Dementia Demystified: Front-Line Real-World Care

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Why is Dementia So Hard?

Diagnosis is Complicated & Time-consuming

- Clinical diagnosis: no “one test” to prove it; extensive evaluation needed
- Delivering a diagnosis and care plan takes time & attention
- Specialty expertise is limited and hard to access

Stigma & Resistance

- Patients lack insight: “there is nothing wrong with me”
- Families have denial: “my mom is fine, she’s just old”

No Good Answers

- The disease is progressive and (mostly) untreatable
- Dementia makes it harder to manage other medical problems

Better Care for Dementia

- **HCP's and families recognize signs** of cognitive impairment
- PCP's can make a **timely and accurate diagnosis** of dementia
- Patients and caregivers have access to **education, support, and treatment** options
- Treatment of **other medical conditions adjusts** appropriately
- Patients and families **plan for the future**
- **Palliative approach to care** is available in late stage disease.

What is Dementia, anyway?

Definitions and Clinical signs

Instead of Dementia, people may say

NEUROCOGNITIVE DISORDER

ALZHEIMER'S

COGNITIVE IMPAIRMENT

MEMORY LOSS OR "MEMORY PROBLEMS"

Dementia is a Clinical Syndrome

Dementia is an *umbrella term* for a clinical syndrome: loss of memory and thinking severe enough to interfere with daily life

There are *several disease processes that cause* the clinical syndrome of dementia. These are sometimes referred to as “types” of dementia.

Most older adults have more than one type (“mixed” dementia).

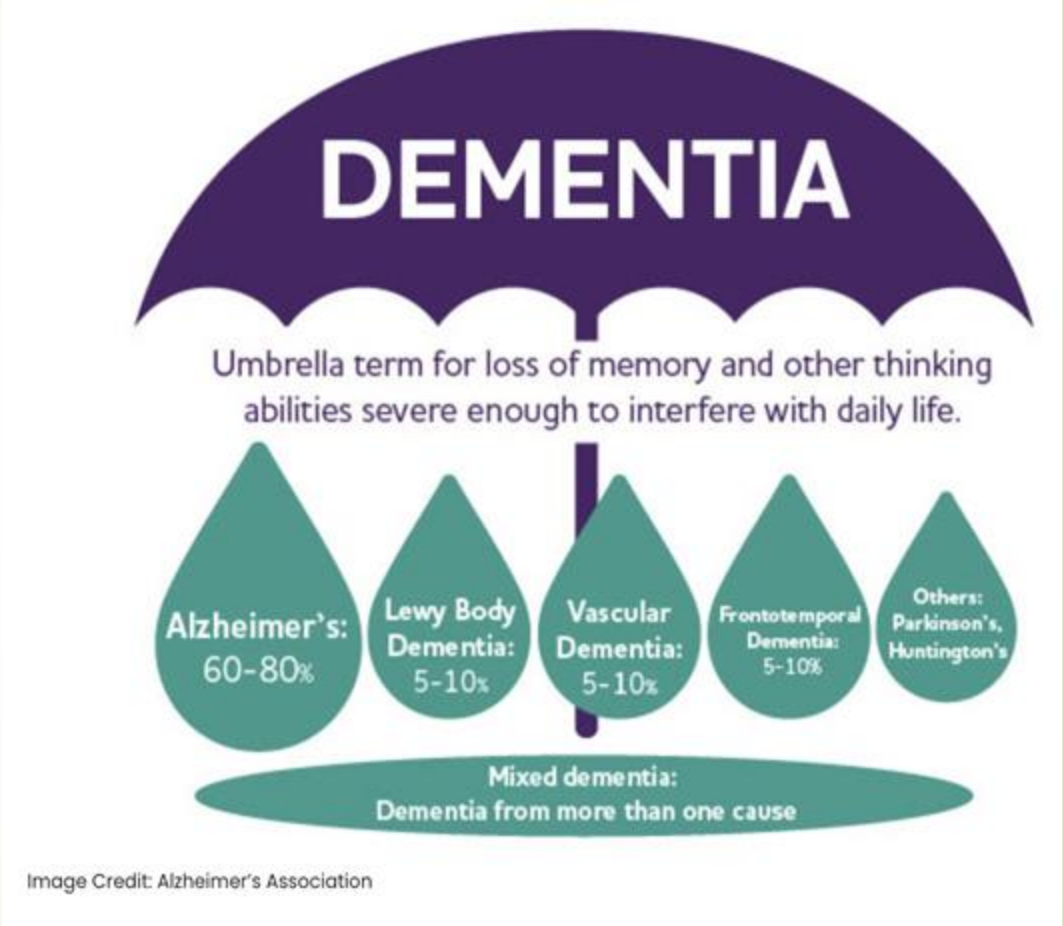


Image Credit: Alzheimer's Association

Do I have Dementia? Or do I have Alzheimer's?

- Alzheimer's disease is the most common type (or cause) of dementia
- Most older adults have Alzheimer's or mixed dementia.
- We cannot tell Alzheimer's with certainty without advanced testing (PET scan).
- Especially in later stages, the treatment of all dementia types is the same.
- It is common to hear the words "Alzheimer's" and "Dementia" used interchangeably.

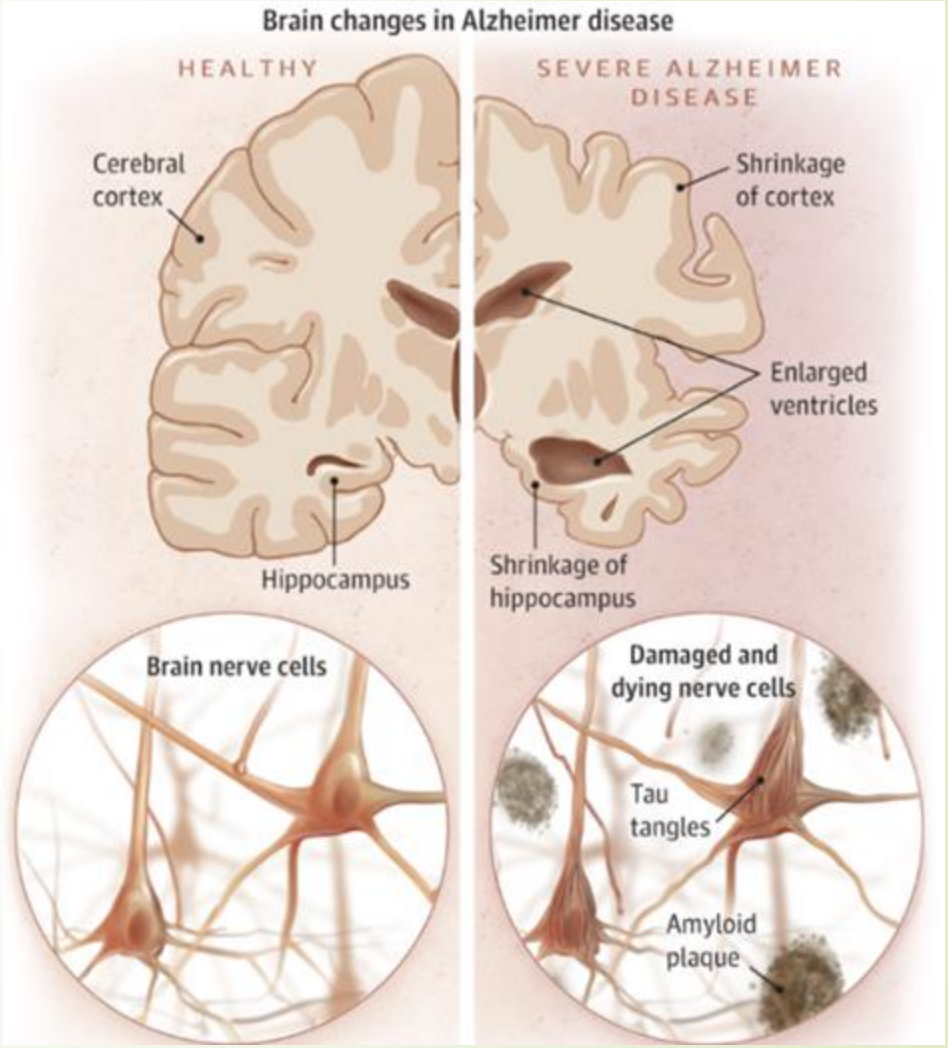
Alzheimer's Disease Pathology: Plaques & Tangles

The forest of neurons in the brain gets cluttered with plaques of amyloid & tangles of tau protein

Neuronal death

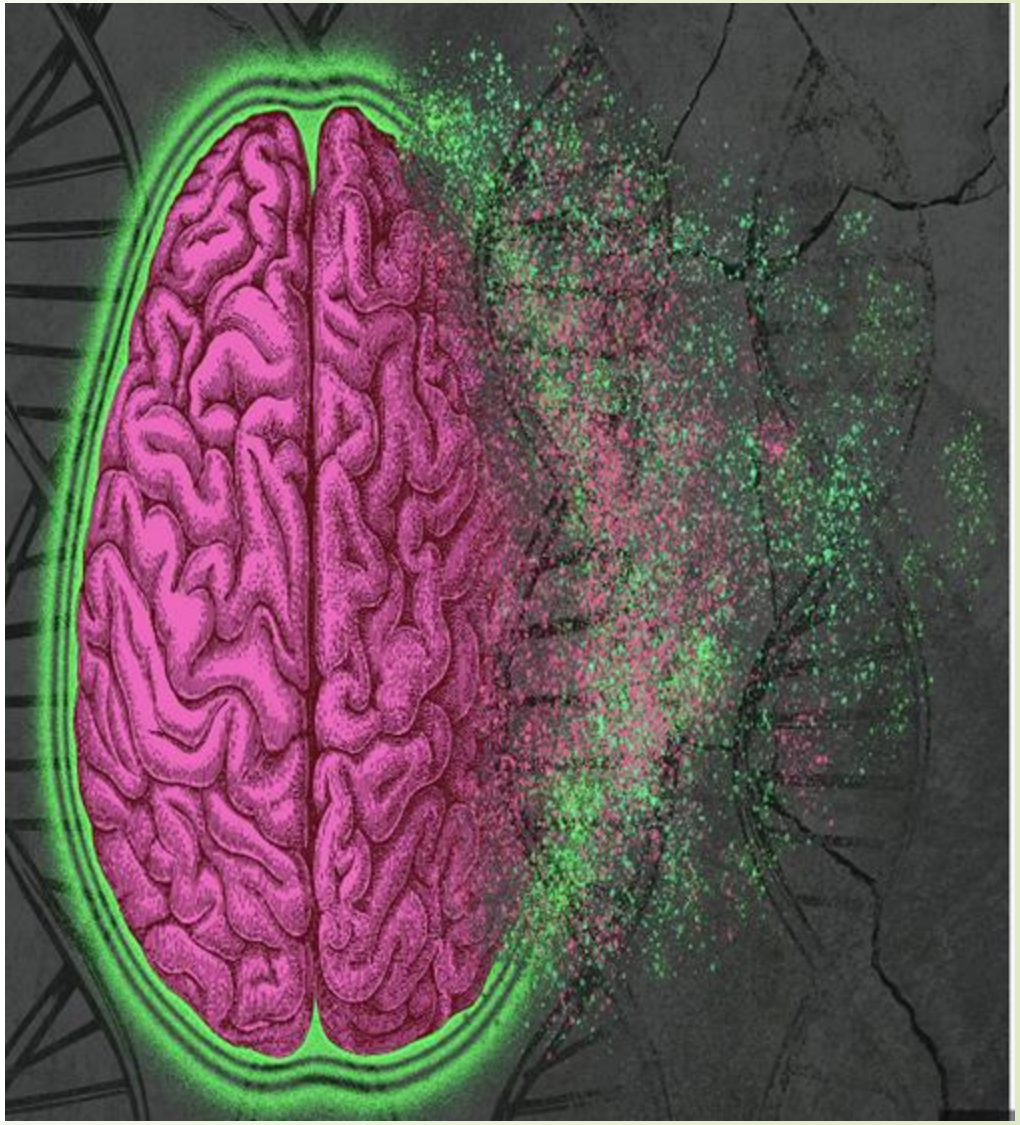
Death of neurons produces symptoms

Death of neurons is irreversible



More Than Memory Loss | 10 warning signs of Alzheimer's Disease

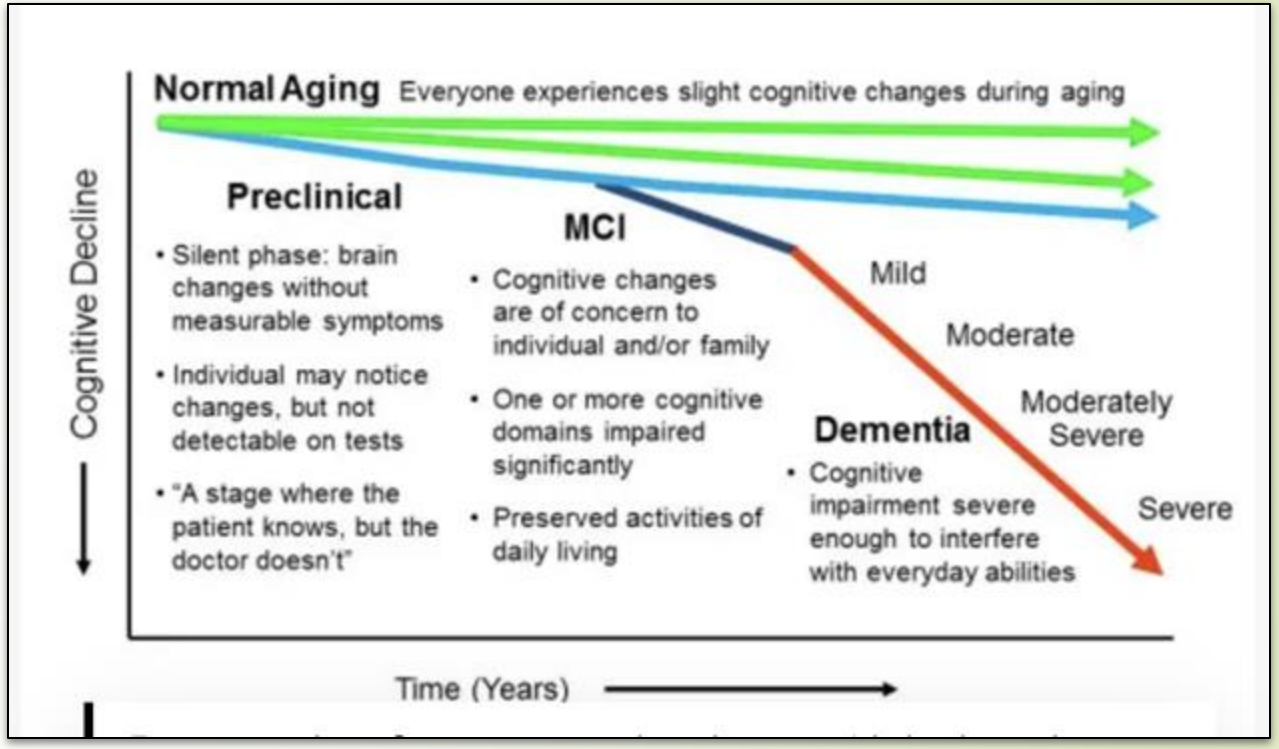
1. Memory loss that disrupts daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks
4. Confusion with time or place
5. Trouble understanding visual images and spatial relations
6. New problems with words in speaking or writing
7. Misplacing things and losing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



Source: CDC; Alzheimer's Association

Three stages of Alzheimer's Disease & Related Dementias (ADRD)

1. **Preclinical**: Pathologic changes only
2. **Mild Cognitive Impairment**: Impaired cognition without functional changes
3. **Dementia**: Cognitive and functional impairment



Source: NIH Diagnostic Criteria for Alzheimer's Disease, 2011; UCI-MIND

A Common Clinical Dilemma

- Maria is 82 years old. She lives with her daughter, Anna. Maria performed poorly on her cognitive screen at her last doctor's visit, but wasn't give a diagnosis.
- Maria is a former smoker, with hypertension and diabetes. She had acute delirium during a hospitalization for pneumonia last winter. She was found wandering in her neighborhood.
- She seems "slower and more forgetful" according to her daughter. Anna says, **"but that's all just normal for an 82 year old, right?"**

What Now?

When is it time to worry?

Normal Aging

Mild Cognitive Impairment

Dementia

Clinical Features

Normal Aging

- Slower recall, harder to find words; but can recall information eventually.
- Interests and preferences may change, but personality and mood should not.
- Insight and judgement are normal.

MCI

- Cognitive changes apparent on testing but function is still mostly normal.
- Usually, someone has noticed something is different, **but may attribute the change to something else.**

Dementia

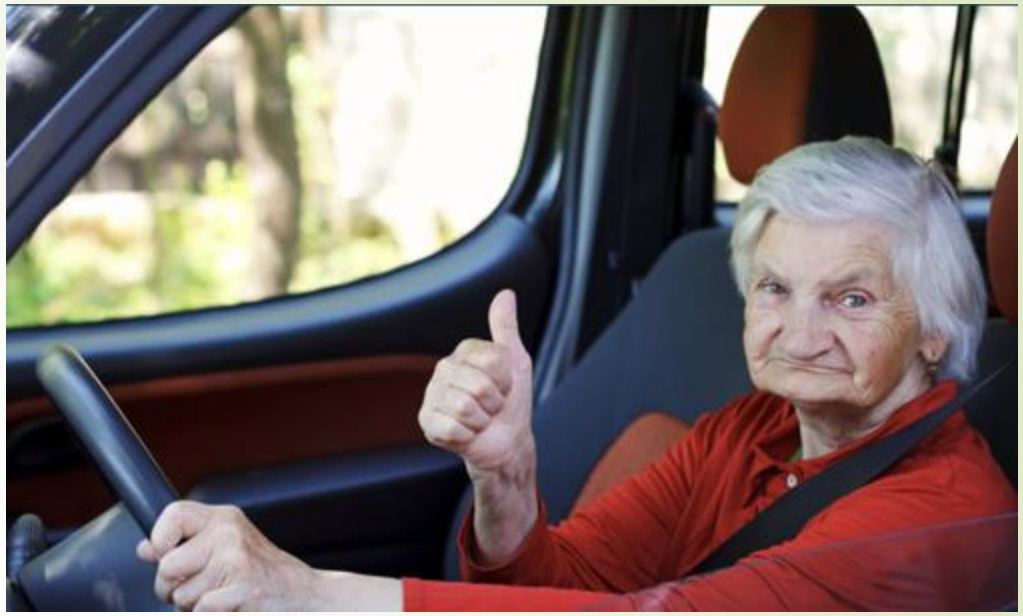
- Changes across several cognitive domains
- Person functions differently than they did before

- Remember the 10 Warning Signs

Dementia Diagnosis

Timely and accurate

Why is Diagnosis Important?



Safety Concerns

- Driving
- Medication Management
- Financial decisions
- Wandering
- Cooking

Alzheimer's Takes a Financial Toll Long Before Diagnosis, Study Finds

New research shows that people who develop dementia often begin falling behind on bills years earlier.

"Early diagnosis of dementia allows patients and families an opportunity to plan for the future while the affected individual is still able to to participate in the decision-making process"

- *Alzheimer's and Dementia 9 (2013) 141-150*

Source: Lifespan, NYTimes May 2024

Underdiagnosis is a widespread problem

January 27, 2025 | 2 min read SAVE

‘Sobering’ data show most adults who likely have dementia unaware of diagnosis

Add topic to email alerts

Key takeaways:

- Overall, 81% of adults who likely had dementia had not received a diagnosis.
- PCPs’ hesitation to diagnose dementia and a lack of dementia-specific training may be explanations behind the findings.

Making the Diagnosis of Dementia: by the DSM

Diagnostic Criteria: DSM-5

Significant cognitive decline from a previous level of performance in one or more cognitive domains based on concern of individual, informant, clinician, *and documented by clinical assessment*

Cognitive deficits interfere with **independence in everyday activities**

Cognitive deficits are **not better explained by another mental disorder** and do not occur solely in the context of a delirium.

Source: CAMH

Dementia Diagnosis Simplified

Cognitive Impairment
(a decline from baseline)

+

Functional Compromise
(a decline from baseline, due to cognitive dysfunction)

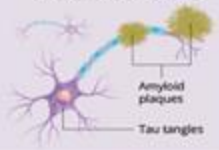
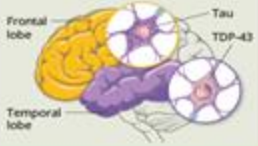
=

Dementia

Understanding Different Types of Dementia

As we age, it's normal to lose some neurons in the brain. People living with dementia, however, experience far greater loss. Many neurons stop working, lose connections with other brain cells, and eventually die. At first, symptoms can be mild, but they get worse over time. Read on to learn more about four different types of dementia.

TYPES OF DEMENTIA

Alzheimer's Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
What Is Happening in the Brain?*			
Abnormal deposits of proteins form amyloid plaques and tau tangles throughout the brain. 	Abnormal amounts or forms of tau and TDP-43 proteins accumulate inside neurons in the frontal and temporal lobes. 	Abnormal deposits of the alpha-synuclein protein, called "Lewy bodies," affect the brain's chemical messengers. 	Conditions, such as blood clots, disrupt blood flow in the brain. 
*These changes are just one piece of a complex puzzle that scientists are studying to understand the underlying causes of these forms of dementia and others.			
Symptoms			
Mild • Wandering and getting lost • Repeating questions **Moderate** • Problems recognizing friends and family • Impulsive behavior **Severe** • Cannot communicate	**Behavioral and Emotional** • Difficulty planning and organizing • Impulsive behaviors • Emotional flatness or excessive emotions **Movement Problems** • Shaky hands • Problems with balance and walking **Language Problems** • Difficulty making or understanding speech *There are several types of frontotemporal disorders, and symptoms can vary by type.*	**Cognitive Decline** • Inability to concentrate, pay attention, or stay alert • Disorganized or illogical ideas **Movement Problems** • Muscle rigidity • Loss of coordination • Reduced facial expression **Sleep Disorders** • Insomnia • Excessive daytime sleepiness **Visual Hallucinations**	• Forgetting current or past events • Misplacing items • Trouble following instructions or learning new information • Hallucinations or delusions • Poor judgment
Typical Age of Diagnosis			
Mid 60s and above, with some cases in mid-30s to 60s	Between 45 and 64	50 or older	Over 65

Diagnosis

Symptoms can be similar among different types of dementia, and some people have more than one form of dementia, which can make an accurate diagnosis difficult. Symptoms can also vary from person to person. Doctors may ask for a medical history, complete a physical exam, and order neurological and laboratory tests to help diagnose dementia.

Treatment

There is currently no cure for these types of dementia, but some treatments are available. Speak with your doctor to find out what might work best for you.

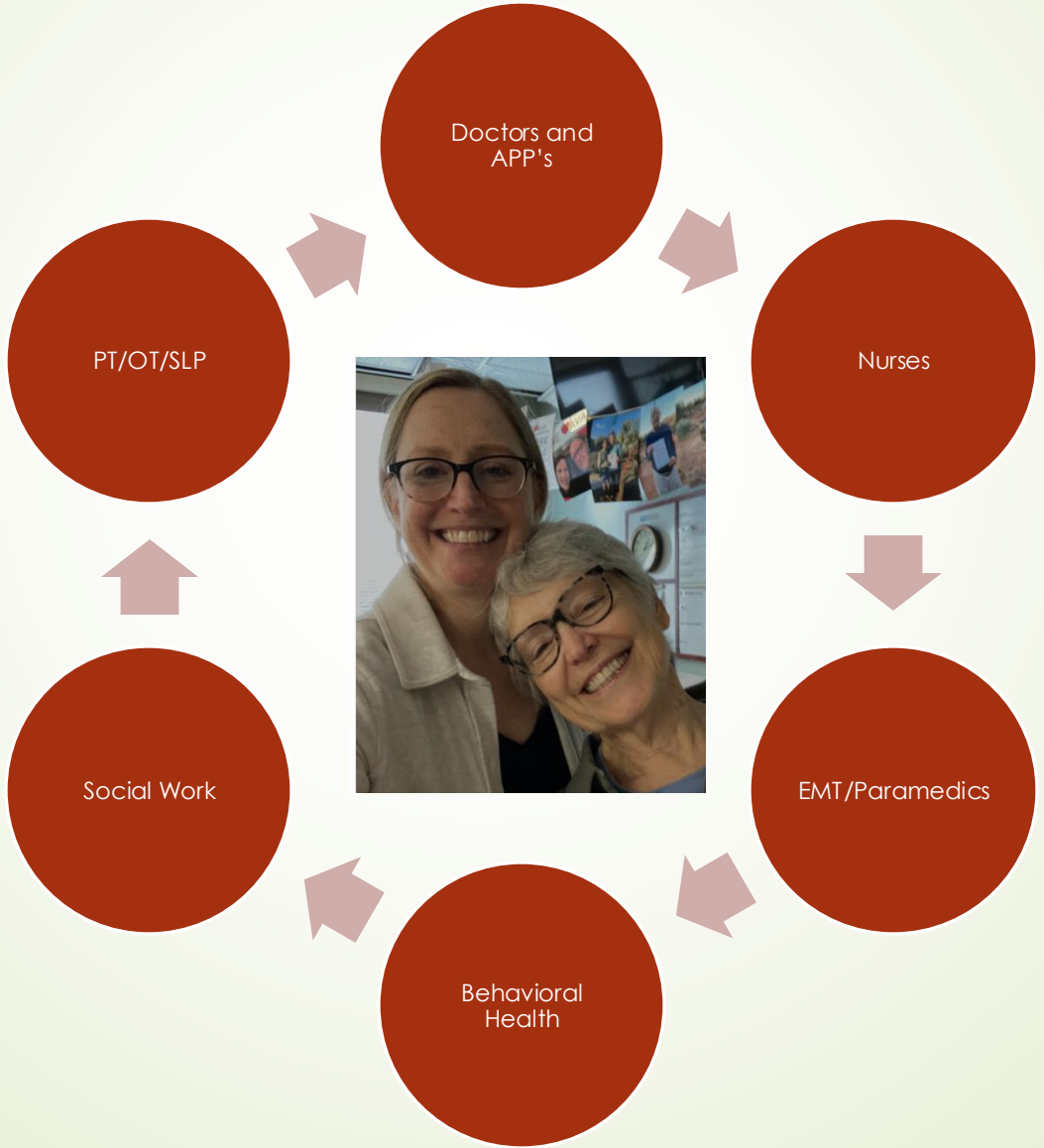
Source: National Institute on Aging (NIA)

Support and Education

Support is the Treatment!

Managing behavioral disturbance (BPSD)

Patient-Caregiver Dyad at the Center



WA State Resources

COMMUNITY LIVING CONNECTIONS
LINKING YOU TO
Personalized Care & Support Options

Call Toll-Free
1-855-567-0252

- Dementia Road Map, a product of the Dementia Action Collaborative
- Area Agencies on Aging: 13 AAA's in Washington
- WA family caregivers learning portal for support groups and education
- Caregiver Tip Sheets for Families and Care Partners
- Legal Planning Toolkit
- Washington State Community Living Connections
- Dementia Care Plan: clinical tools beyond dx

Additional Resources

- Alzheimer's Association
- AARP
- For Medicare patients: CMS GUIDE services through Rippl Care.
- Memory Hub and Dementia Friends and Momentia
- ZinniaTV: therapeutic TV for dementia, available by subscription
- Memory Café more than 20 available in Washington

Behavioral Disturbance in Dementia

“BPSD” (Behavioral and Psychological Symptoms of Dementia) or “NPS” (“Neuropsychiatric Symptoms”) are common in middle to later stages of dementia

May occur in dementia from any cause

- A 76 year old group-home patient who fights caregivers over his weekly shower
- A 90 year old with pacing, anxious mood, and a habit of hiding hearing aids in her trash can
- An 85 year old who cries frequently and says she wants to die
- A 67 year old who strongly believes that his son is stealing from him and his wife is being unfaithful

Managing BPSD

- Behavioral disturbance is a major source of stress for caregivers
- There is no good evidence for medications to treat BPSD.
- An acute change may signify a medical condition (delirium, stroke)
- Recognize that the difficult behaviors are not "intentional".
- Methods to identify and manage: DICE, IDEA, Teepa Snow
  - Promote caregiver support and education.

Planning for the Future

Resources for families

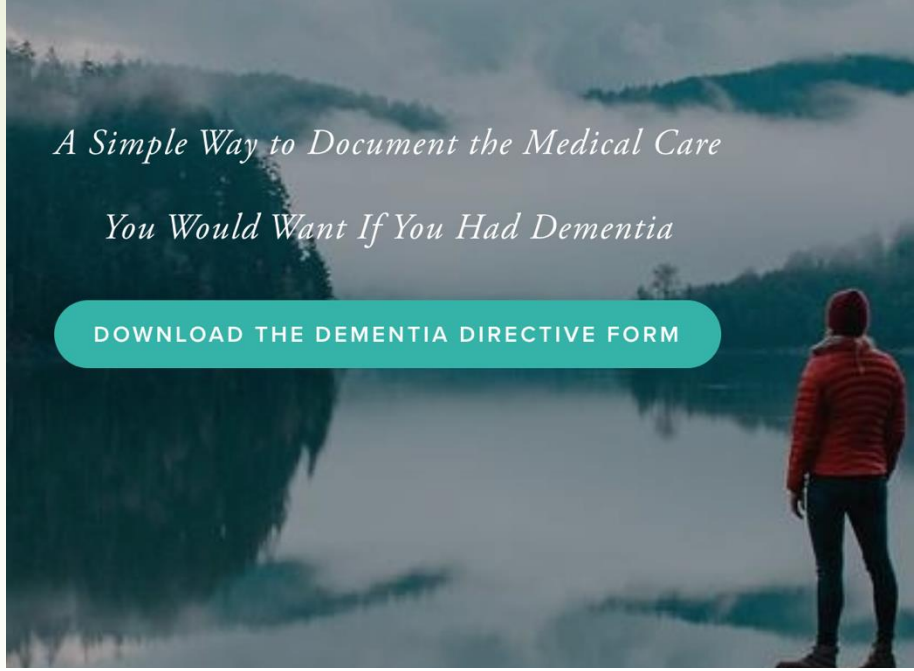
Late Stage Disease

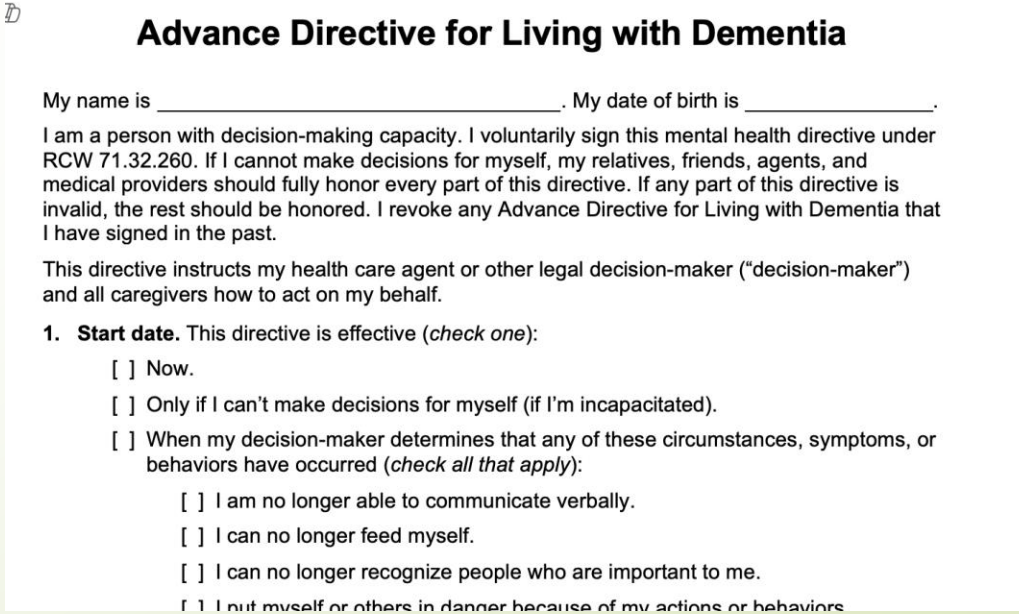
Preparing for the Future

- Choosing a decision maker is job one.
- When more help is needed, what is the plan?
- POLST and Advance Directives
- Goals of care evolve over time

What Matters Most

- Shared decision-making: there is not a "right" answer
  - Involve patient AND healthcare proxy throughout the course
- Goals of care evolve over time.
- Tools:
  - Advance Directive for Living with Dementia
  - Dementia Directive





Advance Directive for Living with Dementia

My name is _____. My date of birth is _____.

I am a person with decision-making capacity. I voluntarily sign this mental health directive under RCW 71.32.260. If I cannot make decisions for myself, my relatives, friends, agents, and medical providers should fully honor every part of this directive. If any part of this directive is invalid, the rest should be honored. I revoke any Advance Directive for Living with Dementia that I have signed in the past.

This directive instructs my health care agent or other legal decision-maker ("decision-maker") and all caregivers how to act on my behalf.

1. **Start date.** This directive is effective (*check one*):
   - [ ] Now.
   - [ ] Only if I can't make decisions for myself (if I'm incapacitated).
   - [ ] When my decision-maker determines that any of these circumstances, symptoms, or behaviors have occurred (*check all that apply*):
     - [ ] I am no longer able to communicate verbally.
     - [ ] I can no longer feed myself.
     - [ ] I can no longer recognize people who are important to me.
     - [ ] I put myself or others in danger because of my actions or behaviors

Transitioning to Comfort-Focused Care

- A transition to a palliative approach to care may include any of the following
  - No routine blood draws or tests
  - Avoiding ER and Hospital – or going only for comfort, not cure.
  - Stopping routine "preventive" meds like Aspirin, Statin, Anti-hypertensives
  - Avoiding antibiotics for infections, focusing instead on comfort
  - Hospice referral when appropriate
- "I want to do everything possible to keep him comfortable."

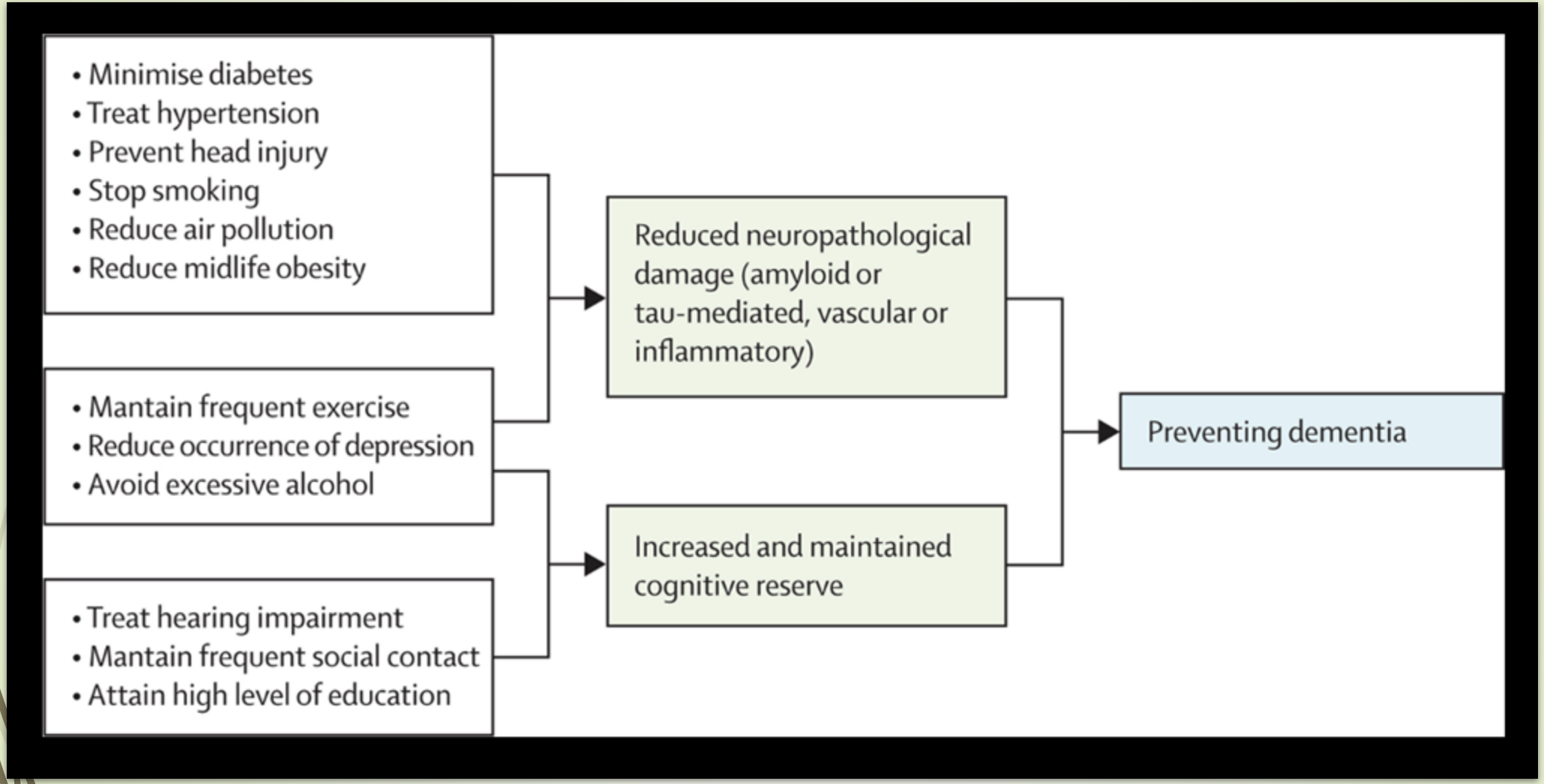
Better Care for Dementia

- **HCP's and families recognize signs** of cognitive impairment
- PCP's can make a **timely and accurate diagnosis** of dementia
- Patients and caregivers have access to **education, support, and treatment** options
- Treatment of **other medical conditions adjusts** appropriately
- Patients and families **plan for the future**
- **Palliative approach to care** is available in late stage disease.


Thank you
Questions/Comments? ACHaymon.consulting@gmail.com

Appendix & Extra Slides

Dementia Prevention | The Lancet Commission 2020

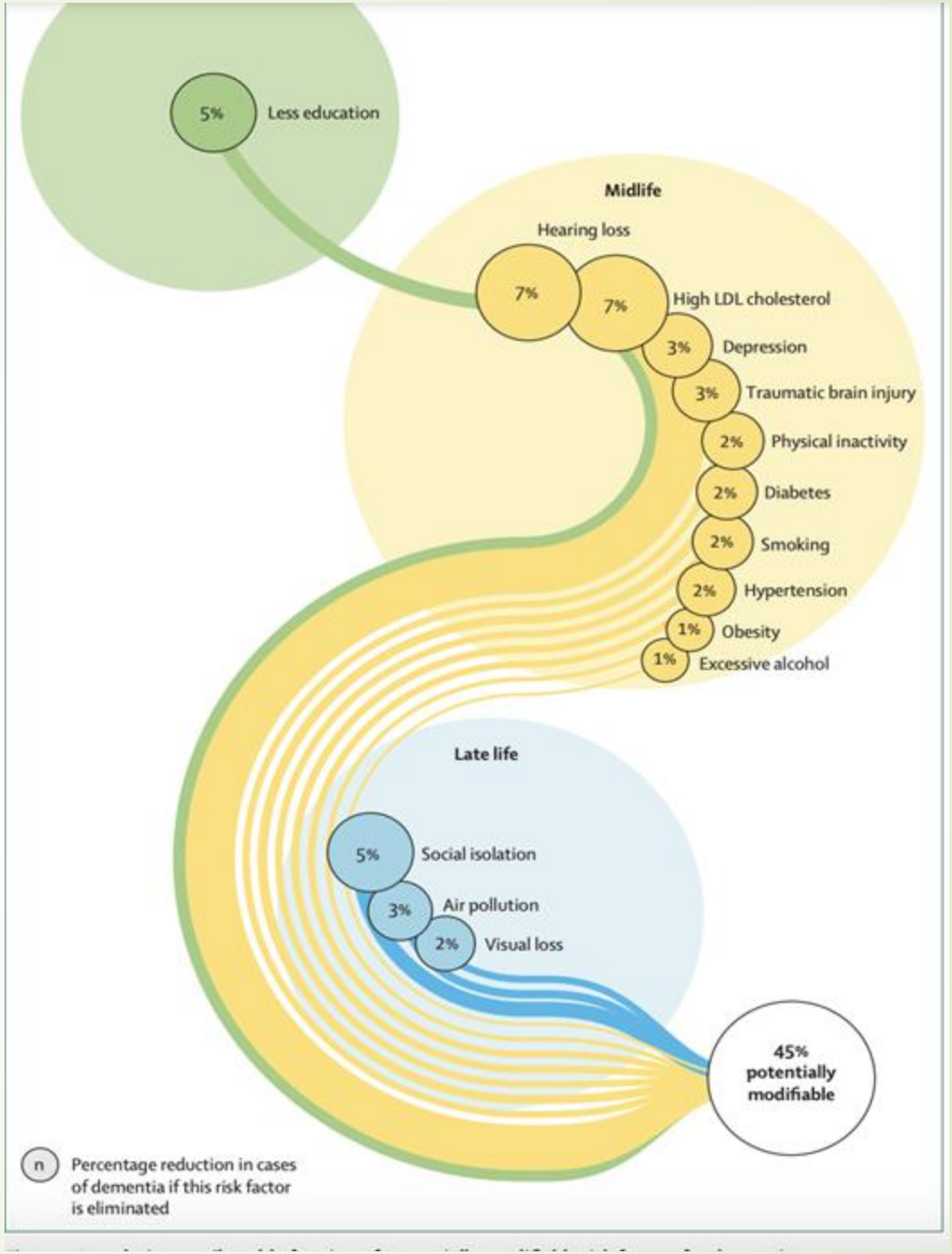


Source: The Lancet

Dementia Prevention | The Lancet Commission July 31, 2024

New Risk Factors Added in 2024:

Vision Loss
LDL cholesterol



Source: The Lancet

Brain Health: General Rules for Dementia Prevention

What's good for your heart is good for your brain

- BP, lipids, blood sugar control
- Stop smoking, moderate alcohol use

Primary care/ Lifestyle Medicine 101

- "Eat food, not too much, mostly plants"
- Manage mood disorders
- Encourage physical activity
- Make and keep social connections

Pay special attention in older adults

- Sleep apnea - consider a sleep study
- Hearing loss & Vision loss

Meet Binh

Binh is 87. She lives with her son and his family. She has moderate stage dementia.

Binh was very close to her younger sister Rose, who lived nearby.
Rose died of cancer about 5 years ago.

Binh asks her son: “When is Rose coming over?” When she is reminded that Rose has died, she is grief-stricken. The next day, she asks again.

What advice would you give to Binh’s family?

Meet Luis

Luis lives in a senior apartment and has a caregiver with him during the day. His grandson comes over in the evenings and spends the night.

This morning, he refused to take a shower and wants to stay in his pajamas. This is distressing to his grandson, because Luis has always been a very snazzy dresser who cares about his appearance.

What advice would you give to Luis's family?

Bathing assistance tips, from Island Health