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.

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

<table>
<thead>
<tr>
<th></th>
<th>1998</th>
<th>2008</th>
<th>2018</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enrolled</td>
<td>12,829</td>
<td>60,488</td>
<td>210,000</td>
</tr>
<tr>
<td>Percent of Total</td>
<td>3%</td>
<td>6%</td>
<td>14%</td>
</tr>
<tr>
<td>Rank</td>
<td>12th</td>
<td>6th</td>
<td>1st</td>
</tr>
<tr>
<td>Length of Stay (days)</td>
<td>67</td>
<td>105</td>
<td>110</td>
</tr>
</tbody>
</table>
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**

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

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
Dementia Hospice Eligibility: Baseline Guidelines Plus 
Disease Specific Criteria

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
Typical Illness Trajectory for People with Progressive Chronic Illness

<table>
<thead>
<tr>
<th>Common Dementia Etiologies</th>
<th>ICD 10 Code</th>
<th>Etiology Criteria</th>
</tr>
</thead>
</table>
| 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 F02.81 | • 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 |

Alzheimer’s Disease and Other Dementia Coordinating Council, Utah Dept. of Health
3. Dementia Etiologies & Key Points
Important Implications of Course & Prognosis (Vary Greatly)

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

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


