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THE LONG RUN

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Who decides when you die?

It's hard enough for a dying patient to declare an end to medical intervention. It's far harder when anguished loved ones disagree.

By Kay Lazar, Globe Staff | February 16, 2009

Obstetrician Luann DePodesta has delivered life into this world for most of her career. She now spends much of her time helping to gently usher it out.

In her care of terminally ill patients in Boston's northern suburbs, she has seen firsthand how a patient's desire to stop treatment can collide with a family's unwillingness to let them die. More than once, DePodesta has witnessed elders changing course and undergoing more medical intervention solely to ease the emotional pain of a distraught son or daughter.

"People don't make decisions in a vacuum," she said. "They make decisions at the end of life based on the people they care about and how it's going to affect the people they love."

Conflicting wishes and demands regarding end of life care are a common - but not often discussed - problem, with no clear solution.

A recent article in the New England Journal of Medicine by three doctors from Boston's Brigham and Women's Hospital illustrates the emotional dilemma.

The doctors, including the journal's editor in chief, Dr. Jeffrey M. Drazen, recount how an 83-year-old woman who had survived melanoma for more than seven years arrived in the hospital's intensive care unit with an array of other ailments including kidney failure. The woman, speaking with great clarity, told her doctors she wanted no more treatment.

The doctors, following usual protocol, arranged a bedside family meeting to discuss treatment options and to explain that her chances of living more than a year were slim. The woman's husband, son, and daughter (who was her designated healthcare proxy) then asked for privacy. Doctors left the room, and 45 minutes later her son emerged to tell them they should "do everything possible" to save his mother. Later, doctors learned that she had set aside her wishes in order to please her son.

The woman went on to receive chemotherapy and implantation of a dialysis catheter, but died within three months of leaving the intensive care unit. She never returned home.

"Since her departure, we have not stopped questioning whether we, as her physicians, did right by this woman," they said. "Try as we might to keep the family focused on the patient, we often fail."

Scenarios similar to this case played out three times that week in the Brigham's ICU, wrote the doctors.

How often have variations of this situation occurred in hospitals across the country?

While precise numbers are hard to pinpoint, surveys have shown that most Americans say they would not want to be kept alive at any cost. Yet many also fail to make their end of life wishes known to their families when they are still healthy.

A 2005 Massachusetts End of Life Care Survey found that 83 percent of those questioned said they didn't want to be a burden on loved ones at the end of their lives. But only about half, 53 percent, said they have

spoken with their spouse or partner about their wishes for end of life care, and 57 percent indicated they had spoken with family. A mere 10 percent had discussed the issue with their primary care physician.

Another set of numbers paints a disturbing picture from a different perspective. The 2008 Dartmouth Atlas of Health Care found that billions of dollars are spent each year in the United States on aging patients in the last six months of their lives.

Yet the Dartmouth researchers found that hospitals, regions, and states that use more services per patient did not necessarily provide higher quality care than those where fewer interventions, and dollars, were employed. A review of millions of records found that, on average, \$25,358 was spent on each Medicare patient in his or her last six months of life.

Paul Levy, president and CEO of Beth Israel Deaconess Medical Center in Boston, understands the urge to keep treating even as death hovers.

"One of the things that happens in hospitals," he said, "is the medical staff, I think, often feels an obligation to keep trying everything very often because families push them."

About four years ago, Beth Israel Deaconess established a policy for handling cases when doctors and patients - or patients' families - disagree about stopping treatment. The policy sets up a methodical appeal, hearing and review process when a doctor concludes further treatment would be ineffective or harmful, and a patient or family feels otherwise. The process includes review by a committee with a social worker, clergy member, and doctors not involved with the case.

If the committee decides further treatment is ineffective and/or harmful, the patient or family is offered the opportunity to seek transfer to a facility willing to provide that treatment. They also are advised that they can seek legal intervention.

Given how emotionally charged - and intertwined with family dynamics - the decision often is, "sometimes we have to help the patient figure out what the patient really wants," said Dr. Lachlan Forrow, director of Beth Israel's palliative care and ethics programs. Forrow helped write the policy.

Brigham and Women's Hospital says its policies are similar to Beth Israel's. All hospitals, as part of a national accreditation process, are required to have written policies on patient rights, end of life care and staff rights to refuse to participate or give care, according to the Massachusetts Hospital Association. Most often conflicts are addressed by ethics committees.

It is amazing, said palliative care nurse Karla Kay Shearer, how aging and ill elders still seek to protect their now-grown children in these wrenching debates.

Shearer, who has worked in hospice care for 12 years and coordinates palliative care at Mercy Mount Airy Hospital in Cincinnati, said she has often found that aging parents will say they want to receive more treatments, even if they don't, in order to shield a son or daughter who is unable or unready to face the parent's death.

In those cases, Shearer said she tells anguished sons and daughters that aggressive interventions may keep a parent breathing, but not experiencing what makes life worth living - as she puts it, "doing everything to live may actually take everything that is living away from their loved one."

Specialists say there have to be some frank family discussions about dying wishes well before the time comes.

Recognizing that many people are squeamish about the topic, a Beverly healthcare communications company president last fall launched an online campaign, called Engage with Grace, (www.engagewithgrace.org) that provides resources and tips for jump-starting the conversation.

"I always tell people, when I do community presentations, that you have to get all your family members

involved because it's the daughter or son from California who hasn't seen Mom in years who will say mom wants to fight on," said Christine McCluskey, executive director of Better Ending Partnership, a Worcester-based community coalition that helps families with end of life decisions and care.

"You need to engage the whole family," McCluskey said, "so there aren't surprises."

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