



# How Alzheimer's Disease Affects the Brain, Behavior, Cognition, and Personality



UNIVERSITY  
OF MINNESOTA  
Driven to Discover®

SCHOOL OF  
**PUBLIC HEALTH**

UNIVERSITY OF MINNESOTA

Robyn Birkeland, Ph.D., Study Counselor  
Families and Long-Term Care Projects



UNIVERSITY  
OF MINNESOTA

**Driven to Discover®**

# Dementia and Alzheimer's

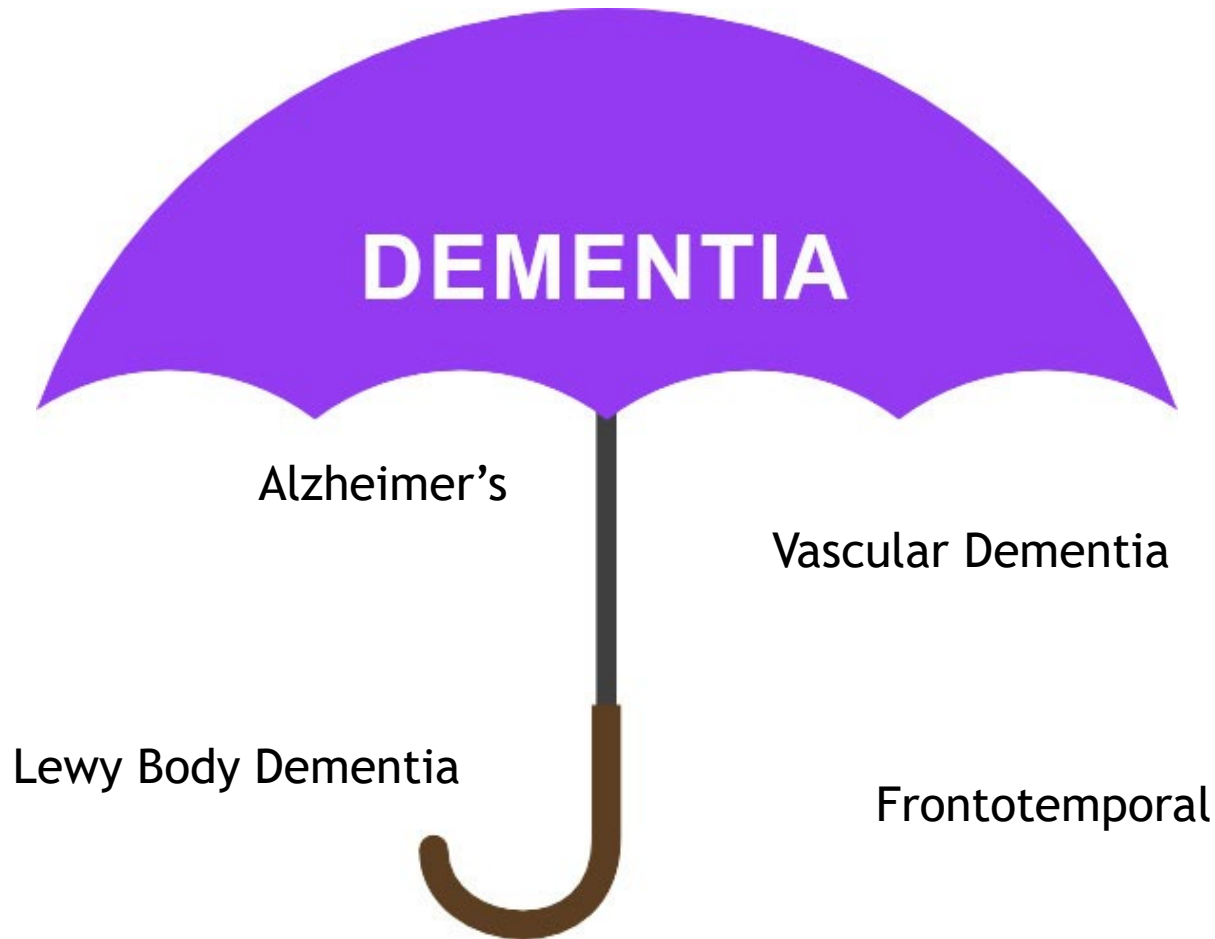
Are dementia and Alzheimer's disease the same thing?

Let's talk about it...

# What is Dementia?

- Dementia is a general term for a decline in mental ability severe enough to interfere with daily life.
- Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms
- Symptoms of dementia can vary greatly
  - At least two of the following core mental functions must be significantly impaired to be considered dementia:
    - Memory
    - Communication and language
    - Ability to focus and pay attention
    - Reasoning and judgment
    - Visual perception

# The Dementia Umbrella



# Most Common Types of Dementia

- There are 100 types of dementia.
- Alzheimer's disease is the most common cause of dementia, but there are other types of dementia too. It is possible to have more than one type of dementia at the same time. Up to 50% of cases with Alzheimer's disease are actually mixed dementia
- 60% Alzheimer's

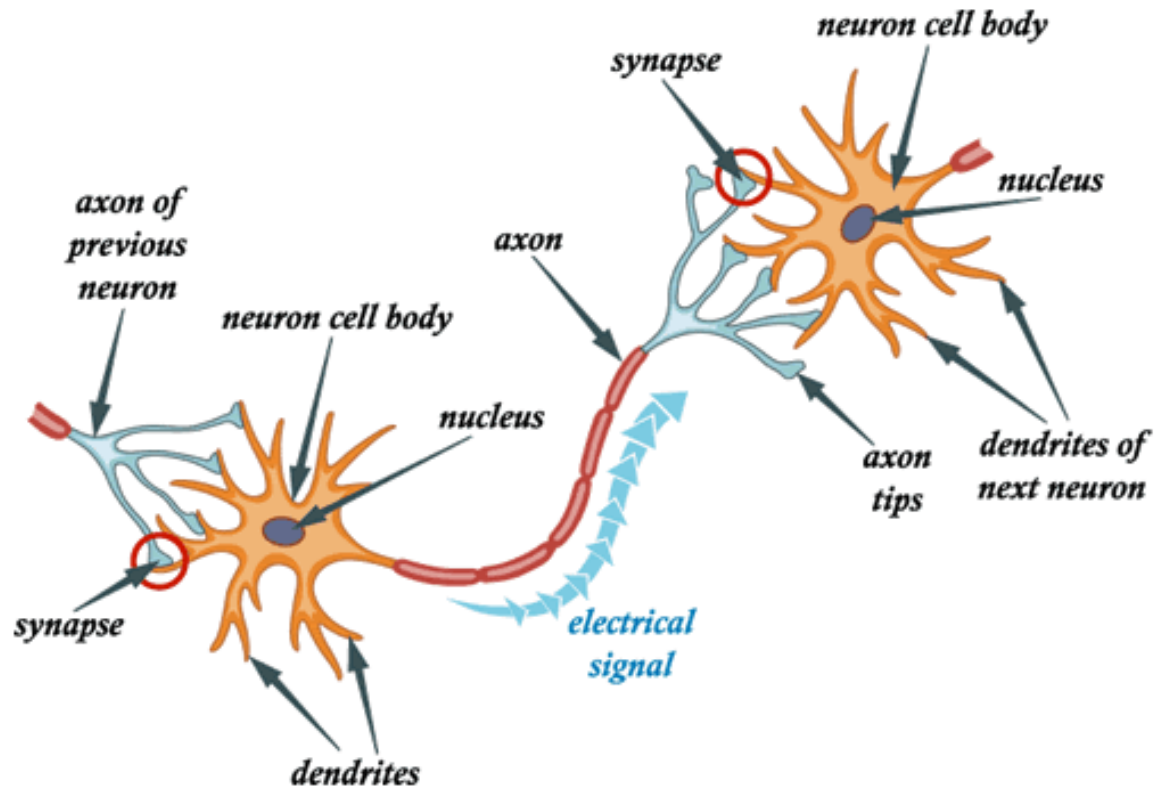
# Let's Delve into Alzheimer's Disease

# What is Alzheimer's Disease (AD)?

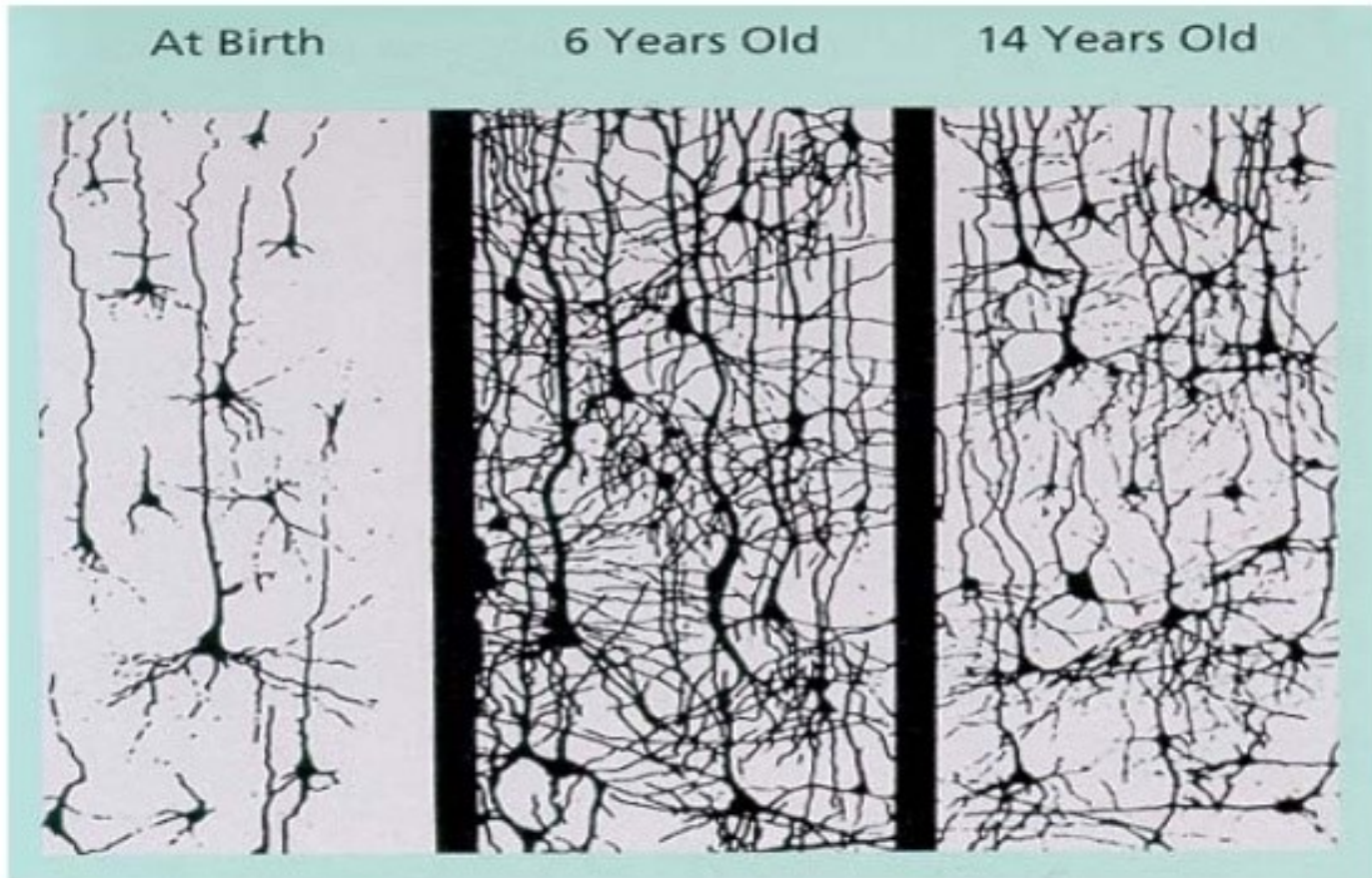
- Alzheimer's is a type of dementia that causes problems with memory, thinking, and behavior
- Alzheimer's is the most common form of dementia
- Alzheimer's worsens over time
- Alzheimer's has no current cure



# Brain Cell (Neuron)



# Synaptic Density



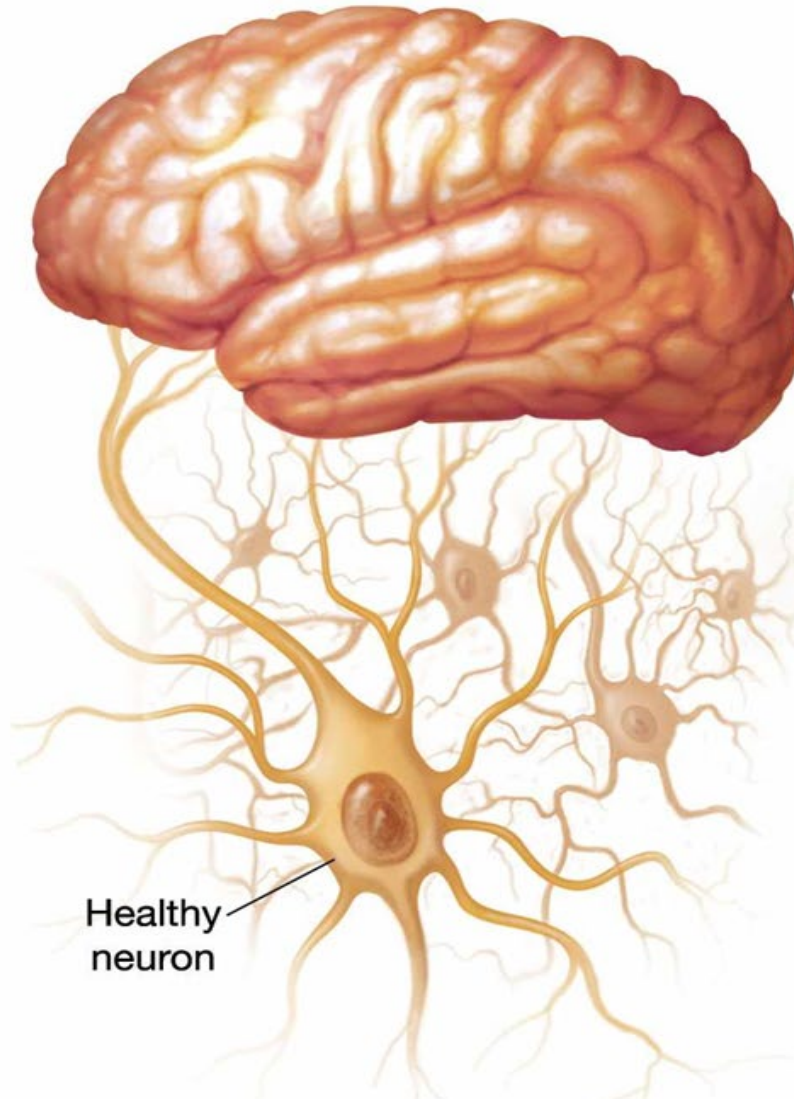
From *Rethinking the Brain: New Insights into Early Development* by Rima Shore (NY: Families and Work Institute, 1997)

**Synaptic Density:** Synapses are created with astonishing speed in the first three years of life. For the rest of the first decade, children's brains have twice as many synapses as adults' brains. (Drawing supplied by H.T. Chugani)

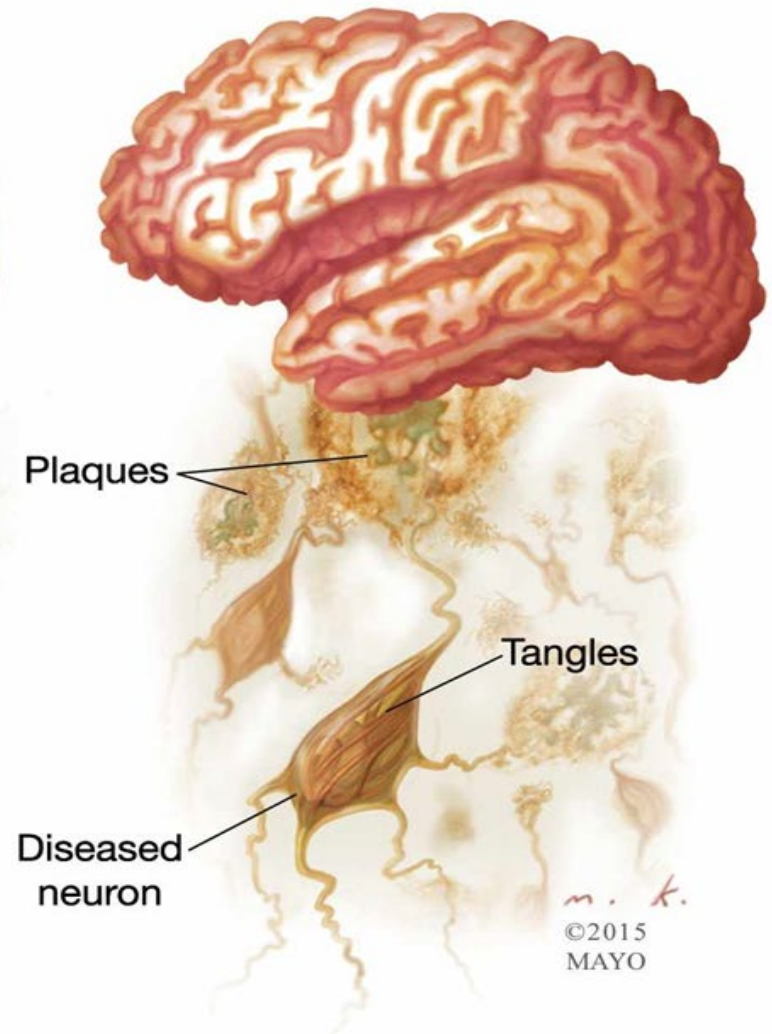
From: Harvard University, Shonkoff, J.P. 2008

# What Causes AD?

Healthy brain



Alzheimer's brain





Mild AD



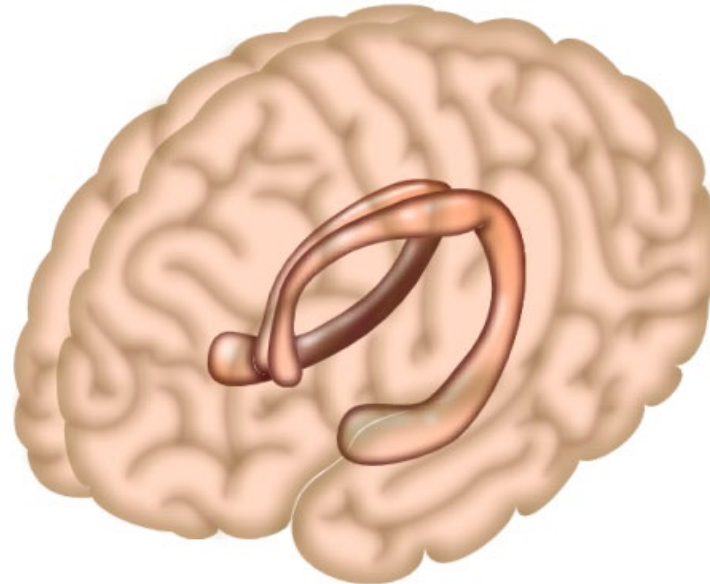
Moderate AD



Severe AD

# Hippocampus

- Alzheimer's starts attacking the brain here
- What it is responsible for: Short Term Memory
  - Some of the first signs of AD you likely will see:
    - Memory Loss
    - Disorientation



Source: Health Central website

<http://immersive.healthcentral.com/alzheimers/d/LBLN/how-alzheimers-disease-changes-the-brain/flat/>

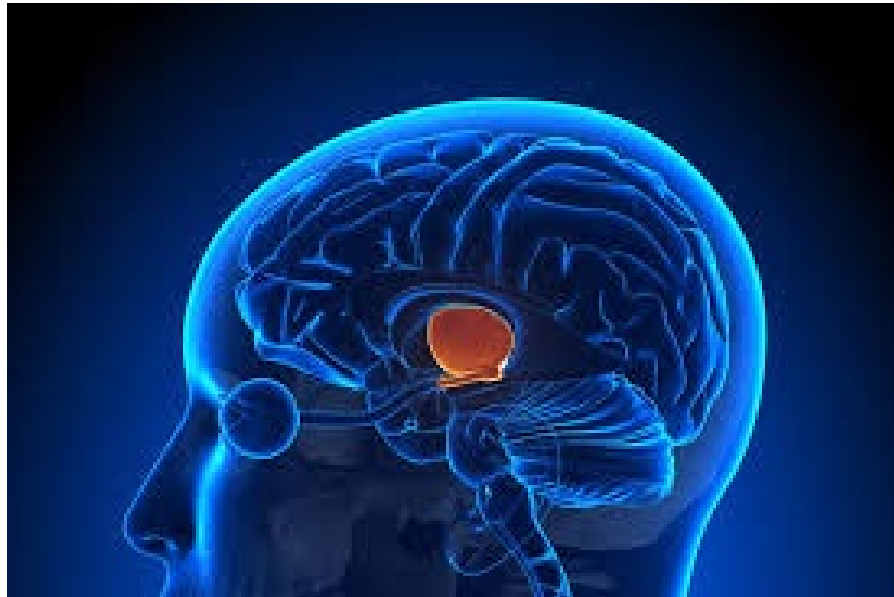


# Effect on Hippocampus Size

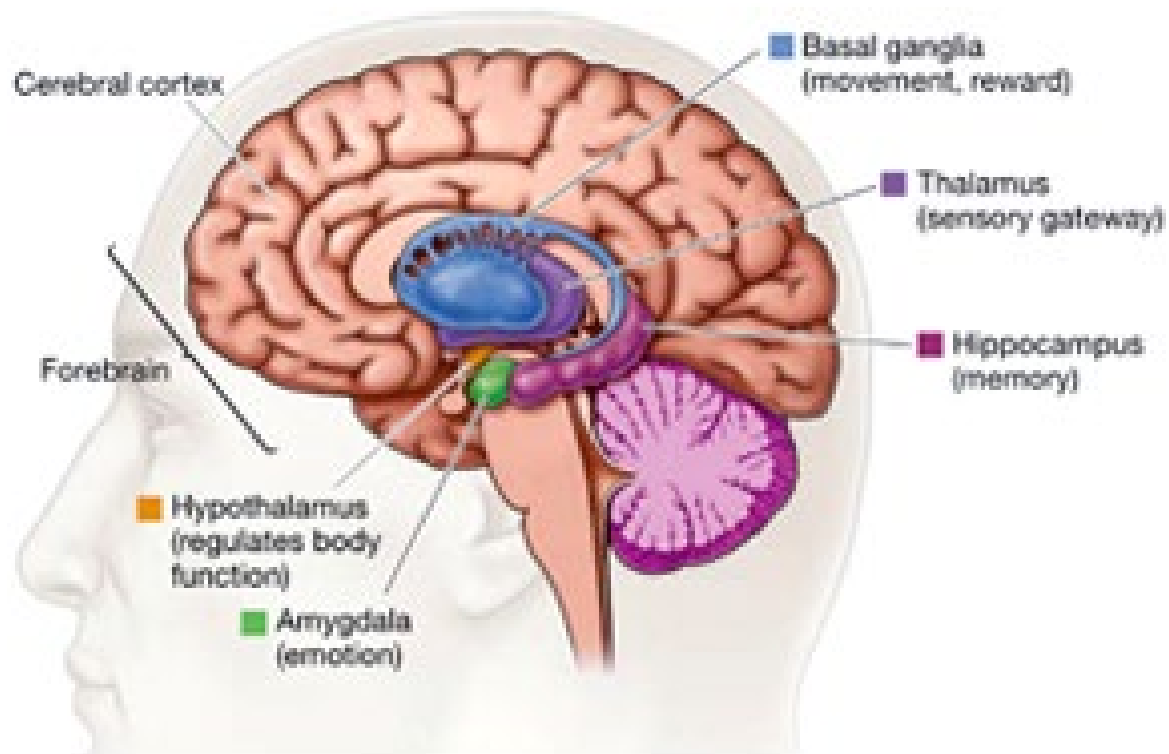
- A study found that the volume and ratio of the hippocampus was reduced, on average, by 25% in AD.

# Hypothalamus

- What it is responsible for: a lot of the body's hormone production
- Some effects you might see: Changes in internal temperature, thirst, hunger, sleep, sex drive



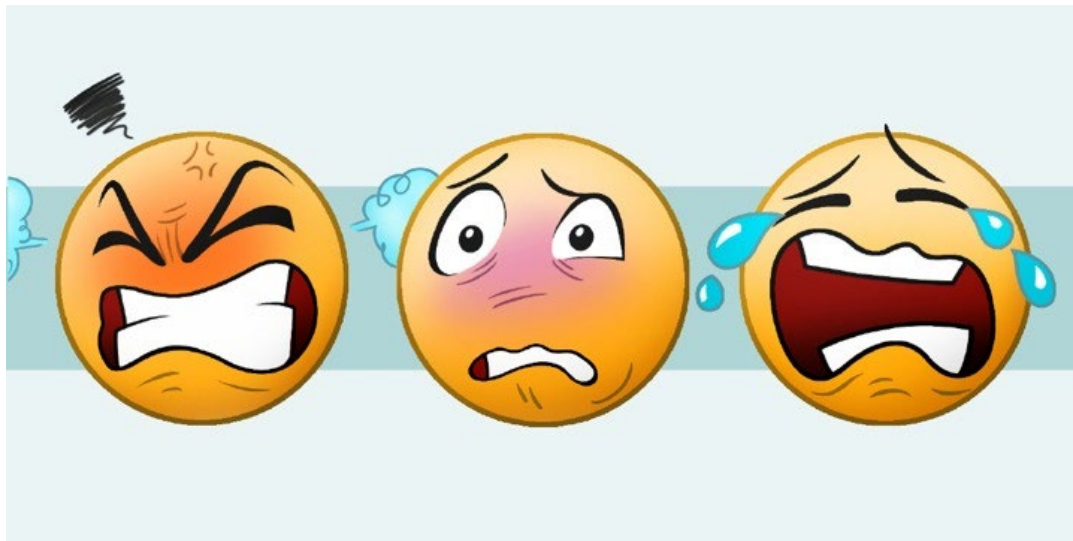
# Amygdala



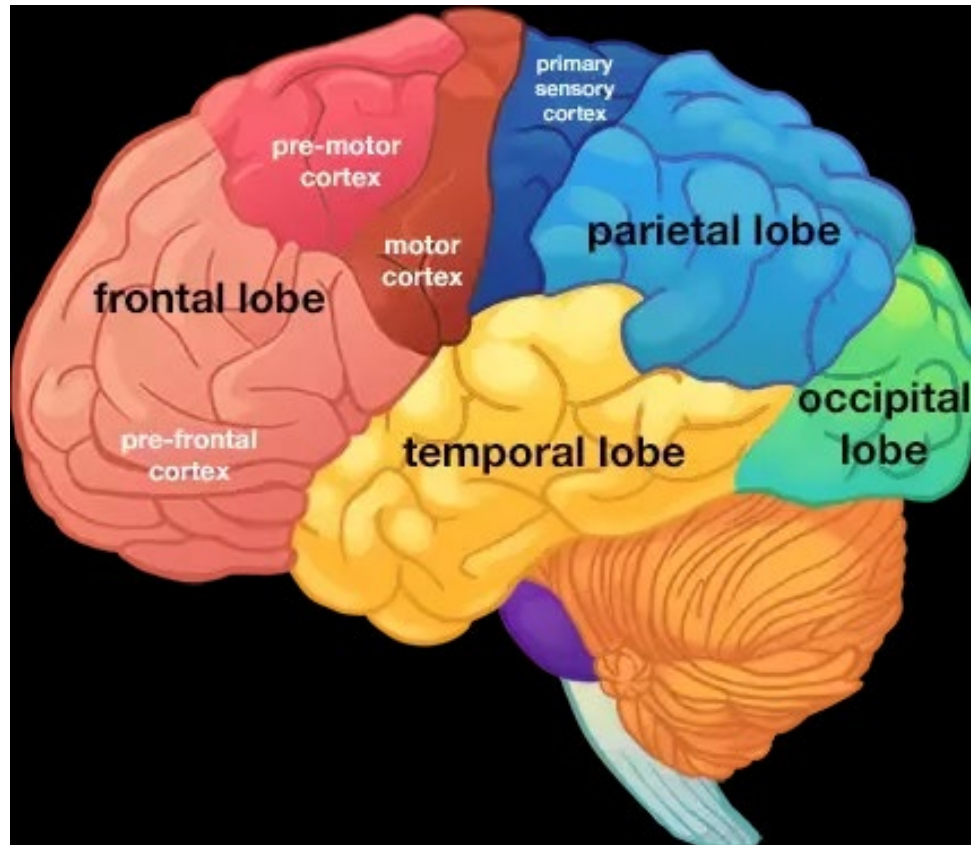


# Amygdala

- Emotion house of the brain
- Volatile emotions
- Anger, sadness, anxiety,
- Agitation and aggression
- Paranoia



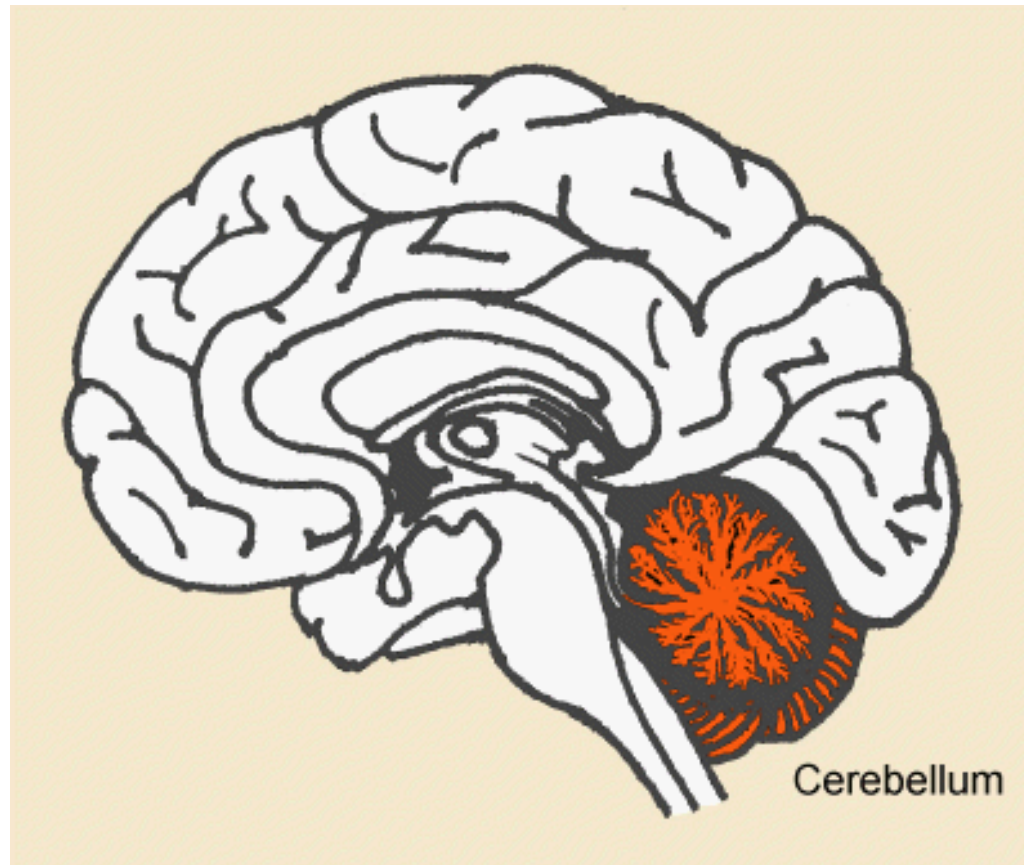
# Frontal Lobe



# Frontal Lobe

- What it is responsible for: higher-order thinking
  - decision-making, voluntary movements, solving problems, making plans, judgement, weighing consequences, controlling impulses and emotions, and maintaining speech and writing skills.
- What you may see:
- Loss of motivation & lethargy
- Poor judgement
- Loss of filter
- Difficulty making decisions
- Doing or saying the same thing over and over
- Bizarre or inappropriate behavior
- Behavior by stages: Health Resources & Services Administration (HRSA) –Module 5
- <https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum>

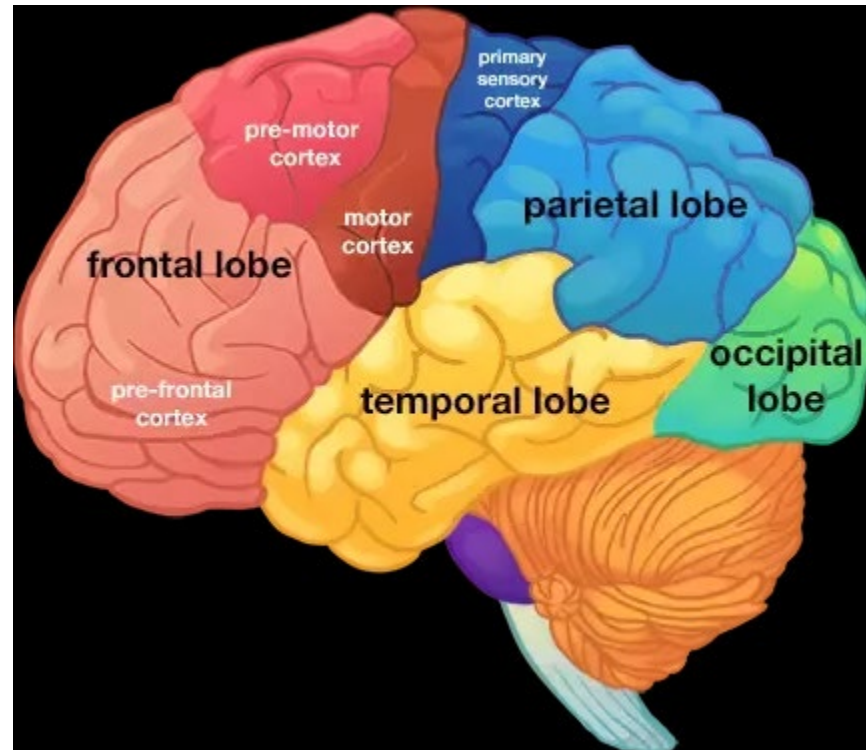
# Cerebellum



# Cerebellum

- What it is responsible for:
- Balance
- Coordination
- Fine motor planning
- Where you might see it affect behavior:
  - Gait, posture, speech, and motor functions.
  - Lack of balance
  - Lack of coordination
  - Slowed movements
  - Slurred speech
  - Abnormal eye movements
  - Tremors

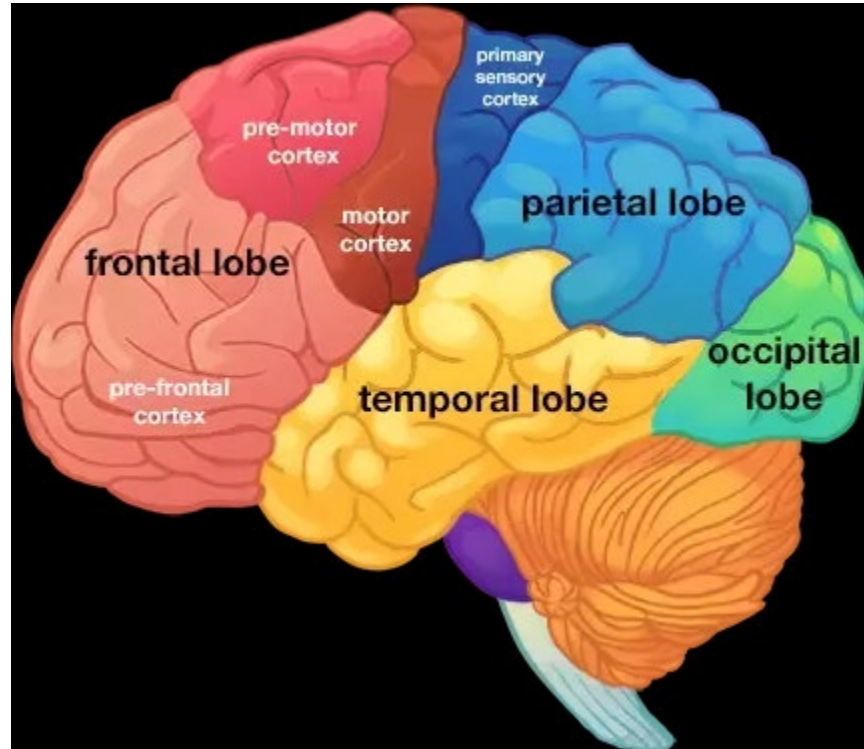
# Occipital Lobe



# Occipital Lobe

- Makes sense of what our eyes are seeing.
- This region of the brain is not always affected by Alzheimer's disease
- But when it is:
  - May have trouble recognizing everyday objects
  - May misinterpret their environment:
- Illusions: ex. seeing patterns in faces
- Misperceptions: ex. thinking a shadow on the ground is a hole
- Hallucinations: seeing something that is not there

# Temporal Lobes





# Temporal Lobe

## Language

- Speech comprehension, semantics, naming, verbal memory, remembering what they were saying from the start of a sentence
  - Talking on the phone becomes difficult
    - Video calls may work better

## Memory

- 'How to do things' memories
- More recent long term memories

# Perception of Time

- Keeping Track of Time
- Memories Act as Mile Markers for Time
  - Difficulty Recognizing Family and Friends
    - Emotional Attachment remains

# What is NOT Affected?

- Derogatory Language
- Music
- Rhythm
- Non-Verbal Communication
  - Important way to communicate with individuals with memory loss
    - Eye contact, body positioning, holding hands

# “Remember When?”

- A way we connect with people
- Common part of our vernacular
- Can make individuals with memory loss feel anxious, pressure to respond, pressure to respond correctly
  - “I should know this.” “This must be important.”
  - Instead, tell the story.
    - They can join in, if they want to.

# Behaviors You May Notice

- Repetitive Questions or Statements
  - Repetitive behaviors are often caused by anxiety, stress, frustration, or fear
  - How to handle:
    - Try to stay calm
    - Understand that they are not meaning to annoy you.
    - Keep your answers simple and brief.
    - Distract
    - Respond to their emotions, not the words
    - Walk away if you are feeling frustrated

# How to Handle Emotional Questions and Statements

Two questions to consider:

1. Why are they saying or asking what they are asking?
2. Do they really need to know the answer?
  - Look for the reason they are asking or saying what they are saying and reassure/calm the source of the issue.
  - Determine will the true answer cause emotional discomfort
  - Weigh do they really need to know; is knowing worth the emotional distress they may experience? Are they experiencing more emotional distress now not knowing the answer?
    - Tell the truth
    - Therapeutic lying
    - Distraction
    - Reminisce about who/what they are talking about

# Behaviors You May Notice

- Poor Grooming
  - Don't remember
  - The first thing they see is the first thing they put on
    - Put away their worn or dirty clothes.
    - Put out clothes to wear for the next day.
    - Consider putting temperature inappropriate clothes away somewhere they won't be able to see them.
  - Binocular Vision
  - Showering

# Common Behaviors by Stages



# Early-Stage Behaviors

Common behaviors in early stages of dementia include:

- Boredom and depression
- Personality and behavioral changes
- Complaints about memory
- Repeating questions

# General Tips for Managing Early-Stage Symptoms

To manage behaviors, you might try:

- Prevention
  - Maintain structure
  - Simplify the environment
  - Provide written reminders
  - Give positive reinforcement throughout the day
  - Provide activity, but gauge their enjoyment/interest (don't overschedule/overwhelm)
- Responding
  - Watch for frustration and provide reassurance
  - Avoid “testing” memory
  - Get depression treated, if present

# Moderate-Stage Behaviors

New behaviors that show up may include:

- Wandering
- Arguing
- Sleep disturbances
- Agitation, hitting, biting
- Sudden and significant changes in behavior
  - Consider testing for a UTI

# General Tips for Managing Moderate-Stage Behaviors

Address moderate-stage behaviors by:

- Prevention
  - Break tasks into small steps
  - Provide verbal reminders
- Responding
  - Be reassuring and offer simple answers
  - Don't argue back!
  - Let go of little things
  - Seek home and community-based services

# Tips to Help Prevent Agitation

- Create a calm environment.
- Avoid environmental triggers. Noise, glare and background distraction (such as having the television on) can act as triggers.
- Monitor personal comfort.
  - Check for pain, hunger, thirst, constipation, full bladder, fatigue, infections and skin irritation.
  - Make sure the room is at a comfortable temperature.
  - Be sensitive to fears, misperceived threats and frustration with expressing what is wanted.
- Simplify tasks and routines.
- Provide an opportunity for exercise.

# Tips to Prevent Wandering

- **Carry out daily activities.** Having a routine can provide structure.
- **Identify the most likely times of day that wandering may occur.** Plan activities at that time. Activities and exercise can reduce anxiety, agitation and restlessness.
- **Reassure the person if he or she feels lost, abandoned or disoriented.** If the person with dementia wants to leave to "go home" or "go to work," use communication focused on exploration and validation. Refrain from correcting the person. For example, "We are staying here tonight. We are safe and I'll be with you. We can go home in the morning after a good night's rest."
- **Ensure all basic needs are met.** Restroom, hungry, thirsty?
- **Avoid busy places that are confusing and can cause disorientation.** Ex. malls, grocery stores
- **Place locks out of the line of sight.** Install either high or low on exterior doors, and consider placing slide bolts at the top or bottom.
- **Use devices that signal when a door or window is opened.** Ex. a bell above a door or an electronic home alarm.
- **Provide supervision.** Do not leave someone with dementia unsupervised in new or changed surroundings. Never lock a person in at home or leave him or her in a car alone.
- **Keep car keys out of sight.** If the person is no longer driving, remove access to car keys. The person may forget that he or she can no longer drive. If the person is still able to drive, consider using a GPS device to help if they get lost.

# Did you know...

- 94% percent of people who wander are found within 1.5 miles of where they disappeared.
- So, it is important that when someone with dementia is missing, search-and-rescue efforts begin immediately.

# Be Ready: Make a Plan

- Keep a list of people to call on for help. Have telephone numbers easily accessible.
- Ask neighbors, friends and family to call if they see the person alone.
- Keep a recent, close-up photo and updated medical information on hand to give to police.
- Know your neighborhood. Pinpoint dangerous areas near the home, such as bodies of water, open stairwells, dense foliage, tunnels, bus stops and roads with heavy traffic.
- Wandering generally follows the direction of the dominant hand.
- Keep a list of places where the person may wander. This could include past jobs, former homes, places of worship, or a restaurant.
- Consider enrolling the person living with dementia in a wandering response service.
- If the person does wander, search the immediate area for no more than 15 minutes. If the person is not found within 15 minutes, call 911 to file a missing person's report. Inform them that the person has dementia.



# Tips to Help Manage Sleep Disturbances

- Maintain regular times for waking up, bedtime and meals
- Seek morning sunlight exposure
- Encourage regular daily exercise, but no later than four hours before bedtime
- Avoid alcohol, caffeine and nicotine
- Treat any pain
- If the person is taking a cholinesterase inhibitor [tacrine (Cognex), donepezil (Aricept), rivastigmine (Exelon) or galantamine (Razadyne)], avoid giving the medicine before bed
- Make sure the bedroom temperature is comfortable
- Provide nightlights and security objects
- If the person awakens, discourage staying in bed while awake; use the bed only for sleep
- Discourage watching television when awake at night
- Avoid technology that emits blue light before bed
- Medication as last resort

# Late-Stage Behaviors

During the later stages of dementia, individuals lose the ability to respond to their environment, to carry on a conversation and, eventually, to control movement.

The person living with dementia may:

- Change eating and sleeping habits
- Have difficulty finding the “correct” words
- Show difficulty following instructions
- Become agitated
- Talk constantly or not at all
- Need extensive help with daily activities.
- Lose awareness of recent experiences as well as of their surroundings
- Experience changes in physical abilities, including the ability to walk, sit and, eventually, swallow
- Become vulnerable to infections, esp. pneumonia

# General Tips for Managing Late-Stage Behaviors

To address late-stage behaviors, consider:

- Prevention
  - Pay attention to non-verbal signs
  - Distract, touch gently
  - Work closely with medical team/home health care/hospice
- Responding
  - Learn what the emotion is
  - Refocus and make a connection

# QUESTIONS?

**Be Sure to Take Care of YOU!**

HRSA Module 4

<https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum>

Robyn Birkeland, PhD

birke015@umn.edu

612-626-8872

University of Minnesota

School of Public Health

Division of Health Policy and Management

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES



Bureau of Health Workforce  
Division of Medicine and Dentistry

***Geriatrics Workforce Enhancement Program***

**Funding Opportunity Number:** HRSA-19-008

**Funding Opportunity Type:** New and Competing Continuation

**Catalog of Federal Domestic Assistance (CFDA) Number 93.969**

**NOTICE OF FUNDING OPPORTUNITY**

Fiscal Year 2019

**Application Due Date: February 6, 2019**



# Support for GWEP

This Program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS or the U.S. Government.

The Minnesota Northstar GWEP is supported by the University of Minnesota Office of Academic Clinical Affairs.



# **OPPORTUNITY TO HELP TEST AN EXCITING NEW RESEARCH PROGRAM!**



UNIVERSITY OF MINNESOTA  
Driven to Discover®

**Are you considering retiring from driving  
or have you already retired from driving?**

**Or do you have a family member with memory loss who is  
considering retiring from driving or recently retired from driving?**

The University of Minnesota is examining the effects of an 8 session educational program to support persons with memory loss who are considering retiring from driving or are dealing with driving retirement and/or their supportive family member.

Sessions are:

- conducted via video conferencing or phone
- led by a trained coach

**Learn more about participating in this study: [www.sph.umn.edu/research/projects/carfreeme](http://www.sph.umn.edu/research/projects/carfreeme)**

# Appendix:

# Caregiving Support Resources



# Learn All That You Can!

- Learn as much as you can about:
  - the disease,
  - its progression,
  - how it affects behavior and personality
    - <http://immersive.healthcentral.com/alzheimers/d/LBLN/how-alzheimers-disease-changes-the-brain/flat/>
  - and what caregiving may involve.
- Webpage on caregiving topics:
  - [https://alz.org/help-support/caregiving/daily-care?WT.mc\\_id=enews2019\\_08\\_21&utm\\_source=enews-aff-99&utm\\_medium=email&utm\\_campaign=enews-2019-08-21&utm\\_content=homeoffice&utm\\_term=Story2](https://alz.org/help-support/caregiving/daily-care?WT.mc_id=enews2019_08_21&utm_source=enews-aff-99&utm_medium=email&utm_campaign=enews-2019-08-21&utm_content=homeoffice&utm_term=Story2)

# COVID-19 Resources

- <https://metroaging.org/resources-for-older-adults-during-covid-19/>
- Senior Linkage Line
- Presentation: "Caring in Times of Uncertainty: Helping Adult Children of Aging Parents Find Support" with Dr. Elizabeth Lightfoot and Dr. Rajean Moone  
<https://youtu.be/wjhoc91I0DM>
- COVID-19 and Living with Dementia: Maintaining Well-Being and Purpose Webcast:  
<https://mngwep.umn.edu/education/webcast-covid-19-and-living-dementia>
- The CDC website: <https://www.cdc.gov/coronavirus/2019-ncov/index.html>
- Local Health Department Numbers:  
[https://www.cdc.gov/coronavirus/2019-ncov/downloads/Phone-Numbers\\_State-and-Local-Health-Departments.pdf](https://www.cdc.gov/coronavirus/2019-ncov/downloads/Phone-Numbers_State-and-Local-Health-Departments.pdf)

# EARLY STAGE RESOURCES/SELF-IDENTIFICATION AS CAREGIVER

- The Wilder Foundation: What is a caregiver?
  - <http://www.whatisacaregiver.org/>
  - <https://www.wilder.org/what-we-offer/healthy-aging-caregiving-services>
  - 651-280-2500
- Lyngblomsten
  - <https://www.lyngblomsten.org/community-services/caregiver-resources/>
  - 651-632-5320
- Family Means in Stillwater
  - <https://www.familymeans.org/help-for-caregivers/>
  - 651-439-4840
- Senior Linkage Line
  - 1-800-333-2433
  - The Senior LinkAge Line is answered from 8 a.m. to 4:30 p.m. weekdays.

# EARLY STAGE RESOURCES/SELF-IDENTIFICATION AS CAREGIVER

- Community dementia programs
  - [https://www.alz.org/mnnd/helping\\_you/programs\\_for\\_people\\_with\\_dementia](https://www.alz.org/mnnd/helping_you/programs_for_people_with_dementia)
  - Art, choir, dance, landscape, and more

# EARLY STAGE RESOURCES/SELF-IDENTIFICATION AS CAREGIVER

- The Alzheimer's Disease Education and Referral Center
  - *Understanding Memory Loss* (<https://order.nia.nih.gov/publication/understanding-memory-loss>)
  - *Forgetfulness Age Page: Knowing When to Ask for Help* (<https://order.nia.nih.gov/publication/forgetfulness-knowing-when-to-ask-for-help>)
  - *What Happens Next? (Early-Stage Dementia Resource)* (<https://www.nia.nih.gov/health/now-what-next-steps-after-alzheimers-diagnosis>)
- Email lists/Newsletter
  - *National Institute on Aging* (<https://www.nia.nih.gov/about/stay-connected>)
  - *Perspectives* (<http://adrc.ucsd.edu/news.html>)
- Decision-Making Aid
  - *Alzheimer's Disease: Should I Take Medications?* (<https://www.healthwise.net/cochrane/decisionaid/Content/StdDocument.aspx?DCHWID=ty7566>)
  - *Gene Test or Not?* (<https://genetestornot.org/>)

# SEEKING ASSISTANCE/FORMAL SERVICE USE

- List of Dementia Clinics in Minnesota: Contact the Minnesota-North Dakota Chapter of the Alzheimer's Association: 952.830.0512
- ACT on Alzheimer's (<http://www.actonalz.org/supporting-family-and-friend-caregivers>)
  - *Understanding Stages and Symptoms of Alzheimer's Disease* (<http://www.nia.nih.gov/alzheimers/topics/symptoms>)
  - *The Basics: Memory Loss, Dementia, and Alzheimer's Disease* (<http://training.alz.org/products/1016/the-basics-memory-loss-dementia-and-alzheimers-disease>)
  - Alzheimer's disease at the Centers for Disease Control and Prevention (<http://www.cdc.gov/aging/aginginfo/alzheimers.htm>)
  - *The Alzheimer's Project* (HBO; <http://www.hbo.com/alzheimers/>)
  - *Caring for Mom & Dad* (PBS; <http://www.pbs.org/wgbh/caringformomanddad/>)
  - *Caring for a Person with Alzheimer's Disease* (<https://order.nia.nih.gov/publication/caring-for-a-person-with-alzheimers-disease-your-easy-to-use-guide>)
  - *Inside the Brain* visual tour of Alzheimer's disease, in multiple languages ([http://www.alz.org/alzheimers\\_disease\\_4719.asp](http://www.alz.org/alzheimers_disease_4719.asp))

# SEEKING ASSISTANCE/FORMAL SERVICE USE

- *Caregiver's Guide to Understanding Dementia Behaviors*  
([http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=391](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=391))
- Alzheimer's Association: Care consultation and support groups  
([https://www.alz.org/mnnd/helping\\_you](https://www.alz.org/mnnd/helping_you))
- Area Agency on Aging (<http://metroaging.org/>)
  - Living Well with Chronic Conditions (<http://metroaging.org/community-work/healthy-aging/living-well-chronic-conditions/>)
  - A Matter of Balance (<http://metroaging.org/community-work/healthy-aging/matter-of-balance/>)
  - Tai Chi ([http://www.tcaging.org/findinghelp/tai\\_chi.html](http://www.tcaging.org/findinghelp/tai_chi.html))
  - Multiple caregiver support programs (<http://metroaging.org/help-information/family-caregiver-resources/>)
  - Health insurance counseling (<http://metroaging.org/help-information/senior-linkage-line/counseling-sites/>)

# SEEKING ASSISTANCE/FORMAL SERVICE USE

- Care management
  - Find a care manager/National Association of Professional Care Managers (<http://memberfinder.caremanager.org/>)
  - Pathfinder Care Management: (<http://www.pathfindergcm.com/about-us/>)
- Conference and similar information:
  - *Meeting of the Minds, Alzheimer's Association/Mayo Clinic* ([https://www.alz.org/mnnd/events/meeting\\_of\\_the\\_minds\\_dementia\\_conference](https://www.alz.org/mnnd/events/meeting_of_the_minds_dementia_conference))
  - Community education events (<https://www.alz.org/mnnd/events>)
  - *Caring for a Person with Memory Loss Conference, University of Minnesota* (<http://z.umn.edu/memoryloss>)
    - Free library of all past presentations and recordings: <http://bit.ly/1xuQy6r>
- Dementia and Driving Resource Center (<http://www.alz.org/care/alzheimers-dementia-and-driving.asp>)
- From ACT: Advance Care, Financial, and Legal Resources (<http://www.actonalz.org/legal>)
  - Maser Amundson Boggio Hendricks (<http://www.maserlaw.com/>)
  - Volunteers of America (<https://www.voamnwi.org/estate-and-elder-law>)



# SEEKING ASSISTANCE/FORMAL SERVICE USE

- Home modification
  - Home modifications ([http://www.eldercare.gov/ELDERCARE.NET/Public/Resources/Factsheets/Home\\_Modifications.aspx](http://www.eldercare.gov/ELDERCARE.NET/Public/Resources/Factsheets/Home_Modifications.aspx))
  - *Home Safety for People with Alzheimer's Disease Booklet* (<https://www.nia.nih.gov/health/home-safety-and-alzheimers-disease>)
- Respite Services
  - ARCH Respite Locator: <http://archrespite.org/respitelocator>
  - LeadingAge of Minnesota: ADS Center and other community services locator (link not working at <https://www.leadingagemn.org/family-resources/locate-options-in-your-community/>)

# SEEKING ASSISTANCE/FORMAL SERVICE USE

- Spiritual Resources
  - *Action Resources: Faith Communities* (<http://www.actonalz.org/faith-communities>)
- Eldercare Locator:  
(<http://www.eldercare.gov/Eldercare.NET/Public/Index.aspx>)
- Family Caregiver Alliance Family Care Navigator  
(<https://caregiver.org/family-care-navigator>)
- Alzheimer's Association Caregiver Center: Online Tools  
(<https://www.alz.org/help-support/resources/online-tools>)