Medical Due Diligence: A Living Will Should Spell Out the Specifics

By JANE E. BRODY
When I ask people whether and how they have made preparations for the ends of their lives, the most frequent response is, “Well, I have a living will.” But chances are they are unaware of the serious limitations inherent in such a document and how it is likely to be interpreted by medical personnel should a life-threatening crisis arise.

A living will is an advance directive, a document that states your wishes about how you should be cared for at the end of your life. It is meant to be activated when you are unable to say what you do or do not want to be done medically — if, for example, you are in a terminal condition, your heart and breathing cease, you are in a persistent vegetative state because of severe brain damage or you are too demented to understand the situation.

A living will lists your general preferences for or against life-prolonging treatment like cardiopulmonary resuscitation if your heart suddenly stops, or mechanical respiration if you cannot breathe well enough on your own. But the simple statements contained in most living wills, more often than not, are hard to apply to the great variety of medical situations that can arise.

For example, let’s say you’re a 70-year-old active retiree with congestive heart failure who develops pneumonia and has trouble breathing. You go to the emergency room, living will in hand, stating that if you become terminally ill, you do not want to be treated with antibiotics or placed on a ventilator.

Open to Misinterpretation

The admitting physician reading your living will may interpret it as a “do not resuscitate,” or D.N.R., statement, meaning you want no treatment for your life-threatening infection, in which case you would probably die. Yet a course of antibiotics and a week or so with assisted breathing could restore you to your previously active state.

Dr. Ferdinando L. Mirarchi, chairman of emergency medicine at Hamot Medical Center in Erie, Pa., tells of a very active 64-year-old woman who nearly died because a nurse read her living will as a D.N.R. statement. The woman had slipped on ice and broken a leg, which was reset surgically. On the second postoperative day she began bleeding in her abdomen, and excreted and vomited blood. But the nurse saw her living will and told the physician on call that she was D.N.R. and thus did not warrant admission to the intensive care unit. Fortunately, another physician overrode the nurse’s interpretation and resuscitated the woman, who successfully underwent emergency surgery to stop the bleeding.

Living wills became popular — and were established as legally binding documents in all states except New York, Massachusetts and Michigan — after personal experiences and highly publicized cases like that of Terri Schiavo demonstrated the futility of prolonging lives that met few people’s definition of living.
Countless billions of dollars have been spent to support the hearts and lungs of people who will never leave the hospital alive. Many people, appalled by these torturously medicalized deaths, completed a notarized document to prevent this when they neared the end of their lives. About 20 percent of the population has a living will. But will it really help, or might it harm?

An Improved Document

Dr. Mirarchi (pronounced mir-AR-ki) has studied how health professionals interpret living wills and found that the overwhelming majority think they mean that the patient wants to be treated as D.N.R., when in fact aggressive life-saving interventions could restore some patients to their previous state of health.

Accordingly, he has devised a more comprehensive living will — an advance directive he calls a medical living will with “code status” — that people can fill out in consultation with their physicians and perhaps an attorney to help assure they get the kind of care they would want if they could ask for it. The “code status” tells medical personnel exactly how someone wants to be treated in a life-threatening medical emergency, removing the guesswork.

If, for example, you choose “full code,” the directive would say: “I would like to receive all lifesaving and supportive measures should an emergency arise. Should my condition fail to improve and I am no longer able to make my own decisions, then I would like my advance directive to be active and followed.”

Only at that point, then, would individually stated requests be honored, such as not being resuscitated, defibrillated, ventilated, fed by tube, transfused, given antibiotics or placed on a dialysis machine.

You could also choose “full code except cardiac arrest,” meaning that all measures short of restarting your stopped heart should be tried. Or let’s say you are a terminally ill cancer patient and recognize the futility of continued treatment. You could choose “comfort care, hospice care” and have only your symptoms treated to ease your departure from this life. Dr. Mirarchi’s reasons for the revised living will are spelled out in his forthcoming book, “Understanding Your Living Will: What You Need to Know Before a Medical Emergency” (Addicus Books).

Dr. Mirarchi strongly recommends that people periodically review and update their living wills as needs and medical conditions change. He points out that if you choose to be an organ donor, your living will should state that and give permission to temporarily suspend the document to preserve the viability of your organs.

Medical consultants writing in Patient Care (Nov. 15, 2000) noted that “the less inclusive a living will is, the more trouble it can cause.” Doctors may be uncomfortable following vague directives. The consultants suggested that living wills could be more useful if the directives were disease specific. For example, if you have emphysema, you may want to accept antibiotics and mechanical ventilation if you develop pneumonia, but you may not want such treatment if you are near death from cancer.

Your living will should also state that you (or your heirs) will not sue health care workers or facilities for following your stated wishes. The document can also call for a two-physician conference before life-prolonging treatments are withdrawn. The final document should be notarized.

Make several copies of your completed living will. File them with your personal physician or local medical center, your next of kin and attorney, and include a copy with your medical records and your last
will and testament. You might also carry a wallet-size card stating your chosen “status code,” emergency information and name and phone number of your health care proxy.

Have a Health Care Proxy, Too

As may already be apparent, it is not enough to have a living will. You should also assign someone you trust to voice your medical wishes when you cannot speak for yourself. That person should first have a detailed conversation with you about how you want to be treated under various circumstances and also have a copy of your living will.

It may be best if that person has no vested interest in your estate and is younger than you. In most states, the health care proxy is recognized as acting for the patient, compelling medical personnel to follow the proxy’s instructions.

Finally, it should also be obvious that both a living will and a health care proxy should be in place as soon as a person turns 18 and becomes an adult in the eyes of the law. You never know how old or healthy you may be when its instructions are needed. Ms. Schiavo was only 26 when she suffered a brain-damaging cardiac arrest.