

# StarTribune Editorial

## Our perspective

### Dying well

#### *What caregivers, and the culture, can do*

The moment may come only once a year, perhaps just once in a lifetime, but it comes: The sky is black, the world is quiet, and you're seized by the fact that someday your life will end. It's hard news to take in — the immutability, the mystery of it. But though there's no disputing that death will someday come, it need not come in the company of anguish. In a land teeming with specialists and shrinks and syringes, a good death should not be hard to find.

And yet it is hard to find — astonishingly hard. Many of the 2.4 million Americans who die every year suffer mightily in their last days — writhing in pain, gasping for breath, fighting a tangle of gadgetry that postpones deliverance. Doctors don't know what their patients want, and often the patients don't, either. Most of them die in hospitals — away from the bedroom wallpaper and the well-worn quilt and the other textures that define a life.

People deserve a better fate, and it shouldn't be so hard to arrange. Medical ethicist George Annas offers the beginnings of a plan: "If dying patients want to retain some control over the dying process," he says, "they must get out of the hospital if they are in and stay out of the hospital if they are out."

That's right, as far as it goes. Unfortunately, steering clear of hospitals is no guarantee of a good death. It's just as possible to die miserably in a nursing home — or your own living room — as in an intensive care unit. Indeed, when it comes to dying, most Americans seem to feel they have only two options: interminable agony and Dr. Kevorkian's van.

They shouldn't have to think this way. If people want to make death less horrible and more human, they've got to insist on change. Several national groups are already insisting; the Soros Foundation's Project on Death in America and the Robert Wood Johnson Foundation's Last Acts Coalition are the most prominent. And Minnesota is on the front lines as well: For four years now, the Allina Foundation's Project Decide has been exploring what makes for good end-of-life care; now it's nudging caregivers to make use of what it's learned.

But it doesn't take a scholar to see what must be changed to help people die well. This is some of what society must do:

- Acknowledge death as a fact, not a failure. Our culture's "never say die" attitude prevents acceptance of death as a natural process. Through education and reflection, we must come to see death not as a disaster, but a sad eventuality. We've got to grant the truth of playwright Tom Stoppard's flip but factual line in the play "Jumpers": "Death is always a great pity of course, but it's not as though the alternative were immortality."

- Help the professionals get a grip on death. Too many doctors hang up their first shingle without giving half a thought to death. But from the first time they pick up a medical text, doctors- and nurses-in-training should be learning about dying. Professional schools must embolden students for the twin tasks of comforting the dying and healing the sick. Clinical rotations should include required stints in hospice programs; residents and practicing professionals should be taught to speak sensitively about death and to care competently for the dying. And why shouldn't doctors and nurses make a point of going to patients' funerals?

- Talk about death, and plan for it. Living wills are still a rarity in America. The few that exist are often so vague that they're meaningless. Doctors don't seem to look at them anyway. When they get together, doctors and patients are more likely to talk about the end of winter than the end of life. People seem nearly as reluctant to raise the subject with family and friends.

What is needed is a toppling of

## Learning to die

### *Rethinking one's care at life's end*

the taboo so that death becomes a proper after-dinner topic — and an expected part of doctor-patient interactions. To start the toppling, families must dare to share their ideas about what life's end should be like. Paperwork is important, but serious talk is critical. That's why doctors should resolve to follow a communication schedule — similar to the vaccination schedule for children — that triggers detailed end-of-life discussions with patients at regular intervals.

- Control pain and suffering. Many dying people suffer profound pain — largely because doctors are stingy with pain medicine. The agony of the dying is an abdication of medical duty, whether born of ignorance, ambivalence or fear of overzealous narcotics agents. Doctors must resolve to do whatever it takes to control pain; lawmakers should protect them from groundless prosecution.

- Help people die at home. Most Americans die in hospitals and nursing homes, where their last days tend to be lonely and laborious. Many would be far better off in their own beds — and in the hands of family members and hospice workers who can offer medical and emotional support. But hospice programs don't help as many people as they could. To bring the good death within common reach, doctors must refer more patients to hospice — and policymakers and insurers must see that every American has access to the programs.

- Awaken hospitals to the hospice ethic. Some people can't help but die in hospitals, but they shouldn't have to die in distress. Palliative care, the comfort-oriented heart of the hospice philosophy, should be embraced by every intensive care unit and hospital ward. Pain management, symptom control and emotional support for the suffering and dying should be the rule.

- Measure the quality of end-of-life care. The folks who assess health-care quality can tell you how your local hospital performs when it comes to heart surgery or childbirth or hip replacements. They know less about how well a hospital cares for the patients who die there. If such measurements were made and released, institutions that care for the dying might try as hard to comfort as they do to cure.

- Honor medicine's power to ease the dying process. Some people wince at the idea that the medical profession might have a proper role in facilitating death. But there is much doctors can legally do — and too often decline to do — to make dying easier. And there is more they ought to be free to do: When a terminally ill patient pleads for release, they ought to be able to provide it.

- Comfort the bereaved, and make way for mourning. One of the ingenuities of the hospice movement is its attention to family members both before and after a death. The dying process isn't over once the funeral is finished. It concludes in a time of mourning. Caregivers, like friends, have a role to play in supporting survivors through the grieving process.

Of course, all the prescriptions in the world can't guarantee a good death, and planning may be of little use in the case of sudden, accidental or violent death. But most Americans will take leave of life slowly — fully aware that their days are drawing short. They deserve more consideration in those last days than they get, and they ought to consider those last days more carefully than they do. Since they must die, shouldn't they have a chance to die well?