

Hospice and Palliative Care for Fronto Temporal Dementia

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Grandma Rood

- First major symptoms at 57, doing “bicycles” at grandpa’s funeral.
- Long course at a nursing home, dying at 73.
- No hospice care provided in the '70s, no support groups, no caregiver conferences.

Things have changed!

- 1974-first hospice programs in the US. Major focus was cancer.
- 1983-Medicare decides to cover hospice & the end of life disease states covered by hospice begins to expand.
- ~2000-Palliative care programs are formed to bridge the gap between “healthy” and “hospice”.
- Better understanding of FTD.
- Much better support.

How Will I Know?

- A loved one has an advanced chronic illness characterized by worsening of a disease that is not responsive to curative measures.
- Poor quality of life; suffering.
- Increasing worry on the part of the caregiver.
- Needing support and someone to talk to about the many issues.

Palliative Care

- A program of medical services for symptom management and social service for patients with severe chronic illness.
- Must be home bound to additionally use home care services like nursing visits or physical therapy.
- Covered by Medicare Part B like regular office visits.

- Can still be pursuing active treatment.
- Less focus on the disease itself but on management of the symptoms.
- Holistic in that it focuses on physical, psychological, spiritual and social aspects of care.
- Can assist with family conflicts regarding care.

Hospice Care

- Must have an end-of-life diagnosis and an attending physician that predicts the patient has 6 months or less to live.
- Hospice is a team approach to end of life care involving nursing care, social workers, aides, spiritual care personnel, volunteers and physicians.
- No further curative care is planned
- Goals of care are control of symptoms such as pain and nausea, assisting the patient and family and easing the transition from this life.

- Assist with decision making, allay fears, navigate with experienced, caring staff.
- Covered 100% by Medicare Part A.

Broadening the Spectrum of Palliative Care



Some Facts About Hospice

- The optimal time in Hospice is 2 months or more because there is often a lot to accomplish.
- The median stay nationwide is 2 weeks.
- Stays of 2 hours to a few days are not uncommon giving the families and staff very little time to get a lot done!

Cont'd

- Aside from the "Thank you"s on our satisfaction surveys at HOWC, a very common comment is "I wish we would have called hospice sooner!"

Hospice facts

- In a recent study, recipients of hospice care lived an average of 29 days longer than others with similar disease.
- All too often, physicians refer very late in the disease process or patients/family are not ready until the patients are in the dying process.
- Physicians overestimate survival by an average of 2 months.
- Disease courses can be very difficult to predict especially COPD and dementia.

Hospice Guidelines for Dementia

- Severity of dementia: FAST 7C
 - Unable to walk
 - Incontinent
 - Unable to speak more than 6 words
- Severe comorbid condition in the past 6 months
 - aspiration pneumonia

continued

- kidney infection
- septicemia
- Stage III or IV decubitus ulcers
- Fever despite antibiotics
- Unable to maintain caloric intake
- If a feeding tube in place, wt loss >
 - 10 %/6 months or albumin <2.5 gm/dL

Advocating for your loved one

- Ask questions.
- Don't be afraid to ask for help.
- Ask about palliative care or hospice.
- Know your loved one's wishes regarding care at the end of life.

QUESTIONS???