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Personal Health

World Enough and Time for ‘a Good Death’

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As sudden deaths from heart attacks continue to decline and more people leave this life after a protracted illness, the concept of “a good death” has become ever more important to both the dying and those who survive them.

But what is a good death, and is it really the same for everyone? And what are the consequences of different approaches to death for those left behind?

Nearly four decades ago, Dr. Elisabeth Kübler-Ross outlined what she recognized as five stages people go through after the diagnosis of an incurable illness: denial, anger, bargaining, depression and finally acceptance of their impending death. She recognized that people approaching the end of life might seesaw between the various stages, but that those who reached “acceptance” were most likely to die in peace with the least trauma to their survivors. Indeed, hospice care practically demands that people who are dying reach acceptance, since they must accept only comfort care and give up all treatments aimed at staving off their demise.

Still, there are many people who choose to continue fighting for life, leaving no therapeutic stone unturned, until they take their last breath. There are people who will not acknowledge that they have a fatal illness, remaining in denial even as their bodies shrink under the onslaught of disease. There are people who weather their medical storm in fury because they are being robbed of their future. There are people who cannot emerge from depression over the prospect of losing everyone they love.

Can these people, who never achieve acceptance, also have a good death? The answer seems to be yes, although the consequences for survivors may sometimes be less than desirable.

Nails Polished to the End

Dr. Joseph Sacco, a palliative care specialist at Bronx-Lebanon Hospital Center in New York, tells about a patient, Mrs. Santana, in his book, “On His Own Terms,” the story of his father’s losing battle against lung cancer. Mrs. Santana had terminal cancer and was near death, but she never uttered the words “cancer” or “death.” During her final hospital stay, she maintained her lifelong elegance and dignity, polishing her nails, grooming her hair, always cheerful and calm, until the day she died.

Dr. Sacco’s father, Joe, on the other hand, kept insisting he would “beat this thing,” even as his breathing became ever more labored and his weight dropped by half. Though Dr. Sacco, based on his training, thought his father should come to accept his fate, he felt he had no choice but to humor the dying man and play along.

Joe’s death was peaceful enough, occurring as it did on his terms. But it took its toll on Dr. Sacco, who laments: “Had my father not been frozen by fear, he might have been able to talk openly and reaffirm his knowledge that his son really did love him. Instead, paralyzed by the implication that death was imminent, he brushed me aside with a wave of the hand and the comment that he wasn’t going to die.”

Dr. Greg A. Sachs’s father-in-law, Al, who also had lung cancer, chose to have no treatment for his disease and spent not one day of his remaining 18 months in the hospital. As Dr. Sachs told it in The Journal of the American Medical Association (Nov. 15, 2000), Al spent the year “straightening out files; reconciling accounts and labeling everything in the house, including fuse boxes and cabinet drawers, so that his wife would be able to find everything when he was gone.” According to an agreed-upon plan, Al died peacefully at home surrounded by his loving family, with his distressing end-of-life symptoms assuaged by morphine, anti-anxiety medication and oxygen.

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No Easing Existential Suffering

But as Dr. Sachs tells it, Al's equanimity about dying, his methodical preparations and his gentle demise did not ease the family's pain as he lay dying, for they knew Al didn't want to die and nobody in the family wanted to lose him.

Dr. Sachs explained that for survivors, "some of the suffering is existential or spiritual" and even the best end-of-life care cannot ease that kind of suffering.

He cautioned his fellow physicians against "painting too rosy a picture of end-of-life care" and creating unreasonable expectations of "spiritual growth" and "transcendence."

But while no one is likely to rejoice at losing a loved one, having people die in accordance with their wishes is, in my experience, far less painful than the alternative, which all too often involves futile medical rescue efforts that patients do not want and that can get in the way of comforting end-of-life conversations and reconciliations.

When my mother-in-law's cancer recurred four years after treatment, she chose, at 84, not to have anything done that might prolong her life. And no one dared to contradict this decision by a woman who had always lived life on her own terms and was determined to die that way.

A Chance to Say Goodbye

Living will in hand and fully in control of her faculties, she entered the hospital hemorrhaging, and at her request a "Do Not Resuscitate" notice was posted on her door. The family was called, and all had a chance to say goodbye unimpeded by machines, tubes and medical personnel. Twelve hours later, she was gone, leaving behind a sad but grateful family. Her minister, at her bedside until the end, said he had never before seen such a peaceful death.

Dr. Karen E. Steinhauser and colleagues at the Veterans Affairs Medical Center in Durham, N.C., examined the constituents of a good death for patients, their families and health care providers. The 85 study participants had no trouble describing a "bad death" — having

inadequately treated pain while receiving aggressive but futile cure-directed therapy.

Patients felt disregarded, family members felt perplexed and concerned about suffering, and providers felt out of control and feared that they were not providing good care. Decisions not previously discussed usually had to be made during a crisis. Families unprepared for what happens when death is imminent often panicked and rushed the patient to the hospital, where last-ditch and usually futile attempts at resuscitation were made, when both patient and family would have preferred a home death.

The study identified six components of a good death, described in The Annals of Internal Medicine of May 16, 2000:

> ¶Pain and symptom management. Pain, more so than dying itself, is too often the cause of acute anxiety among patients and their families.
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> ¶Clear decision making. Patients want to have a say in treatment decisions.
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> ¶Preparation for death. Patients want to know what to expect as their illness progresses and to plan for what will follow their deaths.
>
> ¶Completion. This includes reviewing one's life, resolving conflicts, spending time with family and friends, and saying good-bye.
>
> ¶Contribution to others. Many people nearing death achieve a clarity as to what is really important in life and want to share that understanding with others.
>
> ¶Affirmation. Study participants emphasized the importance of being seen as a unique and whole person and being understood in the context of their lives, values and preferences.

This study says that dying can, and should, be a much less painful experience for many more people and their loved ones than it now is.