

# Diagnosing Dementia:

Why it Matters, How it's Done and How it Can Help

October 29, 2021



Terry R Barclay, PhD

Adjunct Associate Professor of Neurology, University of Minnesota

Director of Neuropsychology, HealthPartners

# SPONSORED BY:



CATHOLIC CHARITIES  
HAWAII  
CIRCLE OF CARE FOR DEMENTIA



Supported in part by grant No. 90ADPI0011-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy. The grant was awarded to Catholic Charities Hawaii for the Alzheimer's Disease Program Initiative.

# Presentation Outline

---

- Importance of early and accurate diagnosis
- What to expect during a memory loss work-up
- Accuracy of a dementia diagnosis
- Reversible and alternative causes of impairment
- Primary care versus a specialist
- Spectrum of brain aging (normal, MCI, dementia)
- Top treatments and recommendations
- How family members and care partners can help

# Why a diagnosis matters

---

How does it help?

# Our History: Dementia Poorly Recognized

---

- Less than 50% of patients ever receive formal diagnosis
  - Millions unaware and left unprepared
- Diagnosis often delayed on average 2-7 years after symptoms begin
- Significant impairment by the time it is recognized
  - Poor timing: diagnosis frequently occurs during a time of crisis, hospitalization, urgent need for higher level of care/placement



# Why is this?

---

- Patients and doctors not used to talking about brain health
  - Fear and stigma
- Ageism and problems defining “normal” aging
  - “After all she’s 80 years old!”
- Belief doctor will bring concerns to my attention
- Brain historically not a focus of routine exam
  - Not on list of “vital signs”



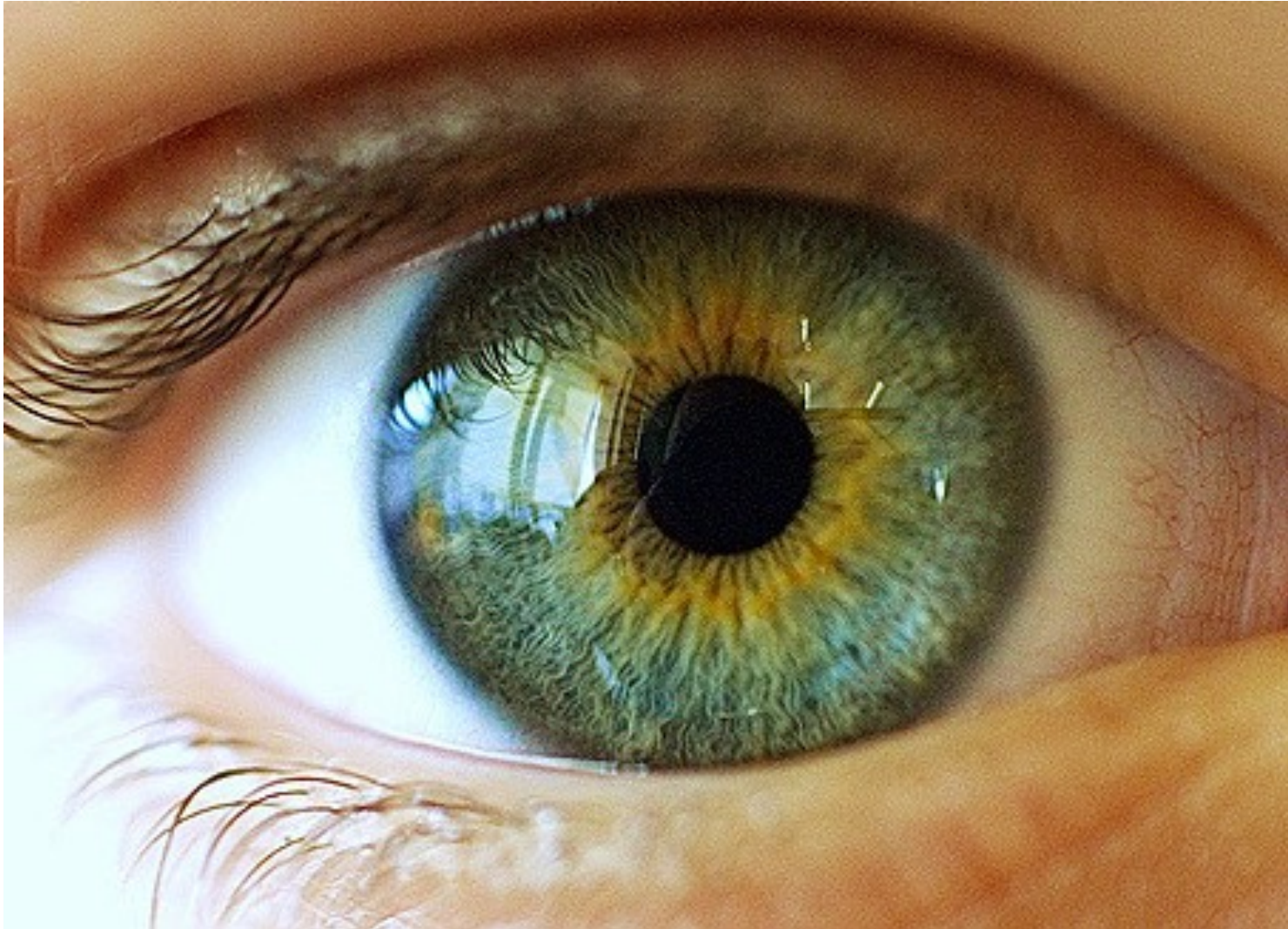
# Why is this?

- Many patients unaware they have a problem
- Changes missed due to familiarity with the patient
- Most medical visits are “problem-focused”
- Limited time
- Patients can “cover up” deficits during short visit
- Some providers may feel they don’t have the training, tools or comfort level





# The Eyeball Method







# Rationale for Timely Diagnosis

---

## 1. Improve **quality** of life

- Access to medication and non-medication treatments
- Be part of important decisions regarding the future
- Increase support of family and friends

## 2. Live at home longer

- Know what to expect and what to do
- Community services and supports

## 3. Improve health and longevity

- Better management of chronic diseases (high blood pressure, high cholesterol, diabetes, congestive heart failure, etc.)

# Rationale for Timely Diagnosis

---

4. Find **reversible** causes of memory loss
  - Vitamin deficiencies, hypoglycemia, depression
5. Stay out of the hospital
  - Prevent diagnosis during crises (wandering, hospitalization, car accidents, falls and head injuries, etc.)



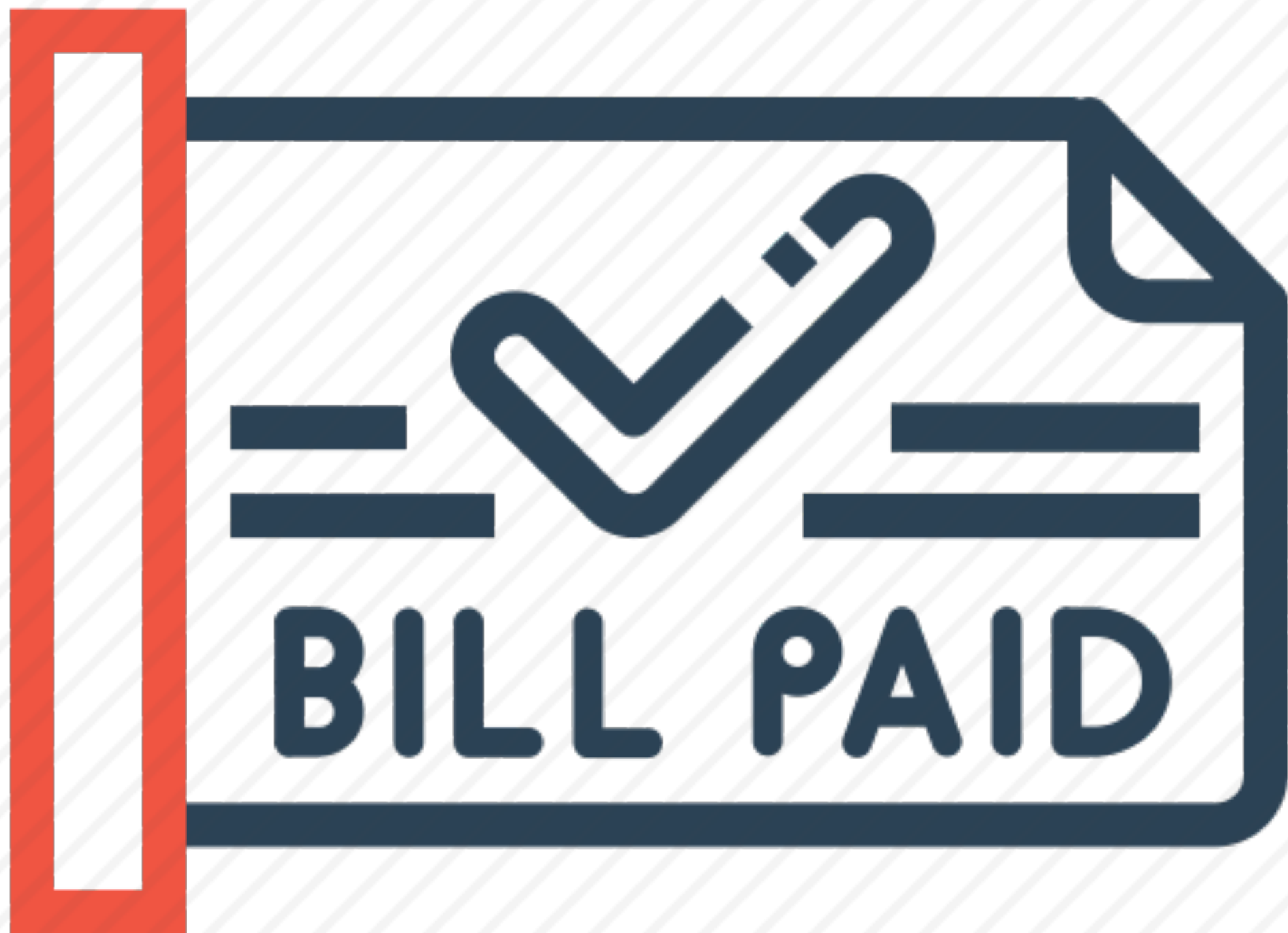
If we don't get a diagnosis, does it still exist?



# How is dementia diagnosed?

---

What can we expect when  
we see the doctor?





# How is Dementia Diagnosed?

---

- Medical history
- Physical exam
- Neurological exam
- Lab tests
- Brain scan (CT, MRI)
- Mental status exam
  - Memory / cognitive testing
- Functional assessment
  - OT/PT evaluation



*No single test can diagnose dementia*

# History & Physical

---

- History: just a conversation
  - Review known medical conditions
  - Confirm medication use
  - Discuss onset and course of symptoms
  - Changes in function?
  - Mood
  - Substance use
- Physical
  - Routine exam



# Neurological Exam

---

- Posture
- Gait
- Balance
- Coordination
- Muscle strength
- Reflexes
- Sensation (e.g., smell, touch)
- Visual field and eye movements
- Hearing



# Cognitive Screening

---



# Lab Tests

---

- White/red blood cell count
  - Infection, inflammation
- Glucose
- Thyroid stimulating hormone (TSH)
- Vitamins and nutrients
  - B12
  - D



# Optional Diagnostic Tools

---

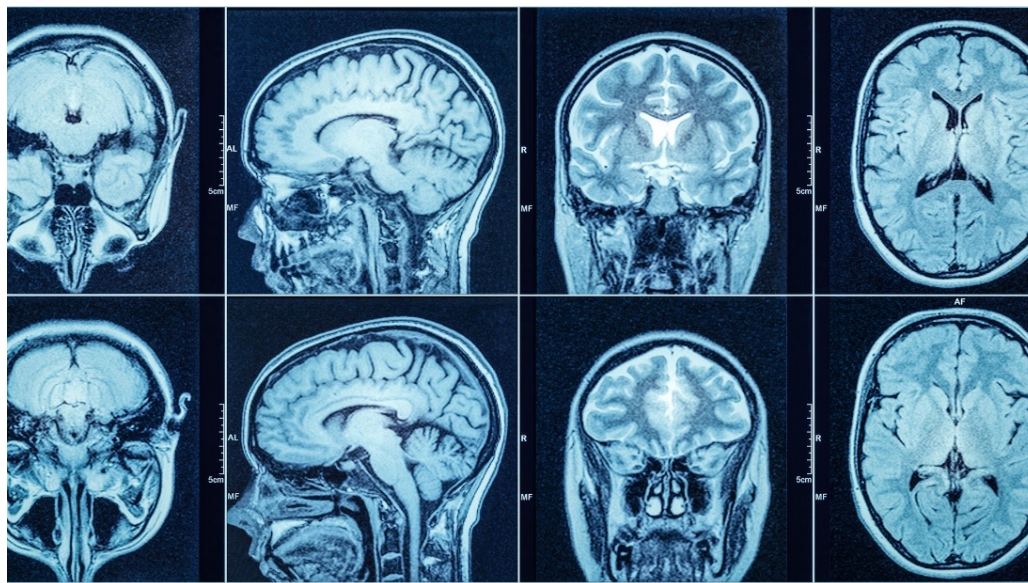
These are not needed in  
every case



# Brain Scan

---

- Purpose is to rule out other causes of memory loss:
  - Stroke
  - Cerebrovascular disease (wear and tear of small blood vessels)
  - Tumor
  - Normal pressure hydrocephalus



# Neuropsychological Testing

---

- Detailed measurement of:
  - Attention
  - Memory
  - Language
  - Processing speed
  - Spatial skills
  - Problem solving / judgment
  - Mood / behavior



# Neuropsychological Testing

---

- Helps tell the difference between dementia and:
  - Normal aging / memory complaints
  - Pre-existing cognitive weaknesses or learning disabilities
  - Mental health issues
  - Effects of medications, current or past alcohol/drug abuse
  - Chronic pain
  - Insomnia, sleep disorders
  - Complex medical conditions
  - Alzheimer's disease versus other forms of dementia

# Neuropsychological Exam

---

- Concrete data concerning:
  - Expectations regarding **employment**
  - Ability to safely live independently vs. with support vs. placement
  - Expectations re: driving, cooking, complex tasks
  - Capacity for financial management, healthcare decisions
  - Cognitive rehabilitation techniques
  - Mental health interventions
  - Medical needs (e.g., sleep study)
  - Education / support for patient and family

# Functional Assessment (OT)

---

## Instrumental Activities of Daily Living (IADLs)

- Shopping
- Preparing meals
- Managing medications
- Using the telephone
- Housekeeping
- Tracking appointments
- Managing transportation
- Caring for pets
- Paying bills
- Following safety procedures

## Activities of Daily Living (ADLs)

- Bathing
- Personal hygiene
- Dressing
- Use of the toilet
- Eating
- Mobility

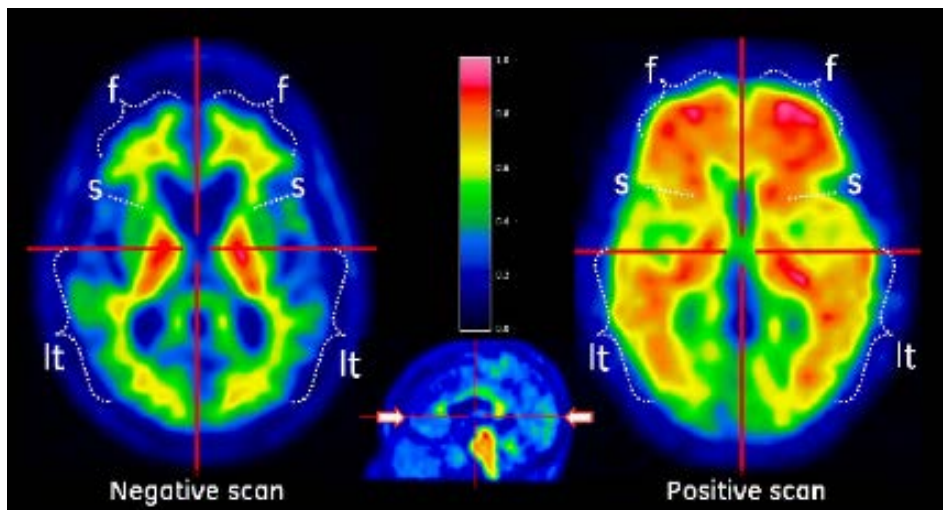




# Emerging Diagnostic Tools

---

- Biomarkers will be used more often in the future:
  - PET scans
  - Amyloid and tau imaging
  - Cerebrospinal fluid
  - Blood test





# Diagnostic Accuracy

---

How much can you trust a diagnosis?

# Diagnostic Accuracy



High

- Over age 65
- No atypical symptoms
  - First symptom is trouble recognizing faces, food fad, loss of social skills or sig. language deficit
- Patient completes standard work-up



Variable

- Younger than 65
- Atypical symptoms or very complex medical history (and only see primary care)
- Patient refuses exam

# Reversible and Alternative Causes

---

It's not always Alzheimer's  
disease

# Reversible Causes

---

- Vitamin, nutritional, hormonal deficiencies
  - Undiagnosed thyroid conditions, endocrine disorders, frequent hypoglycemic events, very low B12
- Drug interactions and medications with cognitive side effects
- Non-alcohol related liver cirrhosis/failure
- Normal pressure hydrocephalus
- Insomnia and untreated sleep disorders
  - Obstructive sleep apnea
- Serious depression



# “Rapid Onset” Confusion

---

- Medication interactions
- Urinary retention
- Infection (UTI, pneumonia)
- Dehydration
- Uncontrolled blood sugars
- Late onset psychiatric conditions
- Sleep deprivation

# Alzheimer's is One Type of Dementia

---

Alzheimer's disease: 60-80 %

- Includes mixed AD + VD

Lewy Body Dementia: 10-25 %

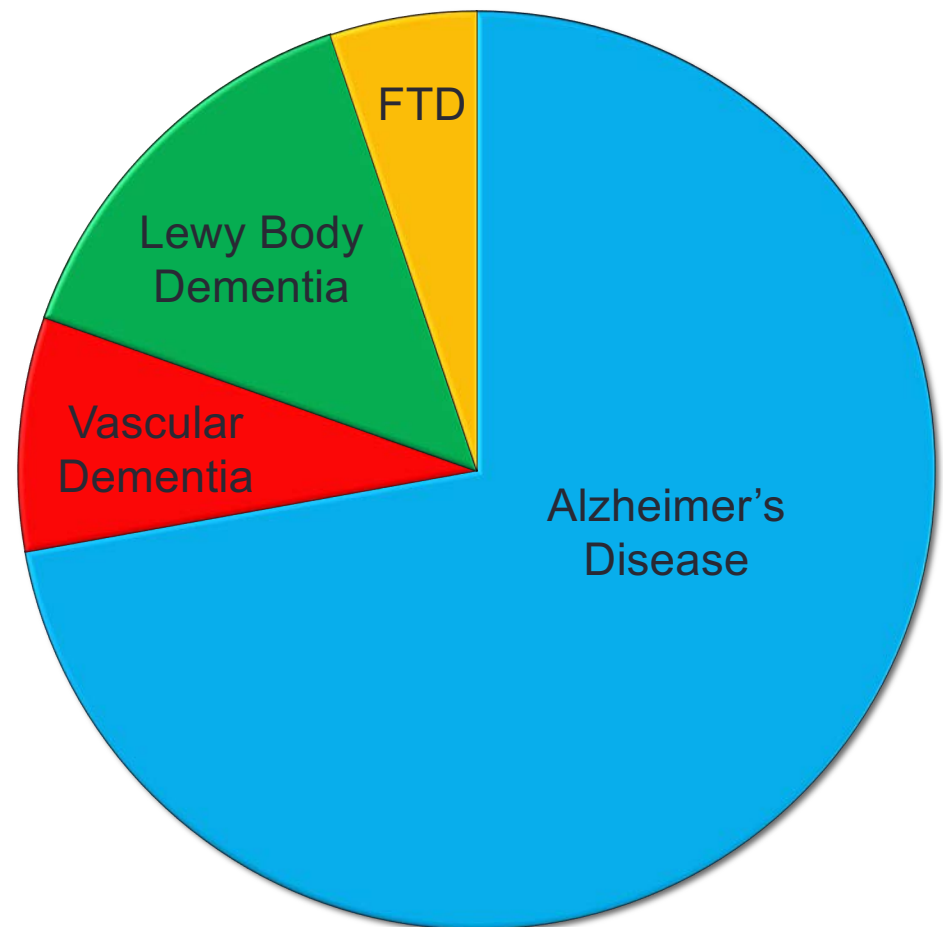
- Parkinson spectrum

Vascular Dementia: 6-10 %

- Stroke related

Frontotemporal Dementia: 2-5 %

- Personality or language problems





# Primary Care or a Specialist?

---

Which is best?

# Who Should We See?

---

- **Primary care**
  - Good place to start in most cases
  - Over the age of 65
  - Provider agrees to do a work-up (blood work, objective memory screening)
  - Diagnosis more specific than “memory loss”, “dementia”
    - What is the most likely cause?
- **Specialist (neurologist)**
  - Younger than 65
  - Unusual symptoms (muscle jerking, tremors, frequent falls, early visual hallucinations)
  - PCP not willing to investigate

# Options When Seeing a Specialist

## Diagnosis Only

- Your PCP is comfortable prescribing and following the treatment recommendations of the specialist/neurologist

## Diagnose and Follow

- Your PCP is uncomfortable or not inclined to treat you
- You have more confidence in the specialist
- Your diagnosis is something other than Alzheimer's disease

# The Aging Spectrum

---

# Cognitive Continuum

Normal



Mild Cognitive  
Impairment



Dementia



# Normal (Healthy) Aging

---

- Characteristic pattern:
  - Sensory/motor declines (i.e., hearing, vision, gait)
  - General slowing of processing speed
  - Intelligence remains stable
  - Mild decrease in:
    - Ability to recall names of people, places, objects
    - Mental flexibility (e.g., math problem in your head)
    - Memory (e.g., “senior moments”)



# Normal (Healthy) Aging

---

- Independence in daily activities **preserved**
  - Can operate common appliances
  - Balances checkbook, pay bills, manage finances
  - Manages medications
  - Drives safely
  - Grocery shopping, meal preparation
  - Keeps track of appointments, schedule
- Memory intact for recent events
- Normal performance on memory testing at doctor's office

# Mild Cognitive Impairment (MCI)

---

- Mild, but **measurable**, changes in thinking ability
  - Symptomatic presentation
- Abnormal results on memory screening or neuropsychological evaluation
- Unlike dementia, function is more still relatively independent (IADLs)
  - May need prompting/reminders or light support

# Dementia

---

Disease of the brain that causes a decline in memory and intellectual functioning from some previously higher level of functioning severe enough to interfere with everyday life

*Dementia is NOT normal aging*

# Dementia vs. Alzheimer's

---

What is the difference  
between **dementia** and  
**Alzheimer's disease**?

# Flowers

```
graph TD; Flowers[Flowers] --> Pansies[Pansies]; Flowers --> Tulips[Tulips]; Flowers --> Roses[Roses]; Flowers --> Daisies[Daisies]; Flowers --> Mums[Mums];
```

Pansies

Tulips

Roses

Daisies

Mums

# Dementia

```
graph TD; Dementia[Dementia] --> Frontotemporal[Frontotemporal dementia]; Dementia --> Vascular[Vascular dementia]; Dementia --> Alzheimer[Alzheimer's dementia]; Dementia --> Lewy[Lewy body dementia]; Dementia --> Parkinson[Parkinson's dementia];
```

Frontotemporal  
dementia

Vascular dementia

Alzheimer's dementia

Lewy body dementia

Parkinson's  
dementia



# Many Causes of Dementia

---

- **Alzheimer's disease**
- CVA/Stroke
- Parkinson's disease
- HIV/AIDS
- Multiple Sclerosis
- Huntington's disease
- Lewy Body dementia
- Frontotemporal dementia
- Creutzfeldt-Jakob disease
- Traumatic brain injury
- Toxic exposures(industrial strength solvents/chemicals)
- Chronic hypoxia
- Syphilis
- Brain tumors
- Normal pressure hydrocephalus
- Wernicke-Korsakoff's Syndrome

# Alzheimer's Disease Is:

---

- A **slowly** progressive, degenerative, neurological disease of the brain
- A steady decline in memory and cognitive functioning severe enough to interfere with everyday life
- Related to specific **chemical and structural changes** in the brain
- **NOT** reversible

The brain changes of  
Alzheimer's begin  
10-20 years before  
symptoms appear

# How Common is Alzheimer's?

- 1 in 9 people 65+ (11%)
- 1 in 3 people 85+ (32%)

| Age Range | Percent with Alzheimer's |
|-----------|--------------------------|
| < 65      | 4%                       |
| 65 -74    | 13%                      |
| 75 -84    | 44%                      |
| 85 +      | 38%                      |

# How Common is Alzheimer's?

---

- Almost 2/3 are **women** (longer life expectancy)
- Some populations at higher risk
  - Older **African Americans** (2x as whites)
  - Older **Hispanics** (1.5x as whites)
- AD 6<sup>th</sup> leading cause of death
- If disease could be detected earlier (pre-symptomatic stages) prevalence would be **much higher**

# Top Treatments and Recommendations

---

It's more than medication



# What Families Need & Deserve

1. Timely detection
2. Clear diagnosis
3. Proactive care
4. Referral to education and support services
5. Team approach that involves care partner(s)
6. Opportunity to participate in planning and decision making
7. Access to care coordination
8. Supportive communities

# Reducing Medications



# Medication Treatment

---

- Medications increase memory chemical in the brain
  - Donepezil ([Aricept](#))
  - Galantamine (Reminyl)
  - Rivastigmine (Exelon)
  - Memantine (Namenda)
- Can slow progression of [symptoms](#) for some patients
  - Do not slow or alter brain pathology

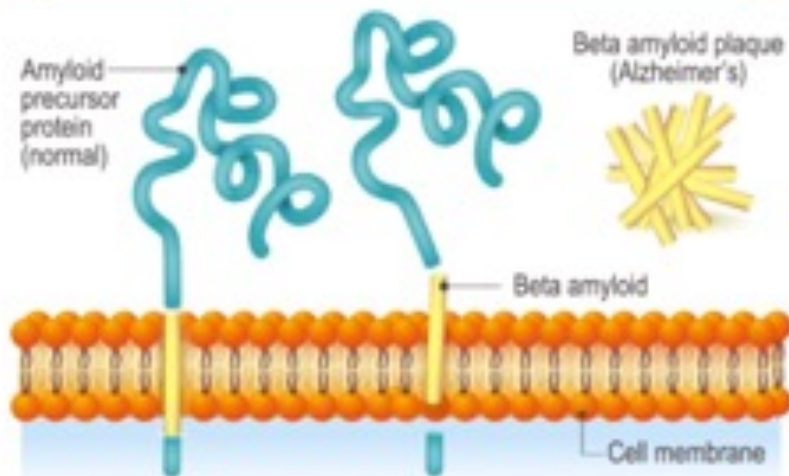
# New Infusion Drug

## WHAT IS ADUCANUMAB?

Developed with  
the amyloid  
hypothesis in mind



Monoclonal  
antibody



Directed against soluble  
and insoluble amyloid



**FIRST** FDA approved  
disease-modifying  
drug for AD

# Not Affordable

Estimated at approximately  
**\$56,000/year**

The Institute for Clinical  
and Economic Review (ICER)



Actual health-benefit  
price benchmark (HBPB)  
ranged from **\$3,000-\$8,400/yr**

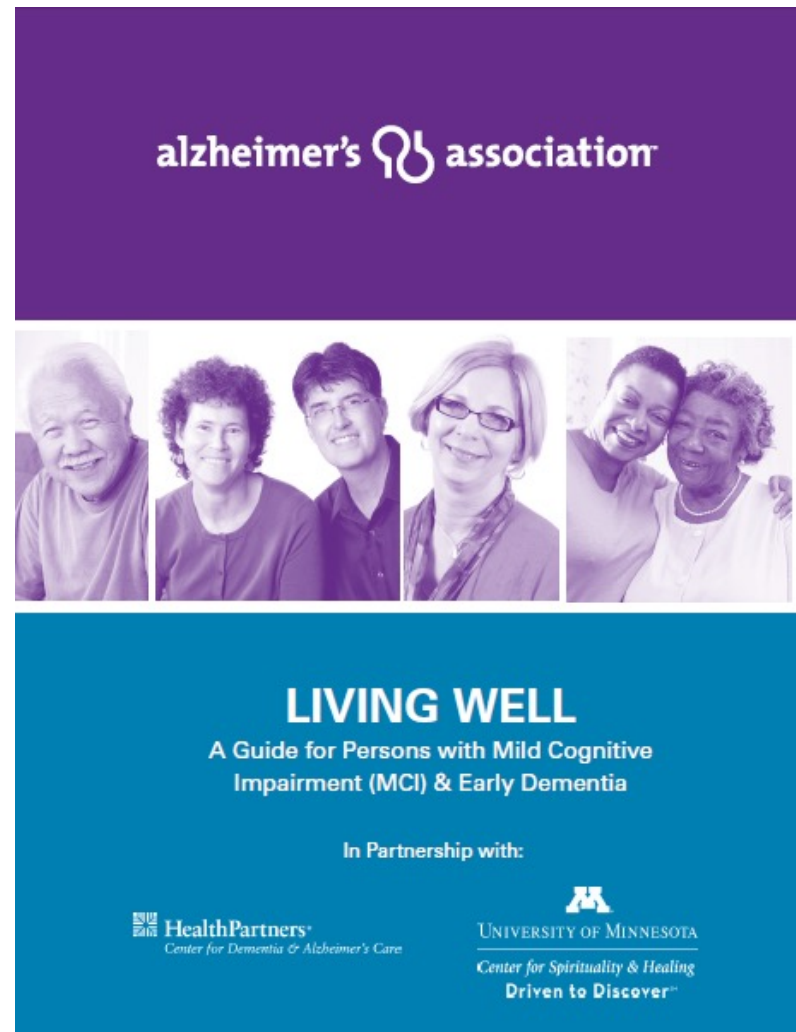


# More Research Needed



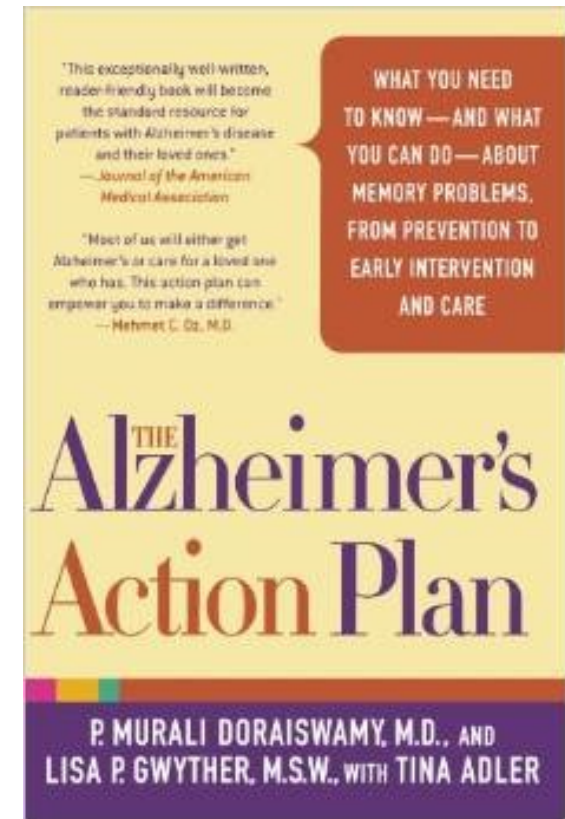
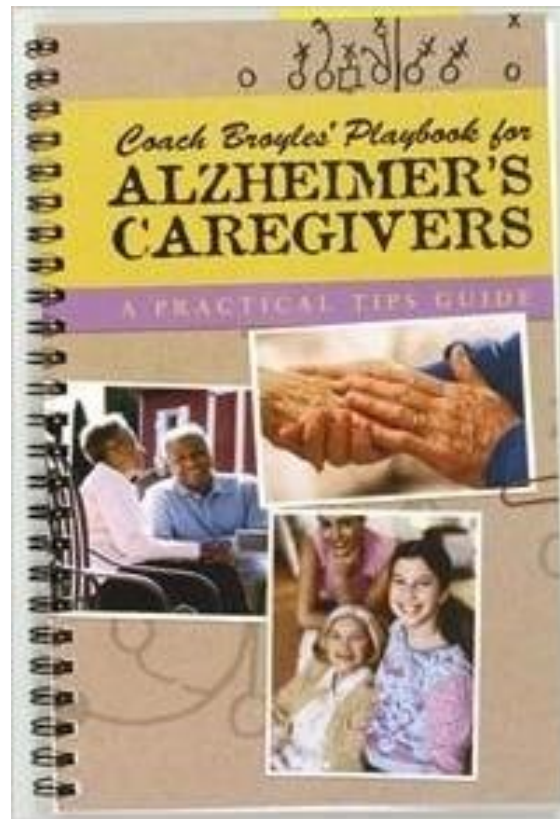
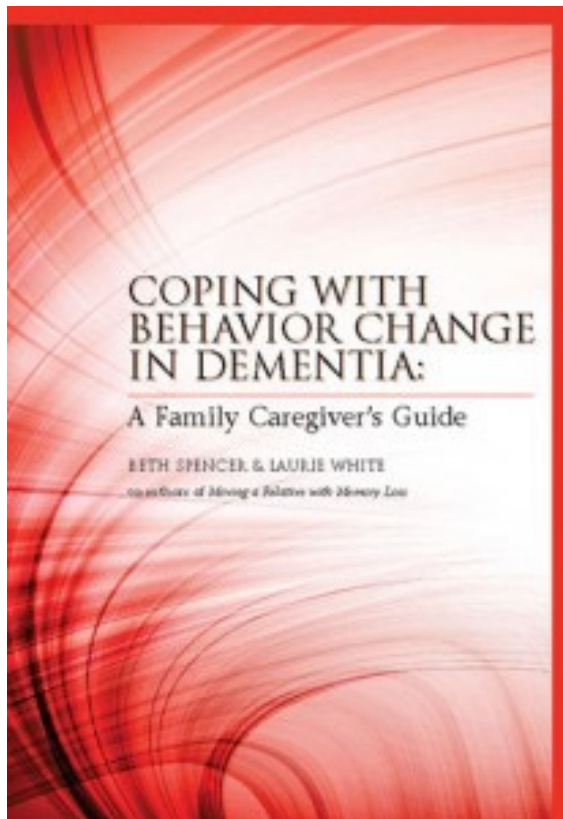


# #1 Promoting Wellness



[www.healthpartners.com/ucm/groups/public/@hp/@public/documents/documents/cntrb\\_028820.pdf](http://www.healthpartners.com/ucm/groups/public/@hp/@public/documents/documents/cntrb_028820.pdf)

## #2 Addressing Behavioral Challenges



# #3 Caregiver Support

alzheimer's  association®

800.272.3900 | [www.alz.org/hawaii](http://www.alz.org/hawaii)

808.591.2771

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. **The Aloha Chapter** serves individuals with memory loss, caregivers, health care professionals, concerned family and friends, and the general public. Services are statewide with specialists in every county.

The Association offers: information and referral, including multilingual information; care consultation; education for caregivers, community and professionals; support groups; safety programs, such as MedicAlert® + Alzheimer's Association Safe Return®; a clinical trials index, Alzheimer's Association TrialMatch®; and, online training and dementia certification; advocacy

Aloha Chapter Headquarters: 1130 N. Nimitz Hwy., Suite A-265, Honolulu, HI 96817

## #4 Medication Review

### PharmD Consult

- Medication review, simplification
- Reminder strategies
- Family support, supervision



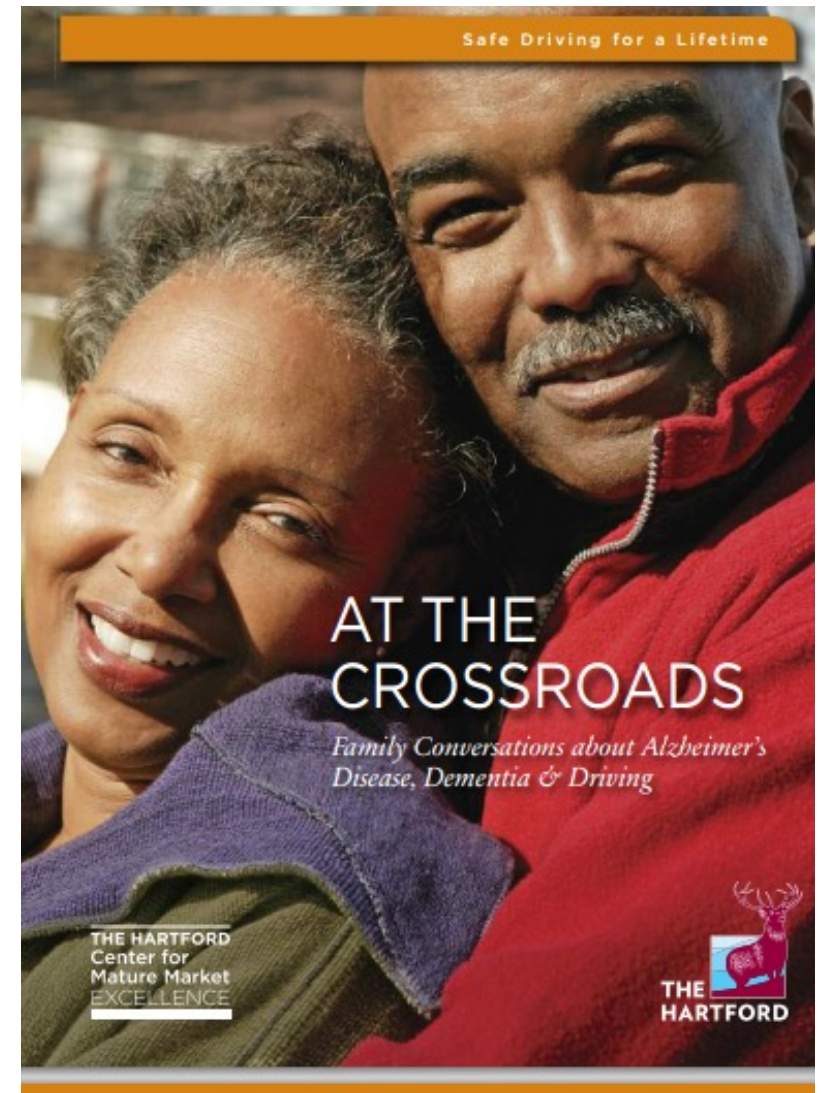
# #5 Driving

Alzheimer's Association Driving Center:  
[www.alz.org/help-support/caregiving/safety/dementia-driving](http://www.alz.org/help-support/caregiving/safety/dementia-driving)

Watch how four families deal with different issues related to dementia and driving.



**A Supportive Conversation:** Frank has early stage Alzheimer's and the doctor said it's no longer safe for him to drive. His wife doesn't drive, but knows it's time to discuss finding alternative transportation. Full Screen



[www.thehartford.com/sites/thehartford/files/at-the-crossroads-2012.pdf](http://www.thehartford.com/sites/thehartford/files/at-the-crossroads-2012.pdf)

# Knowledge Questions

---

Quick review

# How You Can Help

---

Moving past fear and  
resistance

# My Loved One/Friend is Reluctant to See the Doctor

---

- Focus on the positive
  - “I love you. I want us to stay healthy. Will you do this for me?”
- Emphasize opportunity to find reversible cause, treat symptoms
- Send provider a message with your concerns before patient’s annual exam or next appointment
  - Keep it concise: symptoms, concerns, onset/course
  - Ask for what you want
  - Make an appointment, tell loved one it’s routine



# Our Provider Won't Do an Evaluation (or Hasn't Told Us Much)

---

- Send provider a message with your concerns
  - Ask for what you want
- Ask for a referral:
  - Colleague in same practice (primary care)
  - Specialist (neurologist, geriatrician, psychiatrist)
- It's okay to seek a second opinion on your own:
  - Medicare and most insurance types do not require a referral

# I'm Afraid to Say Anything

---

- Send provider a message with your concerns
  - Ask them to bring it up during visit
  - Make it clear you may not be able to say much
- Go with the patient to their appointment
  - Pass the nurse a note when they enter/leave the room



# SPONSORED BY:



CATHOLIC CHARITIES  
HAWAII  
CIRCLE OF CARE FOR DEMENTIA



Supported in part by grant No. 90ADPI0011-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy. The grant was awarded to Catholic Charities Hawaii for the Alzheimer's Disease Program Initiative.