Offering hope in the face of apparent hopelessness: Hospice enhances end-of-life care

This article, written by Dr. Tara Friedman, senior medical director at VITAS Innovative Hospice Care® of Blue Bell, Montgomery County, PA, is a general introduction to hospice services and identifies patients who might benefit. Future articles in this series will address hospice in specific disease states and provide guidance for discussing end-of-life options.

Consider this example:

Mr. James is a 79-year-old diabetic with mild dementia, coronary and peripheral vascular disease, and chronic renal insufficiency. He wants to stay at home, but his 83-year-old wife struggles with his care. He is periodically agitated and has significant diabetic neuropathic pain. He was hospitalized twice in the past six months for non-healing leg ulcers and atypical chest pain. He and his family refuse the recommended below-the-knee amputation. While visiting his doctor, he is mildly agitated and complains of leg pain, constipation, and no appetite. He now spends almost all day in bed or in a chair and cannot walk well. It was hard to get him to the visit.

In this setting of progressive incurable illness, physicians often avoid suggesting palliative care, because they fear removing hope. Getting better? Quite the opposite is true: When a cure is unavailable, establishing realistic goals permits hope in the face of apparent hopelessness.

Advanced illness changes a doctor's role from achieving a cure to relieving suffering. Goals like good quality of life, time with family, and good pain and symptom management while avoiding prolonged hospitalization are achievable.

Although nearly 90 percent of Americans die after prolonged illness, the National Hospice and Palliative Care Organization (NHPCO) estimates only 35 percent of decedents received hospice services in 2006.

When the modern United States hospice movement began 30 years ago, almost all referred patients had cancer. Today, more than half of hospice patients have nonmalignant disease. Not commonly considered "terminal," dementia and chronic medical-disease patients also require symptom control when their conditions reach advanced stages.

Adults or children in advanced stages of dementia, Parkinson's disease, HF, COPD, pulmonary fibrosis, cerebrovascular disease, hepatic disease, renal failure, AIDS, ALS, and Huntington's disease may be appropriate for hospice.

We learn our patient's care preferences by asking, "Given where we are today, what are you hoping for?" Palliative care discussions follow naturally.

Ideally, such conversations begin with the patient well enough to participate and evolve as illness progresses.

When is "too early" for hospice?

In discussing care goals, the physician learns Mr. James hates the hospital but that his wife is barely coping at home. Hospice provides additional home support.

Dr. Daniel Haimowitz, a geriatrician in Bucks County, notes, "There is far more benefit from hospice if it's started earlier, rather than waiting until only days before someone dies." However, NHPCO's 2006 data shows the median hospice stay is only 20.4 days.

NHPCO's guidelines help identify advanced illness patients with a significantly decreased prognosis. However, the clinician's judgment is the most essential factor in determining prognosis.

A patient may be appropriate for hospice when:

- the patient understands she/he has a life-limiting condition;
- the patient and/or family elect palliative, not curative, treatment goals;
- the patient has either:
  - nutritional status (i.e., unintentional weight loss of greater than ten percent over the prior six months); or
  - documented clinical deterioration:
    - multiple ER visits or hospitalizations over the prior six months;
    - physician or home care nurse determines the disease is progressing;
    - recent functional decline or dependence in activities of daily living.

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How can I best manage pain and other physical symptoms for patients with advanced illness?

As is common, Mr. James doesn't take his prescribed Percocet because it constipates him. Adding daily laxatives and/or adjuvant analgesics for neuropathic pain might be warranted. However, monitoring side effects will be difficult if Mr. James can't come in. The hospice nurse provides weekly pain assessments. His doctor can manage Mr. James' pain, so Mr. James' quality of life improves; he avoids the hospital, stays home, and continues care with his own physician.

Dr. Haimowitz says, "Hospice can be extremely useful for me as a physician. I get the extra input and experience of the hospice nurse and hospice medical director. They can help me with adjusting pain medicines, for example."

What hospice services are available at home?

Mr. James sleeps all day and is up at night. After assessing the environment and medications, the hospice nurse recommends behavioral changes that keep him up longer during the day. The couple's sleep improves even more after his physician prescribes Mr. James a low-dose antipsychotic at bedtime. The hospice certified nursing assistant (CNA) bathes Mr. James several times weekly. Diet adjustment helps him enjoy his food again.

Hospice nurses recommend symptom management strategies. CNAs provide custodial help with bathing, dressing, feeding, and other tasks. Quality of life improves and the patient remains at home, wherever he or she lives — private residence, nursing home, or assisted living facility.

Hospice services are adjusted as the patient's condition changes. In some situations, inpatient hospice may be required as well.

How can I help families struggling with a terminal illness?

The hospice nurse updates the couple's adult children frequently about both parents and helps them understand the natural disease progression. The hospice social worker works with the parents on advance directives and with the children on planning future care of both parents.

Dr. Haimowitz adds, "Hospice staff helps me with communication with the family and with other health care professionals. I find the biggest benefit is the way hospice staff are able to help patients and their families understand exactly what is going to happen. This really eases their fear and anxiety."

How does hospice work with individual cultural and religious beliefs and values?

Mr. James can no longer go to church. The hospice chaplain and his own pastor both provide spiritual care. A hospice volunteer stays with Mr. James so his wife can attend services.

Hospice social workers address the emotional and social components of suffering. Hospice chaplains are trained to provide spiritual care to patients from many different religious backgrounds, customs, and practices. They also provide grief and bereavement counseling to families. The hospice team also includes trained volunteers, some skilled in palliative therapies and others trained to listen, hold a hand, or run an errand. Everyone's expertise helps.

AmeriHealth's Commercial hospice benefit may cover hospice team physical and spiritual support services, home medical equipment and supplies, and prescription and over-the-counter medications related to the terminal illness. Providers should continue billing for services they perform. Coverage may vary among plans and groups. Please contact Provider Services for specifics. Members may contact Customer Service at the number on their ID card. Hospice is covered by Original Medicare. Medicare Advantage members are eligible. Please contact Medicare Member Services for details.

Reference:

The National Hospice and Palliative Care Organization website, *www.NHPCO.org.*

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