Let's Not Forget: Building Rapport with Patients and Caregivers Suffering with Dementia

BRIAN K. UNWIN MD, FAAFP, AGSF, CMD

SECTION CHIEF, GERIATRICS AND PALLIATIVE MEDICINE
MEDICAL DIRECTOR, CARILION HOME HEALTH AND HOSPICE

VTC

Virginia Tech Carilion
School of Medicine

Disclosures: None

Learning Objectives:

- Discuss the identification, recognition, and treatment of patients with dementia
- Recognize the different levels of capacity and competency of patients with dementia
- Identify ways to engage with patients with dementia and their families
- Discuss strategies to support the preservation of dignity for patients with dementia

In short:

Apply disease-state management principles to assist the patient and their supporters on a *routine and systematic basis* by addressing COGNITION, MOOD, PATIENT BEHAVIORS, And FUNCTION

Definition of Geriatrics:
Medical and Social Care of Older Adults

Mentors: William R. Hazard, MD and Sharon Falzgraf MD

Goal of Geriatric Medicine:
Best Possible Safe Function in Least Restrictive Environment

Brian K. Unwin MD

What older adults want = Aging In Place

Housing Planning

Health and Wellness

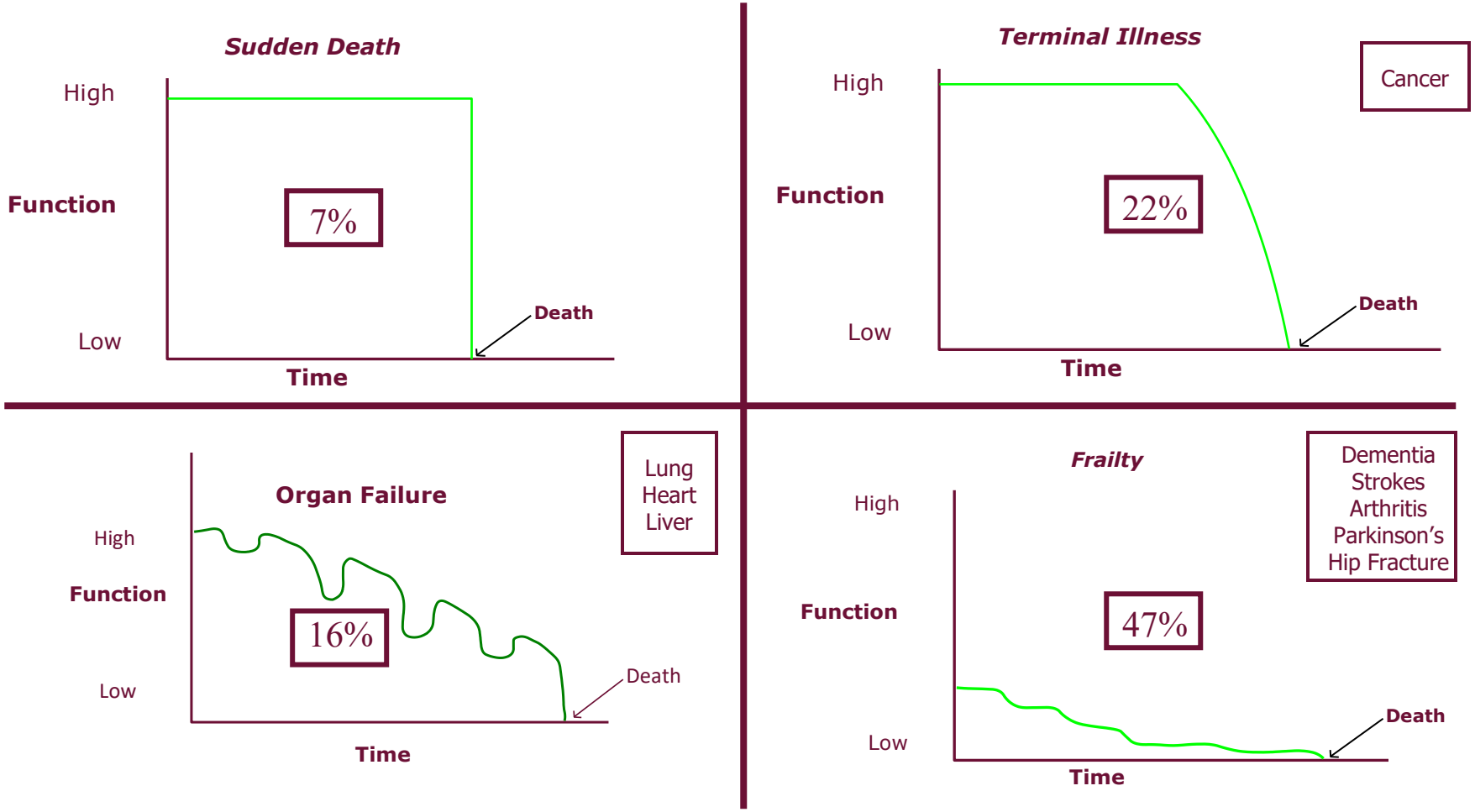
Personal Finance

Transportation

Social Engagement

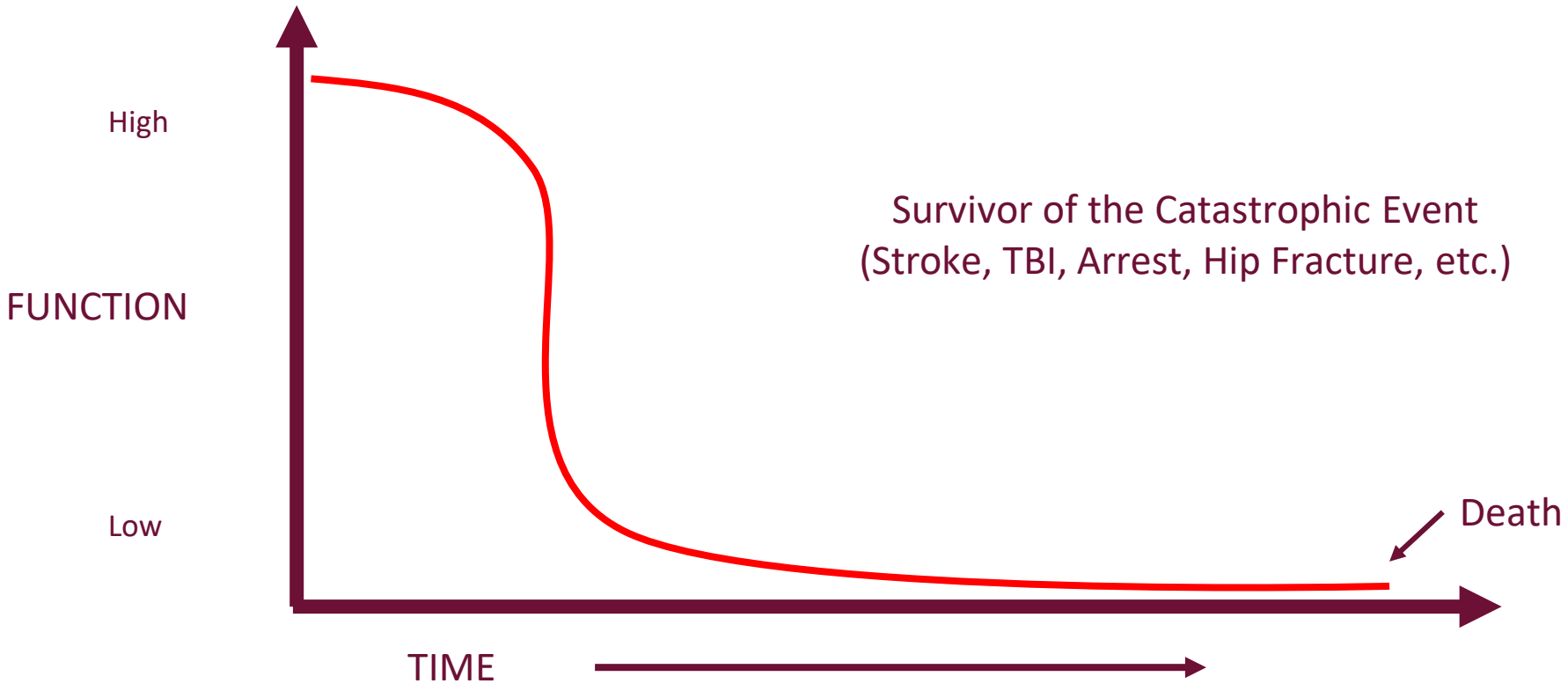
National Aging in Place
NAIPC
Council ®

End of Life Trajectories



Lunney, JR, Lynn J, Hogan, C. Profiles of Older Medicare Decedents. JAGS 50:1108-1112, 2002

"THE FIFTH TRAJECTORY"



The California State University: Shiley Institute for Palliative Care

Geriatric Medicine in a Nutshell:

Promote Strengths to Increase Function

Geriatrics

Normal

"Function"

Poor

Palliative Care

Frail

Promote Six Strengths:

Physical

Organ

Cognitive

Emotional

Social

Spiritual: Meaning in Life

"Strength"

Low

High

Established Populations for Epidemiologic Studies of the Elderly (EPESE) . J Gerontology, 1994;49(3):M109-15

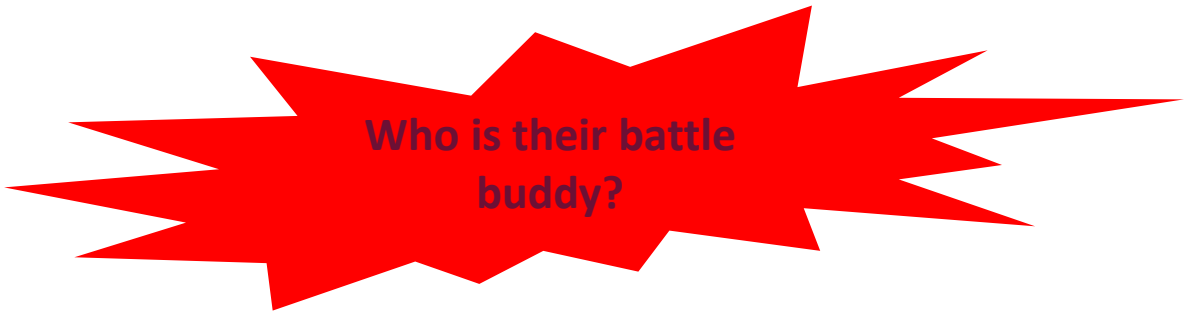
Population Health Problem #1:

JAMA Int Med 2015; 175(7): 1180

AARP Public Policy Institute

“Elder Orphans” or “Solo Seniors”

- Roughly 18% of men and women 50+ never had biologic children
- In 2018; 35% of those 25-50 had never married.



The Homebound:

- Those who never or rarely leave home in past month
- Semi-homebound = need assistance or have difficulty
- About 5.6% of community dwelling Medicare population (2M Americans)
- **11.9% of completely homebound patients got primary care**

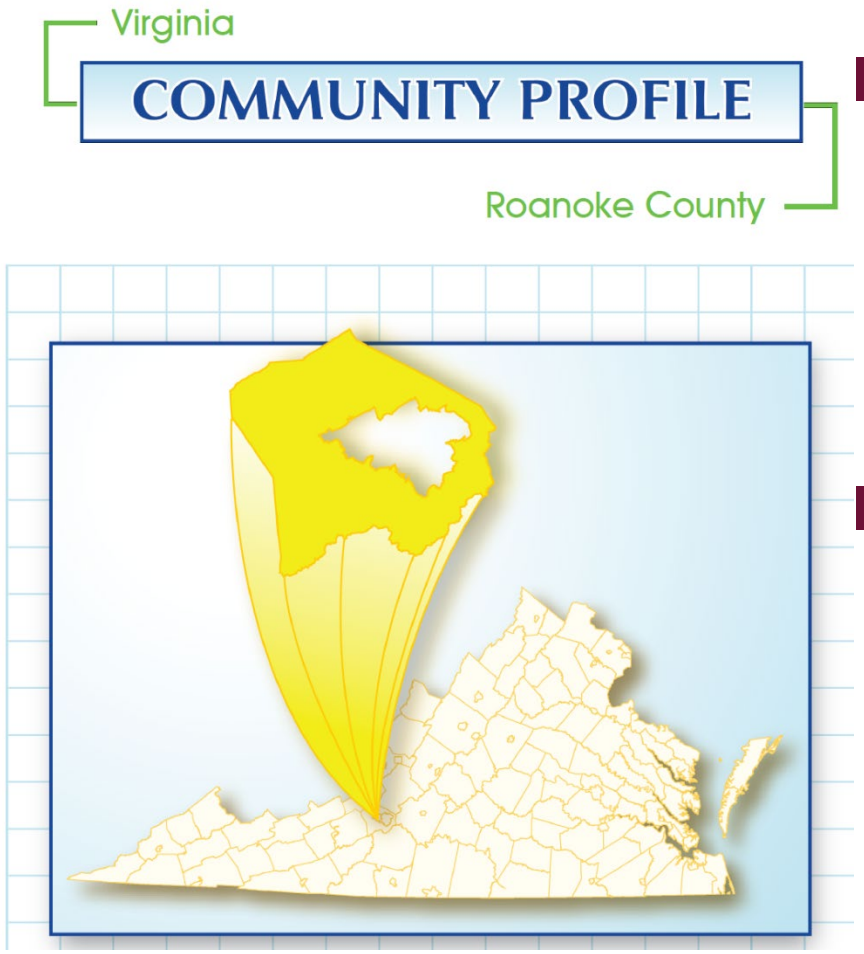
Public Health Problem #2: Neurodegeneration is Common

1:2 women and 1:3 men will develop dementia, stroke, or parkinsonism in their lifetime

Licher S, et al. *J Neurol Neurosurg Psych.* 2019;90:2:148-56

Image Credit:
https://www.epigenomicslab.com/neurodegeneration-and-dementia/

Population Changes (Locally)



- Roanoke City
  - 13,836 (14%) age 65+ (2010)
  - 20,255 (20%) age 65+ (2040)
  - Over 2800 over the age 85
- Roanoke County
  - 15,912 (17%) age 65+ (2010)
  - 27,437 (25%) age 65+ (2040)
  - Approx 5000 over the age 85

~9500 citizens with dementia

NOT ENOUGH SPECIALISTS TO DO THIS ALONE

Geriatrics Workforce Data (Bragg E, et al. *J American Society on Aging*. 2010-2011;34:4:11-9)

- 2010: 3.6 geriatricians per 10,000 (age 75+)
- 2040: 1.7 geriatricians per 10,000 (Age 75+)

Neurology Workforce Data (beta.aan.com/globals/axon/assets/9008.pdf)

- 2010: mean wait for a new patient = 28 days
- vs. cardiology (15), ortho (16) and FP (20)

Geriatric Psychiatry Workforce Data

- 2010: 0.9 geriatric psychiatrists/10,000 (age 75+)
- 2040: 0.4 geriatric psychiatrists/10,000 (age 75+)

Identification, Recognition and Treatment of People with Dementia

The Spectrum of Cognitive Impairment

Normal Aging	Mild Cognitive Impairment	Dementia
Occasional bad decisions	Cognitive change/concern	Interferes with usual activities
Forgetting an event	**Evidence of deficit by cognitive testing**	**Decline from prior levels of function**
Forgetting the day	**Preserved independence in functional abilities**	Not due to delirium or major psychiatric disorder
Occ. word finding problem	Not demented	History from patient **AND** informant **AND** objective assessment
Losing something, able to re-trace	R/O other phenomenon	Two or more domains of cognitive or behavior

Albert, et al. *Alz and Dementia* 7(2011) 270-279 and McKhann, et al. Alz and Dementia 7(2011) 263-269

Differential Diagnosis of Dementias

Alzheimer's Disease	Vascular Dementia	Dementia with Lewy Bodies	Frontaltemporal Lobe Dementia
Sort term memory loss, slowly progressive, impaired executive function, behavioral changes, disorientation	Impaired short-term memory, executive dysfunction, associated with CVA, slower decline, verbal memory preserved, impaired reasoning	Hallucinations, parkinsonism, cognitive fluctuation, impaired executive function, memory relatively spared, psychosis and personality changes, REM sleep changes	Progressive personality and behavioral changes that impair social skills, language impairment, memory may be relatively spared

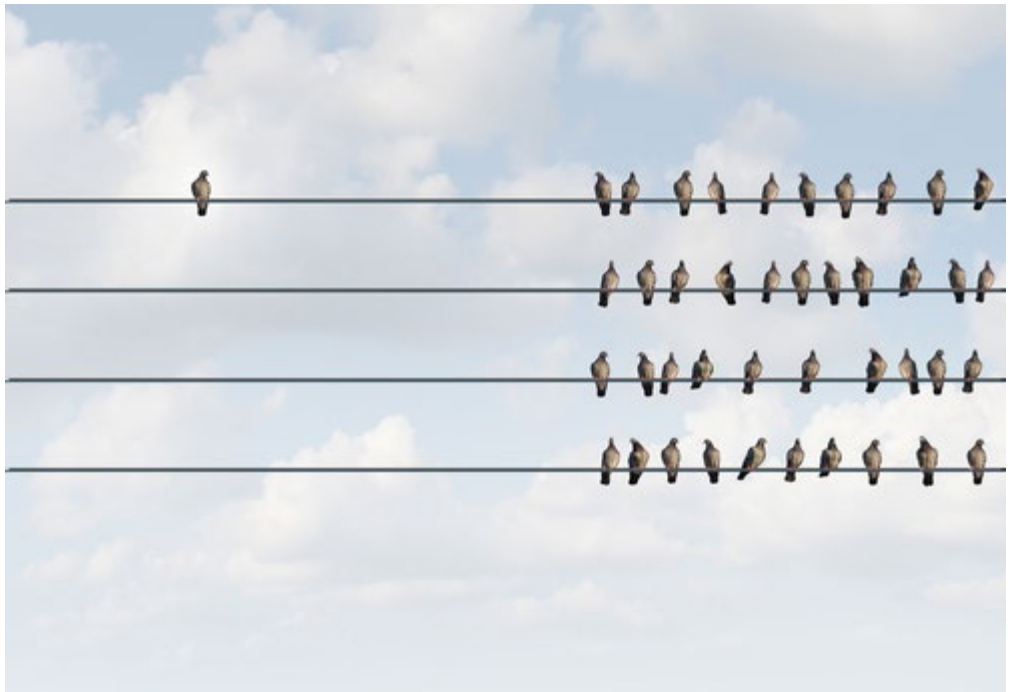
Defining “Severity” or “Stage” alz.org

Mild	Moderate	Severe
Word finding	Longest stage	Can’t respond to environment
Work or social challenges	Remembers remote life	ADLs impaired
Forgetting new material	Loss of IADLs	Difficulty communicating
Losing valuable objects	Behavior changes	Loss of mobility
Trouble planning/organizing	Disorientation	Aspiration, infections, skin failure
	Changes in sleep	

Worried >>>>>>>>>>> Working (longest) >>>>>> Waiting (shortest)

“Treatment” of Dementia is Different

1. Typically, no definitive test
2. “Clinical Diagnosis”
3. No shot, pill, or surgery to cure
4. Treatment is **caring**
5. Caring is HARD
6. FEAR and FRAILTY become drivers



Dementia Quality Measures Group (2017)

American Psychiatric Assoc., American Academy of Clinical Neuropsychology, AAPMR, Humana, VA, GSA, APTA, others

Dementia Quality of Care Measures (2017)

1. Disclosure of dementia diagnosis
2. Caregiver education and support
3. Functional status assessment
4. Screening and treatment of behavioral and psychiatric symptoms
5. Safety concerns-screening and follow-up
6. Advanced Care planning and palliative care counseling
7. Pain assessment and follow-up
8. “Treatment” of dementia (Aricept, etc.)

Am J Psych 174:5, May 2017

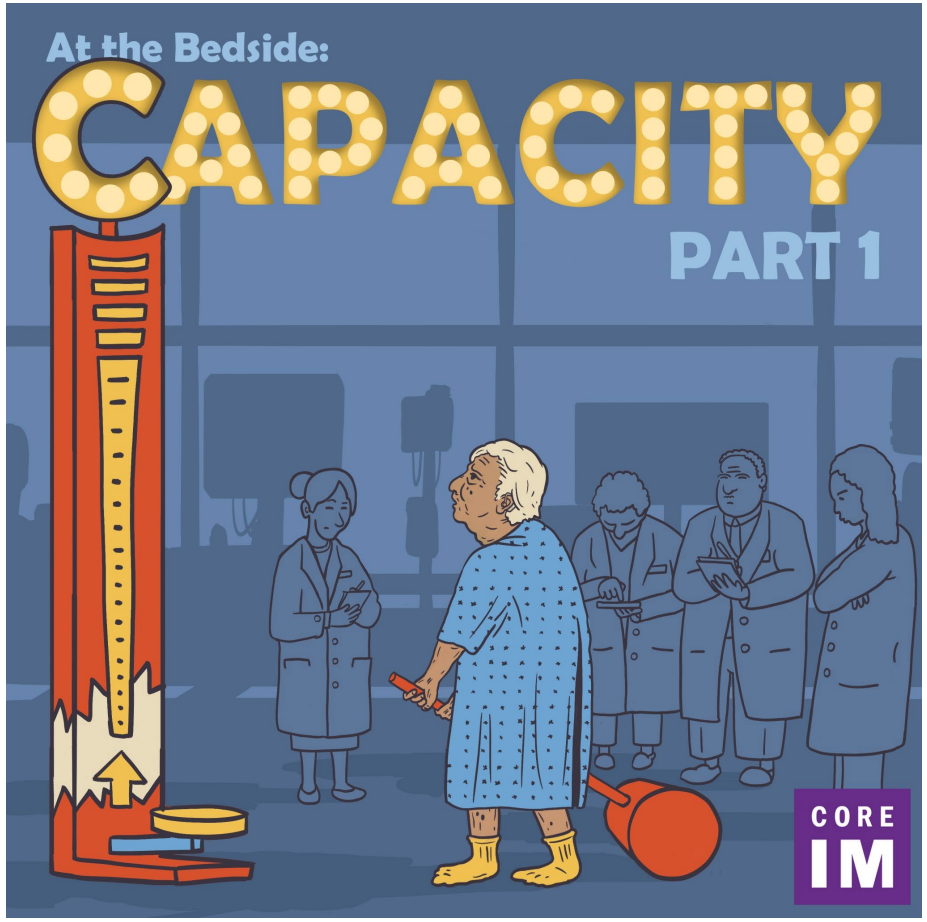
Recognize different levels of capacity and competency of patients with dementia

Virginia Law

We're supposed to notify the patient and their agent if we feel the patient lacks capacity and in writing

Impaired Capacity

Image: coreimpodcast.com (Capacity, Part 1)



With dementia, cognition is “taken away” from the patient…
…who now does “the thinking” ?

Who is going to lift this ‘hammer’ (who is going to act on the patient’s behalf)**?**

Standing around doesn’t help…

Usually, this is not formally addressed…the son/daughter/spouse starts showing up at clinic visits or “taking care of things…”

This *informal arrangement* often isn’t good enough in a crisis or when someone needs to take charge

Transfer of Decision Making…

1. Ultimately can be HELPFUL!
2. Peace of Mind to Patient and Caregiver
3. Empowered to make a decision in a crisis
4. Utilization of resources to support care
5. Most common form of maltreatment is SELF-NEGLECT
6. One-in-ten older adults experiences maltreatment
7. Help the patient and caregiver see the need for transfer…
8. And yes, exploitation happens

Types of Capacity

1. **Medical decisional capacity**
2. **Executive (Legal and Financial)**
3. Manage property
4. Live alone without assistance
5. Naming surrogates
6. Driving
7. **Stipulating Advanced Directives**
8. Firearms
9. Voting

CAPACITY ASSESSMENT TOOL

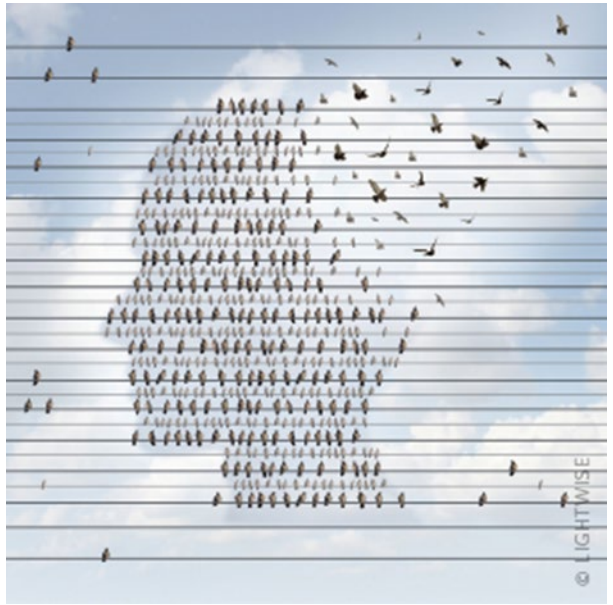
- Communication
  - Can the patient communicate
  - Can the patient maintain a choice for it to be implemented
- Understanding
  - Can patient understand and retain new information
  - Can patient 'teach back' that information
  - Parroting ≠ Understanding
- Appreciation
  - Patient recognize the problem and decision at hand
  - Appreciate consequences of decision
    - "Tell me what you believe about your medical condition(s)"
    - "Why do you think this ___ is important for you?"
    - "What will happen if you do/What will happen if you don't _____"
- Reasoning
  - Can patient rationally manipulate information?
  - Does reasoning reflect core beliefs and values?
  - How did they come to this conclusion?

Evaluating Medical Decision-Making Capacity in Practice

Craig Barstow, MD; Brian Shahan, MD; and Melissa Roberts, MD
Womack Army Medical Center, Fort Bragg, North Carolina

Am Fam Physic. 2018; 98(1):40-46

- Aid to Capacity Evaluation
  - https://www.aafp.org/afp/2001/0715/afp20010715p299-f2.pdf



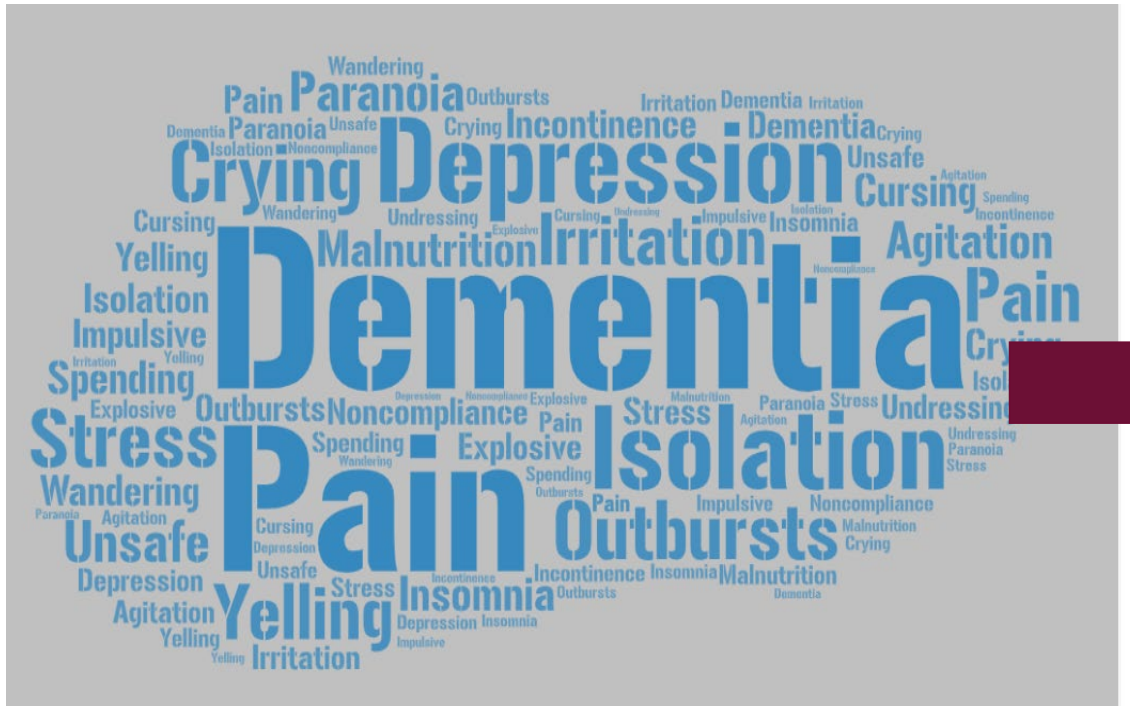
Is the patient aware that they are being:

Neglected?
Exploited?
Abused?

Joint Centre for Bioethics—Aid to Capacity Evaluation (ACE)
www.jcb.utoronto.ca/tools/ace.shtml

Identify ways to engage with persons with dementia and their families

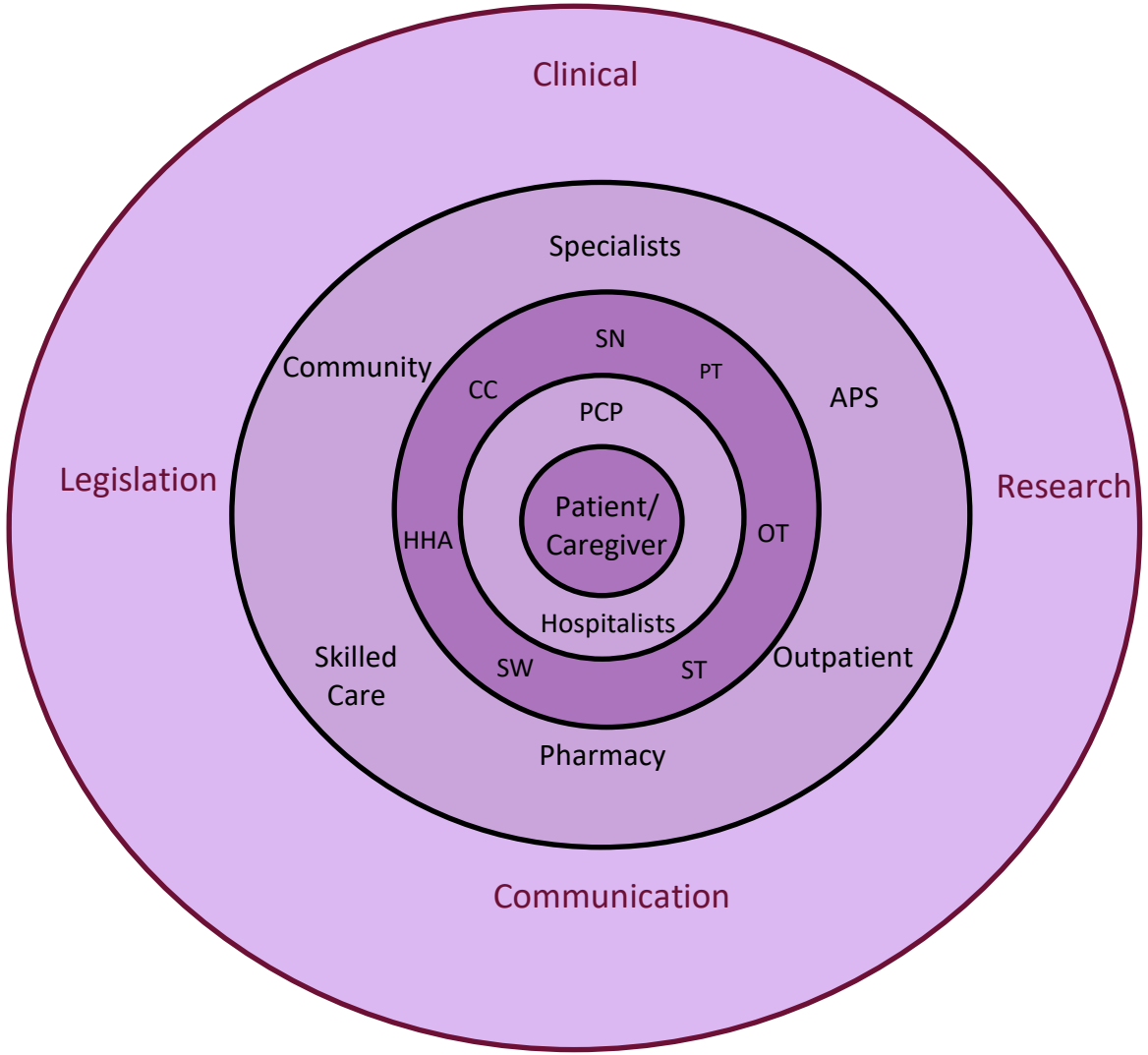
Engagement



Slide Credit: Carilion Home Health Dementia Care Services

Carilion Home Health Cognitive Care Program – Making the Most of a Difficult Diagnosis *

- Improves patient care/communication through a vast organizational and community interdisciplinary network and reporting system
- Improves patient's "best ability to function"
- Enhances caregiver understanding of communication techniques and behavioral triggers/strategies
- Decreases caregiver stress and burnout
- Not a 'permanent' service
- Not 24/7, no non-skilled services

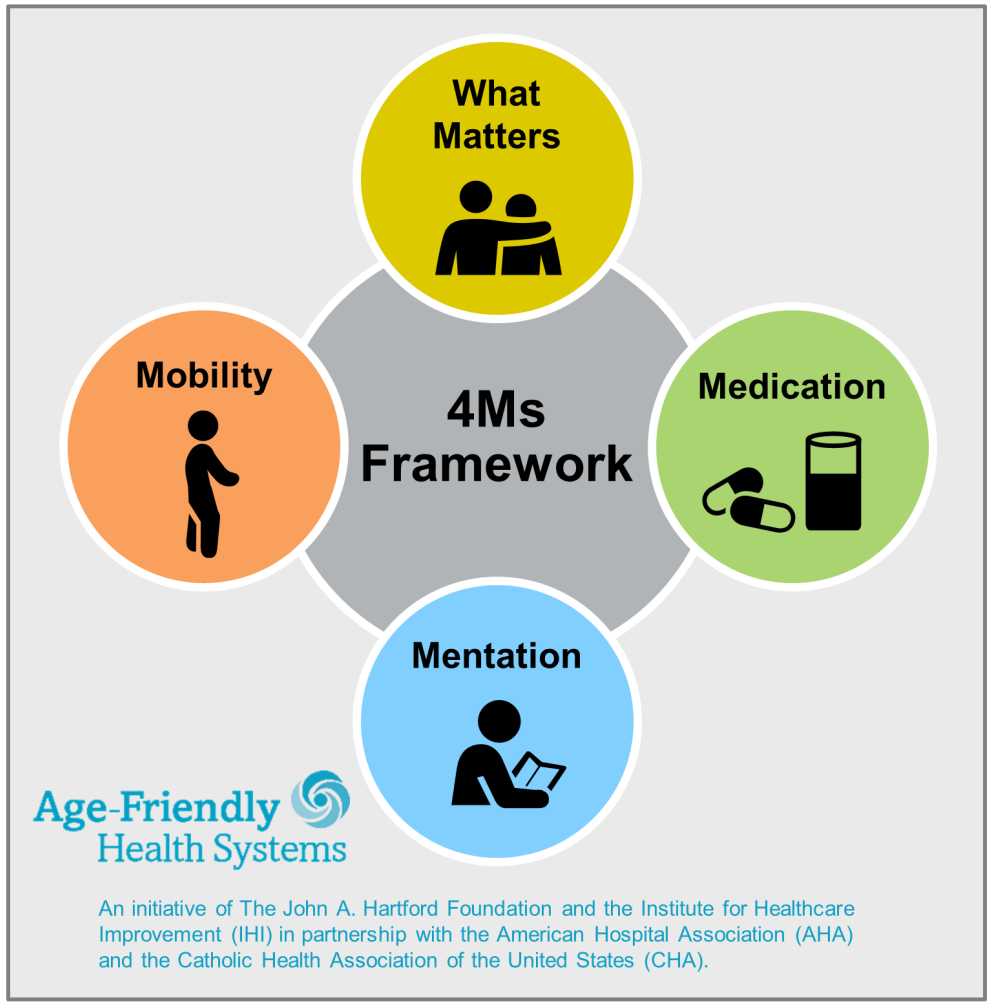


*To date, this program has served over 4,000 patients in our community with a dementia diagnosis.

Slide Credit: Carilion Home Health Dementia Care Services

Institute for Healthcare Improvement

Age Friendly Health Systems



What Matters

Know and align care with each older adult's specific health outcome goals and care preferences including, but not limited to, end-of-life care, and across settings of care.

Medication

If medication is necessary, use Age-Friendly medication that does not interfere with What Matters to the older adult, Mobility, or Mentation across settings of care.

Mentation

Prevent, identify, treat, and manage dementia, depression, and delirium across settings of care.

Mobility

Ensure that older adults move safely every day in order to maintain function and do What Matters.

Functional Assessment: Can you communicate with your patient?

Pocket Talker: $99-$169 at your favorite retailer

Disposable ear buds in your bag or desk drawer

Do a sound check:
"Can you hear me okay? Too loud? Too Soft?"
Lower timber
Ideally, allow lip reading
Slower speech (but don't infantilize)

Are you yelling at your patient?
Improve with amplification?
Have patient read a prescription bottle to you, or hand-held vision card

ENGAGEMENT

Patient	Caregiver
Cognition: Testing	**Cognition:** "Homework," support group, understanding, literacy
Mood: GDS	**Mood:** GDS, others
Behaviors: Apathy	**Behaviors:** Adaptive vs. Maladaptive, self care
Function • ADLs: bathing, toileting, transfer, continence, feeding, dressing • IADLs: phone, meds, telephone, appointments, driving, appointment, meal prep, shopping, driving • AADLs: hobbies, driving, etc.	**Function:** • Zarit Caregiving Burden (4, 12, 22 item) : time demands, role stress, uncertainty, strain themes • Physical health • Respite care, coaching • Who's on the team?
Co-morbidities: • May get BETTER with identification of the dementia! • Worsening due to compliance/refusal • May become less important over time	**Co-Morbidities:** • What is their health • Who is the caregiver's new POA? • What is the caregiver's AD? • What are their limits?
	What's "Plan B"? Goals of Care?

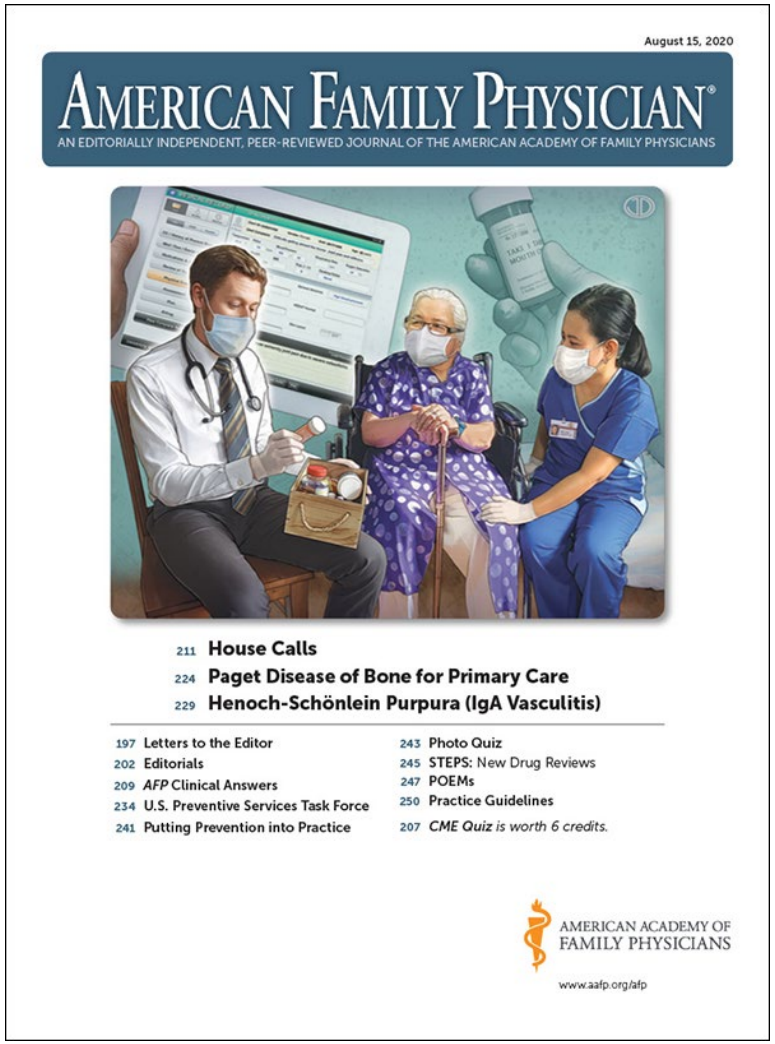
ENGAGEMENT

Caregiver Education and Support

- Social Work Referral
- Alzheimer's Association (www.alz.org, 1-800-272-3900)
- Frontal Temporal Dementia: www.theaftd.org
- Lewy Body Dementia: www.lbda.org
- www.Caregiver.com
- **Carilion Home Health Dementia Service Team**
- Area Agency on Aging: https://loaa.org
- Dementia Care Plan: Tools for Better Dementia Care (aafp.org)
- www.eldercare.gov or Eldercare Locator (1-800-677-1116)

Strategies to support the preservation of dignity for people with dementia

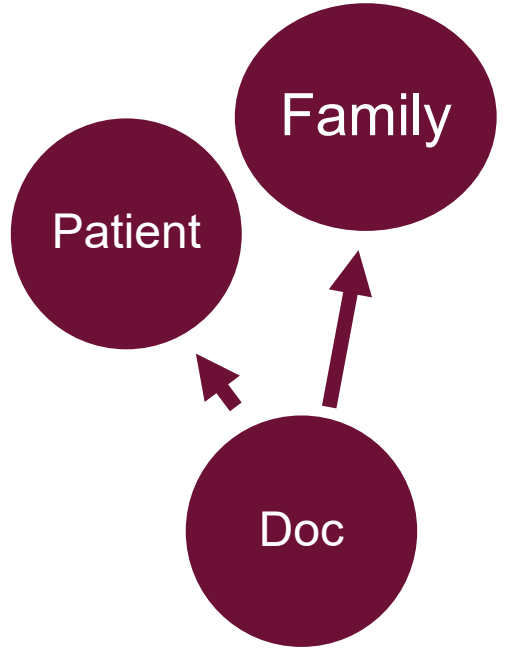
- Get on their good side (vision and hearing)
- **INALHOMESSS**
- Impairments
- Nutrition (coupled with dysphagia)
- Advanced Directives
- Health Literacy- can they navigate the maze of care?
- Home
- OTHERS
- Medications and **who is managing the meds???**
- Examination (especially mood, mobility, and mentation)
- Safety (especially medications and falls)
- Spirituality– what keeps them going???
- Services—Who/what comes into the home?



- **What are their STRENGTHS?** **Ask yourself, ask the patient, and ask the family….**
  - Emotional
  - Spiritual/Meaning in Life
  - “Organ Health”
  - Cognitive
  - Physical
  - Social
- **Use Strengths to Overcome weaknesses**

Practicalities

- Pick your seat…
- Let the patient speak
- Seek patient's understanding of situation
- "Just my knee problem…" (no mention of CHF, COPD, cancer and CKD…)
- Seek caregiver's understanding of situation
- "Kidney problems, what kidney problems?"
- Don't rush it…
- Last appointment of the session
- Brown bag med reconciliation….



Things to say and questions to ask…

- “I’m not judging you…”
- “May your (son/daughter/spouse) sit with us today?”
- “May I ask ___ questions also?”
- Ask the patient and caregiver if they think cognitive functional problems are going in… “Is this normal aging, or something else?”
- If on ‘the dementia page’ together: “What goal can I help you with?” “What’s most important for this visit?”
- Goal: help people see and understand the problems

Things to say and questions to ask…

- “Did you care for your parent(s) in late life?” “Tell me about that…” and point out that family is tying to do the same.
- Paint a clear picture of what is causing the troubles and what can be done…

Sleep

Normal Aging

Depression

Vitamin B12 and Folate

Medications

Medical Problems

Alcohol and Drugs

Memory
Concentration
Reasoning
Personality
Behavior

Vision and Hearing

Large Strokes

_____

Brain Injury

Small Strokes

Alzheimer's Disease

Thyroid

Rare things

Side 1

Normal Aging vs. Dementia

- Normal Aging
  - Forgetful
  - Preserved function
  - Normal behavior and mood/personality
  - Can adapt/learn
- Mild Cognitive Impairment
  - Normal Function
  - Abnormal Testing
  - “Worried”
- Dementia
  - Memory impaired
  - Loss of function
  - Changes in mood/personality
  - Difficulty learning new things

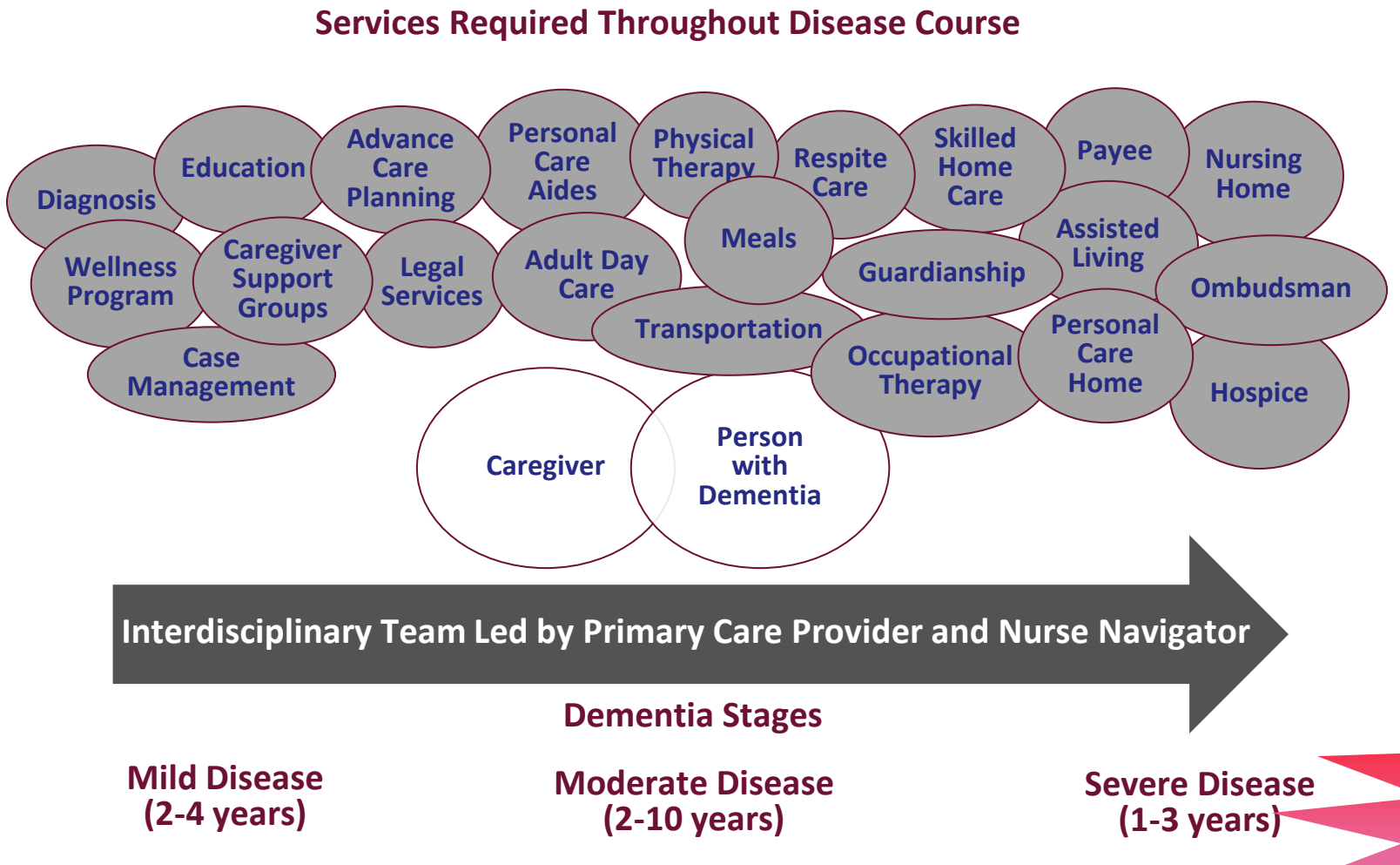
- Types of Dementia
  - Alzheimer’s
    - Brain degeneration
  - Vascular
    - Injuries from stroke
  - Frontal-Temporal Dementia
    - Front part of the brain shrinks
  - Lewy Body Dementia
    - Movement disorder, hallucinations, sleep disorder, cognitive problems
  - “Mixed”
  - Rare

Neurodegeneration is Common:

- One out of two women
- One out of three men
- From Alzheimer’s, Stroke or Parkinsonism

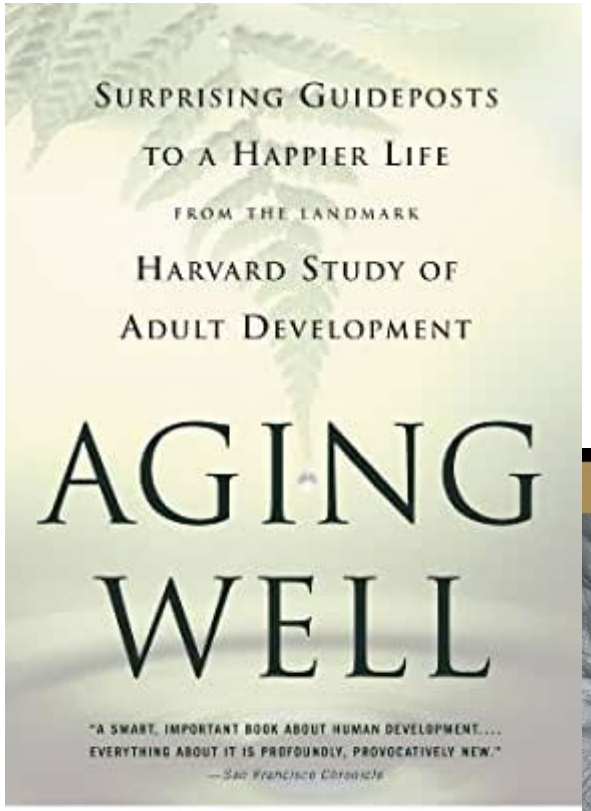
Side 2

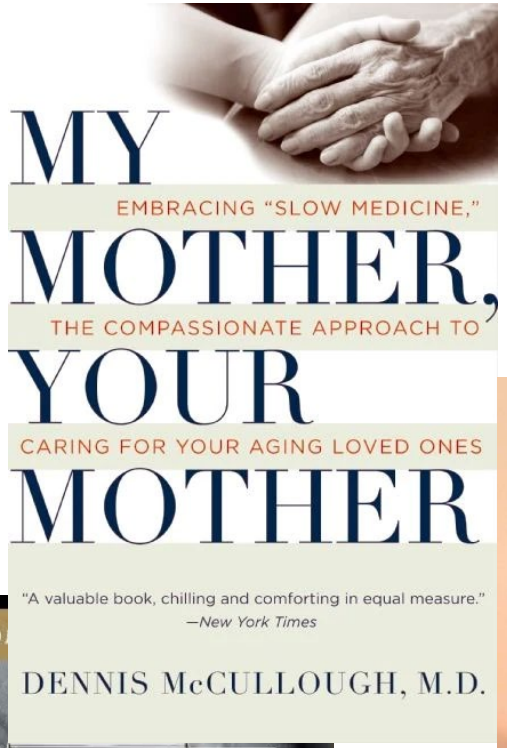
Preservation of Dignity:
Consultation, Co-Management, Collaborate, Community Care

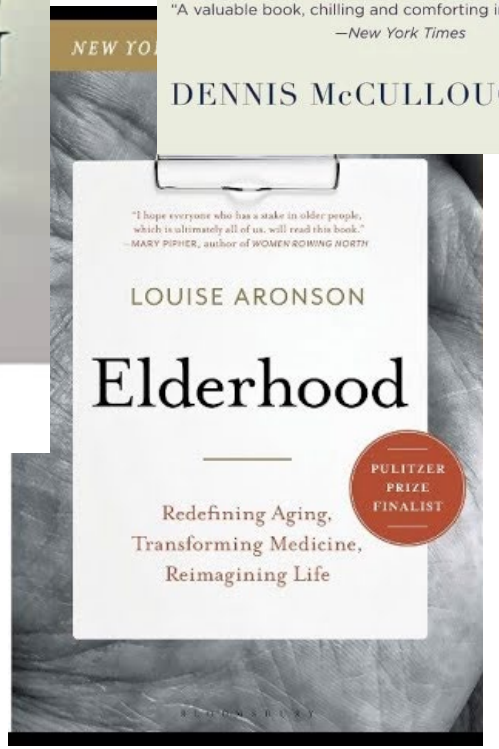


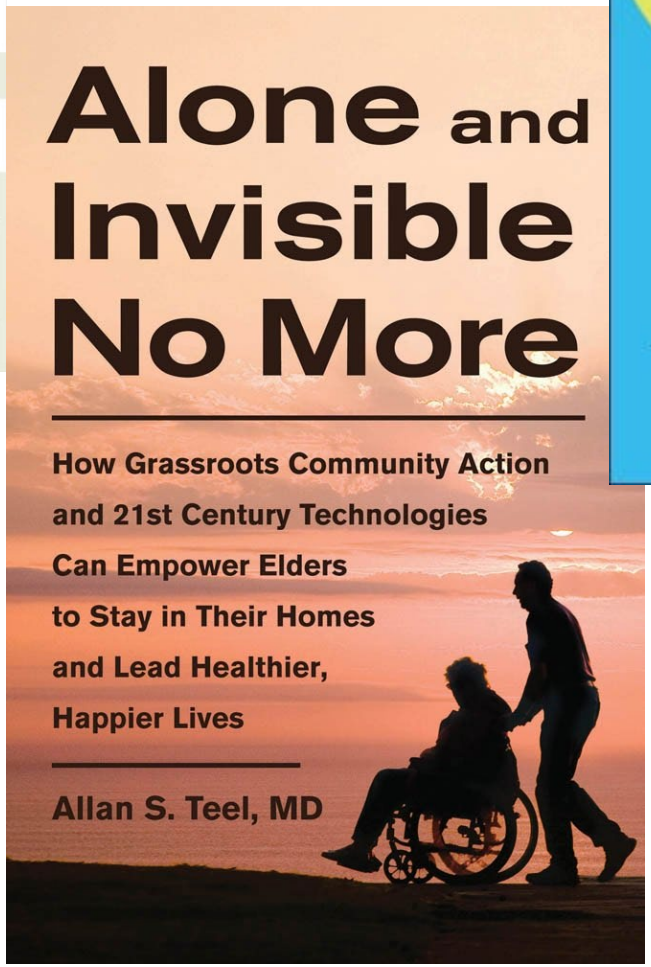
- Team-based, multicomponent interventions to improve patient- and family-centered care
- Collaborative care can lead to improved patient- and family-centered outcomes

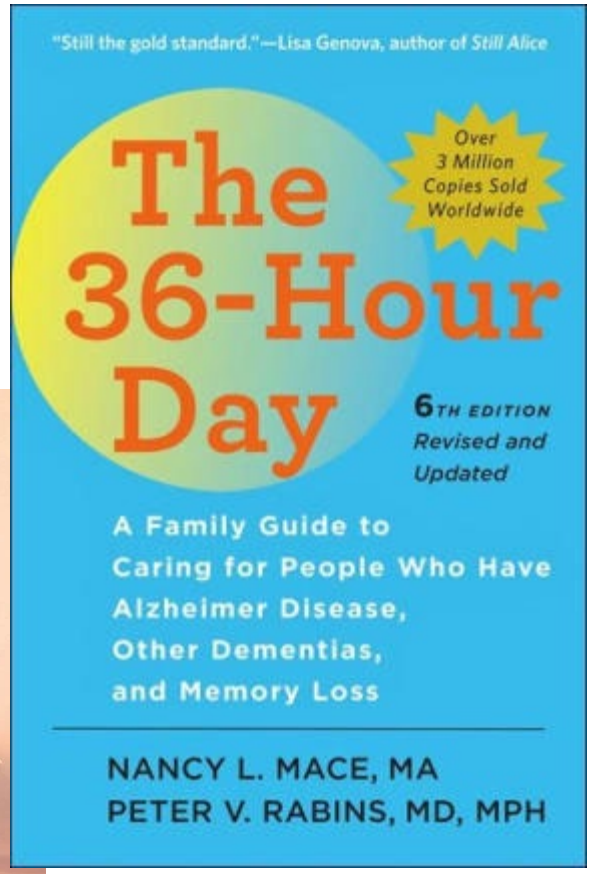
Join us for Part 2 in October!


Surprising Guideposts to a Happier Life
from the landmark
Harvard Study of Adult Development
AGING WELL
"A smart, important book about human development.... Everything about it is profoundly, provocatively new."
—San Francisco Chronicle
George E. Vaillant, M.D.


MY MOTHER, YOUR MOTHER
Embracing "Slow Medicine," the Compassionate Approach to Caring for Your Aging Loved Ones
"A valuable book, chilling and comforting in equal measure."
—New York Times
Dennis McCullough, M.D.


"I hope everyone who has a stake in older people, which is ultimately all of us, will read this book."
—Mary Pipher, author of Women Rowing North
Louise Aronson
Elderhood
Redefining Aging, Transforming Medicine, Reimagining Life
Pulitzer Prize Finalist


Alone and Invisible No More
How Grassroots Community Action and 21st Century Technologies Can Empower Elders to Stay in Their Homes and Lead Healthier, Happier Lives
Allan S. Teel, MD


"Still the gold standard."—Lisa Genova, author of Still Alice
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The 36-Hour Day
6th Edition Revised and Updated
A Family Guide to Caring for People Who Have Alzheimer Disease, Other Dementias, and Memory Loss
Nancy L. Mace, MA
Peter V. Rabins, MD, MPH

Thanks for Listening!