Will We Ever Arrive at the Good Death?

NY Times ROBIN MARANTZ HENIG

The death rattle is what's so unnerving. People who sit beside someone who is close to death, someone in a stage the experts call "active dying," might hear a sound that's not quite a snore, not quite a gurgle, not quite a rasp. It doesn't hurt; it probably isn't something the dying person is even aware of. But it sounds terrible.

"Once the so-called death rattle starts," says Charles G. Meys, a hospice nurse with the Visiting Nurse Service of New York, "that's usually an indication that the person is not coming back."

The sound, made with each intake of breath, is merely air moving across phlegm. "Healthy people can cough it up or spit it out or swallow it," Meys says, but a dying person is just not strong enough, so the secretions collect in the upper airways. "And as they breathe in and out, it makes that sound -- that sound that we have learned to fear." To those watching, the person seems to be gasping for breath, asking to be saved.

Meys tells family members that he can offer atropine to dry up the airways and soften the death rattle, and most of them ask for it. "But it's not for the dying person," he says. "It's for the family."

Charles Meys is the vanguard of dying in contemporary America. He's a hospice nurse of the kind that people in pain wish for: compassionate, soft-spoken, dedicated. He doesn't look the part of a nurse: he's 50 years old and a skinny 6-foot-3, with intense brown eyes and a long, graying ponytail. His mission is to help people get ready to die -- even if it means, as it does surprisingly often, allowing them to deny that they're dying.

Hospice today is as different from its grass-roots origins as Charles Meys is from Florence Nightingale. It began in the 1960's as an antiestablishment, largely volunteer movement advocating a gentle death as an alternative to the medicalized death many people had come to dread. People still dread those deaths; surveys show most of us want to die at home, not in a hospital, and want to die naturally, not hooked up to life support. But in recent years, hospice itself has become institutionalized, and it no longer means quite what most people take it to mean. Today there are hospice patients on ventilators, hospice patients with feeding tubes, hospice patients getting pacemakers, hospice patients receiving blood transfusions and cardiopulmonary resuscitation, hospice patients who panic when they can't breathe and call 911.

It's all part of the new trend in hospice toward "open access," meaning that terminally ill patients can continue chemotherapy and other treatments and still get hospice benefits through Medicare. The idea began in the 1980's, when AIDS patients started enrolling in hospices and weren't quite ready to give up all medical options. Today hospice workers are also aligning with doctors in a field known as palliative medicine -- an approach that emphasizes pain relief, symptom control and spiritual and emotional care for the dying and their families. With hospice becoming so inclusive, and with palliative care on its way to becoming a new medical subspecialty with its own licensing exam, the natural, machine-free deaths we say we want are starting to look a lot like the medicalized deaths they were meant to replace.

The trend reflects society's deep ambivalence about dying. During the long and public agony over the death of Terri Schiavo, debate centered on the right to make end-of-life decisions. But underlying the political posturing was a shared assumption that was barely acknowledged: the belief that dying is something over which we have some control. This death-denying culture has led to a system of care for the terminally ill that allows us to indulge the fantasy that dying is somehow optional.

In many ways, we act as if we can avoid death indefinitely if only we're quick enough or smart enough or prepared enough. Even hospice workers call their field by a new name that accentuates the positive: they used to say they specialized in "death and dying," but today the umbrella term is "end of life." The shift is subtle but significant -- an emphasis on "life" rather than "death."

What we have, then, is a medical system for the dying that is as ambivalent about dying as we are ourselves. Goldie Gold was ambivalence personified. When I met her at the beginning of the summer, she was, at 72, still an attractive woman, even though her hair was sparse from recent chemotherapy. She sparkled and flirted with Charles Meys during his twice-weekly hospice visits, and she had a beautiful smile.

The story of Gold's final illness raises some questions that underlie the modern American death. How do we let go of a life? How much intervention is too much? When do all the small fixes stop making sense? How does a person know when to say, "O.K., so this is what I'll finally die of"? We rarely ask such questions, because we don't believe, in our bones, that a terminal disease will end in an actual death. We don't want to cut short a closing life by even a matter of days. We want to be able to say that we did everything we could.

But the denial of death comes at a cost -- a cost that goes beyond mere dollars and cents (though the dollars and cents involved are no small thing). Saving a dying person from one condition "extends life a bit, changes the manner of dying, and may or may not, on balance, be a good thing," writes Dr. Joanne Lynn, former president of Americans for Better Care of the Dying, in her book "Sick to Death and Not Going to Take It Anymore!"

Gold put a brave face on her situation. "I'm not afraid of dying," she said one wet summer afternoon, her head resting on a fluffy baby blue pillow. "But I'm terribly unhappy about not living."

Gold was a smart, feisty woman, an atheist who called herself "an ethical Jew and an ethnic Jew." Pictures of her family -- handsome husband, three children, eight grandchildren -- were scattered around her tidy one-bedroom apartment in Greenwich Village, perched beside plush white couches and grinning down from the walls and shelves.

After raising her children in Howard Beach in Queens, Gold returned to Manhattan, where she grew up. For 25 more years, she and her husband, Neil, a taxi driver, thrived on its vibrant street life. Then Neil got sick with pancreatic cancer, and Gold nursed him for two years until 1998, when he died in a hospital, with Gold and their children there with him in the I.C.U.

Shortly after her husband died, Gold was found to have non-Hodgkins lymphoma. She went through aggressive chemotherapy and was declared cured. But last Thanksgiving she got a new diagnosis, metastatic ovarian cancer, and things were looking grim.

Gold pursued chemotherapy at Memorial Sloan-Kettering, but after several months of that, her children persuaded her to sign up for hospice care as well. They wanted her to get the services hospice offered: home visits by nurses, social workers, dietary counselors and doctors; free medicine, with free delivery; free medical appliances, hospital beds, walkers; services from home health aides, physical therapists, chaplains; short-term 24-hour nursing care if she needed it; short-term hospitalization if she needed it; bereavement services for her survivors; and all of it covered by Medicare.

Medicare regulations require that hospice patients must have a prognosis of less than six months if the disease runs its normal course. Gold probably understood that, but she may have expected to beat the odds -- after all, Neil was given three months, and he lasted two years. And she had already beaten the odds once herself, with the lymphoma.

Gold was able to stay upbeat, as long as she was feeling basically well. She remained feisty and provocative, sprinkling her conversation with language that could get a bit salty. But one night in June, she had trouble breathing. It was a Sunday night. She panicked. Her live-in home health aide panicked. They dialed 911.

Dialing 911 is something that can get hospice patients into situations they don't want to be in. Once they're in an emergency room, all their careful planning to avoid high-tech interventions is subsumed by the medical imperative. Emergency-room workers don't have time to wonder whether a dying person will benefit from rescue efforts, or whether the patient they pound back to life will ever recover anything like normal functioning. In fact, when physicians are asked whether they will abide by a patient's advance directives, like do-not-resuscitate orders, the majority of them say, in essence, "It depends." In July of last year, the Archives of Internal Medicine published a survey that found that 65 percent of physicians wouldn't necessarily follow a living will if, for example, its instructions conflicted with the doctor's own ideas of the patient's prognosis or expected quality of life.

For a dying person, a trip to the emergency room might feel like a way to defeat death, but of course it won't. One study of patients in hospital intensive care units, where the sickest E.R. patients go, showed that of elderly patients who survived their time in the I.C.U. -- and who therefore were counted as medical successes -- 50 percent were dead within the year.

But Gold was frightened, and even though she knew she was dying, she didn't want to die. So she asked the medics to take her to Sloan-Kettering. She was admitted that Sunday night and didn't get out until Wednesday, after physicians had drained an accumulation of fluid in her abdomen, a common result of her kind of cancer. They took seven liters' worth.

"That's a lot of fluid, and it probably accounted for her distress," Meys told me later. "But when patients on hospice call 911, it's not necessarily because they're in physical distress. It could be emotional distress." Meys says he has seen it often: people who act as if they have accepted their terminal status but who really have not. "They may say, 'I'm ready for the end, I'm ready for the disease to run its course.' But in a moment of pain or distress, they get frightened, and they're not ready."

Meys came to nursing late, enrolling in nursing school at SUNY Binghamton at age 36 after several years spent teaching at a middle school and traveling through Europe and Africa. His first job was at New York University Medical Center, where he worked with many cancer and AIDS patients and saw a lot of people die. "I hate to say it, but I was put off by the way they treat some people in hospitals," he says. "Some doctors did really wonderful work, but others -- well, it seemed to me that other doctors treated people past the point where you'd think it was appropriate." If a stroke patient had been mentally incapacitated, for instance, "and their quality of life was what I would perceive as being pretty poor, doctors would still be drawing their blood every day, balancing this medication and that, checking to see if the potassium is too high or the calcium is too low. To me, that was just staving off the inevitable -- it didn't make any sense."

Meys's travels in Africa had made him want to find a way to "do something I thought was useful," he said. But his work as a hospital nurse wasn't it. So in 1996 he quit his job at N.Y.U. He considered the Peace Corps, but by then, after a solitary life, he had met his wife, Nancy, and they wanted to stay in New York. So Meys took a job with the Visiting Nurse Service of New York and in 2002 became a part of its hospice program.

In early June, Meys took me to meet Goldie Gold, who had just gotten home from the hospital after her 911 phone call. She was sitting up at the table in her little dinette, dressed in a T-shirt and slacks, bantering with her private health aide, a pretty blond woman from Colombia named Martha Bernal. ("I love this girl," Gold told me. "She's magical; I want to adopt her.") As Gold and I spoke, Bernal hovered nearby, hugging Gold and sitting on her lap and speaking baby talk and putting girlish barrettes in her hair. It almost felt as if Bernal were trying to keep us from discussing anything that might upset the older woman, or maybe it was Gold who was trying to protect Bernal.

For whatever reason, we didn't talk much about dying that day. We talked about how she was getting ready to begin more chemotherapy the following week, and about how sad she was that her children had to watch her go through cancer treatment after having done so with their father seven years before. "He was a saint as a patient," she said. "I don't know if I can be as brave."

When I visited again in early July, the weather was wet and unseasonably chilly, and Gold was sicker. She was lying in a hospital bed that had recently been squeezed into her bedroom, and she had such bad acid reflux (which causes severe heartburn) that she was unable to keep down any food. She apologized each time she burped, and again whenever she vomited into a white plastic-lined wastebasket. Now she was wondering whether it was time to give up. "I think about stopping everything," she said. But her oncologist wanted her to keep fighting: "The doctor says, 'We're not there yet,' when I talk about stopping. So I say, 'That's easy for you to say; you're not the one who's throwing up.'"

If she didn't eat or drink, she didn't have reflux and didn't throw up. I asked Gold if she was hungry or thirsty; she wasn't. So I asked why she kept eating. She didn't quite understand my question, and I didn't press it. But still I wondered: why did she keep eating? Out of habit? Obedience? Fear of worrying her loved ones? Bernal kept pressing food on her, spooning applesauce into her mouth as if she were a child, bringing her a can of diet ginger ale with a straw, urging her to eat a piece of the cheese danish that her son dropped off that morning. But each spoonful or sip came right back up within minutes, and Gold was clearly uncomfortable and embarrassed by her vomiting. Why not leave her be, I wondered, and have starvation be the way she dies?

Meys was in Gold's apartment that rainy day in July, taking her blood pressure, feeling her pulse, checking her back for bed sores, checking her ankles for the swelling that had bothered her the week before. Mostly he talked to her, crouching at her bedside. He gently stroked her arm and admired her manicure as they talked about symptoms. Gold's big complaint was the reflux, so Meys made a phone call to the pharmacy for Carafate, a drug often taken for ulcers, which would coat her esophagus and might provide some relief.

"You're taking Protonix and Pepcid now and they're not doing you any good," he told her. "But this should help. You have to stop taking the Pepcid, but you can keep taking the Protonix, and then start the Carafate too. It comes in liquid form, but I think you'll be able to keep it down." He reminded Gold that it might take three days to see any result. He ticked off the days: Saturday, Sunday, Monday. "By Monday this should help you feel better," he said. He repeated all the instructions to Bernal too.

But by Monday Gold was back in the hospital. Meys was disturbed to find out that Gold had never even started taking the Carafate, which arrived from the drugstore on Friday afternoon; she and Bernal seemed to have misunderstood his instructions and were afraid that it would interact badly with the pills Gold was already taking. "If we can't treat the symptoms," Meys said to me in frustration, "what good is hospice?"

Gold had gone to the hospital for another tap to drain the fluid in her abdomen. While she was there, her oncologist, who had been so gung-ho up to that point, sat down with Gold and her children and agreed that it was time to shift gears: the chemotherapy wasn't working, and there would be no more of it, not for symptom relief, not for treatment. As the family tried to wrestle with this new information, the oncologist admitted Gold to the hospital -- a surprise to everyone, since the fluid tap was usually done as an outpatient procedure. Was Gold much sicker than they realized?

In the hospital, Gold's doctors diagnosed aspiration pneumonia, which forced her to remain hospitalized for another five days so she could get antibiotics intravenously. Another bit of ambivalence: here was a woman who had just been told that it was time to stop all chemotherapy, yet when she developed an infection, no one even raised the question of whether to treat it. Treating pneumonia is done almost instinctively, it seems; even Meys seemed flummoxed when I asked him whether antibiotics should have been withheld. It would have seemed a shame, I guess, to let her die, after all her struggling, of something so easily fixed. But what did she gain from those extra days? What did her anguished children gain? And what did society gain by spending thousands of dollars on her care? Since she was about to die anyway, did anyone ask: Is pneumonia the thing that Goldie Gold should die of?

You could argue that Gold should have been allowed to die of starvation at her home, or of pneumonia in the hospital. But you could just as easily argue that it was better to help her hold on for as long as she could. Who can count the value of an extra week, or the feeling that you went out fighting? Gold said she was willing to enter hospice care in the first place only because of the recent innovation of open access. When her husband was dying, she didn't sign him up for hospice because she didn't want him to think she had given up on him. But with open access, there was no need to renounce treatment to enroll. That was why Gold was able to continue chemotherapy for the first three months that she was a hospice patient. It's a classic case of having your cake and eating it: you can enroll in hospice and get the wide range of support services free through Medicare's hospice benefit and still allow yourself to believe that you can live forever.

The concept of hospice originated in Great Britain, where Dame Cicely Saunders, a social-worker-turned-physician who died July 14 at age 87, opened the world's first modern hospice, St. Christopher's, in 1967. The first American hospice, built on the St. Christopher's model, opened in Connecticut in 1974 with financing from the National Cancer Institute. From then the movement grew, led by a handful of nurses and a slightly larger handful of volunteers.

As a home-based health care service (except for a few free-standing residential hospices), hospice seemed to be a way to achieve more humane care and to reduce the nation's ballooning health care bill. At the time, roughly a quarter of Medicare expenditures were for people in the last year of life. So Congress decided to push hospice through Medicare partly as a cost-cutting measure. This has led to an explosion in hospice nationwide: from about 1,500 programs in 1985, taking care of about 160,000 people, there are now about 3,300 hospices in the United States, caring for some 950,000 people a year. But strangely, there has been little change in the proportion of Medicare expenditures spent on people in the last year of life. Although the absolute dollar amount has changed -- it was, on average, $25,000 for someone who died in 1999 -- the proportion remains stubbornly at about 25 percent.

Roughly two million Americans die anticipated deaths -- as distinct from deaths from accidents, violence or sudden illness -- every year. Of these, about one-third died while in hospice care -- some 710,000 people in 2003, the most recent year tabulated. This is a significant rise from the early 1980's. But even as the hospice philosophy penetrates the health care marketplace, gaps remain. The length of stay in particular is a concern, with most hospice patients dying within two or three weeks of enrollment. This means that hospice, despite its growing public profile, despite its comprehensive coverage and despite open access, is still thought of as a place of last resort.

This is where palliative medicine comes in. In simplest terms, palliative medicine is the care a patient gets at first diagnosis of a terminal illness; it's a kind of pre-hospice care. The term itself was created as a euphemism, introduced in 1975 by an oncologist in Montreal, Dr. Balfour Mount. Mount realized that his French-speaking patients would respond poorly to a facility that was called a hospice, since the word in French refers to an almshouse for the aged and infirm. The word "palliative," derived from the Latin for "to cloak" or "to shield," was already being used to mean treatment to relieve symptoms rather than to cure the underlying disease. It seemed a small step from there to the way the word has come to be used, as a branch of medicine that takes as its mission the prevention and relief of suffering, in particular the suffering associated with terminal illness.

One leader in the American palliative-care movement is Dr. Diane Meier, a petite whirlwind of a woman who is head of the palliative-care program at Mount Sinai Hospital in Manhattan and is director of the Center to Advance Palliative Care, a national advocacy group with headquarters at Mount Sinai. She has taken on palliative care as her personal mission -- a mission that began about a decade ago, when she peered into the open door of a hospital room and saw a patient writhing, arms and legs tied to the bed, trying to remove his feeding tube.

Meier asked in horror what was going on and learned that the patient had first come to Mount Sinai about six or eight months earlier with a lung mass. He was found to have lung cancer and a single brain metastasis and was advised to have surgery, radiation and chemotherapy. He refused all three. His wife, it turned out, died of lung cancer two years earlier, and he did not want to go through what she had gone through. Against their better judgment, the hospital staff sent the man home, under the watchful, worried eye of his three children.

Dying at home is not easy. Even though surveys indicate that about 70 percent of Americans say they want to die at home, few realize how grueling the work of dying can be. Almost everyone eventually needs care from either a paid assistant or, more often, a relative -- and the toll is enormous. Think of it: the aide or family member is expected to bathe, dress and feed the dying person, to assist in the bathroom and to keep track of the narcotics and other powerful medications, as well as doctor visits. Even loving, healthy people have trouble when they're thrust into this role for a family member or friend; what of family members who are ill themselves, or resentful, overburdened, exhausted, depressed?

Few services were available at the time to the Mount Sinai patient. His cancer spread, and one day the man's son found him unresponsive on the kitchen floor, where he had fallen during a seizure brought on by brain metastases. The son called 911.

Readmitted to Mount Sinai, the man was sedated by a combination of antiseizure medication and the cancer itself. He was plagued by delirium and was only sporadically alert. He was in no position to reiterate his earlier decision to refuse therapy. The doctors decided that the only way to get food into the man, who was having trouble swallowing, was through a feeding tube, which has to be inserted through the nose, down the throat and into the stomach. It's uncomfortable to get it in and to have it in, and the patient kept pulling it out. The doctors restrained his hands. He pulled it out with his knees. They restrained his feet. Still he somehow managed to dislodge the tube 17 times, and each time the hospital staff replaced it.

Why, Meier asked the intern in charge of the man's care, do you keep reinserting that tube, when it's so clear the patient doesn't want it?

"He looked at me, and I will never forget this young man's face," Meier told me. "And he said, 'Because if we don't do this, he'll die.'"

Meier describes this as her "light-bulb moment," the instant that clarified for her that there was a way to bring medicine back to its original goals of healing and the relief of suffering. "I realized that this young man really cared about this patient, wanted to do the best for him, was upset about the suffering he was causing -- but he didn't see any other way to do it." Meier decided to help people like him find another way.

Had there been a palliative medicine program in place in the hospital -- of the kind Meier estimates are in place in or planned for about half of the 400 major teaching hospitals nationwide -- the intern could have asked for a palliative consultation for the distressed patient Meier had witnessed. The palliative team might have advised how to care for a terminally ill patient who was rejecting his feeding tube. They might have offered some alternatives instead: prescribing antianxiety medication, for instance, or taking out the tube and offering small amounts of semisolid foods. Since the palliative physicians would have been the intern's peers -- unlike nurses, who would have lacked the authority to insist on leaving the patient alone -- they could have presented their treatment perspective in a way that, in theory, might have got a more receptive response. This is generally how palliative-care consultations are now offered and received around the country.

The American Board of Hospice and Palliative Medicine accredits fellowship training programs, and close to 2,000 internists, family physicians and other doctors have passed its certification exam. The next step would be for the American Board of Medical Specialties to recognize palliative medicine as a formal subspecialty, like neurology or cardiology. Meier says she hopes this will happen in the next few years.

But while a palliative perspective is making inroads into hospital-based medicine, there is still something of a turf battle today between palliative medicine and hospice. Is hospice a subcategory of palliative care, or is it the other way around? Is it better to focus end-of-life care in the hospital or the home? Will palliative medicine put physicians back in charge of dying, remedicalizing the experience all over again? Will it turn suffering into just another disease to be cured?

Death often comes as something of a surprise - which is odd, when you think about it, because people who die tend to be old and sick already. Some 80 percent of the Americans who die every year are on Medicare; the vast majority of them are suffering from one or more forms of what Joanne Lynn calls "serious, eventually fatal chronic illness." But death doesn't usually announce itself in advance, like the Grim Reaper knocking on the door in an old New Yorker cartoon. The major killers have idiosyncratic "dying trajectories," says Lynn, most of which make the prediction of the actual time of death virtually impossible.

Cancer has a dying trajectory that best fits the hospice model: a very gradual decline in function, usually over months or even years, so gradual as to be hardly noticeable, and then a sudden turn, a sharp decline and, within a couple of months, death. It's with cancer deaths that physicians can make prognoses that are closest to accurate. When a patient with advanced cancer takes to bed with no clear and correctable cause, that usually means death is a matter of weeks, or at most a few months, away.

But cancer is involved in only about 25 percent of anticipated deaths. Other common causes of death, together accounting for another 35 percent, are heart disease and lung disease. The dying trajectory for organ failure, which includes not only heart and lung failure but also failure of the liver or kidneys, is trickier than that for cancer. This one is a downward-spiraling roller coaster, a long, slow decline punctuated by valleys of periodic, and unpredictable, crises. The person often recovers from each crisis, though not quite to the same level of function. Eventually there's a crisis that turns out to be the final one. And there are those people -- with Alzheimer's or Parkinson's disease -- who can dwindle over many years. These are the people who are the most difficult to care for.

Death generally comes for most of us "with unpredictable timing from predictably fatal chronic disease," Lynn wrote in "Sick to Death and Not Going to Take It Anymore!" But since the diseases are "predictably fatal," why do we so often feel blindsided by death, even the death of an elderly person suffering from a long-term condition? Because the hardest thing to do is to really, deeply believe that we or our loved ones will die.

This explains why people keep going back to the hospital for more care. "Even knowing that one more transfusion will not make a difference or that one more round of antibiotics or one more trip to the intensive care unit will not help," wrote James Hallenbeck, an assistant professor at Stanford University, in his book "Palliative Care Perspectives," "many have trouble breaking the cycle." Patients and their families and even their physicians say they despise the miserable roller-coaster ride, he wrote, yet they often act "as if they are addicted to it."

What we're addicted to, it seems, is the belief that we can micromanage death. We tend to think of a "good death" as one that we can control, making decisions about how much intervention we want, how much pain relief, whether it's in the home or the hospital, who will be by our sides. We even sometimes try to make decisions about what we will die from. This can be valuable, as when a cancer patient with little hope of survival, like Goldie Gold back in mid-July, rejects debilitating chemotherapy. But often, our best-laid plans can go awry. Dying is awfully hard to choreograph.

Charles Meys had a patient this summer who thought he had in fact arranged his dying, just as he had arranged most other things in his life. Meys didn't know this patient well -- like most people in hospice, he was under Meys's care for only a short time -- but he got an impression of him as a man who stuck to his decisions even in the face of conflicting new information. The patient, age 88, had been taking 10 to 12 different medications, many of them more than once a day, for hypertension and Parkinson's disease, and in early 2005 he had been put on dialysis three times a week because his kidneys were failing.

He was angry, he was tired and at the beginning of June he decided to stop everything. No more medications, he said -- his Parkinson's was making the pills too hard to swallow anyway, and if his wife chopped them up they tasted awful -- and no more dialysis. This was when he was assigned to Meys.

The patient and his doctors assumed that it would be kidney failure that killed him. Usually, death from kidney failure is relatively peaceful: a short time after dialysis is withdrawn, the patient slips into a coma and, soon after, quietly dies. To this man, that kind of death seemed preferable than the agony of living indefinitely with three chronic, progressive, debilitating diseases.

"I told him the first day I met him that it was entirely his decision," Meys recalls, "but that he had to realize that his blood pressure was extremely high, and that there were certain hazards associated with allowing it to stay that high without treatment," like stroke or heart attack.

The man's withdrawal from dialysis did not spell the end for him. He lived on and on, his kidneys performing their job at suboptimal but tolerable levels for weeks. Still, he kept to his plan.

Three weeks after he stopped dialysis, his hypertension still untreated, he suffered a stroke. Dying of kidney failure was the death this man chose. But dying after a stroke -- which can be "hellish," Meys says, with the risk of incontinence, immobility and a long, dependent lingering -- was the death he got.

The uncertainty of prognosticating death makes it hard to devise a system of care for dying patients. Hospice was the first -- and to date, most comprehensive -- attempt, but it has several weaknesses. It depends on an accurate prediction of the time and manner of death. It is also essentially home-based care, with Medicare regulations requiring that any licensed hospice program have at least 80 percent of its services offered to people at home. But not everyone can manage a home death.

"There are some families who say, 'If she dies at home, I'll never be able to go back in that house,'" says Dr. Kathleen Foley, former chief of the pain and palliative-care service at Memorial Sloan-Kettering Cancer Center in New York. "Or an elderly woman will say: 'I can't let my husband die in this bed. I'd never be able to sleep in it again.'" Or someone might realize, at the last minute, that the idealized fantasy home death -- with the whole extended family gathered around the beloved scion in the four-poster bed -- is just that, a fantasy, and that a hospital death somehow feels safer, more comfortable or more appropriate. "We have to recognize that reality, that some families just never could have kept their loved one home to die," Foley told me. "We want hospice to be able to provide most of the care in those last days. But if the patient ends up dying in the hospital, that may be best for everyone."

Goldie Gold ended up in a residential hospice because her children didn't feel they could cope with sole responsibility for the round-the-clock care she eventually required. On July 22, they moved her by ambulance from her apartment in the Village to the Hospice Inn in Melville on Long Island. By that point Gold was already spending most of her time in a delirious state, and her daughter Jaymie Corinella, who is 45, decided that Gold wouldn't even notice her surroundings. "Jaymie told me that in order to keep Goldie at home, they would have to spend all their energy trying to juggle everything, wondering how they could patch together 24-hour care for her," Meys said that afternoon. "If they put her in a facility, Jaymie said to me, 'We can just focus on loving her.'"

Hospice's biggest recruitment hurdle is its reputation as last-ditch, brink-of-death care. Most sick people still don't ask for it; it seems too much like giving up. Doctors are hesitant to recommend hospice, because it requires them to speak frankly about the inevitability of a patient's death -- something that most physicians are unwilling to do and that most patients are unable to hear.

The six-months-to-live requirement for hospice admission was part of the 1982 legislation that made hospice a benefit under Medicare. Today hospice administrators chafe under it, and some would like to have it removed. But the rule serves an important purpose, says Carolyn Cassin, director of Continuum Hospice Care, the largest hospice in New York City. It limits the number of people entitled to the expensive benefit -- and it provides an important psychological demarcation.

"It throws down the gauntlet" is how Cassin puts it. "It's not a bad length of time for Americans, who don't want to die too soon. With six months left, you'll still feel pretty good for most of that time. You could still make that trip to see your grandchildren or go to Hawaii or see the Eiffel Tower." Who can say what it's really like to die? You get only one chance to do it, and there's no reporting back from the field. In her book "Handbook for Mortals," written with Joan Harrold, Joanne Lynn, who is also a senior scientist at the RAND Corporation, wrote about a seriously ill patient who opens his eyes and sees a nurse. "Am I dead yet?" he asks. "No," says the nurse. He thinks for a moment and then asks, "How will I know?"

"Studying death is somewhat like studying a black hole," Hallenbeck, the Stanford palliative-care expert, says. "You can study around it, but with death, like with black holes, there's something intrinsic to the very process that defies our ability to analyze it."

Not long ago, Hallenbeck was the palliative-care consultant for two patients at the same time: an old woman dying of breast cancer and her middle-aged son, who was dying, too. The son, who had colon cancer, died first. The woman sat with Hallenbeck at her son's bedside, finding herself in the odd -- and you would think unbearable -- position of watching her own child's death from the disease that was also killing her. She studied her son's face, asleep yet not asleep, not quite of this earth but not quite dead yet either. As Hallenback recalled, he breathed a little raggedly, making catlike purrs, and his features were slack, mouth open and eyes at half-mast. Then the old woman turned to Hallenbeck. "I guess he's getting close," she said. Hallenbeck nodded. The old woman turned back to gaze at her son. "Doesn't look so bad, does it?" she murmured.

It's true: the last stage of dying can look surprisingly peaceful -- at least to the people who have seen it over and over. But what's going on inside? Hallenbeck has spent a good deal of time wondering about that. He says he would love for someone to attach electrodes to a dying person's head to record electroencephalogram readings of the brain-wave patterns of dying -- patterns that he suspects would look much like those of someone in a dream. But he adds that such an experiment would probably never be done. The moment of dying is considered too sacred, too intimate, for any scientist to ask to intrude with his electrode machines. Even though many people die with wires and tubes protruding from their bodies, those are theoretically there for the benefit of the dying person, not for the furthering of what some would see as a ghoulish kind of knowledge.

Still, scientists are able to guess some things about the dying person's state of mind. They have observed that anywhere from 25 to 85 percent of the actively dying are in altered states of consciousness during their final days. This is a wide range, probably explained by variations in how the investigators defined "altered state" and how they determined the dying person's mental status. Most things about a dying person's state of consciousness must be inferred. Dying people may say things that sound delusional; they'll talk about seeing their long-dead relatives assembling in the sick room, or they'll ask, "Where are the train tickets?" or "How can I travel with all this baggage?" Hallenbeck considers this altered state to be a hallmark of dying. "I'm pretty comfortable saying I'm not sure what this is about or what it signifies," he says. "But what I am comfortable saying is that we'll all get a chance to find out."

Hallenbeck distinguishes toxic delirium -- by which he means altered states caused by pain medication and other drugs -- from terminal delirium, which is sometimes part of the dying process. The distinction is often made by process of elimination; if the patient is not taking drugs known to affect mental status, the presumption is that the delirium must be caused by something else, something intrinsic to dying. No one knows for sure what that "something else" might be -- activity in the optic region of the brain, perhaps, or the effects of the release of endorphins and other brain chemicals; a side effect of the dehydration common in the last days of life; a result of electrolyte imbalance; a psychological tool for tidying up unfinished business. According to Hallenbeck, all of this is prime material for further investigation.

But even if scientists can't say for sure what's going on inside a dying person's head, or why, they do tend to know how the last hours look. With the exception of those who die suddenly -- that is, those who die from trauma, heart attack or stroke -- death has many familiar hallmarks.

Imagine that the person dying is you. This is something that is all but impossible to do -- even in dreams we usually force ourselves awake before the last, fatal moment -- but it's an interesting exercise. So try to picture it: you've been in hospice care for, say, three weeks, and Charles Meys has been coming to your home twice a week to take your pulse and listen to your heart and talk about how to treat your pain and constipation. Today he tells your caretaker that you may have only a few days left to live.

Your hands are cold to the touch; so are your feet. You twitch occasionally. Your face is drawn, your lips are dry and you don't get out of bed even to use the bathroom. Using the bathroom is irrelevant by now anyway; you haven't eaten anything for days, so your urinary and digestive tracts have just about shut down. Slowly, though you can't necessarily feel it, all your other organs are shutting down, too.

If you could see yourself, you'd see that your lips might look blue. Your hands and feet might be blue as well. You breathe rapidly, except for the long stretches of time when you don't really seem to breathe at all.

You spend your time in a kind of limbo between waking and sleeping. You know who you are and where you are, yet you're seeing visions. Those relatives who have been dead for years appear and disappear at your bedside. You want to tell them something, but you don't talk to them, nor do you mention them to your caretaker. Indeed, you don't talk much to anyone, imaginary or real.

Sometimes you moan, but you're probably in no distress; that's just what happens when your throat muscles go flaccid. Toward the end, your jaw moves up and down with every breath, almost as if you're chewing something. And as you breathe, you make an eerie sound. It's the death rattle; you are not coming back. The scariest part about dying, at least to me, is how it ends: with the immutable fact of no longer existing. But there are other common fears: dying alone and dying in pain. Today, say specialists in end-of-life care, no one has to do either.

Palliative care began as the control of pain, and pain relief remains the hallmark of most end-of-life care, no matter where it takes place. At Continuum Hospice Care, six full-time doctors specialize in pain and symptom control at the end of life, and Cassin, the C.E.O., tells her staff members that "no patient you come in contact with should ever be in pain." She does not mean just physical pain, either, but also the kinds of pain that are more difficult to diagnose: emotional pain -- which Cassin describes as "I'm frightened"; psychological pain -- "my family hurts, my friends hurt"; and spiritual pain -- "I don't know where I'm going, I haven't been a very good person, I haven't done the right things with my life." As she explains to her nurses and health aides, "You have just as much responsibility to alleviate that as you do to alleviate the physical pain -- and if you can't, you can know who to call in to help you, know when to call a chaplain, a massage therapist, a pet therapist, a doctor, a volunteer to play the harp."

Pain relief is much better than it used to be, but it comes at a cost, and for different patients, balancing the risks and benefits can be tricky. For one thing, the more you medicate someone for pain, the less likely the patient is to stay alert. Morphine, the most commonly used pain medication for the dying, can increase the dulling of the senses, contributing to the inability to think clearly, to articulate coherent thoughts. At the end of life, when clarity is slipping away, this befuddlement can be difficult to bear. "It's hardest for the family," Foley says. "They already feel so bad about losing their loved one, and if he takes this medication and becomes confused or delirious, they feel like they're losing him that much sooner."

Pain medications can also make the patient constipated, sometimes so badly that a nurse must empty the bowels manually in order to avoid fecal impaction. Occasionally, laxatives act unpredictably, causing patients to soil themselves before they can get to a toilet. All of this can be mortifying. Just as some might rather stay awake and suffer, others might rather stay continent and suffer.

For all that palliative-care physicians have learned about pain relief, however, most terminally ill patients still don't get enough -- partly because of fear of complications, partly because of uncertainty about how much the patient is suffering. In 1995, the Robert Wood Johnson Foundation published a landmark study, which surveyed the dying experiences of more than 9,000 Americans in the early 1990's. The investigators surveyed family members who had observed the deaths and reported that half of the patients had spent at least half of their last 72 hours on earth in moderate to severe pain. Of course, studies like this, which depend on family observations, might be misleading, since relatives can easily misinterpret the reflexive moans and twitches of active dying, which need not indicate pain. Still, the overall impression was one of a dying process that was unnecessarily hard.

"There's no reason for anyone who's dying to be in pain," Meys says. "Pain is how we start. If we haven't controlled pain, then nothing will be good." My father died while sitting on the toilet. The terrible unseemliness of this, the image of him falling to the cold tile floor with his pants down around his ankles, has haunted me in the nine years since his death. I was living in a distant city, not involved at all in those final moments, but I imagine it anyway: my mother hearing the thump, rushing up the stairs and shouting: "Sidney! Sidney!" through the closed bathroom door, opening it at last to see him slumped there, stripped not only of life but of dignity. For months, she held onto the torn pants that the medics ripped off during their doomed attempts at C.P.R.

And yet, as humiliating as it would have been for my father and horrifying as it was for my mother, this was in many ways a good death. My father was chronically ill with kidney disease and had spent the previous five years getting dialysis three times a week. He had trouble walking. Yet at age 76 he was still active, still independent, still engaged; he still drove and went to movies and visited with friends and went to art museums. He had spent the last day of his life at a three-hour figure-drawing class that he loved. The heart attack that killed him was probably merciful in its deadliness. Had he recovered, he might have emerged permanently damaged, presenting his family with decisions to make about surgical intervention and end-of-life care that could have been wrenching.

So we were spared many of the horrors I encountered while researching this article: no futile bouts in the intensive care unit, no fighting off the tubes or vents or machines, no need to ask ourselves what it was my father would have wanted.

But just as we were spared something terrible, we were denied something good too: the chance to make my father's death not only mercifully quick but meaningful. I found myself, as I read about hospice deaths and talked to my friends about the way their loved ones died, trying to imagine what kind of death I'd want for my mother, my husband, myself. I'd like a hospice nurse taking care of us, a nurse like Charles Meys, with comforting hands and a gentle voice and a direct, nonjudgmental gaze. And for myself, rather than dying of a sudden heart attack like my father's, I'd wish for foreknowledge. I'd like to know that death was imminent, and approximately when it would come, and approximately how. But beyond that, the fantasizing stops. Like a dreamer seeing herself fall off a cliff, I can't let myself get to the bottom, can't imagine the final splat.

Most of us will be old and sick when we die and will have had years to tell our loved ones just what it is about dying that most frightens us and, in broad brush strokes, just how we hope to die.

The trouble is, most of us aren't talking. The silence is another example of our ambivalence about death, our unwillingness to look it straight in the face even as we make noises about accepting it. We're all so coy about the words we use. Last spring, on a visit to the Zicklin Residence, a new 18-bed hospice in the Riverdale section of the Bronx, only one of the four patients I interviewed admitted that she was dying. The others, despite the fact that they had needed medical prognoses of less than six months to get into Zicklin, all danced around the subject, and I, like their doctors and nurses, was hesitant to press the point. If they were choosing denial, who was I to force them to confront the ugly truth?

"I don't use the word 'dying' very often," says Cassin, whose company owns the Zicklin Residence. "I try not to say 'dying' or 'terminal' or 'end of life.' I say 'the last phase of your life.'"

This hesitation about saying things out loud was a surprise to me. The big push in the early hospice movement was to get people talking frankly about death and dying. To pioneers like Cicely Saunders and Elisabeth Kübler-Ross, the medical profession's unwillingness to talk about death, its complicity in pretending that the patient would eventually recover, was the very thing that made dying so terrible.

Yet it seems, for all the medical edifices we've built to cater to the dying, we haven't really changed much in the past 35 years. For months, I kept butting up against euphemisms. When I talked to a patient to whom Meier referred me -- a smart, thoughtful woman with advanced ovarian cancer who was officially part of Mount Sinai's palliative-care program -- she said quickly: "Palliative care? Oh, no, I'm not ready for that yet." When I talked to a home hospice patient with advanced AIDS -- a charming, introspective, plain-spoken man who confided that he had plans to end his life if the pain got too bad -- he made me call it not "dying" but "passing over," not "assisted suicide" but "hastening death."

Even Goldie Gold, who spent a lifetime being blunt, pulled her punches a little at the very end. A few days before she died, on July 26, of multiple-organ failure, she turned to her daughter Jaymie and said, "This will be my final curtain."

These euphemisms can have profound implications about what kind of system is in place to cater to the dying -- and what kind of treatment we can expect for ourselves when our time comes. According to the National Hospice Foundation, one-quarter of American adults over 45 say they would be unwilling to talk to their parents about their parents' death -- even if their parents had been told they had less than six months to live. Half of all Americans said they were counting on friends and family members to carry out their wishes about how they wanted to die -- but 75 percent of them had never spelled out those wishes to anyone. A significant subset of that 75 percent had probably never even articulated their wishes to themselves.

As J. Donald Schumacher, president of the National Hospice and Palliative Care Organization, said last April to the Senate Committee on Health, Education, Labor and Pensions, "Americans are more likely to talk to their children about safe sex and drugs than to their terminally ill parents about choices in care as they near life's final stages."

Diane Meier has worked against this reticence, not only in her professional life but in her personal life as well. Her father, 81 years old, suffered a debilitating stroke 10 years ago and was recently advised to have a diagnostic procedure for a possible aortic aneurysm, which might have required an operation. Meier, who is her father's health care proxy, refused the procedure, and would have refused the operation too. "I know that the more doctors do to my parents, the more problems they will create; I know that deep in my heart," she says. "I'm hoping to screen and protect them from that kind of well-intended but harmful intervention."

As for how she will face her own death, she admits that she doesn't know. "I hope and I pray that when that time comes for me, my work will give me greater restraint and perspective than I otherwise would have," says Meier, who is 53. "But my guess is that I'd be panicked and terrified, the same as everyone else."