

# Welcome to

## Project ECHO® - on

***Supporting People Living with Dementia and their Care Partners -  
Implementing Best Practices Across the Stages***

While waiting, please type in your Name, Organization, and Role into the chat box.



For educational and quality improvement purposes, we will be recording this session

By participating in this session, you are consenting to be recorded- we appreciate and value your participation

If you have questions or concerns, please email, [emorse@healthcentricadvisors.org](mailto:emorse@healthcentricadvisors.org)

OR

Use the chat function to contact us directly. There is an option under chat to send private message to anyone from the drop-down list.

# Rhode Island Geriatrics Workforce Enhancement Program (RI-GWEP)

- “This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number (U1QHP53064) Geriatrics Workforce Enhancement Program. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.”
- This program was supported by Cooperative Agreement NU58DP007525, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.
- This project is supported by United Health Plan. The contents are solely the responsibility of the authors and do not necessarily represent the official views of UnitedHealth.
- There is no actual or potential conflict of interest in relation to this program.

# What to Expect During an ECHO Session

- Acknowledgements and Introductions (5-10 min.)
- Brief Didactic (15-20 min.)
- Case Presentation (10 min.)
- Case Discussion & Recommendations (remaining time)
- Announcements



# Participants

Administration/Management

Community Health Worker/Advocate

Direct Support Professional

Medicine

Nursing and Nurse Care Manager (RN, BSN, MSN, etc....)

Nurse Practitioner

Occupational Therapist

Physician Assistant

Quality Improvement Specialist

Social Work – Case Management

# Settings

Ambulatory-Primary Care

Assisted Living

Community Site

Consulting

Home Health

Hospital

Long-Term Care

Nursing Home

Private Practice

# RI G ECHO Hub (Content Expert) Team

- **Erica Estus, PharmD, BCGP**; Clinical Professor, URI College of Pharmacy
- **Nick Nikolopoulos, DO**; Chief Medical Officer, PACE-RI
- **Cynthia Padula, PhD, RN**; Professor Emeritus, RI College School of Nursing
- **Kim Rickler, MSW, LICSW**; Clinical Teaching Associate, Family Medicine  
Warren Alpert Medical School of Brown University
- **Corinne Russo, MSW, ASWCM**; Adjunct Faculty and GWEP Program Lead,  
Interprofessional Geriatrics for Health Professions Students

# The 4M Framework

## The 4M Framework

- Evidence-based and practice tested
- Aligns with What Matters to older adults
- Improves outcomes
- Used reliably across settings
- Able to be adapted locally
- RI-GWEP endorses and supports Age-Friendly care
- RI-GWEP programs are guided by the 4M Framework

(PH, Hartford Foundation, American Hospital Assoc., Catholic Health Assoc. US)



# Caring for Persons Living with Dementia by Caring for those Caring for Them

Christine Seel Ritchie, MD, MSPH  
Professor of Medicine  
Harvard Medical School

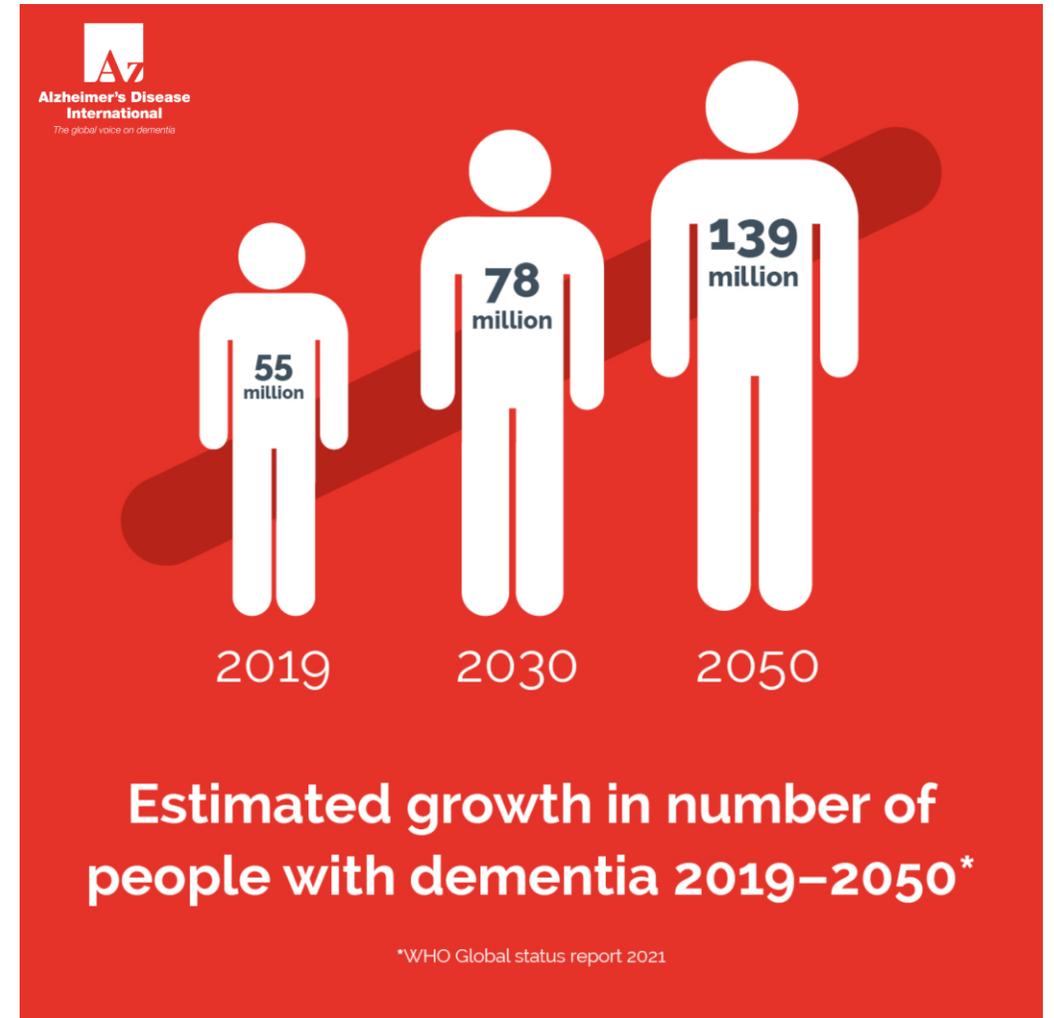
# Goals for today

Review dementia prevalence, types, and course of illness

Describe the epidemiology of caregiving

Discuss ways to support caregivers as they support those living with dementia

# Dementia Epidemiology



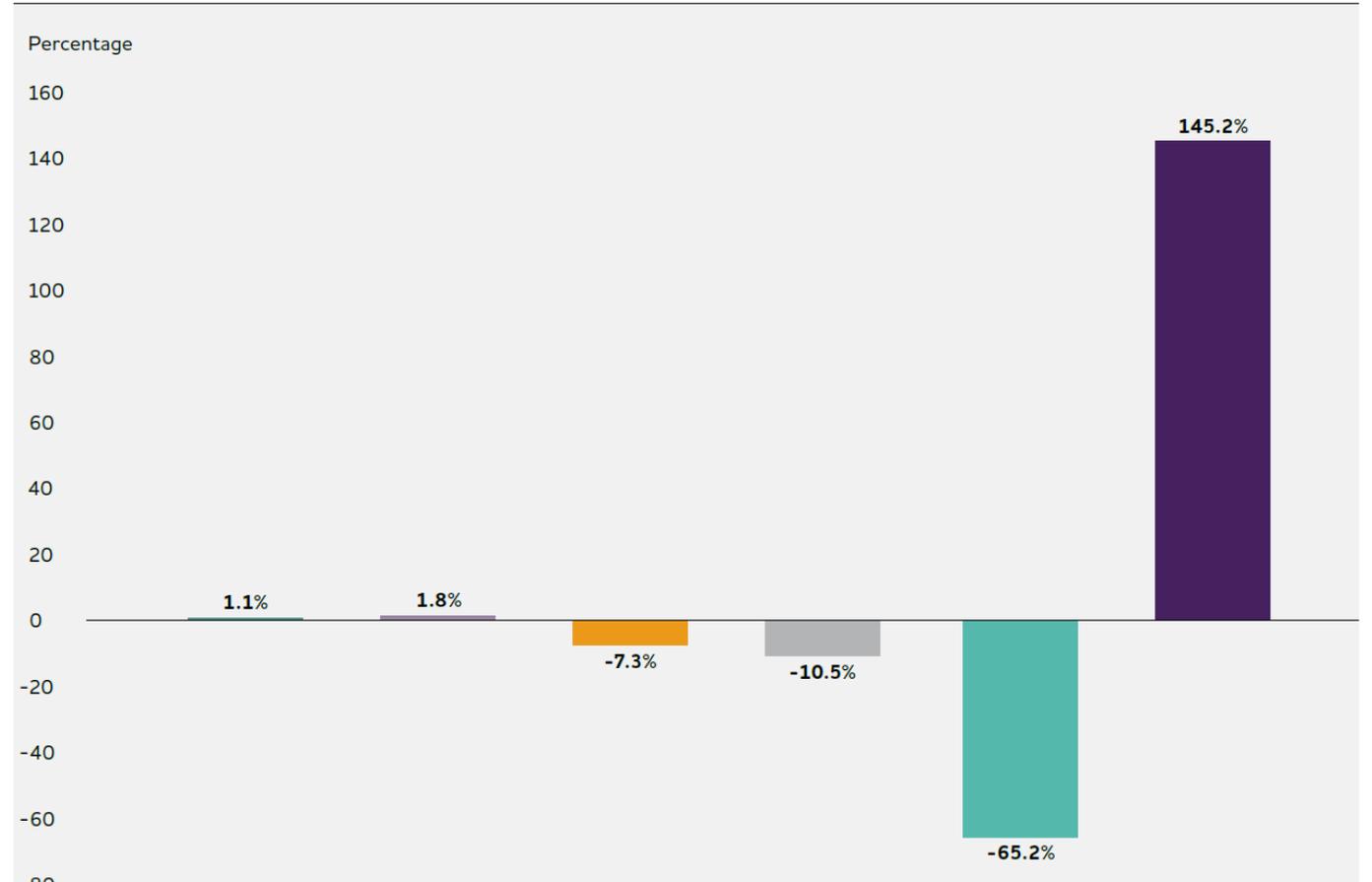
# Epidemiology of dementia in the U.S.

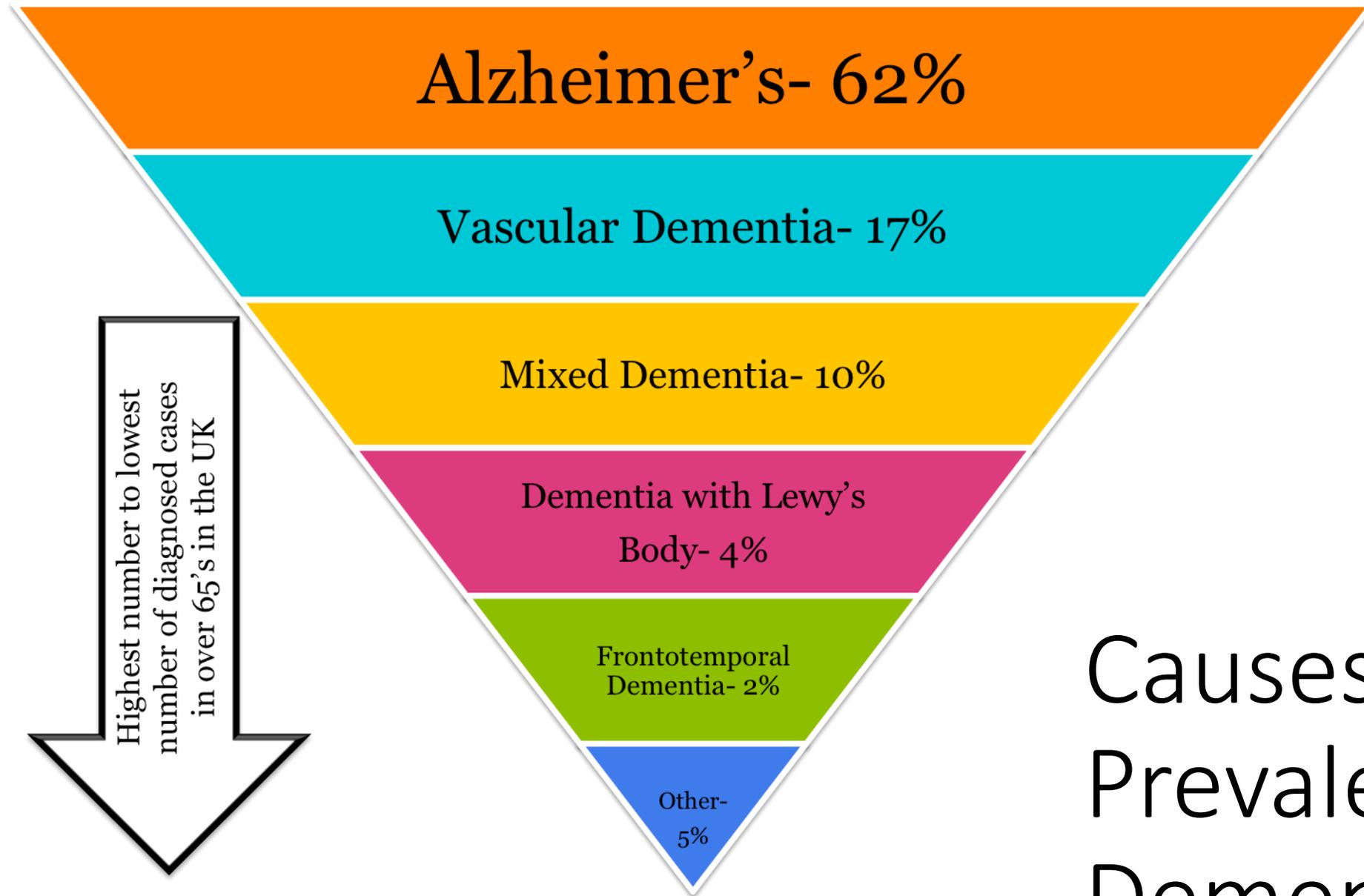
## Prevalence

An estimated 6.9 million Americans are living with Alzheimer's dementia.

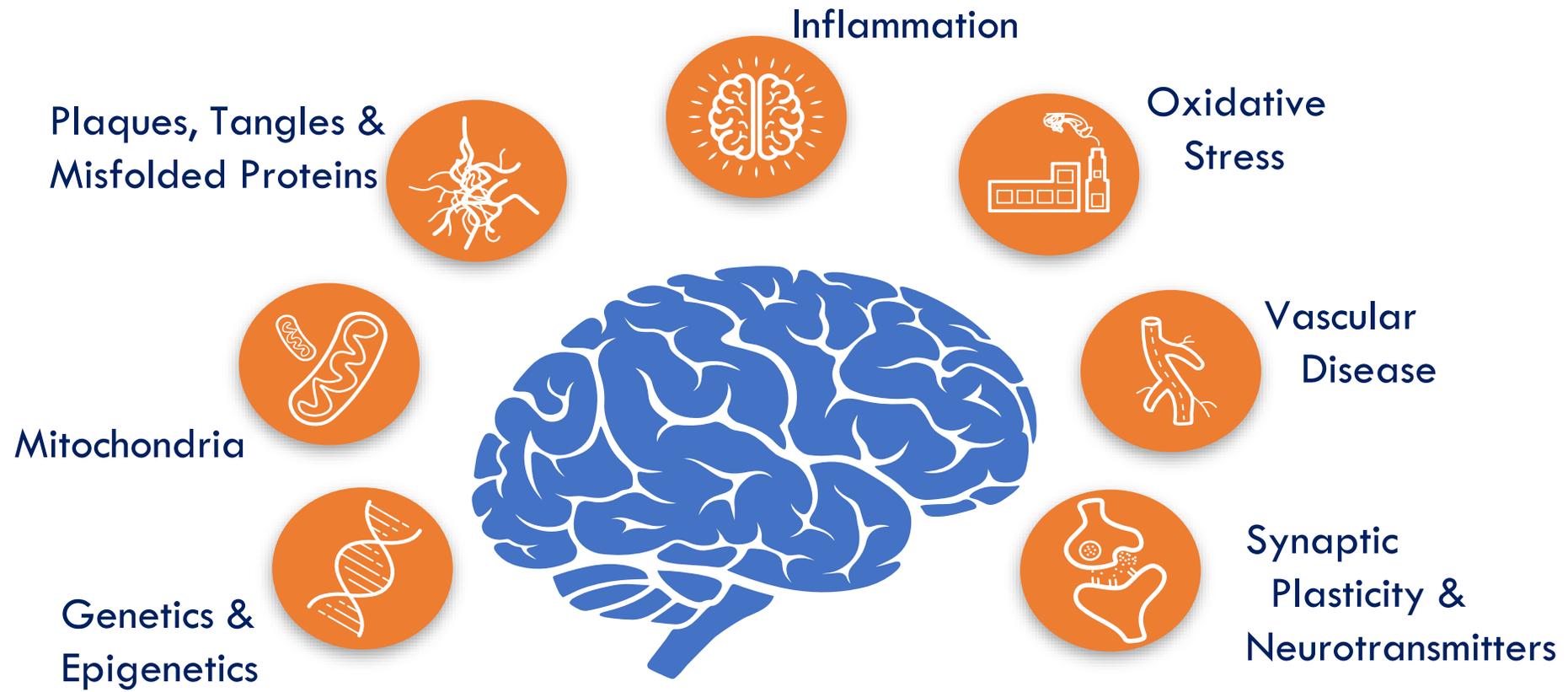


Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2019





# Causes/ Prevalence of Dementia



# Caregiver Epidemiology

More than 11 million Americans provide unpaid care for a family member or friend with dementia, a contribution to the nation valued at nearly \$350 billion

# Dementia public health impact in the United States

- Average hours of care per week: 48
- Family expenditures \$61,000 in last year of life – **HIGHEST** cost of any disease
- With passage of Recognize, Assist, Include, Support, and Engage Family Caregivers Act in 2017, HHS is charged with a national caregiver strategy



*Personal photo-shared with permission*

Dementia—  
no longer mainly institutional care

But also in the community:

2.1+ million older adults live at  
home with mod-severe dementia

# Family members provide the majority of care for people with dementia

- Approximately 60% of caregivers are women and about 30% are daughters; 30% of caregivers are 65 years or older
- Most caregivers (66%) live with the person with dementia in the community
- Approximately one-quarter of dementia caregivers are “sandwich generation” caregivers
- Race and ethnicity of caregivers reflect dementia prevalence in the US



# Strategies to Support Caregivers in Dementia Care

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# HHS Public Access

Author manuscript

*J Alzheimers Dis.* Author manuscript; available in PMC 2022 December 01.

Published in final edited form as:

*J Alzheimers Dis.* 2022 ; 90(3): 1301–1320. doi:10.3233/JAD-220536.

## **“I didn’t sign up for this”: perspectives from persons living with dementia and care partners on challenges, supports, and opportunities to add geriatric neuropalliative care to dementia specialty care**

Krista L. Harrison, PhD<sup>1,2,3</sup>, Sarah B. Garrett, PhD<sup>2</sup>, Madina Halim, BA<sup>1</sup>, Alissa Bernstein Sideman, PhD, MPH<sup>2,3,4</sup>, Theresa A. Allison, MD, PhD<sup>1,5,6</sup>, Daniel Dohan, PhD<sup>2,4</sup>, Georges Naasan, MD<sup>7</sup>, Bruce L. Miller, MD<sup>3,8</sup>, Alexander K. Smith, MD, MS<sup>1,5</sup>, Christine S. Ritchie, MD, MSPH<sup>1,9</sup>

# Strategies to Address Dementia Care/Caregiver Care Gaps

Diagnostic disclosure

Anticipatory guidance

Caregiver support

Symptom/behavior management

Decision making/planning

Erratic follow-up, erratic coordination, erratic engagement with community resources

# Diagnostic disclosure

## Caregiver

I was bound to feel bad anyway, because my feeling was that he'd get diagnosed with mild cognitive impairment....So, it was a bit of a shock, kind of a punch in the stomach when he said, "Well, this is probably Alzheimer's." But it was hard to hear...And he didn't really offer any follow-up, like, let's meet again in a couple of weeks to see how you're doing with this. **Caregiver 1**

## Patient

We had a great rapport with him, but it was literally a 5 to 10-minute conversation. And it was, "Here's what all the test results say....I'm pretty sure you have younger-onset Alzheimer's, here's the medication I'm gonna start you on...." That was our diagnosis. So we obviously walked out of there stunned, you know, not really realizing what hit us. At the time I...withdrew from all the activities I enjoyed doing..." **Patient 1**

# PASS



PREPARE



ASSESS



SHARE



SUPPORT

# Anticipatory guidance

**Prognosis  
and expected  
disease  
trajectory**

Disease  
trajectory

Unique  
dementia  
syndromes

Uncertainty

Clarity of  
dementia as  
a terminal  
condition

**Behavioral,  
safety, and  
caregiving**

Safety

Behavior

Caregiving

**Planning for  
the future**

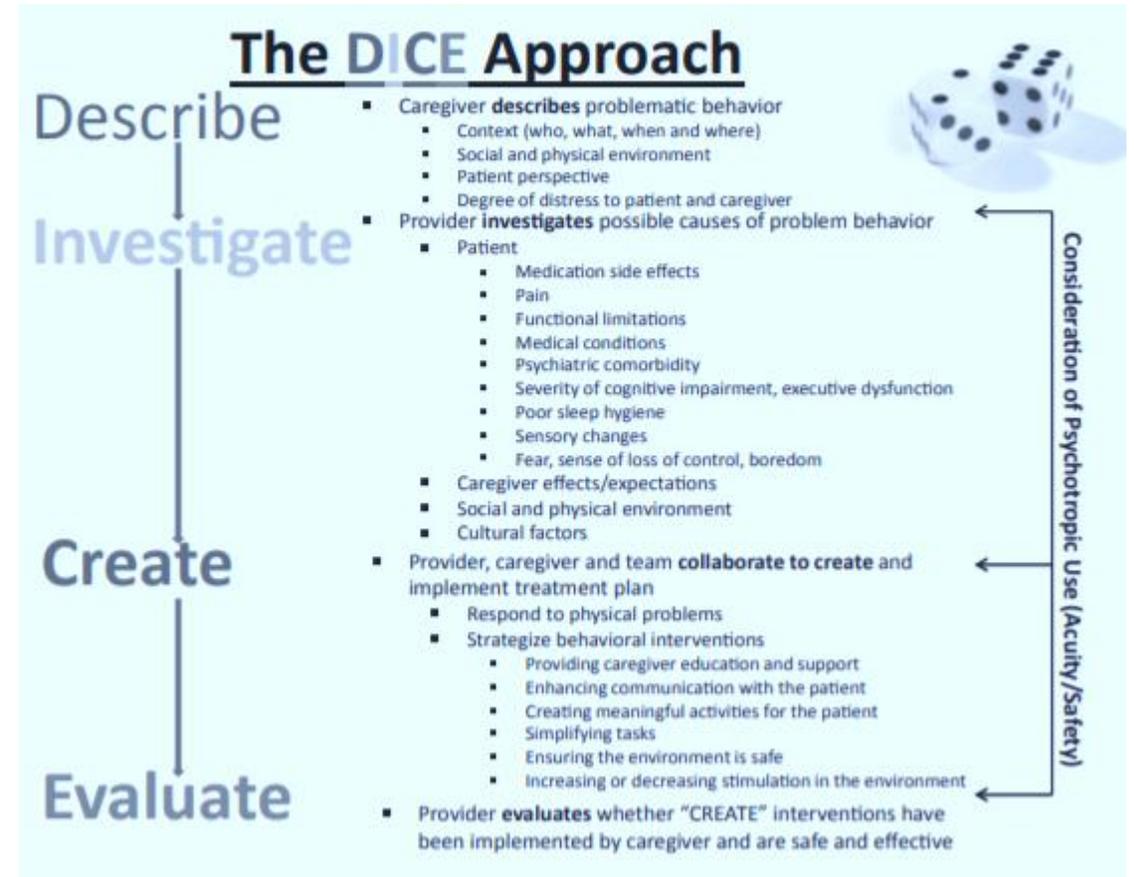
Financial and  
legal

Advance care  
planning

Change in  
living/care  
settings

# Management of Behavioral Symptoms

- Depression
- Psychosis
- Apathy
- Agitation
- Aggression
- Delusions
- Hallucinations
- Sleep disturbances
- Wandering and argumentativeness



Kales HC et al. J Am Geriatr Soc. 2014 Apr;62(4):762-9. PMID: 24635665; PMCID: PMC4146407.

# Supporting the Care Partner

Therapeutic  
Communication

Safe Physical  
Environment

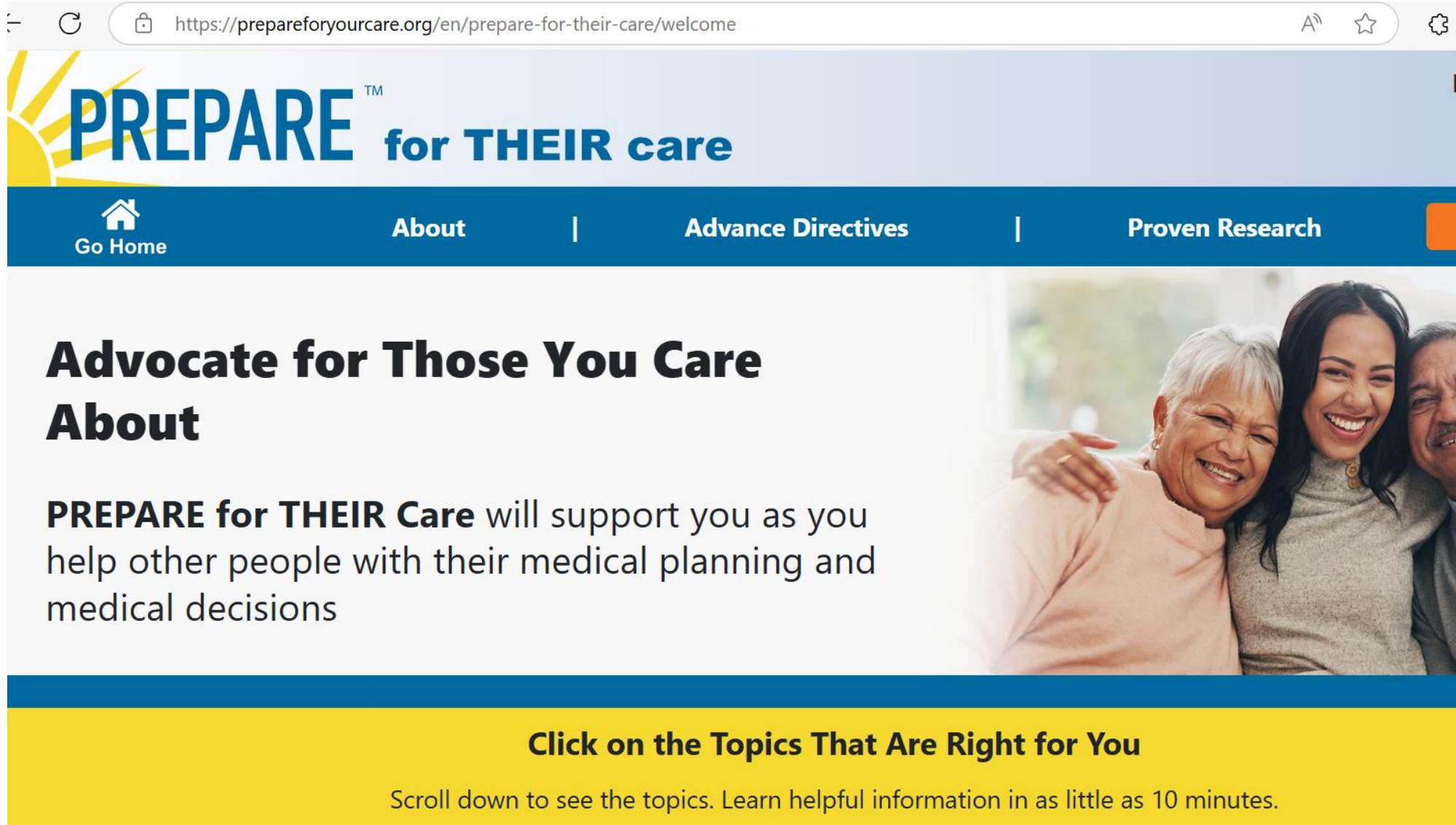
Activity and  
Engagement

Behavior as  
communication

Routine and  
Structure

Positive Emotions

# Advance care planning



The image shows a screenshot of a web browser displaying the homepage of the organization 'PREPARE for THEIR care'. The browser's address bar shows the URL 'https://prepareforyourcare.org/en/prepare-for-their-care/welcome'. The website features a blue header with the organization's logo, which includes a sun icon and the text 'PREPARE™ for THEIR care'. Below the logo is a navigation menu with a 'Go Home' button (represented by a house icon) and three main menu items: 'About', 'Advance Directives', and 'Proven Research'. The main content area has a white background with a large, bold heading 'Advocate for Those You Care About' and a sub-heading 'PREPARE for THEIR Care will support you as you help other people with their medical planning and medical decisions'. To the right of the text is a photograph of three people (two women and one man) smiling and embracing each other. At the bottom of the page is a yellow banner with the text 'Click on the Topics That Are Right for You' and 'Scroll down to see the topics. Learn helpful information in as little as 10 minutes.'

https://prepareforyourcare.org/en/prepare-for-their-care/welcome

**PREPARE™ for THEIR care**

Go Home | About | Advance Directives | Proven Research

## Advocate for Those You Care About

**PREPARE for THEIR Care** will support you as you help other people with their medical planning and medical decisions

**Click on the Topics That Are Right for You**

Scroll down to see the topics. Learn helpful information in as little as 10 minutes.

# Roadmap for Supporting Caregivers and Persons with Dementia

## THROUGHOUT CARE

- Reassess:  
disease progression  
changing care needs  
home care service needs
- Communicate  
Employ serious illness  
communication  
strategies  
Acknowledge uncertainty  
Normalize experiences  
Offer emotional support
- Optimize quality of life  
Enable (adapted) PLWD-CP  
meaningful activities CP well-  
being/self-care

+PCP & Provider care coordination  
+ Engage IDT

## EARLY DISEASE

- Share information  
Diagnosis & counseling  
Type-specific information  
Expected cognitive, functional, &  
behavioral changes over time  
Financial & legal planning
- Collaborate & assess goals  
PLWD-CP priorities, preferences  
for future care settings,  
treatments  
Assist with ACP paperwork

+ Connect to dementia specialist  
+ Offer disease-specific educational  
resources (books, handouts, internet  
resources)  
+ Connect to support groups

## MODERATE-SEVERE

- Monitor progression  
Address coexisting conditions or frailty  
Assess & address safety
- Manage disease  
Symptom management  
Address CP distress, grief
- Begin de-escalating care burden  
Customize preventative care for time-  
to-benefit, PLWD-CP goals
- Continue deprescribing medication
- Transition to telehealth, home visits

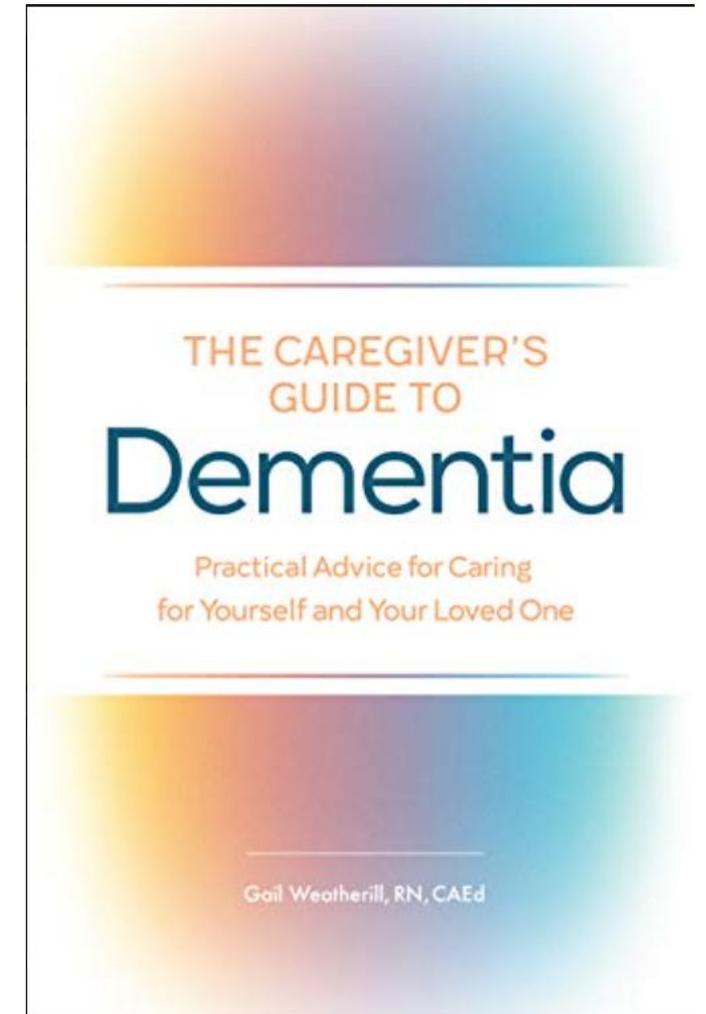
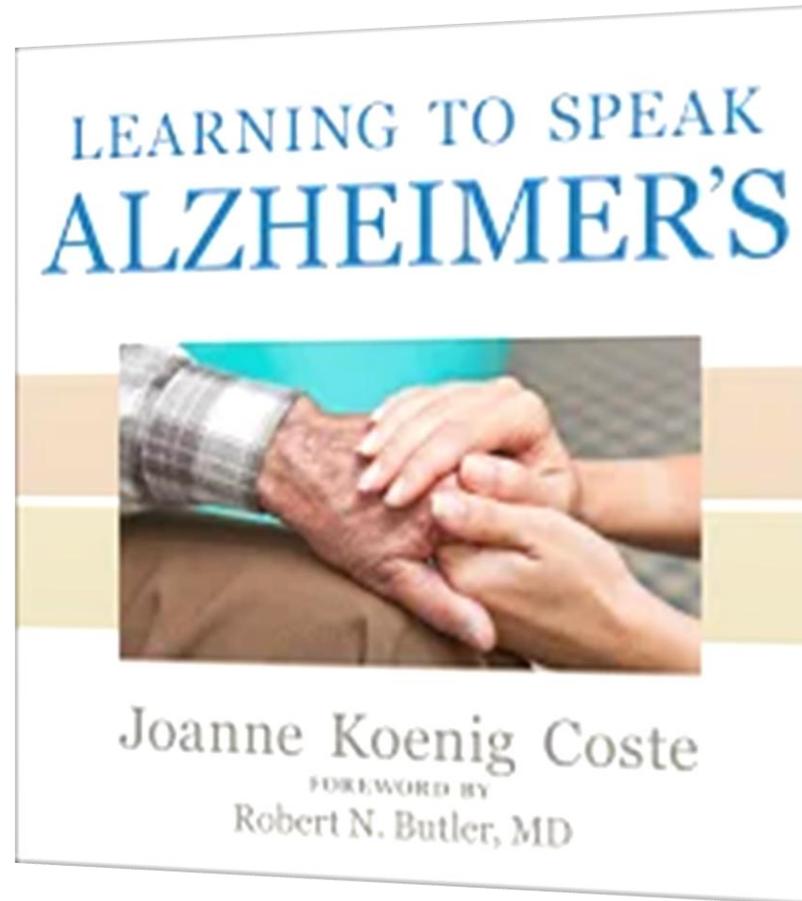
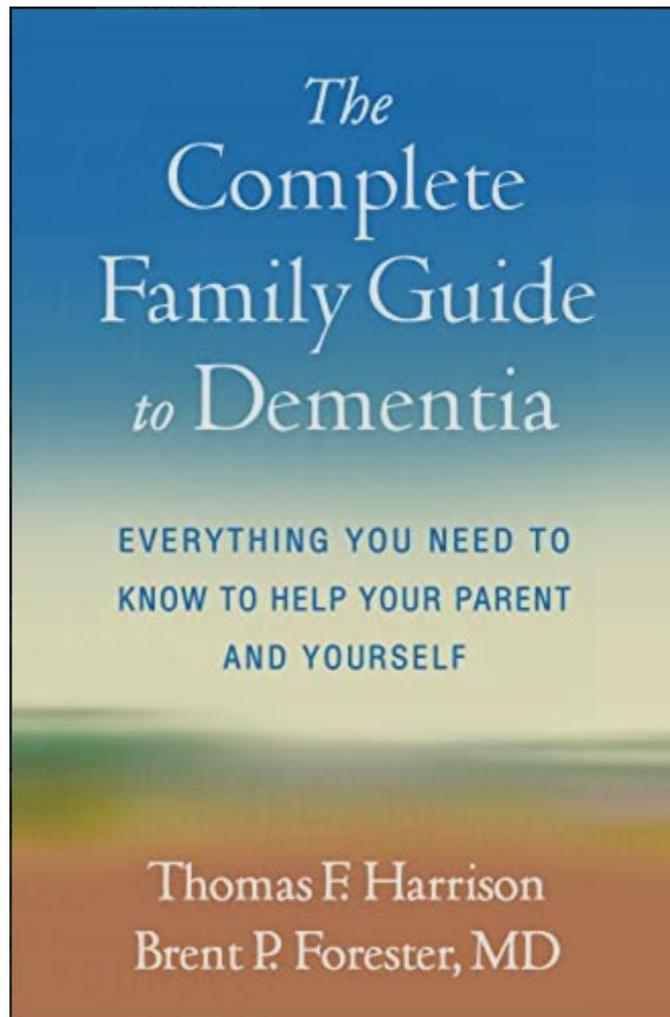
+ Connect to supportive services (accessible  
transportation, home meal delivery, letters  
for disability/benefits)  
+ Provide guide to local personal aide  
& care services  
+ Connect to palliative care, geriatric care, or  
both

## END-OF-LIFE

- Promote comfort  
Manage physical disability  
Assess polypharmacy, side effects  
Minimize symptom burden
- Facilitate goals; reduce transitions  
Manage end-of-life expectations  
Foster resolution of family conflict  
Support CP spiritual needs  
Guide CP on reducing burdensome  
treatments, setting changes

+ Help with facility selection and transition  
+Hospice referral  
+Caregiver bereavement support, grief  
counseling

# Supporting the Care Partner: Education



# SUMMARY

- Optimal dementia care involves the care partner
- Care gaps are numerous
- Strategies to support care partners will require routine care partner engagement, education and an optimized ecosystem for persons with dementia





Thankyou!

Questions?

[csritchie@mgh.harvard.edu](mailto:csritchie@mgh.harvard.edu)

## CME Credits (currently available for MDs, PAs, Rx, RNs, NPs, PsyD, PhD) and Social Work Credits

- Please provide us your feedback! You can use the link below or Use your phone camera to scan the QR code.

<https://www.surveymonkey.com/r/82V3M9F>



- Please request CME credits when filling out the evaluation at the end of the meeting
- Continuing education credits(CEUs) in social work are available to individuals who complete the entire activity and submit the post training evaluation.

- A copy of the slides and link to our program evaluation will be emailed after this session.
- You can access slides and recording through your iECHO account shortly.
- Enduring CME credits will be offered: *The AAFP has reviewed the Geriatric Project ECHO Series: “ECHO Series Focused on Best Practices and QI” and deemed it acceptable for AAFP credit. Term of approval is from 9/2/24 to 9/2/25. Participants should claim only the credit commensurate with the extent of their participation in the activity. NPs and RNs can also receive credit through AAFP’s partnership with the American Nurses Credentialing Center (ANCC) and the American Academy of Nurse Practitioners Certification Board (AANPCB).*
- \* Enduring credits for social work are not available

