

Medical-Legal Aspects of Dementia Care

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Outline

- What is Dementia
 - What is the difference between Alzheimer's disease and Dementia?
 - Is it normal aging?
- Medical-Legal aspects of dementia care... from a Physician's point of view
 - Capacity
 - Proactive care
- Inside the brain

Dementia (from DSM-IV R)

- The development of multiple cognitive deficits manifested by both:
 - Memory impairment
 - One or more following disturbances
 - Aphasia
 - Apraxia
 - Disturbance in executive function
 - Agnosia
- Cognitive deficits each cause significant impairment in social or occupational functioning
- Subtypes (in DSM-IV)
 - Alzheimer's
 - Vascular
 - Due to other medical conditions
 - Substance-inducing persisting dementia
 - Dementia due to multiple etiologies
 - Dementia NOS



National Institute on Aging

National Institutes of Health



ALZHEIMER'S DISEASE

Unraveling the **Mystery**



The Impact of AD

Once considered a rare disorder, Alzheimer's disease is now seen as a major public health problem that is seriously affecting millions of older Americans and their families.



The Federal government's lead agency for Alzheimer's disease research is the National Institute on Aging, part of the National Institutes of Health. NIH is part of the U.S. Department of Health and Human Services.

What is AD?



Alzheimer's disease is an irreversible, progressive brain disease that slowly destroys memory and thinking skills.

Although the risk of developing AD increases with age – in most people with AD, symptoms first appear after age 60 – AD is not a part of normal aging. It is caused by a fatal disease that affects the brain.

What is AD?

AD Statistics....

- AD is the most common cause of dementia among people age 65 and older.
- Scientists estimate that around 4.5 million people now have AD.
- For every 5-year age group beyond 65, the percentage of people with AD doubles.

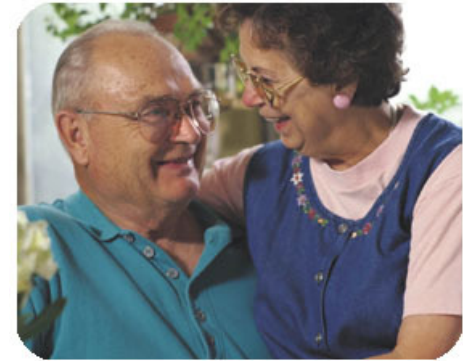


- By 2050, 13.2 million older Americans are expected to have AD if the current numbers hold and no preventive treatments become available.

What is AD?

Where are people with AD cared for?

- home
- assisted living facilities (those in the early stages)
- nursing homes (special care units)



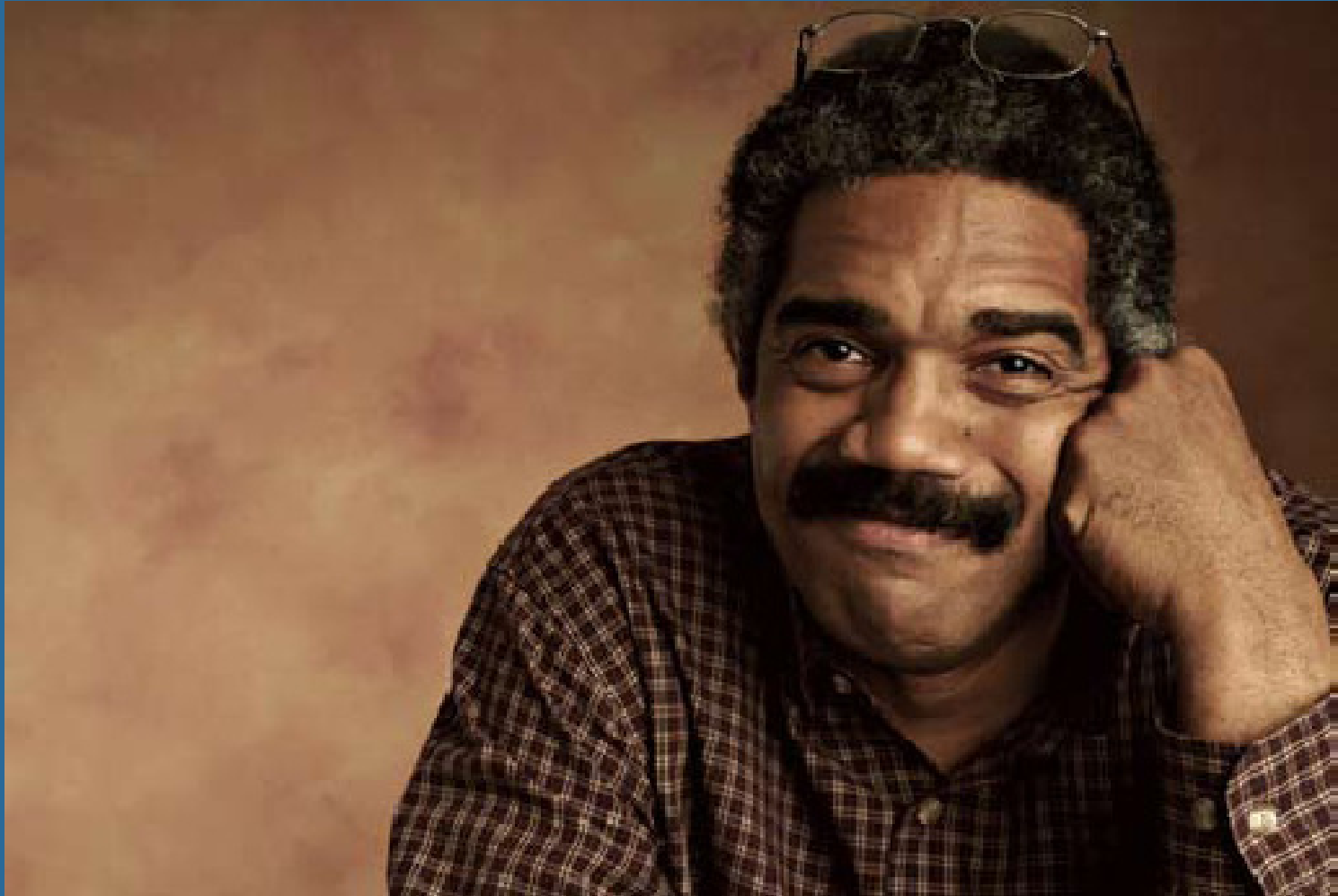
- The national cost of caring for people with AD is about \$100 billion every year.

Diagnosing AD



Experienced physicians in specialized AD centers can now diagnose AD with up to 90 percent accuracy. Early diagnosis has advantages:

- Doctors can rule out other conditions that may cause dementia.
- If it is AD, families have more time to plan for the future.
- Treatments can start earlier, when they may be more effective.
- It helps scientists learn more about the causes and development of AD.



Is it Alzheimer's or just signs of aging?

Alzheimer's Association

10 warning signs of Alzheimer's disease©

The Alzheimer's Association has developed a checklist to help you recognize signs of Alzheimer's disease

- One - Memory loss
- Two - Difficulty doing familiar tasks
- Three - Problems with talking or writing
- Four - Confusion about time and place
- Five - Loss of judgment
- Six - Problems with abstract thinking
- Seven - Misplacing things
- Eight - Changes in mood or behavior
- Nine - Changes in personality
- Ten - Loss of motivation

But, what's considered "Normal" and what's not?

One

Memory loss

- Memory loss that disrupts everyday life is not normal aging
- Forgetting recently learned information is one of the most common early signs of dementia.
- A person begins to forget more often and is unable to recall the information later.

What's normal?

Forgetting names or appointments occasionally



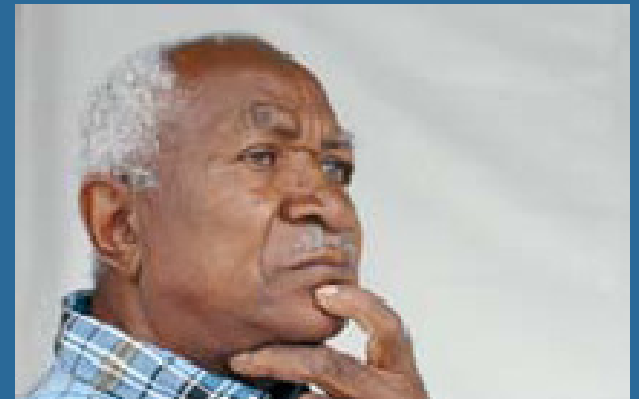
Two

Difficulty doing familiar tasks

- Loss of well honed skills, such as cooking or cleaning
- Difficulty with activities of daily living

What's normal?

Forgetting names or appointments occasionally



Three

Problems talking or writing

- People with Alzheimer's disease often forget simple words or substitute unusual words, making their speech or writing hard to understand.
- They may be unable to find their toothbrush, example, and instead ask for "that thing for my mouth."

What's normal?

Sometimes having trouble finding the right word

for



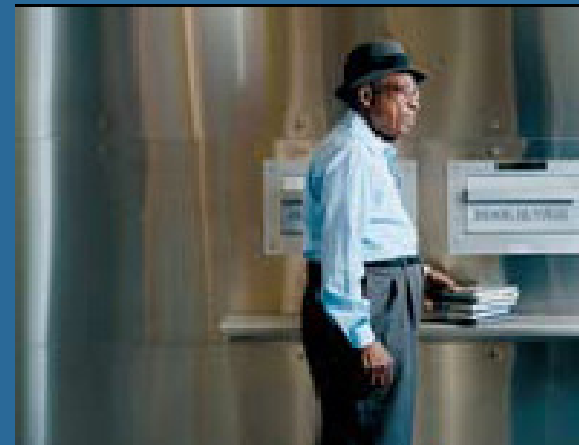
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Confusion about time and place

- Lack of “Orientation”
- Not being aware of where they are
- Not knowing the season, month or year
- Orientation to self is usually preserved

What's normal?

Forgetting the day of the week
or where you were going



Five

Loss of Judgment

- Those with Alzheimer's may dress inappropriately, wearing several layers on a warm day or too little clothing in the cold.
- They may show poor judgment about money, like giving away large sums to a scam artist.

What's normal?

Making a questionable or debatable decision from time to time



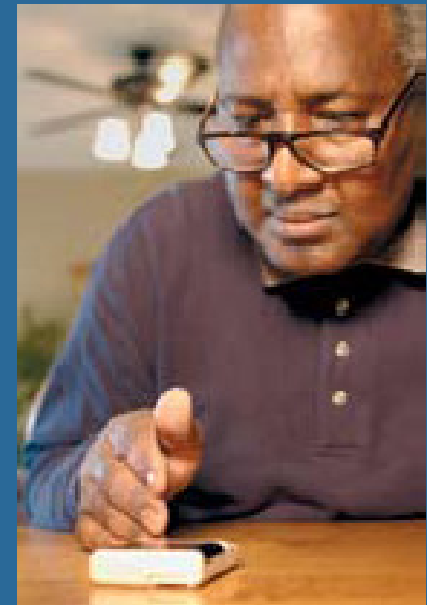
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Problems with abstract thinking

- Someone with Alzheimer's disease may have unusual difficulty performing complex mental tasks, like forgetting what numbers are and how they should be used.

What's normal?

Finding it challenging to balance a checkbook



Seven

Misplacing things

- A person with Alzheimer's disease may put things in unusual places: such as an iron in the freezer or a wristwatch in the sugar bowl.

What's normal?

Misplacing keys or a wallet temporarily



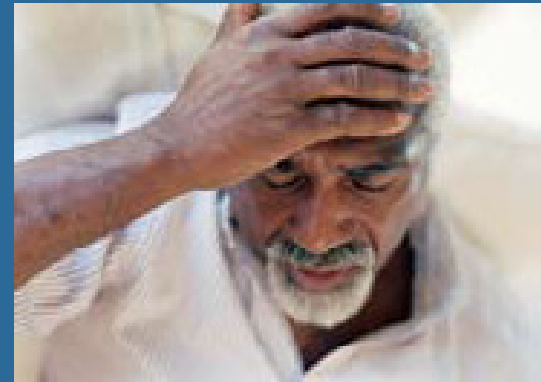
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Changes in mood or behavior

- Someone with Alzheimer's disease may show rapid mood swings – from calm to tears to anger – for no apparent reason.

What's normal?

Occasionally feeling sad or moody



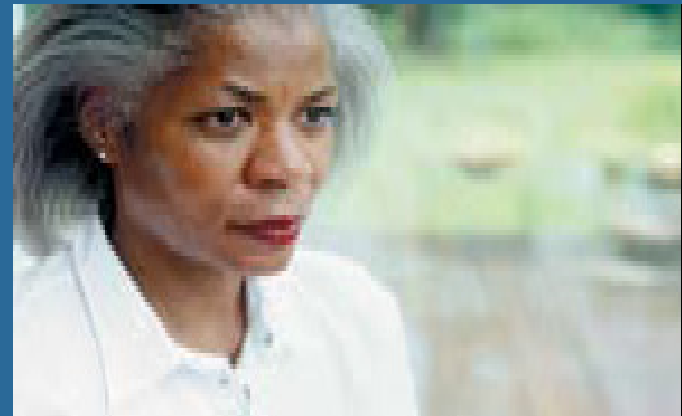
Nine

Changes in personality

- The personalities of people with dementia can change dramatically. They may become extremely confused, suspicious, fearful or dependent on a family member.

What's normal?

People's personalities do change somewhat with age



Ten

Loss of motivation

- A person with Alzheimer's disease may become very passive, sitting in front of the TV for hours, sleeping more than usual or not wanting to do usual activities.

What's normal?

Sometimes feeling weary of work or social obligations



Diagnosing AD

Physicians today use a number of tools to diagnose AD:

- a detailed patient history
- information from family and friends
- physical and neurological exams and lab tests
- neuropsychological tests
- imaging tools such as CT scan, or magnetic resonance imaging (MRI). PET scans are used primarily for research purposes



Medical Legal Aspects of Dementia Care

- Part of a Proactive Dementia Care Plan
- Competence / Capacity
- Medical Power of Attorney
- Living Will
- Driving
- Long-term care coverage
- Finances and property
- Guardianship

Legal Capacity

- term used to define someone who is able to understand and appreciate the consequences of his/her actions.
- A person who lacks legal capacity cannot, for example, enter into a contract, give a power of attorney, make a will, consent to medical treatment, or transfer property.
- Issue specific (“capacity to do what?”)
- Not a straightforward issue
- http://www.nlrc.aoa.gov/nlrc/Legal_Issues/Capacity/capacity.aspx

Measuring Capacity

- Mini-mental status test
 - aka. Folstein, MMSE
 - Screening measure only
 - Not diagnostically sufficient
- Neuropsychological Testing (~ 4 hours)
 - Aides in diagnosis by providing an accurate description of cognitive strengths and weakness.
 - The test results can be used to monitor changes over time
 - Can be variable (need an experienced, certified rater)
 - Is a standard part of the evaluation at the University of Utah Alzheimer's Center

Neuropsychological Evaluation

- **Cognitive Abilities Tested:**
 - Verbal and Nonverbal Intelligence
 - Executive Abilities (Planning, Problem Solving, etc.)
 - Attention and Concentration
 - Learning and Memory
 - Expressive and Receptive Language Skills
 - Visual and Spatial Functions
 - Psychomotor Skills
 - Emotional Status

Resources for Capacity Assessment

- Assessment of Older Adults With Diminished Capacity: A Handbook for Lawyers (2005)
 - ABA Commission on Law and Aging (COLA) & APA
- Judicial Determination of Capacity of Older Adults in Guardianship Proceedings: A Handbook for Judges (2006)
 - ABA-COLA, APA & NCPJ
- Assessment of Older Adults With Diminished Capacity: A Handbook for Psychologists (2008)
 - ABA-COLA & APA

Living Will

- A **Living Will** states a person's choices for future medical decisions, such as the use of artificial life support. A living will only comes into play when a doctor decides that the person is irreversibly ill, or critically injured and near death.
- “How aggressive do you want us to be?”

Medical Power of Attorney

- Designates a person to act on their behalf
- Becomes effective only upon the happening of an event that is designated
- Separate from other forms of POA

Support for Caregivers

Who are the AD Caregivers?

- Spouses – the largest group. Most are older with their own health problems.
- Daughters – the second largest group. Called the “sandwich generation,” many are married and raising children of their own. Children may need extra support if a parent’s attention is focused on caregiving.
- Grandchildren – may become major helpers.



- Daughters-in-law – the third largest group.
- Sons – often focus on the financial, legal, and business aspects of caregiving.
- Brothers and Sisters – many are older with their own health problems.
- Other – friends, neighbors, members of the faith community.

Support for Caregivers

Demands of Caregiving

AD takes a huge physical and emotional toll. Caregivers must deal with changes in a loved one's personality and provide constant attention for years. Thus, caregivers are especially vulnerable to physical and emotional stress.

- Peer support programs can help link caregivers with trained volunteers. Other support programs can offer services geared to caregivers dealing with different stages of AD.

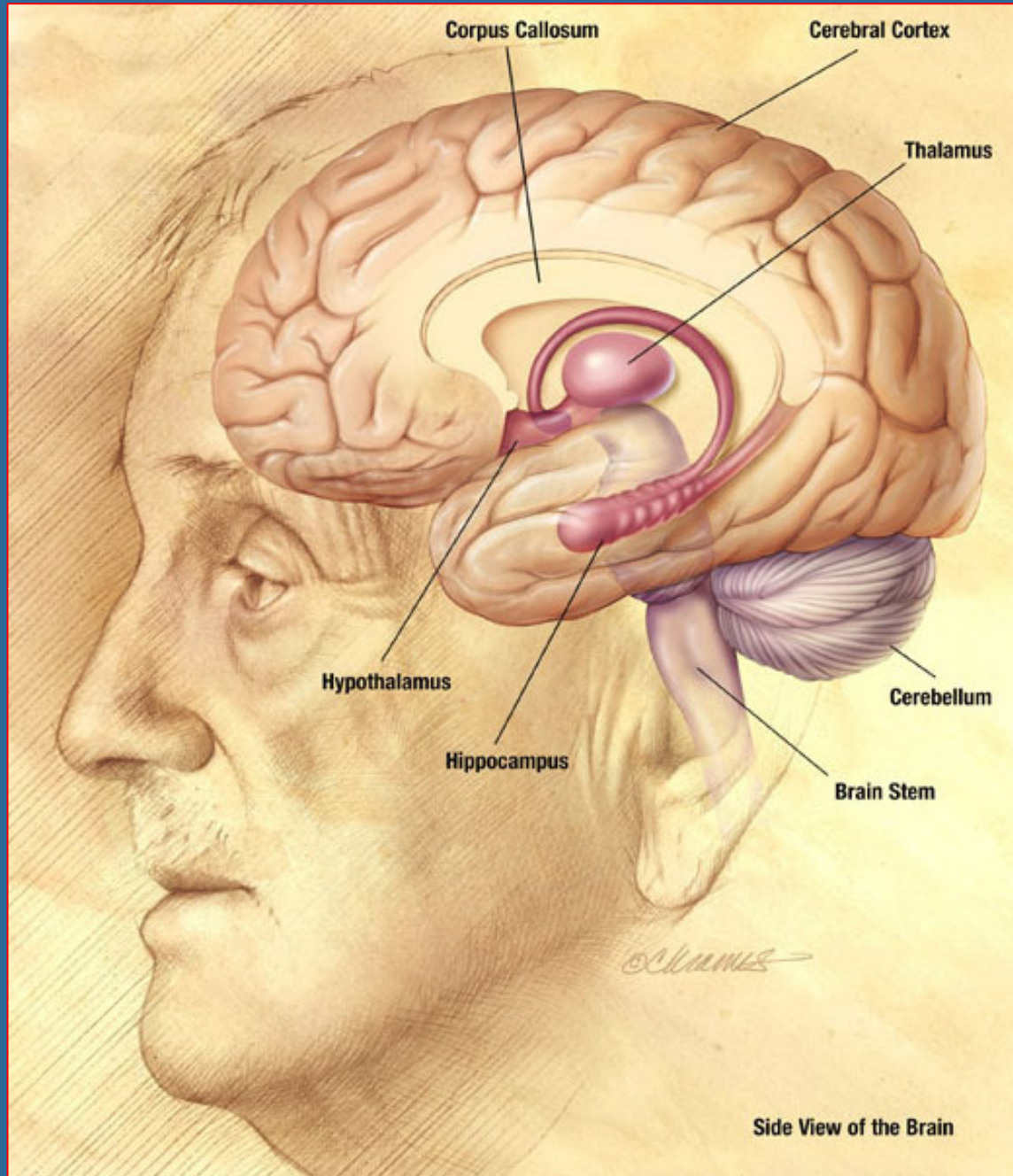


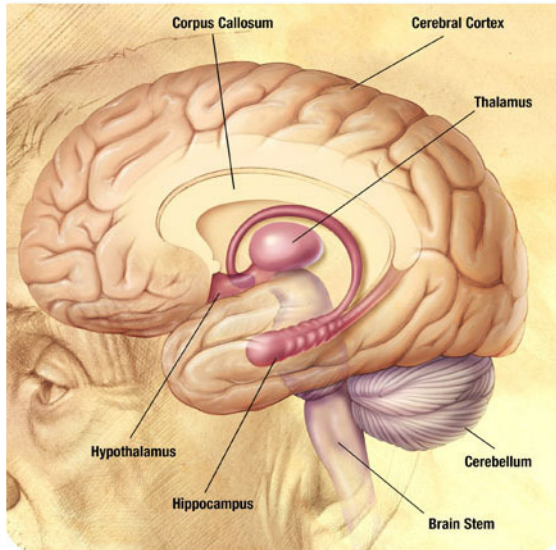
Inside the Human Brain

To understand Alzheimer's disease, it's important to know a bit about the brain...

The Brain's Vital Statistics

- Adult weight: about 3 pounds
- Adult size: a medium cauliflower
- Number of neurons: 100,000,000,000 (100 billion)
- Number of synapses (the gap between neurons): 100,000,000,000,000 (100 trillion)

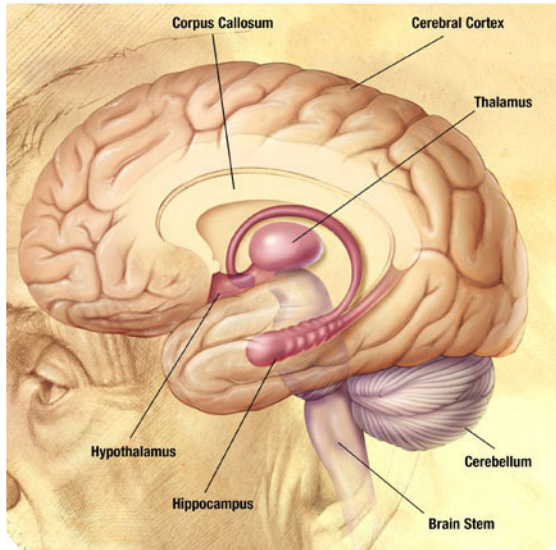




Inside the Human Brain

The Three Main Players

1. **Cerebral Hemispheres** – where sensory information received from the outside world is processed; this part of the brain controls voluntary movement and regulates conscious thought and mental activity:
 - accounts for 85% of brain's weight
 - consists of two hemispheres connected by the corpus callosum
 - is covered by an outer layer called the cerebral cortex

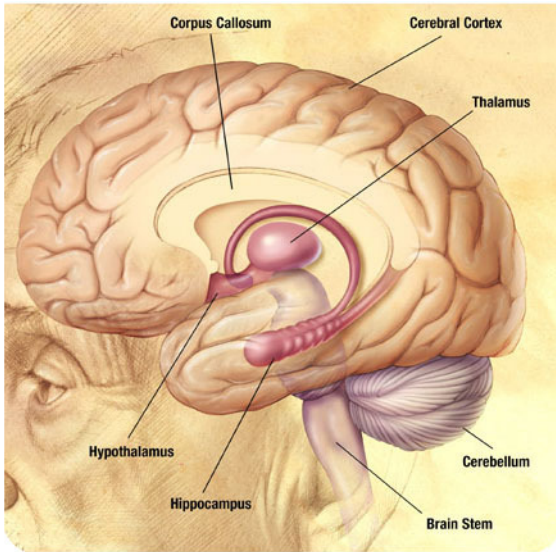


Inside the Human Brain

The Three Main Players

2. Cerebellum – in charge of balance and coordination:

- takes up about 10% of brain
- consists of two hemispheres
- receives information from eyes, ears, and muscles and joints about body's movements and position

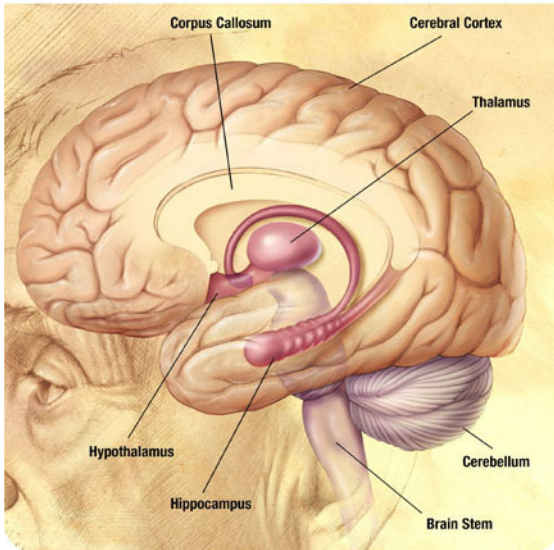


Inside the Human Brain

The Three Main Players

3. Brain Stem – connects the spinal cord with the brain

- relays and receives messages to and from muscles, skin, and other organs
- controls automatic functions such as heart rate, blood pressure, and breathing



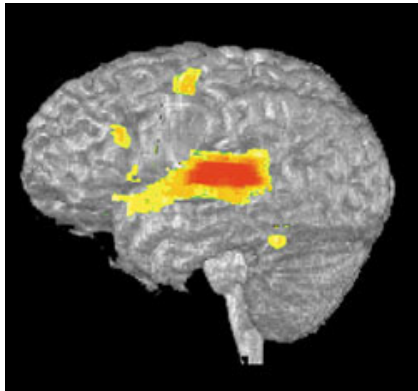
Inside the Human Brain

Other Crucial Parts

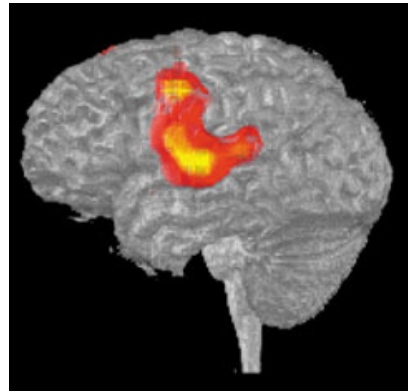
- **Hippocampus:** where short-term memories are converted to long-term memories
- **Thalamus:** receives sensory and limbic information and sends to cerebral cortex
- **Hypothalamus:** monitors certain activities and controls body's internal clock
- **Limbic system:** controls emotions and instinctive behavior (includes the hippocampus and parts of the cortex)

Inside the Human Brain

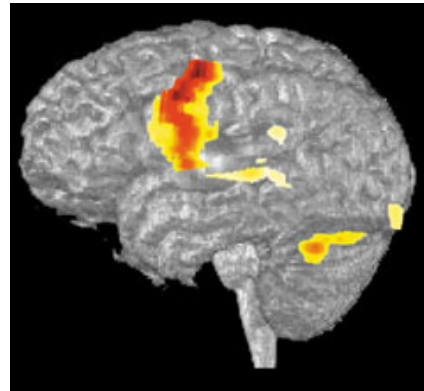
The Brain in Action



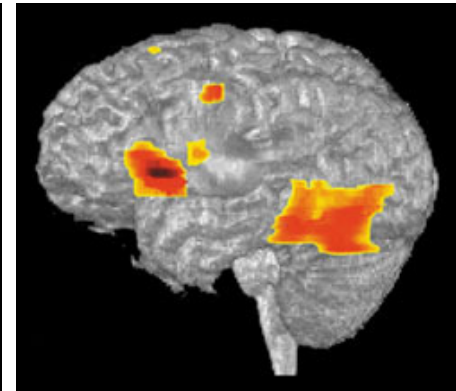
Hearing Words



Speaking Words



Seeing Words



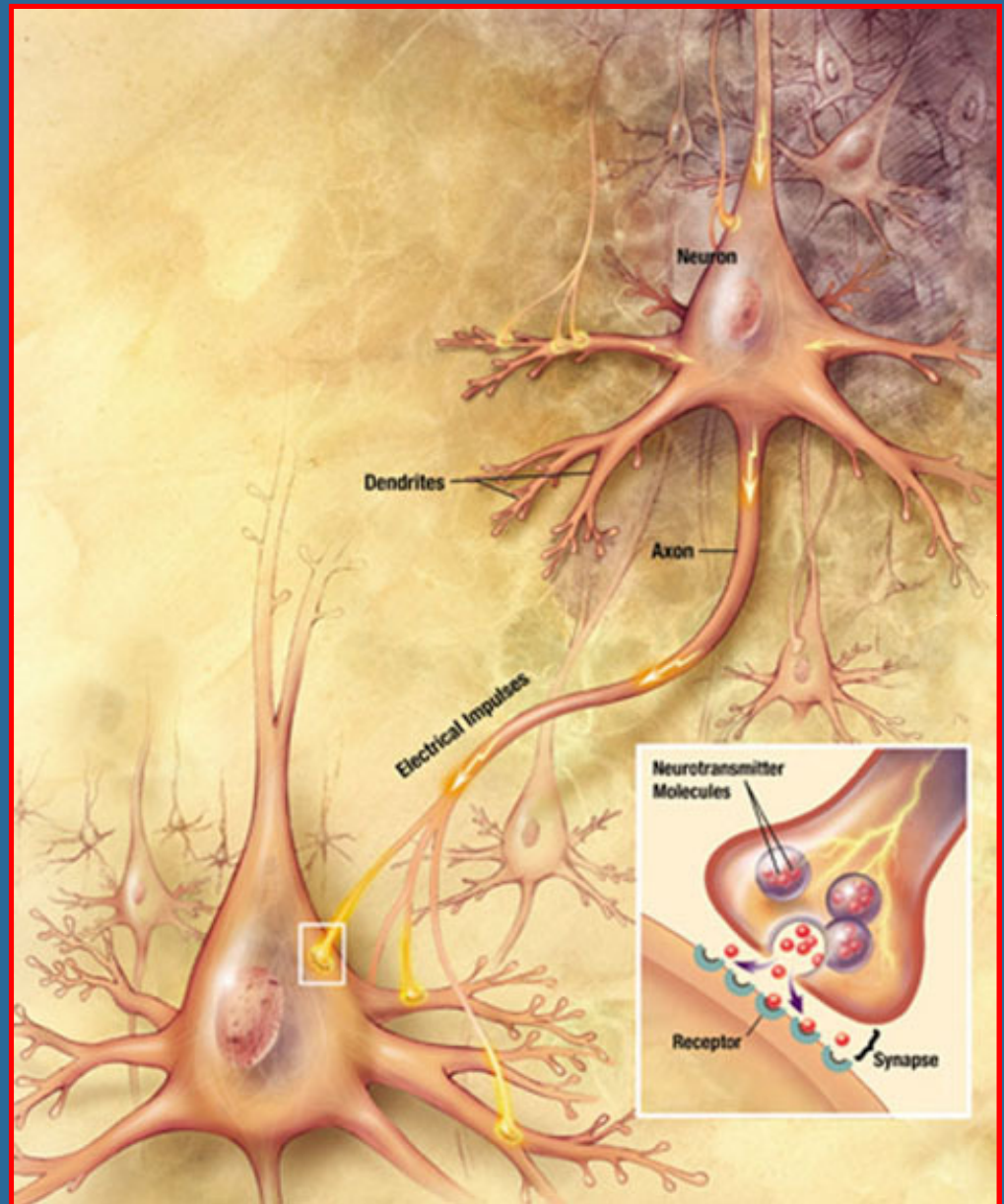
Thinking about Words

Different mental activities take place in different parts of the brain. Positron emission tomography (PET) scans can measure this activity. Chemicals tagged with a tracer “light up” activated regions shown in red and yellow.

Inside the Human Brain

Neurons

- The brain has billions of neurons, each with an axon and many dendrites.
- To stay healthy, neurons must communicate with each other, carry out metabolism, and repair themselves.
- AD disrupts all three of these essential jobs.

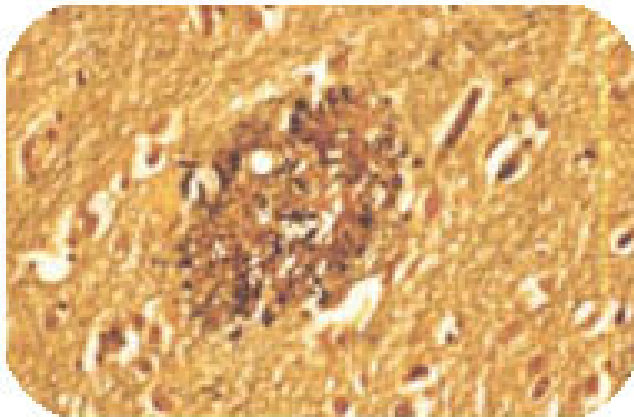


AD and the Brain

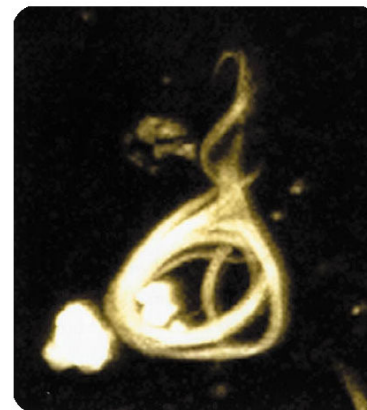
Plaques and Tangles: The Hallmarks of AD

The brains of people with AD have an abundance of two abnormal structures:

- beta-amyloid plaques, which are dense deposits of protein and cellular material that accumulate outside and around nerve cells
- neurofibrillary tangles, which are twisted fibers that build up inside the nerve cell



An actual AD plaque



An actual AD tangle

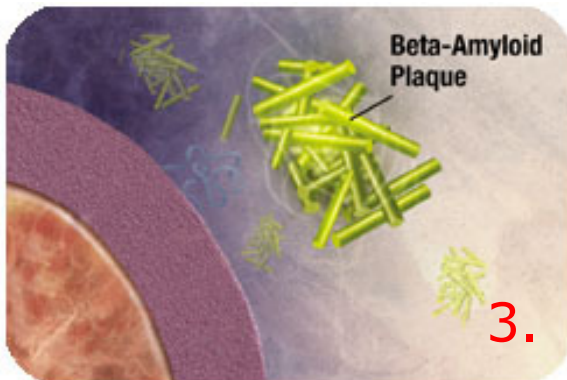
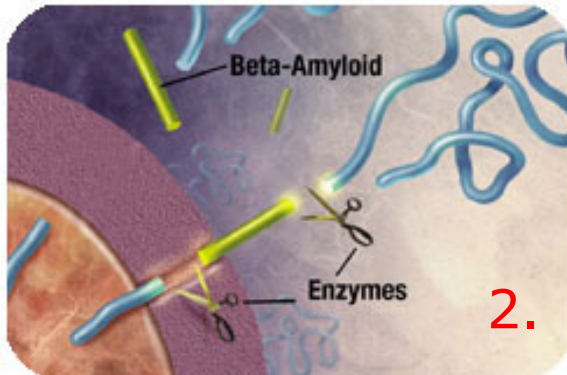
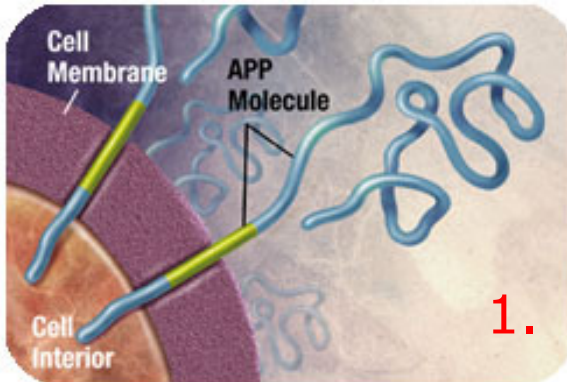
AD and the Brain

Beta-amyloid Plaques

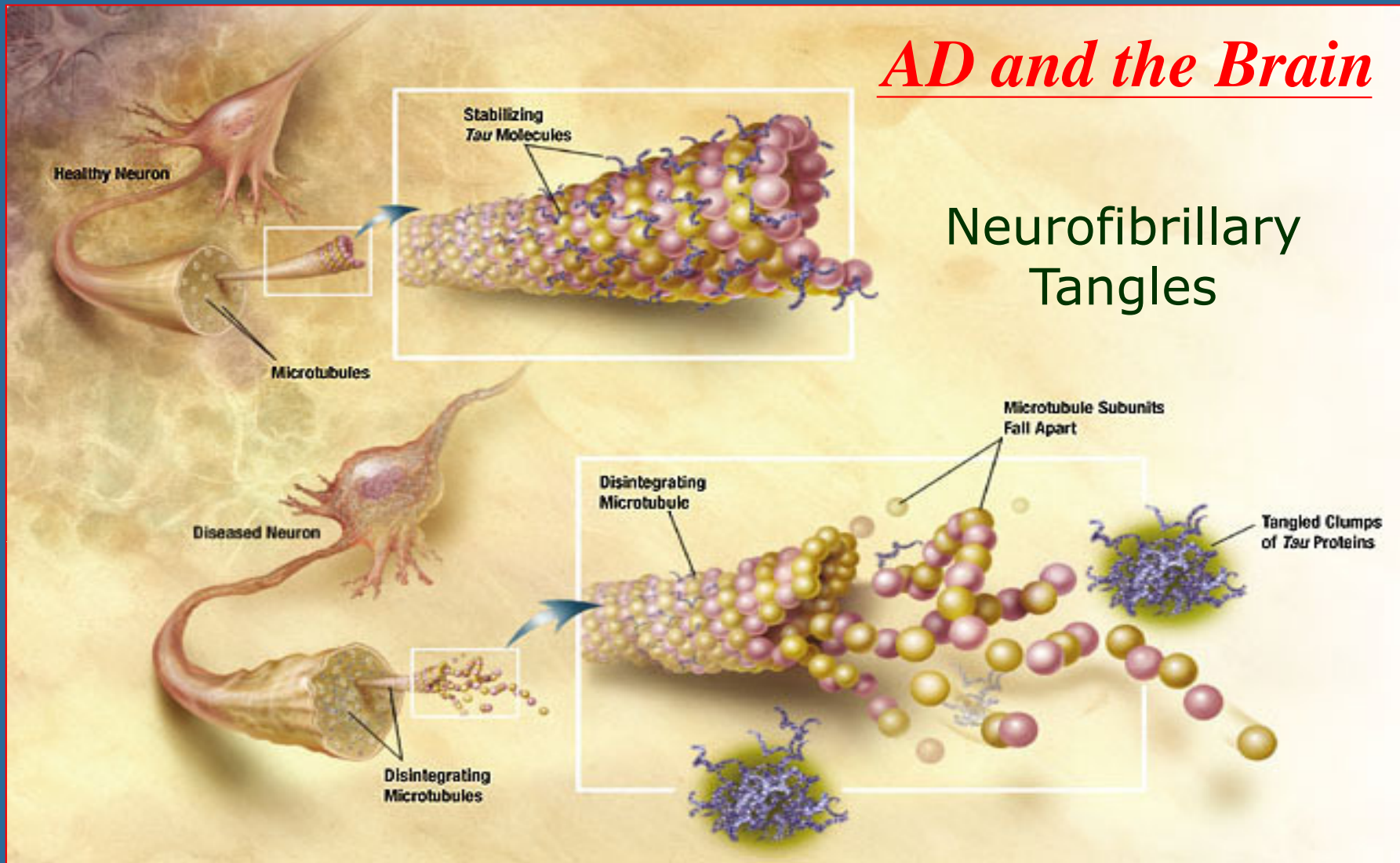
Amyloid precursor protein (APP) is the precursor to amyloid plaque.

1. APP sticks through the neuron membrane.
2. Enzymes cut the APP into fragments of protein, including beta-amyloid.
3. Beta-amyloid fragments come together in clumps to form plaques.

In AD, many of these clumps form, disrupting the work of neurons. This affects the hippocampus and other areas of the cerebral cortex.



AD and the Brain

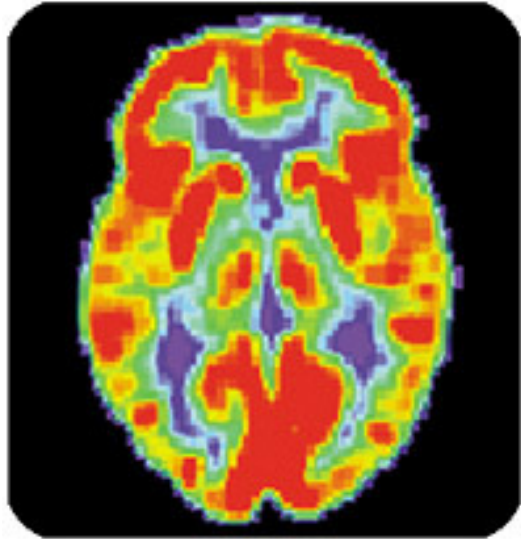


Neurons have an internal support structure partly made up of microtubules. A protein called *tau* helps stabilize microtubules. In AD, *tau* changes, causing microtubules to collapse, and *tau* proteins clump together to form neurofibrillary tangles.

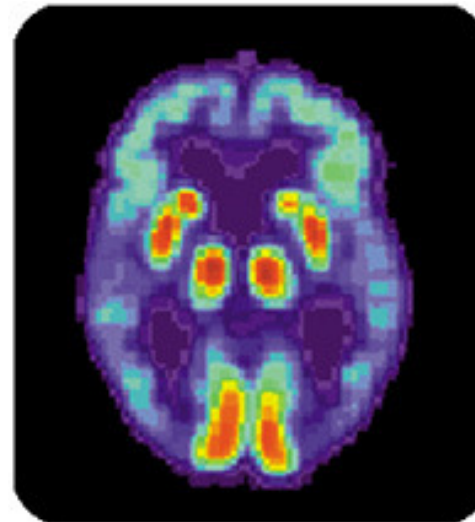
AD and the Brain

The Changing Brain in Alzheimer's Disease

No one knows what causes AD to begin, but we do know a lot about what happens in the brain once AD takes hold.



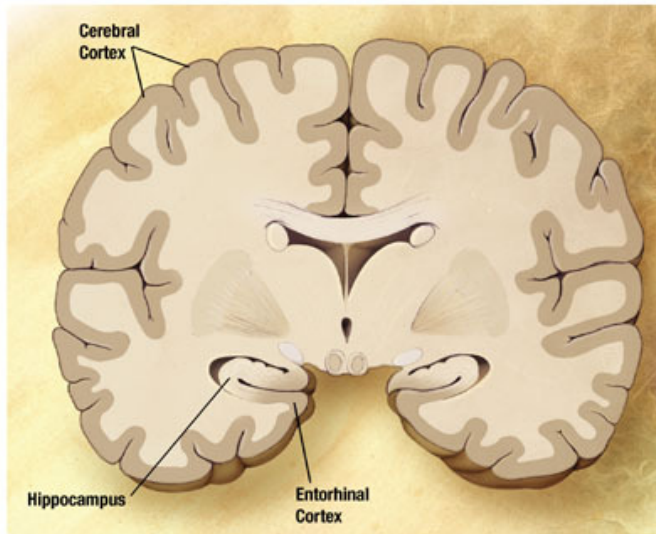
Pet Scan of
Normal Brain



Pet Scan of Alzheimer's
Disease Brain

AD and the Brain

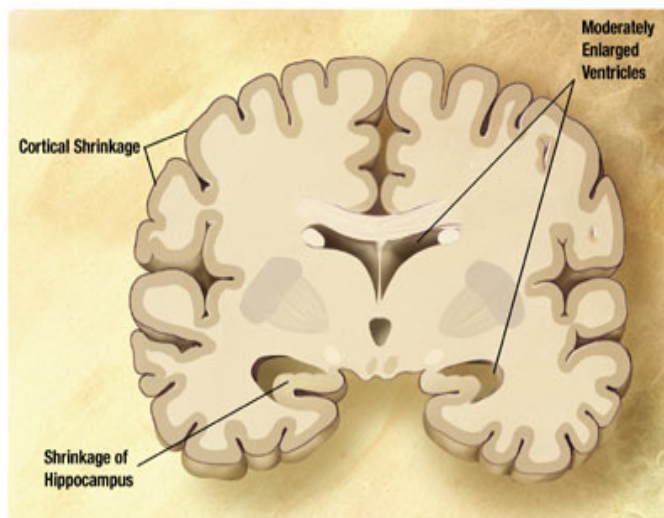
Preclinical AD



- Signs of AD are first noticed in the entorhinal cortex, then proceed to the hippocampus.
- Affected regions begin to shrink as nerve cells die.
- Changes can begin 10-20 years before symptoms appear.
- Memory loss is the first sign of AD.

AD and the Brain

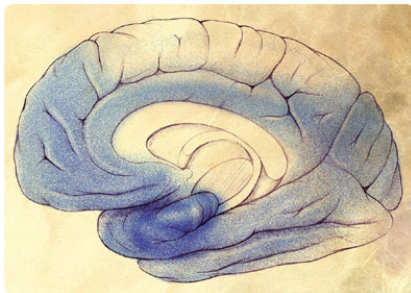
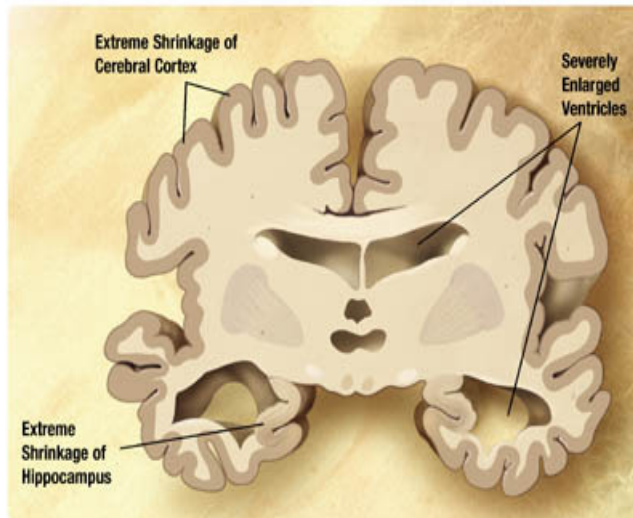
Mild to Moderate AD



- AD spreads through the brain. The cerebral cortex begins to shrink as more and more neurons stop working and die.
- *Mild AD signs* can include memory loss, confusion, trouble handling money, poor judgment, mood changes, and increased anxiety.
- *Moderate AD signs* can include increased memory loss and confusion, problems recognizing people, difficulty with language and thoughts, restlessness, agitation, wandering, and repetitive statements.

AD and the Brain

Severe AD



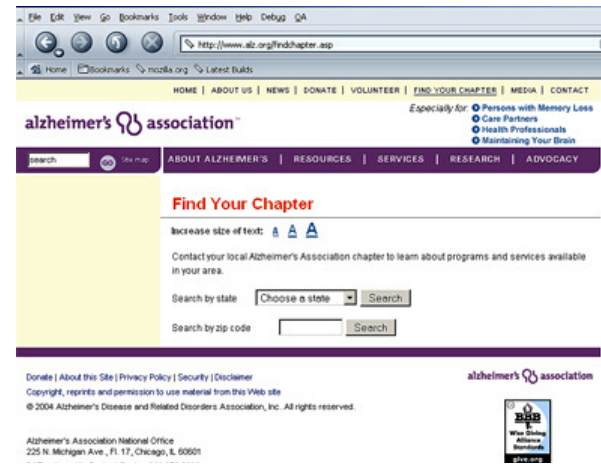
- In severe AD, extreme shrinkage occurs in the brain. Patients are completely dependent on others for care.
- Symptoms can include weight loss, seizures, skin infections, groaning, moaning, or grunting, increased sleeping, loss of bladder and bowel control.
- Death usually occurs from aspiration pneumonia or other infections. Caregivers can turn to a hospice for help and palliative care.

National Resources

Alzheimer's Association

- Local chapters provide referrals to area resources and services, and sponsor the Safe Return Program, support groups, and educational programs:

1-800-272-3900



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