

Family Connect

Hospice Approach to End-of-Life Dementia Care

The Facts

- Progressive dementia affects over five million people.
- Cause of death is often a medical complication secondary to dementia, such as infection.
- No effective treatment exists for progressive dementias like Alzheimer's disease, making them terminal diseases.
- Less than 1% of those with dementia are enrolled in hospice care programs.
- Decisions about life-sustaining methods tend to be made in a hurry at the moment of a medical crisis and without the benefit of full information.
- Hospice and palliative care emphasize quality of life at the end of life.

Hospice Goals

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

- Promotes comfort and quality of life without using life-extending methods; however, acute care services and treatments can still be utilized.
- Focuses on close, working relationships between healthcare team members and family:
 - Thoughtful discussion of the individual's beliefs and wishes
 - Review of advance directives
 - Encouragement of family consensus, discussion, and use of spokespersons
 - Help families to think about risks and benefits of treatment or withholding of treatment
 - Provide information needed to make decisions about:
 - Characteristic losses/problems related to terminal dementia (see pg. 2)
 - Risks, issues, and potential benefits of various medical interventions
 - Referral to alternative sources for information (e.g., *Your Life, Your Choices*)
 - Involvement of spiritual and religious counselors (e.g., a 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 patient is dyspneic

¹*Your Life, Your Choices* is a workbook designed to assist individuals and family members with understanding and developing advanced directives. https://books.google.com/books/about/Your_Life_Your_Choices_Planning_for_Futu.html?id=ECKSr69RNuEC

Information is provided well in advance of crisis situations that demand immediate decisions.

Characteristic Problems

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

Mental Capacity

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

Nutrition

Eating difficulties, with associated malnutrition and weight loss due to:

- Chewing difficulties
- Swallowing difficulties
- Food refusal

Mobility

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

Causes of Death for Persons with Dementia

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

- *Pneumonia (54-69%)*
- *Cardiovascular accidents (25%)*
- *Urinary tract infections (6%)*
- *Sepsis (5%)*

Risks of Discomfort with Medical Treatment

The potential benefit of medical treatments must be weighed against possible risk of fear, increased confusion, and discomfort created by the treatment. Treatment of dementia consists primarily of symptomatic treatment of behavioral problems, insomnia, and co-occurring illnesses. 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 may also increase suffering.

Resuscitation

CPR may produce undue stress and discomfort for a severely confused person.

Transfers

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 injury and increased confusion.

Feeding Tubes

Use of artificial feeding tubes (nasogastric or gastric) 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 about when or how to remove feeding tubes are complex.

Barriers to Hospice Use in Dementia Care

The right to refuse treatment is generally recognized. There is no consensus on the appropriate way to obtain approval of decisions to limit treatment for incompetent individuals.

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 may not be able to make a decision to select hospice care, except through advance directives.

Slow onset and course make advanced planning and decision-making difficult.

- Wishes often are not discussed with family during the early stages.
- Advance directives are not used after the disease has progressed, which undermines decision-making.
- Proxy directives, including durable power of attorney, may not be in place in time, because the person is already too compromised to assign legal authority.
- The physical appearance of the patient may not be consistent with the need for end-of-life care:
 - The person may look good but is unable to engage in 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.

Hospice Enrollment Criteria for Patients with Advanced Dementia

Criteria for enrollment in hospice include:

1. Signs of severe cognitive impairment.

Low mental status scores (e.g., a mini-mental state exam score of 1 or less), and all of the following symptoms 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

2. Serious complications of dementia

Includes a history of one or more of the following:

- Difficulty swallowing food
- Aspiration pneumonia (lung infection caused by inhaling food, liquid, or vomit)
- Dehydration
- Malnutrition
- Severe urinary tract infections
- Decubitus ulcers (bed sores)
- Septicemia (blood poisoning)
- Other serious complications

Care Conference Decision-Making

Decision-making in advanced dementia requires close, collaborative working relationships between family members and the medical team providing care. Recommendations to reduce the number and type of life-extending measures 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 appropriate. Later, use of a DNR (do not resuscitate) order may be a better choice. As the person deteriorates, no additional treatment of infections and no use of feeding tubes 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 the risks associated with various treatments. Losses outlined in the Hospice Enrollment Criteria section (see pg. 3) provide important criteria for recommendations to family members regarding the appropriate level of care.

Process of Hospice Care Conference

1. Care team members develop a consensus on optimal level of care.
 - Team members may include the head nurse and/or nurses involved, social workers, 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 the family.
2. The family is asked about the individual's known or expressed wishes.
 - Survival in a mentally debilitated state.
 - Desire for mechanical devices.
 - Other advanced directives discussed with family prior to incapacitation.
3. Staff recommendations are reviewed and discussed with family, and agreement is reached regarding specific life-sustaining actions related to level of care.
4. Decisions are summarized in written format and sent to the family for review.
 - Family may sign or make recommendations for revisions.
 - Summary states that the family can change their decision about optimal care at any time.
5. A signed summary statement is included in the individual's care plan.
6. A physician order specifying level of care is recorded on the physician's order sheet.
7. The order sheet is reviewed and renewed monthly.
8. The family care conference is repeated upon substantial change in condition or upon family request.



References

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