



## Understanding Hospice — An Underutilized Option for Life's Final Chapter

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It was Mr. G.'s third exacerbation of congestive heart failure in the past 6 months. Eighty-three years old, he had New York Heart Association class IV heart failure, end-stage coronary artery disease,

and insulin-dependent diabetes. Although he had never wanted to be put on a ventilator, this time his shortness of breath was so terrifying that he felt he had no choice. After having a good response to diuresis, he was successfully extubated and transferred out of the coronary care unit.

Two days later, a hospitalist suggested to Mr. G. and his wife that given his advanced disease, he should consider going home and receiving hospice care there. Sensing the couple's fear, she reassured them that death was not imminent and that members of the hospice staff would work to ensure the best possible quality

of life. Relieved, Mr. G. acknowledged that he would prefer to avoid rehospitalization.

Introduced in the United States as a grassroots movement more than 30 years ago and added as a Medicare entitlement in 1983, hospice care is now considered part of mainstream medicine, as evidenced by growing patient enrollment and Medicare expenditures (see table). In 2005, more than 1.2 million Americans received hospice care, and between 2000 and 2004, the percentage of Medicare decedents that had been enrolled in hospice programs increased by almost 50%. But despite its increased use,

many aspects of hospice care are still misunderstood by both physicians and patients.

For instance, many would not consider Mr. G. to be a candidate for hospice care. He did not have cancer, and his death was probably months, not days, away. The fact is, however, that slightly less than half of hospice patients have terminal cancer; nearly 40% of hospice admissions are for end-stage cardiac disease, end-stage dementia, debility, pulmonary disease, and stroke.<sup>1</sup>

Patients and clinicians may also not realize that hospice care at home is free. Medicare is the primary payer for hospice care in approximately 80% of cases, with care most often provided in the patient's home. Commercial insurers also provide hospice benefits, but the specifics of coverage vary. Under Medicare, most

Use of Hospice Care among Medicare Beneficiaries from 2000 to 2004.*			
Variable	2000	2004	% Increase, 2000–2004
Beneficiaries in hospice care (no.)	534,261	797,117	49
Payment (billions of \$)	2.9	6.7	130
Time in hospice care (millions of days)	26	52	101
Decedents who had been in hospice care (%)	22	31	—

\* Data are from the Center for Medicare and Medicaid Services and the Medicare Payment Advisory Commission (MedPAC) and include Puerto Rico.

expenses related to the terminal diagnosis are paid in full, including all medication and equipment and all visits by hospice nurses and home health aides. (Expenses related to other diagnoses remain covered by the patient's primary insurance provider.) Other hallmark hospice services include intensive emotional and spiritual counseling, 24-hour crisis management, and bereavement support for at least 1 year after the patient's death.

Hospice care can successfully address the critical end-of-life concerns that have been identified in numerous studies: dying with dignity, dying at home and without unnecessary pain, and reducing the burden placed on family caregivers.<sup>2-4</sup> Evaluation studies reveal consistently high family satisfaction, with 98% of family members willing to recommend hospice care to others in need.<sup>1</sup> And the extensive expertise of physicians specializing in hospice and palliative medicine was recognized in 2006, when the field was accredited as a fully independent medical subspecialty.

Despite these benefits and the general understanding by clinicians that at least 6 months of care are provided, the median

length of hospice service is only 26 days, with one third of patients referred to hospice care during the last week of life.<sup>1</sup> Factors contributing to late referral include application of a curative model to end-stage incurable illnesses; Medicare's per diem hospice reimbursement, which precludes costly, aggressive therapies; and the mistaken view that patients must have a do-not-resuscitate order.

However, the most important factors in delayed referrals appear to relate to physician attitudes. In its first position paper on the topic of cancer and dying, the American Society of Clinical Oncology acknowledged that many oncologists and other physicians regard the death of a patient as a professional failure.<sup>5</sup> Many also fear that they will destroy their patients' hope, which physicians may believe lies only in efforts to increase the quantity rather than quality of life. Furthermore, physicians receive little training in the compassionate discussion of bad news. But perhaps the most critical factor is that physicians view hospice care as something reserved for the imminently dying instead of as a service designed to help people live as well as

possible in the face of advanced incurable disease.

To determine eligibility, the attending physician and hospice medical director must certify that to the best of their judgment, the patient is more likely than not to die within 6 months. Responsibility for determining ongoing eligibility rests with the director. To assist physicians in prognosticating, Medicare provides broad guidelines for many medical conditions (see box), but these guidelines do not represent hard-and-fast requirements. Coexisting conditions or a particularly rapid functional decline can outweigh strict adherence to written requirements.

After enrollment, a plan of care is developed in accordance with the needs and wishes of the patient and family, often tempered by the presence or absence of caregivers to participate in day-to-day care. The primary goal is to ensure that pain and such symptoms as insomnia, dyspnea, depression, constipation, agitation, nausea, and emotional and spiritual distress are aggressively addressed. Most clinical care is provided by a hospice nurse, and the vast majority of patients are not seen by a physician. Mr. G.'s plan of care included continuing high-dose furosemide, adding low-dose lorazepam for the anxiety that typically accompanies shortness of breath, and initiating low-dose liquid opioids, a mainstay in the management of dyspnea.

To address Mr. G.'s nonmedical needs, a home health aide provided assistance with personal hygiene and dressing for an hour each day, 5 days a week. The hospice social worker offered to have a volunteer shop

### Medicare Hospice Eligibility Guidelines for Selected Diagnoses.\*

#### Alzheimer's disease

Eligibility is based on Reisberg Functional Assessment Staging (FAST), stage 7 or greater. Stage 7 is defined by the following criteria:

- need for assistance with at least three activities of daily living
- increased frequency of incontinence of bowel and bladder
- ability to speak only six or fewer intelligible words in the course of an average day

In addition to the FAST criteria, the patient must have one of the following:

- a history of upper urinary tract infection, sepsis, or pneumonia within the past 12 months
- multiple stage III or IV decubitus ulcers within the past 12 months

If the patient meets neither of the two preceding criteria, the patient must show nutritional decline, as evidenced by one of the following:

- unintentional progressive weight loss of 10% of body weight over the past 6 months
- a serum albumin level of <2.5 g/dl

#### Pulmonary disease

Eligibility is based on severe chronic lung disease, as defined by the following criteria:

- disabling dyspnea at rest and poor response to bronchodilators, resulting in decreased functional capacity
- disease progression reflected in increased emergency department or physician visits or by increased hospitalizations
- hypoxemia at rest — oxygen saturation  $\leq 88\%$  with patient breathing ambient air

#### Heart disease

Eligibility is based on New York Heart Association classification of class IV, as defined by the following criterion:

- inability to carry out any physical activity without discomfort (documentation of an ejection fraction of <20% is helpful but not required)

In addition, the patient must be optimally treated with diuretics and vasodilators as tolerated in relation to blood pressure and renal function

If the criteria for class IV do not apply, eligibility can be based on one of the following:

- the patient has angina, which must be present at rest or resistant to standard nitrate therapy
- the patient is not a candidate for or declines invasive procedures

#### Debility (no one specific terminal diagnosis identified)

Eligibility is based on the progression of disease, as documented by one of the following:

- recurrent or intractable infections, such as pneumonia, upper urinary tract infections, or sepsis
- progressive weight loss of >10% of body weight over the past 6 months
- dysphagia leading to recurrent aspiration or inadequate nutritional intake
- progressive deep decubitus ulcers

\* The guidelines do not represent hard-and-fast requirements. The presence of clinically significant coexisting conditions or rapid functional decline can substitute for some criteria. The guidelines may also vary with the Medicare fiscal intermediary. Information is from National Government Services ([www.ugsmedicare.com/providers/LMRP/documents/Hospice%20REVISED%2010-01-06.pdf](http://www.ugsmedicare.com/providers/LMRP/documents/Hospice%20REVISED%2010-01-06.pdf)) and is based on personal communication with James Cope, medical director of National Government Services.

for groceries and provide companionship. The social worker also talked with the family and identified the need to address Mr. G.'s anxiety and his wife's fears about the future. Noting that Mr. G. had concerns about whether God was punishing him

for past acts, she encouraged visits by the hospice chaplain.

Hospice emphasizes an interdisciplinary approach to care. In most cases, at least once every other week, the hospice team — nurses, social workers, a pastoral counselor, the bereavement

coordinator, and the medical director — meet to discuss the needs of the patient and family. In the interim, nurses call attending physicians with their recommendations.

One serious challenge in hospice care is that attending physi-

cians typically receive little to no training in the use of medications for pain and symptom management and thus rely on a presumed level of expertise on the part of the hospice nurse. Given the current nursing shortage, however, such an assumption of competency may or may not be well founded. Attending physicians should routinely evaluate recommendations and should have a low threshold for reviewing cases with the hospice medical director.

As a patient's disease progresses, the hospice plan shifts to accommodate decreasing independence, alterations in symptoms, and changing psychosocial needs. In Mr. G.'s case, the realization that his symptoms could be managed at home lessened his anxiety, which in turn decreased episodes of chest pain. Flash pulmonary edema occurred less

frequently; during one such episode, he received intravenous furosemide in his home, since he wanted to avoid further hospitalizations. During 4 months of hospice care, Mr. G.'s condition gradually deteriorated, with increasing weakness, dyspnea, and cardiac cachexia. Near the end, his family and friends gathered, and he died peacefully with his wife and nurse at his side. Despite his family's grief, they expressed their appreciation that Mr. G. had maintained a reasonably high quality of life and had died in his home as he had wished.

With the growing number of baby boomers seeking more control over all aspects of their health care, the use of hospice care will probably continue to increase. It is especially important, therefore, that physicians become more familiar with what

hospice care offers and work to overcome barriers in talking frankly with patients about what lies ahead.

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## Letting Go of the Rope — Aggressive Treatment, Hospice Care, and Open Access

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More Americans are choosing hospice for end-of-life care, but ironically, hospice patients increasingly are forced to give up effective palliative treatments along with aggressive medical intervention. For Joanne Doolin, a 64-year-old mother of three who spent her last 2 years of life fighting colon cancer that eventually made it impossible to eat, enrollment in hospice care involved a difficult trade-off: with only a few weeks left to live and her daughter's wedding approaching, Doolin was forced to choose between entering hospice care

and continuing to receive total parenteral nutritional support.

Unfortunately, treatment options are often limited by the economic constraints of hospice care. The hospice that was the closest to Doolin's Boston-area home would accept only patients willing to forgo life-sustaining treatments, including chemotherapy and parenteral nutrition. It cares for only about 20 patients at a time with three nurses, a manager, a part-time chaplain, and a medical director who works there one morning a week. As a small program, it can-

not negotiate pricing or spread the cost of expensive medications across many patients. A few large hospices offer what is called open-access care, which allows patients to add hospice care to their current medical treatment, but this option is not available in Massachusetts.

The Medicare hospice benefit reimburses hospices on a per diem basis, paying fixed inpatient and outpatient fees regardless of services provided. Despite adjustments for inflation, the fees have not kept up with the cost of cutting-edge palliative treat-