Caring for Members with Advanced Dementia

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May 14, 2008

Geriatric Education Center of Greater Philadelphia-HRSA funded
Objectives

• To appreciate dementia as a terminal diagnosis
• To recognize the signs of pain or distress in members with dementia
• To advocate for members who seem distressed or uncomfortable to address client needs
• To recognize physical changes indicating a member may be dying
Member Case: Mr. S

• Mr. S is a 88 year-old male member with Alzheimer’s Dementia who has lived with his daughter for the past 8 years since his wife passed away.
• He requires cueing for all basic activities of daily living, however eats independently. He is able to use his wheel chair with minimal assistance for transfers.
• His caregiver reports that lately he is having difficulty sleeping at night and “talking to someone in the room who is not there”.
Discussion Points

- What is dementia?
- How is this member coping with the diagnosis of dementia?
## Stages of Dementia

<table>
<thead>
<tr>
<th></th>
<th>MILD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Function</td>
<td>- independent of all ADLS, may need assistance with complex task</td>
</tr>
<tr>
<td>Cognition</td>
<td>- difficulty learning new information</td>
</tr>
<tr>
<td></td>
<td>- memory loss interferes with everyday functions</td>
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<tr>
<td></td>
<td>- mild word finding difficulty but maintain social conversation</td>
</tr>
<tr>
<td></td>
<td>- mild judgment impairment</td>
</tr>
<tr>
<td>Behavior</td>
<td>- mild personality changes</td>
</tr>
<tr>
<td>MMSE</td>
<td>$\geq 19$</td>
</tr>
</tbody>
</table>
# Stages of Dementia

<table>
<thead>
<tr>
<th>MODERATE</th>
</tr>
</thead>
</table>
| **Function** | - independent of all ADLS, may need reminders or minimal assistance  
- assistance or complete dependence with IADLs |
| **Cognition** | - substantial memory loss, disoriented in time and often to place  
- conversation disorganized, rambling  
- impaired judgment |
| **Behavior** | - may have psychotic behavior, wandering, agitated verbal or physical symptoms  
- sleep disturbance  
- appears well enough to be taken to functions outside of home environment |
| **MMSE** | 12-19 |
## Stages of Dementia

<table>
<thead>
<tr>
<th>SEVERE</th>
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</thead>
</table>
| **Function** | - dependent of all IADL  
- dependent of ADLs (incontinent, may need assistance with eating) |
| **Cognition** | - oriented to person only  
- only fragments of memory retained  
- severe language impairment  
- inconsistent recognition of familiar people  
- vary short attention span |
| **Behavior** | - emotional lability  
- restlessness  
- inability to focus on tasks  
- appears to ill to be taken to functions outside of the home environment |
| **MMSE** | 0-11 |
## Advanced Stages of Dementia

### PROFOUND

| Function                      | -dependent of all IADL  
|                              | -dependent of ADLs (loss of ambulation, feeds with assistance)  
| Cognition                    | -speaks <6 words  
|                              | -consistent difficulty in recognizing familiar people  
| Behavior                     | -repetitive vocalizations, calling out  
| MMSE                         | <11  

### TERMINAL

| Function                      | -inability to walk or sit up without assistance  
|                              | -inability to smile or hold head up  
|                              | >10% body weight loss, pressure ulcers >stage 2, UTIs, aspirations pneumonias  
| Cognition                    | -few words spoken  
| Behavior                     | -passive  
| MMSE                         | Not testable  

Trajectory of Chronic Illness

A. Cancer

B. Organ System Failure

C. Dementia/Frailty
Mr. S Continued:
Previous 6 months

- Functional decline noted by both daughter and caregiver.
- Less cooperative with care.
- Less talkative and less appropriate with answers.
- Needing more assistance with all basic ADLs.
- He has lost 20 lbs over the past 2 months.
Discussion Points

• Does our member have advanced dementia?
• Do you have a member that you are concerned about who meets these criteria?
Mr. S Continued: Hospital Stay

- Found to have ARF thought to be pre-renal due to dehydration and poor intake resolves with IVF.
- As well as UTI resolves with antibiotics.
- During her hospitalization she develops a stage 3 pressure ulcer.
- Patient no longer able to get out of bed and requires maximum assistance with all ADLs. She is also not cooperating with physical therapy.
Evidence Based Medicine for Dementia Prognosis… What there is of it!

- 1997 Luchins’ Study published in JAGS around the same time as development of Dementia Criteria for hospice admission

- 2004 Mitchell Study published in JAMA
Functional Assessment Staging

Stages
1. No difficulties
2. Subjective forgetfulness
3. Decreased job functioning and organizational capacity
4. Difficulty with complex tasks, instrumental ADLs
5. Requires supervision with ADLs
6. Impaired ADLs, with incontinence
7. A. Ability to speak limited to six words  
   B. Ability to speak limited to single word  
   C. Loss of ambulation  
   D. Inability to sit  
   E. Inability to smile  
   F. Inability to hold head up

Fast Fact and Concept #150: Prognostication in Dementia. Sing Tsai MD and Robert Arnold MD
Luchins’ Study

• Followed two cohorts separated by time and place (N=47) of hospice patients for 2 years

• Of both groups: median survival time of 4 months, average of 6.9 months, and 37% survived longer than 6 months

• Score >7c had mean survival time of 3.2 months

• Score <7c had mean survival time of 18 months
### Mitchell’s Dementia Prognosis Study

**Table 1. Description of Functional Assessment Stages and Comparable Minimum Data Set Variables**

<table>
<thead>
<tr>
<th>Functional Assessment Stage</th>
<th>Minimum Data Set Variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>6a = Improperly putting on clothes without assistance/cueing occasionally or more frequently over the past weeks</td>
<td>Limited or more extensive assistance required to dress on at least several occasions during the last 7 days</td>
</tr>
<tr>
<td>6b = Unable to bathe properly (e.g., difficulty adjusting water temperature) occasionally or more frequently over the past weeks</td>
<td>Supervision or more assistance required to bathe during the last 7 days</td>
</tr>
<tr>
<td>6c = Inability to handle the mechanics of using the toilet occasionally or more frequently over the past weeks</td>
<td>Limited or more extensive assistance required to use the toilet on at least several occasions during the last 7 days</td>
</tr>
<tr>
<td>6d = Urinary incontinence occasionally or more frequently over the past weeks</td>
<td>Urinary incontinence at least twice a week</td>
</tr>
<tr>
<td>6e = Bowel incontinence occasionally or more frequently over the past weeks</td>
<td>Bowel incontinence at least twice a week</td>
</tr>
<tr>
<td>7a = Ability to speak limited to ≤1 intelligible word in an average day</td>
<td>Rarely/never makes self understood</td>
</tr>
<tr>
<td>7b = All intelligible vocabulary is lost</td>
<td>Rarely/never makes self understood</td>
</tr>
<tr>
<td>7c = Nonambulatory</td>
<td>Extensive assistance (or total dependence) required for locomotion (i.e., move between locations) during the last 7 days</td>
</tr>
</tbody>
</table>
### Palliative Performance Scale (PPS)

<table>
<thead>
<tr>
<th>%</th>
<th>Ambulation</th>
<th>Activity and 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 No Evidence of Disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>90</td>
<td>Full</td>
<td>Normal Activity Some Evidence of Disease</td>
<td>Full</td>
<td>Normal</td>
<td>Full</td>
</tr>
<tr>
<td>80</td>
<td>Full</td>
<td>Normal Activity with Effort Some Evidence of Disease</td>
<td>Full</td>
<td>Normal or Reduced</td>
<td>Full</td>
</tr>
<tr>
<td>70</td>
<td>Reduced</td>
<td>Unable Normal Job / Work Some Evidence of Disease</td>
<td>Full</td>
<td>Normal or Reduced</td>
<td>Full</td>
</tr>
<tr>
<td>60</td>
<td>Reduced</td>
<td>Unable Hobby / House Work Significant Disease</td>
<td>Occasional Assistance Necessary</td>
<td>Normal or Reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>50</td>
<td>Mainly Sit/Lie</td>
<td>Unable to Do Any Work Extensive Disease</td>
<td>Considerable Assistance Necessary</td>
<td>Normal or Reduced</td>
<td>Full or Confusion</td>
</tr>
<tr>
<td>40</td>
<td>Mainly in Bed</td>
<td>As Above</td>
<td>Mainly Assistance</td>
<td>Normal or Reduced</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
<td>30</td>
<td>Totally Bed Bound</td>
<td>As Above</td>
<td>Total Care</td>
<td>Reduced</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
<td>20</td>
<td>As Above</td>
<td>As Above</td>
<td>Total Care</td>
<td>Minimal Sips</td>
<td>Full or Drowsy or Confusion</td>
</tr>
<tr>
<td>10</td>
<td>As Above</td>
<td>As Above</td>
<td>Total Care</td>
<td>Mouth Care Only</td>
<td>Drowsy or Coma</td>
</tr>
<tr>
<td>0</td>
<td>Death</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Family Discussion

• Family does not wish to pursue aggressive work-up.
• Due to the progressive decline over the past 6 months the team discusses options, including feeding tube.
Discussion Points

• How do we as a team come together with the family on nutrition at the end of life?
• How do we know how to feed in patients with advanced dementia?
Member Case Continued: Mr. S

POA, daughter, feels that comfort goals of care is the most appropriate and would support her father’s previously expressed wishes. She would like to focus on pain and symptom management, maintaining dignity and peacefulness.
Back to Our Member Mr. S

• He receives home visits from RN 1-2x/week and agency caregiver for 20hours/week.
• He is mainly bed bound and is put in a reclining chair with hoyer lift 2-3x/week.
• His daughter is concerned about pain or symptom management issues during this time.
Pain and Symptom Assessment

• How can you tell if Mr. S is in pain or uncomfortable?
• How do you communicate this with his family and medical team?
Adequate Pain Assessment

• Requires repeat comprehensive assessments
• Older adults under-report pain → ”normal aging”
• Scales—choose a scale that is appropriate based on cognitive and communication abilities of the individual (re-assess using the SAME scale)
  – 1-10
  – Faces
  – Non-verbal assessment

Pain Assessment IN Advanced Dementia (PAINAD)

5 Categories (uses scale 1-10)

• Breathing
• Negative vocalization
• Facial expressions
• Body language
• Consolability

Back to Our Member: Mr. S

- Restless at rest (moving his legs)
- Nonverbal, barely opening her eyes
- Grimacing with any movement of his body
Plan of Care for Mr. S

• His caregiver felt that he was in pain from pressure points.
• After negotiating a plan of care with the family, all agreed to start her schedule acetaminophen (tylenol).
• A few days later, he was still uncomfortable...scheduled morphine was added with good relief.
Is Mr. S Dying?

What signs and symptoms would you look for in any Member?
Signs and Symptoms of Dying

- Pain
- Difficulty breathing (dyspnea, irregularity)
- Oral secretions
- Confusion (delirium)
- Nausea/Vomiting
- Poor appetite (anorexia/cachexia)
- Tired/weak (fatigue)
- Spiritual Suffering
- Anxiety/Depression
- “Unfinished business”
Syndrome of Imminent Death

**Early**
- Bed Bound
- Loss of appetite or ability to take anything by mouth
- Cognitive changes: more sleeping and/or delirium

**Middle**
- Further decline in mental status to obtundation
- Pooling of oral sections that are not cleared due to loss of swallowing reflex

**Late**
- Coma
- Fever (felt to be from aspiration pneumonia)
- Altered respiratory pattern
- Mottled extremities
Preparing a Family to Know When Death Has Occurred

- No breathing and heartbeat
- Loss of control of bowel or bladder
- No response to verbal commands or gentle shaking
- Eyelids slightly open; eyes fixed on a certain spot
- Jaw relaxed and mouth slightly open
1 Week Later…

Mr. S died at home peacefully and comfortably with his daughter at his side.
Summary

• To appreciate dementia as a terminal diagnosis
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• To advocate for members who seem distressed or uncomfortable to address client needs
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References


