

# SIU MEDICINE

DALE & DEBORAH SMITH CENTER  
FOR ALZHEIMER'S RESEARCH  
& TREATMENT

# DEMENTIA CAREGIVING 101

A GUIDE TO CARING FOR SOMEONE WITH ALZHEIMER'S DISEASE AND RELATED DISORDERS

Presented by: Debbie Kuhns



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# COURSE OBJECTIVES

- Learn tips on being a confident caregiver
- Gain a better understanding of Alzheimer's disease and related disorders
- Learn how to effectively communicate with persons with memory loss
- Discover meaningful activities for the person with memory loss
- Understand how families can work as a team
- Improve the well being of the caregiver



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# SESSION 1 OBJECTIVES

- Better understanding of Alzheimer's disease and related disorders
- Learn about risk factors and early signs of Alzheimer's disease
- How Alzheimer's disease is diagnosed
- Stages of Alzheimer's disease
- What's next after the diagnosis?



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# In 1906:

Dr. Alois Alzheimer identified changes in the brain tissue of a woman who died of unusual mental illness

Symptoms were memory loss, language problems and unpredictable behavior

Brain autopsy found abnormal clumps (amyloid) and tangled bundles of fibers (tau)

❖ National Institute on Aging



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# Dementia

- ✓ Dementia is not a disease itself but a group of symptoms that may accompany certain diseases or conditions.
- ✓ Group of illnesses that destroy brain cells and lead to a progressive loss of memory and other cognitive abilities....  
memory, language, thought processes, behavior, mood
- ✓ Although some changes in memory may occur with normal aging, the symptoms of dementia include the loss of intellectual/cognitive functions of such severity to interfere with a person's daily functioning



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# Video

## Understanding Dementia



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# Alzheimer's Disease and Related Disorders are **CHRONIC** and **PROGRESSIVE**:

- ✓ Alzheimer's Disease (most widely known)
- ✓ Lewy Body Dementia
- ✓ Frontotemporal Dementia
- ✓ Vascular Dementia
- ✓ Progressive, degenerative brain disease with gradual onset due to death of nerve cells in brain
- ✓ Disease progresses over 2-20 years and varies considerably from person to person



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# Brain Changes

- Amyloid plaques
- Neurofibrillary tangles
- Inflammation
- Reduced ability to metabolize glucose
- Atrophy

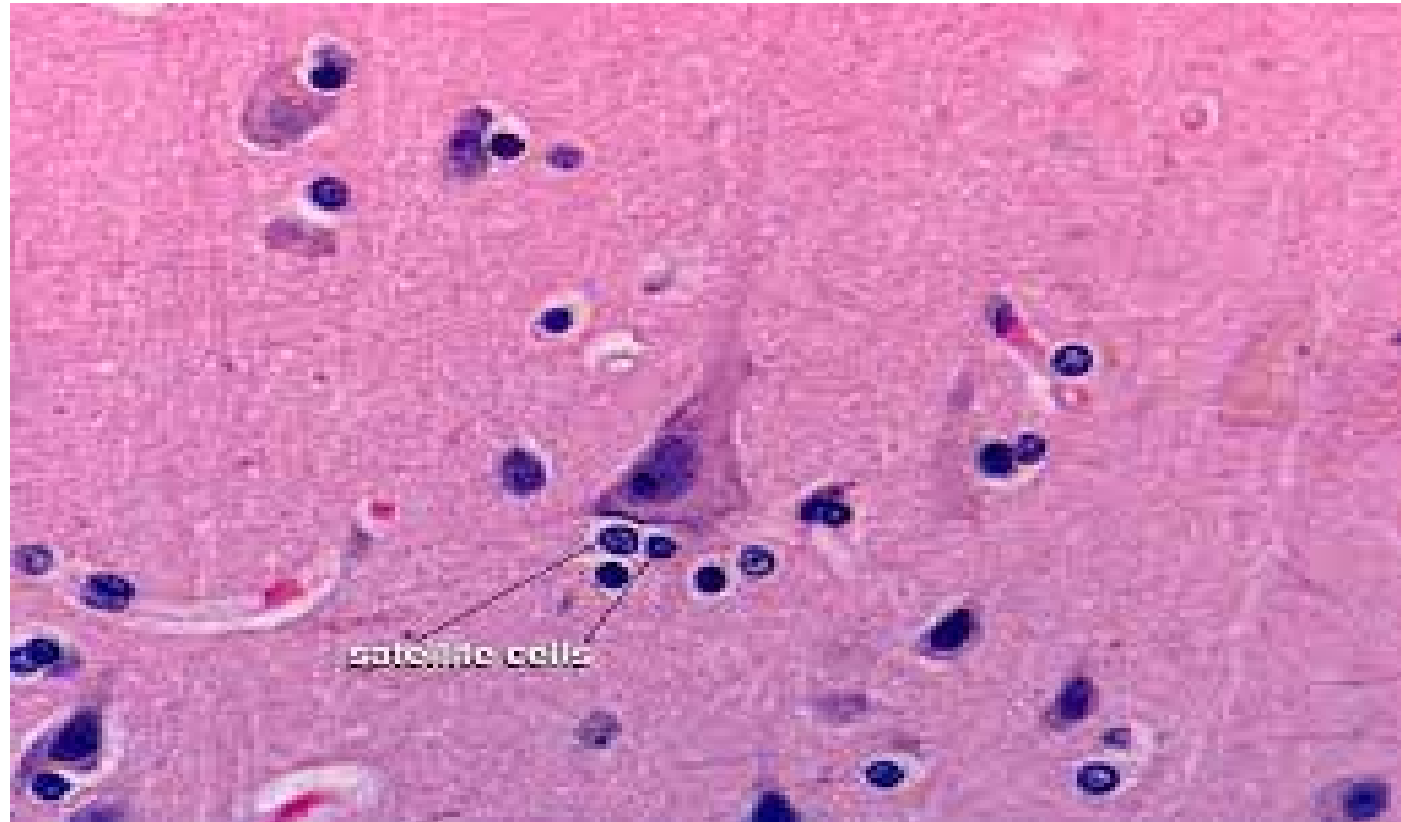


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# Brain Changes

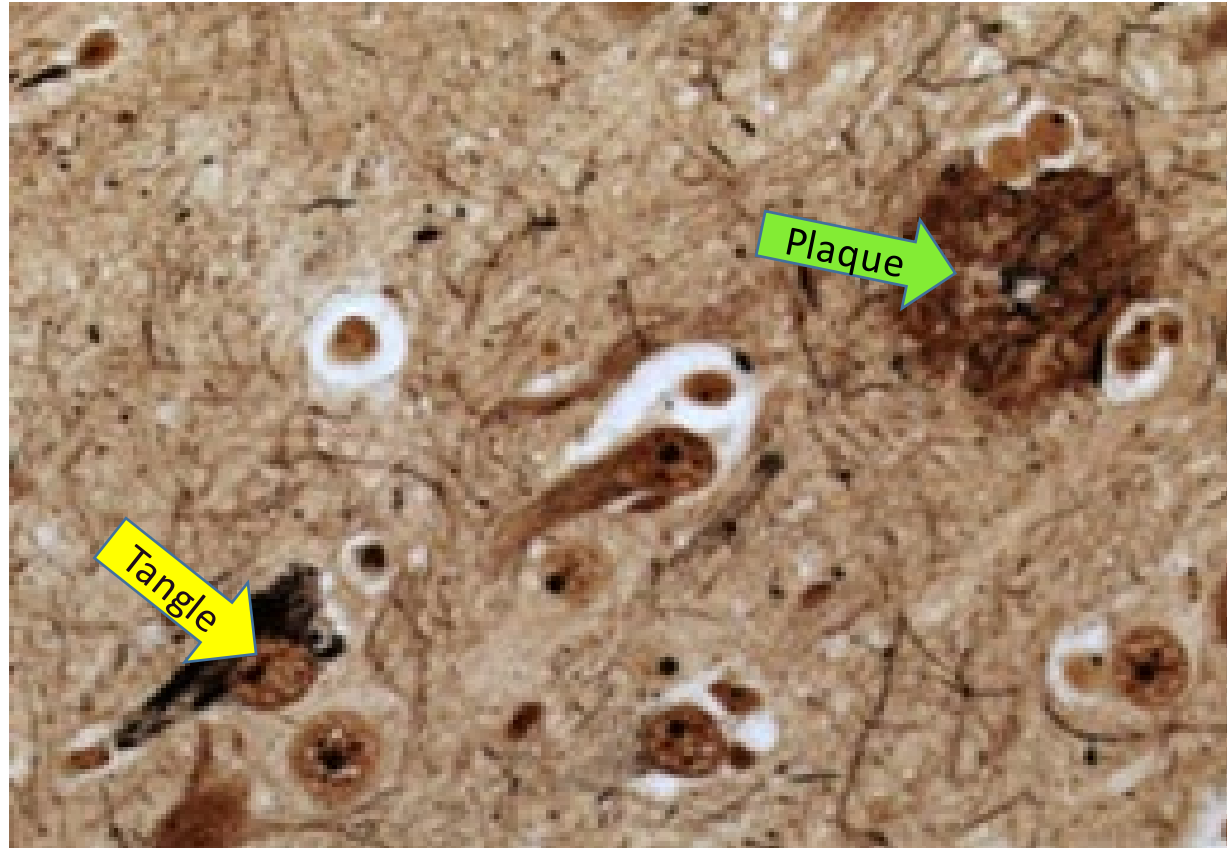
- Normal Brain Cell



(Seidman, R. J., 2019)

# Brain Changes

- Amyloid Plaques and Neurofibrillary Tangles



(Keene et al., 2021)

# Video

## How Alzheimer's Changes the Brain



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# FACTS AND FIGURES

- ❑ Alzheimer's disease is the **3rd leading cause of death** in the US
- ❑ More than **6 million Americans** are living with Alzheimer's
- ❑ By 2050, the number of people age 65 and older with Alzheimer's is projected to reach **12.7 million**
- ❑ **1 in 3 seniors die** with Alzheimer's disease or related disorder
- ❑ It kills more than **breast cancer and prostate cancer combined**



# FACTS AND FIGURES

- ❑ In 2020, Alzheimer's and related disorders will cost the nation \$305 billion and could rise as high as \$1.1 trillion by 2050
- ❑ Between 2000 and 2018 deaths from heart disease have decreased while deaths from Alzheimer's have increased 146%
- ❑ 16 million Americans provide unpaid care for people with Alzheimer's
- ❑ These caregivers provided an estimated 18.6 billion hours valued at nearly \$244 billion
- ❑ **Update** - Family members and friends provided more than **\$271** billion in unpaid care to people living with Alzheimer's and other dementias in **2021**



\*Source Alzheimer's Association

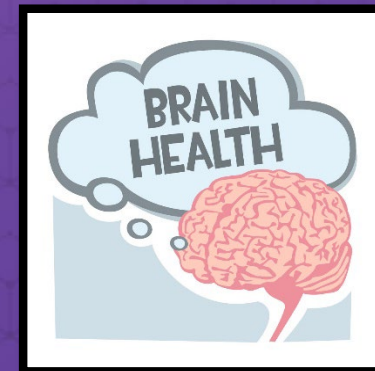


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# Risk Factors – Modifiable

- Cardiovascular – prevent or delay 40% of dementia
- Smoking
- Hypertension
- Hyperlipidemia
- Diabetes
- Diet
- Exercise

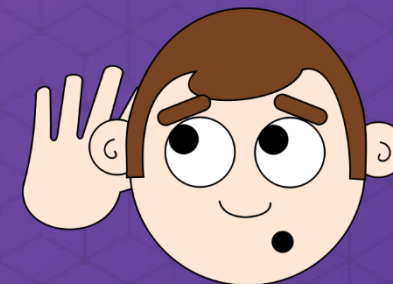
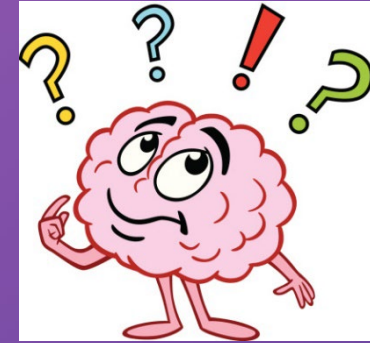


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# Risk Factors- Modifiable

- Traumatic Brain Injury (TBI)/Chronic Traumatic Encephalopathy (CTE)
- Depression
- Hearing Impairment



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# 10 EARLY SIGNS AND SYMPTOMS OF ALZHEIMER'S

1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks
4. Confusion with time and place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood and personality

Source: Alzheimer's Association



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# Alzheimer's and related disorders versus typical age-related changes

<b>Signs of Alzheimer's and Related Disorders</b>	<b>Typical Age-Related Changes</b>
Poor judgment and decision-making	Making a bad decision once in a while
Inability to manage a budget	Missing a monthly payment
Losing track of the date or season	Forgetting which day it is and remembering it later
Difficulty having a conversation	Sometimes forgetting which word to use
Misplacing things and being unable to retrace steps to find them	Losing things from time to time



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# DIAGNOSTIC PROCESS

- Medical history
- Mental status exam
- A series of evaluations that test memory, reasoning, vision-motor coordination, and language skills
- Physical exam
- Brain scan
- Laboratory tests
- Psychiatric evaluation
- Need to rule out other medical conditions as causes first

Source: Alzheimer's Association



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# STAGES



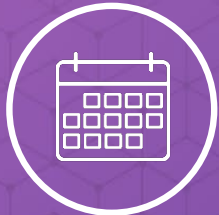
## EARLY

- Mostly independent
- Problems with short term memory
- Problems losing track
- May be impulsive or hesitant



## EARLY-MIDDLE

- Needs reminders
- Needs help staying on track
- Easily frustrated, distracted and may be impulsive
- Trouble with language



## LATE-MIDDLE

- Confused. Easily rushed or startled
- Thinking is severely impaired in all areas; may not remember caregiver
- Has to be handed things and needs prompting and cuing



## LATE

- Needs total care
- Sleeps most of the time
- Little to no consciousness or awareness

Source: Savvy Caregiver

# CHANGES:

## In Cognition:

- Memory loss
- Learning difficulties
- Language problems
- Reasoning

## In Behavior

- Communication skills worsen
- Safety becomes an issue
- Negative behaviors increase

## In Emotion

- Disorganized and confused
- Apathy increases
- Change in moods



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# Is there a cure?

**NO.**

There are medications on the market that may delay symptoms for some individuals. Talk to the doctor before taking any over the counter medications that claim to help with memory loss

Learning how to manage the symptoms and behaviors is the best way to help a person with Alzheimer's or related disorders

# We have the diagnosis. What next?

Think of it as a journey and you need a  
roadmap.



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# Now What?

## Next Steps After an Alzheimer's Diagnosis

A diagnosis of Alzheimer's disease can be difficult, but getting accurate information and support can help you know what to expect and what to do next. Use this checklist to help you get started.



### Learn about Alzheimer's disease

Being informed will help you know what to expect as the disease progresses. Here are some resources:

- ✓ Alzheimer's and related Dementias Education and Referral (ADEAR) Center [www.alzheimers.gov](http://www.alzheimers.gov) | 800-438-4380
- ✓ Alzheimer's Association [www.alz.org](http://www.alz.org) | 800-272-3900
- ✓ Alzheimer's Foundation of America <https://alzfdn.org> | 866-232-8484
- ✓ Local hospitals and community centers may have educational programs about Alzheimer's disease and related dementias.

### Get regular medical care

- ✓ Make regular appointments with your primary care doctor or specialist (neurologist, neuropsychiatrist, geriatric psychiatrist). [www.nia.nih.gov/health/doctor-patient-communication/talking-with-your-doctor](http://www.nia.nih.gov/health/doctor-patient-communication/talking-with-your-doctor)
- ✓ Consider going to a memory disorders clinic. Ask your doctor for a referral if desired.

### Find local services and support

- ✓ Find local services by contacting Eldercare Locator <https://eldercare.acl.gov> | 800-677-1116
- ✓ Contact your local Alzheimer's Disease Research Center [www.nia.nih.gov/health/alzheimers-disease-research-centers](http://www.nia.nih.gov/health/alzheimers-disease-research-centers)
- ✓ Find local chapters, organizations, and support groups:
  - Alzheimer's Association [www.alz.org](http://www.alz.org) | 800-272-3900
  - Alzheimer's Foundation of America <https://alzfdn.org> | 866-232-8484

### Do some legal, financial, and long-term care planning

- ✓ Get information to help you plan. [www.nia.nih.gov/health/legal-and-financial-planning-people-alzheimers](http://www.nia.nih.gov/health/legal-and-financial-planning-people-alzheimers)
- ✓ Prepare or update your will, living will, health care power of attorney, and financial power of attorney. To find a lawyer, contact your local bar association or the National Academy of Elder Law Attorneys. [www.naelsa.org](http://www.naelsa.org)
- ✓ Learn about care you may need in the future and how to pay for it. <https://longtermcare.acl.gov>
- ✓ Explore getting help to pay for medicines, housing, transportation, and more. [www.benefitscheckup.org](http://www.benefitscheckup.org)

### Get help as needed with day-to-day tasks

- ✓ Use simple memory aids like a notepad or sticky notes to jot down reminders, a pillbox to keep medications organized, and a calendar to record appointments.
- ✓ Ask family members or friends or find local services to help with routine tasks, such as cooking, paying bills, transportation, or shopping.
- ✓ Consider using technology solutions for medication management, safety (e.g., emergency response, door alarm), and other care.
- ✓ See tips about coping daily changes in relationships, and more. [www.nia.nih.gov/health/alzheimers/caregiving](http://www.nia.nih.gov/health/alzheimers/caregiving)



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# Questions

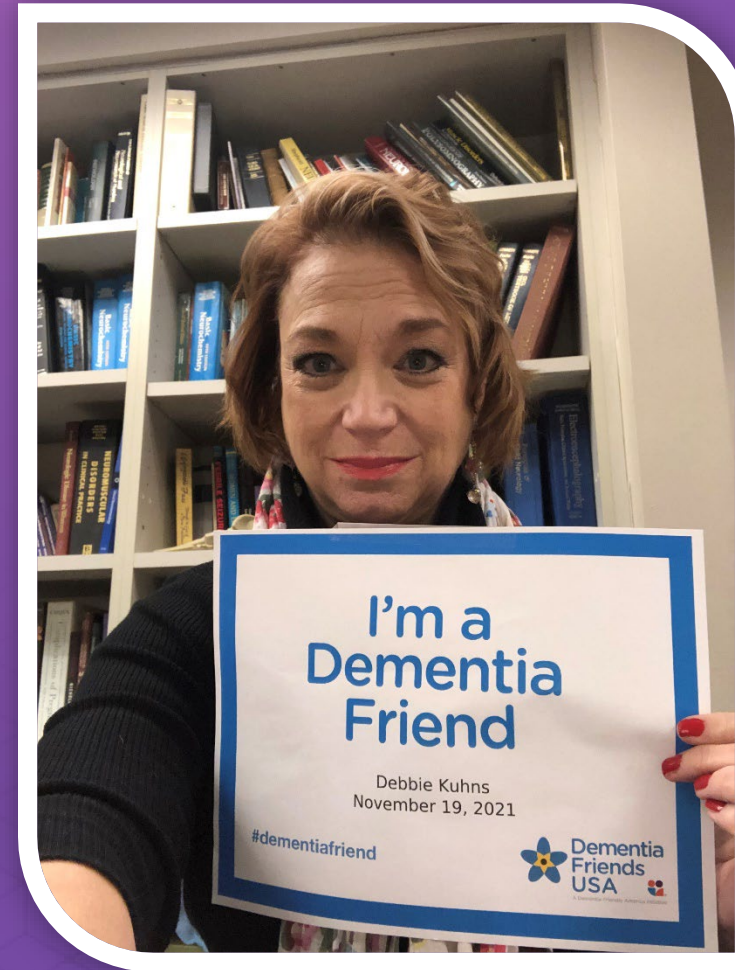
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