

Protect your wishes by filling out health care proxy

Apr. 16, 2011

BY DAVID C. LEVEN AND MARY BETH MORRISSEY

In February a new patient's rights law, the Palliative Care Information Act, became effective in New York. Terminally ill patients now have the right to receive information and counseling regarding palliative care and end-of-life options. Many of us, when terminally ill, will no longer have decision-making capacity and will not be able to make decisions about those options. What if we have not appointed a health care agent to make decisions for us and no one knows what treatment we would want or not want? Would decisions be made for us contrary to what we would have decided?

Too many times we have heard, and you may have as well, stories about people no longer able to make health care decisions for themselves, suffering terribly at the end of their lives, and being kept alive on machines because no one knew their health care wishes. Many of us have in fact considered our end-of-life treatment preferences and, of course, expect and want them to be honored. Still, only about 30 percent of us have communicated these preferences to loved ones or our doctors and have actually appointed a health care agent to make health care decisions if we lose decision-making capacity. The time to appoint a trusted person to make these decisions for us and to have conversations with our loved ones and doctors about our goals of care is now, while we are healthy. This is a gift to our loved ones and ourselves.

Approximately 70 percent of us will lose decision-making capacity at the end of life. For this reason among others, completing a health care proxy, designating a health care agent and alternate agent, and communicating our health care preferences, are extremely important. Failure to do so makes it much more likely that decisions made for us by others, when we can no longer make them, may well be made by someone we would not have chosen and will not be consistent with decisions we would have made for ourselves.

There are many reasons that people do not take the time to discuss their treatment options with loved ones and their doctors such as "I don't have time," or "It's too overwhelming," or "I don't like talking about these things." None of these reasons is good enough, particularly when considering the significant benefits to us and those close to us when conversations occur and a health care proxy is completed. When people know our wishes and understand the reasons behind them: our wishes may be more likely to be honored; communication between loved ones and doctors may be facilitated when the time comes for health care decisions to be made for us, relieving the burdens on all involved; serious and sometimes never-ending conflicts, which often

arise between family members, may be avoided; and we may feel good about having had these discussions, and our stress level about end of life may be reduced.

We should discuss our values, religious and otherwise, about what makes life worthwhile, what gives life meaning. Decisions concerning life-sustaining treatment are the most difficult for people to make and so we might discuss different scenarios to help guide the person making decisions for us as well as other family members. A few short examples of situations that might arise and that might be considered for discussion are:

- You have advanced dementia, are 90 years old, have been bedridden for years and no longer recognize your loved ones. You now cannot eat or even be hand fed. Would you want a feeding tube?
- If you were terminally ill and in great, intolerable pain, would you want to be sedated to unconsciousness if it were necessary to control the pain (this is known as "palliative sedation")?
- If you were permanently unconscious, would you want a feeding tube?

Completing the simple two-page health care proxy form, for which a lawyer is not needed (two witnesses are needed, neither of whom can be the agent who is appointed) is easy to do. The person appointed as the agent (an alternate agent should also be appointed) should be: willing to speak on our behalf, able to act on our wishes even if different from his/hers, a strong advocate who is trusted, someone who knows us well and understands what is important to us and who would be able to handle conflict if it arises.

After discussions have been had with loved ones and doctors and the health care proxy form is completed, copies should be made for all. We should continue to have discussions about end-of-life preferences through the years as our thinking may change and we want to be sure that our loved ones continue to understand us and our current preferences. By having conversations about health care and end-of-life decisions and appointing a health care agent, a significant gift will be given to those who most matter to us — as well as to ourselves. Do it today.

Learn more

- The Westchester End-of-Life Coalition today will have health care proxies and related information available at libraries throughout central and southern Westchester including Bronxville, Tuckahoe, Eastchester and White Plains. Today is National Health Care Decisions Day. The Health Care Proxy Campaign is funded in part by the Community Fund.
- Health care proxy forms, with instructions and frequently asked questions, can be obtained from the New York State Department of Health website, <http://www.health.state.ny.us/forms/doh-1430.pdf>, or by calling David C. Leven at 914-907-6156 or Mary Beth Morrissey at 914-714-2241.

Leven, a resident of Pelham, is the executive director of Compassion & Choices of New York and serves on the board of the Westchester End-of-Life Coalition. Morrissey, a resident of White Plains, is president of the Westchester End-of-Life Coalition and chair of the Collaborative for Palliative Care of Westchester and for the Southern Region of New York.