



Indiana Dementia Training for Direct Care Providers

Alzheimer's Disease

Course Description:

This is a course about Alzheimer's disease, a progressive disease that causes physical changes in the brain and results in damage to brain cells. Persons with Alzheimer's Disease develop changes that affect them physically, emotionally, and socially. Although many with Alzheimer's Disease will demonstrate some classic changes associated with the disease, each person you care for will have a different experience with dementia.

Learning Objectives:

- 1. Understand that dementia results from actual brain damage.*
- 2. Understand that the symptoms and dementia-related behaviors experienced by each person with dementia will be unique.*
- 3. Understand the typical stages of Alzheimer's disease.*
- 4. Become familiar with commonly utilized treatments for Alzheimer's disease.*

This activity contains a post-test. You must complete the entire learning activity and test and score an 80% or higher to obtain a certificate of completion. Partial credit will not be given.

Contact Hours: 30 minutes, including a required quiz.

Dementia is a broad term representing as many as 70-80 different conditions. Dementia is the gradual loss of mental functioning that affects memory, mood, thinking, concentration, and judgment. These changes often affect a person's ability to perform normal activities and to care for oneself. The most common type of dementia is Alzheimer's disease (AD), representing as many as 60-80% of all dementias. (Alz.org)

Alzheimer's disease is an irreversible progressive dementia, meaning it starts slowly and insidiously and worsens over time. For most with Alzheimer's disease, the damage begins in the hippocampus and this is the part of the brain that helps us maintain short-term memory. Generally, in AD, the damage has begun years or even decades before the symptoms are first noticed. A common misperception about Alzheimer's is that it only affects memory, and although memory is often one of the early indications of Alzheimer's, it is only one of the many cognitive domains affected. And eventually, the disease process will affect all cognitive functioning resulting in problems with perception, executive functions, behavioral irregularities, language, physical functions, and emotional regulation.

Very early in the disease, it can be difficult for the casual observer to recognize the changes happening in someone with AD, but by the mid to late stages, the changes are very evident. The course of Alzheimer's disease is highly variable but generally is about 3-5 years



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and in some, the progression may be as long as 10-20 years. But, regardless of the timeframe, if allowed to run its customary course, eventually the person with AD will change dramatically in both physical appearance and in their ability to care for themselves and understand and interact with their surroundings.

Alzheimer's Disease is characterized by two well-recognized abnormalities: plaques and tangles. Amyloid plaques are found inside the tissue between the nerve cells. Scientists still don't understand exactly how beta-amyloid kills neurons. But, in those with AD, this beta-amyloid protein clumps which interfere with brain cell transmission. What further complicates researchers' understanding of the plaques in the brain is that nearly 1/3 of clinically normal people have sufficient levels of amyloid plaques in the brain to warrant an AD diagnosis. One theory is that some people's brains are simply more resilient to plaques than others and there is some research that higher education and cognitive stimulation throughout a lifetime may assist some in developing a cognitive reserve so that it takes more damage to the brain cells before AD symptoms appear.

In normal brains, tau helps the cell's microtubules transport important substances throughout the cell and help provide the microtubules with structure. But in AD, the tau protein becomes twisted and forms bundles, called neurofibrillary tangles that are inside the neurons.

Both plaques and tangles are thought to contribute to reduced cell function and nerve-cell death, but scientists do not fully understand this relationship. It is still not clear, for example, if the plaques and tangles cause the disorder, or if their presence flags some other process that leads to cell death in AD. There are many theories suggesting that AD is caused by a combination of genetic, lifestyle, and environmental factors that affect the brain and neurons over time resulting in the death of the neurons and ultimately the brain damage that results.

Other theories for AD include:

- Antioxidant hypothesis: the thought that free radicals accumulate in the brain which can damage proteins by altering their chemical structure and DNA and potentially causing mutations.
- Diabetes hypothesis: the thought that there is a link between diabetes and dementia. Dementia is thought to disturb glucose metabolism. Scientists theorize that either the brain of a diabetic person lacks sufficient glucose to function properly or excess sugar in a diabetic person's blood does vascular damage that affects blood flow to neurons.

There are particular risk factors that increase the likelihood of a person's chance of getting AD. Age is the primary risk factor. Other risk factors include a family history of AD, female gender, few years of education, head injury, strokes, elevated homocysteine levels, and other risk factors for cerebrovascular disease. One hypothesis is that inflammation may play a key role in AD by creating damage to existing neurons, so any type of systemic inflammation may increase the future risk for AD.



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Symptoms

A key predictor of symptoms presentation is where the damage is occurring in the brain. Researchers have found that AD begins at least 8-10 years before symptoms become prominent enough for a diagnosis to be made. As the disease progresses and the brain can no longer compensate for the damage, the person's symptoms will interfere with their ability to function normally. As AD progresses, the damage to the brain becomes greater and in advanced Alzheimer's disease, the dramatic loss of neurons actually causes the brain to shrink.

While the course of Alzheimer's can vary and no two individuals will have the same experience, there are some typical symptoms that begin early in Alzheimer's dementia. Early-stage dementia is often difficult to recognize, since initial signs like memory loss and confusion may happen in a slow gradual way. The person may have good and bad days. So, it is hard for those around the person to recognize if there is an issue or not.

But, in general, progressive memory loss is the most characteristic symptom of Alzheimer's disease in the earliest stage. Early on, the person merely seems forgetful. But over time, the forgetfulness interferes with their ability to function normally. Often, they may try to compensate by keeping lists or post-it notes all over the house; but eventually, they forget to look at the notes. They may forget their medications, MD appointments, social engagements, and where they put their glasses or keys. They may forget conversations or ask the same questions over and over, which may interfere with them maintaining social relationships. For a while, they can use routines and habits to get them through the day. Eventually, memory problems will contribute to increasing disorientation. Even very early, people may lose the sequencing of events or lose track of time.

Changes in language usually present with difficulty with word-finding in the early stage. The person may be unable to think of the right words and get frustrated when this happens. They may try to cover up this ability or make it into a joke. They may substitute a similar-sounding word or a related word and not even notice. In the earlier stage of AD, the person may still be able to carry on casual or social interactions without problems. They depend on their humor and social graces to be able to get through encounters still fairly well.

Early in the disease, people start to have problems with planning for events or doing multi-step processes. Another issue is people usually begin to have trouble with the IADLs or instrumental activities of daily living. They may begin to have problems balancing their checkbook or keeping up with their bills. They may even begin to have problems working with money or making change.

Poor judgment and lack of insight can lead to becoming a victim of scams. Also, impulsiveness may develop which can cause them to buy things they don't really need or pay more money for things than would seem reasonable.



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Finally, it is the changes in mood and personality that are often the thing to convince the family that something is definitely not right. Apathy is common, and many people with Alzheimer's lose interest in their usual activities. They may no longer want to do the things they have always done and may begin to refuse to attend social situations. A person may become withdrawn, irritable, or even angry. Depression may also develop, partly as a result of chemical and biological changes in the brain caused by the disease itself and partly as a reaction to the realization of what is happening and their loss of functioning.

There is no real mechanism for determining when one leaves the early stage or enters the more moderate stage of dementia. Again, the changes may not happen in a systematic way, so some of the problems with thinking, behavior, or perception may be happening at different paces. But in general, once a person has entered the middle stage of AD, the symptoms are now noticeable to even those who are unfamiliar with the person. Memory issues will be more pronounced and they will have problems remembering the names of people they may not know as well. They may forget where they put items and may blame others for their absence. They may now begin to forget things that happen to them throughout the day, who visited, what they ate, or even if they ate. They now require supervision over medications and meal preparation and may require assistance with bathing, dressing, and toileting.

Also, generally, as AD progresses, the person will have more difficulty with orientation and may even get lost in familiar areas. They may not be able to locate where the bathroom is in their own home. They may wander or pace as they try to find cues in their environment to help them know what it is they are supposed to do.

Generally, in the mid-stage, the damage is now interfering with the "thinking" part of the brain as well as the area for speaking and memory. They are often unsafe now to live alone unsupervised. They may not recognize unsafe situations any longer and may not know what to do in an emergency or understand how to get help. They may become obsessive about things that others think are unimportant and may begin shadowing or calling caregivers on the phone multiple times a day or even in the middle of the night to help them feel safe and oriented. They may begin having misperceptions or delusions that are troubling to them and their caregivers. Delusions are fixed false beliefs. Because the person's thinking is impaired, logic and reasoning will no longer convince them that their delusion is wrong. Common delusions are that their spouse is not faithful or that someone is watching them or trying to hurt them or steal something from them.

Generally, at this stage, their gait, mobility, and balance may begin to be an issue. They may develop a slowed and unsteady gait. Apraxia or purposeful movements may become more difficult. They may no longer be able to tie a tie or tie their shoes or write their name.

As loss of speaking develops, behaviors become an important form of communication. "Behaviors" is the term commonly used when referring to those things a person with cognitive impairment does that our society finds to be inappropriate or not socially acceptable. It is a common term used in dementia education, research and practice, but it does have a negative



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connotation. In fact, behaviors are a means of communicating a need, such as pain, boredom, frustration, confusion, anxiety, or overstimulation. When a person with dementia behaves differently, this is often mistakenly seen as a direct result of dementia. However, this is often not the case. The behavior may have many causes, including difficulties relating to cognitive changes in the brain (such as memory loss, language, or orientation problems), but also mental and physical health, personality, interactions with others, and the environment can all contribute to problems for the person. Therefore, understanding what triggers “behaviors” is important in helping reduce them.

Because a person with AD will often also lose insight into their memory issues, they may resist receiving help or recognizing they are no longer safe in their current environment. As loss of speaking develops, behaviors become an even more important form of communication. Therefore, understanding what triggers specific behavior is important in helping reduce them. Things to explore when behaviors are observed include things such as physical discomfort (hot, cold, hungry, pain, fatigue, need to toilet, illness), boredom (loss of meaningful activities), too much demand placed on the person, or inability to interpret overwhelming or misleading stimuli in their environment.

Some people with dementia start to pace. This may not be a problem for a person with dementia. However, it can be very stressful for carers, especially if the person with AD stays out for long periods of time or leaves the home unexpectedly or during the night. They may develop mobility issues along with cognitive problems, so they are more likely to fall.

By late-stage Alzheimer’s, most areas of the brain have been affected resulting in the need for 24-hour supervision and assistance. Generally, the person will lose most speech and have more difficulty understanding words. It becomes more necessary to provide touch, and visual cues to assist them. They generally now also begin losing some of their long-term memory and may not consistently recognize family members. They begin to spend a lot more time sleeping.

Functioning becomes impaired and a person with AD may become incontinent or require reminders that they need to go to the bathroom. They may eventually lose their ability to ambulate and even to sit upright. They often develop rigidity and their primitive reflexes, such as the grasp reflex return. Finally, they may have issues with pocketing food in their cheeks and forgetting how to swallow and eventually will have issues with choking or may refuse to eat. As their immunity, nutrition and mobility are affected, a person will develop more infections that may no longer respond to treatment. Often times because their brain is so compromised, the very first sign of infection will be a change in behavior or functioning.

Treatment

The most effective treatment plan for Alzheimer’s disease is one that is comprehensive and which encompasses diet, activity, caregiver education, and medication. The medications used in



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AD focus on improving cognition (memory and thinking function), mood as well as behaviors. Currently, there are two types of drugs used to treat cognitive symptoms:

- **Cholinesterase inhibitors.** These drugs work by boosting levels of cell-to-cell communication by providing a neurotransmitter (acetylcholine) that is depleted in the brain by Alzheimer's disease. Acetylcholine is necessary for memory development. But cholinesterase inhibitors can improve neuropsychiatric symptoms, such as agitation or depression, as well in some people. Commonly prescribed cholinesterase inhibitors include donepezil (Aricept), galantamine (Razadyne), and rivastigmine (Exelon). The main side effects of these drugs include diarrhea, nausea, loss of appetite, and sleep disturbances. In people with cardiac conduction disorders, serious side effects may include a slow heart rate and heart block.
- **Memantine (Namenda).** Namenda® is believed to work by regulating glutamate, an important brain chemical. When produced in excessive amounts, glutamate may lead to brain cell death. Side effects may include constipation, dizziness, and headache, and may initially increase confusion. Namenda may help maintain thinking, memory, and communication skills and help with certain behavioral problems. Because Namenda works very differently from cholinesterase inhibitors, the two types of drugs can be prescribed in combination.

These drugs don't change the underlying disease process. They are effective for some, but not all, people and may help only for a limited time. Currently, there is no known cure for Alzheimer's Disease.

Working with people who have Alzheimer's disease can be both rewarding and challenging. AD is a complicated disease process and often co-occurs with other dementia types including Lewy body dementia and vascular dementia. It is important to remember that everyone who has AD will have different symptoms because the brain degeneration in each person occurs in different areas of the brain and because each person's brain is unique. So, some people will have retained abilities in some areas of the brain but not others. This mismatch of skills can be difficult to understand. For instance, a person may be able to still bathe and perform all their ADLs independently, but not know how to dress appropriately for the weather. This causes confusion for caregivers.

Also, there are many different types of memory: visual, auditory, visuospatial, and muscle. So, a person may not remember what is said but may remember what they read or vice versa. Memory is further affected by things such as hydration levels, attention, stress, sleep, exercise, depression, and nutrition. Finally, memory for things with an emotional connection seems to last longer. All these variables with memory can make caregivers think that a person with AD is doing certain things on purpose. It is important for you to support the AD caregivers and recognize the difficulties that exist, but also to educate them on the many variables that can happen with AD and especially memory. It is easy for caregivers to attribute some of the lapses in memory or behaviors to prior personality traits. It is common for families to say, "they



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have always been stubborn so I know they are doing that on purpose” or “he can remember that if he wanted to”. Reinforce that a person’s memory is unpredictable and we can’t choose what we remember and what we can’t remember. Nearly always, those with AD are not purposely forgetting things or trying to irritate their family or caregivers. Rather, they are experiencing the effects of true brain damage.

Resources:

2022 Alzheimer’s Facts and Figures. <https://doi.org/10.1002/alz.12638>