Let’s talk about death: End-of-life decisions

by Daniel Johnson MD FAAHPM in the May 18, 2010 issue

It’s tempting to blame partisan politics for last summer’s debacle over “death panels” and the very idea of doctors and patients holding conversations about the end of life. But the truth is: these conversations are difficult. Although some people welcome them, other people approach the subject of death cautiously. Many of us would rather not explore what awaits us in the final years or weeks of life. Perhaps this reluctance explains why only one in five Americans has completed an advance directive for medical care.

Although the reasons for reticence are complex, our society’s general reluctance to embrace the end-of-life conversation is worth exploring—especially in light of the health-care crisis. Some claim that this reluctance is a result of America’s denial of death: “Others will die, but not me.” Some describe our society as “death-defying.” We’re fighters. We never give up. Americans “wage war” with death. Just look at a headline like this one referring to actor Patrick Swayze: “Swayze Loses His Battle with Cancer.”

Defying death is not cheap. In its quest to restore youth and cure disease, the U.S. spends billions of dollars each year on medical technologies. While we have made great strides in treating serious illness, the progress comes at a great cost. In 2007, $2.2 trillion—16 percent of the nation’s gross domestic product—was spent on heath care. Despite this staggering sum—the highest per capita spending in the world—the United States ranks 27th in the world in life expectancy and 37th in overall quality of care as defined by the World Health Organization.

Our defiance of death also shapes societal expectation. Some of us may feel an obligation to fight death—to not “give up”—even when our instincts or personal values would lead us toward less technological and more comfort-oriented approaches.

As a physician I’ve learned about the challenges of the advance-care planning process from my patients and their families. Predicting one’s preferences ahead of time is difficult. Many patients simply don’t know what they would want in the event of incurable illness. Some respond with “Life support? Well, I suppose it depends. . . . Ask me when I get there.” Others prefer to defer life-and-death decisions to their families: “My family will take care of that. They’ll know what to do.” But studies tell us that our loved ones often struggle to determine “the right thing to do,” and many report feeling overwhelmed with stress and guilt.

Talking about the end of life is often uncomfortable. Why think or talk about something as unpleasant as our own (or our loved one’s) death? Why not think about happier things—and cross that difficult bridge later? Patients have taught me, however, that later is often too late.

Many of us don’t know how to talk about death. It’s not that we’re denying our mortality, or that we’re afraid of expressing emotions to our loved ones. We simply don’t know how to start that conversation. No one has taught us the words or the format for such a discussion. We don’t have a safe space, we don’t know the right time—so we don’t have the conversation.

On the relatively rare occasions when our society does address end-of-life issues, we often talk in extremes. Instead of exploring individual values, choices and expectations for competent and compassionate care, we jump into heated debates about suicide, physician-assisted death and euthanasia.

These all-or-nothing conversations do little to advance dialogue. Emotionally charged conversations invite the public, the politicians and the medical profession to take sides. Rather than helping us to find common ground, these conversations polarize and paralyze discussion. More important, when we limit our conversations to a debate about hastened death, we miss a more fundamental question: How can we better support people who are facing the end of their lives? Do our current systems (hospital, nursing home and hospice care) meet diverse needs? If not, how do we create a better system—one that consistently alleviates suffering without having to consider the idea of hastening death in order to achieve comfort, peace and dignity?

The experiences of residents of Oregon, a state that legalized physician-assisted death (PAD) in the late 1990s, has taught us much about end-of-life care. While as many as one in every six people with terminal illness talk with their families about PAD, only one in 50 talk with their doctors about it. Far fewer—only one in 1,000—end up using a lethal prescription to hasten their death. Studies have shown that the most common reasons that terminally ill patients request PAD in Oregon are that they fear a loss of control over the dying process, are worried about mental decline, are concerned about burdening their families or fear intractable symptoms.

How well does our current medical system manage these complex psycho social and practical issues? Not very well. One of my doctor colleagues observed that society and the medical system pay a lot of attention to the other end of life—birth. When we bring a new human into the world, he noted, families plan. Medically, we harness obstetric care to ensure safety, comfort and support. We coach mothers-to-be and their nervous partners. Doctors work with interdisciplinary teams to predict and address needs and prevent crisis. This comprehensive approach works well at the beginning of life. Might a similar model at life's end lead to more coordinated and compassionate care?

If Americans are to talk more openly about end-of-life care, several things must happen. First, we must create a space for dialogue. We must avoid the all-or-nothing conversation. We must recognize the difference between helpful dialogue that explores individual and community values and damaging rhetoric that preys on fears and anxieties about death. Within our own communities and homes, we should encourage and embrace discussions that explore all aspects of caring for seriously ill persons.

We must create a safe space at the bedside too. Persons with progressive illness should have access to teams of professionals skilled in talking with and supporting patients with incurable illness. Our communities should expect and demand access to high-quality palliative care.

Second, we must to learn how to talk. Ironically, this starts with listening. Instead of trying to fix things, we need to get more comfortable with listening, learning and truly supporting those whom we love—especially when a "fix" might no longer be possible. We must take the journey with those we love, regardless of whether we'd make the same decisions for ourselves.

Finally, we must reframe the end-of-life conversation. When this discussion is treated as a one-time, monumental event—"Mr. Jones, it's time we have the conversation”—it’s no wonder Mr. Jones runs away.

Patients and families have shown me a more helpful paradigm. They prefer frequent, smaller discussions—less in timidating dialogue that allows for ongoing physical, practical and emotional support. For some, these conversations need not focus on dying. Forcing people to talk about death is almost never helpful. Rather, the conversations should provide a flexible, safe space for people to share their needs, fears and hopes.

The earlier these conversations are started, the better medical teams can meet needs before a crisis arrives. We can ensure that care is coordinated, and that it matches the goals and preferences of the patient. We can create stronger relationships and truly support patients and their families.