

# Supporting People with Dementia and Those Who Care for Them

Presbytery of Sheppards & Lapsley

August Presbytery Meeting

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# What I Will Discuss

1. Basics of dementia
2. The psychological "crisis" at diagnosis for patient and caregiver – (or no real diagnosis and “muddling through” )
3. Facilitating conversations
4. Planting seeds for person/caregiver understanding of disease process, family/loved one communication, and planning for care preferences during disease trajectory.
5. Emphasizing the benefits of being "in the know" rather than "staying in the dark" regarding disease and symptoms, ongoing family communication and planning as positive coping and self-care strategies for patient and caregiver.

# Basics of Dementia

What is  
dementia?

What causes  
dementia?

Risk factors  
for dementia

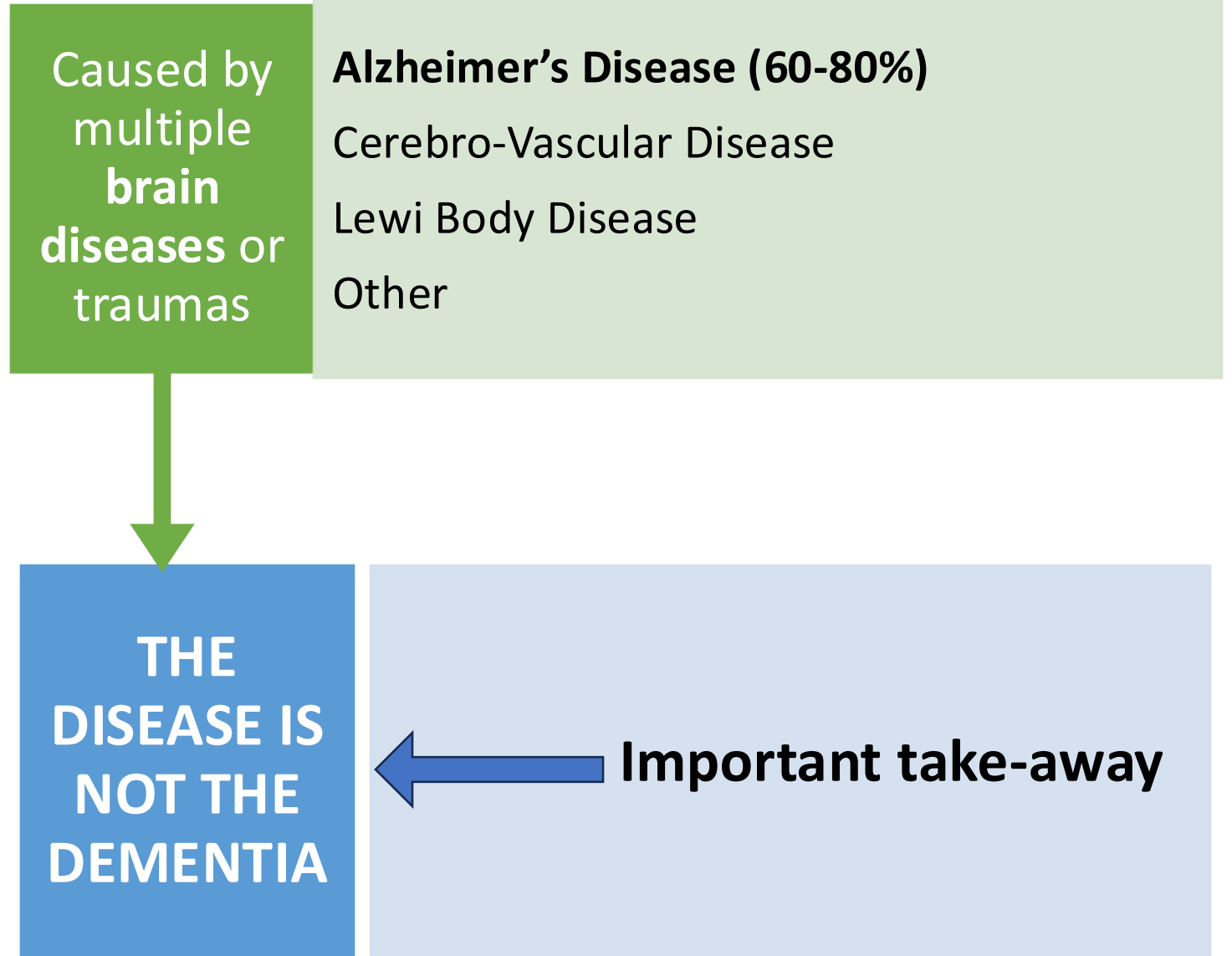
Prevalence  
of dementia

Diagnosing  
dementia

# What is Dementia?

- Gradual, progressive & life-limiting collection of symptoms
  - Thinking/Reasoning/Problem-solving
  - Memory
  - Mood & Behavior Changes
- Reduces ability to live independently
- Later stages - total dependence

# What Causes Dementia?

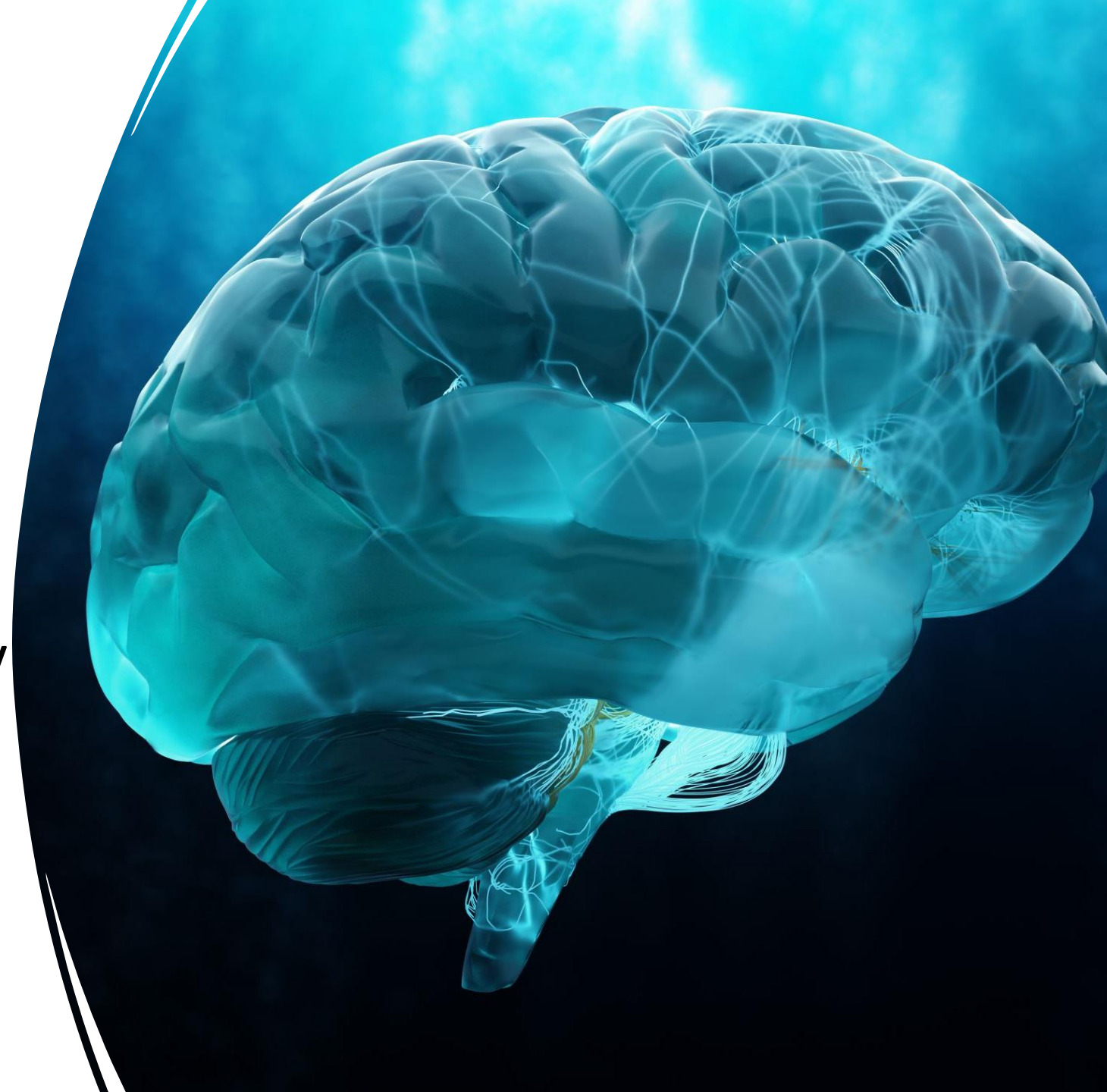





# What Causes Dementia?

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- Detecting brain diseases causing dementia
  - Post-mortem brain autopsy
  - More recently, MRI, spinal tap, amyloid PET scan
  - Very recent: blood test





## Risk Factors for Dementia

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**Age** (Older)

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Sex (Female)

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Race (African American, Hispanic)

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**Genetics** (APOe4 gene)

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**Lifestyle** (Obesity, hypertension, diabetes, sedentary lifestyle)

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[Alzheimer's Disease Facts & Figures](#)

# Prevalence of Dementia

> 7 million Alzheimer's dementia cases in US, and rising

Dementia from other causes not as well documented

Many undiagnosed cases likely

- [Increase in Dementia Expected](#)



# Beyond Today's Scope

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Diagnosing Dementia

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Trajectory (Stages) of Dementia

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Treatments for Dementia

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# PARTNERS

(aka family, loved ones, caregivers, care partners)

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Unpaid caregivers = 12+ million in U.S.  
(and rising)

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Caregivers often unprepared for emotional, physical, and financial burden

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Care needs often extend for years, escalating in burden with patient deterioration

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Caregivers risk health concerns as care demands escalate

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## Caregiver Well-Being

- **Understanding, planning, and communication are linchpins to long-term coping.**
- **Stress management skills**
  - Finding one's circle of support
  - Accepting offers of help
  - Asking for help
  - Examining and enhance one's coping strategies

# Two Roads to Adjustment

[\*Hope for The Best, Plan for the Rest,\*  
Winemaker & Seow, 2023](#)

- “In the Know” vs...
- “In the Dark”

[The Waiting Room Revolution](#): Includes patient handouts for serious diseases, such as Alzheimer’s Planning Roadmap.



## ALZHEIMER'S ROADMAP

Understand Where You Are in the Illness

### WHAT IS THIS FOR

Understanding common signs and stages of how Alzheimer’s evolves is key to getting the right types of support, feeling prepared, and having more choice and control.

This tool allows for open conversations between patient, family / caregivers, and health care teams to talk about **where things are at now** and what to expect later. Revisit this roadmap over time.

### HOW TO USE THIS

The general pattern of Alzheimer’s is typically a slow, gradual and long decline.

Use the space below to **discuss with your team and take notes** on:

1. Your current stage
2. What’s unique to your experience
3. What can be done to maximize quality of life at any stage

### BEGINNING STAGE SIGNS

- Repetition of questions/stories
- Difficulty processing complex information
- Confuse times/places
- Forget recent events & conversations
- Gets lost easily
- Mild personality changes
- Social withdrawal

### NOTES ON MANAGING EACH STAGE

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(With permission)

# Serious Illness Conversation Guide

## Ariadne Labs (for practitioners)

- Not a “one and done”
- Conversational and emotionally safe approach
- Ask permission
- Assess their understanding
- Ask patient (and partner) what matters most to them today (and what their goals are as they manage the illness)

# Goals for Person with Dementia and Carers:

## *Plant the Seeds*

To **understand** the disease and its potential trajectory

To **clarify values** – *When time may be shorter, what's important?* Atule Gawande – Being Mortal

To make critical **planning** decisions early in the disease process

To **encourage revisiting plans and values**

To **talk to loved ones** about diagnosis, preferences and decisions

To keep **talking** (also consider patient letter, video)



# Thank you

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