

# Introduction to Dementia Care

## Instructor Guide



UPDATED JUNE 22, 2011



Care and Compliance Group, Inc • 800.321.1727 • [www.careandcompliance.com](http://www.careandcompliance.com)

## **INSTRUCTOR GUIDE:**

### **INTRODUCTION TO DEMENTIA CARE**

<b>Overview</b>	This module addresses the definition of dementia, symptoms of dementia, stages, and basic challenges our residents face. We will also address care strategies that you can apply to your residents with dementia.
<b>Video(s)</b>	"Introduction to Dementia Care" (31 minutes)
<b>Special Supplies</b>	None
<b>Learning Objectives</b>	<ol style="list-style-type: none"><li>1. Introduction and fundamental precepts of good dementia care;</li><li>2. Anatomy of the brain;</li><li>3. Terminology;</li><li>4. Symptoms of dementia;</li><li>5. Types and causes of dementia;</li><li>6. Diagnosing dementia;</li><li>7. Alzheimer's disease;</li><li>8. Food and dementia;</li><li>9. Metabolic disease;</li><li>10. Vascular dysfunction may be a key element to Alzheimer's Disease;</li><li>11. Cardiovascular disease and AD;</li><li>12. Diabetes and AD;</li><li>13. Inflammation and AD;</li><li>14. Genetics;</li><li>15. Alzheimer's disease in persons with down syndrome;</li><li>16. Related neurodegenerative disease;</li><li>17. Other research;</li><li>18. Current medications;</li><li>19. Neuropsychiatric symptoms;</li><li>20. The stages of Alzheimer's disease.</li></ol>

# QUIZ: INTRODUCTION TO DEMENTIA CARE

Name: \_\_\_\_\_

Date: \_\_\_\_\_

1. Which is most often affected with dementia?
  - a. Vision, hearing, sense of touch
  - b. Orientation, language, ability to sequence tasks
  - c. Heart function, liver function
  - d. None of the above
  
2. Which type of memory function is usually affected first with dementia?
  - a. Short Term
  - b. Long Term
  
3. The ability to remember our parent's names, where we grew up or where we were married are all examples of:
  - a. Short term memory
  - b. Long term memory
  
4. When a resident with dementia refuses to go to the bathroom, often it is because:
  - a. He is angry at the caregiver and wants to exercise his rights
  - b. He doesn't understand what the caregiver wants
  - c. He has a bladder infection
  
5. A resident with impaired judgment needs to be monitored for:
  - a. Safety concerns
  - b. Impulsive actions like crossing the street without looking
  - c. Giving his money away
  - d. All of the above
  - e. None of the above

6. A resident with dementia who keeps trying to get out of the shower before being completely bathed, maybe doing this because:
  - a. He has lost the ability to sequence tasks and simply thinks he is done
  - b. He needs to be disciplined better
  - c. He does not like the facility
  
7. The important thing to remember when caring for persons with dementia is that:
  - a. Every resident should be treated the same
  - b. Residents with dementia will typically lose the ability to love
  - c. Residents are unique individuals and we should recognize their differences
  
8. A resident who has trouble with memory loss, sleeping, cannot dress themselves easily and sometimes gets lost walking around the facility is most likely in what stage of dementia?
  - a. Early stage
  - b. Middle stage
  - c. Late stage
  
9. Residents do best with a "normalized environment". Which of the statements below, best describes a normalized environment?
  - a. An environment that has had all decorations removed so the resident is safe
  - b. An environment where staff carefully treat the residents like babies, lovingly caring for them
  - c. An environment that looks like a regular home with items the resident can successfully use
  
10. What are some reasons for challenging behaviors?
  - a. Poor physical health, pain
  - b. Too much clutter
  - c. Asking the residents to do tasks that are overwhelming
  - d. A and C
  - e. All of the above
  - f. None of the above



11. If a resident has trouble understanding what you are saying you should:

- a. Repeat the statement using the same words
- b. Repeat what you want using different words
- c. Raise your voice so it is louder

12. When speaking to residents with dementia, \_\_\_\_\_ sentences are best to use.

- a. Short
- b. Long

13. When a resident has a catastrophic reaction you may see?

- a. Hitting
- b. Yelling
- c. Running
- d. Combative behavior
- e. All of the above
- f. None of the above

14. When a catastrophic reaction occurs, it is best to:

- a. Use firm clear commands with forceful language
- b. Use force to keep the resident safe
- c. Do not wait until the resident has calmed down, as this sends the message that it is acceptable for them to act that way
- d. All of the above
- e. None of the above

15. When using a technique called "change of face" when a resident is upset, it means to:

- a. Have another caregiver step in to help the resident
- b. Change your facial expression
- c. Massage the residents face gently

## QUIZ KEY: INTRODUCTION TO DEMENTIA CARE

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# Certificate of Completion

THIS IS TO RECOGNIZE

\_\_\_\_\_

FOR DEDICATION TO QUALITY RESIDENT CARE  
THROUGH EDUCATION AND PROFESSIONAL DEVELOPMENT.

INTRODUCTION TO DEMENTIA CARE

\_\_\_\_\_  
Instructor Signature

\_\_\_\_\_  
Date



# Introduction to Dementia Care

## Learner Workbook



UPDATED JUNE 22, 2011



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# INTRODUCTION

## Fundamental Precepts of Good Dementia Care

People who care for persons with dementia have unique values. Outstanding dementia care professionals are committed to individualized resident care. A true care professional will say:

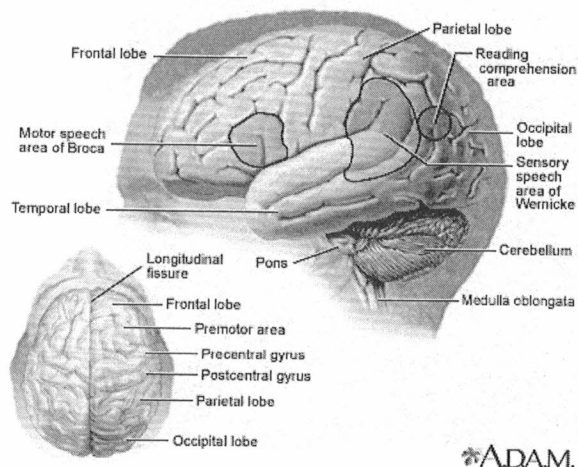
- I know my residents
- I understand the diseases known as dementia
- I am dedicated to life-long learning and skill enhancement
- I put relationships before tasks
- I take responsibility and full accountability for care
- I receive joy and rewards daily from interacting with my residents
- I am not afraid to be silly or look silly
- I know that my way is not always the only way and I listen closely to others
- I am a dementia care professional

Care extended to the person – NOT management of the person – is my goal.

- I need to know that not all care is readily accepted
- Not all care matches family expectations
- Not all care is something done “to a resident” but rather “with a resident”
- When I have concerns or problems about care I will turn to my supervisor

## ANATOMY OF THE BRAIN

To understand how dementia affects the brain, it is helpful to have an understanding of the different parts of the brain.



The average adult human brain weighs 1.3 to 1.4 kg (approximately 3 pounds).

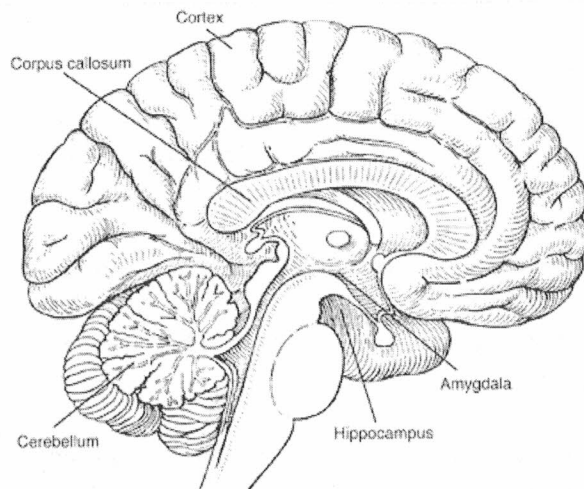


The brain contains about 100 billion nerve cells, called neurons.

The brain is divided into two halves, called cerebral hemispheres that account for 85 percent of the brain's weight. The billions of neurons in the two hemispheres are connected by thick bundles of nerve cell fibers called the corpus callosum.

Scientists now think that the two hemispheres differ not so much in what they do (the "logical versus artistic" notion), but in how they process information. The left hemisphere appears to focus on details (such as recognizing a particular face in a crowd). The right hemisphere focuses on broad background (such as understanding the relative position of objects in a space).

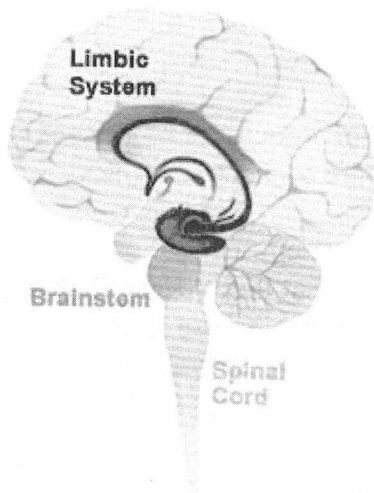
The cerebral hemispheres have an outer layer called the cerebral cortex. This is where the brain processes sensory information received from the outside world, controls voluntary movement, and regulates cognitive functions, such as thinking, learning, speaking, remembering, and making decisions. The hemispheres have four lobes, each of which has different roles, such as vision, memory, problem solving, speaking, remembering, etc.



The cerebellum sits above the brain stem and beneath the occipital lobe. It takes up a little more than 10 percent of the brain. This part of the brain plays roles in balance and coordination. It also is involved with motor learning and remembering how to do things like drive a car or write your name.

The brain stem sits at the base of the brain and connects the spinal cord with the rest of the brain. Its functions are crucial to survival. The brain stem controls the function that happen automatically to keep us alive – our heart rate, blood pressure, and breathing.

Several other essential parts of the brain lie deep inside the cerebral hemispheres in a network of structures called the limbic system.



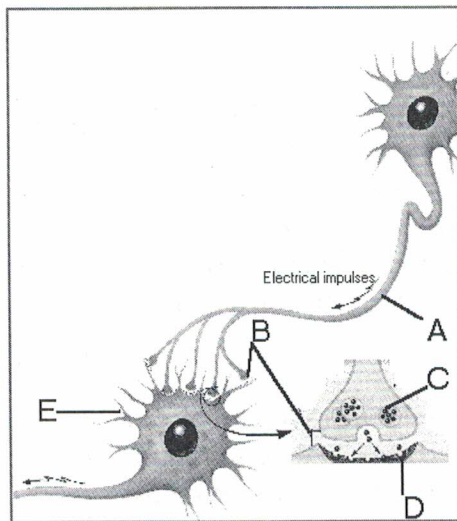
The limbic system plays a key role in developing and carrying out instinctive behaviors and emotions and also is important in perceiving smells and linking them with memory, emotion, and instinctive behaviors.

The limbic system includes:

- The amygdale is involved in processing and remembering strong emotions such as fear.
- The hippocampus is important for learning and short-term memory. This part of the brain is thought to be the site where short-term memories are converted into long-term memories for storage in other brain areas.
- The thalamus receives sensory and limbic information, processes it, and then sends it to the cerebral cortex.
- The hypothalamus monitors activities such as body temperature and food intake. The hypothalamus also controls the body's internal clock.

The real work of your brain goes on in individual cells, called neurons. An adult brain contains about 100 billion neurons, with branches that connect at more than 100 trillion points. (A single neuron has up to 15,000 synapses.) Signals traveling from neuron to neuron form the basis of memories, thoughts, and feelings. Neurons are the chief type of cell destroyed by Alzheimer's disease.

The nerve cells (neurons) in the brain communicate with each other through their axons and dendrites. Each neuron has a cell body that contains a nucleus which controls much of the cell's activities. Axons transmit messages from neuron to neuron. Dendrites also branch out from the cell body. They receive messages from the axons of other neurons.



A – axon  
 B – synapse  
 C – neurotransmitter  
 D – receptor  
 E – dendrite

Very briefly, the transmission of a nerve impulse from one nerve to another happens like this:

- A nerve impulse from one neuron travels to the end of its axon and, once there, passes to another neuron by either electrical current or, more typically, the release of chemical messengers, called release of chemical messengers, call **neurotransmitters**. The neurotransmitters are released from the axon terminal and move across a tiny gap between neurons (called a **synapse**) to specific receptor sites on the receiving end of dendrites of nearby neurons.

During any one moment, millions of these signals are speeding through pathways in the brain, allowing the brain to receive and process information, make adjustments, and send out instructions to various parts of the body.

## TERMINOLOGY

When describing the decline in mental abilities, or cognition, associated with dementia, it is important to use accurate descriptive terms. By using an accurate description of the symptoms of dementia, a caregiver can more accurately describe the changes seen in a resident, and better understand the resident's condition and status. Additionally, in later sections when behavior management will be addressed, an understanding of the symptoms of dementia is also an essential building block.

## REVIEW: THE BRAIN

<b>Cerebral Cortex Functions:</b> <ul style="list-style-type: none"> <li>• Thought</li> <li>• Voluntary Movement</li> <li>• Language</li> <li>• Reasoning</li> <li>• Perception</li> </ul>	<p>The cerebral cortex is the outermost part of the brain. The cortex is deeply fissured. A fissure is also called a sulcus. The cerebral cortex in humans is highly developed and larger than other animals. It is thought that our more developed cortex is what makes us inherently "human" and able to perform much more complex thought.</p>
<b>Cerebellum Functions:</b> <ul style="list-style-type: none"> <li>• Movement</li> <li>• Balance</li> <li>• Posture</li> </ul>	<p>The cerebellum is located behind the brain stem and in some ways is like the cerebral cortex, in that is divided into hemispheres and has a cortex that surrounds these hemispheres.</p>
<b>Brain Stem Functions:</b> <ul style="list-style-type: none"> <li>• Breathing</li> <li>• Heart Rate</li> <li>• Blood Pressure</li> </ul>	<p>The brain stem is the area of the brain between the thalamus and spinal cord. It is responsible for the most basic functions of life such as breathing, heart rate, and blood pressure.</p>
<b>Hypothalamus Functions:</b> <ul style="list-style-type: none"> <li>• Body Temperature</li> <li>• Emotions</li> <li>• Thirst and Hunger</li> <li>• Circadian Rhythms</li> </ul>	<p>The hypothalamus is the size of pea, but is responsible for very important functions such as regulating body temperature and controlling the pituitary.</p>
<b>Thalamus Functions:</b> <ul style="list-style-type: none"> <li>• Sensory Integration</li> <li>• Motor Integration</li> </ul>	<p>The thalamus receives sensory information and relays this information to the cerebral cortex.</p>
<b>The Limbic System and Hippocampus Functions:</b> <ul style="list-style-type: none"> <li>• Emotional Behavior</li> <li>• Learning and Memory</li> </ul>	<p>The limbic system includes structures such as the amygdala, hippocampus, and mammillary bodies and cingulate gyrus. These areas are important for controlling emotion. The hippocampus is critical for memory and learning.</p>
<b>Midbrain Functions:</b> <ul style="list-style-type: none"> <li>• Vision</li> <li>• Eye Movement</li> <li>• Body Movement</li> </ul>	<p>The midbrain is an active part of our ability to process data sent to us from the eye and to coordinate appropriate body movement.</p>



Learning Exercise:

***DEMENTIA SPECIALTY TRAINING: Check for Understanding***

**The part(s) of the brain responsible for memory is/are the:**

- A. Cerebral cortex
- B. Cerebellum
- C. Brain stem
- D. Limbic system
- E. Both A and D

**Explain your answer:**



Learning Exercise:  
***DEMENTIA SPECIALTY TRAINING: Check for  
Understanding***

**The part(s) of the brain responsible for emotions is/are the:**

- A. Cerebral cortex
- B. Cerebellum
- C. Brain stem
- D. Limbic system
- E. Both B and C

**Explain your answer:**

## INTRODUCTION TO DEMENTIA

Dementia is an observable, often irreversible, decline in mental abilities. This decline is progressive and results in functional impairments. The decline in mental abilities in irreversible dementia is related to degeneration (destruction) of important cells in the brain called neurons. There are different types of dementia that have been classified, including Alzheimer's disease, vascular dementia, dementia related to HIV disease, and others.

Dementia refers to an acquired, persistent loss of intellectual functions due to a brain disorder. This is not a normal part of the aging process, even though the vast majority of persons who experience a dementia are persons over 65 years of age. Dementia is really a broad, umbrella term. A medical diagnosis is required to determine the underlying cause of causes of symptoms. In the past, terms like "senility" and "hardening of the arteries" were commonly used to describe dementia, but do not accurately explain the disease's processes at work.

Dementia refers to a "syndrome," not a specific disease. Many different diseases can cause dementia:

- Alzheimer's disease
- Vascular dementia
- Lewy body
- Alcohol-related
- Parkinson's related and so on...

## SYMPTOMS OF DEMENTIA

- A decline in cognitive functions
- Typically progresses over a period of many years, but it can begin abruptly
- While there are common symptoms, they can vary from person to person
- Different causes of dementia also can dictate symptoms and their presentation

Dementia affects some or all of the following cognitive ("brain") functions in persons affected:

- |               |                   |
|---------------|-------------------|
| • Memory      | • Perception      |
| • Orientation | • Concentration   |
| • Language    | • Task sequencing |
| • Judgment    |                   |

## EXERCISE

Looking at the previous page, think about your residents. On a separate piece of paper, give an example of how each function has affected a resident.

Two examples:

- Memory- Mrs. Jones can't remember when she has eaten last.
- Task Sequencing – Bill has difficulty following the directions in activities class.



## SYMPTOMS: MEMORY

The hallmark of dementia is impairment in remembering recent events, what is often referred to as *short-term memory*. Forgetting appointments, conversations, and misplacing items often occur at the onset of dementia. New learning and recall of recent events become impaired while memories from the distant past may be intact.

Nearly everyone will experience a steady rate of natural decline in cognitive (thinking and reasoning) abilities. However, the elderly still can learn and retain new information. This decline in cognitive abilities is NOT dementia; dementia is a disease process that affects the brain.

Memory loss is evident in normal aging but differs from memory loss in Alzheimer's disease and related dementias. There is some evidence that both physical and mental exercise can help maintain thinking abilities in normal aging. Reading, doing crossword puzzles, and engaging in stimulating conversations – as well as ordinary physical exercise – may all help keep one's brain as sharp as possible. However; in Alzheimer's disease and related dementias some of these same memory aids may not be as helpful and affective.

The following chart demonstrates some of the differences one may find in normal aging memory loss compared to dementia memory loss. This information was adapted from the American Medical Association. For more information you can go to [www.ama-assn.org](http://www.ama-assn.org).

Normal Aging	Dementia
Person is capable of operating common appliances despite any unwillingness to learn how to operate new devices	Person is not capable of operating common appliances nor able to learn how to use or operate a simple new device
Capable of independently participating in activities of daily living	Requires assistance in activities of daily living
Has difficulty occasionally with word-finding	Has frequent difficulty with word-finding
Continues to maintain prior level of interpersonal social abilities	Demonstrates loss of interest in social activities; and may exhibit inappropriate social behaviors
Person does not get lost in familiar places but may need a moment to remember the correct direction	Person does get lost in familiar places and may take hours before returning home
Capable of remembering important recent events and able to communicate	Decline of short term memory for recent events and struggle in communication

## EXERCISE

Residents may become agitated when embarrassed. For example when long term memory is relatively unaffected, but there is a decline in short term memory. Below name at least 5 subjects or topics that would you want to avoid in discussions with your resident.

This image shows a single sheet of white paper with horizontal blue or grey ruling lines. The lines are evenly spaced and run across the width of the page. There are approximately 20 lines visible. The paper appears to be a standard notebook page, possibly from a composition book or a legal pad. The edges of the paper are slightly irregular, suggesting it might be a scan of a physical document. There is no handwriting or other markings on the page.

**Possible responses:** Here are examples of what you may have answered:

- What did you have for lunch?
- What time did your daughter call?
- Who was sitting at your table with you at lunch today?

## **SYMPTOMS: ORIENTATION**

The inability to know one's place and time may also be indicative of dementia. This may be seen as the resident easily gets lost or does not know the month/year or time of day.

### **EXERCISE**

Below name 5 prompts, cues, or labels you could use in your facility to help a resident know his way around.

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**Possible responses:** Here are examples of what you may have answered.

- Prompt: Picture of a toilet by the bathroom, picture of a package of cookies outside of a snack cabinet, a stop sign where not to enter.
- Cue: Hand the resident a napkin as a cue to eat, offer a musical instrument as a cue to sing along, give the resident a gardening tool as a cue to weed.
- Label: Labels in the room such as *Toilet* outside the bathroom, *Joyce's Room* on a door, or *Underwear* on a drawer.

## **SYMPTOMS: LANGUAGE**

Residents with dementia may display several forms of language impairments (sometimes referred to as aphasia), either expressive or receptive.

Expressive language impairments are seen when a resident has difficulty finding or remembering words.

Receptive language impairments refer to difficulty understanding language. Rules of syntax and grammar may be impaired, although the physical ability to speak remains intact.

## **SYMPTOMS: JUDGMENT**

Reasoning skills are often impaired, resulting in poor judgment. For example, the resident may not realize or understand that walking into the street can be dangerous.

## **SYMPTOMS: PERCEPTION**

Distortions in interpreting one's environment may also be seen in dementia. Although eyesight itself may be well preserved, the brain's ability to accurately interpret what one is seeing may be impaired. This can diminish the resident's ability to recognize an otherwise familiar object or places as well as impair his ability to use common objects, such as a telephone.

## **SYMPTOMS: CONCENTRATION**

The ability to pay attention or concentrate may also be impaired. Noises, objects or people in his environment may distract the resident. For example, when sitting down for dinner, the resident spends the entire mealtime moving around the napkins, utensils, and salt and pepper shakers rather than eating the meal.

## **SYMPTOMS: TASK SEQUENCING**

Performing any task requires the ability to put a series of steps together in the right order. Someone with dementia may forget the steps in preparing a meal or shopping for groceries.

## EXERCISE

Let's take a look at what is meant by task sequencing. Most of us do this without really thinking about it. Think about the steps involved in a resident getting dressed in the morning. Below write down all the individual steps the resident would take.

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How many steps did you identify? There are no right or wrong answers, but here is an example of a possible sequence for the task of getting dressed:

- Decide what to wear
- Open the dresser drawer(s) and/or closet
- Get out underwear, socks, and other undergarments
- Remove soiled clothes
- Place soiled clothes into appropriate laundry hamper or basket
- Put on undergarments
- Put on shirt/blouse, pants/skirt, socks, shoes, belt, watch, etc.

Correct task sequencing also means that the end result has the outer garments on the outside and the undergarments on the inside!



Learning Exercise:

***DEMENTIA SPECIALTY TRAINING: Check for Understanding***

**Beatrice is 73 years old and lives in a large Long Term Residential Community. Nearly every morning after breakfast in the dining room she gets lost finding her way back to her room. Which category best describes her symptom of dementia?**

- A. Perception
- B. Judgment
- C. Orientation
- D. Concentration
- E. Task sequencing

**Explain your answer:**



## **TYPES AND CAUSES OF DEMENTIA**

The most common cause of dementia is Alzheimer's disease, but there are as many as 50 other known causes (most of these causes are rare). The frequency of dementia in America is believed to be 5 – 8% of all people over the age of 65. This percentage doubles for every 5-year increase in the age group. It is estimated that as many as half of people 85 or older suffer from dementia.

Some are reversible through proper treatment. Reversible dementias have the potential for being reversed with necessary and timely medical treatment. Others are irreversible and progressive. Irreversible dementias will not get better. There may be interventions that can slow the progression, but the effects will be permanent and will often get worse.

### **REVERSIBLE DEMENTIAS**

Let us start by looking at reversible dementias. Reversible dementias are caused by an underlying disorder. The disorder and/or the dementia may be cured partially or completely with proper treatment. The degree of reversibility often depends on how quickly the underlying cause is treated.

Below is a list of causes of reversible dementias. Dementia caused by any of the following is often at least partially treatable by treating the underlying condition.

- Chronic drug abuse
- Tumors that can be removed
- Subdural hematoma (an accumulation of blood in the brain from a broken blood vessel, usually as a result of a head injury)
- Medications
- Infections
- Metabolic disorder, such as B12 deficiency
- Depression
- Normal pressure hydrocephalus
- Hypothyroidism (low thyroid)
- Hypoglycemia (low blood sugar)

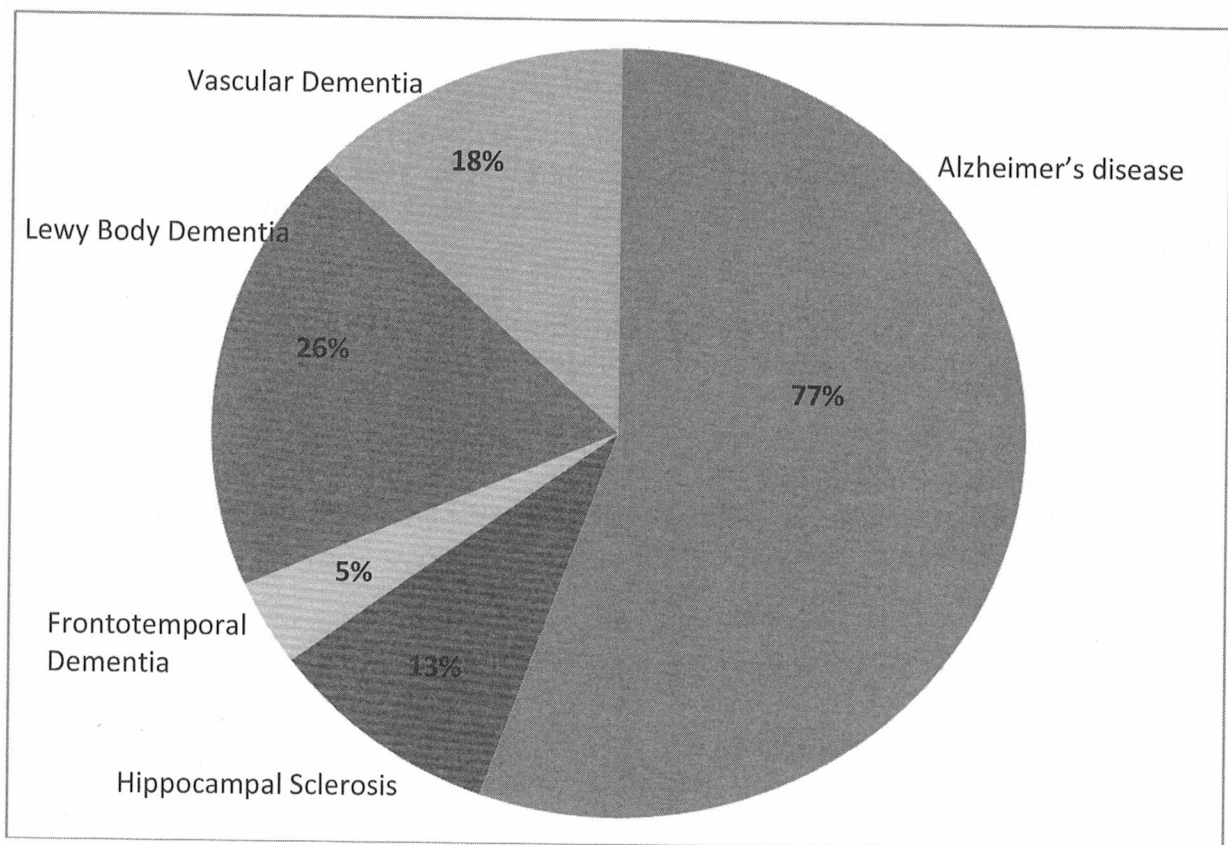
### **IRREVERSIBLE DEMENTIA**

Now let's look at irreversible dementia. Irreversible dementias are caused by an incurable condition, such as Alzheimer's disease. Alzheimer's disease is believed to account for 77% of all dementias. Currently, every 72 seconds someone in America is diagnosed with Alzheimer's disease. It is expected that by the year 2050, that will reduce to every 33 seconds due to our aging population.

Below is a list of irreversible dementias. Dementia caused by any of the following are not considered to be reversible, though some medications may slow the progression of the disease.

- Alzheimer's disease
- Lewy body disease
- Parkinson's disease
- Multi-infarct (vascular) dementia
- Pick's disease (also known as Pick disease)
- Creutzfeldt-Jacob disease
- Huntington's disease
- AIDS dementia complex

The chart below shows data obtained from autopsies at the Florida State Brain on the frequency of common types of dementia.



Source: Arizona Geriatrics Society, 2009 Spring  
Geriatric Mental Health & Aging Conference



Learning Exercise:

***DEMENTIA SPECIALTY TRAINING: Check for Understanding***

**Alzheimer's disease is considered a:**

- A. Reversible dementia
- B. Irreversible dementia

**Explain your answer:**

## DIAGNOSING DEMENTIA

The early signs of dementia may be very subtle, inconsistent, and vague. Early signs of dementia may include:

- Problems with memory, especially recall of recent events
- Confusion
- Personality change
- Apathy and withdrawal
- Loss of ability to do everyday tasks

Usually a friend, loved one, or caregiver is the first to notice when a person with dementia begins to display outward signs of memory and cognitive impairment. Persons with dementia are often unable to identify a problem. Often the person must be encouraged to seek medical help.

Determining the cause of dementia may require a variety of medical tests that are chosen to match the most likely etiology. For example:

- Cerebrovascular disease, hydrocephalus, and tumors may be diagnosed with x-rays, CT or MRI scans, and vascular imaging studies.
- Blood tests may reveal nutritional deficiencies or hormone imbalances.

Other diagnostic considerations:

- Depression is common in the elderly and can be mistaken for dementia; therefore, ruling out depression is an important part of the diagnosis.
- Distinguishing dementia from the mild normal cognitive decline of advanced age also is critical.

In the early stages of dementia the signs and symptoms may be characteristic of many different causes of dementia. Several different tests may need to be conducted to determine the type and cause of the dementia.

NOTE: There is no single "test" for dementia... diagnosis is still a clinical judgment.

Most dementias progress very slowly, contributing to a failure to recognize early changes. However, prompt intervention and treatment has been shown to help slow the effects of dementia, so early diagnosis is important. Let's take a look at how dementia may be diagnosed.

A medical evaluation for dementia may include the following:

1. Assessment of clinical features, including review of history or onset of symptoms
2. Medical history and medications
3. Mental status testing (also called cognitive or neuropsychological testing)
4. Laboratory tests to rule out vitamin deficiencies or metabolic conditions
5. Neurologic examination
6. Brain imaging

## **Assessment of Clinical Features**

The medical assessment often begins with an assessment of clinical features, including review of history or onset of symptoms. The patient will be asked to describe his/her subjective memory observations and complaints. This assessment usually includes comments from family members or caregivers describing the behaviors they are seeing.

## **Medical History and Medications**

The patient will receive a complete medical history, including a thorough physical exam. The medical history includes a complete listing of drugs being taken, since a number of drugs can cause dementia-like symptoms. A family history of dementia, Alzheimer's disease, or cerebrovascular disease may provide clues to the cause of symptoms.

## **Patient History**

A thorough patient history includes:

- Patient's identifying information
- Chief complaint
- History of current illness
- Past medical history
- Current health status
- Psychosocial history (marital status, living conditions, employment, sexual history, significant life events)
- Mental status
- Family history (including any illnesses that seem to run in the family)
- Review of symptoms

## **Physical Exam**

The physical exam includes examination of:

- Vital signs (temperature, blood pressure, pulse)

- Height and weight
- Skin
- Head, eyes, ears, nose
- Throat/neck
- Chest, including lungs and heart
- Breasts
- Abdomen
- Bones and muscles
- Nerves
- Rectal/genital area

A physical examination should also include an assessment of cognitive domains, including speech (aphasia), motor memory (apraxia), sensory recognition (agnosia), and complex behavior sequencing (executive functioning). Let's look at some testing examples for each of the above assessments.

Testing examples:

*Aphasia* may be detected by asking the patient to name body parts or objects in the room.

*Apraxia* may be detected by asking the patient to pantomime the use of a common object, such as a toothbrush.

*Agnosia* may be evaluated by first asking the patient to close his/her eyes, place an object (such as a key) in the patient's hand, and ask the patient to identify it without looking at it.

*Executive function* may be evaluated by asking the patient to perform a series of simple tasks. For example, ask the patient to count backwards (serial subtraction) by 7s from 100 to 65.

## **Mental Status Testing**

One of the first assessments will be mental status testing, also called cognitive or neuropsychological testing. A mental status test is taken to check the range of intellectual functions such as memory, the ability to read, write, and calculate which may be affected by dementia. A common assessment is the Mini-Mental State Examination (MMSE). Psychiatric assessments may also be conducted to identify other disorders that may mimic dementia, such as depression, and to manage psychiatric symptoms such as anxiety or delusions that may occur alongside dementia.

The Mini-Mental State Examination (MMSE) is frequently given to assess cognitive function and document subsequent decline. It is NOT diagnostic of dementia, and does not distinguish well between various confusion states. It does NOT assess judgment and insight, so other questions need to be asked to assess these aspects of cognition.

The MMSE is a research-based set of questions that provides a score about a person's general level of impairment. The Min Mental State Exam is generally a reliable, valid measure of cognitive impairment. However, highly educated people tend to score higher on the MMSE even if they have a dementia. The MMSE take only 5 to 10 minutes to complete. Although it might seem like a simple procedure, only trained clinicians – such as physicians, nurses, and psychologists – should give and score the MMSE.

The MMSE is a brief 30-point questionnaire test that is used to screen for cognitive impairment. It asks questions that assess five areas:

- Orientation
- Short-Term Memory (Retention)
- Attention and Calculation
- Short-Term Memory (Recall)
- Language

## **Laboratory Tests**

The most common laboratory tests are blood tests and a urinalysis. Blood tests involve a series of tests routinely done on blood to look for abnormalities associated with various diseases and disorders. Blood tests also may be used to look for the presence of a specific gene that has been identified as a risk factor for Alzheimer's disease.

Urinalysis is a test in which a urine sample is evaluated to detect abnormalities, such as improper levels of sugar or protein. A urinalysis may be used by the doctor to help rule out other disorders that may be causing symptoms similar to those of dementia.

In addition to lab tests, other tests may be ordered. For example:

- A chest x-ray may be ordered to assess the presence of pneumonia, tuberculosis, or other underlying disease that may be related to the dementia symptoms.
- An electrocardiogram (ECG or EKG) may be ordered to assess any underlying heart conditions by measuring the electrical activity of the heart.

## **Neurologic Examination**

Some neurologic tests may help doctors with diagnosis. For example, in a neurological exam the doctor may detect slowing of particular eye movements, changes in the typical reflexes, and muscle stiffness or slowness.

## **Brain Imaging**

A variety of brain imaging tests may be ordered. Here are some examples:

- Computed tomography (CT or CAT) scan
- Magnetic resonance imaging (MRI)
- Electroencephalography (EEG)
- Positron emission tomography (PET) scan
- Single photon emission computed tomography (SPECT) scan
- Magnetic resonance spectroscopyimaging (MRSI)

### **Computed Tomography (CT or CAT) Scan**

Multiple X-rays of the body are taken from different angles in a very short period of time. Images are then fed into a computer, which creates a series of cross-sectional “slices” of the body. CT scans often can reveal certain changes that are characteristic of dementias in later stages. These changes include a reduction in the size of the brain (atrophy), widened indentations in the tissue and enlargement of the fluid-filled chambers called cerebral ventricles.

### **Magnetic Resonance Imaging (MRI)**

MRI produces very clear pictures, or images, of the human body without using X-rays. MRI uses a large magnet, radio waves and a computer to produce these images. MRI is beneficial in ruling out other causes of dementia, such as tumors or strokes. It also may help to show the physical and functional changes in the brain that are associated with Alzheimer’s disease.

### **Electroencephalography (EEG)**

This measures brain function by analyzing the electrical activity generated by the brain. It measured through special electrodes applied to the scalp and is a completely non-invasive procedure. Electroencephalography often is used to study various brain processes, such as perception, memory, attention, language and emotion and is most helpful in identifying disorders which can mimic dementia.

### **Positron Emission Tomography (PET) Scan**

PET scan is a non-invasive, three-dimensional imaging technique. PET scans also can show how the organs are functioning; unlike X-ray, CT or MRI, which show only body structure. PET imaging can show the region of the brain that is causing a patient to have seizures, and is useful in evaluating degenerative brain disease such as Alzheimer’s, Huntington’s and Parkinson’s. PET scans can show the difference in brain activity between a normal brain and one affected by



Alzheimer's disease. PET can also help differentiate Alzheimer's disease from other forms of dementia.

### **Single Photon Emission Computed Tomography (SPECT) Scan**

SPECT scans use radionuclide imaging – a technique that involves the injection of a very small amount of a radioactive substance called tracer. Energy from the tracer in the body is detected by a special camera, which then takes the pictures. SPECT can map blood flow in certain regions of the brain, and is useful in evaluating specific brain functions. This may reveal abnormalities that are characteristic of dementia.

### **Magnetic Resonance Spectroscopy Imaging (MRSI)**

MRSI allows the doctor to observe certain substances throughout the brain without the use of radioactive materials. It is used to study metabolic changes in brain tumors, strokes, seizure disorders, Alzheimer's disease, depression and other diseases affecting the brain. MRSI can be done as part of a routine MRI, but they are different tests. An MRI creates an image, and an MRSI creates a graph of the types and quantity of chemicals in the brain or other organs.

As you can see, a wide variety of diagnostic tests are available to help doctors make a differential diagnosis and begin appropriate treatment.

Here are some very brief examples of how test results may begin to indicate a specific type of dementia:

- Impairment in recent memory: ALZHEIMER'S
- Associated with parkinsonism: LEWY BODY
- Abrupt onset of deficits with stroke: VASCULAR
- Dominant language or judgment deficits: FRONTAL LOBE
- Very characteristic "magnetic gait" disorder: NORMAL PRESSURE HYDROCEPHALUS
- Frontotemporal lobe degeneration and behavioral symptoms: PICK'S DISEASE

## **ALZHEIMER'S DISEASE**

Alzheimer's disease (AD) is an irreversible, progressive brain disease that slowly destroys memory and thinking skills, and eventually even the ability to carry out the simplest tasks. In most people with AD, symptoms first appear after age 60. AD is the most common cause of dementia among older people. Although we still do not know what starts the AD process, we do know that damage to the brain begins as many as 10 to 20 years before any problems are evident.

Memory problems are one of the first signs of AD. Note: some people with memory problems have a condition called amnesic mild cognitive impairment (MCI). People with MCI have more memory problems than normal for people their age, but their symptoms are not as severe as those with AD. More people with MCI, compared with those without MCI, go on to develop AD.

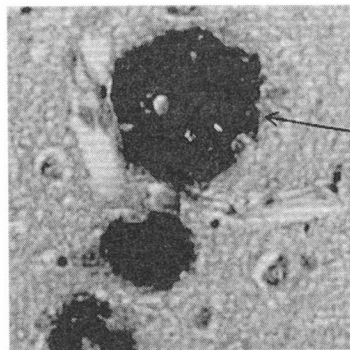
Alzheimer's disease disrupts critical metabolic processes that keep neurons (nerve cells) in the brain healthy. These disruptions cause nerve cells in the brain to stop working, lose connections with other nerve cells, and finally die. The destruction and death of nerve cells causes the memory failure, personality changes, problems in carrying out daily activities, and other features of the disease.

Alzheimer's disease is thought to be caused by changes in the brain characterized by amyloid plaques and tangled bundles of fibers (called neurofibrillary tangles). Plaques and tangles in the brain are two of the main features of AD. The third is the loss of connections between nerve cells (neurons) in the brain.

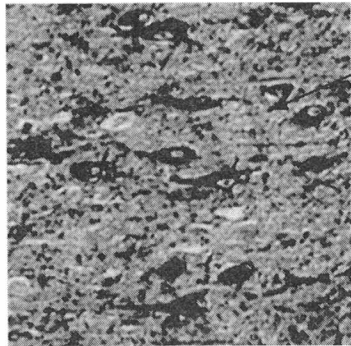
### **PLAQUES AND TANGLES**

Build up of plaques and tangles in the brain lead to death of neurons (nerve cells in the brain). Plaques are made up of amyloid protein. Tangles are insoluble twisted fibers that build up inside the neuron.

## HALLMARKS OF ALZHEIMER'S DISEASE

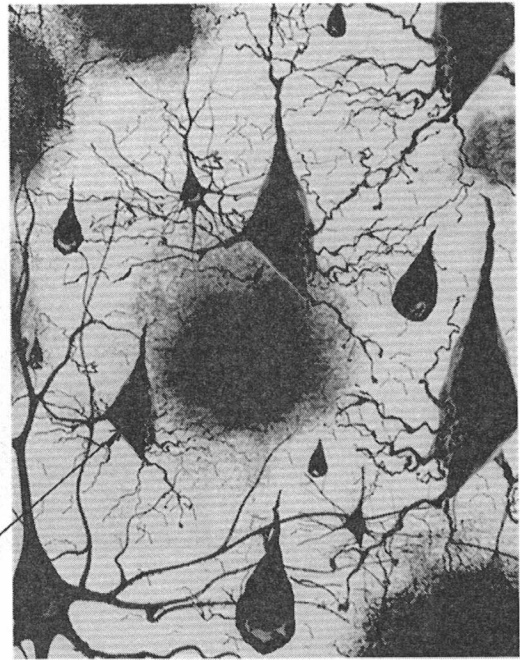


Amyloid plaques



Neurofibrillary tangles

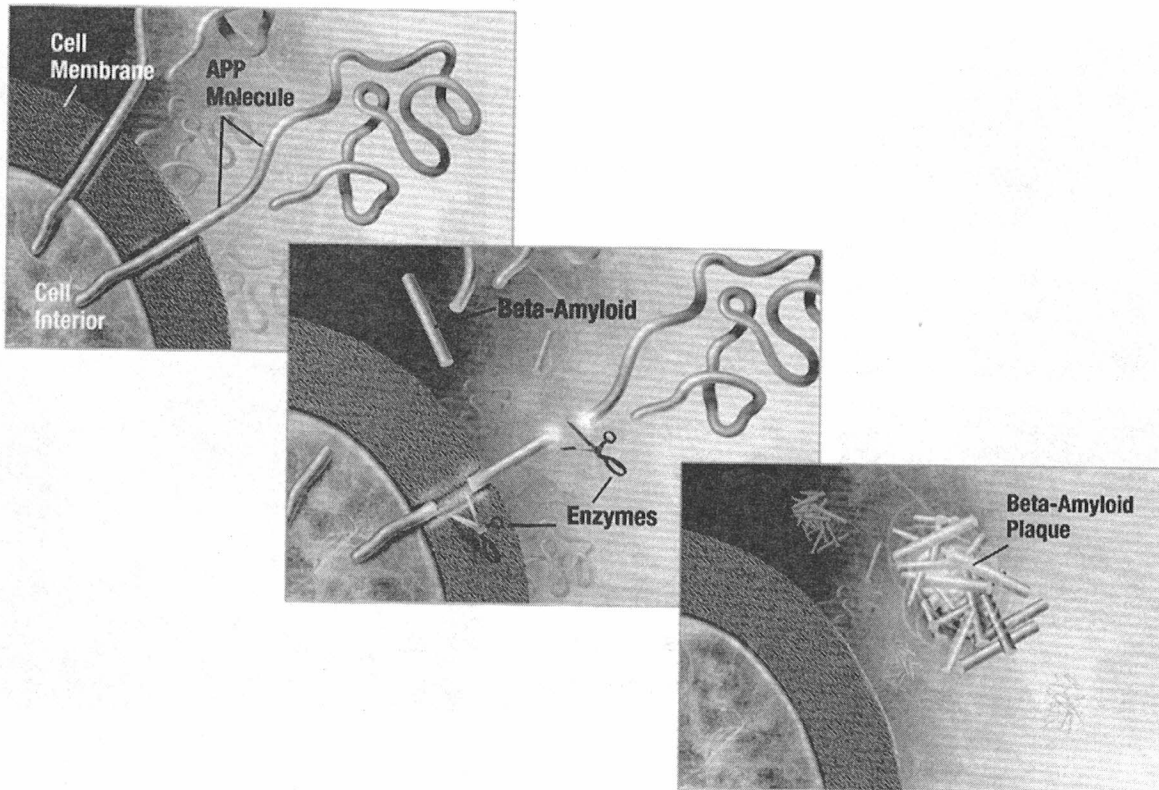
Cell death of neurons (nerve cells) in the brain



### Amyloid Plaques

Amyloid plaques are made of beta-amyloid, a protein fragment snipped from a larger protein called amyloid precursor protein (APP). APP is a protein that appears to be important in helping neurons grow and survive. APP may help damaged neurons repair themselves and may help parts of neurons grow after brain injury. In AD, something causes APP to be snipped into fragments, one of which is called beta-amyloid; the beta-amyloid fragments eventually clump together into plaques.

# Amyloid Precursor Protein (APP)

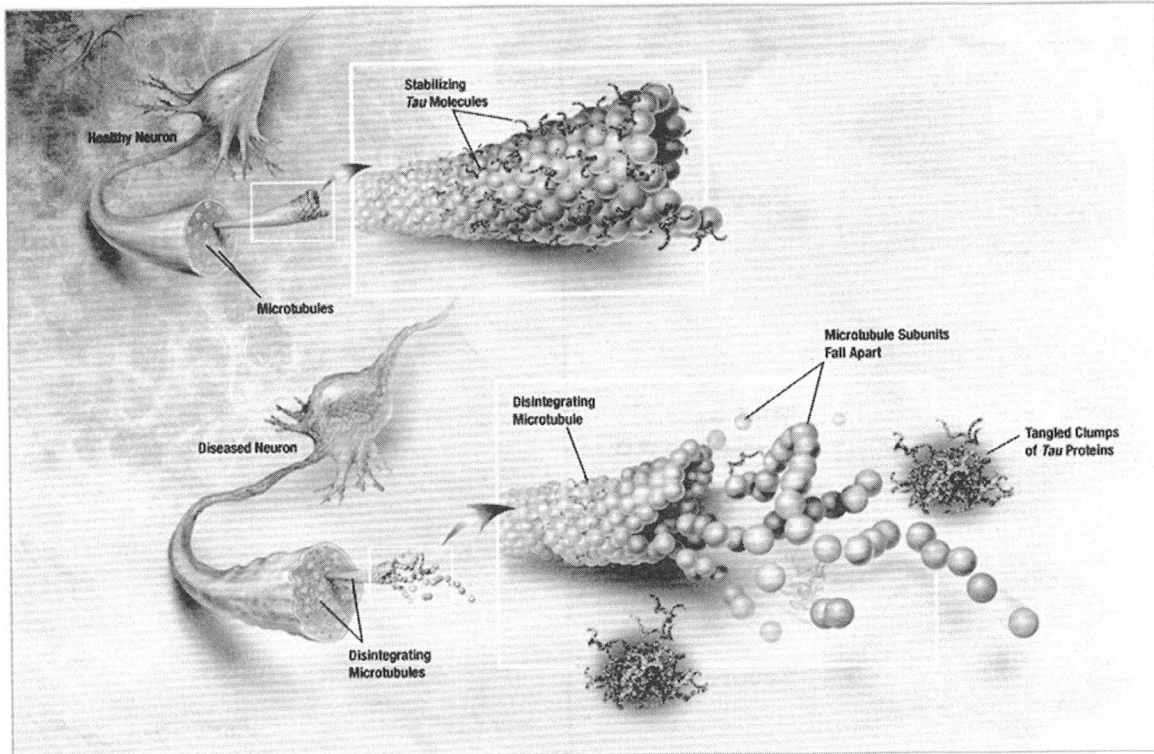


Fragments clump together and are mixed with other molecules, neurons, and non-nerve cells forming the "plaques." In AD, plaques develop first in the hippocampus, a structure deep in the brain that helps to encode memories, and then progress into other areas of the cerebral cortex that are used in thinking and making decisions. It is still unclear whether beta-amyloid plaques themselves cause AD or whether they are a by-product of the AD process.

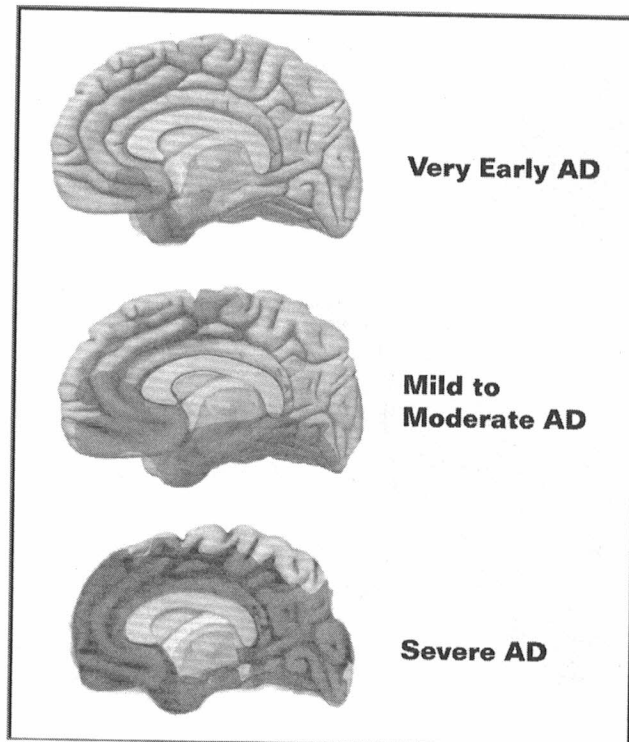
## Neurofibrillary Tangles

Healthy neurons have an internal support structure partly made up of structures called microtubules. Microtubules act like tracks, guiding nutrients and molecules from the body of the cell down to the ends of the axon and back. A special kind of protein, *tau*, makes the microtubules stable. In AD, *tau* is changed chemically becoming tangled. When this happens, the microtubules disintegrate, collapsing the neuron's transport system. This may result first in malfunctions in communication between neurons and later in the death of the cells.

# Neurofibrillary Tangles



As Alzheimer's disease progresses, neurofibrillary tangles spread throughout the brain (shown in shadow portion). Plaques also spread throughout the brain, starting in the neocortex. By the final stage, damage is widespread and the brain tissue has shrunk significantly.

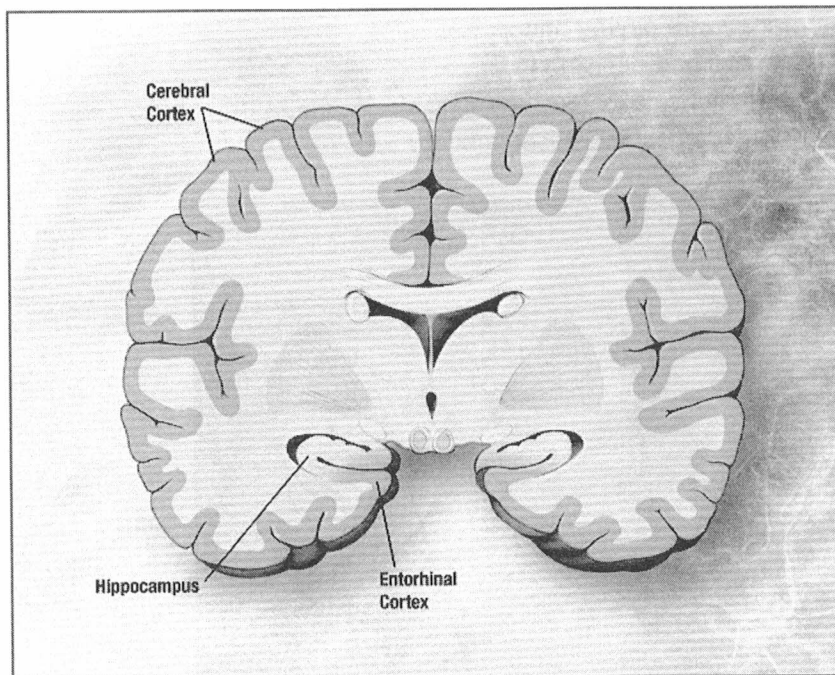


## **ALZHEIMER'S DISEASE: CHANGES IN THE BRAIN**

Now that you have an idea about what happens at the cellular level in Alzheimer's disease, let's take a look at how the disease progresses. This section will discuss how the disease affects the different portions of the brain and the clinical signs and symptoms that you can observe.

## CHANGES IN THE BRAIN: PRECLINICAL

Alzheimer's disease begins in the entorhinal cortex which lies deep in the brain. Then, the disease proceeds to the hippocampus, the structure that is essential to the formation of short-term and long-term memories. As the cells die, the affected regions begin to atrophy (shrink).



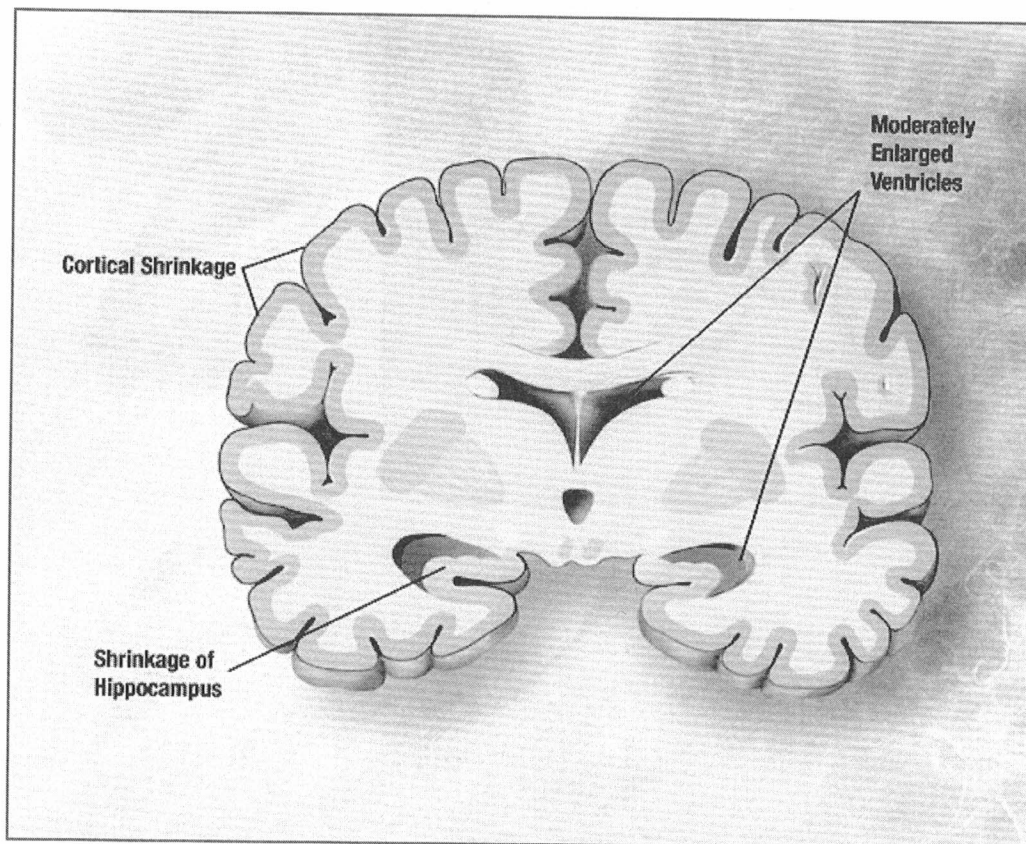


## CHANGES IN THE BRAIN: MILD ALZHEIMER'S DISEASE

As the disease begins to affect the cerebral cortex, memory loss continues and changes in other cognitive abilities emerge. The clinical diagnosis of AD is usually made during this stage.

Signs of mild AD can include:

- Memory loss
- Confusion about the location of familiar places (getting lost begins to occur)
- Taking longer to accomplish normal daily tasks
- Trouble handling money and paying bills
- Poor judgment leading to bad decisions
- Loss of spontaneity and sense of initiative
- Mood and personality changes; increased anxiety





## **CHANGES IN THE BRAIN: MODERATE ALZHEIMER'S**

In moderate Alzheimer's disease the damage has spread further to the areas of the cerebral cortex that control language, reasoning, sensory processing, and conscious thought. Affected regions continue to atrophy and signs and symptoms of the disease become more pronounced and widespread. Behavior problems, such as wandering and agitation, can occur. More intensive supervision and care become necessary, and this can be difficult for many spouses and families.

Symptoms at the moderate stage can include:

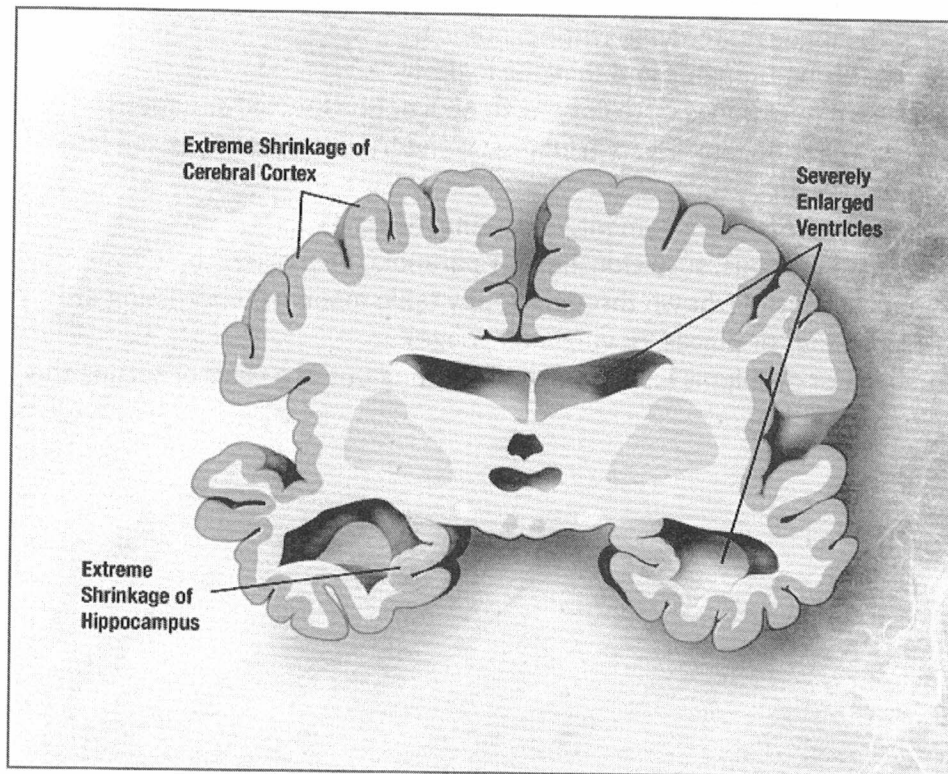
- Increasing memory loss and confusion
- Shortened attention span
- Problems recognizing friends and family members
- Difficulty with language; reading, writing, numbers
- Difficulty organizing thoughts and thinking logically
- Inability to learn new things or to cope with new or unexpected situations
- Restlessness, agitation, anxiety, tearfulness, wandering - especially in the late afternoon or at night
- Repetitive statements or movement, occasional twitches
- Hallucinations, delusions, suspiciousness or paranoia, irritability
- Loss of impulse control (shown through sloppy table manners, undressing at inappropriate times or places, or vulgar language)
- Perceptual-motor problems (such as trouble getting out of a chair or setting the table)

## CHANGES IN THE BRAIN: SEVERE ALZHEIMER'S

Changes in the brain with severe Alzheimer's disease are pronounced.

- Plaques and tangles are widespread throughout the brain.
- Areas of the brain have atrophied further.
- Residents cannot recognize family and loved ones or communicate in any way.
- Residents become completely dependent on others for care.
- All sense of self seems to vanish.

Below is an example of the changes in the brain during severe Alzheimer's stage.



## RISK FACTORS FOR ALZHEIMER'S DISEASE

Several factors increase a person's risk for Alzheimer's disease. We are going to discuss 8 of the most commonly noted factors:

- Age
- Family history
- Heredity (Genetics)
- Sex
- Mild cognitive impairment
- Lifestyle
- Education level
- Head injury

**Age:** The greatest known risk factor for Alzheimer's is increasing age. Most individuals with the disease are 65 or older. The likelihood of developing Alzheimer's doubles about every five years after age 65. After age 85, the risk reaches nearly 50 percent.

**Family History:** Another risk factor is family history. Research has shown that those who have a parent, brother or sister, or child with Alzheimer's are more likely to develop Alzheimer's. The risk increases if more than one family member has the illness. When diseases tend to run in families, either heredity (genetics) or environmental factors or both may play a role.

**Genetics:** Another risk factor is genetics. There are two categories of genes that can play a role in determining whether a person develops a disease. Alzheimer genes have been found in both categories:

1. Risk genes increase the likelihood of developing a disease, but do not guarantee it will happen.
  - Scientists have so far identified one Alzheimer risk gene called apolipoprotein E-e4 (APOE-e4).
  - Much research is being conducted on APOE-e4.
2. Deterministic genes directly cause a disease, guaranteeing that anyone who inherits them will develop the disorder.
  - Scientists have found rare genes that directly cause Alzheimer's in only a few hundred extended families worldwide.
  - When Alzheimer's disease is caused by deterministic genes, it is called "familial Alzheimer's disease."
  - True familial Alzheimer's accounts for less than 5 percent of cases.

**Sex:** Women are more likely than men are to develop the disease, in part because they live longer.

**Mild Cognitive Impairment (MCI):** People who have mild cognitive impairment have memory problems that are worse than what might be expected for people of their age, yet not bad enough to be classified as dementia. It has been found that a higher number of persons who have MCI will go on to develop Alzheimer's disease.

**Lifestyle:** It has been found that certain lifestyle related conditions that put a person at a higher risk for heart disease also increases his/her risk of Alzheimer's disease. Specifically, the following lifestyle factors are linked to a higher likelihood of AD:

- High blood pressure
- High cholesterol
- Poorly controlled diabetes

**Education level:** Studies have found an association between less education and the risk of Alzheimer's. But the precise reason why this occurs is unknown. It may be that the more you use your brain, the more synapses you create, so you have a greater reserve as you age. Or, Alzheimer's may just be harder to detect in those who exercise their minds frequently or who have more education.

**Head injury:** There appears to be a strong link between serious head injury and future risk of Alzheimer's. Protect your head by keeping your seat belt buckled, always wear a helmet when participating in sports, and use common sense to prevent falls and head injuries.

## **FOOD AND DEMENTIA**

In recent years, investigators have performed studies to explore whether diet can play a role in preserving cognitive function or even reducing risk of AD.

A nutritious diet rich in fruits, vegetables, and whole grains and that is low in fat and added sugar can reduce the risks of many chronic conditions, including heart disease, diabetes, obesity, and some forms of cancer. Researchers also search to find links between foods and dementia.

A long-held theory about aging suggests that, over time, damage from free radicals (molecules that chemically react easily with other molecules) can build up in neurons, causing loss of function. This damage is called oxidative damage. The brain's unique characteristics, including its high rate of metabolism and its long-lived neurons, may make it particularly vulnerable to oxidative damage. Previous epidemiologic and laboratory studies have suggested that fruits and vegetables that are high in antioxidants might protect the brain against this kind of damage.

A group of Harvard Medical School researchers explored this possibility by examining data from more than 13, 000 Nurses' Health Study participants aged 70 and older. They found that the women who ate the most vegetables – especially green leafy vegetables (like spinach and romaine lettuce) and cruciferous vegetables (like broccoli and cauliflower) – experienced a slower rate of cognitive decline than did women who ate the least vegetables.

### **Curcumin**

Curcumin is the main ingredient of turmeric, a bright yellow spice used in curry. Scientists are extremely interested in this compound because it has powerful anti-inflammatory and antioxidant properties and can suppress the accumulation of beta-amyloid in brain tissue.

### **Fish Oil**

Another possible link with diet and dementia is the omega-3 fatty acid called docosahexaenoic acid (DHA), which is found in abundance in some kinds of fish. DHA is a primary component of the membranes of nerve cells in the brain and is involved in multiple brain functions, including nerve cell communication. DHA is reduced in the brains of people with AD, and some evidence suggest that higher levels of DHA in the blood may be protective for dementia and AD.

An ongoing trial is examining whether treatment with DHA, and omega-3 fatty acid found in fish, will slow cognitive decline in AD.

## **Weight Management**

Evidence increasingly suggests that overweight and obesity may increase AD risk.

Research conducted at the Kaiser Permanente Division of Research in Oakland, California investigators found:

- Participants who were obese (a body mass index of 30 or more) during midlife had a threefold increase in AD risk.
- Participants who were overweight (a body mass index of 25 to 29) had a twofold increase in AD risk.

In the second study, Boston University School of Medicine researchers concluded that controlling abdominal obesity and hypertension in midlife may help reduce the risk of cognitive problems and dementia in later life.

As with other areas of research into lifestyle factors and AD, we have tantalizing hints about particular dietary components, but few firm conclusions about diet as a whole and its relationship to cognitive decline and AD. One reason for this is the complexity of the diet. Because person's diet has numerous components and varies from day to day, researchers often must rely on supplements to isolate particular factors. Nutrient supplements on their own are not the same as nutrients within the context of whole foods, however, so caution is in order when applying these results to actual dietary patterns.

## **BRAIN EXERCISES**

The phrase "use it or lose it" may make you think of your muscles, but scientists who study brain health in older people have found that it may apply to cognitive skills as well. Multi-site trials (the Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE) study) are designed to test the effects of cognitive training in older adults.

### **ACTIVE STUDY**

The multi-site Advanced Cognitive Training for Independent and Vital Elderly (ACTIVE) study is designed to test the effects of brief cognitive training in older adults. In the *2005 – 2006 Report*, study results included 2,802 healthy adults age 65 and older took part in computer-based training sessions that targeted a specific cognitive ability – memory, reasoning, and speed of processing (in other words, how fast participants could respond to prompts on a computer screen). They found that the improvements from the training roughly counteracted the degree of decline in cognitive performance that would be expected over a 7 – to 14-year period among older people without dementia.

#### Recent Update:

Additional ACTIVE studies summarized in the *2007 Report* suggests that older adults with pre-existing mild memory impairment may not benefit from memory training as much as those with normal memory function, but they benefit just as much from certain forms of cognitive training that do not rely on memorization. This training may be able to improve the ability of older adults to maintain skills that allow them to carry out daily and lead a higher quality of life.



Learning Exercise:

***DEMENCIA SPECIALTY TRAINING: Check for Understanding***

**Which of the following do researchers think may have an impact on dementia and/or Alzheimer's disease?**

- A. Stress
- B. Exercise
- C. Sleep
- D. Diet
- E. All of the above
- F. None of the above; these factors are only related to cardiovascular disease

**Explain your answer:**



## **METABOLIC DISEASE**

As we have seen with exercise and diet, evidence suggests that what may be good for the heart may be good for the brain. Moreover, metabolic changes that occur in a variety of chronic diseases of aging, such as heart disease, stroke, high blood pressure, and diabetes, may contribute to the development of AD, affect the severity of AD, or cause vascular dementia.

Recent findings linking health conditions and dementia:

- At least four long-term studies have linked diabetes with a decline in cognitive function. In one of these studies, a Columbia University research team found that diabetes was associated with a significantly increased risk of a MCI as well as other types of MCI.

## **VASCULAR DYSFUNCTION MAY BE A KEY ELEMENT IN AD**

Even though the brain makes up only 2 percent of the body's mass, it receives 20 percent of the body's blood flow. The blood delivers oxygen and glucose to neurons. Maintaining a constant and adequate blood flow in the brain is essential for neuronal survival and brain function, and decreased blood flow in parts of the brain affected by AD is an early feature of the disease.

## **CARDIOVASCULAR DISEASE AND AD**

Investigators with the Memory and Aging Project examined the brain tissue of deceased participants. Results showed that about one-third of the participants had evidence of strokes, which increased the odds of having AD-related reductions in memory function.

This has lead NIA to support several clinical trials to explore issues related to the association between heart disease risk and AD, including:

- Simvastatin and AD progression
- Supplements to reduce homocysteine and slow the rate of the cognitive decline
- The ongoing clinical trial, ACCORD-MIND, will examine if interventions to reduce cardiovascular disease (glucose, blood pressure, and lipid management) can reduce rates of cognitive decline.

## **DIABETES AND AD**

The possible association of diabetes, insulin processing, and AD also is generating much interest among AD investigators. A number of epidemiologic studies have suggested that people with diabetes have an increased risk of late-life cognitive problems, including MCI and AD, either as a direct result of high levels of blood sugar (hyperglycemia) or because of the conditions that are often associated with diabetes, namely high blood pressure, abnormal blood cholesterol levels, or too much insulin in the blood.

## **INFLAMMATION AND AD**

Several studies are being conducted to investigate the relationship between inflammation and AD.

Scientists at the University of North Dakota School of Medicine and Health Sciences have been investigating cytokines, a substance secreted by immune cells during the body's response to inflammation. The investigators found that a cytokine which is present in the brain during an inflammatory response can begin a process in nerve cells that ultimately leads to cell death. These findings may help explain one mechanism leading to cell death in AD and related diseases.

## **GENETICS**

Genetic studies of complex neurodegenerative diseases such as AD have focused on two key issues:

- Whether a gene might influence a person's overall risk of developing a disease, and
- Whether a gene might influence some particular aspect of a person's risk, such as the age at which the disease begins.

## **AD IN PERSONS WITH DOWN SYNDROME**

Individuals with trisomy 21, or Down syndrome (DS), develop a clinical syndrome of dementia that has almost identical and neuropathologic characteristics of AD as described in individuals without DS. The main difference is the early age of onset of AD in individuals with DS. DS patients present with clinical symptoms in their late 40s or early 50s. Mean age at the time of clinical diagnosis is  $51 \pm 6$  years.

### **Why Do People With Down Syndrome Get Alzheimer's Disease?**

Current research shows that the extra "gene dosage" caused by the abnormal third chromosome of Down syndrome may be a factor in the development of Alzheimer's disease. The early aging of the Down syndrome brain may also be a factor. People with Down syndrome show physical changes related to aging about 20 to 30 years of people of the same age in the general population.

Several studies document that most if not all individuals with DS develop AD. This is unrelated to the degree of mental retardation; AD is not more prominent in individuals with mental retardation from other causes. Due to better clinical management, most persons with DS now reach the age of 40 years. Thus, the frequency of AD is likely to increase.

The percentage of people with DS and AD varies in some of the epidemiologic studies presented. A review of these studies showed:

- 10 -25% of patients had AD when aged 40-49 years
- 20- 50% had AD when aged 50 -59 years
- 60 -75% had AD when older than 65 years

## **GENES AND EARLY-ONSET AD**

In the early days of AD genetics research, scientists realized that some cases, particularly of the rare early-onset AD, ran in families. This led them to examine DNA samples from these families to see whether they had some genetic trait in common. Chromosomes 21, 14, and 1 became the focus of attention. Mutations in these three genes are linked to early-onset form of familial AD.

Early-onset AD is very rare, and mutations in these three genes do not play a role in the more common late-onset AD. However, these findings were crucial because they showed that genetics was indeed a factor in AD, and they helped to identify some key cell pathways involved in the AD disease process.

Until recently, only four of the approximately 30,000 genes in the human genome were conclusively shown to affect the development of AD (first three mentioned previously with early onset AD). The fourth gene, APOE contains a form ( $\epsilon 4$ ) that is a known risk factor of the common late-onset form of AD. It may be that having APOE  $\epsilon 4$  not only increases the risk of AD, but also leads to poorer outcomes in those who do not yet have symptoms of the disease. People who have two copies of the APOE  $\epsilon 4$  allele may be at high risk than people with only one copy.

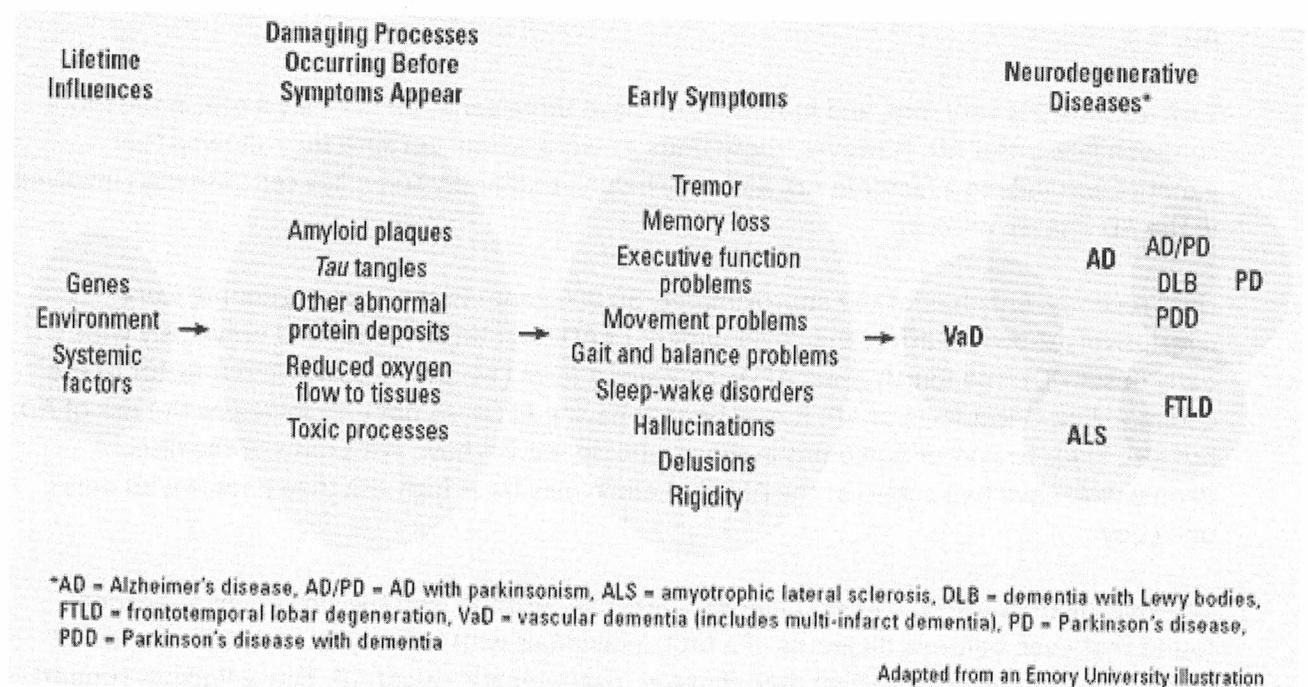
The investigators with the Mayo Clinic in Scottsdale, Arizona, and the University of Arizona found that even before a diagnosis of a MCI, individuals with two copies of APOE  $\epsilon 4$  showed higher rates of cognitive decline than those at lower genetic risk of AD. These findings support the notion of a pre-symptomatic state of disease, the identification of which might aid in early detection and diagnosis of AD among people at increased genetic risk. Scientists have yet to understand the steps in that process. Many think that it involves an interaction between genetic and environmental factors, such as high levels of stress.

In 2007, scientists unveiled their discovery of one new AD risk-factor gene. This AD risk-factor gene is called SORL1. It is involved in recycling APP from the surface of cells, and its association with AD was identified and confirmed in three separate studies. Studies are ongoing to clarify SORL1's role in the AD process.

## RELATED NEURODEGENERATIVE DISEASES

Researchers explore neurodegenerative “cousins”. Neurodegenerative diseases like AD, Parkinson’s disease, amyotrophic lateral sclerosis (ALS), and dementia with Lewy bodies share more than the basic characteristic of misfolded proteins. They also share clinical characteristics. For example, sleep-wake disorders, delusions, psychiatric disturbances, and memory loss occur in all of these diseases. These diseases also result from a combination of genetic, lifestyle, and environmental causes and they develop over many years.

By investigating the unique characteristics of these diseases as well as the characteristics they share, scientists hope to learn even more than they would if they focused on each disease by itself. The graphic below may be linked as well as what makes them unique.



Scientists at the University of Pennsylvania School of Medicine identified, for the first time, a protein called TDP-43 as a component of the protein aggregates that form in ALS and in some forms of frontotemporal dementia. Finding the same molecular signature in the two diseases suggests that they may represent different facets of the same neurodegenerative disorder. Research at the University of Texas Southwestern Medical Center on ApoE (a genetic risk factor implicated in AD) suggests that AD and Parkinson’s disease may share a molecular link.

## OTHER RESEARCH

Other research and clinical trials are investigating the following and others:

- Genetics and AD
- Similar neurodegenerative diseases
- Caregivers and AD
- Immunization for AD
- Home-based assessment for cognition, daily functioning, mood and other factors.
- Anti-inflammatory medication and AD
- Depression, agitation, and other behavioral concerns in AD
- Estrogen and AD progression
- Insulin and cognitive decline

Question: What Causes Alzheimer's Disease?

The answer to that question depends on what form of Alzheimer's disease you are talking about: "early-onset" or "late-onset" AD. The exact cause of late-onset AD is still unknown; however researchers believe the causes probably include the following:

- Genetic factors
- Environmental factors
- Lifestyle factors
- Others

The importance of these factors in increasing or decreasing the risk of developing AD differs from person to person.

Perhaps the greatest mystery is why AD largely strikes the elderly. Why does it take 30-50 years for people to develop signs of the disease? It is possible that the processes that cause AD happen slowly and simply take a long time to reach a critical magnitude? Is it possible that the environment of the aging brain is subtly different from that of the young brain? Research on how the brain changes normally as people age will help provide answers.



Learning Exercise:

***DEMENTIA SPECIALTY TRAINING: Check for Understanding***

**Researchers are finding the people with diabetes may be at higher risk for Alzheimer's disease and other dementias.**

- A. True
- B. False

**Explain your answer:**

## CURRENT MEDICATIONS

Only four medications have been approved by the U.S. Food and Drug Administration (FDA) to help control the cognitive loss that characterizes AD. The first three, known as cholinesterase inhibitors, work by stopping or slowing the action of acetylcholinesterase, an enzyme that breaks down acetylcholine. They are prescribed to treat mild to moderate AD symptoms:

- donepezil (Aricept<sup>®</sup>) (also approved for severe AD as well)
- rivastigmine (Exelon<sup>®</sup>)
- galantamine (Razadyne<sup>®</sup>)

Another drug, Cognex<sup>®</sup> (tacrine), an early cholinesterase inhibitor medication is rarely prescribed today due to safety concerns.

Scientists do not yet fully understand how cholinesterase inhibitors work to treat AD, but research indicates that they prevent the breakdown of acetylcholine, a brain chemical believed to be important for memory and thinking. As AD progresses, the brain produces less and less acetylcholine; therefore, cholinesterase inhibitors may eventually lose their effect. No published study directly compares these drugs. Because they work in a similar way, switching from one of these drugs to another probably will not produce significantly different results. However, an AD patient may respond better to one drug than another.

The newest approved medication is memantine (Namenda<sup>®</sup>), which is prescribed to treat moderate to severe AD symptoms. Namenda<sup>®</sup> is believed to work by regulating glutamate, another neurotransmitter involved in memory function. When produced in excessive amounts, glutamate may lead to brain cell death. Like the cholinesterase inhibitors, memantine also does not stop or reverse AD.

Because NMDA antagonists, such as Namenda<sup>®</sup>, work very differently from cholinesterase inhibitors, the two types of drugs can be prescribed in combination. The FDA has also approved Aricept<sup>®</sup> for the treatment of moderate to severe AD.

## Dosage and Side Effects

Doctors usually start patients at low drug doses and gradually increase the dosage based on how well a patient tolerates the drug. There is some evidence that certain patients may benefit from higher doses of the cholinesterase inhibitors. However, the higher the dose, the more likely are side effects. The recommended effective dosages of drugs prescribed to treat the symptoms of AD and the drugs' possible side effects are summarized in the tables on the next two pages.

DRUG NAME	DRUG TYPE AND USE	HOW IT WORKS
<b>Razadyne® (galantamine)</b>	Cholinesterase inhibitor prescribed to treat symptoms of mild to moderate AD	Prevents the breakdown of acetylcholine and stimulates nicotinic receptors to release more acetylcholine in the brain
<b>Exelon® (rivastigmine)</b>	Cholinesterase inhibitor prescribed to treat symptoms of mild to moderate AD	Prevents the breakdown of acetylcholine and butyrylcholine (a brain chemical similar to acetylcholine) in the brain
<b>Aricept® (donepezil)</b>	Cholinesterase inhibitor prescribed to treat symptoms of mild to moderate, and moderate to severe AD	Prevents the breakdown of acetylcholine in the brain

Chart from: National Institute on Aging. Retrieved from  
<http://www.nia.nih.gov/Alzheimers/Publications/medicationsfs.htm>



DRUG NAME	DRUG TYPE AND USE	HOW IT WORKS
<b>Namenda® (memantine)</b>	N-methyl D-aspartate (NMDA) antagonist prescribed to treat symptoms of moderate to severe AD	Blocks the toxic effects associated with excess glutamate and regulates glutamate activation
DRUG NAME	MANUFACTURER'S RECOMMENDED DOSAGE	FOR MORE INFORMATION
<b>Namenda® (memantine)</b>	<ul style="list-style-type: none"> <li>Initial dose: 5-mg tablet once a day</li> <li>May increase dose to 10 mg/day (5 mg twice a day), 15 mg/day (5 mg and 10 mg as separate doses), and 20 mg/day (10 mg twice a day) at minimum 1-week intervals if well tolerated</li> <li>Also available as oral solution; same dosage as above</li> </ul>	For current information about this drug's safety and use, visit <a href="http://www.namenda.com">www.namenda.com</a> . Click on "Prescribing Information" to see the drug label.

Chart from: National Institute on Aging. Retrieved from <http://www.nia.nih.gov/Alzheimers/Publications/medicationsfs.htm>

These drugs may improve some person's ability to:

- carry out activities of daily living
- certain thinking, memory, or speaking skills
- help with certain behavioral symptoms

However, they do not stop or reverse Alzheimer's disease.

## NEUROPSYCHIATRIC SYMPTOMS

In addition to these medications, physicians use a number of drug and non-drug approaches to treat the behavioral and psychiatric problems that occur frequently as AD progresses. Between 70 and 90% of people with AD eventually develop one or more behavioral symptoms.

These problems include:

- agitation
- wandering and pacing
- verbal and physical aggression
- depression
- sleeplessness
- hallucinations and delusions

## THE STAGES OF ALZHEIMER'S DISEASE

This section on the Stages of Alzheimer's Disease is adapted from [www.helpguide.org](http://www.helpguide.org) and the Alzheimer's Association. Helpguide was created in 1999 by the Rotary Club of Santa Monica to create a free, non-commercial resource for people in need. Additional information can be found on each of their websites:

- [http://www.helpguide.org/elder/alzheimers\\_disease\\_symptoms\\_stages.htm](http://www.helpguide.org/elder/alzheimers_disease_symptoms_stages.htm)
- [http://www.alz.org/alzheimers\\_disease\\_stages\\_of\\_alzheimers.asp](http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp)

Some organizations, such as the Alzheimer's Association characterize the disease into as many as 7 stages:

- *Stage 1:* No impairment
- *Stage 2:* Very mild cognitive decline (may be normal age-related changes or early AD)
- *Stage 3:* Mild cognitive decline (early stage AD may be able to be detected in some people, but not all)
- *Stage 4:* Moderate cognitive decline ( mild or early-stage Alzheimer's disease; careful medical examinations can detect deficiencies in functioning at this stage)
- *Stage 5:* Moderately severe cognitive decline (Moderate or mid-stage AD; major gaps in cognitive functioning evident)
- *Stage 6:* Severe cognitive decline (Moderately severe or mid-stage AD)
- *Stage 7:* Very severe cognitive decline (Severe or late-stage AD)

Other organizations characterize the stages of Alzheimer's disease into three stages: mild, moderate, and severe. In this course, we are going to describe these three stages of AD. Because the stages overlap, it may difficult to definitively place a person in a particular stage. People vary in the length of time spent in each stage, and in which stage the signs and symptoms appear. However, the progression is always toward a worsening of symptoms.

The stages identify groups of symptoms that reflect an increase in brain decay and subsequent dependence on caregivers. Persons with Alzheimer's disease typically die either from the inability of the brain to keep the body going or by another disease. People with Alzheimer's die an average of four to six years after diagnosis.

If you are a caregiver of a person with AD, you may be wondering what to expect with the disease as it progresses. Understanding the stages of AD can help understand how the disease may unfold and help with making of future plans. The three main stages Alzheimer's have the following characteristics.

## The Main Stages of Alzheimer's Disease

Early-stage Alzheimer's (Mild)	Mid-stage Alzheimer's (Moderate)	Late-stage Alzheimer's (Severe)
Memory loss or other cognitive deficits are noticeable, yet the person can compensate for them and continue to function independently.	Mental abilities decline, the personality changes, and physical problems develop so that the person becomes more and more dependent on caregivers.	Complete deterioration of the personality and loss of control over bodily functions requires total dependence on others for even the most basic activities of daily living.

Apathy is a characteristic at all stages of Alzheimer's disease. More than 40% of people in early-stage Alzheimer's show a lack of interest, initiative, and emotional involvement. In the last stage of Alzheimer's, more than 90% of people are apathetic.

Now, let's take a more detailed look at each of the three stages of Alzheimer's disease.

### Early-stage (mild) Alzheimer's Signs & Symptoms

Early-stage Alzheimer's begins the noticeable cognitive decline. The Alzheimer's sufferer, family, friends, co-workers, and medical practitioners start to notice deficiencies. Memory and concentration problems are evident and measurable by cognitive tests. Communication issues surface. Changes in personality and a few idiosyncratic behaviors begin to appear.

### Early-stage (mild) AD: Brain changes

AD begins deep in the brain, and changes begin in the brain before any clinical symptoms are apparent. Healthy neurons near the hippocampus begin to work less efficiently, lose their ability to communicate, and ultimately die. Affected regions begin to atrophy. Ventricles, the fluid-filled spaces inside the brain, begin to enlarge as the process continues. Researchers are increasingly interested in the very early stages of the disease process. By knowing more about the early stages, they also hope to be able to develop drugs or other treatments that will slow or stop the disease process before significant impairment occurs.

**Early-stage (mild) AD: The cognitive and memory problems that may begin to appear include:**

- Increased confusion
- Word or name-finding problems; might make up words or quit talking to avoid mistakes
- Decreased ability to remember names when introduced to new people.
- Repeats questions, phrases or stories, *in the same conversation*
- Less able to plan, organize, or think logically
- Increasing difficulty with routine tasks such as planning dinner, grocery shopping, paying bills
- Difficulty making decisions; defers to others' choices
- Difficulty with problem solving and math problems
- May become lost in familiar places.
- Trouble concentrating and learning new things; avoids change
- Withdraws from social and mental challenges
- Loses or misplacing valuable objects, including may put things in odd places and forget where they are
- Reduced memory of personal history

**Early-stage (mild) AD: Communication problems that may be observed include:**

- May converse "normally" until a memory lapse occurs
- Begins to have difficulty expressing themselves
- Still able to respond to your emotional reactions and humor
- Reads a passage and retains little material

**Early-stage (mild) AD: Personality changes that may become evident include:**

- May seem apathetic, subdued, and withdrawn, especially in socially or mentally challenging situations
- May become anxious, irritable, agitated
- Easily angered when frustrated, tired, rushed, or surprised

**Early-stage (mild) AD: Idiosyncratic behaviors that may start to develop include:**

- May begin to hoard, check, or search for objects of little value
- May forget to eat, or eat constantly, or eat only one kind of food

When Alzheimer's has been diagnosed early, the loss of abilities is often mild, and with a little help, the individual can continue living independently much as they did before. However, by the time this condition is diagnosed, some of the problems described above may have already progressed to the point where the individual is already in the middle stage of the disease, needing considerable caregiver support.



Learning Exercise:

***DEMENTIA SPECIALTY TRAINING: Check for Understanding***

**Which of the following may be an indication that a resident could be entering an early stage of Alzheimer's disease?**

- A. Difficulty recalling an individual's name when introduced to a new resident
- B. Inability to carry on a coherent conversation
- C. Misplacing keys, but immediately recalling where they are
- D. Very socially outgoing and actively engaged in activities programs

**Explain your answer:**

## **Mid-stage (moderate) Alzheimer's: Brain Changes**

By this stage, AD damage has spread to the areas of the cerebral cortex that control language, reasoning, sensory processing, and conscious thought. Affected regions continue to shrink, ventricles enlarge, and signs and symptoms of the disease become more pronounced and widespread. Behavioral problems can occur. More intensive supervision and care become necessary, which can be difficult for many spouses and families.

## **Mid-stage (moderate) Alzheimer's Signs & Symptoms**

In mid-stage Alzheimer's disease, the cognitive problems of early Alzheimer's get worse and new ones begin to develop. Memory, cognition, and communication problems become more severe, and the personality is transformed. Some assistance with day-to-day activities becomes essential. This stage is the longest of the three stages. Persons in this stage who are able to recognize their own decline are at risk of becoming suicidal.

May have increasing episodes of urinary or fecal incontinence could be included in the moderate stage. The person has a marked change in appearance and hygiene as they become less and less able to take care of themselves. Wandering, aggressiveness, hallucinations, paranoia, or compulsive, repetitive behaviors may appear.

## **Mid-stage (moderate) AD: Significant cognitive decline and memory problems continue and may:**

Becomes confused about where they are or about the date, day of the week or season. Increasing difficulty in sorting out names and faces of family and friends, but can still distinguish familiar from unfamiliar faces. Still knows their own name, but no longer remembers their own address or phone. Loses track of their own possessions. May take others' belongings.

In the moderate stage the person can no longer think logically or clearly. Arithmetic and money problems escalate. Disconnected from reality; may think that a television story is real. He or she may not recognize self in the mirror. Needs help choosing proper clothing for the season or occasion. May need help getting dressed properly; without supervision may put shoes on the wrong feet or put daytime clothes over pajamas.

## **Mid-stage (moderate) AD: Impaired communication skills worsen and may include:**

Problems with speaking, understanding, reading, and writing and he or she may repeat stories, words, and gestures; repetitive questions. He or she may still be able to read, but cannot respond correctly. The person in the mild-stage may have problems finishing sentences and may revert to their first speaking language (and need a multilingual caregiver).



**Mid-stage (moderate) AD: Personality changes become more significant and may include:**

- Apathetic, withdrawn, anxious, agitated, unmannerly, aggressive, or threatening
- Suspicious, paranoid; for example may accuse family members of stealing
- Delusional, has hallucinations; for example, may hear, see, smell, or taste things that aren't present
- May have an exaggeration of their normal personality characteristics

**Mid-stage (moderate) AD: Idiosyncratic behaviors evolve and may include:**

- Inappropriate sexual behavior: may mistake another person for their spouse, may disrobe or masturbate in public
- Rummages through things, hides things
- Restlessness, pacing, repetitive movements: fingers certain objects over and over; tries doorknobs; hand-wringing; tissue-shredding
- Wandering, including chatting to oneself while wandering. May wander away from the caregiver and familiar, safe surroundings. (One-quarter to one-half of all people with Alzheimer's wander.)
- Disruption of the normal sleep-wake cycle: "sundowning" (naps during the day, active from late afternoon through the night)

**Mid-stage (moderate) AD: Dependence and need for help with the activities of daily living increases including:**

- May or may not require assistance with eating and toileting.
- May have increasing episodes of urinary or fecal incontinence.
- The person has a marked change in appearance and hygiene as they become less and less able to take care of themselves.
- Wandering, aggressiveness, hallucinations, paranoia, or compulsive, repetitive behaviors may appear.
- May eat without help, but needs help remembering to drink enough liquids and to eat enough
- May need help putting clothing onto the correct body part.
- Needs help with grooming: bathing, brushing teeth, combing hair
- May no longer be safe when left alone: could fall, burn self, poison self, neglect self. Although able to care for self in some ways, needs full-time supervision for safety.
- Voluntary control over the body declines, such as incontinence, muscle twitches, etc.





Learning Exercise:

***DEMENTIA SPECIALTY TRAINING: Check for Understanding***

Which of the follow may be an indication that a resident could be in the mid-stage of Alzheimer's disease?

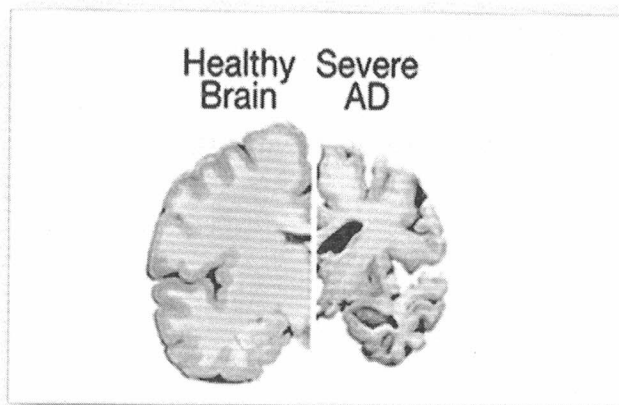
- A. Clear about today's date and what time it is
- B. Cannot distinguish familiar from unfamiliar faces
- C. May have difficulty choosing correct clothing and getting dressed
- D. Able to read a book and clearly discuss the themes during a book club meeting

**Explain your answer:**

The focus of late-stage Alzheimer's is the complete deterioration of the personality. Cognitive symptoms worsen, and physical symptoms become profound. The loss of brain cells in all parts of the brain leads to lack of functioning in all systems of the body. The wild behaviors of earlier stages disappear, replaced by a dulling of the mind and body.

### **Late-Stage (severe) AD: Brain Changes**

In the last stage of AD, plaques and tangles are widespread throughout the brain, most areas of the brain have shrunk further, and ventricles have enlarged even more. People with AD cannot recognize family and loved ones or communicate in any way. They are completely dependent on others for care.



### **Late-Stage (severe) AD:**

Near the end, the person may be in bed much or all of the time. The most frequent cause of death for people with AD is aspiration pneumonia. This type of pneumonia develops when a person is not able to swallow properly and takes food or liquids into the lungs instead of air.

**Late-Stage (severe) AD: Cognitive and memory problems decline further, and complete dependence on others is necessary. Problems may include:**

- Doesn't recognize familiar people, including their spouse and family members (a lack of visual ability may contribute to this)
- Needs complete help with all activities of daily living
- Requires full-time care

**Late-Stage (severe) AD: Communication skills are nearly gone and include:**

- Loses capability for recognizable speech, although words or phrases may uttered
- Appears uncomfortable, but cries out when touched or moved
- Can no longer smile
- May call or cry out repetitively, groan, or mumble loudly
- Can't write or comprehend reading material

**Late-Stage (severe) AD: Voluntary control of the body increasingly disappears and may include:**

- Can't control their movements; muscles are rigid
- Need help with eating and toileting; complete urinary and bowel incontinence
- Unable to walk without assistance; then, loses the ability to sit or hold up their head without support
- Generally bedridden
- Can't swallow easily, may choke on food
- Wandering ceases; can't move voluntarily

**Late-Stage (severe) AD: Health declines considerably and may include:**

- Frequent infections
- Seizures
- Loses weight
- Skin becomes thin and tears easily
- Reflexes are abnormal

**Late-Stage (severe) AD: The body shuts down and may include:**

- May refuse to eat or drink
- Can't respond to the environment
- May quit urinating
- Little response to touch
- Sensory organs shut down: the organs may function correctly, but the brain can't interpret the input.
- May only feel cold and discomfort
- Exhausted, sleeps more

**Late-Stage (severe) AD: Personality changes and idiosyncratic behavior become extreme and may include:**

- Apathetic, withdrawn (continues from early-stage Alzheimer's)
- Dulling of the personality
- May pat or touch things repeatedly

As the end of life approaches, the Alzheimer's patient may require around-the-clock care. It will be necessary for loved ones to decide whether that care can occur at home or in a facility. The guidance of a physician or a hospice team will be needed.



Learning Exercise:

***DEMENTIA SPECIALTY TRAINING: Check for Understanding***

Which of the follow may be an indication that a resident is in the late stage of Alzheimer's disease?

- A. Wanders constantly and is very active
- B. Repeats questions or stories within the same conversation
- C. Cannot smile and muscles become rigid
- D. May become paranoid and accuse the caregiver of stealing his/her hearing aid

**Explain your answer:**

