

Welcome

Michael S. Heller Memorial
Young-Onset Alzheimer's
Conference



University of Nebraska
Medical Center



Nebraska
Medicine

Early-Onset, Alzheimer's Disease: An Introduction

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University of Nebraska
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Why Focus on Early Onset AD?

- Alzheimer's disease (AD) isn't expected at such a young age
- Atypical forms of AD are more common in young onset patients, making diagnosis harder and often delayed
- Genetic contribution is more common
- More psychosocial issues, because of younger age when symptoms start



Topics to Cover



HOW
FREQUENT?



CAUSES AND
GENETICS



TYPICAL VS
ATYPICAL
PRESENTATIONS



DIAGNOSIS &
STAGING WITH
BIOMARKERS



TREATMENTS

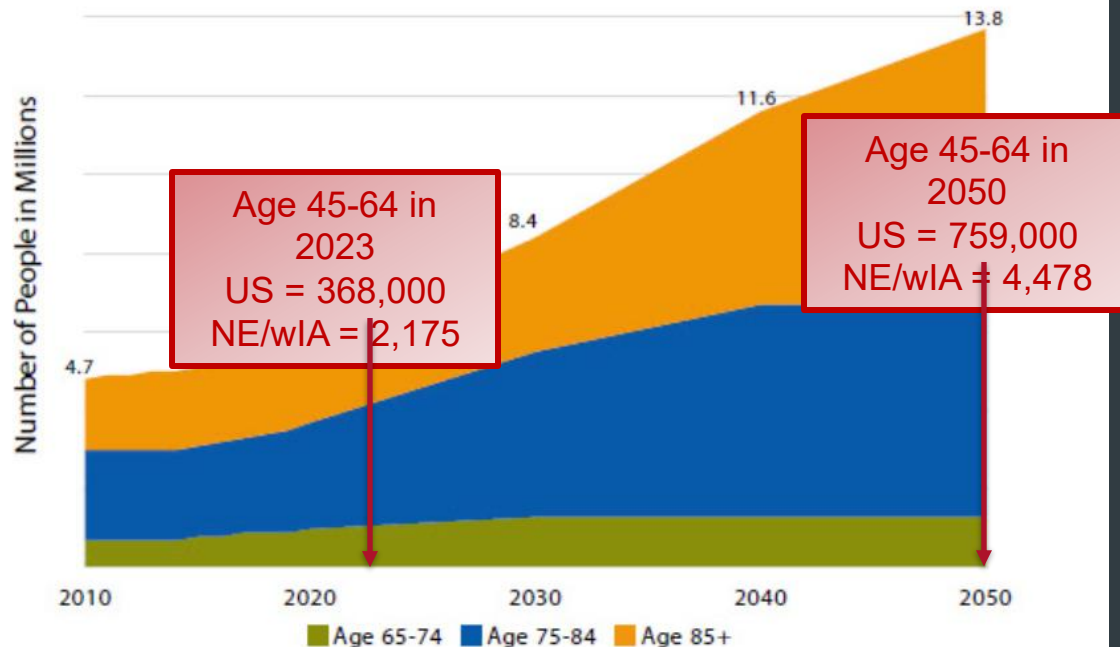


RESEARCH
OPPORTUNITIES

AD Projections over next 30 years

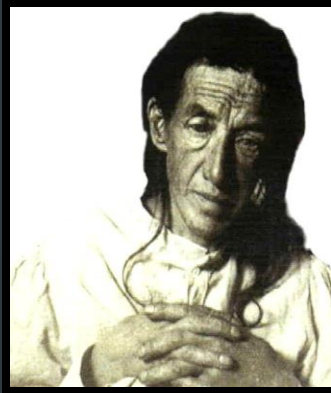


Projected Number of People Aged 65 or Older With Alzheimer's Disease, by Age Group, United States, 2010–2050



Source: Created from data in Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer disease in the United States (2010–2050) estimated using the 2010 Census. *Neurology*. 2013;80(19):1778–1783.

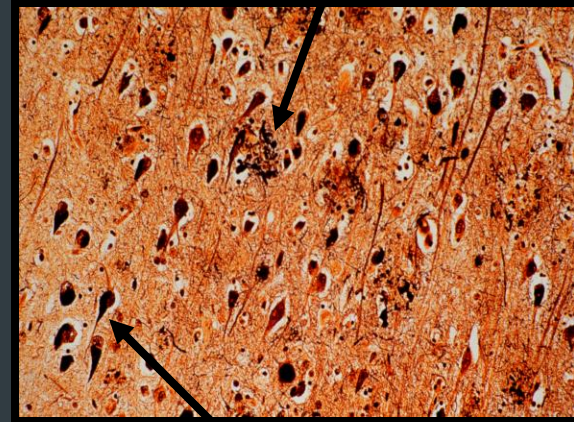
Alzheimer's Disease



Auguste
D.



Alois
Alzheimer

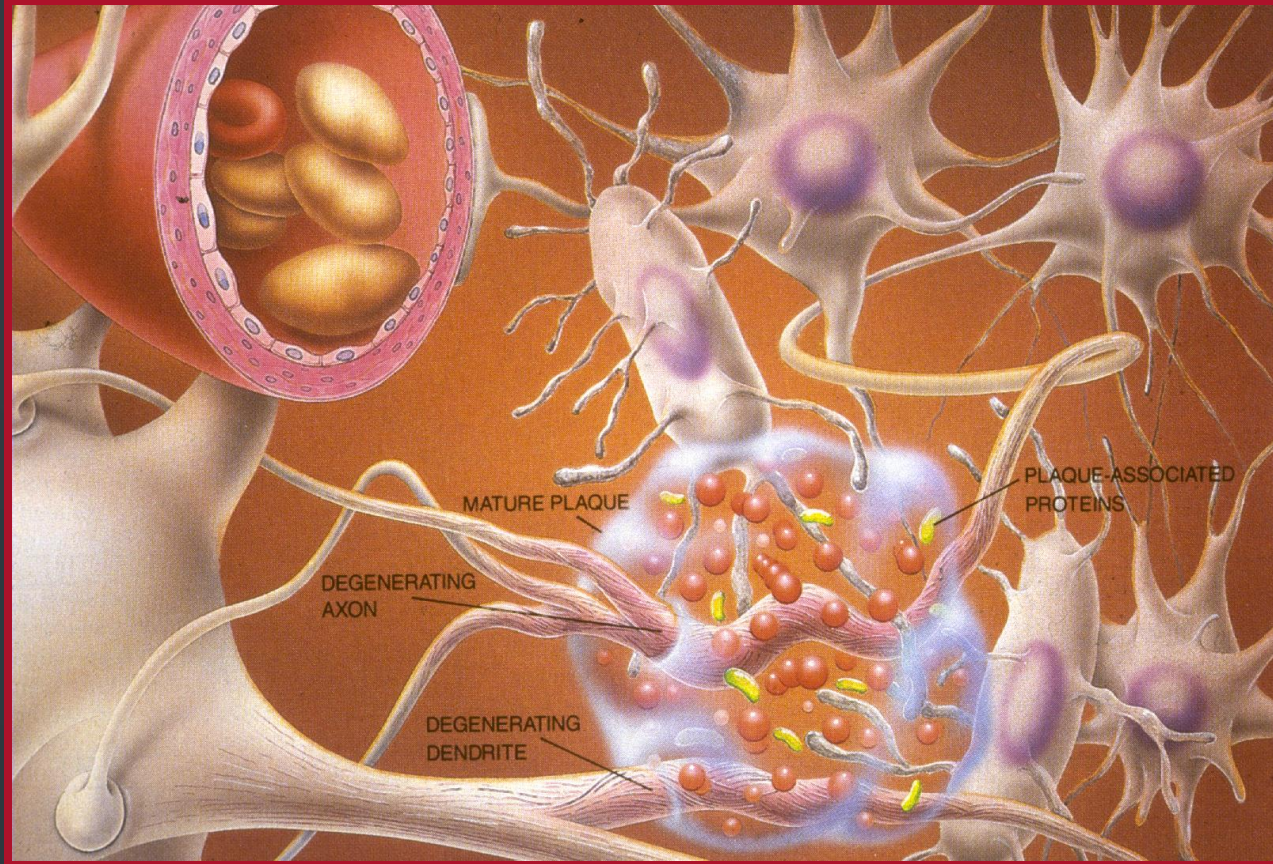


Amyloid
Plaques

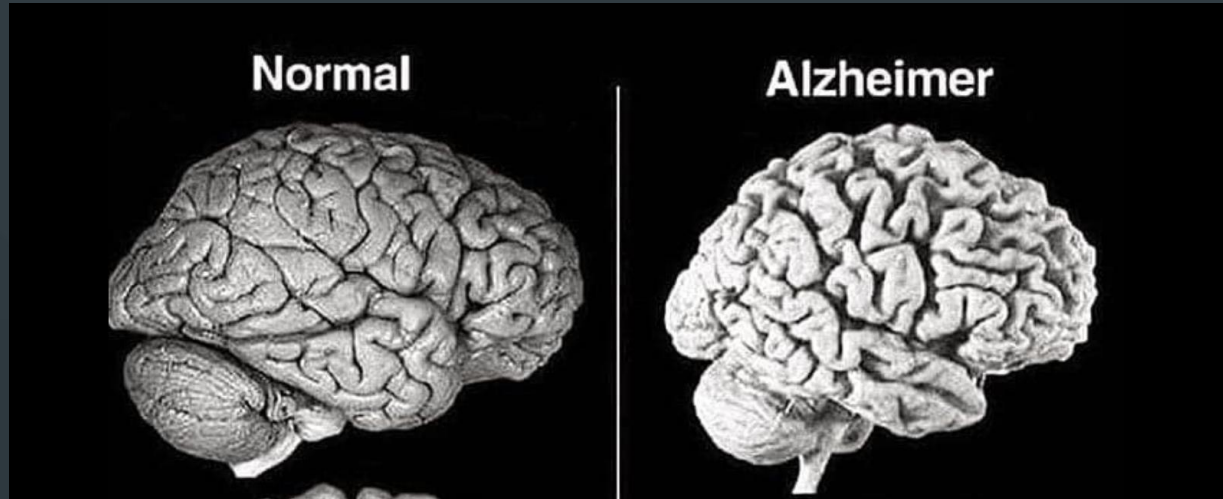
Neurofibrillary
Tangles

What Alois Alzheimer's saw and described in
1906

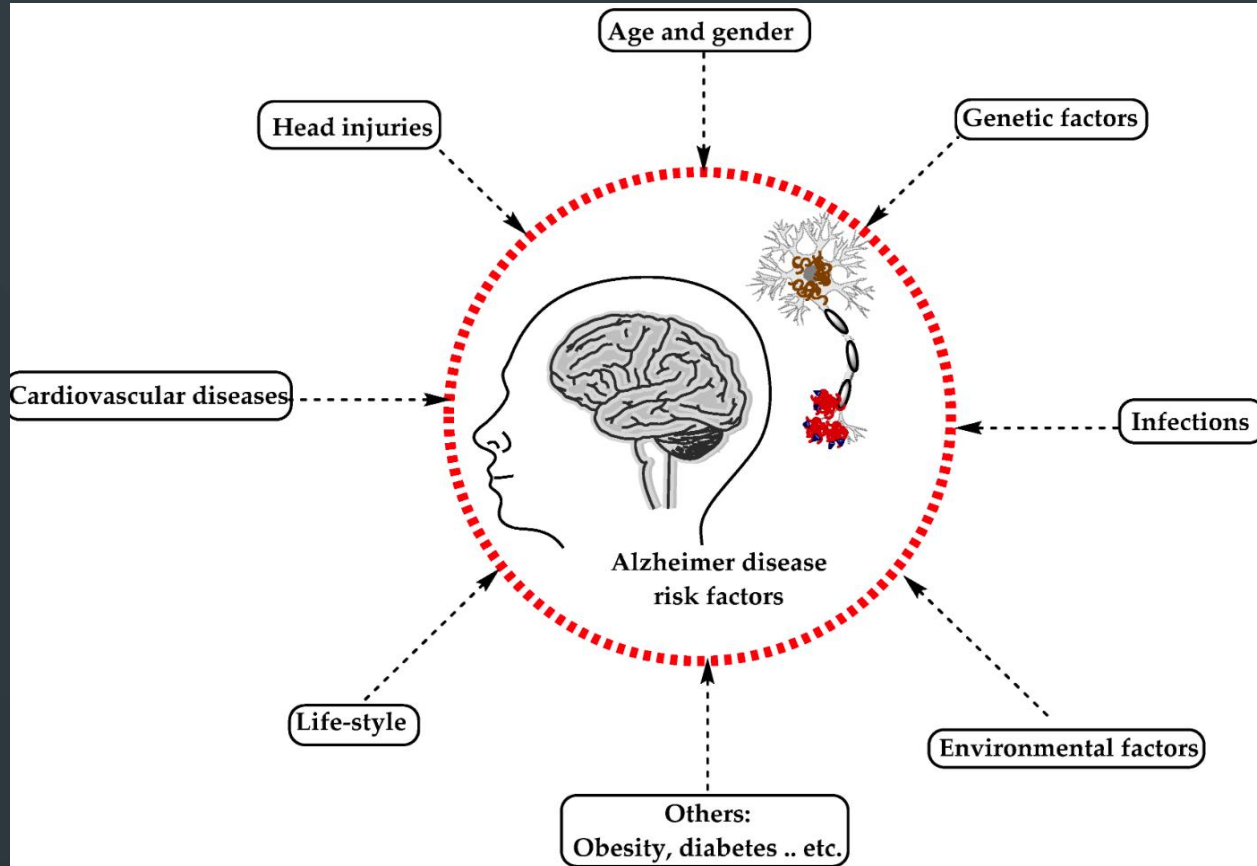
The Picture Now



Brain Atrophy (Shrinkage) in AD



AD Risk Factors



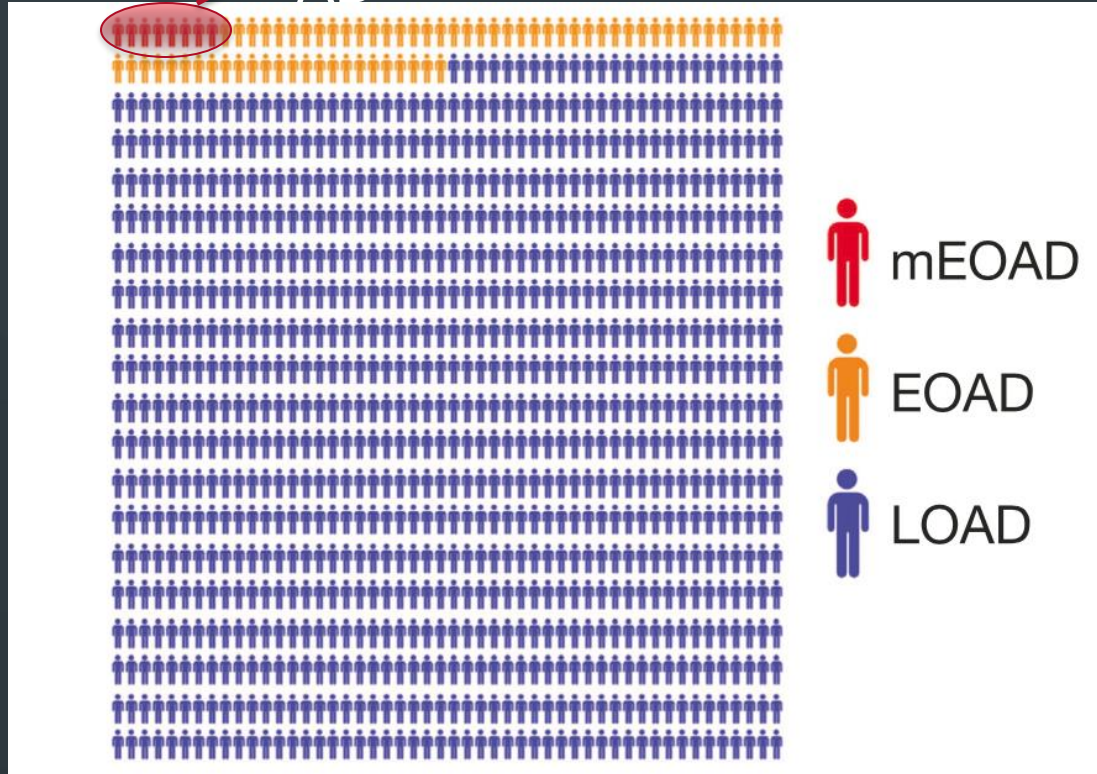
Genes Involved in AD



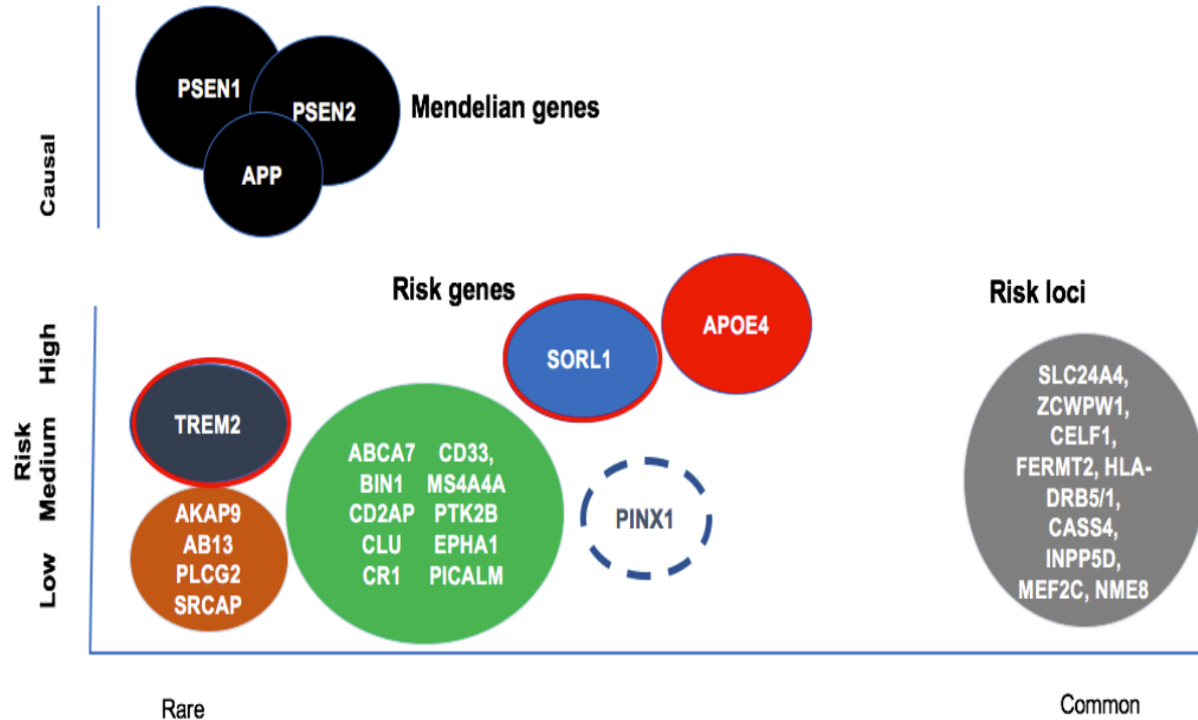
- Causative Genetic Mutations
 - Very early onset (40's and 50's), autosomal dominant inheritance
 1. Presenilin 1 (PSEN1)
 2. Presenilin 2 (PSEN2)
 3. Amyloid Precursor Protein (APP)
- Susceptibility Genes
 - Increase risk but are not sufficient by themselves, other factors impact risk
 1. Apolipoprotein E (APOE) ϵ 4 allele
 2. Approximately 30+ other genes

Causative Genes in AD

10% of EOAD, 1% of all
AD

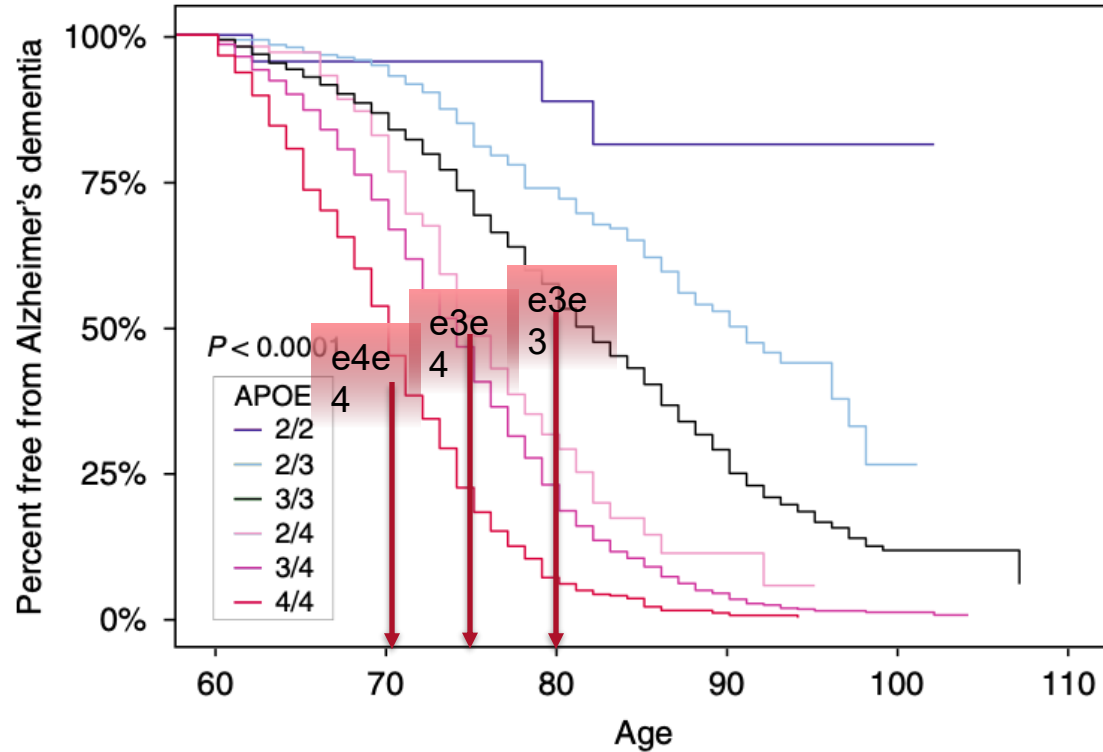


Gene Variants and AD Risk



Genetic Landscape: The spectrum of genetic influences on Alzheimer's disease spans rare to common variants that add more or less risk. [Image courtesy of Richard Mayeux.]

APOE genotype and Age of Onset of AD





Lifetime Risk of AD

Risk for MCI or dementia due to AD based on *APOE* genotype⁴

<i>APOE</i> genotype ^a	Lifetime risk estimate ^b
$\epsilon 4/\epsilon 4$	30%-55%
$\epsilon 3/\epsilon 4$	20%-25%
$\epsilon 3/\epsilon 3$	10%-15%

AD, Alzheimer disease; *APOE*, apolipoprotein; MCI, mild cognitive impairment.

^a For the remaining genotypes ($\epsilon 2/\epsilon 2$, $\epsilon 2/\epsilon 3$, $\epsilon 2/\epsilon 4$), insufficient data exist to calculate reliable estimates.

^b Through age 85.

From Qian J, et al. PLOS Med 2017.

Having a first degree relative with AD increases your baseline lifetime risk of AD by 30%

Woman age 45, lifetime AD risk = 19%, with FH 25%

Man age 45, lifetime AD risk = 10% with FH 13%

Summary: Causes and Genes



- AD is a multifactorial disease, with many risk factors/causes.
- Formation of aggregated forms of amyloid beta and tau that produce the amyloid plaques and neurofibrillary tangles are key events in the development of AD
- Strongly genetic forms of AD are very rare, but many genes impact risk of AD
- The APOE e4 allele increases risk of AD, with average age of onset between age 70 and 75, but risk is influenced by many other factors.

Alzheimer's Symptoms

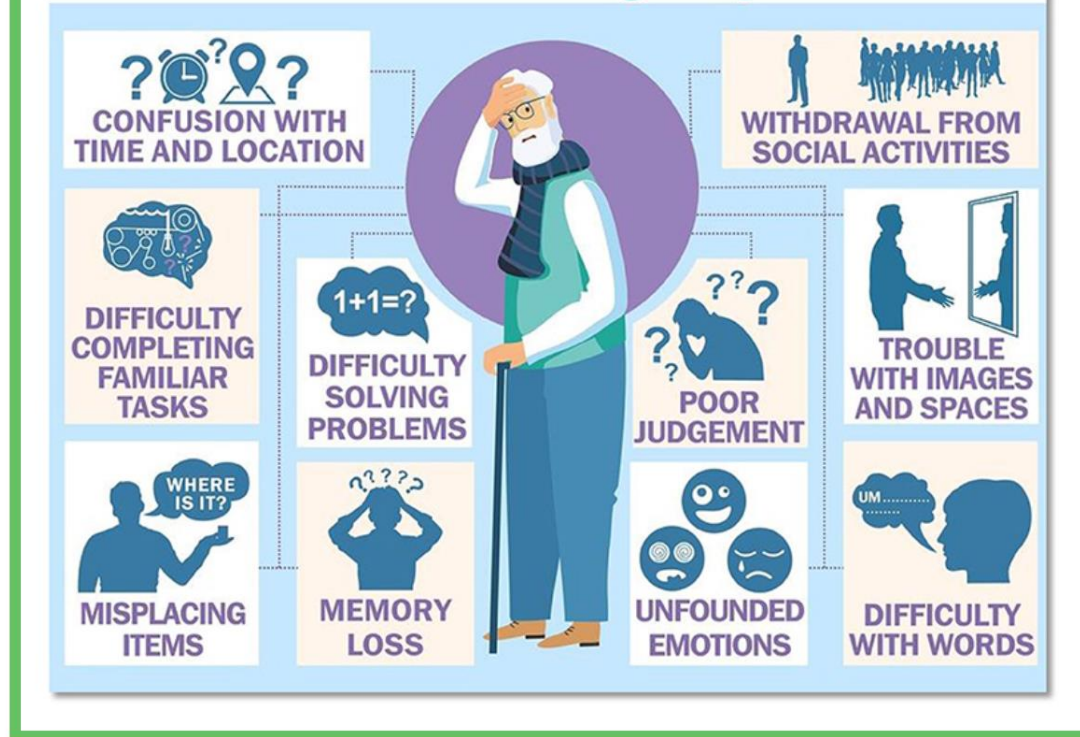


Figure 1 - Symptoms of AD.

The disease is accompanied by a variety of symptoms that impact the way the patients live their lives. Notice how similar these AD symptoms are to the signs of normal aging. Based on these outward symptoms alone, would you be able to tell an AD patient apart from a healthy person of the same age? (Image credit: <https://www.askdrray.com/a-new-drug-for-alzheimers/>).



Variants of Alzheimer's Disease

➤ Typical

- Memory Predominant Variant

➤ Atypical

- Language Predominant Variant
(logopenic Primary Progressive Aphasia)
- Frontal Lobe Predominant Variant
(behavioral/dysexecutive AD)
- Visual-Spatial Predominant Variant
(Posterior Cortical Atrophy variant)
- Asymmetric Cognitive and Motor Variant
(Corticobasal Syndrome)

Dementia Staging



- ***Mild Cognitive Impairment***
 - Cognitive decline without significant functional limitations
- ***Mild Dementia***
 - Cognitive decline sufficient to cause impairment of some instrumental ADLs
- ***Moderate Dementia***
 - Cognition impaired to point that need some help with basic ADLs
- ***Severe Dementia***
 - Severe limitations of cognition and need help with all basic ADLs

Completely Independent

Independent with IADLS

Reminders

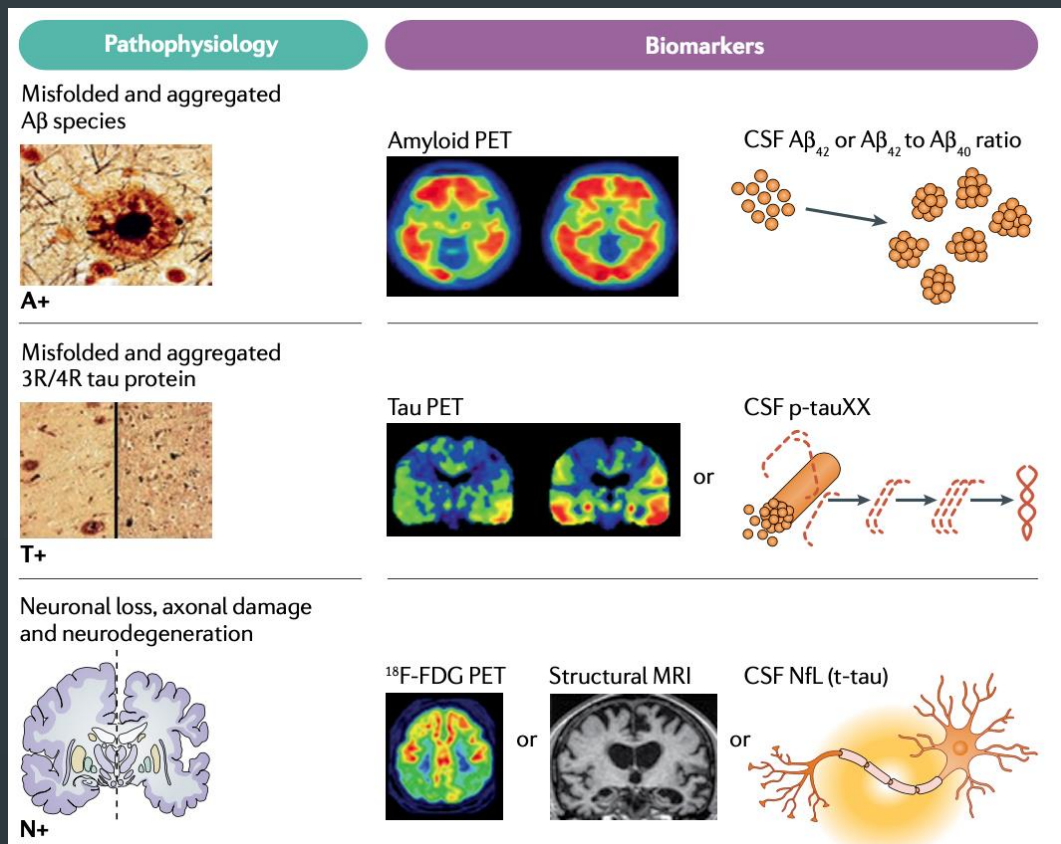
Assistance with IADLS

Supervision

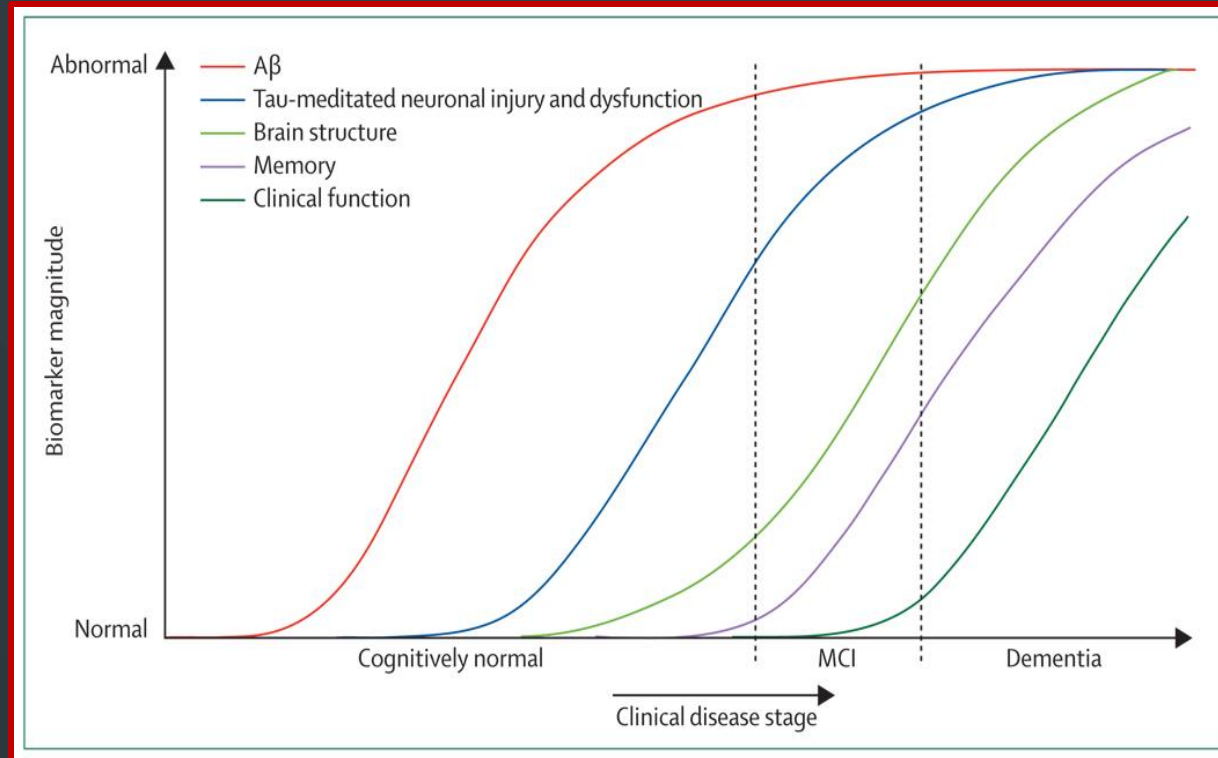
Assistance With Basic ADLs

Completely Dependent

ATN Biomarker Classification

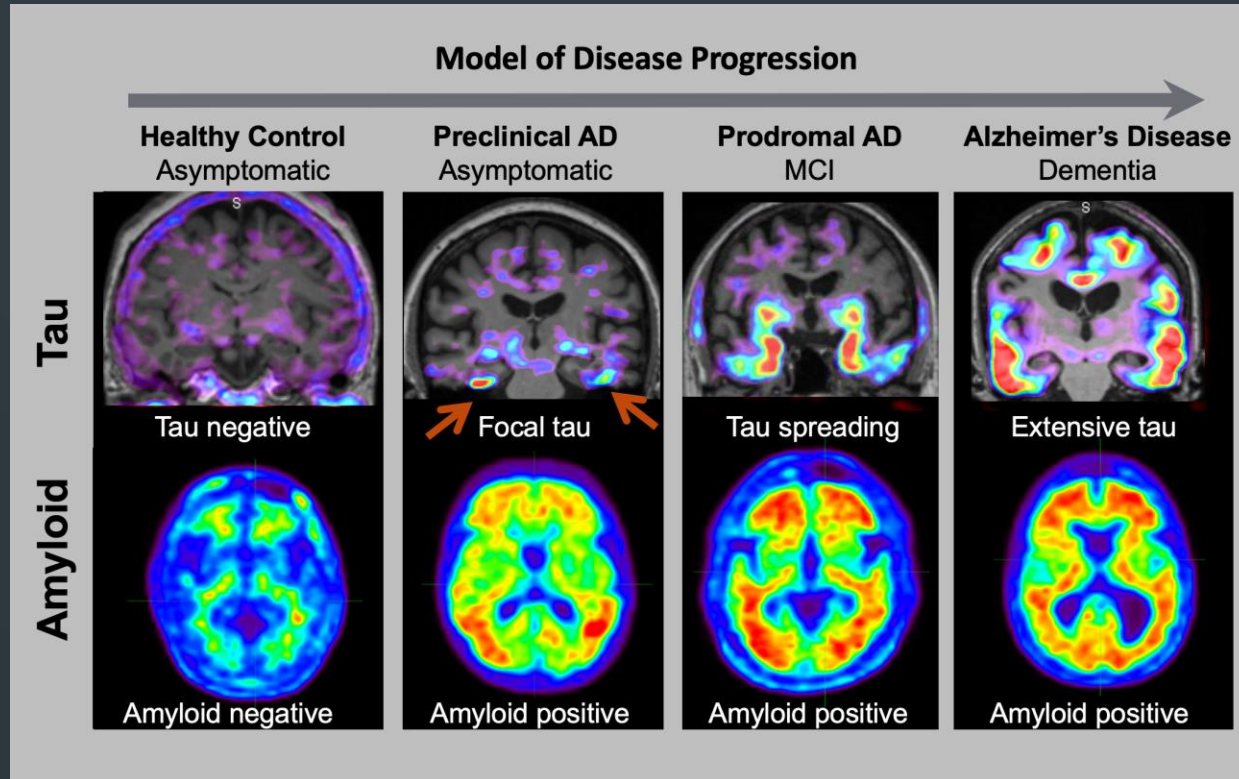


Time Course of AD Biomarkers

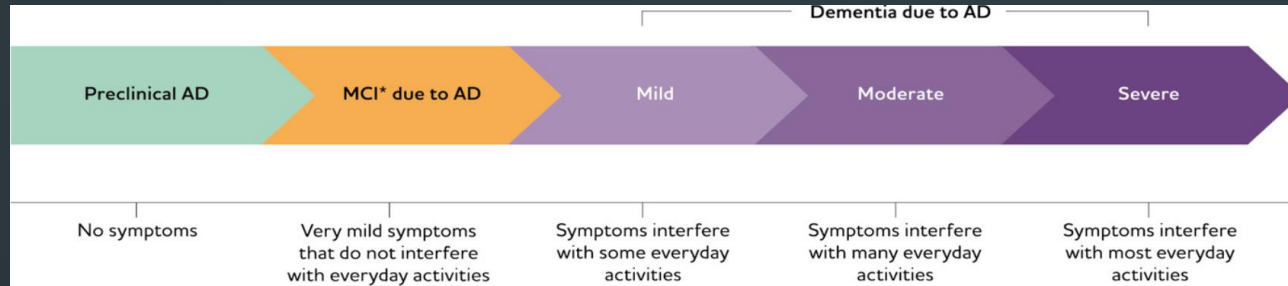
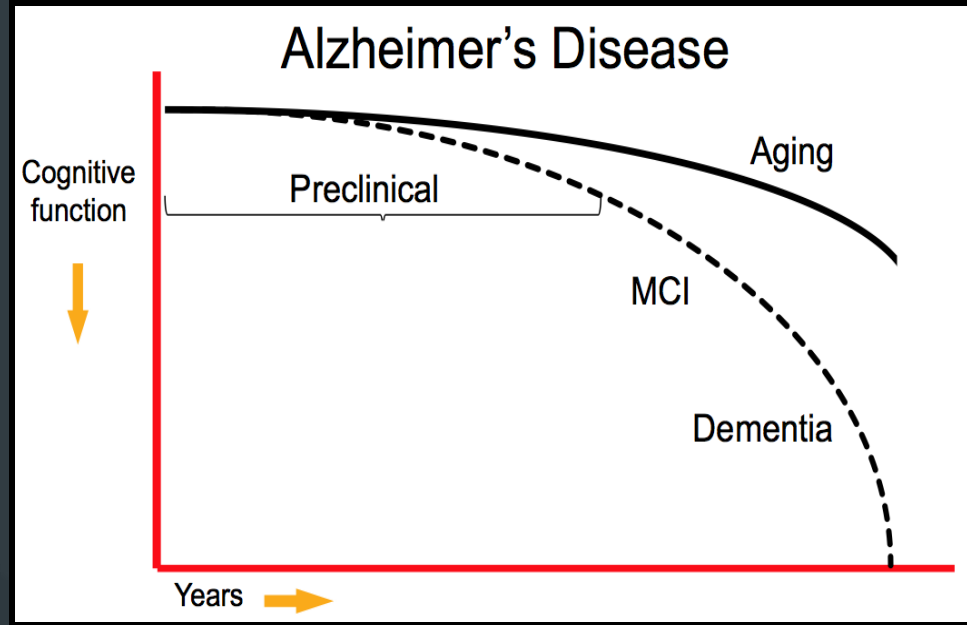


From Jack CR, et al. Lancet Neurol 2010; 9:119-128.

Evolution of Amyloid (“plaque”) and Tau (“tangle”) Accumulation in AD



The Time Course of AD



Lifestyle for “Brain Health”



The infographic is titled "Lifestyle for Brain Health" and features a central white box with a red border containing a list of seven lifestyle tips. Surrounding this box are several circular callouts with text and icons. The callouts include: "Hit the Books" (Formal education will help reduce risk of cognitive decline), "Butt Out" (Smoking increases risk of cognitive decline), "Follow Heart" (Ease risk of high blood pressure, high cholesterol, and diabetes), "Up!" (Increase risk of falls and injury by not wearing your seat belt when driving or riding in a car), "nt" (What is higher in risk of cognitive decline?), "Bud" (Staying supported. Find ways to support your loved one or share your experience with friends), "Stun You" (Challenge your brain. Build a habit. Play games like bridge), and "Break a Sweat" (Engage in cardiovascular exercise that elevates heart rate and increases blood flow to the brain, which reduces risk of cognitive decline). At the bottom, there are two more callouts: "you have depression, anxiety or stress" and "problems with memory and thinking".

- Exercise Regularly
- Stay Mentally Engaged
- Eat a Healthy Diet
- Keep Socially Connected
- Control HTN, Lipids, DM
- Get Good Sleep
- Avoid Toxins/Head Trauma

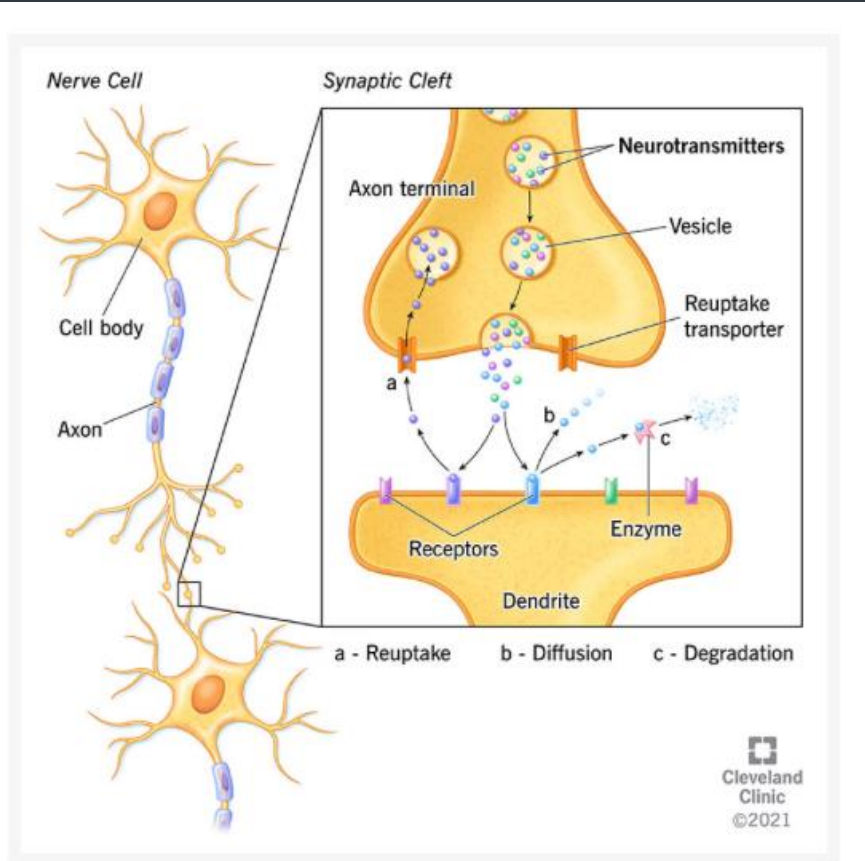
FDA-approved Medications for AD



- Cognex (tacrine) - 1993*
- Aricept (donepezil) - 1996*
- Exelon (rivastigmine) - 2000*
- Razadyne (galantamine) - 2001*
- Namenda (memantine) - 2003*
- Aduhelm (aducanumab) - 2021*
- Rexulti (brexpiprazole) – 2023*
- Leqembi (lecanemab) - 2023*
- Kisunla (donanemab) – 2024*

*FDA approval year

The Brain Uses Electrical and Chemical Signals to Communicate



Neurotransmitter

Examples:

Acetylcholine

Glutamate

Serotonin

Dopamine

Drugs modify
neurotransmitters
and this
communication

Symptomatic Medications for AD



➤ **Cholinesterase Inhibitors**

(Aricept/donepezil, Exelon/rivastigmine, Razadyne/galantamine)

- Increases acetylcholine at the synapse
- Side effects can include: nausea, diarrhea, runny nose, vivid dreams
- Improves memory, everyday function and decreases psychiatric symptoms

➤ **Glutamate Modulators**

(Namenda/memantine)

- Modulates glutamate at NMDA receptors
- Side effects can include: dizziness, confusion/"spaciness"
- Improves memory and everyday function

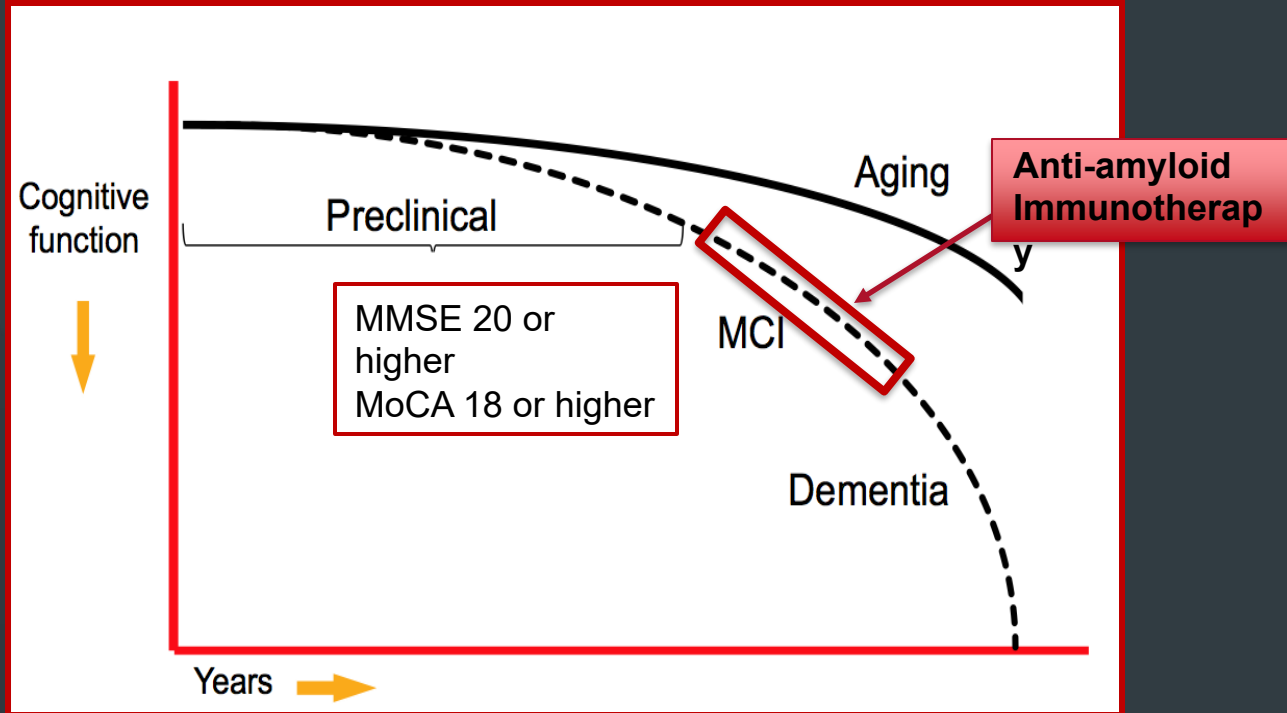


Anti-Amyloid Immunotherapy

- Monoclonal antibodies that target and remove amyloid plaques in the brain
- Given as IV infusion (every 2-4 weeks)
- Two drugs are available
 - lecanemab/Leqembi,
 - donanemab/Kisunla
- Slow declines in cognition tests and everyday function by about 30% in early stages of AD
- Can be associated with Amyloid-Related Imaging Abnormalities (ARIA)



Stage for New AD Medications



Anti-Amyloid Immunotherapy for AD



An example: lecanemab in prodromal to mild AD

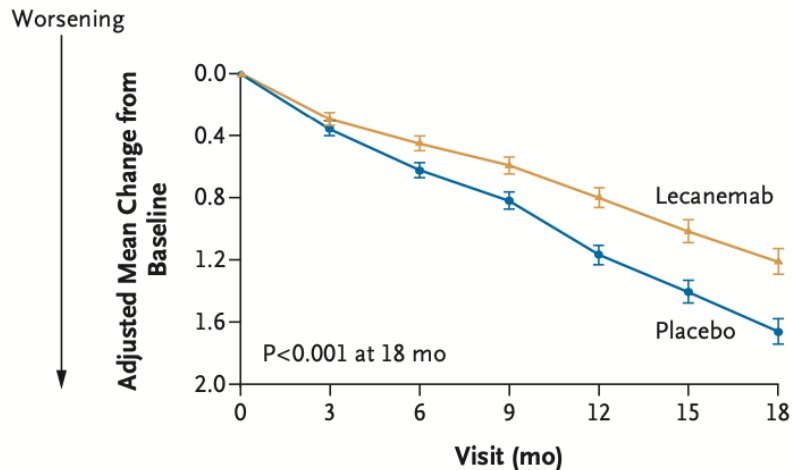
A CDR-SB Score

Benefits

27% less decline on CDR

36% less decline on IADLs

71% reduction of amyloid plaques on PET scan*



No. of Participants

Lecanemab	859	824	798	779	765	738	714
Placebo	875	849	828	813	779	767	757

*average level of amyloid plaques on PET at end of trail was in "normal" range in those receiving lecanemab

van Dyck CH, et al. NEJM 2022

Anti-Amyloid Immunotherapy for AD



An example: lecanemab in prodromal to mild AD

Amyloid-Related Imaging Abnormalities (ARIA)

ARIA with
lecanemab

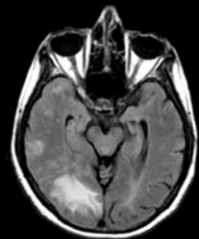
ARIA-E: 13%

ARIA-H: 8%

78% were
asymptomatic;
3% had severe AE;

ARIA-E is reversible;
Risk of ARIA higher
with APOE e4

ARIA-E:
Multi-focal
parenchymal
edema
with gyral
swelling
(FLAIR)



ARIA-H:
Micro-
hemorrhages
(GRE)



- Patients must be able to have multiple brain MRI scans to monitor for ARIA
- Patients cannot be on strong blood thinners (e.g. Coumadin, Eliquis)



Anti-Amyloid Immunotherapy in AD

Kisunla (donanemab) in prodromal to mild AD

➤ Benefits

- CDRsb 29% slowing
- IADLs 40% slowing
- 83% reduction of amyloid plaques
- Donanemab was stopped when the subject's amyloid PET scan normalized

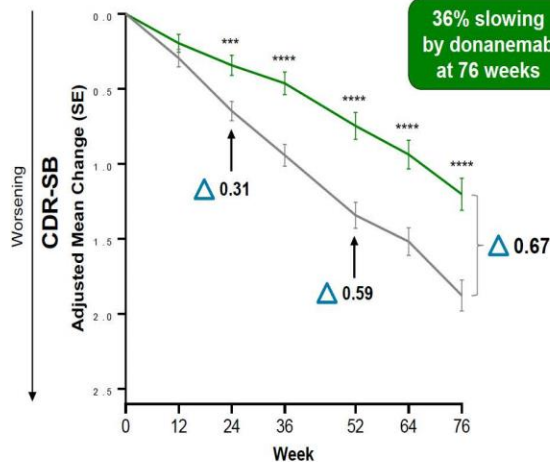
➤ Risks

- ARIA-E = 16%*
- ARIA-H = 15%*
- * with modified dosing
- No symptoms with ARIA in >90%
- Severe ARIA = 3%
- Three deaths related to complications of treatment (0.4%)



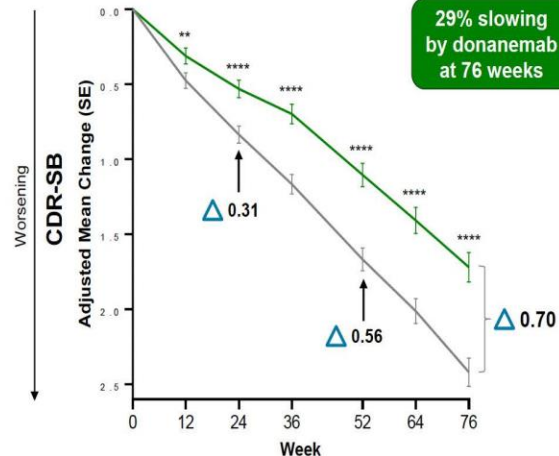
Benefits: CDR & donanemab

CDR-SB: Low-medium Tau Population



— Placebo	569	561	540	516	486	461	459
— Donanemab	546	530	499	471	451	418	424

CDR-SB: Combined Tau Population



— Placebo	838	825	784	752	713	678	672
— Donanemab	794	774	731	682	650	603	598

For CDR-SB: adjusted mean change from baseline, SE, 95% CI and p-value are derived using pre-specified mixed model repeated measures methodology with fixed factors for treatment, visit, treatment-by-visit interaction, and covariates for baseline score, baseline score-by-visit interaction, age at baseline, pooled investigator, baseline acetylcholinesterase inhibitor/memantine use and baseline tau level (Combined model only). ** P<0.01, *** P<0.001, **** P<0.0001. Abbreviations: CDR-SB = Clinical Dementia Rating – Sum of Boxes n = number of participants; SE = Standard Error



Clinical AD Research at UNMC

- **Early Diagnosis & Monitoring**
 - Driving for early detection of Alzheimer's
 - TCD measures of CVR
- **Novel Treatments**
 - Trailrunner study of remternetug
 - Trontier study of trontinemab
- **Caregiver Research**
 - AD patient-caregiver synchrony and AD patient & caregiver outcomes
 - Possible new study comparing two treatments for caregiver depression



Email for more info: adtrials@unmc.edu

- **AD Prevention Trial – Trailrunner Study**
 - Age 65-80, normal cognition, positive AD blood biomarker test
 - **Remternetug** vs placebo, sq for 1.5 years, then 3-5 years of follow-up
- **AD Treatment Trial of drug using BBB shuttle technology – Trontier Study**
 - Age 50-90, prodromal to mild AD, amyloid PET positive
 - **Trontinemab** vs placebo, IV for 1.5 years followed by opportunity everyone to go on the study drug

National Early Onset AD Research



- Longitudinal Early-Onset Alzheimer's Disease Study: LEADS
 - Observational study of 500 EOAD patients and includes cognitive testing, lab tests, spinal fluid tests, and brain imaging (MRI, PET)
 - Closest sites in Rochester, MN (Mayo Clinic), Chicago, IL (Northwestern Univ.) and St. Louis, MO (Washington Univ.)
- Dominantly Inherited Alzheimer's Network (DIAN)
 - Study patients with a genetic mutation causing AD and their families. Located in St. Louis, MO at Washington University.
 - DIAN Treatment Unit (DIAN-TU) is conducting clinical trials for patients and at-risk family relatives.





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Partnering with Providers and Navigating the Healthcare System

Julie Pavelka MS, APRN-NP

Nebraska Medicine Department of Neurological Sciences
Memory Disorders Team

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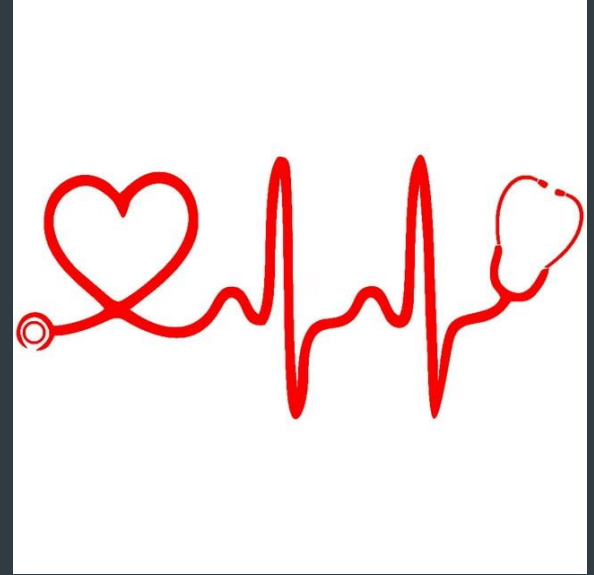




Gate Keeper

Primary Care Provider (PCP)

- Physician
- Nurse Practitioner (NP)
- Physician's Assistant (PA)





Memory Disorders Team

Memory Disorder Specialist

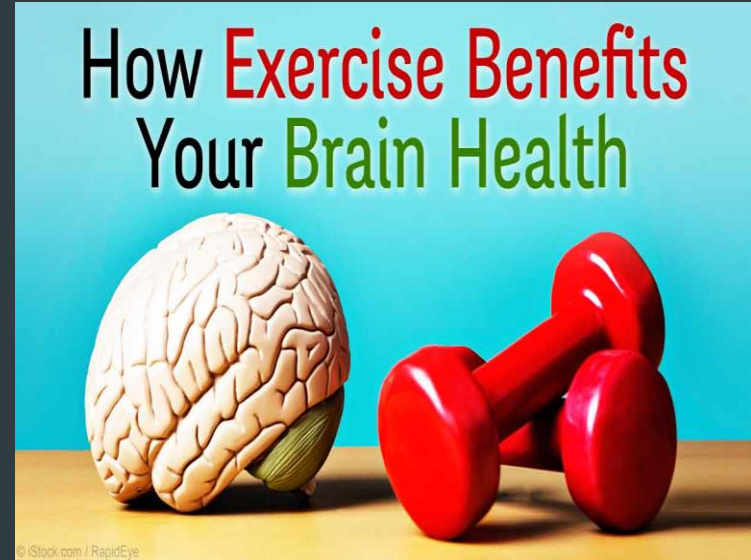
- Neurologist
- NP/PA
- Memory Disorders Registered Nurses
- Medical Assistants/Certified Nursing Assistants





Therapy

- Physical Therapy
- Speech Therapy
- Occupational Therapy
- Nutrition Therapy
- Trainer





Additional Team Members

- Social Worker
- Pharmacist
- Mental Health
 - Psychiatrist or NP/PA (that specializes in Psychiatry)
 - Psychologist
 - Therapist/Counselor



Additional Team Members

- Financial Planner
- Attorney
- Support Groups
- Faith Affiliations
- Family and Friends





Preparation for Visits

1. Complete necessary paperwork
2. Minimize stress
3. Keep a medication record
4. Be ready to answer questions
5. Take notes
6. Discuss future care
7. Ask for recommendations
8. Leave with a plan





Complete Necessary Documents

Early in the course of the disease, it's important to complete paperwork that assists with future decision-making and care. Make sure the Provider's office has copies. Revisit these documents periodically during doctor visits to ensure that your care decisions and written goals are consistent. The documents include:

- Privacy Release of Information
- Advanced Directive
 - Living Will
 - Durable Power of Attorney for Health Care



Complete Necessary Documents

Privacy Release – form at the Provider's office that indicates who can discuss diagnosis, treatments, and other medical concerns.

Advanced Directive – legal documents that provide instructions for medical care and only go into effect if you cannot communicate your own wishes.

- **Durable Power of Attorney for Health Care** – designates who can make medical care decisions when the person with dementia is no longer able to do so.
- **Living Will** – legal document that tells your Health Care Team what medical treatments you want if you are unable to make these decisions.



Minimize Stress

For some people with dementia, talking about an appointment ahead of time may be helpful. For others, it may be stressful. Use past experiences as a guide. To minimize stress:

- Schedule appointments, when possible, during the best time of day for the person with dementia.
- Allow for plenty of time to travel.
- Bring a friend/family member to serve as a back-seat companion for the person with dementia.
- Ask the provider's office ahead of time if there is a quiet place to wait for the doctor.
- Bring a favorite book, magazine or activity for the waiting time.
- Focus on something enjoyable to do after the appointment, such as going out for a treat.



Keep a Medication Record

Keep a list of all medications, including over-the-counter drugs and dietary supplements. You might bring a bag of all prescription and nonprescription drugs for the doctor to review. A complete record should include:

- Name of the medication
- Daily dosage
- Purpose
- Name and contact information of the prescribing doctor
- Prior medications that have been tried and stopped

Keep a log of daily medication use. Record any possible side effects, changes in behavior or problems that may be related to medication use. Note any missed dosages.

Prepare a list of questions you have about any medication or side effect. If the person with dementia lives in a care facility, ask the staff ahead of time about any concerns regarding medications.



Be Ready to Answer Questions

Keep a log between appointments to help the person with dementia or you to answer the doctor's questions. Record changes in memory, behavior or mood. Make notes of times of day or types of experiences that are challenging and those that are positive.

Before the appointment, write down any questions you have regarding symptoms and behaviors.



Take Notes

Take notes during the appointment. You might also invite a friend/family member to take notes. If you don't understand something the doctor tells you, ask for clarification. If the doctor prescribes a new medication or adjusts a dosage, record the following:

- Name of the medication
- Instructions for taking the medication
- Reason for taking the medication or for adjusting dosage
- Possible side effects
- Instructions for when to call the doctor or to stop taking the medication



Discuss Future Care

Over the course of the disease, treatment goals will change. Discuss with your doctor expected care needs in the short term and long term. Discussions may include plans for:

- Decisions about driving
- Need for supervision or adult day services
- Memory care centers
- Nursing home care
- Palliative care
- Hospice services

Discuss how these decisions meet overall treatment goals and align with advance directives.



Ask for Recommendations

If you need help, ask. The Provider can refer you to various community resources, such as the local area agency on aging, meal services, senior centers, respite care and support groups. Some clinics or hospitals may have a social worker to help identify and arrange support services.



Leave with a PLAN

Write down any instructions or tasks that need to be addressed between now and the next appointment, including:

- Appointments or tests that need to be scheduled
- Details about changes in treatment or care
- Concerns or instructions to share with other caregivers
- Behaviors or changes in signs or symptoms to watch out for



Organize Information



Together

T

E

Everyone

Achieves

A

M

More





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Navigating Resources Through All Stages

COLLEEN HOARTY, LCSW

THE MICHAEL S. HELLER MEMORIAL YOUNG-ONSET
ALZHEIMER'S CONFERENCE

NOVEMBER 15, 2025



Today's Objective

- ▶ To provide information on resources that can be helpful across stages of a diagnosis of Alzheimer's Disease
 - Information on disability benefits
 - Care options as care needs increase
 - Services that can be helpful in later stages
 - Other resources to have on your radar

Employment and Disability Benefits

Decision to stop working is often not an easy one

Better to make the decision yourself rather than having an employer make it for you

File for disability benefits from your job BEFORE you stop working or you lose them

Take advantage of Short-term Disability and Long-term Disability (STD and LTD) benefits offered through work

Types of Disability Benefits

**Employer-sponsored
benefits**

Private disability policy
(short and/or long-term)

Social Security Disability
(SSI or SSDI) - can check
whether you have
enough work quarters
earned for SSDI at
ssa.gov/myaccount

Social Security Disability (SSDI)and AD

- Alzheimer's Disease is one of the diagnoses on the Compassionate Allowances list
- Information on applying and helpful tips for applying with this diagnosis:
 - <https://www.alz.org/help-support/caregiving/financial-legal-planning/social-security-disability>
 - SSDI toolkit checklist - <https://www.ssa.gov/pubs/EN-64-110.pdf>
 - Can apply by phone, in-person or online <https://www.ssa.gov/applyfordisability/index.htm>
- Eligibility depends on how many work quarters you have earned over a lifetime of earnings and how recently you have earned them
- Benefit amount varies based on what you have paid into it

Insurance Coverage

- Need to consider insurance options if you are no longer working and you have had insurance tied to your employment (and compare not only monthly premiums but co-pays and coinsurance)
 - ▶ **COBRA** – continuation of current coverage through job
 - ▶ **Spouse's insurance**
 - ▶ **Affordable Care Act (ACA) Marketplace plan** (open enrollment going on right now ([healthcare.gov](https://www.healthcare.gov))). If you are losing insurance outside of open enrollment, you can qualify for a **Special Enrollment Period** if applying within 60 days of losing insurance
 - ▶ **Medicaid** – Annual income must be below \$21,597 for a single person and below \$29,187 for a couple
 - ▶ **Medicare starts after two years** of receiving SSDI benefits

Care Options as Care Needs Increase



Planning Ahead is Key

- ▶ Planning ahead with a progressive illness is very important
- ▶ If possible, have conversations about what is important to you as a person with Alzheimer's, as a care partner, or as another loved one
- ▶ Parallel planning – e.g. - planning to maintain care at home while also planning on the possibility of transitioning to a care community if needed - What is your back-up plan?
- ▶ Start to build your care team – identify people in your life that you can go to for help when you need it. What will you do if/when there are any gaps in care?
 - Family members
 - Friends
 - Professional home care agency or other hired caregivers
 - Community supports

Maintaining Care at Home

- ▶ In-home care for companionship, supervision, respite services, or assistance with personal cares
- ▶ Adult Day Services – programs provide above services outside the home for several hours during the day
- ▶ Cost – typical cost of agency in-home care is \$35-\$45/hour, while private individual caregivers often range from \$18-\$25/hour. Adult day services typically range from \$75-\$125/day (5-8 hours of care)
- ▶ Funding options: private payment, veterans benefits, long-term care insurance, Area Agency on Aging programs, respite through Medicare GUIDE program, Medicaid waiver
- ▶ Addressing home safety – emergency response systems, security modifications
(<https://www.alz.org/help-support/caregiving/safety/home-safety>)

Transitioning Care From Home Into a Long-Term Care Community

- ▶ At some point it may be a consideration to transition care from home into a long-term care community
- ▶ Always important to have a back-up plan and to be thinking about Plan B
 - ▣ Plans can change for a variety of reasons (care team changes, complex symptoms that may be hard to navigate at home, care needs may be better met in a long-term care community)
- ▶ Very important to plan ahead
- ▶ It can be helpful to meet with a financial advisor and/or elder law attorney to be able to plan financially
- ▶ Need to make sure Advance Directives are in place

Transitioning Care From Home Into a Long-Term Care Community

- ▶ Memory care communities may be stand-alone or may be part of an assisted living or skilled nursing community
- ▶ Visit communities ahead of time when you are not under pressure to make a quick decision to see what might be a good fit
- ▶ Many communities have waiting lists
- ▶ Utilize senior living advisors if needed
- ▶ Options for payor sources: private payment, long-term care insurance, veterans benefits, and Medicaid programs

Palliative Care and Hospice Care



Palliative Care

- ▶ Care that is focused on alleviating and managing distressing symptoms and providing support
 - Support for both patient and family members
 - Support with decision-making
- ▶ Can be initiated at any stage of a progressive illness
- ▶ Covered by insurance
- ▶ Outpatient services are available if someone is at home or resides in a long-term care community (appointment is either in-person or via telehealth). At Nebraska Medicine this is provided by a physician.
- ▶ A few home health and hospice agencies have in-home palliative services (monthly visits from a nurse practitioner)

Hospice Care

- ▶ Type of palliative care that is focused on providing support in the end stages of a serious illness
- ▶ A physician must certify that someone likely has 6 months or less to live based on the typical course of their illness
- ▶ Must have a doctor's order and is covered by insurance
- ▶ Can be provided in the home, in a long-term care community, or in a free-standing hospice setting
- ▶ Team consists of medical director, nurse case manager, home health aide, social worker, chaplain, volunteers
- ▶ Hospice agencies may offer additional services as well
- ▶ **Hospice indicators with an Alzheimer's diagnosis:** limited speech or speech that does not make sense; increased dependency with ambulation and activities of daily living; incontinence; unintentional and progressive weight loss

NE Caregiver Tax Credit

- The Caregiver Tax Credit Act establishes a nonrefundable tax credit for family caregivers who provide care and support to an eligible family member for tax years beginning on or after January 1, 2025, that requires an application filed with the Nebraska Department of Revenue (DOR).
- The tax credit will equal 50% of the eligible expenditures incurred by the family caregiver during the taxable year with a maximum credit of \$2,000, or **\$3,000 if the eligible family member is a veteran or is diagnosed with dementia.**
- Income limits
- Do not have to be residing with the person
- Care receiver cannot live in a long-term care setting
- <https://revenue.nebraska.gov/caregiver-tax-credit-act>

Medicare GUIDE Program (Guiding an Improved Dementia Experience)

- ▶ 8-year Medicare pilot project that started this past summer (2025)
- ▶ In Nebraska there is one contracted agency to provide these services, called Medicine in Motion
- ▶ Goal is to increase the quality of life for the person with Alzheimer's and to increase caregiver support
- ▶ Provides ongoing support and care management to families with 24/7 availability
- ▶ For people with traditional Medicare (not those who have a Medicare Advantage plan) it can provide up to \$2500/year of respite services
- ▶ Info@MedicineinmotionMD.com or 531-359-6571

Additional Resources

- ▶ Support groups - <https://www.alz.org/nebraska/support>
- ▶ State Health Insurance Program (SHIP) <https://doi.nebraska.gov/nebraska-ship-smp>
- ▶ Area Agencies on Aging –
 - Eastern NE Office on Aging – www.enoa.org
 - Aging Partners - Aging Partners – <https://www.lincoln.ne.gov/City/Departments/Aging-Partners>
 - Connections - <https://www.connectionsaaa.org/>
- ▶ Omaha area and Council Bluffs area resource lists -
 - [douglas-sarpy-county-community-resources-3-2025.pdf](#)
 - [council-bluffs-pottawattamie-county-community-resources-3-2025.pdf](#)

Thank you!

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ESTATE PLANNING ESSENTIALS



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WHAT IS AN ESTATE PLAN?

Putting together legal documents and designations that will help manage your legal, financial and healthcare affairs BOTH during your life and after your passing.



SITUATIONS YOU MAY ENCOUNTER WHERE AN ESTATE PLAN WILL HELP

- Needing to access a bank account;
- Signing a tax return;
- Applying for disability;
- Signing over a deed;
- Managing a retirement account;
- Assigning death benefits



KEY TOOLS TO ANY ESTATE PLAN

1. POWER OF ATTORNEY
 - Financial & Medical
 2. NAMED BENEFICIARIES &
JOINT OWNERS
 3. WILL / TRUST
- 
- 

Benefits of Estate Planning

- Providing for your Family. Making sure your family is provided for the way you would do if you were still able and around.
- Control. Transfer to the individuals you designate – rather than the State of Nebraska determining your heirs or a conniving heir.
- Peace of Mind. One less thing for your family to worry about in a time of crisis or grief.
- Planning for Emergencies. Know who will handle the details if you aren't able
- Limiting the likelihood of family fights. Put in place common sense controls and divisions to limit family strife.
- Efficiency. Think about costs and possible problems ahead of time to make the transfer of assets more timely and cost effective.

HOW TO CREATE

What the process should look like with an attorney:

1. Meet with the attorney in their office or on zoom to discuss your particulars
2. Decide on what type of documents you need
3. Receive drafts for your review; ask questions
4. Review with an attorney and then execute

- Handwritten
 - Easy
 - But easy to challenge
- Internet
 - User-friendly and immediate
 - May not take into account your particular situation
 - You may not know the questions to ask
- Attorney
 - More robust process but often slower and more expensive
 - An ongoing resource when you have questions or changes
 - Better understands the human element of estate planning (e.g. one kid on a bank acct)



POWER OF ATTORNEY

Use: During your life, when you are incapacitated.

- ✓ WHO: Anyone and everyone over the age of 18, married or single
 - ✓ WHAT: A document, like a contract, that delegates your legal authority to another if you become incapacitated or immediately, as you designate.
 - ✓ WHY: So that someone has authority to make decisions for you and manage your finances when you are unable.
- 
- 

DURABLE POWER OF ATTORNEY

- Delegate authority to another
- Either immediately or upon incapacity
- For Financial and Legal Matters such as: paying bills, managing bank accounts, signing contracts, transferring real estate, signing tax returns, protecting your finances

MEDICAL POWER OF ATTORNEY

- Delegate authority to another
- Only upon incapacity
- For healthcare decisions such as:
choosing doctors, treatment options,
having access to HIPPA information
- For end-of-life decisions when you
are deemed to be “terminally” ill

WHEN CAPACITY TO SIGN IS ALREADY AN ISSUE

- Need only to understand the nature and effect of the document at the time they are signing it.
 - Pick the best time of day
 - Can make more than one attempt
 - Signed in front of a notary
- If capacity too much of an issue, can get a guardianship / conservatorship

GUARDIANSHIP/CONSERVATORSHIP

- Guardianship = authority over the body, such as healthcare and living arrangements
- Conservatorship = authority over finances and assets
- Filed through the court
- Helpful to have attorney but not required
- Online Court Resources:
<https://nebraskajudicial.gov/administration/public/guardianship-and-conservatorship-information>

NON-PROBATE TRANSFERS

Pre-planned transfers to be made at death, that do not rely on a Will document:

- Payable-on-death **Beneficiaries** on accounts (e.g. IRA, bank account)
- **Joint ownership** of real estate or accounts (e.g. both husband and wife are on title)
- **Transfer on Death Deed**. A special deed for real estate that creates a beneficiary for your house - Revocable
- **Life Estate**. A deed that allows you to keep your land during your life but then transfers it automatically upon your death – Irrevocable
- Using a **Trust**

PROBATE

What it is: The process of submitting the decedent's Will to the Court to be reviewed and verified as a legitimate Will. Upon favorable review of the Will, the decedent's named executor (personal representative) is authorized by the Court to take legal actions to settle the decedent's estate, pay bills, settle claims, talk to the bank, sign a deed, sell a house, pay taxes, and distribute the remaining assets.

Bad Rep: Probate itself is not particularly expensive – typically less than \$500. The expensive part is hiring the attorney. However, even if you have a trust, your heirs will likely hire an attorney to get advice on what to do. The costs of trust administration and probate are very similar.

LAST WILL & TESTAMENT

Use: After you die, a Will directs how your net assets are divided and to whom – distribution happens within months after death

- ✓ WHO: Anyone and everyone over the age of 18, married or single
- ✓ ESPECIALLY:
 - ❖ Families with young children
 - ❖ Married people with children from a previous marriage
 - ❖ Unmarried partners
- ✓ WHAT: A document which only gains enforceability and grants legal authority upon being submitted to a court for Probate.
- ✓ WHY: To avoid fights, prolonged proceedings, and unintended consequences

TRUSTS

- Kinds. There are many, many kinds of trusts. But the one most people use or think of when referring to a trust is a **Revocable Living Trust**. That is a trust that can be modified, terminated, and fully controlled by you while you are alive.
 - It only becomes irrevocable upon your death
- A Trust is essentially a contract that you make during your life that says how your income and assets should be handled, both during your life, and then upon your death.
- You are the trustee while you are able; however, your trust nominates a few people or a trust company to serve as trustee if you are no longer able to do so. This pre-planned delegation of authority is what makes a trust different than a Will.

MEDICAID PLANNING

- Costs of care are expensive; if you are concerned about running out of resources, Medicaid Planning is wise
- Main program = Spousal Impoverishment Program
 - The program helps protect the resources of the at-home spouse; divides the couples' resources
 - Can keep house and one car
 - At-home spouse may keep a certain level of income and other resources (e.g. retirement)
- If at-home spouse does not have minimal resources after asset split, resources will be shifted to at-home spouse and more of institutionalized spouse's care covered by Medicaid.

Tools of Good Estate Plan

Useful During Your Life

- Durable Power of Attorney for Finances
- Power of Attorney for Health Care and Living Will
- Limited Power of Attorney for Medical Treatment of your Child
- Insurance – Umbrella policies

Useful primarily at or after your Death

- Designated Beneficiaries and Transfer on Death designations on banking and financial accounts
- Joint tenancies with rights of survivorship; Life estates
- Will
- Trust (can be useful during life as well)
- Transfer on Death designations for your real property and vehicles
- Laundry list for personal property
- Pre-planned funeral arrangements

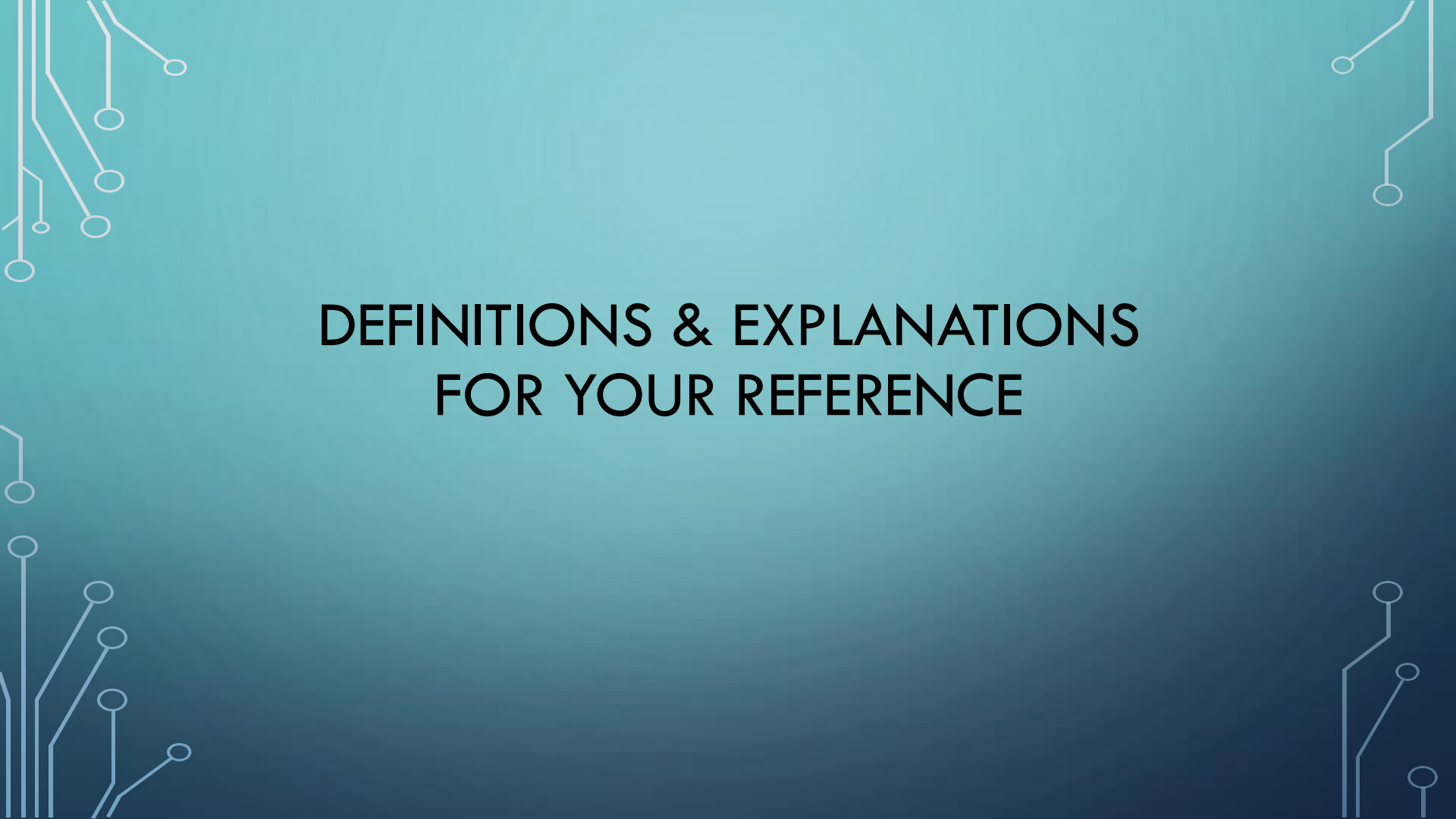


QUESTIONS?

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The background is a teal-to-blue gradient. In the corners, there are white line-art illustrations of circuit boards or neural network connections, consisting of lines and small circles.

DEFINITIONS & EXPLANATIONS FOR YOUR REFERENCE

WILL V. TRUST

Feature	Will	Trust
Takes Effect	Only after death, by submitting to the Court	Effective during life and after death
Distributions	Immediate, within months after death	Can be spread out over decades – good for young kids or people with special needs
NE Inheritance Tax	Must file as part of probate process	Legally required to file with court – saves about 1/2 of probate costs
Updates and revocability	Easy to update; fully revocable	Easy to update; fully revocable but then have to “undo” titling to the trust
Costs	• Easier to set up • Probate costs + attorney fees	• More complex and expensive to set up & maintain • Avoids some probate costs but usually an attorney is still utilized
Taxes	• Not an issue	• Can be an issue for trusts that last for decades – taxed at higher rate
Biggest Downside	• Needing probate, no matter what	• Assets don't get titled into trust so have to do probate anyway

INHERITANCE TAX

- There is inheritance tax or estate tax (so-called “Death Taxes”) at both the Federal and State levels (just like income tax)
- The Federal Tax has a very high exemption: currently \$13,990,000 per person (doubled for married couples)
- Nebraska is one of only 5 states that currently have an inheritance tax. The tax is paid directly to the counties.
 - No tax between spouses
 - 1% tax, after the first \$100k, to children & grandchildren
 - 15% tax, after the first \$25k, to a non-married partner

BENEFICIARIES ON ACCOUNTS

Insurance policies and retirement accounts require beneficiary designations. After death, the financial institution transfers the assets in that account to the designated beneficiary without the probate process. A beneficiary has no power over the account before death. A similar result can be obtained by using transfer-on-death or payable-on-death beneficiary designations on bank and investment accounts.

BENEFICIARIES ON REAL ESTATE & VEHICLES

These designations are similar to designated beneficiary designations but are more formalized. The Transfer on Death Deed is recorded with the Register of Deeds and is a public record. Upon death, title to a residence or other real property automatically transfers to the person designated on the deed without the need for a probate. The Department of Motor Vehicles also provides titles that automatically transfer ownership of a vehicle at death.

Joint Ownership with Right of Survivorship

Ownership of real property, vehicles, and bank and investment accounts can be held jointly with another person. During your lifetime the joint owner has the same power over the asset as you. However, upon death, the surviving joint owner takes immediate ownership of the asset. There is more than one type of co-ownership, so it is important the joint ownership designation provides for “with right of survivorship.”

Living Revocable Trust

A contract between an individual and a trustee for the management of assets placed in the trust. Title to the assets needs to be transferred to the trust. This contract is revocable during life and can be amended or terminated at any time. Upon death, the trust becomes irrevocable and either provides for the distribution of the trust assets (like a Will, but without the need for a probate) or provides for the continued management of the trust assets. (i.e., the trust assets are managed until children reach a certain age and then the assets are distributed).

Taxes

U.S. Estate Tax: First \$13,990,000 of property passed to one's heirs is exempt from federal estate tax. Note that lifetime gifts can use up part of this exemption amount.

NE Inheritance Tax: A tax borne by the heirs, though usually paid by the estate, for all assets inherited by those heirs. The tax applies both to assets which are inherited via probate and assets inherited by beneficiary designations or survivorship rights.

Medicaid: Medicaid can “attach” to inherited assets in an effort to get reimbursed for Medicaid benefits provided to the decedent. It can also retroactively interfere with gifts made by an individual during the 5 years proceeding the date of that individual's application for benefits.

Thank you for attending!

**Don't forget to fill out your
evaluation. Please leave them on
your table.**

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