

The Role of POLST in the Care of People with Dementia

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Objectives

- ❑ Describe the process for discussing advance care plans and POLST when caring for persons with advanced dementia
- ❑ Describe possible approaches to discussing specific medical treatment choices to be considered by persons with early dementia

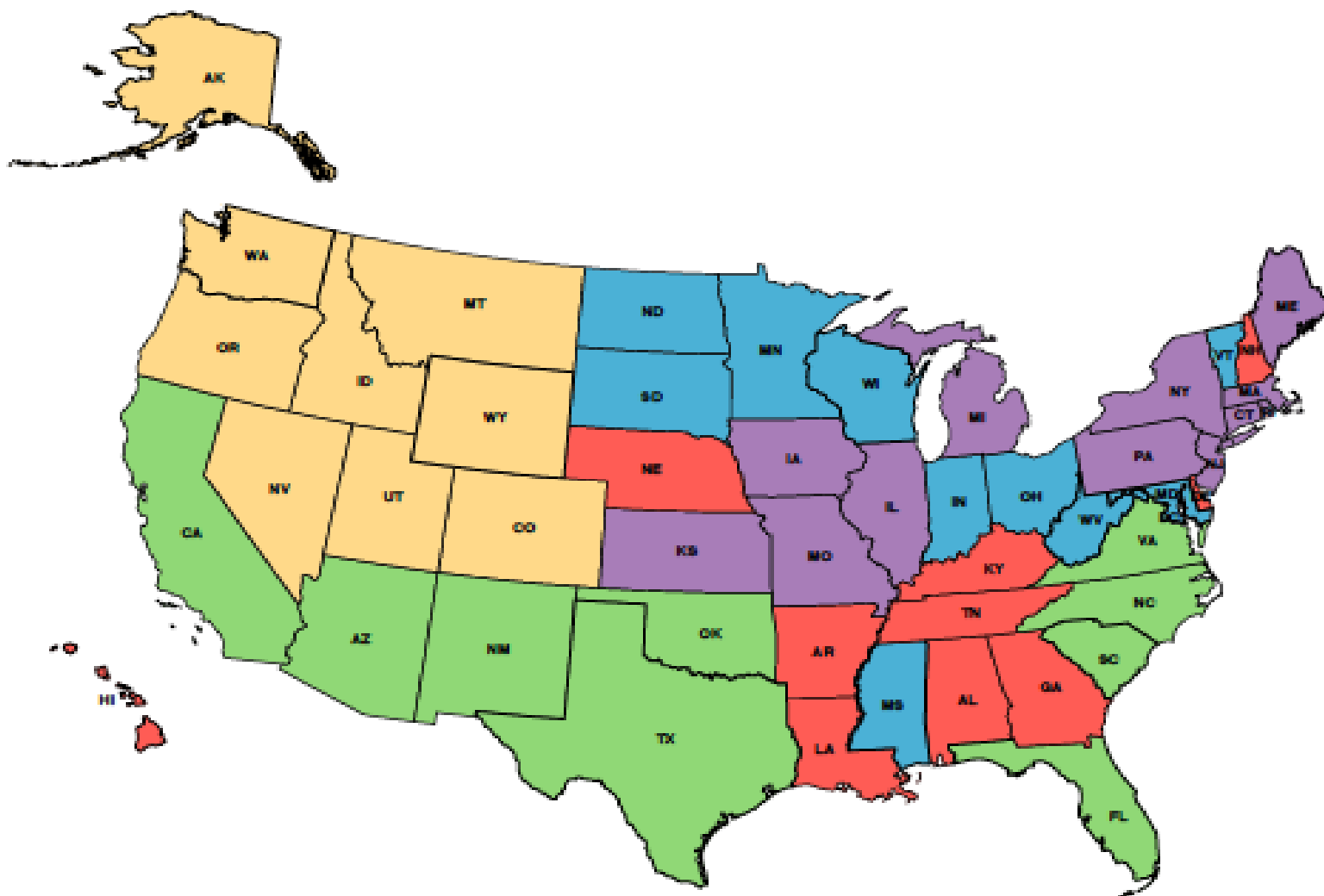
Dementia – The Disease of the Century

- Over 5 million people >65 and 200,000 people < 65 have dementia
 - 11% of those over 65
 - 30% of those over 85
- 2/3 of those with Alzheimer's (AD) are women
- As many as 1/2 of those have not been diagnosed

FIGURE 3

PROJECTED CHANGES BETWEEN 2000 AND 2025 IN ALZHEIMER'S PREVALENCE BY STATE

0 – 24.0% 24.1% – 31.0% 31.1% – 49.0% 49.1% – 81.0% 81.1% – 127.0%



Deaths from Dementia

- Sixth leading cause of death
- Est. 450,000 deaths per year
- Underreported due to death certificates saying “pneumonia,” “cardiopulmonary arrest,” etc.
- May be a long period from diagnosis to death (variable)
 - Functional assessment staging



Fear of Death and Disability

- National Alzheimer's Plan
 - Released in 2010
- No mention of deaths due to dementia or improving end-of-life care
- Almost no mention of long term care services and supports
- Improved after recent Senate Aging Committee hearing on Alzheimer's

Loss of Function in Alzheimer's



Alzheimer Progression

- Finances
- Transportation
- Cooking
- Chores
- Hygiene
- Coordinate Clothes
- Dress
- Toilet
- Feed Self
- Talk
- Walk



Normal Development

Functional Assessment Staging

Stage	Stage
1 No difficulties	6d Urinary incontinence
2 Forgets objects, subjective work problems	6e Fecal incontinence
3 Others notice problems, difficulty traveling	7a Speaks about 6 words
4 Problems planning dinner, finances	7b Single words
5 Assist with clothes for season	7c Nonambulatory
6a Difficulty dressing	7d Unable to sit independently
6b Difficulty bathing	7e Unable to smile
6c Difficulty toileting	7f Unable to hold up head

Dementia Staging in Chronic Care

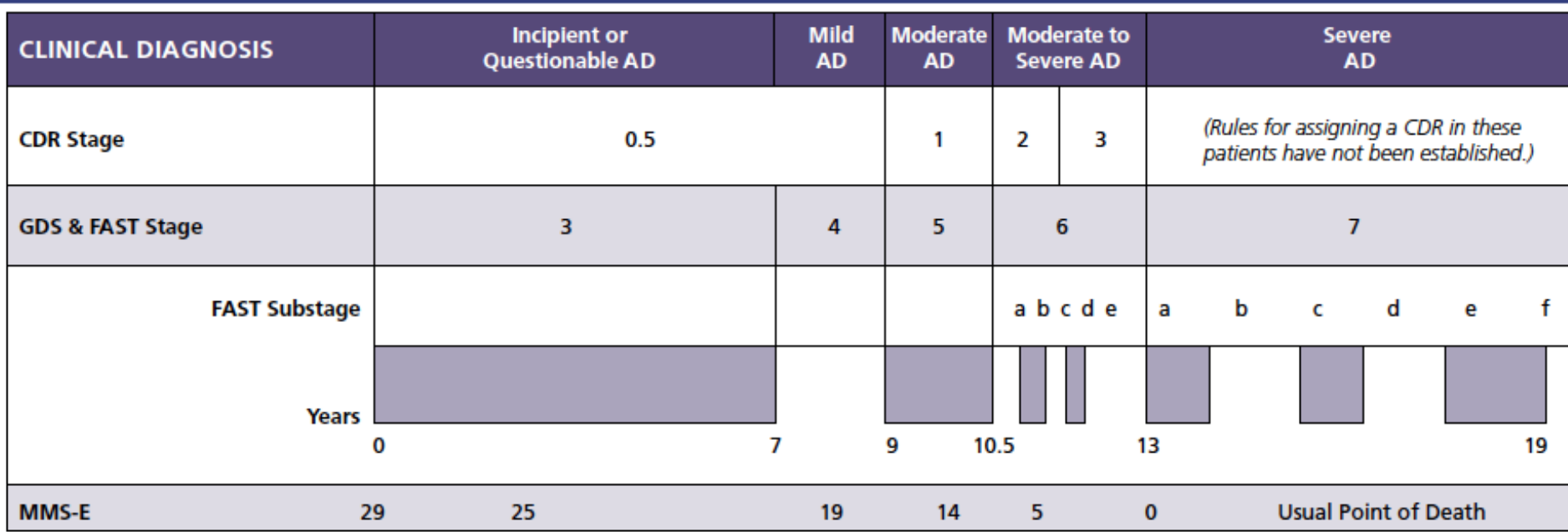


Fig. 1. Typical Time Course of Alzheimer's Disease (AD) *Prog Clin Biol Res* 1989;317:23-41.

Eric Larson – looked at the Group Health population – found that the median survival time from diagnosis was 4.2 years for men and 5.7 years for women.
Ann Intern Med 2004;140:501-509

Definitions – MMSE & MOCA

- Normal – 27-30 (varies with age and education)
- Mild cognitive impairment – 23-26
- Early AD - 17-22
- Moderate AD – 10-16
- Severe AD – 0-9

Advance Care Planning – Stage 6

- Talk with the patient
 - Have the surrogate (proxy) there
 - Try to discern:
 - If the patient understands her situation
 - What is most important to her now
 - If the patient understands her choices
 - Discussion of trade-offs and goals of care
 - Use “compassionate honesty”
- Create or update the POLST form

No Advance Directives?

- What do older people want if they have dementia (cannot care for self or communicate)?
 - 96% do not want CPR
 - 95% do not want ventilator
 - 96% do not want artificial nutrition
 - 67% do not want hospitalization
 - 75% do not want antibiotics

Compassionate Honesty

- All dementias eventually develop total dependency
 - Unless something happens first
- Inability to swallow eventually happens
- If the patient had behavioral expressions, they will likely diminish
- Final stage COD is usually pneumonia, or other infections, or another disease

Artificial Nutrition

- “Choosing Wisely Campaign”
 - ABIM started, now 33 medical societies have list of 5 “Don’t Do” recommendations
- “Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral assisted feeding.”
 - American Geriatrics Society
 - American Academy of Hospice and Palliative Medicine

Discussing Tube Feedings

- “Your mother’s dementia has reached the stage where she can no longer swallow on her own, without breathing food or saliva into her lungs.”
- “This means she’s entered the final stage of her life.”
- “From what you’ve said about her goals, let me suggest the following – we will make sure she is comfortable and well-cared for, but we will not increase her suffering by using artificial feedings or fluids.”

Advance Care Planning – Stage 7

- Achieving goals of care is the focus
- Medication reduction – if desired
 - Maintain all meds that provide comfort
 - Discuss stopping all meds that are for prevention (statins, ASA, hypertension, anticoagulants, Type II diabetes meds)
 - Psychoactive drugs need to be tapered
- Increase person-oriented comfort care
- Create or update the POLST form



ACP and POLST in Early Dementia

- New recommendations
 - Pre-Alzheimer's
 - MCI due to Alzheimer's
 - Alzheimer's
- Specialized scanning and biomarkers
- Even without the new recommendations, more people are being diagnosed at a early stage

Capacity and ACP

- Decisional capacity
 - Communicates
 - Understands the information
 - Makes a choice
 - Understands the consequences of the choice
- Capacity is decision-specific
- Capacity may vary in dementia
- Concept of an “authentic” goal or wish

Notice: the word “rational” is not included in the definition

When Do People With Dementia Lose Capacity?

- When they can't demonstrate they have it!
- Not based on MMSE or MOCA scores, but...
 - MMSE – Cut off score of 18⁽¹⁾
 - MOCA – Cut off score of 17⁽²⁾
- “Persons suffering from a disease such as Alzheimer’s are not presumed to be wholly incompetent.” (NY, *In re Rose S*)

1. Gregory R, *Age Ageing* 2007;36:527-531
2. Karlawish J, *Neurology* 2013;81:1-7
3. Burnette AT, *Health Care Law Monthly*, 2012; 2012: 1-7



POLST and Early AD

- Challenges:
 - Future cognitive impairment is certain
 - Not knowing what advanced AD looks like
 - Questionable appropriateness of whether the patient meets the criteria
 - Serious, progressive, chronic illness
 - Life-threatening, advanced illness
 - Advanced frailty



Video Education on Dementia

- Written description of advanced dementia (Stage 7)
 - 50% desired comfort care
 - 21% desired life-prolonging care
 - 18% something in-between
- Video of a person in Stage 7
 - 89% comfort care
 - None want life-prolongation
 - 8% limited care

Few Studies

- Marson – used vignettes
 - Those with mild & moderate AD were able to express a reasonable treatment choice
 - When asked to provide “rational” reasons for choices 50% of CI and almost none of those with AD could!
 - When asked to discuss an emotional reason and consequences of a choice, all the CI and 40% of AD could

- Mezey
 - 72% of those with MMSE<20 could name a HCP



A Possible Approach

- Engage all patients with the diagnosis of early dementia in an ACP discussion (“routine”)
- Elicit goals of care
- Complete an advance directive
- Name a health care surrogate
- Discuss future use of POLST



Elicit Goals of Care

- Open ended questions
 - Respecting Choices
 - Calif Coalition for Compassionate Care
- Go Wish cards
- Online resources (*more than just goals*)
 - PrepareForYourCare.org
 - MyDirectives.com



MyDirectives.com – My Priorities

1. Not living out my life in a nursing home
2. Not being a financial burden to my family
3. Avoiding prolonged dependence on machines
4. No artificial or assisted nutrition through tubes
5. Being free from pain
6. Being with my family
7. Dying at home
8. Resolving conflicts



Advance Directive & Surrogate

- ❑ Discuss the forms (don't just fill them out)
- ❑ Suggest watching Volandes video with the surrogate
- ❑ Discuss views, questions after the video with someone knowledgeable about dementia care
- ❑ Discuss future treatment plans for co-existing medical conditions

Discussing POLST

- Make clear the frame of the discussion:
 - Now
 - When in moderate stage
 - When severe
- Check understanding of the consequences of choices
- Discuss changing minds
- Consider recording the discussion (iPad)

Completing a “Future” POLST?

- Specify the conditions under which the POLST would be activated
 - “When I am judged to be in FAST Stage 6”
- Link future choices to goals of care
 - “In order to avoid permanent nursing home placement I would choose comfort care over aggressive treatment of other medical conditions.”



Summary

- ❑ Never assume the patient with dementia is unable to engage in advance care planning discussions
- ❑ “Person-centered” care demands gaining knowledge of the person’s goals of care
- ❑ Be the one to bring up inevitable choices
- ❑ Commit to providing comfort no matter what choices are made