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ADVANCED DEMENTIA AND THE HOSPICE PATIENT

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2

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OBJECTIVES

By the end of this session, participants should be able to:

- Know the common types of dementia
- Know the typical course of dementia
- Understand the criteria for determining hospice eligibility of dementia patients
- Understand the rationale for deprescribing dementia medications
- Know common symptoms of patients with advanced dementia, and the hospice approach to treatment.

DEFINITION

Dementia is an acquired loss of memory that is substantial enough to interfere with everyday functioning plus impairment of at least one other cognitive domain.

It is chronic, progressive, and ultimately a terminal condition.

WORD ORIGIN

Derived from Latin, the word dementia literally means “out of one’s mind”. The term was first coined by the French psychiatrist, Phillipe Pinel. During the 18th century, dementia was a term used for people with intellectual deficit, acquired at any age.

THE CONCEPT OF “TOTAL PAIN” THE IMPORTANCE OF SUPPORTING CAREGIVERS

A palliative model should focus on both the patient and caregiver’s physical, psychological, social, and spiritual care.

This underlines the strength of the team approach used by hospice providers.

MOST COMMON ETIOLOGIES OF DEMENTIA IN THE U.S.

Dementia Diagnosis	Relative frequency	Pathophysiology
Alzheimer's Disease (AD)	35%	Beta-amyloid plaques and neurofibrillary tangles (tau)
Mixed (vascular dementia and AD)	15%	Combination of AD and vascular disease.
Dementia with Lewy Bodies	15%	Alpha-synuclein protein
Vascular dementia	10%	Cortical or subcortical infarcts, and leuko-araiosis.
Frontotemporal dementia (Pick's disease)	5%	Tau protein

DIFFERENTIAL DIAGNOSIS

- Chronic Traumatic Encephalopathy (CTE): the result of repetitive brain trauma.
- Age-related cognitive decline.
- Mild Cognitive Impairment.

AD

- Primarily affects the hippocampus and neocortex.
- Memory loss is an early symptom.
- Progresses to disorganized thoughts, confusion, and disorientation.
- Accompanied by language difficulties.
- Impaired executive functioning, leads to impaired judgement.
- Behavioral and psychological symptoms.

AD

- Clinical diagnosis is generally correct (85% correlation with post-mortem)
- Advances in diagnostic methods include:
 - Examination of CSF for biomarkers (low amyloid and high tau)
 - Tracers developed for PET scans to assess for amyloid deposition
(Pittsburgh compound B)

VASCULAR DEMENTIA

- Clinical expression varies, based on the location and extent of lesions.
- Often co-exists with AD and predisposes to clinical expression of AD.

DLB

DLB caused by protein deposition in cortex and subcortex.

- Fluctuating cognition with pronounced variations in attention and alertness.
- Recurrent visual hallucinations.
- Parkinsonian symptoms that occur in parallel with other symptoms.
- Suggestive features: REM sleep behavior disorder, severe neuroleptic sensitivity.

A COMMON END POINT

As the various types of dementia progress to an advanced stage, the distinctive features are less recognizable. Common symptoms and treatment decisions become applicable regardless of the etiology.

EPIDEMIOLOGY

- Incidence and prevalence of dementia increase dramatically after age 65.
- AD affects 2-3% of people older than 65, and the incidence doubles for every additional 5 years of age (near 50% of those older than 85).
- A 2016 study conducted by the Alzheimer's Association reports more than 5 million people in the U.S. with AD.
- This number is projected to increase to 13.1 million by 2050.
- Crushing financial burden which falls on caregivers, employers, and society as a whole.

TYPICAL DISEASE COURSE

- AD is a terminal illness with an average life expectancy of 4-8 years from time of diagnosis.
- Median survival depends on age at time of diagnosis.
- Typical course is one of gradual deterioration, punctuated by episodic declines (usually due to an acute illness or injury).
- If the patient survives the decline, she usually only recovers partially, to a new, lower cognitive and functional level.

WHY HOSPICE FOR ADVANCED DEMENTIA?

- It is a terminal illness with no effective treatment.
- High symptom burden and self-care needs near end of life.
- High burden on caregivers.

Despite this, only a fraction of eligible patients are enrolled in hospice.

WHAT DOES HOSPICE PROVIDE?

- Scheduled RN and CNA visits
- Home visits by a physician
- Availability of MSW and spiritual advisor
- Provision of medications and DME
- Respite stays are covered by Medicare benefit
- Inpatient care available for symptom management

CRITERIA FOR HOSPICE REFERRAL

- Patient or surrogate chooses to forego ‘aggressive’ care in favor of comfort care.
- There is data to show that the patient is terminally ill, with a life expectancy of six months or less *if the terminal illness runs its normal course.*

FUNCTIONAL IMPAIRMENT

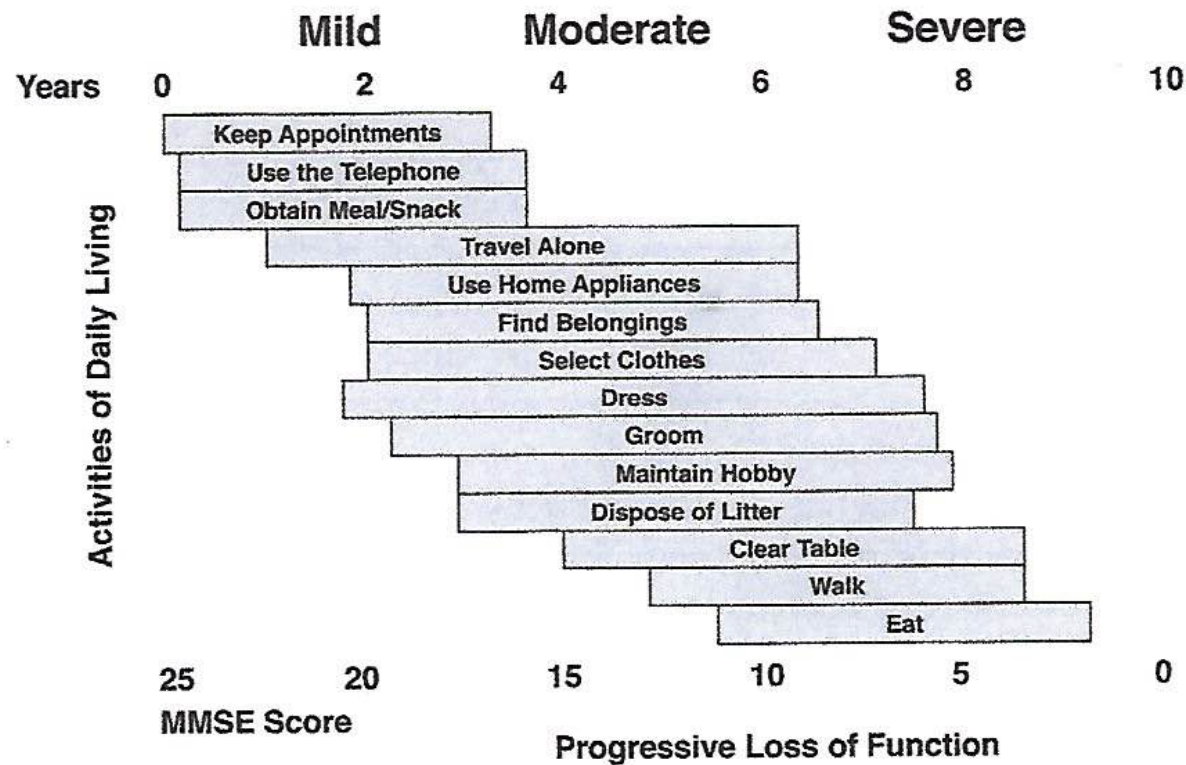
- FAST score stage 7
- Requiring assistance with ambulation, bathing, and dressing.
- Incontinent of stool and urine (intermittent or constant).
- No consistently meaningful speech; six or fewer intelligible words.

FUNCTIONAL ASSESSMENT STAGING (FAST SCALE)

Stage	Stage Name	Characteristic	Expected Untreated AD Duration (months)	Mental Age (years)	MMSE (score)
1	Normal Aging	No deficits whatsoever	--	Adult	29-30
2	Possible Mild Cognitive Impairment	Subjective functional deficit	--		28-29
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks	84	12+	24-28
4	Mild Dementia	IADLs become affected, such as bill paying, cooking, cleaning, traveling	24	8-12	19-20
5	Moderate Dementia	Needs help selecting proper attire	18	5-7	15
6a	Moderately Severe Dementia	Needs help putting on clothes	4.8	5	9
6b	Moderately Severe Dementia	Needs help bathing	4.8	4	8
6c	Moderately Severe Dementia	Needs help toileting	4.8	4	5
6d	Moderately Severe Dementia	Urinary incontinence	3.6	3-4	3
6e	Moderately Severe Dementia	Fecal incontinence	9.6	2-3	1
7a	Severe Dementia	Speaks 5-6 words during day	12	1.25	0
7b	Severe Dementia	Speaks only 1 word clearly	18	1	0
7c	Severe Dementia	Can no longer walk	12	1	0
7d	Severe Dementia	Can no longer sit up	12	0.5-0.8	0
7e	Severe Dementia	Can no longer smile	18	0.2-0.4	0
7f	Severe Dementia	Can no longer hold up head	12+	0-0.2	0

FUNCTIONAL DECLINE

Figure 2. Progressive Loss of Activities of Daily Living



Adapted from Galasko D, et al. *Eur J Neurol.* 1998;5(suppl 4):S9-S17.

Adapted from *An integrated approach to the management of Alzheimer's disease: assessing cognition, function and behavior*, by Galasko D, *Eur J Neurol*, 1998;5(Suppl 4):S9-S17. ©1998 John Wiley and Sons, Inc. Adapted with permission.

PALLIATIVE PERFORMANCE SCALE (PPS)

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%	Ambulation	Activity Level Evidence of Disease	Self-Care	Intake	Level of Consciousness	Estimated Median Survival In Days		
						(a)	(b)	(c)
100	Full	Normal <i>No Disease</i>	Full	Normal	Full	N/A	N/A	108
90	Full	Normal <i>Some Disease</i>	Full	Normal	Full			
80	Full	Normal with Effort <i>Some Disease</i>	Full	Normal or Reduced	Full			
70	Reduced	Can't do normal job or work <i>Some Disease</i>	Full	As above	Full	145		
60	Reduced	Can't do hobbies or housework <i>Significant Disease</i>	Occasional Assistance Needed	As above	Full or Confusion	29	4	
50	Mainly sit/lie	Can't do any work <i>Extensive Disease</i>	Considerable Assistance Needed	As above	Full or Confusion	30	11	41
40	Mainly in Bed	As above	Mainly Assistance	As above	Full or Drowsy or Confusion	18	8	
30	Bed Bound	As above	Total Care	Reduced	As above	8	5	
20	Bed Bound	As above	As above	Minimal	As above	4	2	
10	Bed Bound	As above	As above	Mouth Care Only	Drowsy or Coma	1	1	6
0	Death	-	-	-	-			

(a) Survival post-admission to an inpatient palliative unit, all diagnoses (Vick 2002).

(b) Days until inpatient death following admission to an acute hospice unit, diagnoses not specified (Anderson 1996).

(c) Survival post admission to an inpatient palliative unit, cancer patients only (Morita 1999).

DISEASE COMPLICATIONS IN THE PAST YEAR

- Aspiration pneumonia
- Pyelonephritis
- Septicemia
- Multiple pressure injuries (stage 3 or 4)
- Recurrent fever after antibiotics
- Insufficient oral intake (loss of 10% of body weight in six months, serum albumin < 2.5 gm/dL)

QUOTATION FROM A DANISH BOOK

“It is difficult to make predictions, especially about the future.”

PROGNOSTICATION TOOLS

Current hospice guidelines do a poor job of predicting 6 month mortality.

Tools for SNF residents with dementia:

- Mortality Risk Index
- ADEPT

Both use data from the MDS.

INDICATORS OF POOR PROGNOSIS IN SNF RESIDENTS

- Dependence on total care
- Male gender
- Cancer diagnosis
- Oxygen requirement, CHF, dyspnea
- Oral intake <25% of meals.

INDICATORS OF POOR PROGNOSIS IN SNF RESIDENTS (CONT.)

- Unstable medical condition
- Bowel incontinence
- Bedfast
- Older than 83 years
- Not awake most of the morning and afternoon

TREATMENT OPTIONS

Currently no medical interventions prevent or delay disease onset, or change the course of the disease.

Goals for use of medications for dementia:

- Slow cognitive and functional decline
- Delay the need for placement in a secure facility or SNF
- Alleviate behavioral and psychological symptoms

CHOLINESTERASE INHIBITORS

- Suppress activity of acetylcholinesterase, which degrades acetylcholine in the synaptic cleft of neurons.
- This improves neurotransmission, mitigating some of the cognitive symptoms of AD.
- Also used for other types of dementia.
- Donepezil (Aricept), Galantamine (Razadyne), and Rivastigmine (Exelon).

NMDA RECEPTOR ANTAGONISTS

- In pathological conditions such as AD glutamate causes excessive stimulation of NMDA receptors in the brain.
- By blocking these receptors, memantine (Namenda) modulates the passage of calcium through associated ion channels.
- Approved by the FDA for moderate to severe dementia, alone and in combination with donepezil.

BENEFITS OF TREATMENT

- Benefits are higher for AD patients, and patients with mild to moderate disease.
- Potential benefits include controlling behavioral disturbance and lessening opioid-related somnolence.
- Review of studies indicate that benefits of treatment start to wane about a year after initiation, and that research criteria may not correlate to clinically significant improvement.

BURDENS OF TREATMENT

- Common side effects of anticholinesterases include diarrhea, nausea, anorexia, insomnia, and bradycardia.
- Common side effects of memantine include dizziness, headache, constipation, somnolence, and weight gain.
- Cost of medications can be high, especially for brand name products (\$191 to 255/month for cholinesterase meds, and about \$366/month for Namenda).

TO PRESCRIBE OR TO DEPRESCRIBE

- Limited evidence of benefit to patients with advanced disease that is of clinical significance.
- Take into account patient history of symptom improvement or adverse effects with a particular medication.

FUNCTIONAL ASSESSMENT STAGING (FAST SCALE)

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HOW TO DEPRESCRIBE

- Use a shared decision-making model with patients or surrogates.
- Be prepared to make a clear recommendation based on the best available evidence.
- In case of uncertainty, consider a time-limited trial of continuing the medication or tapering the dose, with serial reassessment.

HOW TO DEPRESCRIBE (CONT.)

- Consider use of alternative medications to treat behavioral and psychological symptoms as dementia meds are being tapered.
- It is recommended to avoid abrupt discontinuation of anticholinesterase or memantine.

MORE ON DEPRESCRIBING

Goal is to improve patient outcomes by minimizing poly-pharmacy.

Chart review to identify medications where:

- Benefits no longer outweigh risk of adverse effects
- Time until benefit is longer than expected survival
- Treatment target doesn't fit the patient's goal of care

Success depends on maintaining clinician-patient trust.

NONPHARMACOLOGIC APPROACHES

Modalities are more useful for mild to moderate dementia:

- Cognitive training
- Social engagement
- Physical activity interventions, such as home exercise programs

SYMPTOM CONTROL: PAIN

- Parenchymal brain changes may modify the perception of pain
- Pain perception in the peripheral and central nervous system are otherwise intact
- Pain is a subjective experience, and management is very challenging for patients who have impaired cognition and communication skills.

ASSESSING FOR PAIN

- Simple questions as to present pain
- Use nonverbal pain indicators
- Try to identify an individual's "pain signature"; rely on guidance from family members or experienced caregivers

MOOD DISORDERS: DEPRESSION

- This is a common comorbid condition.
- Commonly used medications are SSRIs (citalopram, sertraline) and TCAs (nortriptyline). SNRIs have not been studied.
- Stimulant medication e.g. methylphenidate may cause or worsen psychosis.

PSYCHOSIS

- Delusions and hallucinations are common symptoms
- Haloperidol is the first line medication used by most hospices, due to ease of administration and low cost.
- Common side effects of antipsychotics include sedation, extra pyramidal effects, prolonged QT interval and associated arrhythmias, and weight gain and hyperglycemia.
- Quetiapine (Seroquel) is preferred for DLB and PD

AGITATION

Agitation describes a range of behaviors that have varied causes, including:

- Physical symptoms (pain, sleep disturbance)
- Depression or anxiety
- Medical conditions (infection, dehydration, constipation, urinary retention, etc.)
- Unmet needs

AGITATION (CONT.)

- Sensory impairment (vision, hearing)
- Environmental factors
- Medication side effects
- Behavioral disturbance as a symptom of the underlying dementia (diagnosis of exclusion)

These symptoms are distressing to caregivers, and their response may lead to a vicious cycle.

NONPHARMACOLOGIC APPROACHES

- Environmental adjustments
- Engagement/distraction

MEDICATIONS TO ALLEVIATE AGITATION

- Antipsychotics
- Antidepressants: SSRIs, trazodone
- Benzodiazepines (watch for paradoxical worsening)

RESOURCES FOR CAREGIVERS

- <https://teepasnow.com>

“Until There’s a Cure for Dementia ... *There’s a Positive Approach to Care!*”

- <https://www.everettclinic.com/blog/25-hour-day>
- [The Emotional Survival Guide for Caregivers](#) by Barry J. Jacobs, PsyD

ISSUES NEAR END OF LIFE

- Eating difficulties
- Infection treatment
- Osteoporotic fractures

DECREASED ORAL INTAKE

- Address unrelated factors (poor dentition, dry mouth, thrush, GE reflux, constipation)
- Modify diet as needed for apraxia and dysphagia
- Take time to feed, encouraging or assisting as needed

SLOW-HAND FEEDING VS PEG TUBE

The benefits of slow-hand feeding include:

- Personal interaction between patient and caregiver
- Avoiding diarrhea (and increased risk of pressure injuries) associated with tube feedings
- Avoiding use of restraints to prevent patient from pulling out feeding tube
- Avoiding trips to ER and hospital to adjust or replace feeding tube

CHOOSING WISELY CAMPAIGN

www.choosingwisely.org/patient-resources

“When death is near and a person can no longer be fed by hand, the family often worries that their loved one will ‘starve to death.’ In fact, refusing food and water is a natural, non-painful part of the dying process. There is no good evidence that tube feeding helps people live longer.”

OSTEOPOROTIC (HIP, PELVIC) FRACTURES

- The decision for surgical repair vs nonsurgical should take into consideration cognitive and functional status of the patient, and comorbid conditions affecting operative risk
- Regardless of the decision, postop care should address pain management, risk of skin breakdown, and risk of delirium.

Q & A

