End of Life Care in Dementia

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Clinical Course of Dementia

<table>
<thead>
<tr>
<th>Time</th>
<th>Early</th>
<th>Middle</th>
<th>Late</th>
<th>Final</th>
</tr>
</thead>
<tbody>
<tr>
<td>Independence</td>
<td></td>
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</table>

Late Stage Dementia

- Severe short-term and long-term memory deficits
- Limited orientation to place, time, and people
- Severe aphasia
- Inability to dress, eat, toilet
- Limited mobility
- Est. lifespan: 0-3 years

Final Stage Dementia

- Wheelchair/bedbound
- Single words or mute
- Dysphagia
- Anorexia/ weight loss
- Recurrent infections
- Est. lifespan: 0-12 months

Current Realities in Dementia

- No disease modifying drugs
- Most people with advanced live in LTC facilities
- Dementia is the fifth leading of death in older Americans
- EOL care is generally poor
- Crisis responses to expectable decisions are the norm

Dying in LTC: Dementia vs. Non-Dementia

- ↑ Shortness of breath
- ↑ Pressure ulcers
- ↑ Use of restraints
- ↑ Use of sedatives
- ↑ residents dying alone
- ↓ Family communication with physician

Source: Sloane, Zimmerman, Williams & Hanson, 2008.
Common EOL Decisions

- Blood work?
- Drugs? Anti-psychotics?
- Tests & procedures?
- Artificial nutrition?
- Antibiotics?
- Hospitalization? DNH?
- CPR? DNR?
- Palliative care?
- Hospice care?

Key Concept # 1

- The burdens of aggressive care in the advanced stages often exceed the benefits.

- What is the goal of care?

Illinois: 34 physician visits in last 6 months of life, 9 different physicians

Burdensome Care

- 323 nursing home residents with advanced dementia over 18 months, 55% died, with nearly half of deaths occurring within 6 months.

- 40% of residents who died were sent to the emergency room, hospitalized, tube-fed or given IV nutrition during the last 3 months of life.

Source: Mitchell et al., 2008.

Burdensome Admissions

- Estimates of avoidable hospitalizations from NH range from 23% to 55%.

- Dislocation trauma resulting in high risk for cognitive, behavioral and functional decline.

- Professionals make decisions with little or no say by others.

Burdensome Tests

- A study 2,131 women age 70 and older showed that 18% of women with advanced dementia received screening mammography, compared with 45% of women with normal cognitive status.

- An estimated 120,000 screening mammograms were performed on women with advanced dementia.

Source: Mehta et al., 2010.
Key Concept #2

• Distressing symptoms can be prevented and needs can be anticipated.

• Challenging behaviors associated with dementia have many possible triggers: physical, emotional, environmental, and approaches by caregivers.

Anticipate Needs

In simplest terms this means:

• to feed the person before hungry,
• to give fluids before thirsty,
• to help someone lie down before tired or sleepy,
• to manage pain before it is out of control,
• to engage someone before loneliness or boredom set in.

Pain Assessment in Advanced Dementia (PAINAD)

<table>
<thead>
<tr>
<th>Score</th>
<th>Breathing Independent of Vocalization</th>
<th>Facial Expression</th>
<th>Body Language</th>
<th>Consolability</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Normal</td>
<td>None</td>
<td>Relaxed</td>
<td>No need to console</td>
</tr>
<tr>
<td>1</td>
<td>Occasional labored breathing, short period of hyperventilation</td>
<td>Occasional moan or groan, low level of speech with a negative or disapproving quality</td>
<td>Tense, distressed pacing, fidgeting</td>
<td>Unable to console, distract or reassure</td>
</tr>
<tr>
<td>2</td>
<td>Noisy labored breathing, long period of hyperventilation, Cheyne-Stokes respirations</td>
<td>Repeated troubled calling out, loud moaning or groaning, crying</td>
<td>Rigid, fists clenched, knees pulled up, pulling or pushing away, striking out</td>
<td>Unable to console, distract or reassure</td>
</tr>
</tbody>
</table>

Most Common Distressing Symptoms

Source: Mitchell et al., 2009.

Anticipate Needs

A Campaign against Pain

• Pain is grossly underrecognized and undertreated.

• Agitation is often a symptom of pain.

• Sources of pain?

• Anti-psychotics mask pain: 24% of NH residents

Pain Management Steps

1. Meet basic needs
2. Use soft approach
3. Assess location(s)
4. Check for pain hx
5. Empiric trial of analgesic – no PRN
6. Provide non-drug intervention too
7. Re-evaluate in 1 hour
8. Document

Goal: PAINAD score <4 within 48 hours
**Analgesic Therapy**

- WHO Three-Step ladder
- Around the clock vs. PRN
- Start stool softeners with opioid therapy

**Non-Pharmacologic Measures**

- Repositioning
- Broda chairs
- Massage
- Comfort foods
- Aromatherapy
- Music
- Rest periods/sleep
- Heat/cold packs
- "Soft approach"

**Key Concept # 3**

- Crisis decision making can be prevented through education and care planning with families.
- At admission and ongoing through care plan meetings.
- Family events and support groups.

**Family Education**

Families who understand dementia’s terminal prognosis are less likely to allow:
- ED visits
- Repeated hospitalizations
- Feeding tube insertions

Source: Mitchell et al., 2009.

**Encouraging Comfort Care: A Guide for Families of People with Dementia Living in Care Facilities**

www.alz.org/illinois

**Key Concept # 4**

- High quality care is all about interpersonal relationships.
- Know each person’s story
- Involve families as partners in care
- Engage in meaningful activities
What Caregivers Should Know

- What name does the person preferred to be called?
- Where were they born?
- Where did they live?
- What are their parents’ names?
- What did their parents do for a living?
- What are the names of their siblings?
- Work history?
- Favorite food? Drink? Music?

Meaningful Connections

- Hearing
- Smell
- Taste
- Touch
- Sight

Key Concept # 5

- Pleasurable dining experiences can reduce or eliminate weight loss until the end of life.
- Liberalize diets, per American Dietetic Assn. recommendations
- Pleasure foods available 24/7
- Feeding tubes optional

Pleasure Feeding

- Despite difficulty using utensils, finger foods may be enjoyable.
- Consider pleasure tastings such as honey or chocolate

Nutrition Pattern

Regular food → Soft food → Mechanical soft with chopped meat → Pureed → Thick liquids

Pureed Food Presentation
**Tube Feeding?**

Artificial nutrition and hydrationproduce no beneficial outcomes in terms of survival, nutritional status or pressure ulcers for people with advanced dementia.


**Catholic Teaching**

“Medically assisted nutrition and hydration should be morally optional when they cannot reasonably be expected to prolong life or when they would be excessively burdensome for the patient or would cause significant discomfort…”


**Key Concept # 6**

- Referral to hospice & palliative care should be routine.
- Aggressive medical care should be rare.
- Ask: Would you be surprised if this person died in the next 12 months?
- Everyone should know the difference between hospice and palliative care.

**What is Palliative Care?**

- Medical treatment that aims to relieve suffering and improve quality of life simultaneously with all other appropriate treatment for patients with serious illness & their families.
- Palliative care is a holistic approach to care.
- Palliative care can also be consultation service by MDs, NPs, and others.

**Putting it into Practice**

- Expert control of pain and other symptoms.
- Practical support for family & other caregivers.
- Clarify the goal of all care decisions.
- Comfort is the guiding principle of all care decisions.

**A Realistic Approach Dementia**

- Life Prolonging Therapy
- Palliative Care
- Hospice Care
What is Hospice?

- Hospice is a team-based approach to care involving professionals and trained volunteers to help individuals and their families face life-limiting illness with dignity, comfort, and compassion.

- It is primarily home-based care for those with an expected lifespan of 6 months or less.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Hospice</th>
<th>Palliative Care</th>
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<tbody>
<tr>
<td>Eligibility</td>
<td>Prognosis &lt; 6 months</td>
<td>None required</td>
</tr>
<tr>
<td>Professional Services</td>
<td>Interdisciplinary team: Physician, Nurse, Social Worker, Pastoral counselor, Nursing assistants, Others as needed</td>
<td>Single provider or team: Physician, Nurse, Social Worker, Others as needed</td>
</tr>
<tr>
<td>Other services</td>
<td>Medications, DME, Bereavement care</td>
<td>No required services</td>
</tr>
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<td>Determined by org.</td>
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Barriers to Hospice Care

- Nursing homes are paid higher rates for residents with feeding tubes or in skilled care.

- Care plan meetings in nursing homes seldom address expected care decisions in advanced dementia or emotional aspects of caregiving.

- Dementia is poorly recognized as a terminal illness by staff and families.

Hospice in LTC

- At time of admission, only 1% of residents with advanced dementia were perceived by staff to have a life expectancy of less than 6 mos.

- In reality, 71% died within 6 mos. and 6% of these residents enrolled in hospice.

Source: Mitchell et al., 2004.

Hospice Eligibility Criteria

- Without assistance
  - Unable to walk
  - Unable to dress
  - Unable to bathe
  - Urinary or fecal incontinence
  - No meaningful communication

- Plus one of the following in the past 12 months:
  - Aspiration pneumonia
  - Pyelonephritis or other UTI
  - Septicemia
  - Multiple stage 3/4 ulcers
  - Unable to maintain sufficient fluid/caloric intake
Benefits of Hospice

• A large study of 22 NHs homes showed that residents with dementia enrolled in hospice were more likely to receive scheduled pain treatment and their proxies reported fewer unmet needs at EOL.

• Another study showed NH residents with dementia in hospice had better pain management & fewer hospitalizations than those not receiving hospice.

• Family members of hospice recipients with dementia are less likely to report unmet needs and concerns with quality of care.

Sources: Kiely et al. 2011; Kuo et al., 2009; Teno et al., 2011.

Resources


