



INFO-CONNECT

Hospice Approach to End-of-Life Dementia Care

The Facts . . .

- Progressive dementia afflicts over four million.
- Cause of death is often a medical complication secondary to dementia, usually infection.
- No effective treatment exists for progressive dementias like Alzheimer’s disease, making them “terminal diseases” like incurable cancers.
- Fewer than 1 percent of those with dementia are enrolled in hospice care programs.
- Most people with advanced stage dementia receive care in nursing facilities.
- Decisions about life-sustaining methods tend to be made in haste, at the moment of medical crisis, and without benefit of full information.
- Use of hospice and palliative care approaches to advanced dementia emphasizes quality of life at the end of life for those with dementia.

Hospice Goals for Advanced Dementia Care

The hospice approach minimizes patient suffering and provides a compassionate environment for those in the terminal stages.

- Promotes comfort and quality of life without use of life extending measures.
- Focuses on close, collaborative working relationships between health care team members and family:
 - ⇒ Thoughtful discussion of patient’s beliefs and wishes
 - ⇒ Review of advance directives
 - ⇒ Encouragement of family consensus, discussion, or use of ‘spokesperson(s)’
 - ⇒ Assistance to consider risks and benefits of treatment or withholding of treatment
 - ⇒ Provision of specific information needed to make decisions about:
 - Characteristic losses/problems related to terminal dementia
 - Risks, issues, and potential benefits of various medical interventions
 - Information provided well in advance of crisis situations that demand immediate decisions
 - ⇒ Referral to alternative sources for information¹ (e.g. Your Life, Your Choices)
 - ⇒ Involvement of spiritual and religious counsel (e.g. chaplain)
 - ⇒ Recognition of and assistance with grieving processes

- Considers advanced dementia as a terminal illness, much like cancer.
- Offers diverse comfort measures to promote end-of-life care and quality of life.
 - ⇒ Occupational / recreational therapies
 - ⇒ Meticulous nursing care
 - ⇒ Oral hygiene; special diet if applicable
 - ⇒ Antipyretics for fevers
 - ⇒ Analgesics for pain
 - ⇒ Low doses of morphine for restlessness
 - ⇒ Atropine to decrease pulmonary secretions
 - ⇒ Oxygen if the patient is dyspneic

¹ An example is Your Life, Your Choices, a workbook designed to assist patients and family members with understanding / developing advance directives. Provided by the Veterans Health Administration at: <http://www1.va.gov/pugetsound/docs/ylyc.pdf>

Characteristic Problems

Dementia progresses to a ‘terminal’ phase of profound mental and physical impairment.

- Profound loss of mental abilities, including:
 - ⇒ Inability to recognize family, friends, or self
 - ⇒ Inability to initiate meaningful activity
 - ⇒ Inability to verbally communicate needs or desires
- Eating difficulties, with associated malnutrition and weight loss due to:
 - ⇒ Chewing difficulties

- ⇒ Swallowing difficulties
 - ⇒ Food refusal
 - Inability to move independently results in complications of immobility.
 - ⇒ Skin breakdown and pressure ulcers
 - ⇒ Contractures and pain with movement
 - ⇒ Fall risk and injury
 - ⇒ Respiratory, urinary tract, and other infections
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Causes of Death for Persons with Dementia

Research shows that persons with dementia commonly die from infections and other causes:

- Pneumonia - 54 to 69 percent
 - Urinary tract infections - 6 percent
 - Sepsis - 5 percent
 - Cardiovascular accidents - 25 percent
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Risk of Discomfort with Medical Treatment

The potential benefit of medical treatments must be weighted against possible risks of fear, increased confusion, and discomfort created by the treatment.

- Treatment of dementia consists primarily of symptomatic treatment of behavioral problems, insomnia, and intercurrent illness.²

- Aggressive medical treatment in advanced dementia poses an ethical conflict between the obligation to prevent death and the obligation to prevent suffering.
- Many interventions aimed at postponing death also may increase suffering.
 - ⇒ Aftermath of cardiopulmonary resuscitation (CPR) produces undue stress and discomfort for a severely confused person.
 - ⇒ Transfer to inpatient medical care presents many potential discomforts:
 - Relocation increases confusion and fear
 - Invasive diagnostic procedures and treatments may be painful and upsetting
 - Resistance by the confused person may result in restraint use, with risk of increased confusion and injury
- Use of artificial feeding tubes (nasogastric or gastrostomy) decreases risk of aspiration but imposes other problems:
 - ⇒ Tubes are often uncomfortable and frightening to the confused person
 - ⇒ Tubes eliminate the tasting of food as a source of pleasure
 - ⇒ Decisions on when or how to remove feeding tubes are complex

² The term intercurrent (vs. concurrent) illness is preferred because most illness interacts with dementia: other illness (like pneumonia) affects the course of dementia AND dementia affects the course of the illness.

Barriers to Hospice Use in Dementia Care

The right to refuse treatment is generally recognized. Consensus does not exist on the most appropriate way to obtain approval of decisions to limit treatment of incompetent patients.

- Most hospice programs require that death within six months is predicted, but the 'terminal' phase of dementia may be prolonged and difficult to predict.
- People with end-stage progressive dementia lack the decision-making competence to select hospice care, except through advance directives.
- Insidious onset and course confound advanced planning and decision-making:
 - ⇒ Wishes aren't discussed with family during early stages
 - ⇒ Advance directives aren't used or are undertaken after disease has progressed (and therefore are questioned)
 - ⇒ Proxy directives (i.e., durable power of attorney) are not in place 'in time'; the person is already too compromised to assign legal authority
- Physical appearance of patient may be inconsistent with need for end-of-life care:
 - ⇒ Person "looks good" but is unable to execute even simple activities
 - ⇒ Acute illness is often treated aggressively
 - ⇒ Use of extraordinary measures is common, yet often increases suffering
 - ⇒ Financial and emotional costs to families are high

Five Levels of Care Promote Optimal Treatment

Volicer and colleagues developed, implemented, and evaluated a five-level protocol in their program for using hospice and palliative care approaches in advanced dementia care. Each level of care sequentially limits aggressive medical interventions, with specific intensive nursing care interventions.³

Levels 1 through 5					
Treatment/ Interventions	1	2	3	4	5
Diagnostic workup	Yes	Yes	Yes	Yes	Yes
Treat co-existing conditions (e.g., antibiotics for life-threatening infection)	Yes	Yes	Yes	No	No
Transfer to acute care if needed ^a	Yes	Yes	No	No	No
Cardiopulmonary resuscitation if arrest	Yes	No	No	No	No
Tube feeding if normal intake not possible ^b	Yes	Yes	Yes	Yes	No
Comfort measures, antipyretics, & analgesics	Yes	Yes	Yes	Yes	Yes

a-The decision to not transfer the patient to an acute care facility eliminates the use of respirators, cardiovascular support, and other 'medically aggressive' interventions that are only available in the acute medical setting.

b-Use of feeding tubes is encouraged ONLY if swallowing problems are temporary and the person is viewed as having the ability to regain capacity; goal is short-term use only for all levels.

³ Pain assessment and management is critical in the hospice approach to advanced dementia care. Please refer to earlier INFO-CONNECTS on pain assessment and interventions for additional information on this aspect of care.

Care Conference Decision-Making

Decision-making related to patients with advanced dementia requires close, collaborative working relationships between family members and the multidisciplinary team providing care. Recommendations to reduce the number and type of life-extending measures, as outlined in Levels 1 to 5 in the table, are based on thoughtful review of the person's current level of disability.

For example, family and staff may initially agree that using CPR is still appropriate (Level 1). Later, use of a DNR order may be a better choice (Level 2). As the person deteriorates, additional decisions about transfer to acute care (Level 3), treatment of infections (Level 4), and use of feeding tubes (Level 5) may be added to the agreement.

Reviewing losses during care conferences helps family understand their loved one's level of disability, and encourages discussion of "risk" associated with various treatments. Losses outlined under "Hospice Enrollment Criteria" provide important criteria by which disability can be gauged. The following steps are recommended for interacting with family and establishing levels of care.

- Facility team members develop consensus on optimal level of care.
 - ⇒ Team members include head nurse and/or nurses involved, social worker, nurse practitioner, attending physician, and chaplain.
 - ⇒ Current stage of illness, retained abilities, and loss of function are carefully reviewed.
 - ⇒ Consensus is used as a guideline for discussion with family.
- Family is asked about known or expressed wishes.

- ⇒ Survival in a mentally debilitated state
- ⇒ Desire for mechanical devices
- ⇒ Other advanced directives discussed with family prior to incapacitation
- Staff recommendations are reviewed and discussed with family, and agreement is reached regarding specific life-sustaining actions related to level of care.
- Decisions are summarized in written format and sent to family to review.
 - ⇒ Family may sign or make recommendations for revisions.
- Summary states that family can change decision about optimal care at any time.
- Signed summary statement is included in patient chart.
- Physician order specifying level of care is recorded on physician's order sheet.
- Order is reviewed and renewed monthly.
- Family care conference is repeated upon substantial change in condition or upon family request.

Hospice Enrollment Criteria for Advanced Dementia Patients

Patients who are considered 'Level 5' often share common characteristics. Criteria for enrollment in Hospice include:

1. Signs of severe cognitive impairment.

- ⇒ Low mental status scores, if known (e.g., Mini-Mental State Exam score of one or less)
- ⇒ All of the following due to severe cognitive decline:
 - Incontinence
 - Needs assistance with eating
 - Needs assistance with walking
 - Needs assistance with bathing and grooming
 - Very limited speech or cannot communicate meaningfully
 - Unable to engage in purposeful activity

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2. Serious complications of dementia, including history of one or more of the following:

- ⇒ Difficulty swallowing food
- ⇒ Aspiration pneumonia
- ⇒ Dehydration
- ⇒ Malnutrition
- ⇒ Severe urinary tract infections
- ⇒ Decubitus ulcers
- ⇒ Septicemia
- ⇒ Other serious complications

Criteria used in research described in L. Volicer and A. Hurley (1998) *Hospice Care for Patients with Advanced Progressive Dementia*, New York: Springer Publishing Company. Used with permission. This text is highly recommended for additional information about the hospice and palliative care approaches, issues, and methods.

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Hospice Care for Patients with Advanced Progressive Dementia.
 New York; Springer Publishing Company