Intermountain Project ECHO
Dementia Care

HOSPICE & END-OF-LIFE CARE

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Session Objectives

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

- Describe the Medicare hospice care benefit
- Explain timing for referring a patient with dementia to hospice care
- Discuss resources for hospice care with patient caregivers

Medicare Hospice Care Benefit

- Paid by Medicare Part A for people with a life expectancy of 6 months or less (if the illness runs its normal course) and covers everything that is needed for the terminal illness and related conditions
- What happens If you live longer than 6 months? Hospice care can continue as long as the hospice medical director or other hospice doctor recertifies that you're terminally ill.
- You can get hospice care for two 90-day benefit periods, followed by an unlimited number of 60-day benefit periods.
- You have the right to change your hospice provider once during each benefit period.
- At the start of the first 90-day benefit period, your hospice doctor and your regular doctor (if you have one) must certify that you're terminally ill (with a life expectancy of 6 months or less). At the start of each benefit period after the first 90-day period, the hospice medical director or other hospice doctor must recertify that you're terminally ill, so you can continue to get hospice care.

https://www.medicare.gov/what-medicare-covers/what-part-a-covers/how-hospice-works

Dementia: Hospice Enrollment & Length of Stay Have Increased over the Past 20 Years

	1998	2008	2018
Enrolled	12,829	60,488	210,000
Percent of Total	3%	6%	14%
Rank	12th	6th	1st
Length of Stay (days)	67	105	110

Instrumental Activities of Daily Living (IADL)
Score one point for each task that can be done independently

- Using the telephone
- Using transportation
- Grocery shopping
- Preparing meals
- Housekeeping
- Take medications
- Finances

Activities of Daily Living (ADL)

Feeding

Dressing

Ambulation

Transferring

Continence

Bathing

Score one point for each task that can be done independently

Score of 4 = moderate impairment

Score of 2 = severe impairment

Decreased ADL function increases risk for hospitalization and death

Adapted from Gerontologist 10:20-30, 1970
www.ConsultGeriRN.org

Palliative Performance Scale (PPSv2)

version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

http://www.npcrc.org/files/news/palliative_performance_scale_PPSv2.pdf

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Hospice Eligibility Baseline Guidelines

Dependence on assistance for 2 or more ADLs

& Palliative Performance Scale of < 70%

Baseline guidelines do not independently qualify a patient for hospice services.

They are to be used in addition to disease-specific criteria.

From Local Coverage Determination (LCD) Documentation Guide – LCDs provide guidance in determining medical necessity

Disease Specific Criteria for Dementia: FAST 7 and aspiration pneumonia or upper urinary tract infection in past yr (LCD guide)

Functional Assessment Staging Scale (FAST) - *complete on all patients with dementia or suspected dementia*

1. No difficulty, either subjectively or objectively.
2. Complains of forgetting location of objects. Subjective work difficulties.
3. Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.
4. Decreased ability to perform complex tasks, e.g., planning dinner for guest, handling personal finances (such as forgetting to pay bills), difficulty marketing, etc.
5. Requires assistance in choosing proper clothing to wear.

6a: Needs assistance putting on clothes.
6b: Unable to bathe properly.
6c: Inability to handle the mechanics of toileting occasionally or more frequent recently.
6d: Occasional or more frequent urinary incontinence.
6e: Occasional or more frequent fecal incontinence.

7a: Ability to speak limited (1 to 5 words a day)
7b: All Intelligible vocabulary lost.
7c: Non-ambulatory.
7d: Unable to sit up independently.
7e: Unable to smile.
7f: Unable to hold head up.

FAST Stage: 7a

Dementia Hospice Eligibility: Baseline Guidelines Plus Disease Specific Criteria

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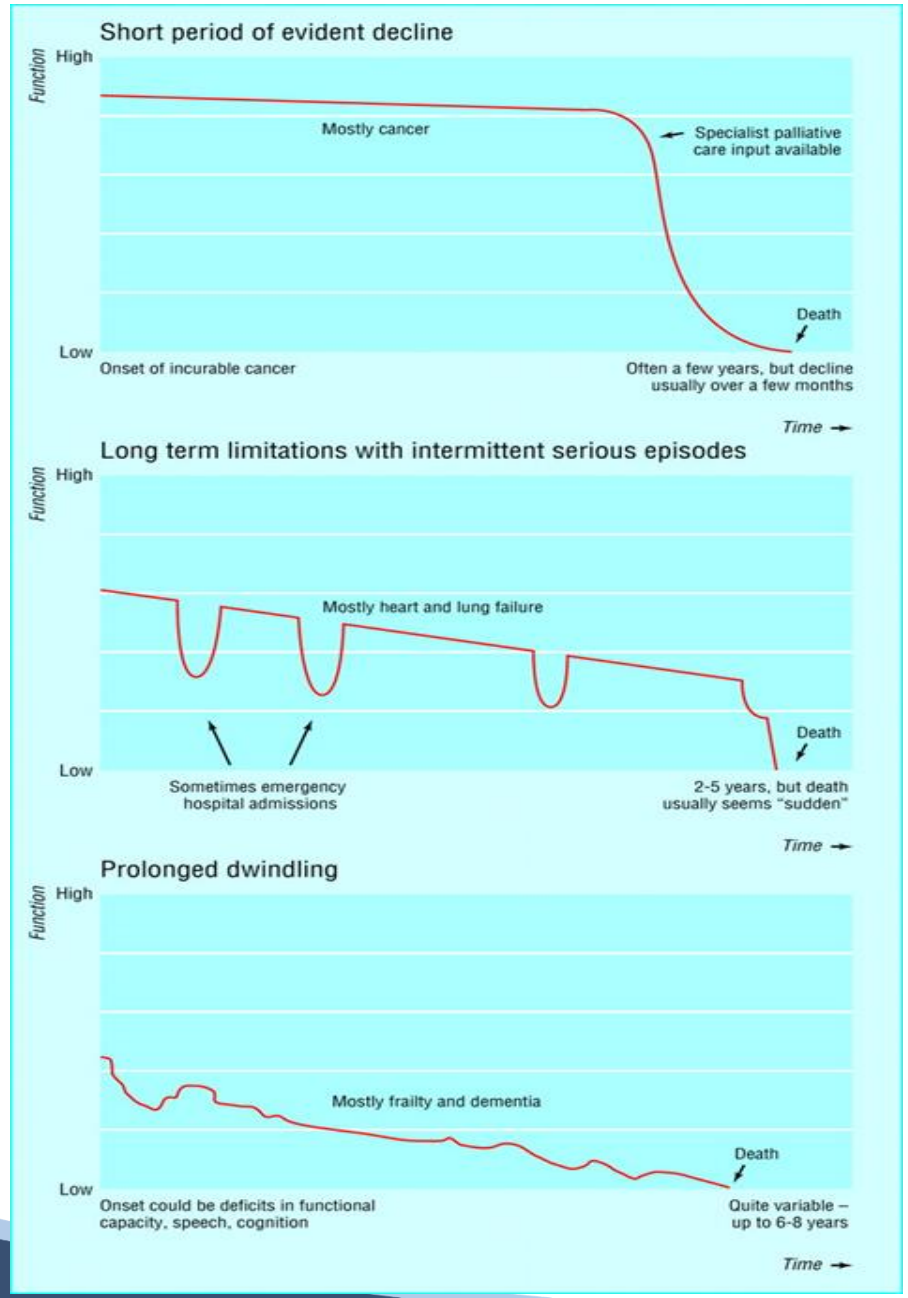

Typical Illness Trajectory for People with Progressive Chronic Illness

Scott A Murray et al. BMJ 2005;330:1007-1011

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Common Dementia Etiologies		
Etiology	ICD 10 Code	Etiology Criteria
Alzheimer's Disease	G30.1 and F02.80 or F02.81	• Gradual onset of symptoms over mo. - yrs. • Most prominent feature is memory • Impaired learning and recall of recently learned information
Vascular Dementia	F01.50 or F01.51	• Process information more slowly • Stepwise decline • May have a hx of stroke r/t cognitive decline
Mixed Dementia	Code predominate etiology first	• Criteria for multiple dementia syndrome etiologies are met; mixed vascular and Alzheimer Disease most common
Dementia with Lewy Bodies	G31.83 and F02.80 or F02.80 or F02.81	• Fluctuating cognition • Recurrent visual hallucinations • Parkinsonism (bradykinesia, muscular rigidity, tremor, postural instability)
Frontotemporal Dementia	G31.09 and F02.80 or F0281, consider Z55-65 or 91	• Disinhibition, Apathy, Loss of empathy, Compulsive behaviors, • Impaired executive function/decision making

3. Dementia Etiologies & Key Points

Important Implications of Course & Prognosis (Vary Greatly)

Etiology	Percentage	Age at Onset	Prognosis (yrs)
Alzheimer Cholinergic, Tx: cholinesterase inhibitor (donepezil)	60 -80 %		8 – 20 (11.2)
Vascular	20%		
Parkinson Disease & Lewy Body α-synuclein deposits	10%	50 and older	5-8
Frontotemporal Tau inclusions, serotonin, dopamine, Tx: SSRI	5%	40 - 65	3- 13 (8.7) bvFTD with motor neuron disease: 3

Other points

1. People with dementia who are hospitalized are at increased risk for readmission and have 80% higher 1 year mortality than patients without dementia (OR: 1.80; 95% CI: 1.69, 1.91). Gagne et al., J Clin Epidemiol, 2011

2. The hospice discharge rate of 15% for people who have a primary diagnosis of dementia is higher than any other qualifying diagnosis. Applying advanced prognostic tools may reduce this number and improve identification of those who may benefit most from hospice.

3. Hospice patients and their caregivers may be referred for education, support, tools outside of the hospice team: alz.org, eldercare.acl.gov

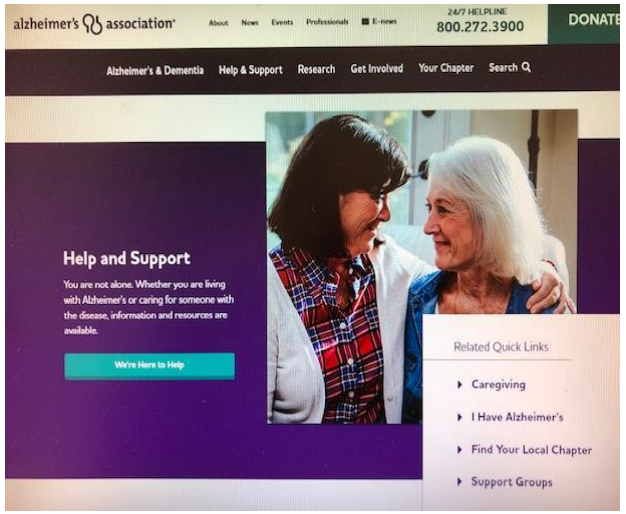
Other points

4. Use the dementia etiology to inform caregivers re: behavior, progression, prognosis, hospice eligibility. For example, FTD with motor neuron disease has much more limited prognosis than others.

5. Consider hospice referral. Review medical record for dementia diagnosis, cognitive evaluations (look for change over time, brain CT or MRI scan) and to identify comorbidities such as chronic kidney disease and clinical status factors: recurrent infections, weight loss, decreasing albumin, dysphagia that support eligibility for hospice admission.

6. Inquire about advance directives and POLST which may have been completed while patient still had decision making capacity.

7. Find out What Matters Most!



Alzheimer's Association Caregiver Support Resources

- Wide variety of printed materials
- ALZ.org
- Community education
- Caregiver support groups
- 24/7 Hotline (800) 272-3900

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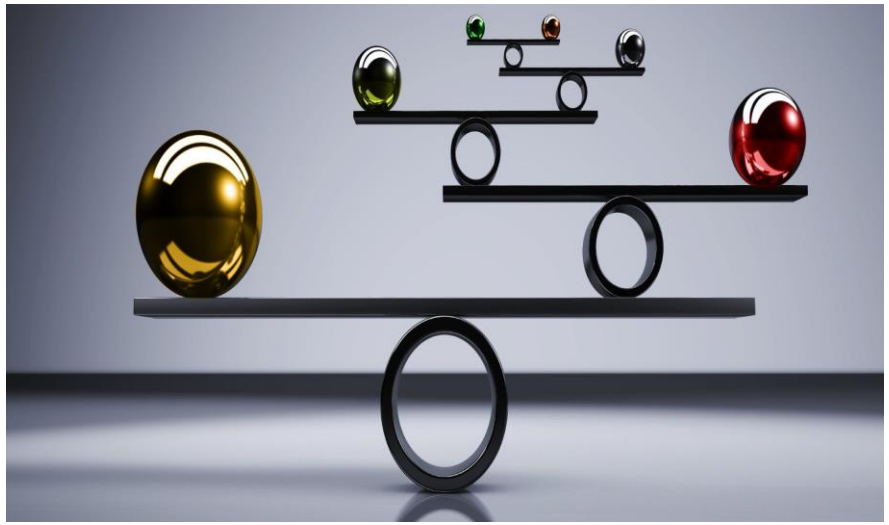
Hospice and Parkinson's Disease/Lewy Body Dementia

Complicated diseases with multiple symptom Domains

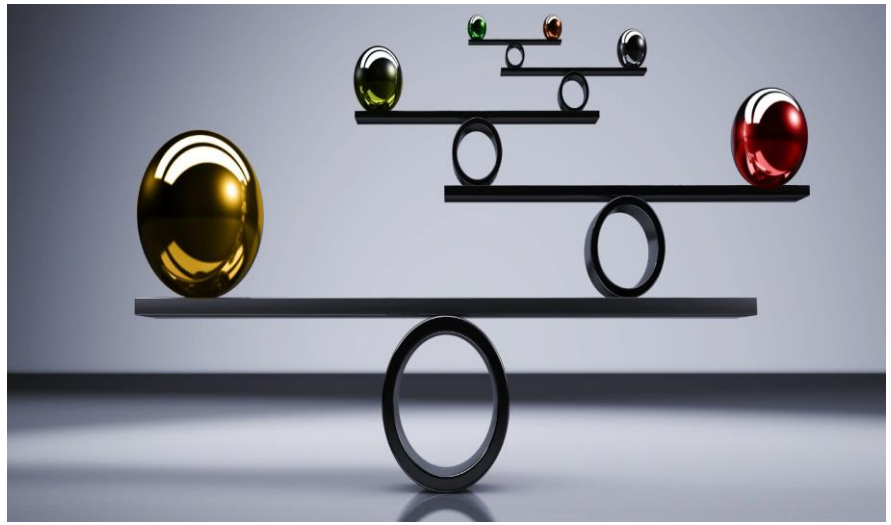
- Up to 80% of Parkinson's patients have cognitive impairment at end stage
- Psychosis and hallucinations are very common and can occur at any stage.



Hospice and Parkinson's Disease/Lewy Body Dementia

Neurologists can be nervous about putting Parkinson's patients on hospice

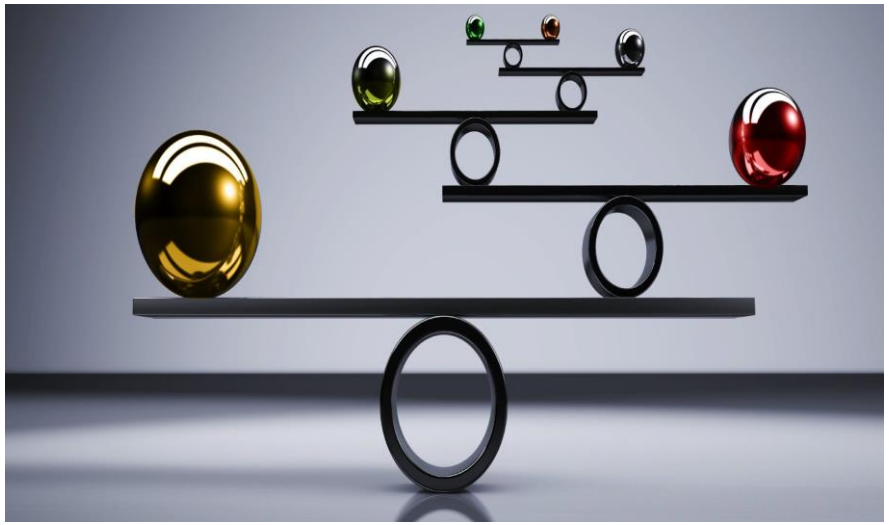
- Movement Medications are very complicated with dosing multiple times a day.
- **The goal is Balance**
- Movement Medications are very important for maintaining quality of life.
- Many common Hospice medications are dangerous for patients with Parkinson's Disease



Hospice and Parkinson's Disease/Lewy Body Dementia

Cognitive symptoms and ADL Function can fluctuate widely.

- Patients can go on and off hospice as it is hard to predict course
- Delirium can mimic end-stage symptoms



Medications That May Be Contraindicated in Parkinson's Disease:

Medical Purpose:	Safe Medications:	Medications to Avoid:
Antipsychotics	quetiapine (Seroquel®), clozapine (Clozaril®)	avoid all other typical and atypical anti-psychotics
Pain Medication	most are safe to use, but narcotic medications may cause confusion/psychosis and constipation	if patient is taking MAO-B inhibitor such as selegiline or rasagiline (Azilect®), avoid meperidine (Demerol®)
Anesthesia	request a consult with the anesthesiologist, surgeon and Parkinson's doctor to determine best anesthesia given your Parkinson's symptoms and medications	if patient is taking MAO-B inhibitor such as selegiline or rasagiline (Azilect®), avoid: meperidine (Demerol®), tramadol (Rybix®, Ryzolt®, Ultram®), droperidol (Inapsine®), methadone (Dolophine®, Methadose®), propoxyphene (Darvon®, PP-Cap®), cyclobenzaprine (Amrix®, Fexmid®, Flexeril®), halothane (Fluothane®)
Nausea/ GI Drugs	domperidone (Motilium®), trimethobenzamide (Tigan®), ondansetron (Zofran®), dolasetron (Anzemet®), granisetron (Kytril®)	prochlormethazine (Compazine®), metoclopramide (Reglan®), promethazine (Phenergan®), droperidol (Inapsine®)
Antidepressants	fluoxetine (Prozac®), sertraline (Zoloft®), paroxetine (Paxil®), citalopram (Celexa®), escitalopram (Lexapro®), venlafaxine (Effexor®)	amoxapine (Asendin®)

Caregiver and Family considerations in Hospice

- Ideally Hospice/ Palliative care is discussed early in the disease process as part of Advanced Care planning with the family.
- Advanced directives Identifying Health Care Agent should be in place
- Family may decide to forgo treatment of a “treatable” condition due to cognitive diagnosis
  - Example: Huntington’s Patient with Type 1 diabetes.
  - It is critical that **ALL** members of the family are on board in these cases.
- Clarification of Medical Goals
  - What is a “Good Death”

Supporting the Family Through Different Types of Deaths

Long-term Illness-Expected Decline

- Most Dementias have a very slow decline
- Anticipatory Grief
  - Can lead to Atypical Grief Reactions upon final passing
- Long Haul
- Uncertainty in planning for long term
- Marathon vs. Sprint

Sudden Death or Sudden Dramatic Downturn

- Even on Hospice passing can be unexpected
- Decision to forgo care can put patients on hospice sooner than families are expecting
- Fear of sudden death can prevent caregivers from getting respite

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Caregiver Resources

- Every Hospice has to have Social Work and Chaplin support
  - Family support for difficult dynamics
  - Practical care coordination
- Most hospices will provide grief support for 6 months or a year following the patient's passing
- Caring Connections Support Groups:
  - https://healthcare.utah.edu/caring-connections/

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