

NEW YORK TIMES - May 29, 2000

PLANNING FOR DEATH *First of two articles.*

At Life's End, Many Patients Are Denied Peaceful Passing

By DENISE GRADY

At the age of 91, Bertha Hyman had a clear mind and a firm resolve. When her life neared its end, she wanted no heroic measures: no resuscitation, no respirator, no tangle of tubes. She signed a "living will" outlining her wishes, informed two nieces and gave one of them power of attorney to make medical decisions for her if she could no longer make them herself.

But when Ms. Hyman had trouble breathing a few days after surgery for a broken hip in 1998, the nieces, Sabena Wilensky and Rosalind Keyes, were horrified to find that she had been put on a respirator. Only then did they learn that her nursing home, in Delray Beach, Fla., had never sent her living will or power-of-attorney document to the hospital.

Ms. Keyes recovered the documents, but doctors said the respirator could not be turned off. That was not true. Experts in law and medical ethics say that doctors could legally have honored Ms. Hyman's wishes. But her distraught nieces did not know that.

Finally, after five days, doctors agreed to remove the respirator, saying Ms. Hyman might be able to breathe on her own. But she could not, and, under sedation, she died a few hours later.

"It was five extra days of miserable life," Ms. Wilensky said. "We were feeling terribly guilty. We were in charge of her, and we didn't do a good job. We didn't know how far we had to go to protect ourselves."

Deaths like Ms. Hyman's are achingly familiar to many people. Although millions of Americans have signed living wills and power-of-attorney documents, thinking the papers would help them avoid unwanted treatment and prolonged deaths, in many cases those measures turn out to be useless.

There are many reasons that the documents, known collectively as advance directives, can fail: people lose or forget them; living wills are too vague to interpret; relatives disagree about what the patient wanted; hospital staff members mistakenly fear prosecution for stopping life support; or doctors overrule the family and refuse to stop treatment. Some experts say the very idea of living wills is flawed, because the course of illness is too unpredictable to be anticipated in a simple document.

But the failure of advance directives is just one symptom of a much larger problem: widespread gaps and deficiencies in the care of people who are dying. "End-of-life care" has become a frequent subject of medical conferences and journal articles, and even the American Medical Association has acknowledged that too many dying patients suffer needlessly, and that the profession needs help to improve their care.

"We have an entire health care system not friendly to end-of-life care, a work force not educated to end-of-life care and an entire population just climbing out of the era when it was taboo to talk about it," said Dr. Linda Emanuel, vice president of ethics at the A.M.A., and a creator of a course on care of the dying that the group hopes will reach every doctor in the United States.

Carol Sieger, a lawyer for Partnership for Caring, a successor to the group that created the first living will in 1967, said, "There is a concern that we have overlegalized the process of dying, and that these are personal decisions between families and doctors."

When end-of-life care is poor, the results can be devastating, not just to patients but to their loved ones. In the training manual for its course, the A.M.A. warns that the doctors of dying patients have only one chance to "get it right," and that if they do not, "suffering may occur unnecessarily, family distress may continue long after the patient's death, and those who watch may worry that their death will be similar."

Families have sued doctors for "medical battery" for forcing life support or resuscitation on unwilling patients, and some states punish doctors who disregard advance directives.

But doctors who go against patients' wishes are not necessarily driven by an urge to impose their will on others. Rather, they may be struggling with complex medical issues. Deciding when to withhold or stop care can be daunting. Advances in medicine have changed the way people die, and it is often difficult to tell when death is near. Most people today decline slowly from chronic diseases with erratic courses, unlike people in earlier times, who were more likely to die quickly from infectious diseases, accidents and heart conditions.

People today are also more likely to die in settings where technology like feeding tubes and ventilators can keep them nourished and breathing, and where decisions about using it must be made. Although surveys show that 90 percent of Americans hope to die at home, only 20 percent get their wish. The majority die in hospitals. Only 17 percent die in hospices, where the focus of care is on keeping the patient comfortable rather than on prolonging life.

For many people, the simple reality is that in this era of managed care and 10-minute office visits, doctors and patients may not find time to discuss patients' feelings or to make plans about treatment near the end of life.

Advance Directives Taking Dying Back From Technology

Living wills were created in 1967, when people began to question the price society seemed to be paying for medical progress: hopelessly ill or brain-damaged patients being kept alive by respirators, feeding tubes and pharmacologic maneuvers that could not be halted without court orders.

The wills were conceived by Luis Kutner, a human-rights lawyer in Chicago and a co-founder of Amnesty International. Mr. Kutner presented his idea to the Euthanasia Society of America, which drew up living wills and began distributing them.

The documents were an effort to wrench dying from technology's grip, and even critics concede that the advance-directive movement played a powerful part in forcing doctors to acknowledge that, for dying people, more was not necessarily better.

Living wills are intended to tell doctors what treatment a patient would or would not want if he or she became critically ill, could not communicate and had little or no hope of recovering. Respirators, cardiac resuscitation, feeding tubes, painkillers and antibiotics are usually among the treatments covered.

Experts recommend that in addition to a living will, or even in place of one, patients sign a durable power of attorney, also called a health-care proxy, appointing someone else to make medical decisions when the patient can no longer do so.

Those documents become especially important when an illness takes an unexpected turn, because a proxy can make decisions in situations that were not anticipated in a living will.

"First and foremost is the health care proxy," said Joseph LaBarbera, an attorney with Lifshutz, Polland & Hoffman, a law firm in New York that specializes in medical issues. "It really gives the doctor somebody to talk to who's familiar with the wishes of the patient. Often, the living will isn't specific enough for day-to-day stuff."

Advance directives can be used in every state and are backed either by legislation or by precedents set in court cases. A 1991 federal law, the Patient Self-Determination Act, requires that hospitals and nursing homes inform patients that they have the right to fill out advance directives.

In theory, people who sign advance directives should expect to have their wishes respected. Doctors and nurses are not punished for honoring patients' requests to stop treatment, Ms. Sieger said. "Doctors are not being criminally prosecuted or disciplined for withholding life support," she said.

On the contrary, she said, doctors have been sued for refusing to stop unwanted treatment.

Nonetheless, three decades after the first living will was signed, many Americans still have painful deaths. Although peaceful deaths do occur in hospices and some nursing homes, and many hospitals try to honor advance directives, over all, they are "ineffectual in shaping care," said Dr. Joanne Lynn, director of Georgetown University's Center to Improve Care of the Dying and co-director of a project known as the Support study, the largest study ever conducted of dying patients in American hospitals.

Dr. Mark Tonelli, a pulmonary specialist at the University of Washington in Seattle and the author of the article "Pulling the Plug on Living Wills" in the journal *Chest* in 1996, said: "People thought you would fill out one of these things and you would die well. But our ability to guarantee each patient a good death is about equal to our ability to guarantee them a good life."

Karen Kaplan, executive director of Partnership for Caring, said of the directives: "They are frequently not followed. We get a lot of calls asking for help in getting them honored."

Renie Rutchick, a social worker at Partnership for Caring, said one of the calls came from the son of a 91-year-old man with advanced Alzheimer's disease. Before developing dementia, the father had named the son as his proxy and signed a living will requesting no extraordinary measures. Now, the father had pneumonia, and the son did not want him to be given antibiotics. But a doctor insisted on treating him.

"He was his father's health care agent, and he just didn't know he could really stick up for himself," Ms. Rutchick said. "That frequently happens." She told him his father did not have to be treated against the family's wishes. "I said, 'If it ever happens again, don't let them bully you into it.'"

Joanne Nicholas, manager of Health Communications at Memorial Sloan-Kettering Cancer Center in New York, was shocked to find that a living will and a health care proxy did not protect her mother, who had advanced dementia, from unwanted, painful treatment at a nursing home in Brooklyn.

Without her daughter's consent, Ms. Nicholas's mother was given various medications, made to choke down a type of adult formula and was hospitalized for a mild fever. "My poor, frightened mother was taken from her bed at night and brought by ambulance to a hospital," Ms. Nicholas recalled. "She was like an infant, in terror. She had a living will, prepared by an attorney, and I worked in health care. I had done lectures, I had handed living wills out to people. How come they didn't work?"

Ms. Nicholas consulted a lawyer and several doctors, who told her that nursing home officials, fearing charges of negligence, would err on the side of overtreatment unless they had specific instructions to do otherwise.

Ms. Nicholas then met with administrators at the home and asked, "How do I help you cover yourself so you can stop torturing my mother and let her die a good death?"

The solution was to state in writing that the nursing home was not to take her mother to a hospital or give her any treatment without first consulting Ms. Nicholas, who provided phone and beeper numbers so that she could be reached 24 hours a day. Notes were attached to the front of her mother's medical chart to alert all staff members. The home also had Ms. Nicholas sign a "do not resuscitate" order so that doctors would not try to revive her mother if her heartbeat or breathing stopped.

"Why didn't they give me that order before?" Ms. Nicholas asked. "In my opinion, they don't want to make this information available, because these people are cash cows."

Ultimately, Ms. Nicholas' strategy worked. There were no more tubes or needles or machines, and a few months after the meeting at the home, with her daughter by her side, Ms. Nicholas's mother died peacefully.

Do Not Resuscitate Final Requests Clash With Procedures

For more than two decades, hospitals have recognized that many terminally ill people do not want aggressive treatment that merely postpones death. And so patients and their families, like Ms. Nicholas, have been given the option of requesting do-not-resuscitate, or D.N.R., orders.

But traditionally, neither D.N.R. orders nor living wills applied in emergencies outside the hospital, and ambulance crews could not honor them. So if a dying patient at home had severe pain or breathing trouble, and a frightened relative dialed 911 hoping for just help with oxygen or medication, the ambulance team would also be obligated to carry out a full resuscitation.

During the 1990's, states began passing laws to allow emergency medical teams to respect "out of hospital D.N.R.'s" for dying patients being cared for at home. The D.N.R.'s are legal documents, signed by a doctor. Patients are generally advised to post them on their bedroom doors or even to wear a special D.N.R. bracelet approved by the state.

Seven states and the District of Columbia do not allow out-of-hospital D.N.R.'s: Delaware, Iowa, Mississippi, Nebraska, North Dakota, Pennsylvania and Vermont. In those states, families who do not want resuscitation are often counseled to avoid or delay calling emergency services.

That was the recommendation given to Dr. Linda Himot, a psychiatrist in Pittsburgh who took care of her father, Jacob, as he succumbed to congestive heart failure at the age of 95. A visiting nurse suggested that if her father died at home, Dr. Himot should wait a while before calling the paramedics to have him declared dead.

When her father died during the night last summer, Dr. Himot waited, as the nurse had advised.

But the paramedics told Dr. Himot they were obligated to try to resuscitate him.

As they began taking out their equipment, Dr. Himot dashed off to find her father's living will. Legally, they were not permitted to honor living wills. But when she produced it, they read it and -- despite the law, apparently -- put their equipment away.

"It would have been a fruitless act," Dr. Himot said. "It seemed almost sacrilegious."

The Critical Period Confusion, Caution and Much Pain

The most exhaustive information about end-of-life care comes from Dr. Lynn's study of dying patients in American hospitals, which included 9,105 patients at five hospitals around the country from 1989 to 1994. The study found that half died with moderate to severe pain, hooked up to machines in intensive care units.

More than half the doctors surveyed had no idea what kind of care their patients wanted at the end of life. Often, both doctors and patients had avoided talking about death. Only 14 percent of the patients had advance directives, only 90 directives said anything specific about treatment and just 22 discussed life support in the patient's current condition.

"Patients and families often seemed adrift, confused and in need of guidance about what was happening and how to respond to it," Dr. Lynn said. She said little had changed since the study was done.

Part of the difficulty in planning care at the end of life is that even with the sickest patients, it can be hard to tell when the end is near.

"Only 20 percent of us die with a phase that is clearly 'dying,' " Dr. Lynn said. While people with terminal cancer often follow a predictable path, more Americans die from chronic diseases of the heart, lung and kidneys, which are less predictable.

A study published in November by Dr. Lynn and her colleagues in *The Journal of the American Medical Association* showed how difficult it can be for doctors to make predictions.

The study included 2,607 patients who were hospitalized and seriously ill with heart failure, liver or lung disease. Using standard criteria to gauge the severity of the illness, doctors judged that 923 would live six months or less -- but 70 percent survived longer. Even when tighter criteria narrowed the six-month prediction to just 19 patients, half outlived the prediction.

Other patients died sooner than expected. Some who were given a 40 percent likelihood of living for two more months died within days.

Dr. Lynn said she and her colleagues concluded that those with terminal diseases "have to make peace with God and be ready to go, but also ready to stay."

The Responsibility For Caretaker Emotional Time

In November, when Bertha Nunez, an 87-year-old Miami resident, developed a respiratory infection and had trouble breathing, her daughter, Bertha Bouza, accompanied her to Kendall Hospital.

The two women signed forms provided by a nurse saying that if Mrs. Nunez were to deteriorate, they would not want resuscitation or other aggressive treatment.

The next day, Mrs. Nunez stopped breathing. "To me, at that precise moment, she died," Mrs. Bouza said. "I had her in my arms, and that's the way I wanted my mother to die." But doctors called guards to remove Mrs. Bouza from the room, began trying to resuscitate Mrs. Nunez and placed her on a ventilator.

"They had no right to do this," Mrs. Bouza said, weeping at the memory.

A day later, Mrs. Nunez was allowed to die. "I feel so guilty," Mrs. Bouza said. "I was her only child, and she put all her confidence in me."

The doctors involved declined to discuss the details of the case, although one, Dr. Julio Ortiz, said: "I don't know what legal implications are involved here for the hospital, for the doctors, for the nurses. When somebody expires, most hospitals have a routine of performing a code blue. Maybe in trying to do the best they could have done they did something wrong, which has no bearing because the patient died anyway."

Doctors who try to revive patients against their will are rarely penalized, said Ms. Sieger, the lawyer for Partnership for Caring.

"A few states, Alaska and Utah, have established penalties in legislation," she said. "But the penalties are not significant."

But lawyers have begun to press "medical battery" claims against doctors and hospitals who do not honor living wills. Few of these cases have been closed so far, but in one, in 1996, a jury awarded \$16.5 million to the family

of Brenda Young, a woman in Michigan, now 42, who was resuscitated in 1992 despite her written instructions, and was left with severe brain damage and little mental function, needing constant care. The case was later settled by the hospital for a sum that the two sides agreed not to disclose.

"The case is being looked to as the beginning of a trend," Ms. Sieger said.

The Final Period Collective Decision Relieves Stress

Most doctors are not well prepared to help patients and their families make painful decisions about dying. Medical schools teach little about how to discuss death with patients, or how to treat pain or provide other palliative care, which is treatment given strictly to keep a patient comfortable.

A 1998 survey by the American Medical Association found that only 4 of 126 American medical schools required that students take even one course on care of the dying. And The Journal of the American Medical Association recently published a harsh assessment of 50 leading medical textbooks, saying that most failed to mention the subject.

Nurses also said their training in end-of-life care was inadequate, according to a national survey published in April in the journal *Oncology Nursing Forum* by Dr. Betty Ferrell, a research scientist at City of Hope National Medical Center in Duarte, Calif. One nurse wrote that end of life was not even mentioned during her training. Another said that the oncologists she worked with were reluctant to mention a terminal prognosis to patients, and simply went on giving chemotherapy until the patients died.

An article in the Feb. 3 issue of *The New England Journal of Medicine* reported that children dying of cancer suffered needlessly from pain, nausea and other symptoms that could have been treated better. Another article in the Jan. 20 issue said patients with advanced Alzheimer's disease were too often given feeding tubes that did not help them medically, but only increased their suffering.

Dr. Emanuel, the medical association's vice president of ethics, said the lack of expertise, particularly in palliative care, was one of the factors driving patients to seek doctor-assisted suicide. If pain and other distressing symptoms were treated properly, she argues, fewer patients would seek to end their lives prematurely.

But patients as well as doctors need education. Dr. Lynn said that rather than depending solely on pieces of paper to make their wishes known, patients must talk with their families and doctors about their illnesses, about what was likely to happen to them with or without various treatments and about their hopes and fears regarding death and aggressive procedures.

Instead of getting into a power struggle over who makes the decisions, Dr. Tonelli, the pulmonary specialist, said, doctors, patients and families should make them together; advance directives may serve as a starting point.

"The idea that advance directives are of significant value for patients or the health care system as a whole is fairly passé," Dr. Tonelli said. Instead, he said, people should try to improve patient-physician communication before the end of life and during the final phase.

"Those efforts are much more likely to be successful in the long run," Dr. Tonelli said, "but they are less appealing to many people, because they're not straightforward or simple."

Dr. Lynn said the approach Dr. Tonelli described, which the medical profession calls "advance-care planning," is more common now than it was five years ago. "But probably no more than 10 to 15 percent of the people who should be doing it are doing it," she said.

Managed care is an obstacle: given 10 or 15 minutes for an office appointment, doctors and patients are more likely to spend the time on immediate problems than on worrying about the future. Often, the discussions do not begin until a crisis develops.

Dr. Tonelli said: "These will remain difficult decisions. Each individual situation is different. When it's done right, you struggle with each of them, and I don't see any shortcut."

Tomorrow in Science Times: A different way of dealing with death.

Charting a Course of Comfort and Treatment at the End of Life Doctors Are Learning How to Treat Terminally Ill Patients With Kindness, Tact and Good Medical Judgment By DENISE GRADY

The patient was in his 40's, with liver failure, hoping that a transplant would save his life. But when a severe infection set in and his kidneys failed, hope ran out. He was taken off the transplant list.

"Without the transplant, his prognosis was death," said his physician, Dr. Susan Dorr Goold, associate director for ethics and health policy at the University of Michigan Medical School. "The question was how." Did he want dialysis? A respirator and other aggressive treatment? He was too ill to answer. And he had left no instructions or legal documents -- no living will, no durable power of attorney naming someone else to decide for him.

It could easily have turned into a medical horror story. But it did not.

"He had a good death, surrounded by his family," Dr. Goold said. "He was comfortable. It was not happy -- he was dying, and young. But it was not awful."

How was it done, in an era of high-tech medicine when aggressive treatment seems to be the norm?

The answer is low-tech and old-fashioned, though by no means simple: conversation.

"We had to have a serious discussion with his wife about what she wanted us to do for him, what her goals were," Dr. Goold said. As next of kin, the wife was entitled legally to make decisions for him, even though he had not signed anything to that effect.

They went to a quiet room, and Dr. Goold began by asking her what she understood about her husband's condition. "She knew he was doing really poorly, and this was maybe the time to make some hard decisions," Dr. Goold said. They spoke for 30 to 45 minutes, when the wife disclosed that her first husband had also died after a long, painful illness.

"We decided not to pursue dialysis or intensive care, not to prolong the end," Dr. Goold said. "That's what most people decide." They arranged a second meeting, to which the wife brought family members, including her teenage children.

"It was beautiful," Dr. Goold said. "They were very supportive of her and her decision to withdraw treatment. They gave her confidence she was doing the right thing."

The absence of a living will or other documents was no impediment. Although such instructions may help to guide decisions when patients face terminal illness, doctors say there is no legal document that can take the place of talking to one another.

Joseph LaBarbera, a lawyer with the New York firm Lifshutz, Polland & Hoffman, which specializes in medical issues, said, "It has to be a team effort." He recommends that while a patient in the hospital or a nursing home is still competent, the patient and family meet with a social worker and itemize specifically what the patient and family will want done if the patient deteriorates. "The doctor keeps a copy, one is put into the patient's records and hopefully the relative keeps it as well," Mr. LaBarbera said. But even then, he added, written instructions may not be specific enough.

For that reason it is important for the patient to name a proxy to make decisions.

"Then the doctor has somebody to talk to," Mr. LaBarbera said. "It's often before you get to the resuscitation point that the problems come up." The willingness to talk and to rethink plans is especially important when patients have illnesses with unpredictable courses. In some cases, the best option may be to try treatment like a respirator or a feeding tube, with the understanding that if it does not work as hoped within a certain time, it will be discontinued.

Dr. Joanne Lynn, director of Georgetown University's Center to Improve Care of the Dying, said: "We had one patient who specifically said, 'I want a trial of seven days, and if it looks like I can't come off the ventilator, I want it stopped and I want to be sedated.' And that's exactly what was done."

"The patient was sort of vaguely aware. It was explained, 'We've reached this point, and we don't think you can pull through. Do you want time to think it over?' He held up his hand and sort of waved."

The give and take can be harder than it sounds. Dr. Goold, who has had years of practice, said: "I've seen doctors in training try to talk to patients about end-of-life issues and totally flub it. I've heard of people going in and dropping a fatal diagnosis just like a bomb, and then saying, 'So, what do you want us to do if your heart stops?' "

There is a growing awareness among doctors and patients that too many people die in pain and fear, cut off from loved ones and from the chance to come to terms with death and to say goodbyes. Treating terminally ill patients with kindness, tact and good medical judgment may come more naturally to some doctors than to others, but the American Medical Association has decided that the skills

can be learned. The group has developed a two-and-a-half-day course, "Education for Physicians on End-of-Life Care." So far, it has been given seven times, in different cities, to groups of 100 to 150 doctors each time.

Dr. Linda Emanuel, a creator of the course and vice president for ethics at the association, said the program coincided with another trend: the "renewed search for the heart and soul of medicine," the mission of helping patients that draws many people to medicine in the first place.

"A lot of doctors and the public feel that medicine isn't as caring as it should be and we've lost our way," Dr. Emanuel said. "But if you can do care at the end of life, you can do medicine."

The program could be described as a crash course in human relations and the nuts-and-bolts medical details of taking care of people whose bodies are shutting down. Participants work in small groups and are coached on how to break bad news to patients, how to recognize depression and anxiety and how to help patients and families plan treatment as illness progresses.

The doctors learn details of pain control that were not taught in medical school, as well as how to use drugs to ease shortness of breath, nausea, seizures, agitation and other problems. They are urged to encourage family members to lie in bed with a dying patient if they wish, and to tape signs to the patient's door asking doctors and nurses to leave the family alone for a while.

They are taught how to turn off a respirator in a way that does not leave the patient gasping for air. They learn how to help prepare a patient's family for the physical changes that take place as a person dies. And they talk about their own grief and feelings of failure when patients die, and ways to avoid burning out.

At a course in March, about half the participants wanted to spend extra time on pain control, and many were riveted by a session called "last hours of living." At that session, Dr. Frank Ferris, medical director for palliative care at the San Diego Hospice, noted that some dying patients lost the ability to close their eyes, a condition that most families find quite upsetting. Could anyone explain it? Dr. Ferris asked.

Not one of a dozen doctors in the room could. The explanation, Dr. Ferris said, was that when people waste away, a fat pad behind the eye also shrinks, causing the eye to sink in and to pull the lid back with it, leaving the eye partly open.

It was worth knowing, Dr. Ferris said, because the simple explanation could often ease a family's distress.

Although doctors who attended the March session seemed enthusiastic about the course, some had reservations about the segment called "advance care planning." Ideally, this part is supposed to begin when a patient is healthy and is designed to help doctors and patients determine the treatment patients would want -- or not want -- if they could no longer make their own decisions.

Recognizing that living wills are often too vague to cover many real-life situations, the program includes a series of work sheets or questionnaires given to patients to help them explore their values and feelings about the kinds of illnesses that most people dread, including permanent coma, severe dementia, severe stroke and terminal illness. The work sheets are not meant to be used as legal documents, but as points of departure for discussions.

The course describes the planning as "a process, not an event," and says that whenever possible doctors should initiate conversations with patients when they are well, encourage them to fill out the work sheets and review and update them periodically.

"It's the discussion that matters, not the piece of paper," Dr. Ferris said.

The patient's proxy, chosen to make decisions when the patient cannot, should take part in the discussions, which can occur over several office visits, rather than taking up too much time at once. Nurses and social workers can also help, so that doctors do not have to do it all.

Some doctors who attended the course thought the work sheets were fine in theory, but impractical: too time-consuming for doctors and too complicated for patients. One doctor said he preferred the work sheets to plan his own care and that of his family, but did not think that most doctors or patients would use them.

But another conference participant, Dr. Michael Stellini of Wayne State University in Detroit, said he hoped to persuade his colleagues to try the approach because surveys had shown that the majority of patients at his hospital wanted to discuss advance care planning -- but that doctors were not doing it.

Dr. Ferris said that doctors who did not want to spend time on advance care planning with healthy patients would probably wind up spending even more time on the same issues -- with worse results -- if they put it off until a crisis hit.

And in a lecture at the course, Dr. Ferris told doctors that the way they treated dying patients would set an example for younger colleagues and dictate how they themselves would be treated at the end of life.

"We're all going to die," Dr. Ferris told his audience. "Are you ready for your turn?"