Hospice and Palliative Care
Alzheimer’s Disease Working Group
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Palliative Care

• Specialized medical care for person with serious illness. Focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family.

• Palliative care is provided by a team of doctors, nurses, and other specialist together with a patient’s other doctors to provide an extra layer of support, appropriate at any age and at any stage in a serious illness and can be given with curative treatment.

CAPC 2012
Hospice Care

• Specialized care for persons and families with terminal illness and life expectancy of 6 months or less
• Provided by interdisciplinary team
• Focused on whole person care and quality of life
• Provided in homes, facilities, or specialized hospice units
• Medicare benefit – paid on per diem rate
Change in Number of Deaths Between 2000 and 2010

- Breast Cancer: -2%
- Prostate Cancer: -8%
- Heart Disease: -16%
- Stroke: -23%
- HIV: -42%
- Alzheimer's Disease: +68%

alzheimer's association
Referral to palliative care based on unmet need
Referral to hospice based on prognosis
AMA Quality Dementia Measure

1. Staging of dementia
2. Cognitive assessment
3. Functional status assessment
4. Neuropsychiatric symptom assessment
5. Management of neuropsychiatric symptoms
6. Screening for depressive symptoms
7. Counseling regarding safety concerns
8. Counseling regarding risks of driving
9. Palliative care counseling and advance care planning
10. Caregiver education and support
Elements of Palliative Care in Patients with Dementia

<table>
<thead>
<tr>
<th>Element</th>
<th>Stage of dementia</th>
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<tbody>
<tr>
<td>Communicating the diagnosis</td>
<td>Mild dementia</td>
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<td>Communicating prognosis</td>
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<td>Helping patient and family with anticipatory grief</td>
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<td>Assessing decisional capacity</td>
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<td>Helping patient assign a surrogate decision maker</td>
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<td>Discussing goals of care</td>
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<td>Discussing the role of artificial nutrition</td>
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<td>Discussing the role of antibiotics</td>
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<td>Helping patient and surrogate complete advance directives</td>
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<td>Planning for transitions in living situation if necessary</td>
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<td>Assessing medication appropriateness</td>
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<td>Assessing for comorbid depression</td>
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<td>Assessing and treating pain</td>
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<td>Assessing and treating delirium</td>
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<td>Reassessing goals of care and appropriateness of hospital transfer</td>
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<tr>
<td>Making hospice referral when appropriate</td>
<td>Moderate dementia</td>
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<td>Managing terminal pain and delirium</td>
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<td>Responding to family’s grief after patient death</td>
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<td>Expressing condolences</td>
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<td>Referring to community resources for grief counseling</td>
<td>Severe dementia</td>
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Merel, Clin Geri Med 2014
Barriers to Palliative Care for Persons with Dementia

• Dementia is not considered a terminal illness
• Lack of clinical knowledge about the course of dementia
• Lack of time to address in clinical visits
• Lack of reimbursement to discuss advance care planning
• Primary care considered the “owner” of advance directives
• Lack of coordination among clinicians, medical organizations (EMR)
• Change of goals as illness changes
Access to Hospice Care

• Utilization of hospice low for persons with dementia

• Estimate of 18-22% of all person dying with dementia receive hospice care

• Virtually all hospices provide care for persons with dementia

• Need is to manage the high symptom burden of pain, agitation and shortness of breath.
Barriers to Hospice Care

• Little research that looks at palliative or hospice care for person with dementia

• Dementia not viewed as terminal illness

• Lack of knowledge

• Difficulty in prognostication
Initiatives to Improve Access

• Educational efforts

• Collaborative efforts

• Teaching Rounds with gero-psychiatrist

• Franciscan Palliative Care Academy
Questions?