

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.



ADVANCING INTEGRATED HEALTHCARE

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

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

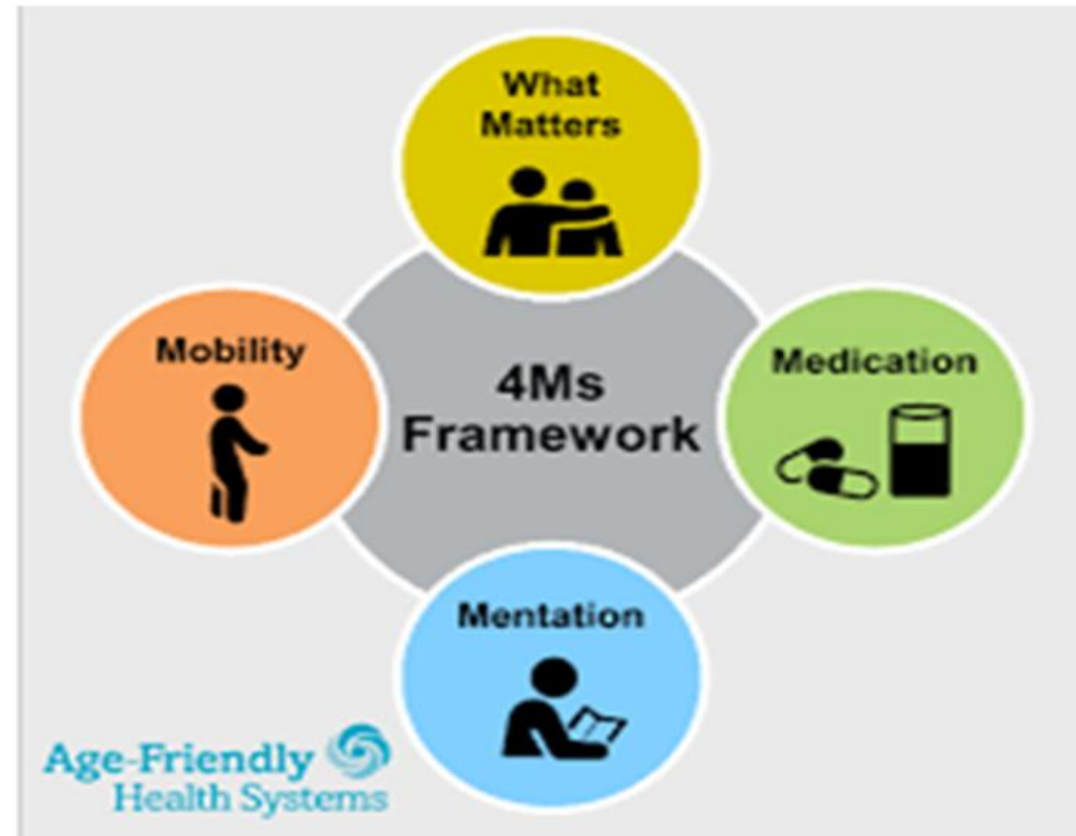
- **Erica Estus, PharmD, BCGP**; Clinical Professor, URI College of Pharmacy
- **Nick Nikolopoulos, DO**; Chief Medical Officer, PACE-RI
- **Cynthia Padula, PhD, RN**; Professor Emeritus, RI College School of Nursing
- **Kim Rickler, MSW, LICSW**; Clinical Teaching Associate, Family Medicine
Warren Alpert 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

(IH, 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

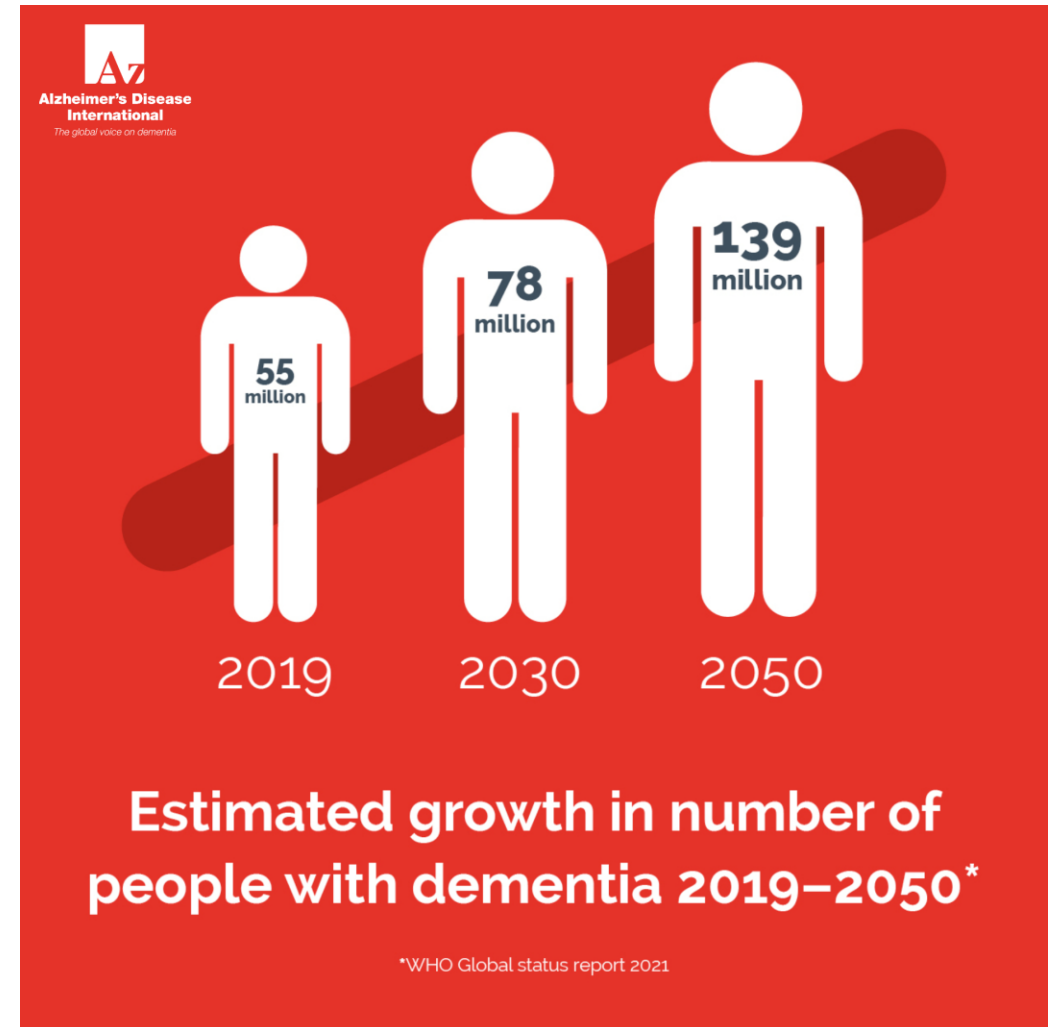
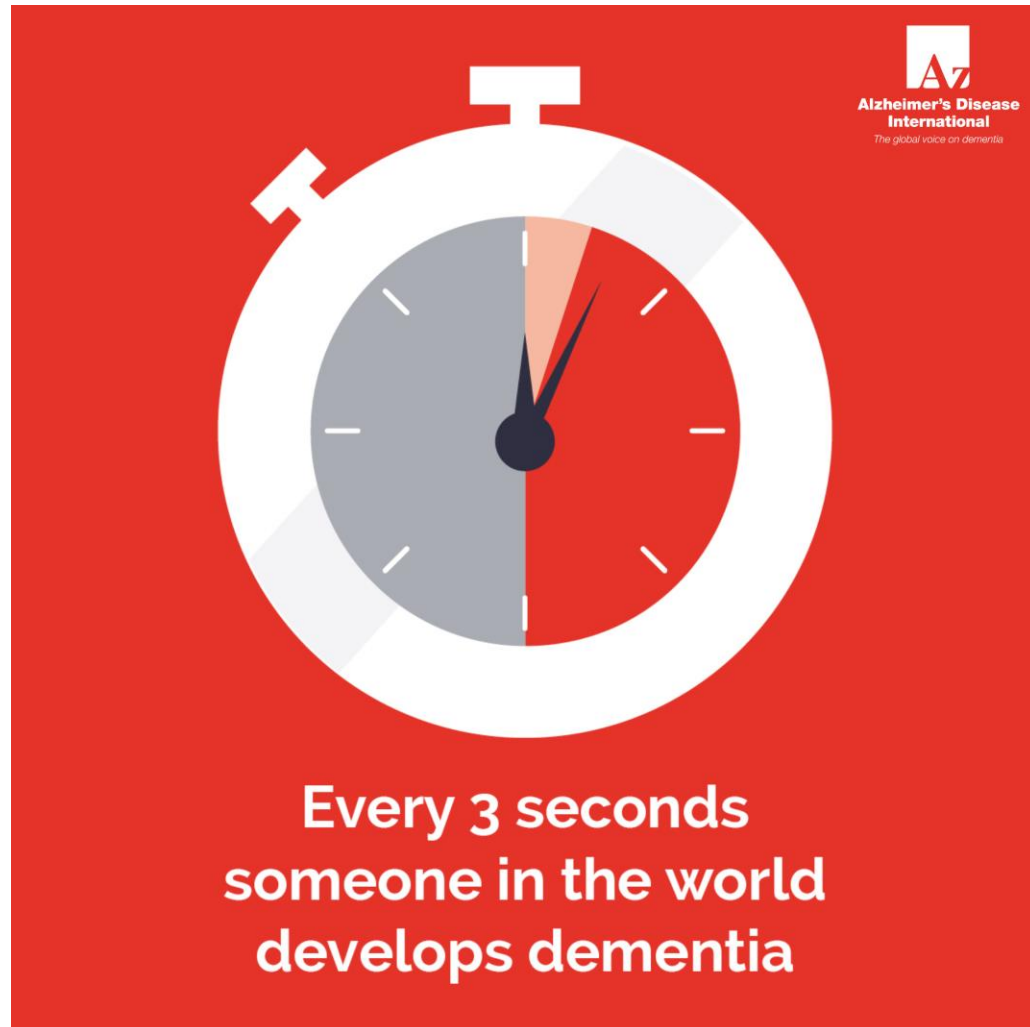
Goals for today

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



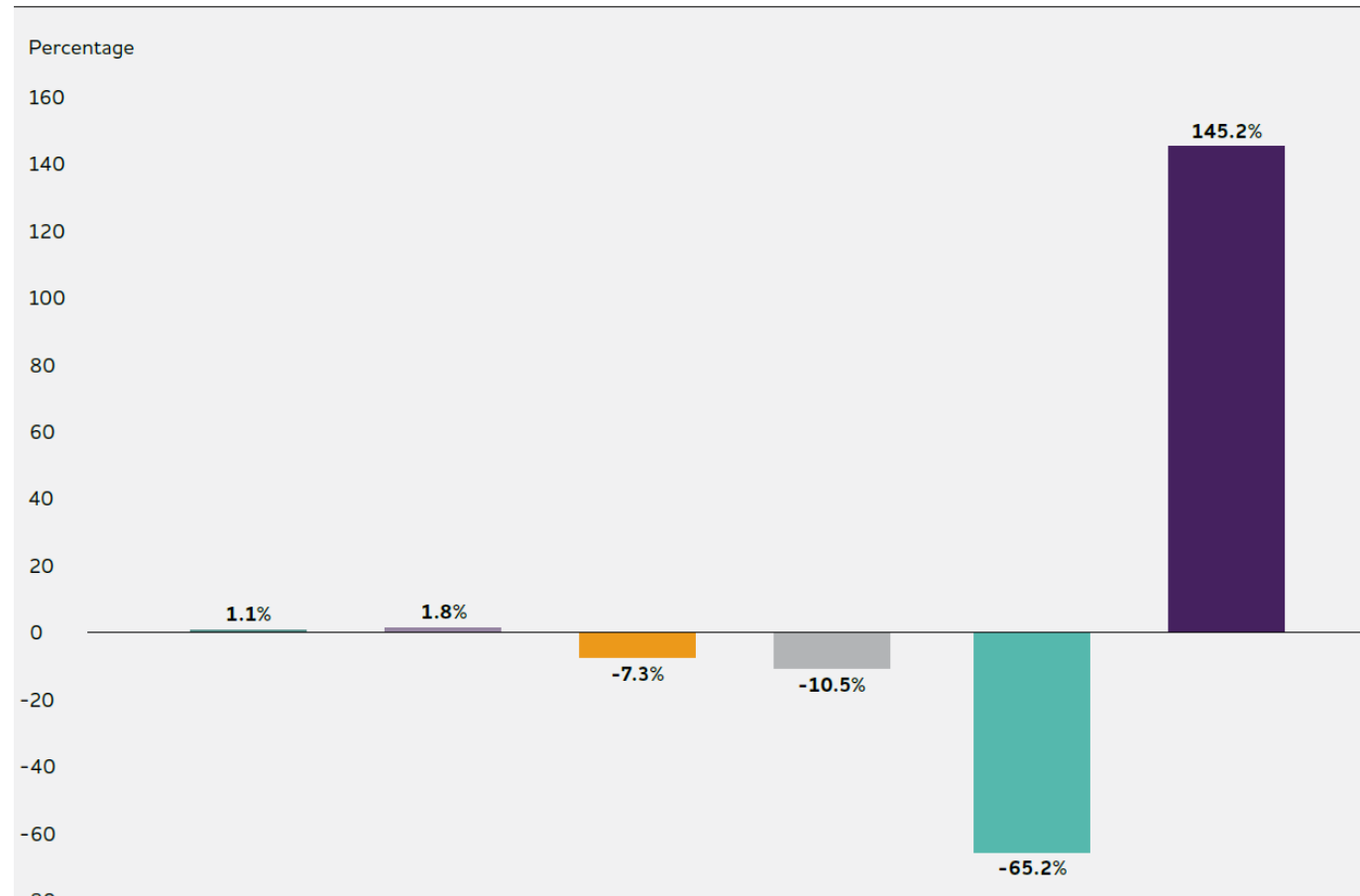
Epidemiology of dementia in the U.S.

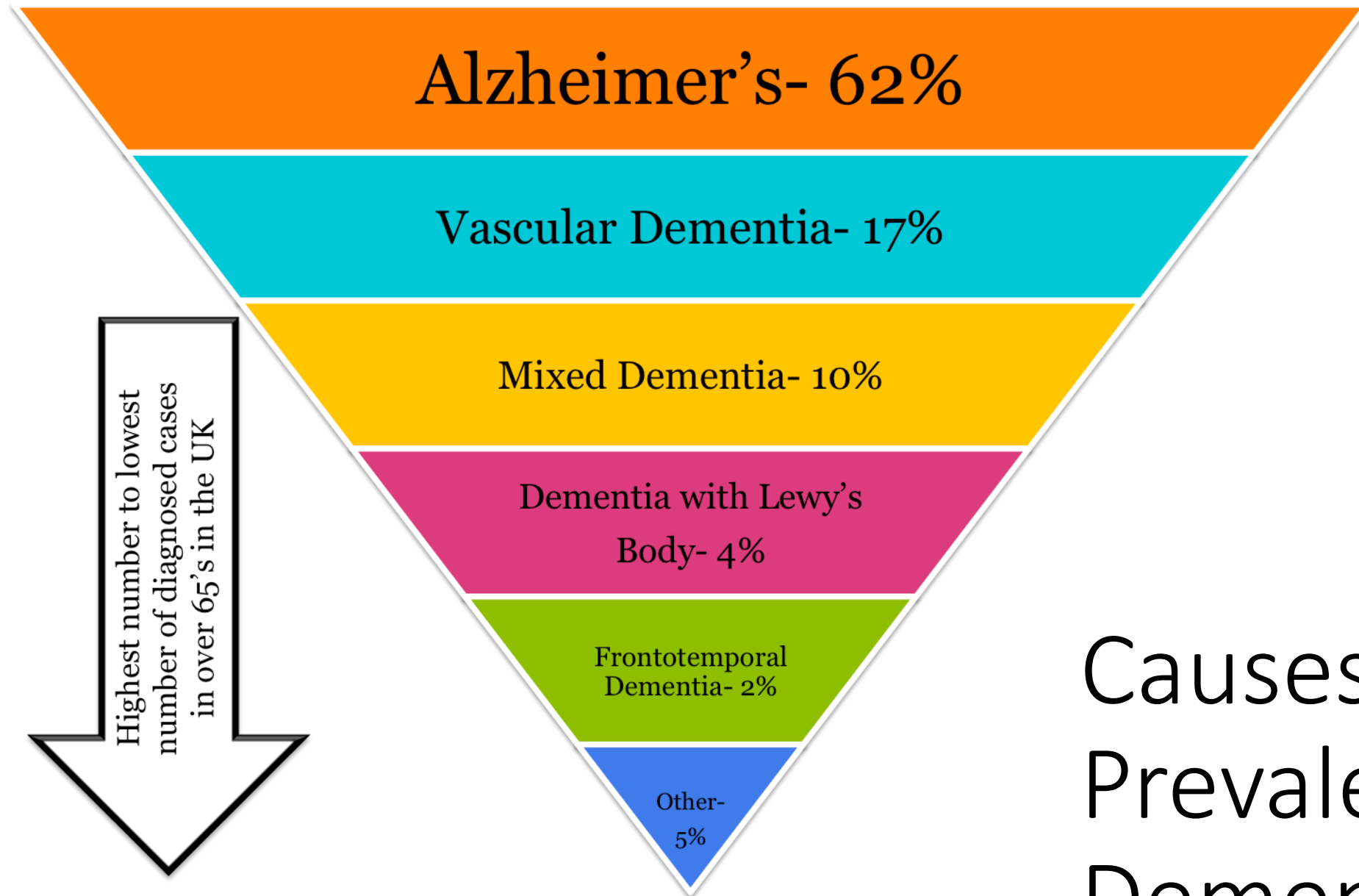
Prevalence

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

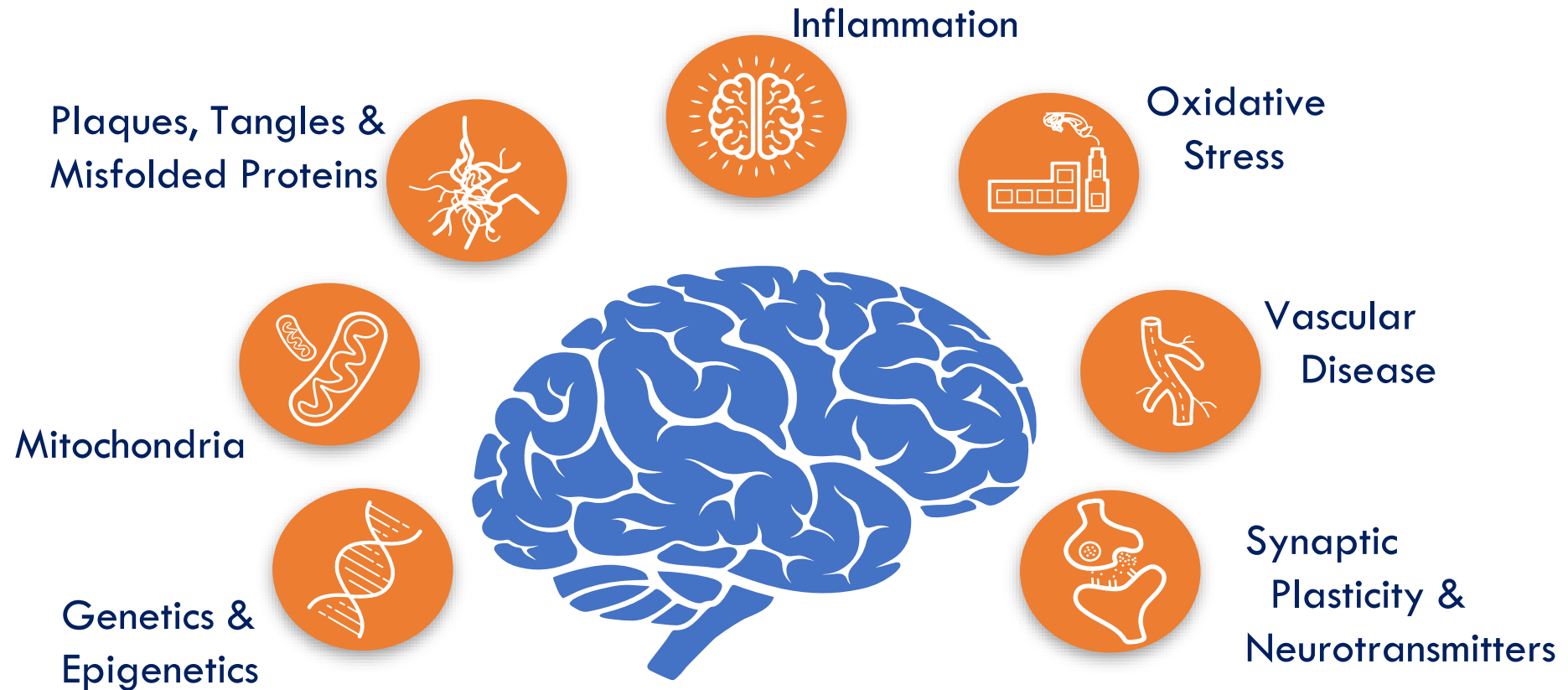


Percentage Changes in Selected Causes of Death (All Ages) Between 2000 and 2019





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





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^{1,2,3}, Sarah B. Garrett, PhD², Madina Halim, BA¹, Alissa Bernstein Sideman, PhD, MPH^{2,3,4}, Theresa A. Allison, MD, PhD^{1,5,6}, Daniel Dohan, PhD^{2,4}, Georges Naasan, MD⁷, Bruce L. Miller, MD^{3,8}, Alexander K. Smith, MD, MS^{1,5}, Christine S. Ritchie, MD, MSPH^{1,9}

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**

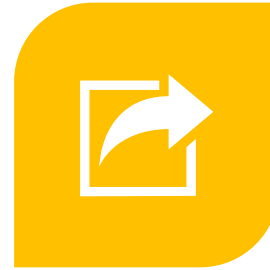
PASS



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**

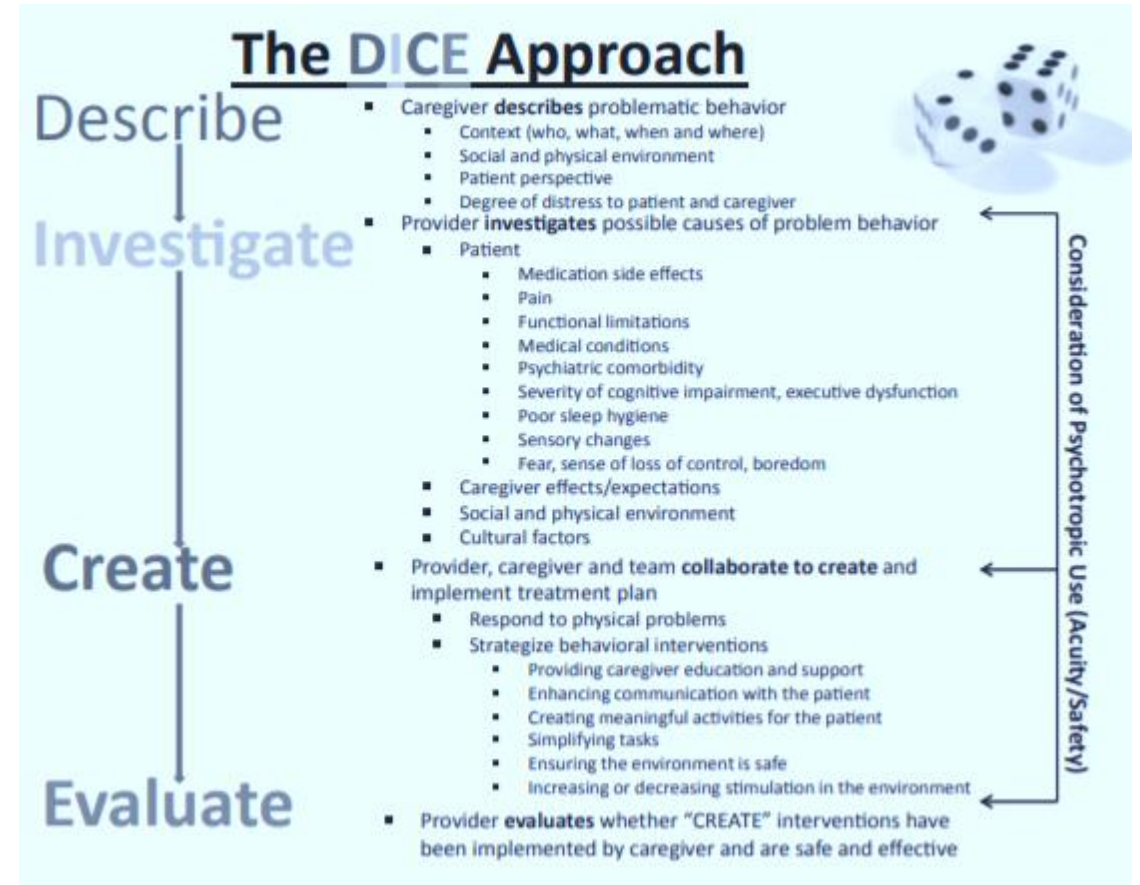
Financial and
legal

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 screenshot shows a web browser window with the URL <https://prepareforyourcare.org/en/prepare-for-their-care/welcome>. The website header features the logo "PREPARE™ for THEIR care" with a sun icon. Below the logo is a navigation bar with links: "Go Home" (with a house icon), "About", "Advance Directives", and "Proven Research". The main content area has the heading "Advocate for Those You Care About" and the text "PREPARE for THEIR Care will support you as you help other people with their medical planning and medical decisions". To the right of this text is a photograph of three people (two women and one man) smiling and hugging. At the bottom, a yellow banner contains 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

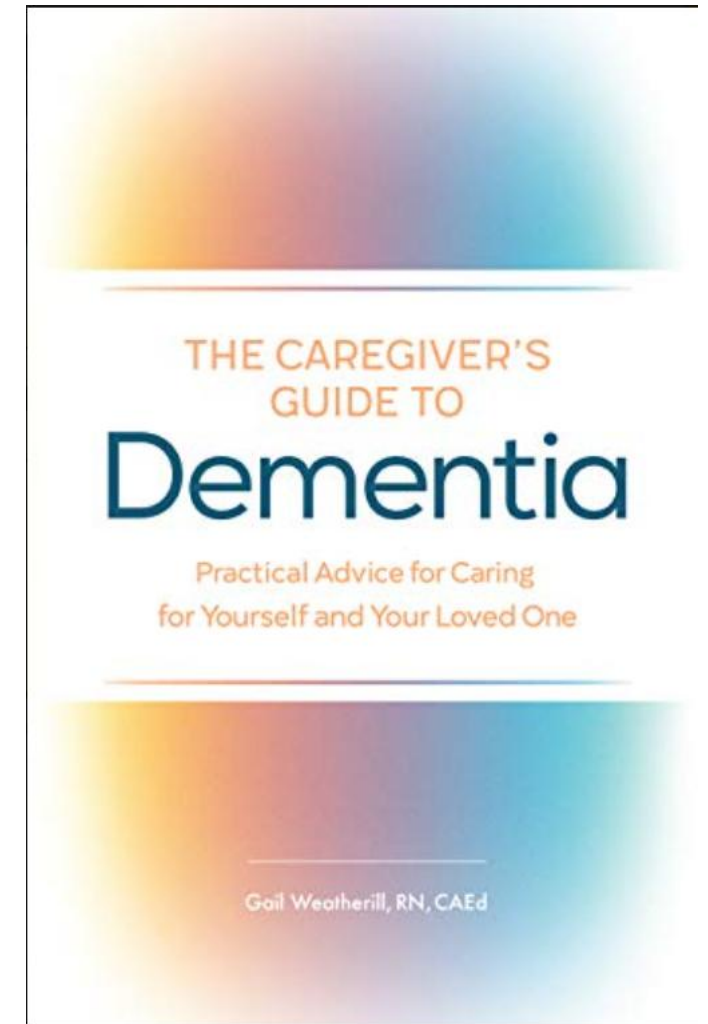
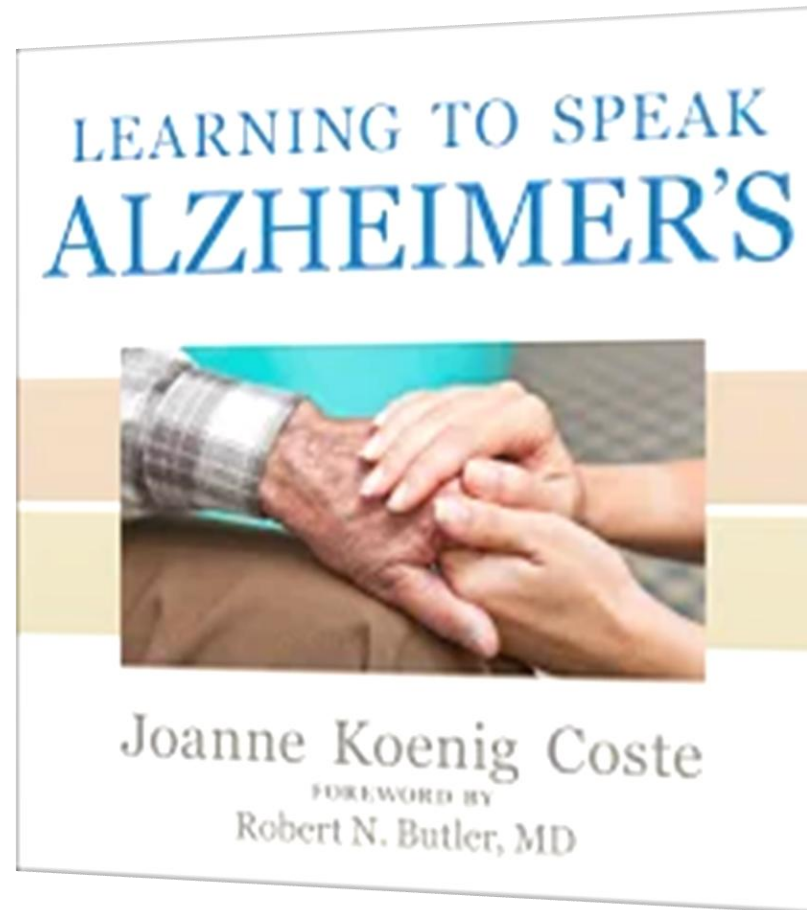
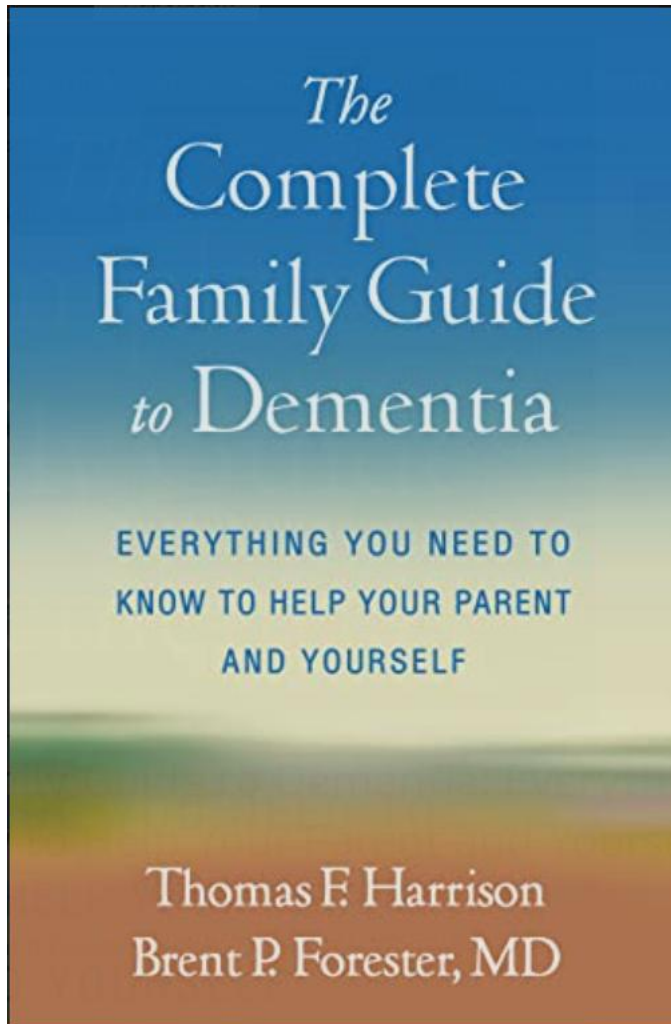
+ Connect to supportive services (accessible
transportation, home meal delivery, letters
for disability/benefits)
+ Provide guide to local personal aide
& care services
+ Connect to palliative care, geriatric care, or
both

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



Personal photo-shared with permission



Thankyou!

Questions?

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

