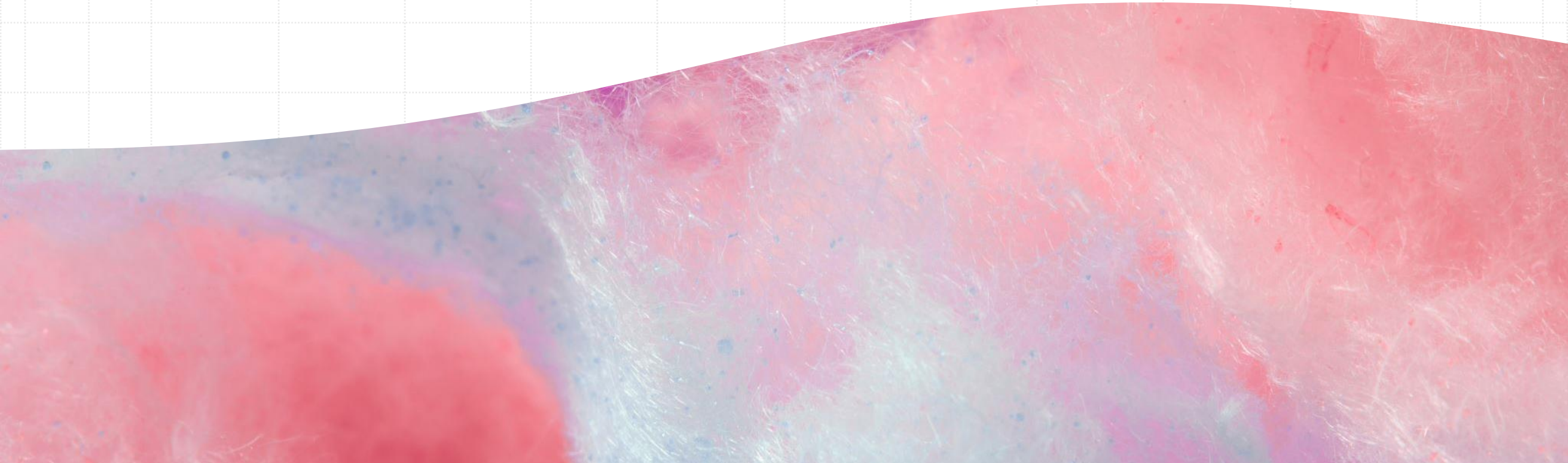
Multicomplexity in Dementia:

Transitioning to a Palliative Approach

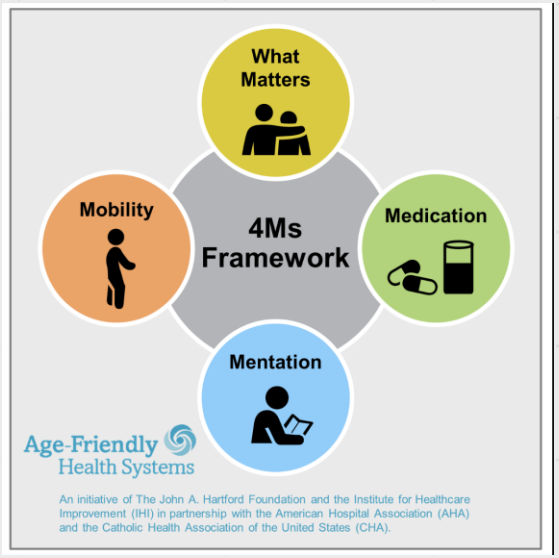
Carroll Haymon MD

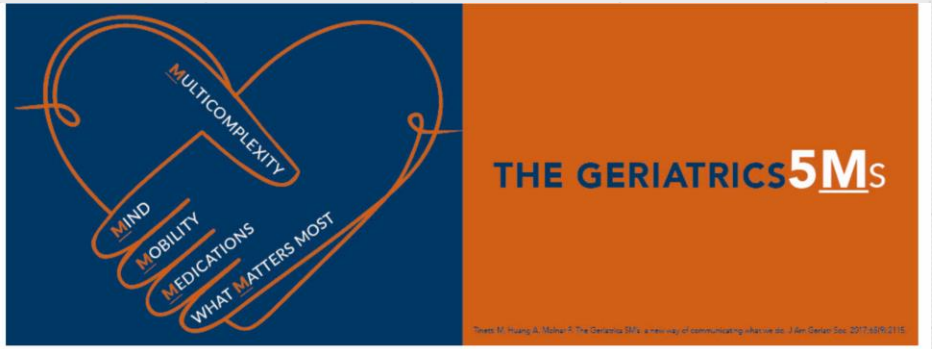
UW Project ECHO Dementia

June 2025



Why Multicomplexity?





Agenda for Today

We will address

- The management of OTHER medical conditions in the setting of advancing dementia
  - Or: To what extent should the presence of dementia CHANGE how I manage my patient's diabetes, blood pressure, and COPD?

We will not address

- How to manage the dementia itself
- Palliative care for late-stage dementia

… as those have been covered in other excellent ECHO dementia presentations

Learning Objectives

- At the conclusion of this presentation, attendees will
  - Recognize the signals that dementia is progressing and that management of other medical conditions needs to shift, and
  - Learn tactics for moving toward a palliative approach of chronic conditions in the setting of progressive dementia.

Carroll Haymon, MD

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iora with one medical

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ACH CONSULTING

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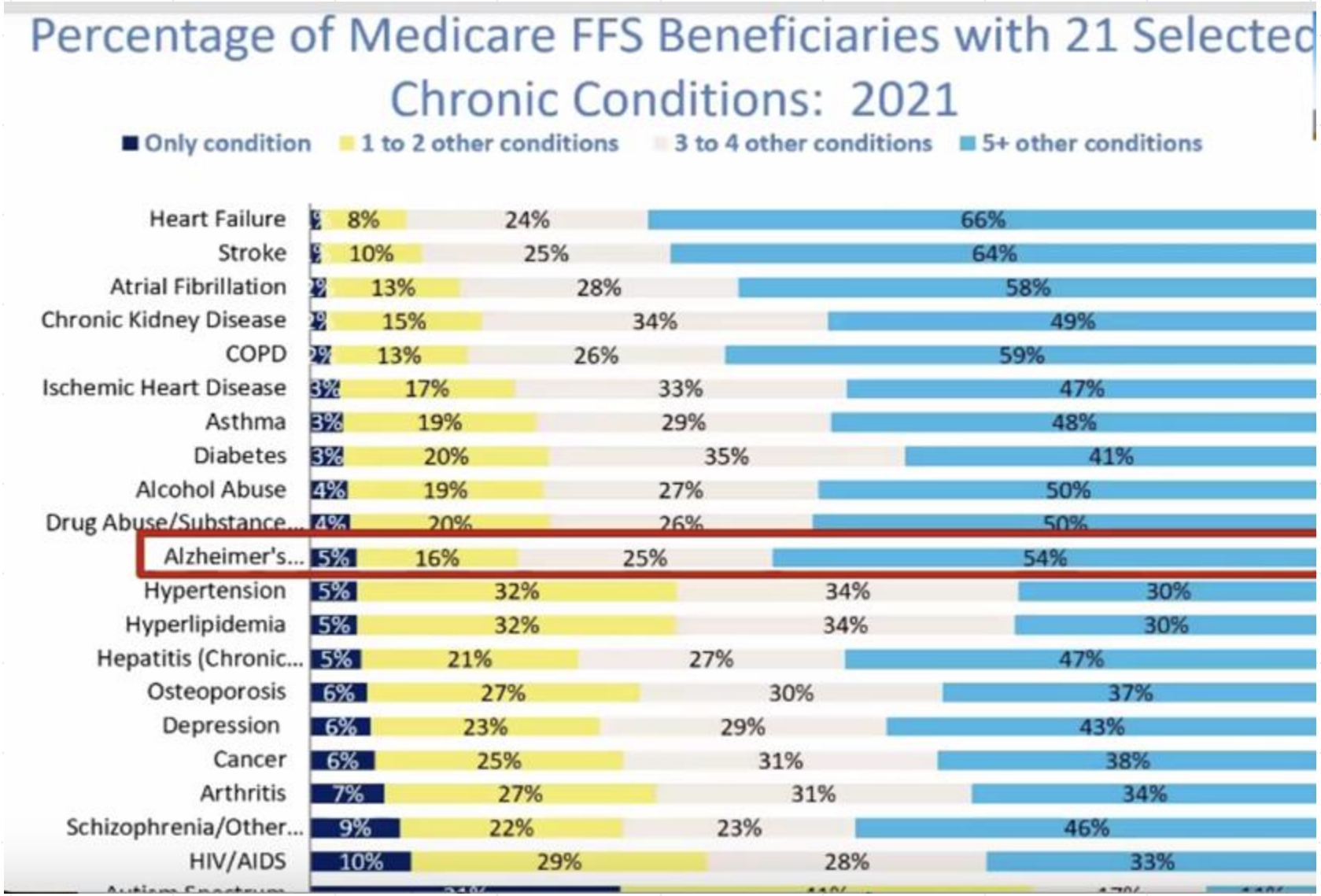
UW Medicine

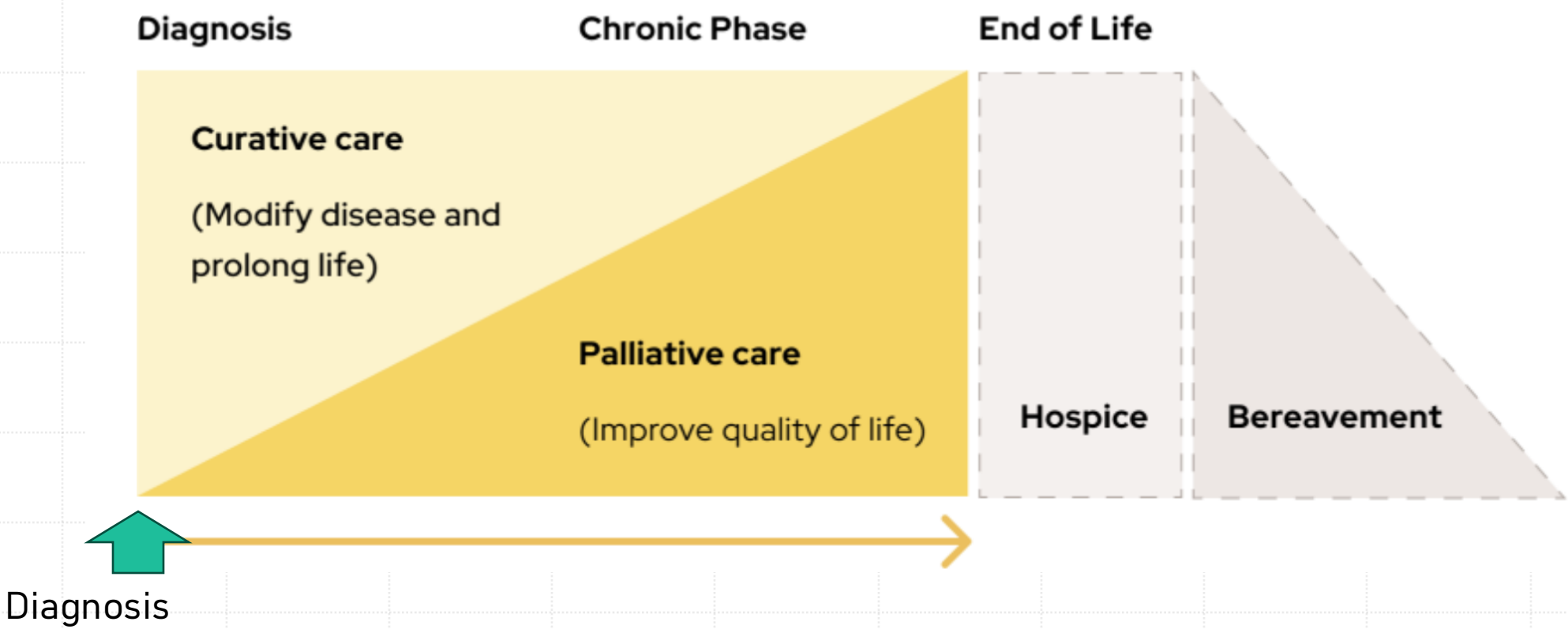
Nothing to disclose

Dementia patients have many co-morbidities



Source: CMS

Ideally, palliative care increases over time



Managing Multicomplexity in Dementia

- Ensure patient and family understand the natural history and prognosis of dementia
- Understand patient's dementia stage and (approximate) life expectancy
- Explore patient/family goals and values.
- Balance benefits and burdens of ongoing care. Grant permission to pull back.
- Revisit regularly over time.


See the Forest through the Trees

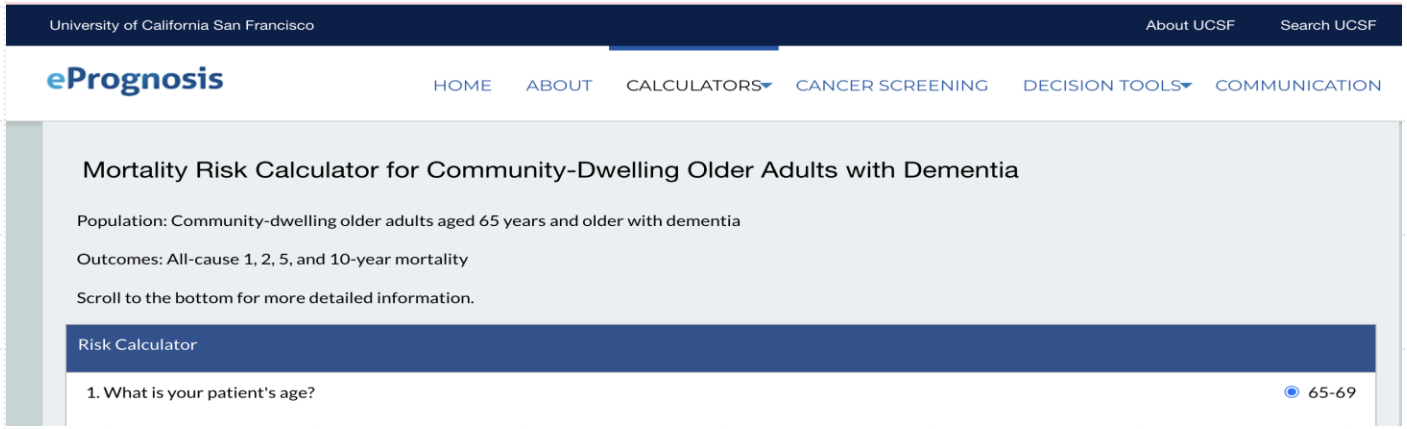
We are better at this in patients with incurable cancers

Dementia Education, Prognosis, and Staging

Dementia Education for Patients & Care Partners: What to Expect, How to Prepare

- Many community resources are available
  - Alzheimer's Association & AARP
  - Memory Hub
  - Area Agencies on Aging
  - Dementia Roadmap, a product of the WA Dementia Action Collaborative

Life Expectancy in Dementia



- [ePrognosis calculator]
- Risk factors
  - Age/Sex/BMI/Smoking
  - Physical activity level
  - ADL/IADL
  - Chronic diseases

"The average life expectancy of people with dementia at time of diagnosis ranged from 5.7 years at age 65 to 2.2 at age 85 in men and from 8.0 to 4.5, respectively, in women."

"About one third of remaining life expectancy was lived in nursing homes, with more than half of people moving to a nursing home within five years after a dementia diagnosis. Prognosis after a dementia diagnosis is highly dependent on personal and clinical characteristics" – BMJ 2025

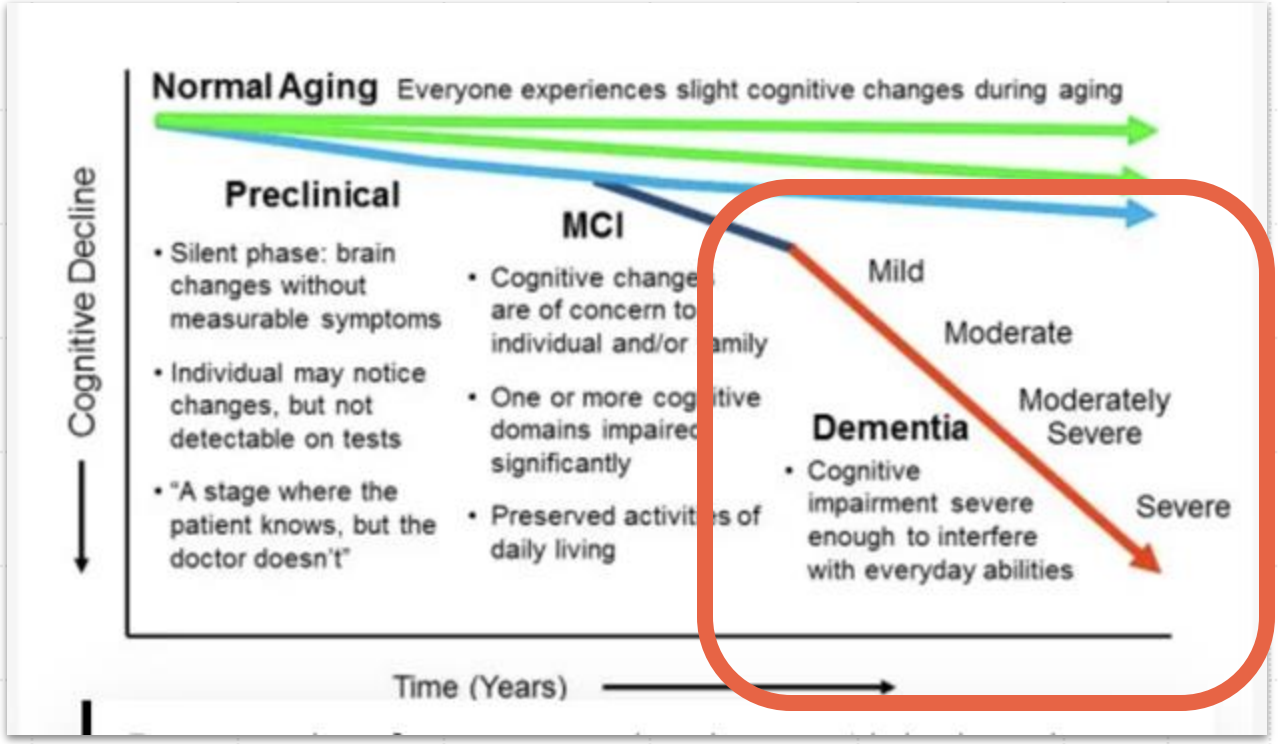
JAMA Int Med 2022
BMJ 2025

The Stages of Alzheimer's Disease and Related Dementias

1. **Preclinical**: Pathologic changes only

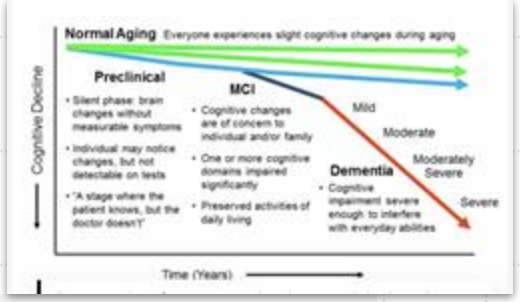
2. **Mild Cognitive Impairment**: Impaired cognition without functional changes

3. **AD Dementia**: Cognitive and functional impairment



Source: NIH Diagnostic Criteria for Alzheimer's Disease, 2011; UCI-MIND

Staging informs prognosis



Dementia Severity Rating Scale

- Completed by informant, covers many domains of function
- Score = Mild, Moderate, Severe
- Useful for monitoring progression over time

DEMENTIA SEVERITY RATING SCALE (DSRS)

PARTICIPANT'S NAME:_____ **DATE:**_____
PERSON COMPLETING FORM:_____
Please circle the most appropriate answer.
Do you live with the participant? No Yes
How much contact do you have with the participant? Less than 1 day per week 1 day/week 2 days/week 3-4 days/week
5 or more days per week
Relationship to participant
Self Spouse Sibling Child Other Family Friend Other _____
In each section, please circle the number that **most closely applies** to the participant. This is a general form, so no one description may be exactly right -- please circle the answer that seems to apply most of the time.

Please circle only one number per section, and be sure to answer all questions.

MEMORY

0 Normal memory.
1 Occasionally forgets things that they were told recently. Does not cause many problems.
2 Mild consistent forgetfulness. Remembers recent events but often forgets parts.
3 Moderate memory loss. Worse for recent events. May not remember something you just told them. Causes problems with everyday activities.
4 Substantial memory loss. Quickly forgets recent or newly-learned things. Can only remember things that they have known for a long time.
5 Does not remember basic facts like the day of the week, when last meal was eaten or what the next meal will be.
6 Does not remember even the most basic things.

Functional Assessment Staging Tool

- Staging done by clinician
- 7 stages, higher score = worse
- Deficits do not always occur in the prescribed order

FAST Scale Stages

Below, you'll find the stages of the FAST Scale for Alzheimer's disease, which range from normal functioning to severe cognitive decline.

Stage	Name	Description
1	No Functional Decline	No cognitive impairment or decline is present.
2	Very Mild Decline	Slight forgetfulness and subtle cognitive changes.
3	Mild Cognitive Decline	Noticeable memory and cognitive deficits become evident.
4	Moderate Cognitive Decline	Individuals struggle with more complex tasks, requiring assistance.
5	Moderately Severe	Patients require assistance with basic activities and may exhibit behavioral

It’s a Balance

- Providing hope
- Remaining realistic

It’s a Journey

Case Presentation: Jorge

Early stage (mild) dementia

Moderate dementia

Advanced dementia

Case: Early-stage (mild) disease

- Jorge is 82 and lives with his wife, Connie. His children live nearby and are involved in his care.
- Jorge has CAD (past MI), diabetes, osteoarthritis, HTN, CKD3, colon polyps, and COPD. He is a former smoker. He has been hospitalized 3 times in the past year.
- You recently diagnosed Jorge with dementia, likely mixed Alzheimer's + vascular.
  - He is independent in basic ADLs but needs helps with med management, finances, and food prep. He recently stopped driving at the family's request. You stage him as a FAST stage 4.
  - Jorge is forgetful, but recognizes people and participates in conversation
- There are no advance directives on file.

Current state

Jorge's medications

- Aspirin
- Atorvastatin
- Metoprolol
- Metformin
- Insulin glargine + insulin lispro w meals
- Lisinopril
- Inhalers: LAMA, LABA, SABA
- Acetaminophen as needed
- Multivitamin and vitamin D

Jorge's specialists

- Cardiology
- Nephrology
- Pulmonology
- Gastroenterology (hx of colon polyps)
- Dermatology (hx of squamous cell carcinoma, removed)
- Ophthalmology (hx of cataracts, removed)

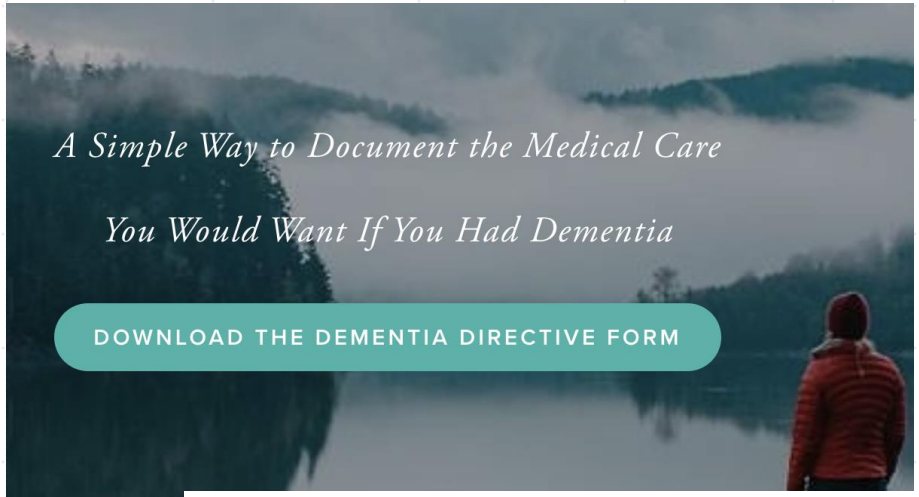
Early-stage disease: priorities

- Dementia education and support; Prognosis and life expectancy
- Identify a health-care proxy/ decision-maker for when Jorge is no longer able to make his own decisions.
- Assess goals of care and complete POLST
- Assess the burden & value of existing treatments: meds, tests, specialist visits.
  - “I want to make sure we are focusing our attention on the interventions that will help the most”
  - “My goal is to be an advocate for you”
  - ”We will be on this journey together”

Got favorite words? Enter in the chat!

What Matters Most

- Shared decision-making: there is not a "right" answer
  - Involve patient AND healthcare proxy throughout the course
- Goals of care evolve over time.
- Tools:
  - Advance Directive for Living with Dementia
  - Dementia Directive



Advance Directive for Living with Dementia

My name is _____. My date of birth is _____.

I am a person with decision-making capacity. I voluntarily sign this mental health directive under RCW 71.32.260. If I cannot make decisions for myself, my relatives, friends, agents, and medical providers should fully honor every part of this directive. If any part of this directive is invalid, the rest should be honored. I revoke any Advance Directive for Living with Dementia that I have signed in the past.

This directive instructs my health care agent or other legal decision-maker ("decision-maker") and all caregivers how to act on my behalf.

1. **Start date.** This directive is effective (*check one*):
   - [ ] Now.
   - [ ] Only if I can't make decisions for myself (if I'm incapacitated).
   - [ ] When my decision-maker determines that any of these circumstances, symptoms, or behaviors have occurred (*check all that apply*):
     - [ ] I am no longer able to communicate verbally.
     - [ ] I can no longer feed myself.
     - [ ] I can no longer recognize people who are important to me.
     - [ ] I put myself or others in danger because of my actions or behaviors

Jorge's life expectancy using ePrognosis

For a patient with these characteristics, the predicted probability of death equals:	
1 year	21%
2 years	43%
5 years	84%
10 years	99%
Median predicted time to death (25th to 75th percentile)	2.4 years (1.2 - 4.1 years)

After discussion

- Jorge designates Connie, his wife, as his decision-maker
- Jorge is willing to be hospitalized if needed, but would not want an ICU stay or a resuscitation. Family concurs. POLST is completed and signed.
- They are finding his insulin regimen to be too complex, now that Jorge can't manage his meds independently.
  - You agree together that a new A1C goal of 8.5 or 9 is appropriate, and you decrease his insulin to once-daily lantus.
- He was due for follow up colonoscopy for a history of polyps and he got a letter from the lung cancer screening program about a CT scan.
  - You recommend against further screening. Jorge and family agree.
- He would like to continue to follow up with his other specialists (Cardiology, Pulm, Derm, Nephrology, Ophtho).

Current state

Jorge's medications

- Aspirin
- Atorvastatin
- Metoprolol
- Metformin
- Insulin glargine ~~+ insulin lispro w meals~~
- Lisinopril
- Inhalers: LAMA, LABA, SABA
- Acetaminophen as needed
- Multivitamin and vitamin D

Jorge's specialists

- Cardiology
- Nephrology
- Pulmonology
- ~~Gastroenterology (hx of colon polyps)~~
- Dermatology (hx of squamous cell carcinoma, removed)
- Ophthalmology (hx of cataracts, removed)

Eight months later

- Jorge is hospitalized for a COPD flare and pneumonia. He develops delirium in the hospital requiring chemical restraint and a sitter. After 8 days in hospital, he is discharged to a SNF for three weeks, then returns home.
- At your follow up visit, Connie notes that Jorge now requires assistance with bathing and dressing, and is sometimes incontinent of urine. He is still ambulatory but his balance is impaired. He is more easily confused and does not always recognize his grandchildren. Taking him to doctor visits is much more challenging and he sometimes refuses his meds.
- As his function fails to improve over several weeks, you re-stage him as Moderate Stage dementia (FAST stage 6)

Priorities in Moderate Stage disease

- Review stage of disease and natural history with family (& patient, if able)
- Revisit POLST – would he still want hospitalization?
- Assess the burden vs the benefit of specialty care.
  - Consider recommending stopping specialist visits, especially for stable conditions (CAD, CKD)
  - “I can manage that for you”. “We can always send you back if something changes”
- Continue quest for medication simplification and consider deprescribing.

Got favorite words? Enter in the chat!

After discussion

- Connie is delighted to hear she can stop taking Jorge to see his specialists every three months, and that he probably doesn't need his scheduled echo, full body skin check, quarterly renal labs, and dilated eye exam.
- The family and Jorge prefer to avoid further hospitalizations, but they would like to continue to treat reversible conditions in the home setting. POLST is updated.
- Chronic medications are continued, although you decrease the dose of lisinopril, as Jorge's blood pressure has been running quite low.

Current state

Jorge's medications

- Aspirin
- Atorvastatin
- Metoprolol
- Metformin
- Insulin glargine ~~+ insulin lispro w meals~~
- Lisinopril (dose decrease)
- Inhalers: LAMA, LABA, SABA
- Acetaminophen as needed
- Multivitamin and vitamin D

Jorge's specialists

- ~~Cardiology~~
- ~~Nephrology~~
- ~~Pulmonology~~
- ~~Gastroenterology (hx of colon polyps)~~
- ~~Dermatology (hx of squamous cell carcinoma, removed)~~
- ~~Ophthalmology (hx of cataracts, removed)~~

One Year Later

- Jorge comes for follow up. He has been reasonably stable except for a UTI that was treated at home and a fall with no fractures. He recovered well each time.
- Jorge's dementia has progressed, and he is now in his recliner much of the day. He requires 24/7 care and assistance with all ADL's. He only speaks a few words and does not recognize his children. He has lost several pounds.
- Jorge often refuses his meds or will spit them out. Connie asks for suggestions.
- He is scheduled for routine blood draw today (A1C, CMP, lipids)
- You re-stage him today as Severe Dementia (FAST stage 7c)

Priorities in Late-Stage Dementia

- Review prognosis/natural history, and common clinical complications in late-stage disease
- Discuss a transition to comfort-focused care, which could include
  - No routine blood draws or tests
  - Deprescribing “preventive” meds like Aspirin, Statin, Anti-hypertensives
  - Avoiding antibiotics for future infections, focusing instead on comfort
  - Hospice referral when appropriate
- “I want to do everything possible to keep him comfortable.”

Got favorite words? Enter in the chat!

After discussion

- Connie chooses no further routine blood tests and no routine glucose fingersticks
- Medications stopped: statin, ASA, metoprolol, lisinopril, metformin, vitamins.
- Medications continued: once daily long-acting insulin; inhalers; acetaminophen
- Family wants to treat future infections with antibiotics in the home setting.
- Connie isn't sure about hospice, but she will think about it.
  - "Hospice is a benefit that Jorge is entitled to – I think he would qualify now."
  - "They can be very helpful in keeping him at home and comfortable."

Got favorite words? Enter in the chat!

Current state

Jorge's medications

- ~~Aspirin~~
- ~~Atorvastatin~~
- ~~Metoprolol~~
- ~~Metformin~~
- Insulin glargine ~~+ insulin lispro w meals~~
- ~~Lisinopril~~
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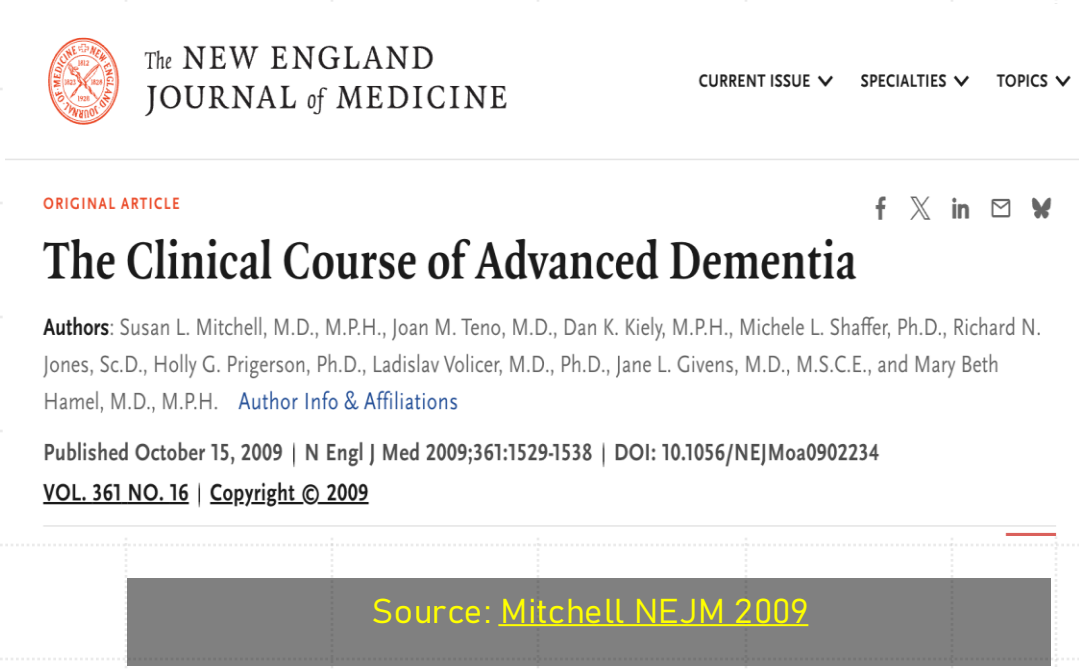
- ~~Gastroenterology (hx of colon polyps)~~
- ~~Dermatology (hx of squamous cell carcinoma, removed)~~
- ~~Ophthalmology (hx of cataracts, removed)~~

How Will We Know When the End is Near?

- 323 NH residents with advanced dementia in Boston area followed for 18 months.

Clinical conditions most predictive of mortality:

- Pneumonia
- Febrile episode
- "Eating problem"



The NEW ENGLAND JOURNAL of MEDICINE

CURRENT ISSUE SPECIALTIES TOPICS

ORIGINAL ARTICLE

The Clinical Course of Advanced Dementia

Authors: Susan L. Mitchell, M.D., M.P.H., Joan M. Teno, M.D., Dan K. Kiely, M.P.H., Michele L. Shaffer, Ph.D., Richard N. Jones, Sc.D., Holly G. Prigerson, Ph.D., Ladislav Volicer, M.D., Ph.D., Jane L. Givens, M.D., M.S.C.E., and Mary Beth Hamel, M.D., M.P.H. Author Info & Affiliations

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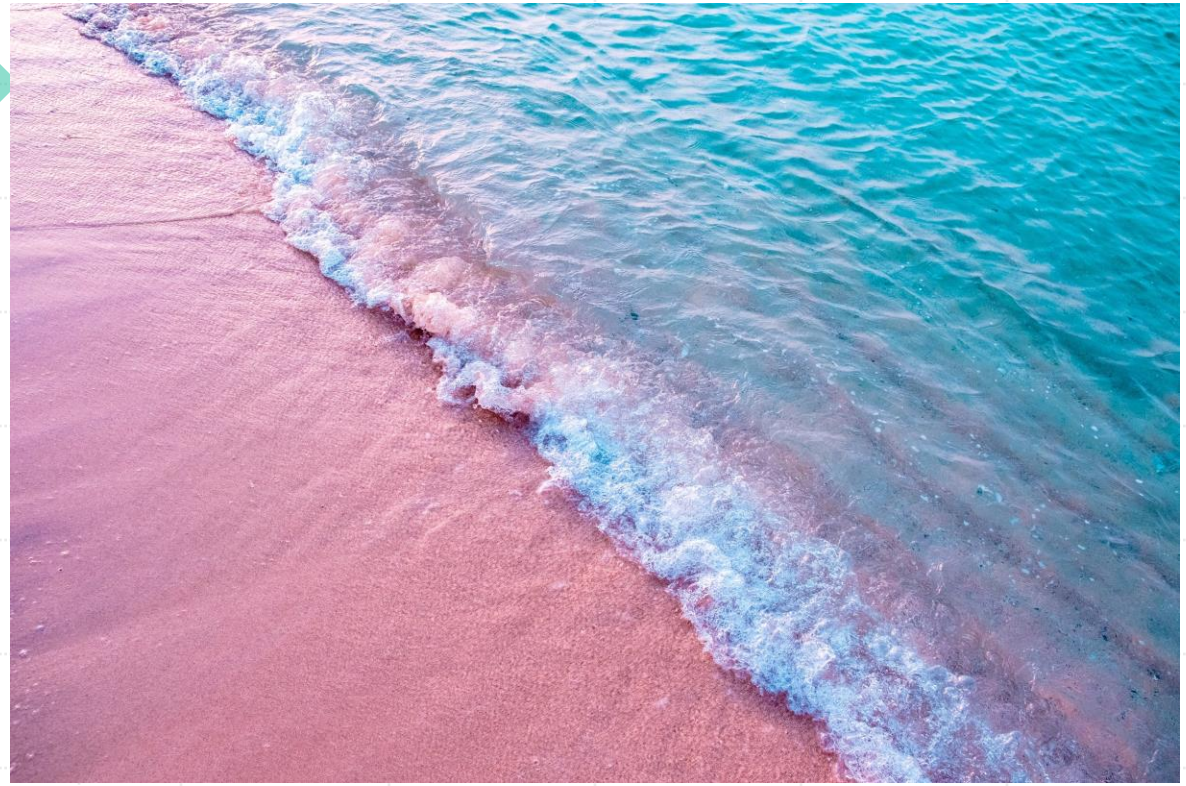
Source: Mitchell NEJM 2009

"…Inform families and care providers that infections and eating problems should be expected and that their occurrence often indicates that the end of life is near."



- 40% of residents who died underwent a “burdensome intervention” of limited clinical utility in their final days or weeks. (ED/hosp visits, IV fluids, tube feeds)

- “Those whose health care proxies believed the resident had less than 6 months to live and understood the clinical complications expected in advanced dementia were less likely to undergo a burdensome intervention during the final 3 months of life” (adjusted odds ratio, 0.12; 95% confidence interval, 0.04 to 0.37)

Managing Multicomplexity in Dementia

- Ensure patient and family understand the natural history and prognosis of dementia
- Understand patient's dementia stage and (approximate) life expectancy
- Explore patient/family goals and values.
- Balance benefits and burdens of ongoing care. Grant permission to pull back.
- Revisit regularly over time.


See the Forest:
A Primary Care Superpower