



GOING GENTLY:

No antiseptic wards // No long-shot measures // No eleventh-hour heroics // Simply, at the end, a decision to choose quality over quantity.

At Home in Hospice

■ BY LINDA KESLAR // PHOTOGRAPHS BY ANNABEL CLARK

When Franklin Wyman, 85, was diagnosed with acute leukemia in December, he thought about how he wanted to die. He could stay in the hospital and perhaps gain a year of life with aggressive treatment. Or he could return to his suburban home outside Boston, where he and his wife could get whatever help they needed, medical and nonmedical, from a nearby hospice. “I’ve had a very good life,” says Wyman, a retired investment banker. “What would be the point of making drastic efforts that might, or might not, keep me alive for another year?”

For now, Wyman doesn’t need much help from Partners Hospice in Waltham, Mass. A nurse stops by to see how he’s doing and to make sure he has medication to relieve his arthritis pain. A walker, a wheelchair and a portable oxygen

generator have been delivered for future use, and the members of his clinical team—a physician, nurses and home-health aides—stand ready to address any discomfort he experiences. There’s also a pastoral counselor and a medical social worker to help Wyman and his family deal with depression, anxiety and spiritual issues.

What Wyman won’t receive is treatment to extend his life. “Hospice recognizes dying as part of the normal process of living and focuses on maintaining the quality of the life one has left,” says Marcia Reissig, former president of Partners Home Care, which owns the hospice. Wyman appreciates having that opportunity, and spends his days reading, surfing the Internet and visiting with family and friends. “It’s important to me to maintain my dignity until the very end and to be a good example for my family,” he says.



The promise of hospice: to live out your days as you choose, with the support you need—in Franklin Wyman’s case, from a bevy of family members and (from left) Angela Twohig, his private-duty nurse, who is with him 12 hours a day, five days a week; she massages his arthritic ankles, cooks his meals and helps him dress. Being with his wife, Ruth, was a chief reason Wyman opted for hospice. The couple’s daughter, Janet Coleman, often looks over her dad’s shoulder as he pays bills online and checks e-mail. Beth Damsky, a social worker, stops by once a week to make sure he’s getting the services he needs.

Given a choice, it’s likely that most people would prefer to end their lives in much the same way. But that’s not how the final weeks usually play out. Most Americans spend their last days in acute-care hospitals and nursing homes, often amid a flurry of desperate though futile medical measures. Half of those who die in hospitals endure pain at least half the time, while almost 40% spend 10 days or more on a ventilator.

By 2030, one-fifth of the U.S. population will be older than 65, and by 2040, the death rate is expected to nearly double from current levels to about 4.1 million deaths annually. Those demographic shifts add urgency to the debate over the American way of dying, and hospice has become an important part of the conversation. Increasing numbers of terminally ill patients have come to view hospice not as a plan for giving up the fight but as a way to emphasize the quality of life during their remaining days. Already, one in three deaths in the United States takes place in hospice, and the aging of the baby boom generation is likely to accelerate that trend.

Still, fewer than half the patients who could use hospice programs end up in one, and for those who do, the time they spend there is frequently short, often fewer than seven days. The hospice industry, meanwhile, is struggling to adjust to new realities, as rapid advances in life-prolonging technologies raise complex medical, ethical and legal issues. There’s also increased competition among providers, spurred in part by for-profit groups that see hospice as a business, not a philanthropic service.

“The hospice industry is evolving,” says Melissa Carlson, an instructor at the Mount Sinai School of Medicine in New

York City. The next few years could be crucial, as more patients choose hospice and more programs enter the marketplace. “The stakes are high,” Carlson adds. “Is care going to get better or worse for this very vulnerable patient group?”

The modern hospice movement, with its aim of addressing both the physical and emotional suffering of terminally ill patients, was founded at St. Christopher’s Hospice near London in 1967 by Dame Cicely Saunders, a British nurse turned physician. Saunders also influenced the founding of the first U.S. hospice in 1974; Florence Wald, then dean of the Yale University Nursing School, had taken a sabbatical to work at St. Christopher’s before helping to get the Connecticut Hospice in Branford up and running.

Several dozen other hospices, charitable endeavors run mostly by volunteers, were established during the following years. But the red-letter date for the hospice movement in the United States didn’t arrive until 1983. With the AIDS epidemic raging, the government created a Medicare hospice benefit.

Since then, the hospice industry has grown steadily. In 2005 more than 1.2 million patients received end-of-life care in more than 4,100 hospice programs. And today, with hospice admissions rising by almost 10% a year—with 75,000 to 125,000 new patients annually, according to the National Hospice and

Palliative Care Organization (NHPCO)—the industry is struggling to keep up. During the past 18 months alone, more than 500 hospices have been started. And though more than 90% of hospice patients still receive their care at home, nursing homes and even hospitals are increasingly opening on-site options.

Yet even now, people interested in hospice care often face obstacles. In 13 states, including Florida and New York,

which calls for doing everything they can to prolong life,” says John Kimberly, a management professor at the Wharton School at the University of Pennsylvania who served for many years on the board of a Philadelphia hospice. Doctors also fear they could be subject to charges of Medicare fraud if they refer a patient who doesn’t expire within six months. So they may be reluctant to make an early referral even if a patient is ready to end life-prolonging care. (That in itself is a tough call for patients, who may worry that their medical needs won’t be aggressively addressed in hospice, and that choosing hospice could mean giving up their relationship with their doctor.)

But many concerns of both doctors and patients are unfounded. Choosing hospice normally doesn’t require severing ties with a doctor. Also, Medicare will now extend hospice payouts through an unlimited number of 60-day service periods for patients who live longer than expected. “There’s nothing sacrosanct about six months,” says Kimberly. “Eligibility



Hospice nurse Christine LaRoche, in weekly visits, practices high-touch, low-tech medicine, checking Wyman’s vital signs and assessing whether his prescribed medications are having the desired effect, keeping him alert but in minimal pain.

hospices are governed by certificate-of-need laws that tend to limit the number of organizations operating there. And Medicare places severe limits on who qualifies for payment. A doctor must certify that a patient has six months or less to live and has agreed to halt such life-prolonging treatments as dialysis, chemotherapy and radiation. Some in the medical community dub this the “terrible choice” because it requires a patient not only to throw in the towel but to forgo care that may fall into the gray area between extending life and improving the quality of what remains.

For many doctors, a referral to hospice care, no matter how sick the patient, itself represents a terrible choice, though a growing number of medical professionals are endorsing it. “The values of hospice fly in the face of physicians’ training,

for the Medicare hospice benefit needed to be defined, and six months seemed reasonable at the time. But there has been talk of changing it ever since.”

Diane Meier, the physician head of the palliative care program at New York City’s Mount Sinai Medical Center, agrees. “The criteria for admission to hospice should have much more to do with what a patient needs than about how long that person has to live,” she says. “A patient with Alzheimer’s who needs help with virtually everything can live 10 years.”

Ann O’Keefe wrestled with the complexities of hospice eligibility last year when searching for end-of-life care for her widowed father. He was 83, had been suffering from debilitating dementia for nearly three years, and had

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been in and out of the hospital with stroke symptoms, panic attacks and injuries from falls. Yet no physician would certify that he qualified for hospice care until it was almost too late.

O’Keefe’s father died last fall after only a nine-day stay in one of the six homey bedrooms of the Miriam Boyd Parlin Residence, part of Parmenter Community Health’s Wayside Hospice outside Boston. On his third day there, he suffered a stroke. O’Keefe, however, describes her experience with hospice as positive, even transformational. “When I visited, I’d see the nurses or aides stroking his hand or hair in comfort, the way my mom would have,” she says. She and her family have also benefited from the hospice’s bereavement program, which has provided support in the months since her father’s death.

Wayside Hospice, however, is struggling. Hospices are paid a per-patient lump sum by Medicare, and that reimbursement may not fully cover the costs of care, leaving many nonprofit hospices operating on shoestring budgets. Wayside, which also provides home hospice care for about 110 patients in the Boston area, runs deep in the red, contributing to an annual operating shortfall of about \$450,000 at its nonprofit parent, says Cindy Mayher, Parmenter’s executive director. The organization depends on private donations, grants and fund-raising to close the budget gap.

Moreover, Wayside now competes against more than 15 other hospice providers, many of them for-profit. That’s typical of a national trend reshaping the hospice industry, as hospices vie for admissions from hospitals and other health care facilities. But for patients and their families, it’s often an unwelcome trend. In Atlanta last fall, when Maureen Wareham’s mother was hospitalized and wasn’t given long to live, Wareham was hounded at work and at home by telemarketers urging her to enroll her mother. “Hospice seemed like any other business,” says Wareham. “Compassion went out of the picture.”

Within the \$10 billion hospice industry, the number of for-profit groups increased almost fourfold from 1994 to 2004, a growth rate more than six times that of nonprofit hospices. For-profits care for about three in 10 hospice patients, compared with just 2% in 1990, and three publicly traded operators account for more than half of the for-profit market.

VITAS, with headquarters in Miami, is the country’s largest for-profit hospice, enrolling more than 11,000 patients in 16 states. During the past six years, VITAS has expanded in both rural and urban areas, including underserved areas in Chicago, St. Louis and Washington, D.C. But though the proliferation of for-profits has expanded patient access, it has also pressured nonprofit groups to evolve or expire. Those that don’t

Hospice’s Growing Pains //

80 Percentage of people 45 or older in a 1999 survey who did not know the meaning of hospice

33 Percentage of people who died in the United States in 2005 under hospice care

75.9 Percentage of hospice patients who die in private residences, nursing homes or other residential facilities. In the general population, 23.4% die at home.

18 Percentage of medical students and residents in a 2003 survey who reported receiving formal end-of-life training

30 Percentage of hospice care provided by for-profit organizations in 2004, a fourfold increase over the preceding decade

9 Times by which profit margins of large hospices owned by publicly traded companies are higher than those of large nonprofits. (One 2004 study found that for-profits were far less likely to provide a full range of services than were nonprofits.)

\$117.10 Average daily cost of routine hospice care, according to a 2001 study

\$500 Average daily cost of end-of-life hospital care ■

Although an oxygen generator and tanks might clash with the elegant decor of Wyman's study, the environment is a vast improvement on hospital sterility.



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have the backing of a deep-pocketed corporate parent may find it difficult to deal with issues that beset hospices of all descriptions.

As the mix of patients in hospice grows more diverse, in terms of both diagnosis and length of stay, it becomes increasingly difficult to manage the costs of severely ill patients, particularly those who require intensive care or expensive treatments. Hospices may decline to accept such patients, and industry statistics suggest that for-profits offer proportionately fewer of the most expensive services. Nonprofits, meanwhile, may be bearing

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more of the burden and falling deeper into a financial hole.

Recent research has shown wide variation in the services and profit margins of the two business models. One 2005 study in the *Journal of Palliative Medicine* found that large hospices owned by publicly traded companies generated profit margins nine times higher than those of large nonprofits and three times higher than privately owned for-profit groups of similar size. In another study of hospice ownership, Mount Sinai's Carlson found that for-profits provided a narrower range of services to patients and their families, particularly in more discretionary areas that are not as closely regulated by Medicare.

The rapid expansion of for-profit hospices in particular has also attracted more government scrutiny. In response, the NHPCO has worked with hospices to develop quality measurements tied to Medicare's revision of hospice conditions of participation (the federal rules governing hospice providers) that are scheduled to be released within the year. Proponents say that releasing data on hospice quality to the public will give consumers a better idea of what they can expect from

providers. But others consider such measures crude yardsticks, particularly when they involve such "noncore" services as social and spiritual support.

Meanwhile, in a report to Congress last year, the Medicare Payment Advisory Commission, the government entity that serves as Medicare's watchdog, released a report suggesting reimbursement payments be adjusted to reflect such factors as diagnosis and length of stay. It also suggested that Medicare payouts be staggered, with larger amounts paid for the beginning and end of hospice stays, which are most costly for providers. The goal is to create a more accurate payment system, though overall payouts to hospices probably would not rise.

Thanks to medical advances that have reduced the incidence of such swift killers as heart attacks and strokes, people today are dying more slowly than ever, while deaths from gradual illnesses, such as Alzheimer's and cancer, are increasing. Those trends, along with the aging of the baby boom generation, are likely to mean mushrooming numbers

of hospice candidates. But not everyone is convinced that hospice is the only answer.

A new medical specialty called palliative care is one alternative. Some 30% of hospitals have launched palliative care programs in recent years, using a team approach to provide curative treatment while also controlling pain and attending to other quality-of-life issues. Such care avoids hospice's unfortunate requirement that patients accept death, says J. Andrew Billings, director of the Palliative Care Service at the Massachusetts General Hospital.

"Hospice and palliative care largely share the same philosophy, though the notion of palliative care is that a patient can get all of the things hospice provides—pain and symptom management, psychological support, a respect for wishes and values, help at home—but also can get well and extend his or her life," says Billings.

Ultimately, though, death will come, and whatever their differences, both palliative care units and hospices must confront the same increasingly complex end-of-life issues. "As a society we've just started tackling the questions of advancing medical technology and how we decide when to use it and when not to use it," says William Colby, a lawyer and the author of *Unplugged: Reclaiming Our Right to Die in America*.

Those questions include how to handle patients who have been admitted to hospice or palliative care units without do-not-resuscitate orders or advance directives about halting aggressive treatment, says Robert Miller, a minister and ethics expert at VITAS. Sometimes, families of patients may push to prolong the lives of patients who can no longer make their own decisions, even when those patients had asked not to undergo such measures as feeding tubes or ventilators.

As deaths surge in the decades to come, the entire U.S. health care system will increasingly face these concerns, but they're already front and center at the U.S. Department of Veterans Affairs. This year alone, more military veterans will die than were lost during all of World War II, and they already account for one in four of the nation's deaths. To provide flexibility for patients, nearly all Veterans Administration facilities offer palliative care that's coordinated with hospice care, either within the hospital or at home through community hospice organizations.

That has helped Charles Bennett, 63, live more comfortably with terminal lung cancer, enabling him to move from the inpatient hospice at the Birmingham VA hospital to his rural home, where his care is monitored by VA physicians.



In a family that cherishes family, Ruth has a wall of personal history to remind her of the full life she and Franklin have shared.

Daily doses of morphine are keeping him pain-free for now, but Bennett, a retired salesman, has made it clear that there will be a time when all treatment should end. He doesn't want to be put on a ventilator or resuscitated when that moment arrives, and all of the doctors and nurses involved in his care will abide by those wishes. "With hospice I can just relax during the time I have left," Bennett says. "I know everyone will do what they're supposed to do." ■

→ DOSSIER

1. *Last Rights: Rescuing the End of Life From the Medical System*, by Stephen P. Kiernan (St. Martin's Press, 2006). Informed by both scientific research and intimate portraits of the dying, Kiernan takes a hard look at how the medical system, including hospice, deals with end-of-life issues and offers some alternatives.
2. *Unplugged: Reclaiming Our Right to Die in America*, by William H. Colby (American Management Association, 2007). Colby, a legal expert, uses poignant case studies to examine some of the perplexing legal, ethical, medical and personal issues at the heart of the right-to-die debate.
3. "Operational and Financial Performance of Publicly Traded Hospice Companies," by Michael J. McCue and Jon M. Thompson, *Journal of Palliative Medicine*, Vol. 8, No. 6, 2005. Insightful study that compares the performance of hospices owned by publicly traded companies with nonprofit hospices, and examines why public companies are able to earn substantially higher profits.