THE ALZHEIMER’S PROJECT CLINICAL ROUNDTABLE

Advance Care Planning through the Stages of Dementia

Introduction

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- Dr. Neel has no financial conflicts of interest to disclose
- Dr. Steinberg received funding for a vaccine implementation study from Moderna in 2025

Learning Objectives

- Be able to describe two staging methods for Alzheimer's dementia
- Gain confidence in discussing resources for living with dementia with caregivers
- Explain what needs should be addressed at differing stages of dementia
- Identify the distinction between palliative care and hospice care for dementia
- Describe hospice criteria for Alzheimer's dementia

Overview of Dementia Staging

- Multiple tools exist for staging dementia
- Many cognitive evaluation CPT codes require knowledge and use of the FAST dementia rating scale.
- The FAST dementia rating scale is also required for hospice referral for dementia
- Other scales may be more helpful in day-to-day life for caregivers of those with dementia, including but not limited to Teepa Snow's GEMS model.

FAST Dementia Rating Scale

Stage	Stage Name	Characteristic	Expected Untreated AD Duration (months)	Mental Age (years)
1	Normal Aging	No deficits whatsoever	--	Adult
2	Possible Mild Cognitive Impairment	Subjective functional deficit	--	
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks	84	12+
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling	24	8-12
5	Moderate Dementia	Needs help selecting proper attire	18	5-7
6a	Moderately Severe Dementia	Needs help putting on clothes	4.8	5
6b	Moderately Severe Dementia	Needs help bathing	4.8	4
6c	Moderately Severe Dementia	Needs help toileting	4.8	4
6d	Moderately Severe Dementia	Urinary incontinence	3.6	3-4
6e	Moderately Severe Dementia	Fecal incontinence	9.6	2-3
7a	Severe Dementia	Speaks 5-6 words during day	12	1.25
7b	Severe Dementia	Speaks only 1 word clearly	18	1
7c	Severe Dementia	Can no longer walk	12	1
7d	Severe Dementia	Can no longer sit up	12	0.5-0.8
7e	Severe Dementia	Can no longer smile	18	0.2-0.4
7f	Severe Dementia	Can no longer hold up head	12+	0-0.2

Teepa Snow GEMS Brain Change Model

Practical staging tool that can be helpful to caregivers

Gems	Basic Characteristics	Interests
Sapphire	• Normal aging • May feel blue due to the changes of aging • No significant changes in cognition • Difficulty learning new things	• They like to choose • May need help or modifications to enjoy interests • Leaving a legacy, fulfilling promises, or making a difference
Diamond	• Can do OLD habits and routines • Becomes more territorial OR less aware of boundaries • Likes the familiar and has difficulty with change • Tells the same stories, asks the same questions	• Things that make them feel competent and valued • What they enjoy and who they like • Where they feel comfortable but stimulated • What gives them a sense of control
Emerald	• Gets lost in past life, past places, past roles • Gets emotional quickly • Loses important things and thinks someone stole them • Needs help, DOES NOT know it or like it	• Doing familiar tasks • Engaging with or helping others • Having tasks or a purpose • Does better with a friend than a boss
Amber	• Need to have sensation (touch, look, feel, smell, or taste) • Private and quiet or public and noisy • Will get into things • Can't wait or put up with things that take time	• Things to mess with or explore • Textures, shapes, colors, movement • Verbal sounds that are familiar (music) • Tastes—usually more sweet or salty
Ruby	• Fine motor skill is lost or stops in the mouth, eyes, fingers, and feet • Hard to stop and hard to get going • Limited visual awareness • One direction—forward only, can't back up safely	• Walking a routine path • Watching others, checking them out • Things to pick up, hold, carry, push, wipe, rub, grip, squeeze, pinch, slap • Rhythmic movements and actions
Pearl	• Not aware of the world around them (most of the time) • Hardly moves • Problems swallowing • Hard to get connected	• Pleasant and familiar sounds and voices • Warmth and comfort • Soft textures • Smooth and slow movement

Need for Empathy

- Take time to listen
  - Allow for longer patient visits and schedule regular check-ins
  - Take opportunity to assess caregiver stress and depression, and recommend separate appointments for caregivers, as appropriate
  - Show empathy and communicate with caregivers
  - Express understanding of the gravity of the road they are traveling
- Between diagnosis disclosure and end of life, there may be many years in which to educate patients and caregivers on the progress of the disease

Be Cognizant of Potential Abuse and Neglect

- Providers have legal responsibility to report suspected abuse and neglect, and diagnosis to DMV
- Abuse may include physical, sexual abuse, abandonment, isolation, financial, neglect, mental suffering/verbal abuse
- What family members should look for – warning signals
  - Online scams, “friends” requesting money
  - Repeated banking withdrawals or online contributions
  - Frequent trips to casinos
  - Poor personal hygiene
- Report suspected abuse/neglect to County Adult Protective Services

Discussing Resources

- Introduce available resources early and often
- It may take several attempts for families to fully understand and take advantage of the resources – avoid information overload
- Remember to listen and empathize
- Give handouts/after-visit summaries/web links and practical recommendations
- Build relationships and connections with resources available in the community
- Resources are valuable tools in providing optimal care for the patients and families

Discuss During Early Stage Dementia

Within a few weeks	Within a few months	Ongoing at appointments
Identify primary decision-maker, medical agent/surrogate/proxy	Suggest family identify important documents	Assess for behavioral symptoms, caregiver stress
Discuss legal and financial issues to consider	Assist family to identify care support team	Introduce care options appropriate to family
Discuss medical treatment and other preferences with patient while they have capacity to make decisions	Ensure an advance health care directive (AHCD) is created. Introduce **POLST** form and choices for specific interventions—advise against artificial nutrition	Encourage using community resources and services; support groups and respite
	A diagnosis of ADRD requires physician notification of DMV if patient has a driver's license	Discuss planning in case of illness of caregiver, alert if caregiver taking over all decision-making
		Discuss optimal communications
		Be vigilant for fiduciary and other elder abuse, report any suspicion

Discuss During Moderate Stage Dementia

- Dementia prognosis/life expectancy, treatment preferences
- General information on dementia progression - may experience aggression and/or delusions/paranoia
- How to deal with patient's behavioral symptoms
- Safety issues
- Where and how to use services/help available at this stage; including long-term placement needs

Behaviors Experienced in Stages of Dementia

% of Patients Experiencing Behaviors

90%
80%
70%
60%
50%
40%
30%
20%

Agitation
Diurnal Rhythm
Depression
Wandering
Aggression
Social Withdrawal
Hallucinations
Anxiety
Paranoia
Socially Inappropriate Behaviors
Suicidal Ideation

Early Stage **Moderate Stage** **Severe/Late Stage**

Source: Jost BC, et al. *J Am Geriatr Soc.* 1996;44:1078-1081

Discuss During Late/Severe Stage Dementia

- May experience motor dysfunction; increased fall risk; contractures, pressure ulcers
- Dysphagia: High risk of aspiration pneumonia/pulmonary infection, failure to thrive/malnutrition/cachexia (also due to losing interest in food/fluids)
- Behavioral issues including agitation, physical aggression, resisting care
- Other infections also at increased risk
- How to apply for care programs if not done already
- Home care vs. facility care—those with high care needs or medical interventions may need skilled nursing facility placement
- Revisit end-of-life issues including hospice, feeding issues, and **POLST** orders

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Respite Programs

- Provides caregivers an opportunity to take a break for a brief period of time (varies widely from a few hours to a maximum of 30 days), while knowing their loved one is in good hands.
- What is meant by respite program widely varies

See Resources sheet for specifics on programs
https://championsforhealth.org/alzheimers/

In-Home Support Services – County of SD

For those on Medi-Cal who qualify, can provide assistance with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). Family or outside caregivers are compensated for their time.

Requirements:

- You must be a California resident, physically residing in the United States.
- You must apply for Medi-Cal if you are not already receiving.
- You must live at home or a dwelling of your own choosing (acute care hospital, long-term care facilities, and licensed community care facilities are not considered "own home").
- You must submit a completed Health Care Certification form.

Adult Day Care Programs

- Non-profit and for-profit organizations can provide engaging activities and allow family caregivers to work, attend to other responsibilities during the day
- Glenner Alzheimer's Family Centers: http://glenner.org
- Gary & Mary West Senior Wellness Center: https://servingseniors.org
- Private For-Profit Programs can be found through care coordinators or online

PACE Programs

PACE = Program of All-Inclusive Care for the Elderly *

- Provides comprehensive healthcare and social services to allow participants to remain at home rather than in assisted living facility
- May cover some or all of the long-term care needs of a person with multiple chronic conditions including dementia living in the community.
- Must meet health needs and income qualifications (Medi/Medi).
- **Several PACE programs in SD County**

** The term "elderly" is generally considered ageist – avoid when possible*

Residential Care

- May become necessary for patients who can't be safely cared for in the home setting (RCFE – Residential Care Facility for the Elderly*)
  - Includes assisted living, dedicated dementia units, and small board-and-care homes
  - Assess if the caregiver is unable to provide needed care or may be at risk for their own health due to caregiving
  - Part-time or full-time paid in-home caregivers can avoid residential placement
  - Take care to reduce guilt feelings of the caregivers

** The term "elderly" is generally considered ageist – avoid when possible*

Residential Care

- Often residential care is not discussed until patient exhibits incontinence, wandering, day/night reversal (sundowning), safety issues (leaving stove on, etc.). However, early discussion advisable.
- Address cultural issues of the family and resources.
- Costs vary dramatically ($4000-15,000 monthly) but generally less than 24/7 paid caregivers at home.
- Medi-Cal Assisted Living Waivers may be available to cover RCFE costs.
- Agencies and individuals available to assist with placement options.

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Advance Care Planning

- Goals of Care conversations entail more than just a **POLST** or code status discussion about specific interventions—discuss priorities, beliefs, preferences, what they would consider intolerable

- **Best if initiated early, before dementia has progressed to the point the patient has lost decisional capacity**

- Educate patient and family; encourage frank discussions between patient, their legally recognized decision-maker, and other family members and friends

Discuss During Advance Care Planning

- What is a **POLST** form, and how it can be amended
- Hospitalizations
- CPR – very poor success rate in frail older adults, especially unwitnessed and in community settings
- Intubation
- Hydration
- Hand Feeding/Modified Diets/Thickened Liquids
- Tube Feeding: Generally **contraindicated** in advanced dementia; burdens and risks outweigh benefits
- Selective Treatments and Surgeries

POLST Orders

- Best to discuss and complete with patient and family members early in disease process when individual with dementia can be involved in decisions
  - especially for those who want to avoid burdensome treatments (e.g., CPR, intubation) and to level-set on feeding tube consideration

POLST Form

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMERGENCY MEDICAL SERVICES AUTHORITY · EMSA · CALIFORNIA

EMSA #111 B
(Effective 1/1/2009)

First follow these orders, then contact physician. This is a Physician Order Sheet based on the person's current medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Last Name

First /Middle Name

Date of Birth | Date Form Prepared

A *Check One*

CARDIOPULMONARY RESUSCITATION (CPR): ***Person has no pulse and is not breathing.***

☐ **Attempt Resuscitation/CPR** ☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)
(Section B: Full Treatment required)

When not in cardiopulmonary arrest, follow orders in **B** and **C**.

B *Check One*

MEDICAL INTERVENTIONS: ***Person has pulse and/or is breathing.***

☐ **Comfort Measures Only** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Antibiotics only to promote comfort. ***Transfer*** *if comfort needs cannot be met in current location.*

☐ **Limited Additional Interventions** Includes care described above. Use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

☐ ***Do Not Transfer to hospital for medical interventions. Transfer*** if comfort needs cannot be met in current location.

☐ **Full Treatment** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. ***Transfer*** *to hospital if indicated. Includes intensive care.*

Additional Orders: ____________________

C *Check One*

ARTIFICIALLY ADMINISTERED NUTRITION: ***Offer food by mouth if feasible and desired.***

☐ No artificial nutrition by tube. ☐ Defined trial period of artificial nutrition by tube.
☐ Long-term artificial nutrition by tube.

Additional Orders: ____________________

D

SIGNATURES AND SUMMARY OF MEDICAL CONDITION:

Discussed with:
☐ Patient ☐ Health Care Decisionmaker ☐ Parent of Minor ☐ Court Appointed Conservator ☐ Other:

Signature of Physician
My signature below indicates to the best of my knowledge that these orders are consistent with the person's medical condition and preferences.

Print Physician Name	Physician Phone Number	Date
Physician Signature (required)	Physician License #	

Signature of Patient, Decisionmaker, Parent of Minor or Conservator
By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Signature (required)	Name (print)	Relationship (write self if patient)

Summary of Medical Condition	Office Use Only

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

(Effective 1/1/2009) treated with dignity and respect.

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☐ Long-term artificial nutrition by tube.

Additional Orders: ____________________

POLST Section A

- DNR applies **only** when individual has stopped breathing and has no pulse (i.e., they are "clinically dead")
- Can request DNR and still check "Full Treatment" in Section B (e.g., patient with COPD who wants ventilator)
- But if you request CPR in Section A, you **must** choose Full Treatment

POLST Section B

- Selective Treatment = Treat issues that are treatable (e.g., infection) without overly burdensome interventions (Generally avoid ICU)
- Translates to “No Heroics” for many
- *Option for “Do Not Hospitalize” unless comfort needs can’t be met in current setting—mostly applies to skilled nursing facility residents*

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POLST Section C

- Choice of long-term, trial period, or no artificial nutrition
- Use of feeding tube confers no benefit for patients with advanced dementia and is contraindicated
  - Does not prolong life
  - Does not improve quality of life
  - Frequent adverse events (aspiration pneumonia, pressure ulcers, dislodgement with peritonitis, etc.)
- Best to discuss this long before dysphagia or loss of interest in food and fluids begins
- If no box is checked, POLST orders default to the most aggressive option
- But a feeding tube decision is never an emergency

Palliative Care

Q: At what stage of dementia are palliative care services appropriate?

A: It depends! Not every dementia patient needs it, and some need it very early in the disease trajectory.

Palliative Care

- Interprofessional, team-based care—holistic, individualized, based on maximizing quality of life, adequate symptom control, advance care planning, and provides support for patient and family
- Appropriate for **any** patient with serious illness and complex needs that are not being adequately managed with current medical care
  - Family conflict, existential suffering, financial concerns, unmanaged symptoms
- Should not be conflated with hospice—can be utilized at any point in the illness trajectory of dementia, can be given alongside 'curative' care (e.g., antibody infusions for Alzheimer's), not only <6 mo. prognosis
- Not all community-based PC programs are alike—become aware of what is available and what they offer

Palliative Care

Refer patients/families who are struggling: early, at any stage of illness, and regardless of prognosis. Look for programs that offer the following features as these will be especially helpful to you and your patients:

- Longitudinal models that follow patients across settings (clinic, hospital, SNF, home)
- Interdisciplinary teams that include MD/NP, RN, SW + chaplain as core with pharmacist, psych as extenders

If a robust program is unavailable, know that ***any*** level of palliative care has been shown to be beneficial

Hospice Care

- Specific benefit for patients with <6 months life expectancy **and** who do not wish additional life-prolonging treatments, hospitalization, etc.
  - Prognostication not an exact science
- Payment through Medicare, Medi-Cal, VA, or other insurance – no cost to patient (some hospices provide charity services to uninsured)
- Provides coverage for medications, DME, nursing, social work, spiritual care, home health aide, physician services (for conditions related to the terminal prognosis)
- Does not provide 24/7 care, or room and board—although can cover 5-day respite, brief inpatient stays or "continuous care" for uncontrolled symptoms or crisis situations

Advanced Dementia—Functional and Cognitive Signs

FAST Scale
6+

Stage	Stage Name	Characteristic
6a	Moderately Severe Dementia	Needs help putting on clothes
6b	Moderately Severe Dementia	Needs help bathing
6c	Moderately Severe Dementia	Needs help toileting
6d	Moderately Severe Dementia	Urinary incontinence
6e	Moderately Severe Dementia	Fecal incontinence
7a	Severe Dementia	Speaks 5-6 words during day
7b	Severe Dementia	Speaks only 1 word clearly
7c	Severe Dementia	Can no longer walk
7d	Severe Dementia	Can no longer sit up
7e	Severe Dementia	Can no longer smile
7f	Severe Dementia	Can no longer hold up head

Hospice Eligibility Criteria

- Based on CMS Local Coverage Determinations (LCDs: Guidelines, not hard requirements—but hospices generally stricter in recent years with increased scrutiny)
- Consider comorbid conditions that would contribute to limiting life expectancy (e.g., COPD, CHF, CKD, liver disease, sarcopenia)
- When in doubt, there is no harm in making a hospice referral—hospice physician and interdisciplinary team will assess eligibility

CMS Hospice Qualifications (LCDs)

Patients with dementia should show all the following characteristics:

- Stage 7 according to the Functional Assessment Staging Scale (FAST);
  - Unable to ambulate without assistance;
  - Unable to dress without assistance;
  - Unable to bathe without assistance;
  - Urinary and fecal incontinence, intermittent or constant;
  - No consistently meaningful verbal communication: stereotypical phrases only or the ability to speak is limited to six or fewer intelligible words.

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CMS Hospice Qualifications (LCDs)

Patients should have had one of the following within the past 12 months:

- Aspiration pneumonia;
- Pyelonephritis;
- Septicemia;
- Decubitus ulcers, multiple, stage 3-4;
- Fever, recurrent after antibiotics;
- Inability to maintain sufficient fluid and calorie intake with 10% weight loss during the previous six months or serum albumin < 2.5 gm/dl.

Keep in mind: Not all of these criteria must be met if there is significant weight loss or other signs of steep decline, or serious comorbid conditions.

Common Causes of Death Related to ADRD

- Common causes of death directly related to ADRD are aspiration pneumonia and hypovolemic shock related to reduced oral intake
- Infections: UTIs, aspiration pneumonia, infected pressure ulcers and skin breakdown
- Complications of trauma (e.g., hip fracture)
- Strokes, myocardial infarction, arrhythmias, pulmonary emboli, any of the other common geriatric scenarios

Medication Deprescribing in Advanced Dementia

Geriatric mantra – initiated early and continued diligently

- Statin drugs
- Anticholinergics
- Blood thinners
- Opioids, sedatives
- Blood pressure medications
- Antipsychotics
- Benzodiazepines
- Cholinesterase inhibitors and memantine

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Advance Care Planning Resources

- Prepare for your Care https://prepareforyourcare.org
- The Conversation Project https://theconversationproject.org
- Coalition for Compassionate Care of California – https://coalitionccc.org/
- Caring Advocates (dementia directives) - https://caringadvocates.org/

Summary

- Advance Care Planning should occur consistently throughout the course of disease
- Palliative care can be added at any stage of disease when needed
- Hospice care has specific CMS qualification and can be highly beneficial for patients and caregivers; patients often live longer
- Repetition, reinforcement and support to caregivers and patients are important to improve adherence, communications and trust
- Caregivers most effective when they care for themselves

The Alzheimer's Project Clinical Roundtable facilitated by

This slide deck can be accessed at

https://championsforhealth.org/alzheimers/

Website updated regularly with most current information and resources

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www.sandiegoimperialgwep.com