NORTHERN VIRGINIA
dementia care
consortium



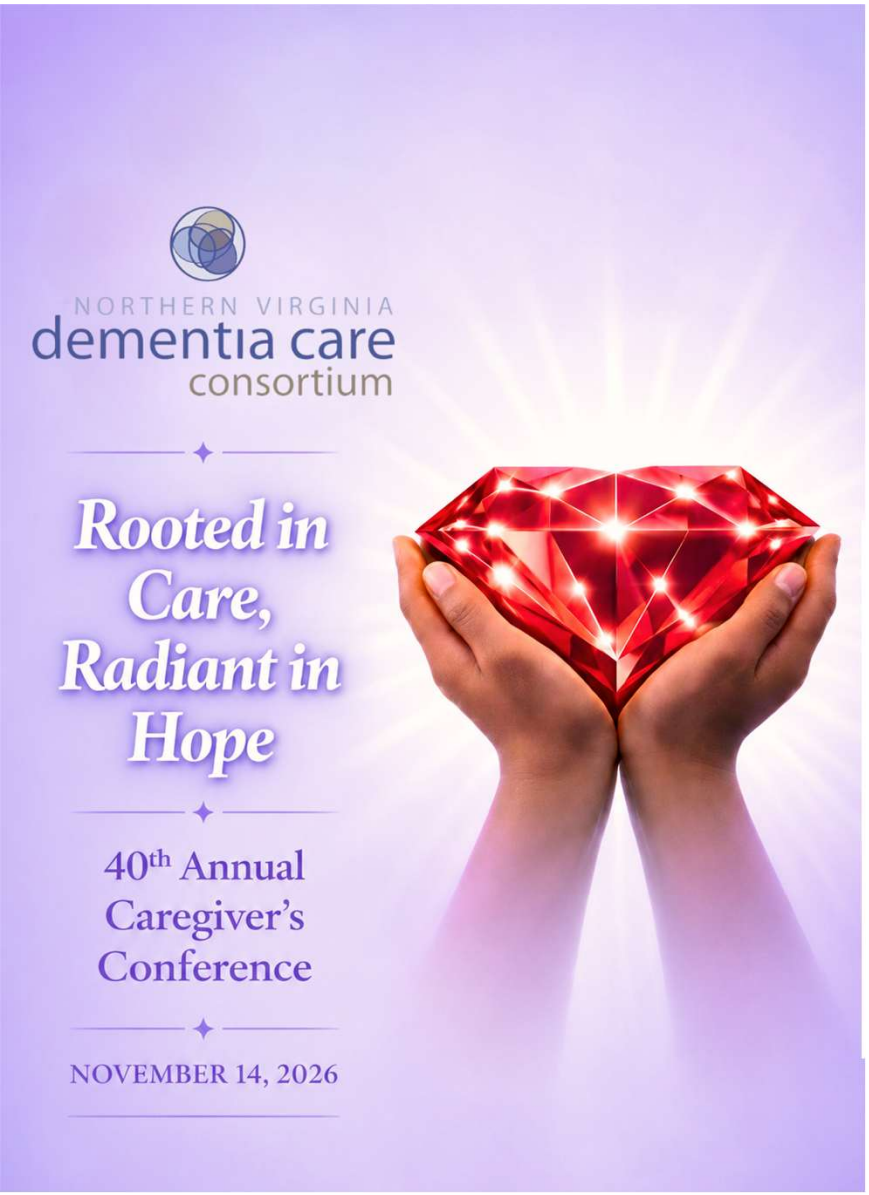
Rooted in Care, Radiant in Hope

40th Annual Caregiver's Conference

November 14, 2026


NORTHERN VIRGINIA
dementia care
consortium
Rooted in Care, Radiant in Hope
40th Annual Caregiver's Conference
NOVEMBER 14, 2026

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Your Care. Our Commitment.



KEYNOTE
Presented By

Dr. Jennifer Pauldurai, MD

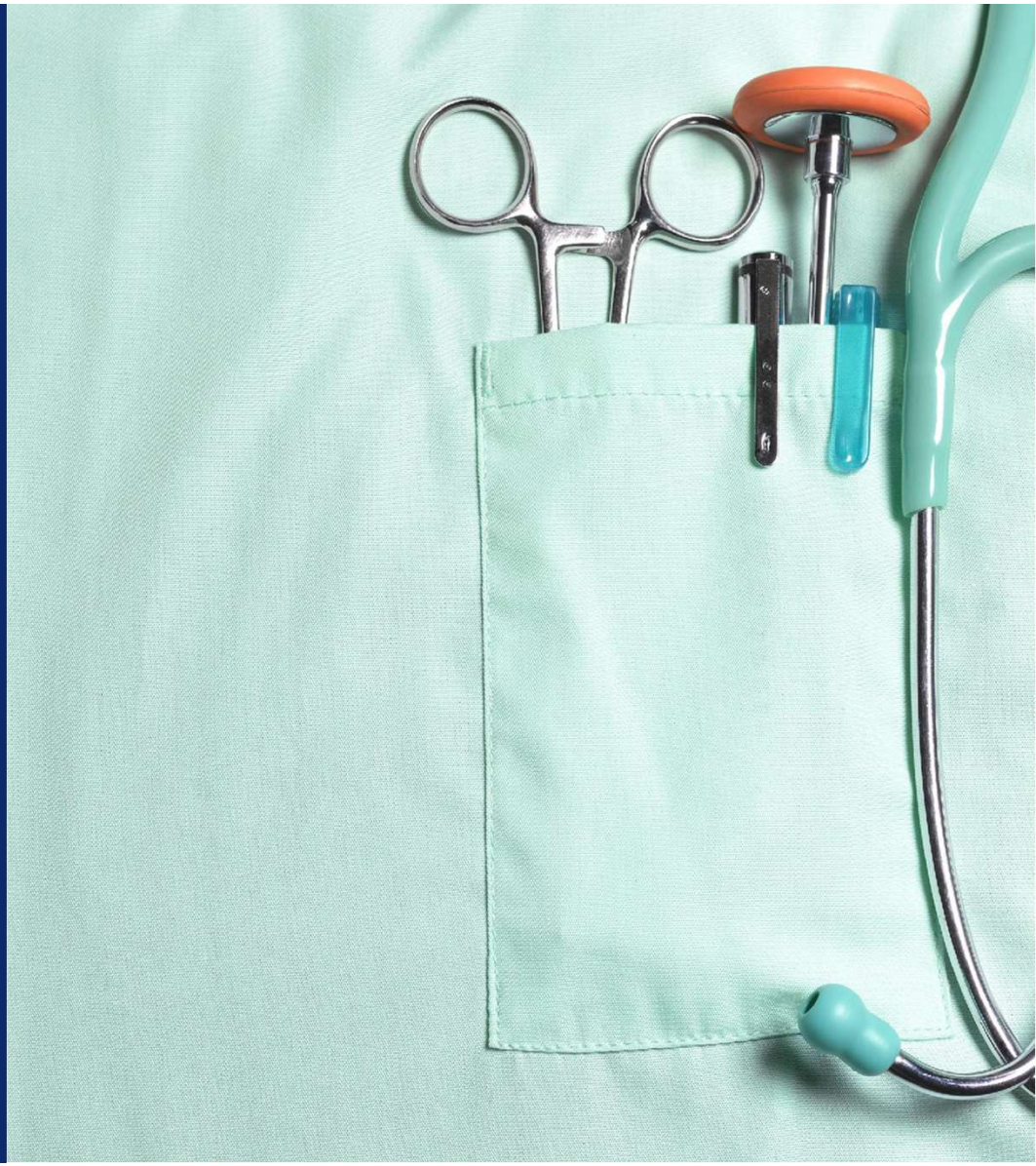
A Cheatsheet for Your Neurology Appointment

Inova™

Brain Health and Memory Disorders Program

A Cheat Sheet for Your Neurology Appointment

Jennifer Pauldurai, MD, MS
Inova Brain Health and
Memory Disorders Program



Disclosures

I have no potential conflicts of interests in relation to this presentation.

There are no financial disclosures.

I did not use AI tools in the creation of this presentation.

I Forget, Do I Need a Neurologist?



<u>Not all forgetfulness originates from a neurologic cause.</u> This initial evaluation may reveal that you need another specialist evaluation. You may have:

- Sleep Apnea
- Thyroid Dysfunction
- Untreated Depression
- Vitamin Deficiencies
- ADHD or Learning Disability

Evaluation of memory loss often starts with primary care:

- **Cognitive screening or short memory test.** Examples, MOCA, SLUMS, MMSE
- **Checking routine bloodwork, to see if there are non-neurologic causes of forgetfulness.** Some important labs to check include CBC, CMP, B12, Vit D, TSH

Referrals for further work-up:

- **Imaging, often an MRI Brain non contrast**
- **Advanced memory testing, such as neuropsychology tests**

I Forget, Do I Need a Neurologist?

Evaluation of memory loss often starts with primary care.

If you have these risks for dementia, your primary care evaluation may suggest seeing a neurologist.

- Abnormal MRI Brain
- Abnormal Cognitive Screening
- Abnormal Cognitive Labs (ptau217, amyloid 42:40 ratios)
- Family history of dementia, APOE 4 risk genes
- Multiple vascular risk factors (hypertension, diabetes, smoking)
- History of head injury or concussions

The greatest risk factors for dementia are advancing age, but there are ways to keep the brain healthy even when aging.

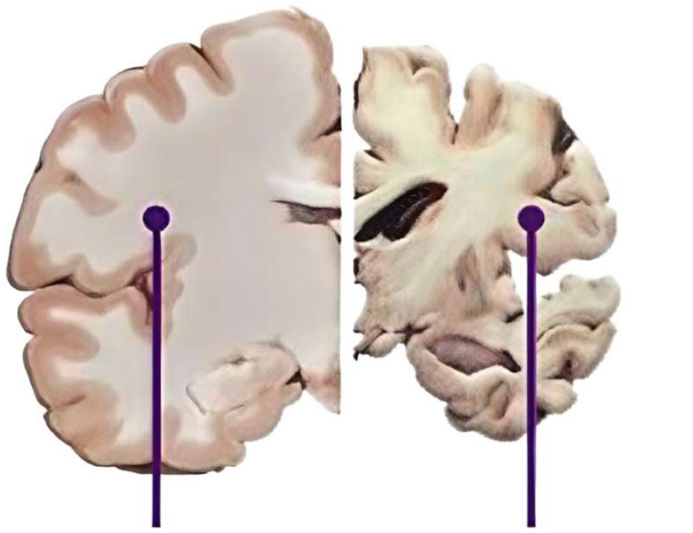
- Treat hearing loss and vision loss
- Stay cognitively and socially active
- Stay physically active
- Get good rest and mental health
- Eat brain healthy foods



I Forget, Do I Need a Neurologist?

Dementia is defined as a progressive loss of brain function and independence with self-care. Dementia is usually caused by different plaque buildup or other structural changes that cause brain cells to degenerate.

Dementia is inherently a neurological disease, and a cognitive neurologist is often involved in defining the specific type of dementia and treatment plan.



Healthy brain

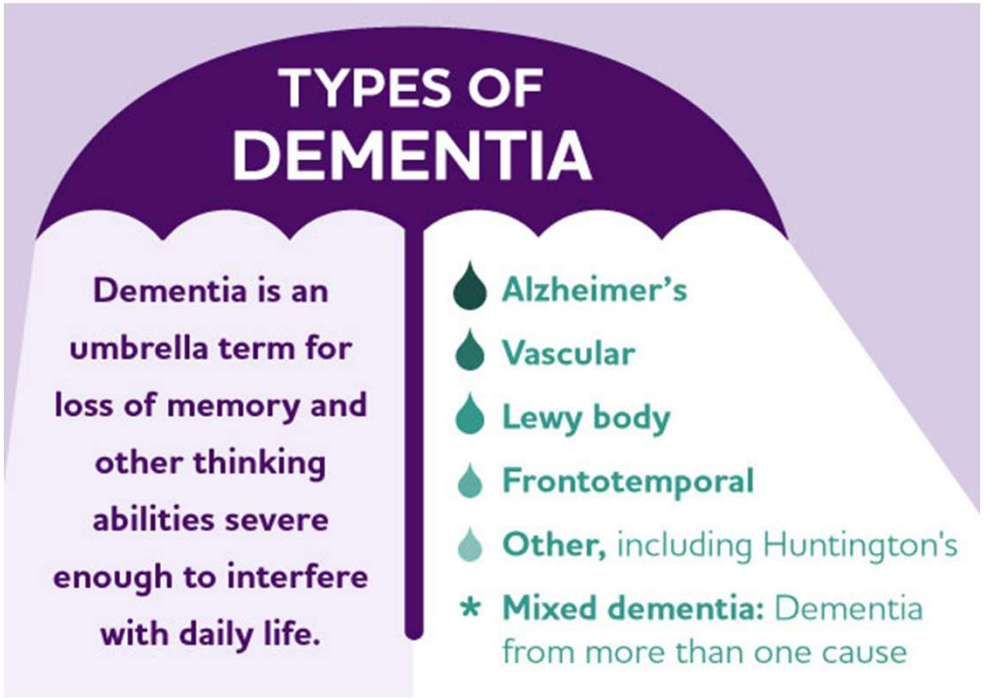
Advanced Alzheimer's

I Forget, Do I Need a Neurologist?

CHEAT SHEET QUESTION #1

Ask your neurologist or cognitive specialist (sometimes geriatrician, psychiatrist) what type and stage of dementia you may be experiencing.

Dementia is not a specific diagnosis, and there are ways to determine what is going wrong in the brain.



Neurologists Help Define the Problem

THE NEURO EXAM:
First, we listen. We want to hear the patient's version of the story.

- Syntax, grammar, word choices
- Social appropriateness, humor, disinhibition
- Detail of memories, short term, long term
- Thought content, delusions, hallucinations
- Task completion, understanding of instructions
- Loss of attention, minimization of symptoms, defensiveness, irritability
- Insight, judgement

"I wasn't paying attention, that part was not important at all," "All of my friends have the same issue, so I don't think this is a big deal."

When the brain has dementia, it may not recognize or understand the severity of symptoms, this is called **anosognosia.**

Try not to correct or fill in the details of the patient's history until the doctor specifically asks you.

Neurologists Help Define the Problem

Consider sharing your care partner observations respectfully, and if needed separately with the doctor (note, phone call). Try not to use confrontational or accusatory language.

The medications are getting confusing, is there a way to help?

Important Symptoms to Discuss:

- **Memory** – when was the change noticed, and how severe is it? Give an example.
- **Attention and Organization** – are we able to maintain appointments, finances, medications?
- **Self-Care** - are regular nutrition and social routines followed? Any declines in hygiene?
- **Behavior and Mood** – any delusions, hallucinations or abnormal mood swings?
- **Safety –** are we driving, living on our own, falling for scams? Mold in the home?

Neurologists Help Define the Problem

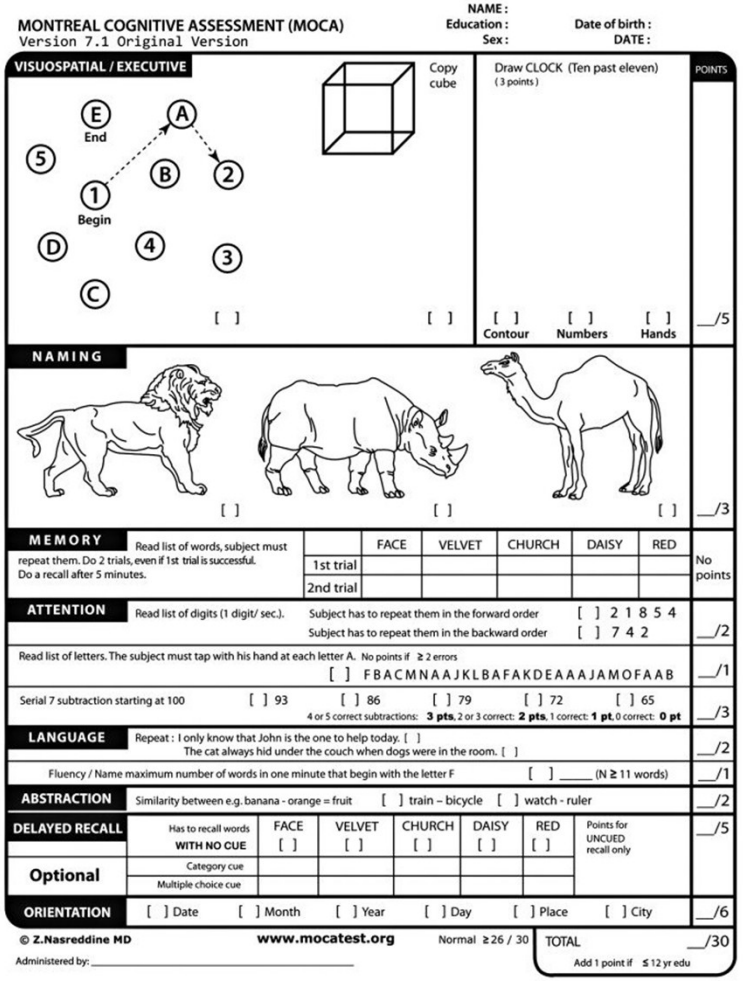
THE NEURO EXAM:
Next, we do a physical exam.

- Facial symmetry and eye contact
- Preference for right or left side
- Focal asymmetry (stroke-like symptoms)
- Weakness, shaking, motor exam
- Vision, depth perception
- Gait, coordination of movement
- Interaction with family and care partners
- Anxious or stress behaviors

Repetitive movements, tapping, aversion of eye contact, may suggest a heightened sense of stress. Fashion, hygiene, hair is also examined.

Let the doctor know if you notice any changes in physical activity or movement. Even seemingly unrelated medical issues could be neurologic.

Neurologists Help Define the Problem



MONTREAL COGNITIVE ASSESSMENT (MOCA)
Version 7.1 Original Version

NAME :
Education : Date of birth :
Sex : DATE :

VISUOSPATIAL / EXECUTIVE — Copy cube — Draw CLOCK (Ten past eleven) (3 points) — [ ] Contour [ ] Numbers [ ] Hands — POINTS __/5

NAMING — [ ] [ ] [ ] __/3

MEMORY — Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No points

ATTENTION — Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order [ ] 2 1 8 5 4. Subject has to repeat them in the backward order [ ] 7 4 2 __/2

Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors
[ ] F B A C M N A A J K L B A F A K D E A A A J A M O F A A B __/1

Serial 7 subtraction starting at 100 [ ] 93 [ ] 86 [ ] 79 [ ] 72 [ ] 65
4 or 5 correct subtractions: **3 pts**, 2 or 3 correct: **2 pts**, 1 correct: **1 pt**, 0 correct: **0 pt** __/3

LANGUAGE — Repeat : I only know that John is the one to help today. [ ]
The cat always hid under the couch when dogs were in the room. [ ] __/2

Fluency / Name maximum number of words in one minute that begin with the letter F [ ] ____ (N ≥ 11 words) __/1

ABSTRACTION — Similarity between e.g. banana - orange = fruit [ ] train – bicycle [ ] watch - ruler __/2

DELAYED RECALL — Has to recall words WITH NO CUE: FACE [ ] VELVET [ ] CHURCH [ ] DAISY [ ] RED [ ] — Points for UNCUED recall only __/5

Optional — Category cue; Multiple choice cue

ORIENTATION — [ ] Date [ ] Month [ ] Year [ ] Day [ ] Place [ ] City __/6

© Z.Nasreddine MD www.mocatest.org Normal ≥ 26 / 30 TOTAL __/30
Add 1 point if ≤ 12 yr edu

Administered by: _____

Bedside cognitive tests (MOCA, MMSE, SLUMS) can be a stressful experience, and we know short quizzes won't capture the full ability of a patient. Allow the patient to do their best without commentary.

Often longer cognitive tests like neuropsychological assessments matter more than bedside screening tests. These "tests" are not pass or fail, but rather troubleshooting.

Neurologists Help Define the Problem

Dementia syndromes follow typical patterns of symptom progression and often have different cognitive changes.

- **Alzheimer's Disease:** short term memory first, social cues intact, orientation impaired.
- **Lewy Body Disease:** visual hallucinations and mood changes, visuospatial difficulties
- **Frontotemporal Disease:** social cues and language impaired, memory usually intact
- **Vascular Dementia:** slower processing and gait

Neurologists put together a clinical syndrome and then order the next steps in diagnosis.

There is no one test to check for all types of dementia, rather there is a step-by-step process for diagnosis. This must start with the clinical evaluation.

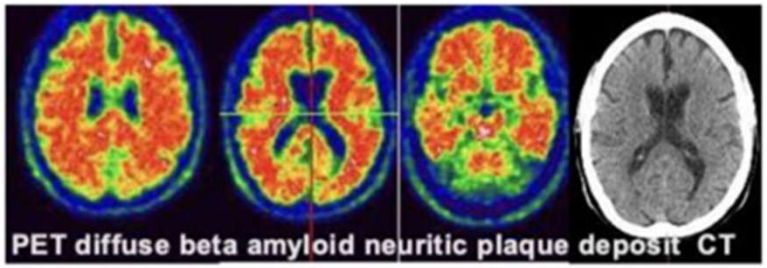
Neurologists Help Define the Problem

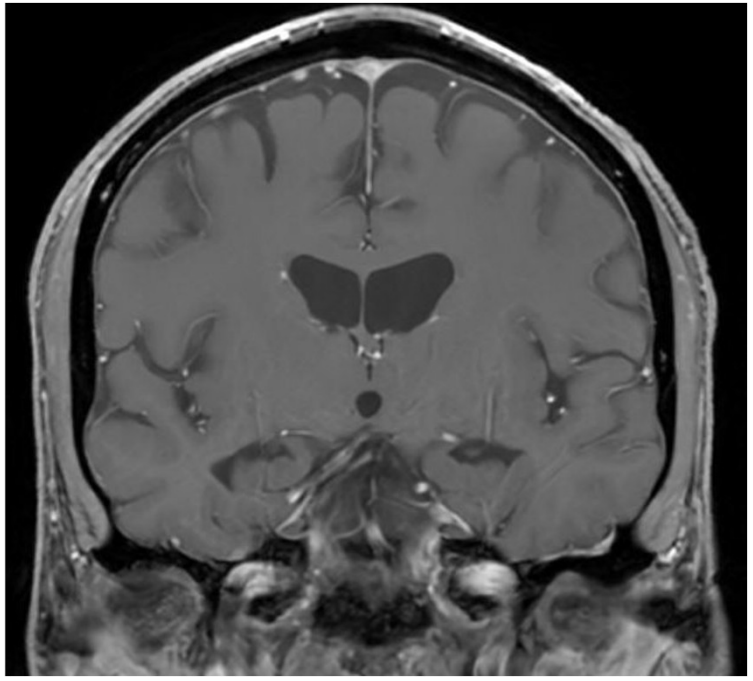
<u>Available Biomarker Assessments:</u>
We no longer have to guess or generalize what type of dementia may exist. Many times, there are mixed presentations.

Alzheimer's Disease: amyloid and tau blood tests, PET amyloid and soon PET tau, CSF spinal tap

Lewy Body Disease: DATscan, skin biopsy, soon CSF spinal tap

Frontotemporal Disease: FDG-PET Brain





Neurologists Help Define the Problem

CHEAT SHEET QUESTION #2

Do we need to complete any more evaluations or testing to determine a care plan?

Sometimes a clinical evaluation is enough to plan for the future. Added diagnostics may be stressful for the patient or yield little benefit.

Stage	Stage Name	Characteristic
1	Normal Aging	No deficits whatsoever
2	Possible Mild Cognitive Impairment	Subjective functional deficit
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling
5	Moderate Dementia	Needs help selecting proper attire
6a	Moderately Severe Dementia	Needs help putting on clothes
6b	Moderately Severe Dementia	Needs help bathing
6c	Moderately Severe Dementia	Needs help toileting
6d	Moderately Severe Dementia	Urinary incontinence
6e	Moderately Severe Dementia	Fecal incontinence
7a	Severe Dementia	Speaks 5-6 words during day
7b	Severe Dementia	Speaks only 1 word clearly
7c	Severe Dementia	Can no longer walk
7d	Severe Dementia	Can no longer sit up
7e	Severe Dementia	Can no longer smile
7f	Severe Dementia	Can no longer hold up head

Neurologists Help Create a Care Plan



It takes a village to care for dementia. Here are examples of partners in care that are important for comprehensive dementia management.

Every family deserves a unique care plan.

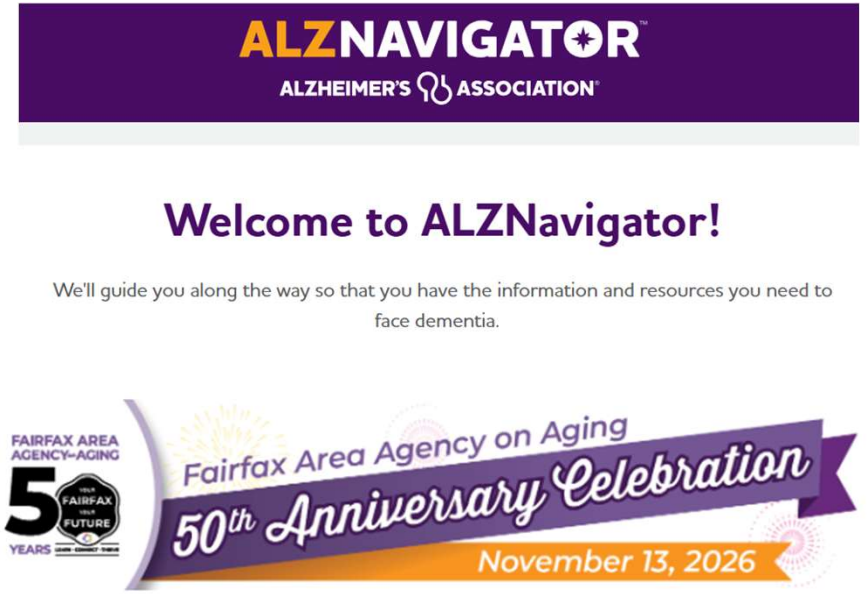
Neurologists Help Create a Care Plan

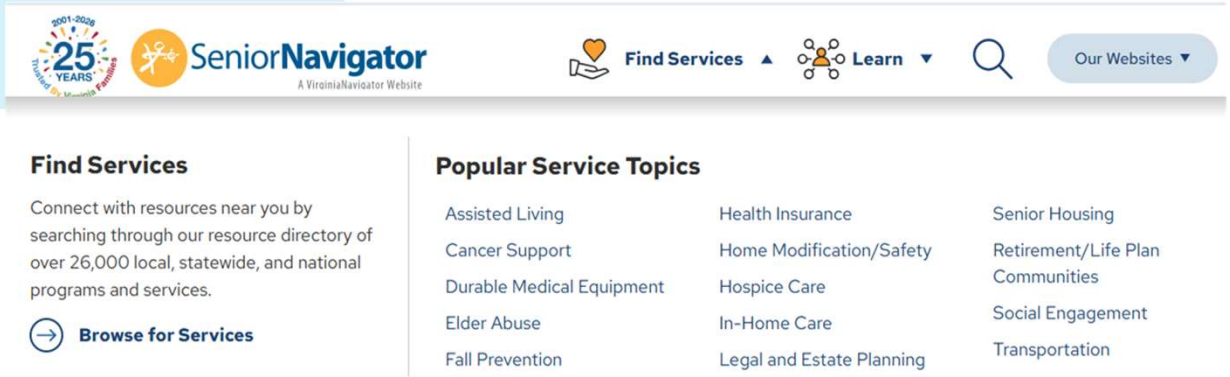
It can be difficult to create this comprehensive care plan all in one 20-30 minute doctor visit. This can lead to a frustrating lack of answers and added fear for the future.

CHEAT SHEET QUESTION #3

What are the most important next steps in care planning and treatment? W ho do we need to connect with for more information?

insight MEMORY CARE CENTER





Neurologists Help Create a Care Plan

Dementia care tasks that neurologists are (usually) able to do:

- Review results of **diagnostic work-up**
- Review **medications** that can help slow down the disease (anti-amyloid therapies can help in early stages of AD).
- Review therapies that can help with **symptom management.** Medications for memory, sleep, appetite, and behavioral control
- **Refer to ancillary services** like rehabilitation, physical therapy, occupational therapy, swallow evaluations, specialty services
- Provide clinical evaluations for **disability, capacity, and competence.**

Dementia care tasks that neurologists are NOT very good at (usually):

- Recommending **specific home care** or home living situations
- **Financial or legal advice**
- **Family counseling,** especially with conflicting opinions on how to care for each other or who should be in charge
- Giving you an **exact timeline or prognostic number** to predict the future

Neurologists Help Create a Care Plan



CHEAT SHEET QUESTION #4

Is there anything else that I should be asking? How do we care for the care team?

Be gracious to yourself. Being a patient is difficult, and being a care partner can be even harder. Neurologists don't know all the answers either. **Together, we find ways to help each other lessen the burden of dementia.**

CHEAT SHEET QUESTIONS FOR THE NEUROLOGY APPOINTMENT

1. What type and stage of dementia?

2. Do we need to do more tests?

3. What is our next step, and who is part of the team?

4. How do we care for the care team?

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Featured Speaker

Healing While Helping: Supporting Loved Ones with Dementia Without Losing Yourself

Liletta Harlem

40TH ANNUAL CAREGIVER CONFERENCE

Healing While Helping

Supporting Loved Ones with Dementia Without Losing Yourself

Northern Virginia Dementia Care Consortium
Saturday, November 14, 2026
Inova Center for Personalized Health Conference Center · Fairfax, Virginia



Meet your presenter



Liletta Harlem

President, M N M Executive Director,
Dementia Caregiver Support Program

01 Recognize the strain
Name stress, grief, and changing roles.

02 Protect your well-being
Practice small, realistic tools for care.

03 Build your support
Share care at home and seek help at work.

Caregiving changes more than your schedule

Stress

Decisions, disrupted sleep, and constant responsibility can feel relentless.

Changing roles

You may be a spouse, child, or friend—and now a care coordinator, too.

Grief

You can mourn changes in a relationship while your loved one is still here.

Guilt and mixed feelings

Love, frustration, sadness, and even joy can exist together.

Reflect: What has caregiving changed for me—and what do I need now?

Source: Alzheimer's Association · Grief and Loss

Notice your own warning signs

Common signals of strain

Exhaustion that does not lift

Sleep or appetite changes

Irritability or frequent worry

Pulling away from other

people Trouble concentrating

Do not dismiss it:
"I just need to push harder."

Respond with support

"My health needs attention, too."

If signs recur or interfere with daily life, talk with your doctor or a mental health professional.

Source: Alzheimer's Association · Caregiver Stress

Pause before the pressure grows

Try this brief check-in, if it feels comfortable. Keep care and safety covered.

1. Pause and breathe comfortably.
   Relax your shoulders. Notice your feet on the floor.
2. Name a feeling or need. "I feel overwhelmed. I need a break."
3. Choose one safe next step. Ask for help. Sip water. Reset the task.

Less conflict. More connection.

Quiet space. Simple words. One question at a time. Give time to respond.

When correction adds pressure

Loved one: "I need to go home."

"You are home. I already told you that."

Try reassurance instead

Listen for the feeling behind the words.

"You want to feel at home. I'm here with you."

Respect dignity: speak directly to your loved one and adapt to their needs.

Protect your well-being without guilt

1. Keep your own health on the calendar.
   Meals, rest, movement, and medical visits matter.
2. Plan safe respite—not just spare time.
   Arrange trusted care while you take a break.
3. Keep something that belongs to you.
   A friend, hobby, faith practice, or quiet moment.
4. Set a limit you can sustain.
   Share the task before you reach exhaustion.

A boundary can sound like this

"I can cover mornings. I need someone else for Tuesday afternoon."

A limit is not abandonment. It helps make care sustainable.

Choose one: What can I protect this week?

Source: National Institute on Aging · Caring for Yourself

Care is a team effort—at home and at work



At home: make the ask clear

"Can you bring dinner on Thursday?" Put agreed tasks in a shared calendar.

At work: start a conversation

Ask HR about flexible schedules, leave policies, and employee assistance, if available.

Share only what you choose.

NIA · Shared care guidance. Workplace options vary.

A local bridge between families and workplaces



Northern Virginia Dementia Support & Workplace Alliance

A program of My Natural Me

CareConnect describes two goals:

Connect caregivers with community support.

Help employers build dementia-informed workplaces.

Serving Prince William County and Northern Virginia. Ask about current programs: info@mynaturalme.info

Source: CareConnect Portal · Confirm current availability

Support for you, too

MNM partner spotlight · Mental health & wellness

Palesa Osei-Tutu, LCSW

Founder, Sit Awhile & Heal LLC

Licensed Clinical Social Worker with more than 23 years across behavioral health and social work.

She provides culturally responsive counseling, clinical supervision, workshops, and consultation.

Connect with Palesa

info@sit-awhile.com · 571-406-3144 sit-awhile.com



MNM Partner

Mental Health & Wellness

Caregiver support: Alzheimer's Association 24/7 Helpline 800-272-3900 · ElderLink 703-324-5374



Break and Visit Exhibitors



Continuum of Care Panel Discussion

Maria Delpizzo
Steff Walker
Heather Suri



Lunch and Visit Exhibitors



Alzheimer's Disease in 2026: From Symptomatic Care to Early Detection and Prevention

Bridgid Reynolds & Alison Perlman

ALZHEIMER'S DISEASE IN 2026: FROM SYMPTOMATIC CARE TO EARLY DETECTION AND PREVENTION

2026 NVDCC Conference

Brigid Reynolds, ANP-BC
Alison Perlberg, BS, MA
11/14/2026

DISCLOSURES

The presenters have no financial disclosures.

Brigid Reynolds is the Memory Disorders Program Site Principal Investigator (PI) for the ADNI Study and the Alzheimer's Clinical Trial Consortium (ACTC) Georgetown Site Co-PI.

Alison Perlberg Coordinated the A4 and LEARN Studies at the Memory Disorders Program.

GEORGETOWN UNIVERSITY MEMORY DISORDERS PROGRAM



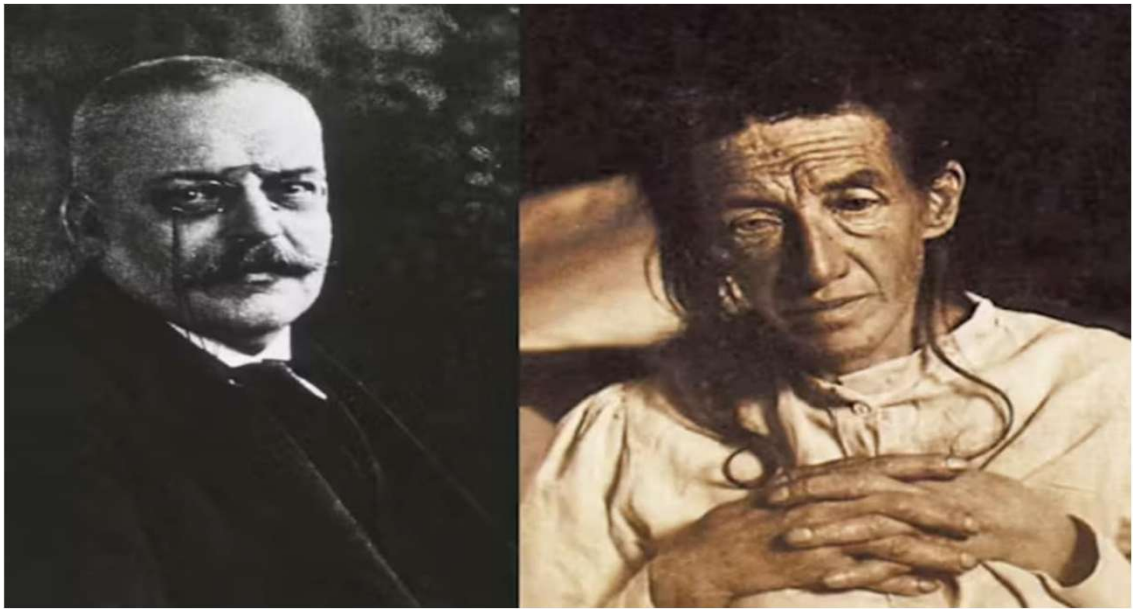
GEORGETOWN UNIVERSITY

PRESENTATION OUTLINE

1. **Case study #1 Auguste's Story- 1906**
2. AD Pathology
3. Dementia and MCI
4. The ADNI Study
5. **Case study # 2 Edith's Story- 2005**
6. **Case Study # 3 Joy's Story- 2015**
7. The Antiamyloid in Asymptomatic Alzheimer's disease study (A4) and LEARN Studies
8. The AHEAD and LEARN Studies
9. The Pointer Study
10. **Case Study #4 Archie's Story- 2025**
11. Blood-Based Biomarkers
12. Amyloid-Reducing Treatments
13. The Alzheimer's Tau Platform Study (ATP)
14. Key Takeaways
15. Websites/Resources

CASE STUDY # 1
AUGUSTE DETER (1906)

In **1906**, German psychiatrist and neuropathologist **Dr. Alois Alzheimer** presented the case of **Auguste Deter**, a 51-year-old woman with profound memory loss and hallucinations.



A Diagnosis in 1906: Auguste's Journey (1850-1906)

The First Signs

BEHAVIOR & MEMORY CHANGES

- Presented with profound memory loss and hallucinations
- Admitted to a Frankfurt psychiatric hospital in 1901
- Died from septicemia due to bedsores and pneumonia at age 55 in 1906

The 1906 Diagnosis

PROCESS OF ELIMINATION

- Following her death, Dr. Alzheimer performed a brain autopsy
- Chemical staining determined Auguste had amyloid plaques and tau tangles
- **Auguste's case defined the hallmark pathologies for Alzheimer's disease**

The Care Plan

MANAGING THE SYMPTOMS

- **No treatments would become available for another 87 years**

Inside the Brain: The 3 Stages of Alzheimer's Disease

How specific protein changes slowly disrupt normal brain function over time.

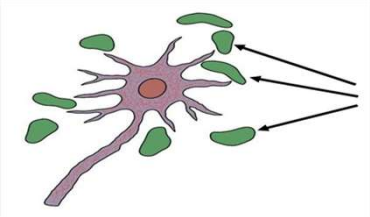
STAGE 1

The "Plaques" (Amyloid)

The External Clumps

Healthy brain cells overproduce small protein fragments called amyloid.

Fragments form sticky **plaques** that build up outside and between brain cells.



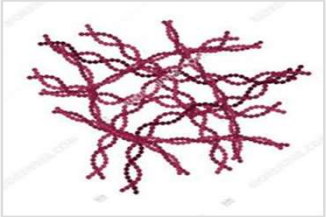
STAGE 2

The "Tangles" (Tau)

The Internal Collapse

Inside brain cells, tau proteins twist into abnormal **tangles**.

Tangles disrupt vital communication between neurons.



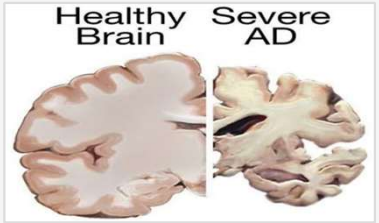
STAGE 3

The "Damage" (Neurodegeneration)

The Communication Loss

External plaques and internal tangles strangle the brain cells.

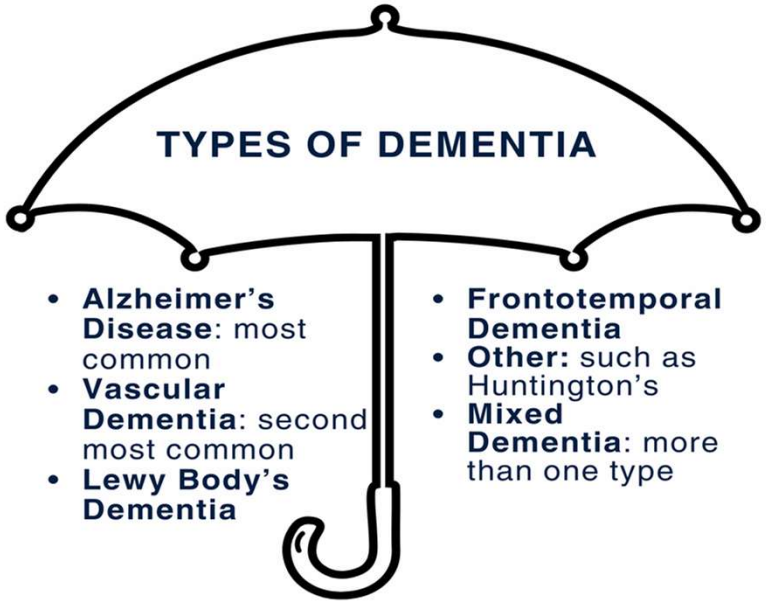
Over time, these cells fail, wither, and completely fade away.

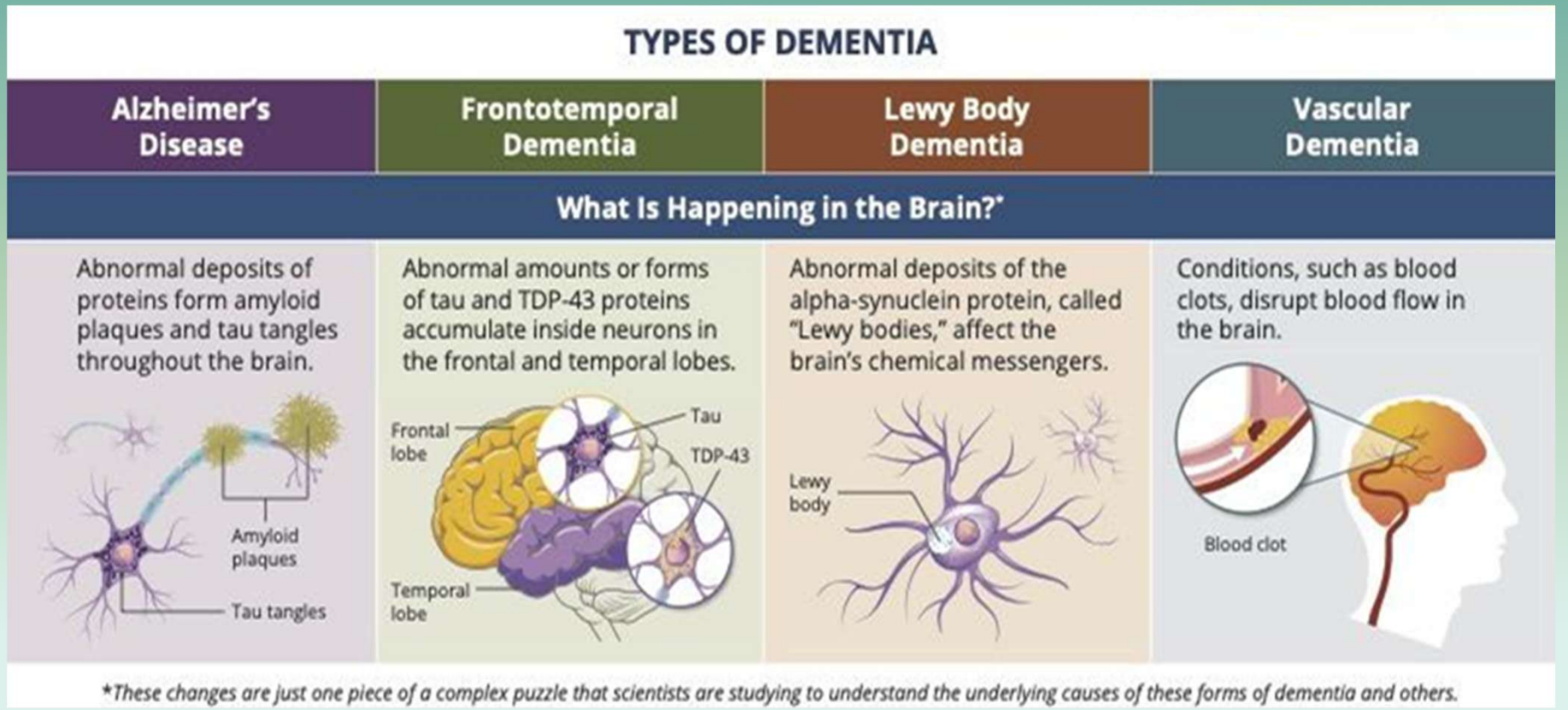


DEMENTIA- AN UMBRELLA TERM

Dementia: progressive, irreversible brain diseases in which a specific neurological process directly destroys brain cells and leads to a loss of function.

Four major types account for the vast majority of all cases.





https://www.nia.nih.gov/health/alzheimers-and-dementia/understanding-different-types-dementia

Understanding Mild Cognitive Impairment (MCI)

The middle ground between normal aging and dementia

What is it?

- A noticeable decline in memory, thinking, or concentration skills
- Changes are clear to the person or family, but do not stop daily independence
- The individual manages daily life on their own
- They can still drive, pay bills, shop, and live safely alone

How it differs

- Normal Aging: Forgetting keys occasionally
- MCI: Forgetting recent events or conversations regularly
- Dementia: Struggles to dress, cook, or live safely without assistance

What comes next?

- It is a warning sign, not a guarantee of dementia
- Some people stay stable or improve; others progress
- Early diagnosis opens doors to lifestyle changes and proactive care.

THE CHOLINERGIC HYPOTHESIS

Alzheimer’s a treatable disease?

Cholinergic hypothesis: dysfunction of acetylcholine in the brain contributes substantially to the cognitive decline observed in Alzheimer's disease.

Key Milestones:

1976: Researchers Peter Davies and A.J.F. Maloney first discovered a major loss of the acetylcholine-synthesizing enzyme in the brains of patients with Alzheimer's disease.

1982: Dr. Raymond T. Bartus and colleagues published a landmark review article in *Science*, titled *"The cholinergic hypothesis of geriatric memory dysfunction,”* - formally established the concept.

CHOLINESTERASE INHIBITORS

Provide symptomatic benefit

Not disease-modifying

Approved for treatment in mild, moderate, and severe Alzheimer's disease:

Aricept (donepezil)- FDA approved in 1996

Exelon (rivastigmine)- FDA approved in 2000

Razadyne (galantamine)- FDA approved in 2001

THE ALZHEIMER'S DISEASE NEUROIMAGING INITIATIVE (ADNI)

A long-term, multi-center study that tracks the progression of Alzheimer's disease using brain scans, memory tests, and biological samples.

Began in 2004 as a private-public partnership supported by the National Institute on Aging, the Alzheimer's Association, and dozens of companies.

- **Study Type:** Observational only (no experimental drugs or medications are given as part of the study)
- **Main Purpose:** To find and validate early-detection biomarkers (such as MRI scans, PET scans, and spinal fluid/blood tests) to help design better clinical drug trials aimed at developing treatments that slow or stop disease progression
- **Data Sharing:** All collected data is shared openly with researchers worldwide. More than 5,000 to 6,000 scientific publications have been produced or facilitated using data from the ADNI study.

ADNI Study Milestones & Timeline

Alzheimer's Disease Neuroimaging Initiative: Shaping biomarker validation since 2004.

ADNI-1

2004 – 2009

Baseline biomarker tracking & standardization across 1.5T MRI, FDG PET, and CSF samples.

Amyloid PET PIB-pilot 2005

ADNI-GO

2009 – 2011

Grand Opportunity expansion adding an early-MCI cohort to catch the earliest signs.

ADNI-2

2011 – 2016

Full clinical spectrum validation, splitting MCI into early and late stages.

Amyloid PET- florbetapir, florbataben

Tau Pet- flortaucipir, introduced during the later phase of ADNI 2

ADNI-3

2016 – 2023

Transition to 3T scanners, adding advanced fMRI sequences and revolutionary Tau PET.

ADNI-4

2023 – Present

Modern digital focus on highly sensitive blood-plasma testing and minority cohort diversity.

CASE STUDY # 2 - EDITH



Edith, is a 68-year-old retired teacher.

Her spouse began noticing changes such as Edith's misplacing her keys, and repeating questions.

The onset of gradually progressive symptoms were first noticed by her spouse approximately two years ago.

Edith was unaware of her memory and thinking changes and was resistant to come in for an evaluation.

Edith stopped driving after getting lost on a familiar route twice.

She screened for enrollment in ADNI-1. Her spouse served as her Study Partner.

A Diagnosis in 2005: Edith’s Journey

What finding out you had Alzheimer's looked like over two decades ago, before modern biomarkers.

The First Signs

MEMORY CHANGES

- Presented with noticeable changes to her memory such as repeating questions and misplacing personal belongings
- Functional changes included no longer driving due to getting lost
- Enrolled in the AD cohort of ADNI-1

The 2004 Diagnosis

PROCESS OF ELIMINATION

- Pen-and-paper tests of memory and thinking
- Medical history and physical exam
- MRI performed to rule out stroke, tumor, or other causes for thinking changes
- Spinal fluid (CSF) analysis for Amyloid-beta (Aβ) and Tau Proteins
- Given a diagnosis of probable Alzheimer’s disease

The Care Plan

MANAGING THE SYMPTOMS

- Encouraged to make lifestyle interventions
- PCP prescribed donepezil (Aricept) for symptomatic management
- Encouraged to initiate long-term care planning
- No disease-modifying treatments were available

LIFESTYLE INTERVENTIONS- 2005

In 2005, the understanding of lifestyle interventions for brain health was in a transitional phase. Medical consensus still overwhelmingly favored the **cholinergic hypothesis** and the search for a pharmaceutical "silver bullet."

Neuroplasticity- From the late 20th century onward, scientists first began proving that the adult brain could change, grow, and protect itself through behavior.

Healthy lifestyle interventions including engagement in physical, social, and mentally stimulating activities were recommended.

The absence of clinical biomarkers to detect and measure change made it difficult to quantify and characterize the impact of lifestyle interventions.

CASE STUDY # 3 - JOY (2015)



Joy, a 71-year-old retired accountant noticed changes in her memory, such as forgetting names and conversations.

She first noticed changes approximately one year ago.

She maintained independence with her daily activities at home.

Her medical history was significant for high blood pressure and diabetes.

She screened for enrollment in ADNI-2. Her sister served as her Study Partner.

A diagnosis in 2015: Joy's Journey

How joining the Alzheimer's Disease Neuroimaging Initiative (ADNI) in 2015 shifted toward advanced biomarker tracking.

The ADNI Screening

CLINICAL & STRUCTURAL BASELINES

- Screened for the ADNI study using extensive testing and standardized functional assessments
- Enrolled in the MCI cohort of ADNI-2

The 2014 Biomarkers

ADVANCED IMAGING & PATHOLOGY

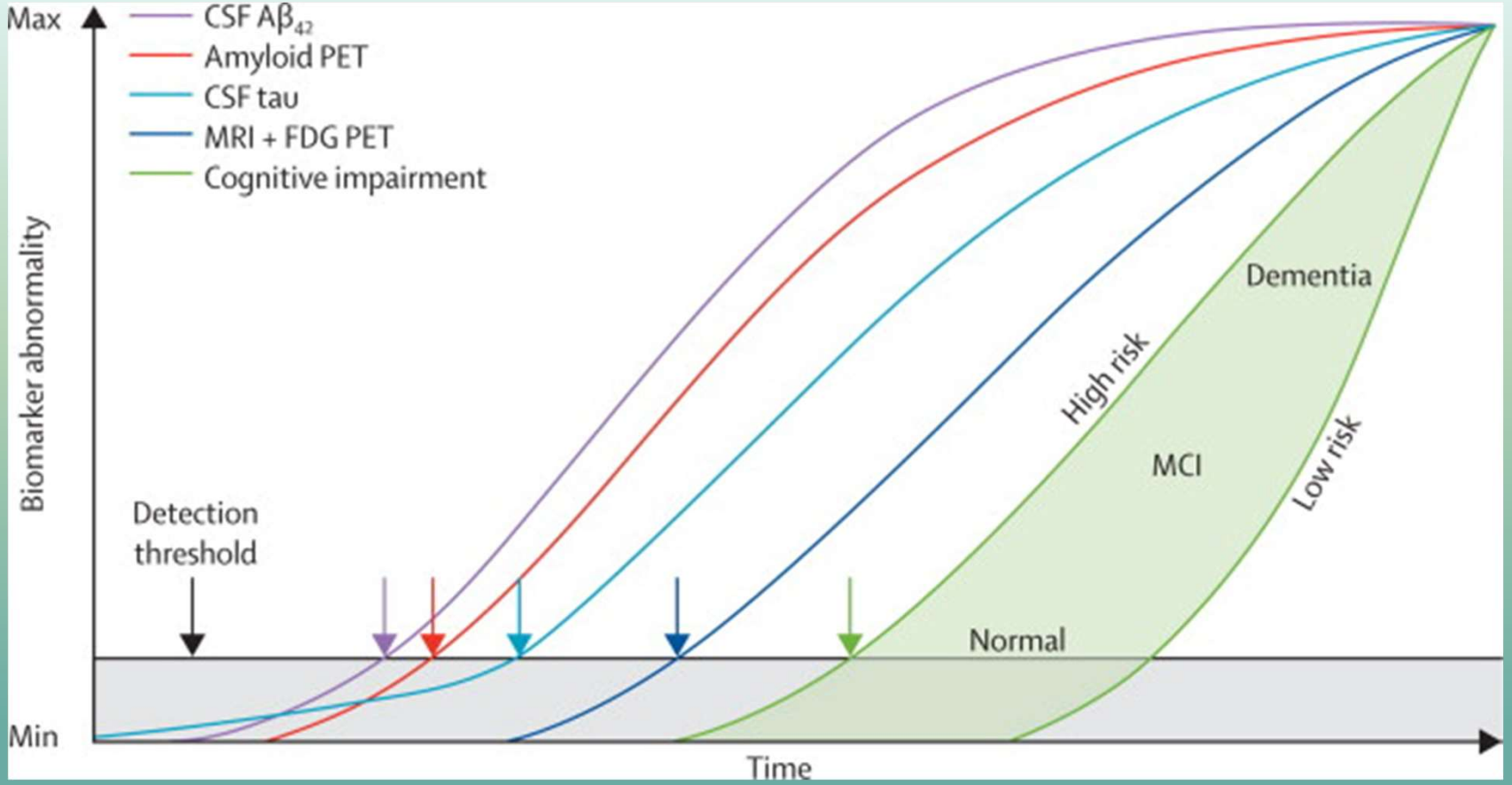
- In addition to paper-and-pencil testing, Joy's evaluation included:
- Amyloid PET scan- visualize amyloid plaques
- FDG PET Scan
- Volumetric MRIs - visualize structural brain changes
- Spinal tap- CSF fluid analysis for Amyloid-beta (Aβ) and Tau Proteins

The Care Plan

LONGITUDINAL TRIAL PARTICIPATION

- Encouragement to make lifestyle changes including physical, social, and cognitive engagement
- Control diabetes and hypertension
- FDA approved medications for the treatment of MCI remained unavailable

THE JACK CURVE- 2010



- https://pubmed.ncbi.nlm.nih.gov/20083042/#&gid=article-figures&pid=figure-2-uid-1

A4: A LANDMARK PREVENTION TRIAL
ANTI-AMYLOID IN ASYMPTOMATIC AD

The A4 Study
Now is the time

ACTC
ALZHEIMER'S
CLINICAL TRIALS CONSORTIUM

Duration: The landmark trial **launched in 2013.** Results were announced in **March 2023.**

- **First-of-its-kind Phase 3 secondary prevention** trial designed to see if an anti-amyloid treatment could slow cognitive decline in individuals at risk for Alzheimer's disease before symptoms appear
- **Participants:** Tracked **1,169 cognitively normal adults** (ages 65–85) over 4.5 years of continuous monthly evaluation
- **Results:** The investigational drug, *solanezumab*, **did not slow memory loss** or lower the risk of progressing to symptomatic Alzheimer's compared to a placebo
- **Amyloid linked to memory:** Proved higher amyloid plaque burden led to more rapid cognitive decline which confirmed plaque buildup is a direct, early driver of the disease
- **Paving the way forward:** While the drug itself failed, the A4 Study successfully proved that pre-symptomatic clinical trials are entirely possible

LEARN THE LEARN STUDY

ACTC ALZHEIMER'S CLINICAL TRIALS CONSORTIUM

- **The "Screen-Fail" Strategy:** Enrolled individuals who did not qualify for the A4 trial due to *negative* screening on amyloid PET scans (low brain amyloid levels).
- **The Control Value:** Serves as a vital, direct longitudinal baseline comparison group to understand true preclinical neurodegeneration absent early amyloid accumulation.
- **No Cognitive Decline:** Over the course of the 240+ week monitoring period, LEARN participants (who were amyloid-negative at baseline) **did not demonstrate cognitive decline.**
- **Biomarkers as Predictors:** Data combining both studies confirmed that higher baseline levels of amyloid-beta and tau are the strongest predictors of subsequent memory loss.

THE AHEAD STUDY

Funding: A public-private partnership- the National Institute on Aging (NIA) and Industry and Philanthropic Sponsors

Sponsor: The Alzheimer's Clinical Trials Consortium (ACTC) provides scientific leadership, trial management, and infrastructure

Purpose: Test whether lecanemab clears brain amyloid plaques and reduces Alzheimer's risk before memory loss starts

Target Population: Adults aged 55 to 80 who are cognitively normal but show elevated or intermediate brain amyloid levels

Study Design: 4-year double-blind, placebo-controlled trial split into two sister studies (A3 for intermediate amyloid; A45 for elevated amyloid)

Study Timeline: First patient infusions began in September 2020

Projected End Dates:

- **Primary Completion: December 21, 2028**
- **Full Study Completion: January 16, 2031**

U.S. POINTER
ALZHEIMER'S ASSOCIATION

A two-year randomized clinical trial sponsored by the Alzheimer's Association evaluated whether multidomain lifestyle interventions can protect brain function and reduce the risk of cognitive decline in older adults.

- **Participants:** 2,111 older adults aged 60 to 79 who were at increased risk for cognitive decline and did not exercise regularly

- **Core Interventions:** The trial tested four main lifestyle areas:
  - **Physical Exercise:** Aerobic activity (30–35 minutes, 4 times per week) plus strength and flexibility training (2 times per week)
  - **Nutrition:** The **MIND diet** (focusing on leafy greens, berries, nuts, whole grains, and lean proteins while limiting red meat and saturated fats)
  - **Cognitive & Social Engagement:** Computerized brain training and group activities
  - **Cardiovascular & Health Monitoring:** Regular checks for blood pressure, weight, and blood sugar

U.S. POINTER
ALZHEIMER'S ASSOCIATION

Universal Improvement: Both the self-guided and structured groups showed marked cognitive improvement over baseline.

Structure Drives Success: The structured group achieved a significantly higher benefit in memory and thinking capabilities than the self-guided cohort.

Turning Back the Clock: Highly structured accountability effectively slowed the cognitive aging clock, yielding test scores on par with adults **1 to 2 years younger**.

Broad Demographic Impact: Cognitive resilience improved across all groups, independent of sex, race, ethnicity, heart health status, or genetic risk factors like the APOE4 allele.

CASE STUDY # 4 - ARCHIE (2025)



Archie, a 59-year-old retired accountant, began noticing changes in his memory, such as forgetting his home address and disorientation while driving. He had recently been involved in a “fender bender”.

His son reported memory loss symptoms were first noted about one year ago and were gradually progressive.

He had missed paying some bills which he had never done before. The debt collectors were calling.

Archie wasn’t concerned about his memory but was unopposed to being evaluated. He and his family had heard about research involving new blood tests that could detect Alzheimer's disease in its earliest stages.

He screened for enrollment in ADNI-4. His son served as his Study Partner.

A diagnosis in 2025: Archie's Journey

What finding out you have Alzheimer's disease looks like today

The ADNI Screening

CLINICAL & STRUCTURAL BASELINES

- Screened for the ADNI study using extensive testing and standardized functional assessments
- Enrolled in the AD cohort of ADNI-4 with a diagnosis of mild, **early-onset** Alzheimer's disease

The 2014 Biomarkers

ADVANCED IMAGING & PATHOLOGY

- In addition to paper-and-pencil testing, Archie's evaluation included:
  - Amyloid PET scan
  - Volumetric MRIs
  - Tau PET scan
  - Blood-based biomarkers

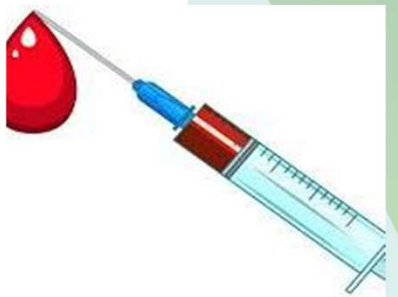
The Care Plan

LONGITUDINAL TRIAL PARTICIPATION

- Archie was diagnosed with Alzheimer's disease
- The POINTER study results motivated Archie to adhere to lifestyle changes to maintain his brain health
- Archie's Neurologist initiated treatment with Aricept
- Archie will consider treatment with Kisunla or Leqembi to help slow disease progression

BLOOD-BASED BIOMARKERS

- **p-tau (Phosphorylated Tau): p-tau217** or **p-tau181;** these proteins track tau tangles and amyloid plaque pathology in the brain. **p-tau217** is currently one of the most reliable markers and is used in FDA-cleared blood tests.
- **Amyloid-beta (Aβ42 / Aβ40 ratio):** A lower ratio of amyloid-beta 42 to 40 in the blood indicates that amyloid plaques are depositing in the brain.
- **NfL (Neurofilament Light Chain):** A general marker of nerve cell (axon) damage and degeneration, though it elevates in many neurological conditions (like ALS or multiple sclerosis) rather than just Alzheimer's.
- **ATN: A** stands for **Amyloid, T** stands for **Tau, N** stands for **Neurodegeneration**
  - A: Blood tests look for the **Aβ42/Aβ40 ratio**.
  - T: Blood tests look for **p-tau217** or **p-tau181**.
  - N: Looks for **NfL (Neurofilament Light)** or **GFAP**.



AMYLOID REDUCING ANTIBODY TREATMENTS

Leqembi (lecanemab) -Eli Lilly and Company—FDA approved in 2023

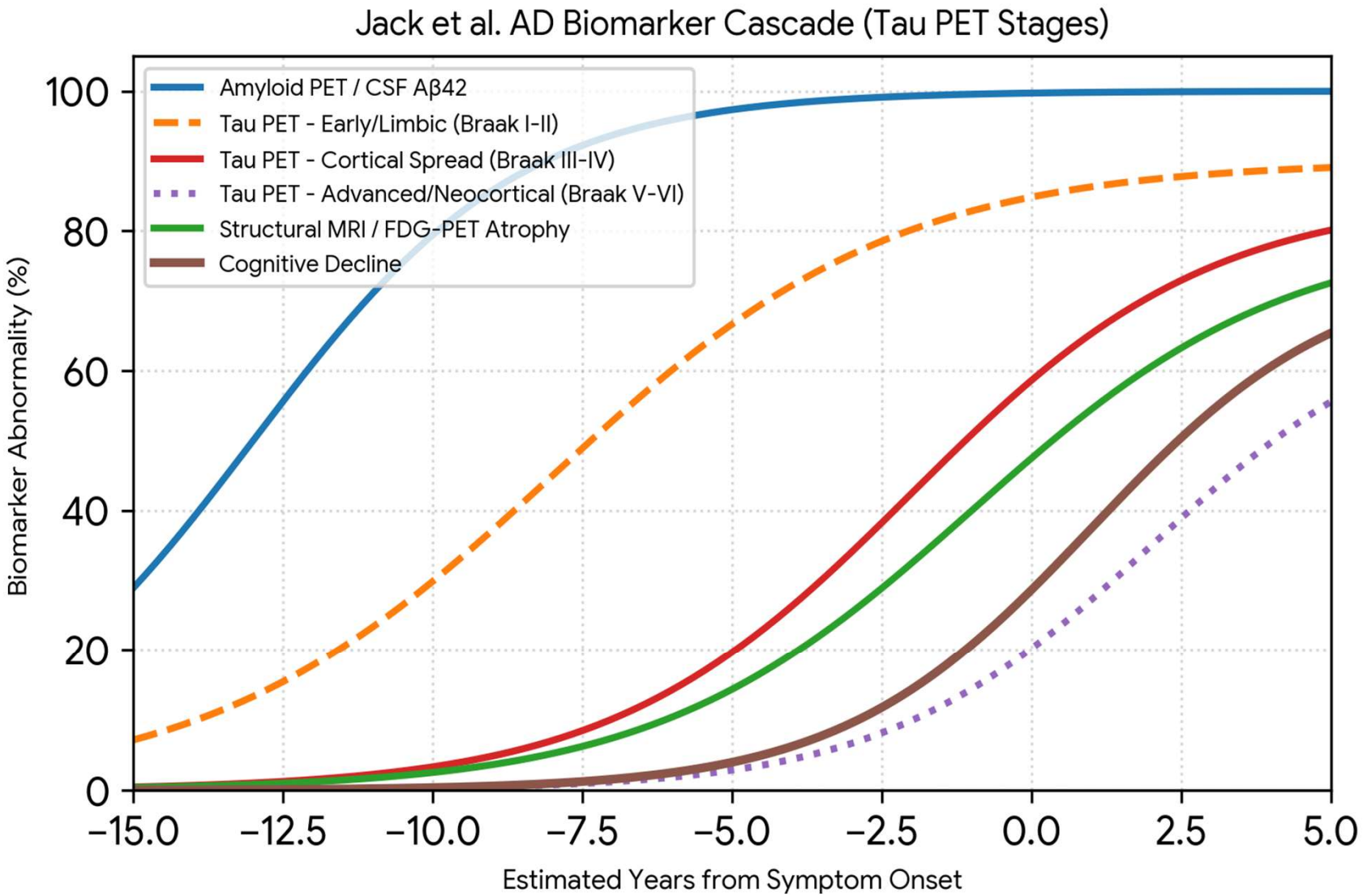
- **Clarity AD- 2019-2022 - November 2022** *The New England Journal of Medicine*

Kisunla (donanemab) -Eisai- FDA approved in 2024

- **Trailblazer Alz 2- 2020-2023 - July 2023** *The Journal of the American Medical Association*

- **Slow down the disease:** By targeting amyloid plaques, slow down memory decline and thinking problems by about 27% to 35%
- **Not a cure:** Cannot reverse existing brain damage or restore memories that are already lost
- **Early stages only:** Only for people with mild cognitive impairment or early-stage Alzheimer's dementia
- **Not for advanced stages:** It does not help, and can be unsafe for, people with moderate or severe Alzheimer's

All medications carry risks and no medication is right for everyone. Speak with your provider about the risks of a antibody treatments and all other medications you are taking!


Jack et al. AD Biomarker Cascade (Tau PET Stages)
Amyloid PET / CSF Aβ42
Tau PET - Early/Limbic (Braak I-II)
Tau PET - Cortical Spread (Braak III-IV)
Tau PET - Advanced/Neocortical (Braak V-VI)
Structural MRI / FDG-PET Atrophy
Cognitive Decline
Biomarker Abnormality (%)
0
20
40
60
80
100
−15.0
−12.5
−10.0
−7.5
−5.0
−2.5
0.0
2.5
5.0
Estimated Years from Symptom Onset

THE ALZHEIMER'S TAU PLATFORM STUDY

Purpose: To evaluate whether tau-directed therapies—either alone or combined with an anti-amyloid drug—can slow down the biological and clinical progression of early Alzheimer's disease

Design: A multicenter, randomized, double-blind Phase 2 trial to test multiple investigational products simultaneously or sequentially

Target Population: Adults aged **50 to 80** showing amyloid and tau changes via PET scans and blood tests, with no or very mild symptoms

Screening and Enrollment: Already underway at several clinical trial sites

We’ve Come a Long Way

- **The Old Way (Expensive & Invasive):** Historically, confirming Alzheimer's pathology required expensive PET brain scan or an invasive lumbar puncture (spinal tap).
- **The New Way (Simple & Accessible):** Highly accurate blood tests can now detect microscopic Alzheimer's proteins at the earliest stages.
- **How It Works (The Biological Clocks):**

p-tau217 (The Early Warning Light): This specific blood marker spikes dramatically during the "incubation period," warning doctors that amyloid plaque is building up in the brain.

Predicting the "caTAUstrophe": By tracking the exact levels of p-tau in the blood, scientists can accurately predict when a patient is approaching the critical tipping point where toxic tau tangles begin to aggressively spread across the brain.

Catching It Early: This gives clinicians a head start to intervene with treatments at early stages of the disease.

THE ALZHEIMER PREVENTION TRIALS WEBSTUDY



RESEARCH OPPORTUNITIES

Georgetown University
Memory Disorders Program

apt webstudy
ALZHEIMER PREVENTION TRIALS

The APT Webstudy follows healthy older adults (ages 50+) through periodic online memory testing and connect eligible participants with Alzheimer's clinical trials.

- There is no cost to participate.
- Complete your first set of online memory tests in about 20 minutes.
- Re-take your online memory tests every 3 and 6 months.

Healthy adults ages 50+ are eligible to participate. Complete online tests every 3 and 6 months. Available languages: English and Spanish. Open to participants worldwide.

KEY TAKEAWAYS



- **Lifestyle is medicine:** Daily healthy habits are vital for patients, caregivers, and everyone who is aging.
- **Early action builds options:** Spotting signs early unlocks access to treatments and gives patients and families time to plan.
- **Science has evolved:** Breakthroughs like simple blood tests can now detect Alzheimer's disease in its earliest stages. Advanced tools mean faster and easier screening.
- **Improved treatments and prevention are the goals:** Many avenues are being explored to develop more effective treatments, and clinical trials are bringing us closer to preventing the disease before it starts.
- **Every voice matters:** We are far from finished, and there is a place for everyone to get involved in Alzheimer's disease and related dementias (ADRD) research.

KEY CAREGIVER TAKEAWAYS



- **Taking care of yourself** is essential to caring for someone else.
- **Ask for help** from friends, family, and the community, and avoid isolating yourself or trying to handle everything alone.
- **Stay engaged** by connecting with local resources including support groups to share experiences and reduce emotional isolation.
- **Knowledge is power** so please stay tunned because advances in clinical care and research are accelerating at a rapid pace.
- **Advances in clinical trial research** are not possible without you because every clinical trial participant requires a “Study Partner”.

RESOURCES

- National Clinical Trials Registry - https://clinicaltrials.gov/
- The Alzheimer's Association- https://www.alz.org/
- The National Institute on Aging https://www.nia.nih.gov/about/alzheimers-and-dementia/about-adear-center
- Local Clinical Trial Research Programs
  - The Memory Disorders Program- https://memory.georgetown.edu/
  - Sana Research- https://www.sanaresearch.com/
  - Re:Cognition Health- https://www.recognitionhealthusa.com/location/fairfax-center/



Thank You





Jessica Guthrie, Navigating Home Hospice as a Dementia Family Caregiver

Jessica Guthrie

Northern Virginia Dementia Care Conference · November 14, 2026

Navigating Home Hospice

as a Dementia Family Caregiver

Jessica C. Guthrie, M.Ed.
CEO, Caregiving Strategist & Alzheimer's Advocate

JessicaCGuthrie.com
@Jessica_C_Guthrie

Welcome

Whatever you carried into this room, you belong here.

Family caregivers

You are caring for someone you love, today, right now.

Professional caregivers

You walk alongside families through the hardest seasons.

Both

Many of us wear both hats. I see you too.

Raise your hand so we can see who is in the room with us.

Before we begin

I am sharing what I have lived, so you can decide with confidence.

Not medical advice

Your care team knows your person. Bring them your questions.

Not speaking for an agency

I am not here on behalf of any company or hospice provider.

Lived experience

Twelve-plus years of caregiving, two hospice admissions, and the lessons I learned the hard way.

My hope: you never have to say "I wish I had known..."

01

My Journey with Constance

Twelve-plus years. Two hospice admissions.
One daughter learning as she went.


A
caregiving
Story
WELL
BEINGS

Meet my mom, Constance





Who I am in this story

I became my mom’s caregiver at 26, and I am still in it.

12+ years

Caring for my mom through early-onset Alzheimer’s disease.

Only child

Solo caregiver: long distance first, then in-home.

Two admissions

Home health, palliative care, and home hospice twice, with two different agencies.

I represent a generation of caregivers who are here, and often invisible.

My why

"I consider it not just a responsibility but the utmost privilege that I get to care for my mother on this journey through Alzheimer's disease. Caring for her is an active and intentional choice I make every day."

Jessica C. Guthrie

Spring 2022

My mom declined faster than our support could keep up.

March 2022

Admitted to home health for physical and occupational therapy.

March 2022

She can no longer hold herself up.

April 2022

I am fully feeding her. We consult a speech therapist.

April 29, 2022

She loses consciousness. Ambulance. Hospital. A severe UTI.

Falls, weight loss, infections and four hospitalizations in about four and a half months.

April 29, 2022

“No more hospitals. I want comfort care. I want home hospice.”

The day I decided what I wanted to be true for my mom.

Our hospice journey

Two admissions, two agencies, two very different experiences.

May 16, 2022

Admitted to home hospice for the first time.

March 2023

She stabilized and was discharged from hospice.

July 2024

Readmitted after significant decline, with a new agency.

Today

More than two years into round two, still at home.

Even after a discharge, your person can return to hospice when their condition changes.

What I learned

You are in the driver's seat.

Hold onto this. We will come back to it.

02

Debunking the Myths

Five beliefs that keep families from support they have earned.

Myth 1 of 5

~~*“Saying yes to hospice means giving up.”*~~

Hospice shifts the goal from cure to comfort.

FROM OUR STORY

Choosing hospice for my mom was not letting go. It was choosing her comfort, her home and her dignity over another ambulance ride. Hospice supports the whole family: medical, emotional, social and spiritual needs.

Myth 2 of 5

~~*“Hospice is only for the last few days or weeks.”*~~

Dementia does not always follow that timeline.

FROM OUR STORY

Hospice eligibility rests on a physician’s judgment that, if the disease takes its natural course, life expectancy is six months or less. People living with dementia often live longer, and keep receiving care. My mom’s current admission alone is past two years.

Myth 3 of 5

~~*“Once you are on hospice, there is no coming off.”*~~

Your person can be discharged and come back.

FROM OUR STORY

In 2023, my mom stabilized and was discharged. In July 2024, after significant decline, she was readmitted. The door stayed open for us, and it can stay open for you.

Myth 4 of 5

~~*“Hospice takes over your home and your decisions.”*~~

Hospice follows your lead.

FROM OUR STORY

When I wanted to wean my mom off medications that were no longer helping, the team followed my lead. They even suggested stopping one that, in the end, helped her stabilize. They will not force anything on you.

Myth 5 of 5

~~*“Every hospice is the same.”*~~

Agencies differ, so choose one like it matters.

FROM OUR STORY

Two admissions, two agencies, two very different experiences. Staffing, communication and culture all varied. You can interview more than one agency before you choose, and you can ask about changing agencies if it is not working.

What hospice at home includes

Hospice brings a team, supplies and support to your door...

The people

Nurse, aide, social worker, chaplain, hospice doctor or NP, volunteers. Music or massage therapy at some agencies.

Supplies & equipment

Hospital bed, Hoyer lift, briefs, bed pads, creams, suction: what your person needs.

24/7 support

An on-call line that becomes your 911, and care that comes to your home.

Medications

Prescriptions related to the hospice diagnosis are managed and delivered.

Covered by the Medicare Hospice Benefit. A physician's referral starts the process.

03

Is Your Person Ready?

What to look for, and how to ask.

Why it is hard to tell

Dementia's decline is slow and uneven, so families wait too long.

Many terminal illnesses

A steady course, then a steep and recognizable decline near the end. The "moment" is easier to see.

Dementia

Long plateaus, sudden drops, partial recoveries. Families keep waiting for a clear sign that may never come.

The question is not "is this the end?" It is "would more support help us now?"

What we saw

Three kinds of change told us it was time to ask.

Mobility

Falls, then she could no longer walk or hold herself up.

Eating & weight

Needing to be fully fed, and losing a lot of weight.

Infections & hospital stays

Repeated infections and four hospitalizations in about four and a half months.

A hospitalization is often a natural time to ask about hospice.

Advocate with your care team

Bring these three questions to your next appointment.

1. Would they qualify?

"Based on what you see, would my person qualify for hospice now? If not, what would change that?"

2. What happens next?

"What does the evaluation look like, who will do it, and how long does it take?"

3. What if they stabilize?

"If we start hospice and my person stabilizes, what happens then?"

Ask your physician for a referral. No question is too small or too big.

04

The Unspoken Rules

What I wish someone had told me.

The unspoken rules, part one

Choose your agency carefully and ask how the process works.

Interview more than one agency

Ask about staffing, after-hours response, and their experience with dementia.

Ask for the timeline upfront

What happens when, what they will evaluate, and who will do it.

Share the full picture

Celebrate the good days, and be complete about the hard ones at every visit.

Every hospice is not the same, and every visit shapes the record.

The unspoken rules, part two

Hospice is a service in your home, and it adjusts to you.

Only the nurse is required

Beyond nursing and recertification visits, you can decline any service or ask for different staff.

Give feedback early and often

Speak up about what you want and need. Don't wait until you are frustrated.

Set the pace of your home

Teams can run on autopilot. Slow them down to how your family lives.

At the end of the day, they adjust to you and your person.

Care for the whole family

Bring your culture and your grief into the plan.

Honor your culture

Name your family's traditions, faith and end-of-life preferences early, and expect your team to respect them.

Use the support for you

Hospice includes support for families, including grief support. I didn't use it the first time. Don't wait.

You don't have to do this alone.

For the professionals in the room

Treat family caregivers as partners in care.

Ask about the vision first

Learn what the family wants to be true before you talk through the plan.

Explain the process early

Walk through recertification, discharge and readmission on day one.

Invite their expertise

The family knows the person. Treat their observations as data.

Move family caregivers from invisible to integral.

Q&A

Your Questions

Ask anything within the bounds of today’s talk and my caregiving experience.

Before you go

Picture what you want to be true when your person reaches the end of life.

How they feel

How do you want your person to feel?

Who is there

Who is around them? What is the energy in the room?

What support looks like

What help is in place, for them and for you?

How you feel

How do you want to feel when you look back?

Let that picture guide every decision you make from here.



Thank you

You are in the driver's seat. And you don't have to do this alone.

JessicaCGuthrie.com · Hello@JessicaCGuthrie.com · @Jessica_C_Guthrie



Break and Raffle Prize Winners



Compassionate Coaching's Playback Theater

Erin Whalen

Compassionate Coaching

Join us for "Behind the Curtain," a unique event for the unspoken side of caregiving.





Ending Remarks & Adjourn

NORTHERN VIRGINIA
dementia care
consortium

Rooted in Care, Radiant in Hope



40th Annual Caregiver's Conference

NOVEMBER 14, 2026



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Your feedback matters to us!

Please scan the QR code below to complete a brief survey.

We appreciate you taking a few moments to share your thoughts!