HAVING YOUR SAY IN END-OF-LIFE CARE

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having your SAY
When 93-year-old Ruth Reese fell down a poorly lit church stairwell and broke her hip, it forced her daughter to make a heart-wrenching decision.

"I kept hanging on and hanging on with her at home, because I had always promised myself I would never put my mom in a nursing home," says Donna Shuster. A nanny, professional clown, and retired teacher from Plum Borough, Mrs. Shuster had always lived with her mother. "Then she just started having so many falls. It got so bad that I had to keep a baby monitor in her room, and I was getting up four or five times a night to help her." After receiving treatment for her shattered hip in the emergency department at UPMC St. Margaret, Ms. Reese moved 18 months ago to Seneca Place, a 180-bed intermediate and nursing care residence in Penn Hills that helps seniors recuperate from a hospital stay and enables the chronically ill to live a more comfortable and meaningful life.

Ms. Reese is a former Senior Olympian who won medals—even into her 80s—in the softball toss, basketball throw, and shuffleboard, raised two children alone, and worked for more than 25 years in the payroll department at a mining equipment company. Today she can no longer hear or see well, requires a wheelchair to move around, and suffers from mild dementia. In spite of her ailments, she gets her hair styled on Fridays, plays bingo and cards, and participates in every sing-along and craft activity at the UPMC Senior Communities facility.

The decision to go with a senior-care facility wasn't easy, Mrs. Shuster admits. But doing it right made it a whole lot easier.

"I think I have come to a calm peace about it," she says.
If you don't write it down, how will anyone know?

Part of Mrs. Shuster's sense of assurance in being separated from her mother after their lifetime together stems from the living will that she helped her to fill out eight years ago at the recommendation of their family physician. Such documentation is important for getting the care you want: if it isn't written down, your loved ones may well not even know.

A living will is a legal document that allows you to make your health care choices known in advance of an incapacitating illness. It might very broadly explain your values and goals for end-of-life care, or it could state specific medical treatments such as ventilators, feeding tubes, or CPR that you do or do not want if you become terminally ill.

Shikha Iyengar, administrative director, University of Pittsburgh Institute on Aging, recommends that everyone age 18 and older complete an advance directive—a legal document such as a living will that outlines how you want to be treated in the event that you become very sick without a reasonable hope for recovery. Another type of advance directive—called “Making Medical Decisions in Advance” at UPMC—is a health care proxy, or durable health care power of attorney, which names someone close to you whom you can trust to make decisions about your health care in the event you cannot.

Don't be misled by the term ‘attorney,’ by the way. While many people choose to put together advance directives with their lawyer, none of the major documents needed to make your desires known to your loved ones and doctors require an attorney to complete.

These documents can help avoid controversy over terminal cases such as the high-profile drama that ensued in Florida in 2005 with the drawn-out death of Terry Schiavo. Ms. Iyengar says, “Everyone should do an advance directive, whether you are young or old, healthy or sick. You could be in an accident tomorrow, and you need to have your end-of-life wishes spelled out ahead of time.”

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Finding the best exit

Dr. Neil Resnick, director, University of Pittsburgh Institute on Aging, says putting your desires on paper early can make it less painful for family members to make difficult decisions when a loved one is dying—and help protect the terminally ill from undesired, medically invasive treatment. He knows from personal experience.

Dr. Resnick's mother spent six difficult years in and out of the hospital fighting end-stage liver failure caused by hepatitis C acquired during a blood transfusion.

“In her final year, when she no longer could recover after each hospitalization, it became clear that her trajectory was only toward the end,” says Dr. Resnick. “My mom asked me to be her health care proxy rather than my dad—she told me that they had been married for 50 years, and she was afraid he would not be able to let go when the time was right.”

Two years ago, a week before Christmas, Dr. Resnick's mother developed serious breathing troubles. His father, also a physician, called his son to say they were leaving for the hospital. As his mother's proxy, Dr. Resnick knew this went against her wishes and talked his father into trying to keep her comfortable at home instead.

“She died that night peacefully in his arms rather than ending up in the ICU on a ventilator,” Dr. Resnick says. “But it was hard not to panic. Even though we talked about it for years, you just don’t know how you are going to react when the time comes.”

Forms for durable power of attorney and a living will are available at many doctors' offices and online with UPMC's patient education materials at http://patienteducation.upmc.com under “Living Wills.” And don’t forget to tell everyone you’ve done the paperwork. Your loved ones, your doctor, and, if you go to the hospital, your attending physician all need to know what’s in there.
Writing it down ... again

UPMC's policy is to honor each patient's decision to accept or refuse medical treatment, including life support, by complying with advance directives. Before the advance directive will be followed, however, the doctor must write an order in the medical record about what treatments to administer or withhold. This step is, with the best of intentions by all involved, sometimes a problem: If the details aren't on paper, doctors may be ethically obliged to err on the side of more care.

Dr. David Nace, chief of medical affairs for UPMC Senior Communities, wants to make sure that families don't suffer the unnecessary pain and heartache of his own mother's death.

Mrs. Nace developed a rare, progressive brain disorder called frontotemporal dementia. One night she became very ill; an ambulance brought her to the emergency department at her local hospital in central Pennsylvania, where doctors put her on a ventilator.

"It was very clear to us that she never wanted a ventilator, but she never wrote it down before she became ill, and the hospital refused to listen to us since it wasn't in writing," Dr. Nace says. "It took us a lot of angst to get what my mother wanted, and she went through a horrible end-of-life path."

POLST, he says, might have prevented this struggle from happening.

POLST — physician orders for life-sustaining treatment — is a new kind of end-of-life directive being implemented at UPMC. The form automatically converts a patient's treatment goals into medical orders. Developed by the Center for Ethics in Health Care at Oregon Health & Science University about 15 years ago, POLST consists of a one-page, two-sided form designed to be filled out by those with advanced chronic progressive illness or anyone who might die in the next two years.

Terminally ill patients should complete a POLST form — and revise it as their medical condition changes — even if they have an advance directive, Dr. Nace says. That's because living wills often lack the clear and consistent wording and medical authority that doctors like to have when making life-or-death decisions. The documents aren't always readily available, or questions arise about the decision-making capacity of a patient and whether the advance directive is in effect. Sometimes living wills also fail to forecast what decisions will need to be made about a patient's care at the end of life.

"Unlike a living will, the POLST form is a physician's order that tells you what treatments this person wants based on how they are right now, not at some time in the future," says Dr. Nace.

For more information on advance directives, check out the link on "Living Wills" on UPMC's health education website at www.upmc.com/HealthManagement/ManagingYourHealth/HealthReference/PatientEducation; the University of Pittsburgh Institute on Aging website, aging Pitt.edu; or call the Institute at 1-888-430-8742.
Pennsylvania adopted legislation last November that updates state law on living wills and creates a hierarchy of who should be in charge of making surrogate health care decisions. The law, Act 169, also requires state officials to form a committee of doctors, lawyers, hospital administrators, and others to consider whether Pennsylvania should mandate the use of POLST forms for late-life patients. (See sidebar on p. 8)

While a good thing in terms of naming decision-makers for people who fail to put their wishes on paper, Act 169 is a one-size-fits-all solution that might not be to every patient’s liking, says Dr. Resnick. For example, it would have automatically made his father the decision-maker for his mother’s care — exactly what she hadn’t wanted. It’s important to remember that the new law isn’t a substitute for documentation, and could in some cases frustrate patients’ intentions.

As the state develops legislation and policies, UPMC is taking the lead in the Pittsburgh region as part of the Coalition for Quality at the End-of-Life. The group of health care organizations, patient advocates, insurers, and government agencies is trying to encourage institutions in western Pennsylvania to use POLST forms. A UPMC collaborative among physicians, directors of nursing, and administrators also is promoting the use of POLST at nursing facilities.

These initiatives are striving to educate the public about POLST and train doctors, nursing homes staff, and EMTs how to use the form and communicate with patients about its importance. So far, more than 25 long-term care institutions in the region, including Seneca Place and all of the other UPMC Senior Communities, are introducing POLST to their patients upon admission. UPMC also is developing a policy that will allow its doctors to honor the end-of-life care wishes in a POLST signed by a physician outside its care network if the form is properly executed and sent with a patient from a nursing home.

According to Dr. Nace, tools like POLST ultimately serve the main goal of end-of-life care: to ensure the right provisions are put in place as early as possible, so patients like Ruth Reese only receive the treatments they want and live their final days in dignity and comfort.

Every day Donna Shuster walks into Seneca Place and wraps her arms around her mother in a bear hug from behind her wheelchair. "Oh, it's so good to see you," Ms. Reese says, as if she hadn't visited with her beloved daughter in weeks.

Mrs. Shuster joins her mother for lunch every afternoon and comforts her by phone each night before bed. She also tries to bring her mother to their church on Sunday mornings, and sometimes she entertains the Seneca residents as "Spangles," her clown persona.

"We are very close — as close as a mom and daughter could probably be," Mrs. Shuster says.

Now that she is no longer her mother’s primary caregiver, Mrs. Shuster can enjoy quality time with her, feeling confident that her needs are being met. With Ms. Reese’s end-of-life care choices spelled out clearly, she can cherish these special moments with her daughter without worrying about whether her wishes will be honored when it comes time to say goodbye.

"I think I have a pretty strong attitude about it now," Mrs. Shuster says. Her mother is a deeply spiritual woman, she adds: "I know there is a better place for her."