implies imagining something that will happen in the future, a consequence, and someone who has Alzheimer’s disease has a limited ability to do this. And finally, the patient’s behavior is a reaction to stress. Why would that person change what she/he is doing simply to cooperate? That would not relieve the source of stress.

4) Do not argue with the patient; he/she simply cannot understand logic or common sense when upset. People who do not have Alzheimer’s disease often cannot “listen to reason” when they are confused and upset, so it is pointless to expect someone who has this disease to respond to logic.

5) Be gentle and make your instructions simple to understand. Repeat them as often as needed and be willing to change what you say and how you say it in order to be understood.

6) Above all, don’t take the behavior personally. The patient with Alzheimer’s disease who is acting aggressively or anxiously in a way that seems inappropriate is simply responding as best they can to what they find confusing and anxiety-provoking.

The following are some tools that will help you work with an Alzheimer’s patient who is under stress, and they can also be used for any patient who has Alzheimer’s disease. As always, look for the source; it may be a lack of sleep, a medication side effect, or simply a change in surroundings

- Aggression: First, make sure that the patient will not hurt themselves or others. Do not be confrontational or argumentative. Do not become aggressive yourself.
Try and gently remove the patient from the situation and distract them, if possible, with something familiar and comforting.

- Anxiety: Look for the source of the patient’s anxiety and change the environment or remove the anxiety stimulus. Gently and consistently reassure the patient that they are in familiar surroundings and with familiar people.

- Agitation: Look for the cause. Change the environment or remove the stimulus and gently and consistently reassure the patient that they are in familiar surroundings and with familiar people.

- Confusion: If you need to explain something to a patient with Alzheimer’s disease who is confused, make your explanations simple and short. Stay calm. Try and find reminders and cues that are familiar, cues that will orient the patient to time, place, and people.

- Repetition: Understand that the patient with Alzheimer’s disease who is repeating behavior or repeating a conversation is trying to comfort themselves. Allow the patient to express themselves while you look for the source of the patient’s anxiety or fear.

- Suspicion: This behavior is almost always triggered by change. It can also be triggered by the fact that the patient with Alzheimer’s may not remember who someone is, even if it is a relative or a long-term caregiver. Don’t be offended, and don’t try and use logic, or common sense to “make the patient understand.” Simply, gently, and consistently try and reassure the patient that they are in a familiar environment with people they know and that they are safe.

- Wandering: This is very common behavior in patient with Alzheimer’s disease, and it can be very dangerous. Wandering can be reduced by encouraging physical activity and providing the patient with appropriate stimulation. Make sure the patient has MedicAlert bracelet.

What about the patient who has Alzheimer’s disease who is non-communicative or non-responsive? In these situations, the best approach can be summarized with two words: slow and predictable. You must, as with any patient who has Alzheimer’s disease, make sure the uncommunicative/unresponsive patient is physically comfortable, is not over-stimulated, and is not confronted with unfamiliar surrounding or new situations, and is not asked to do anything complex. Anything you do with these patients or say to these patients must be done slowly and carefully, and it is best to establish routines. Organize the day and the activities of daily living so that everything is done slowly and predictably and always allow for lots of extra time - far more time than you imagine you might need.