

# Why You Need to Talk About It

By Larry Beresford

## ❖ *What would Americans want if they knew they were nearing the end of life?*

Research conducted by the George Gallup Institute for the National Hospice Foundation found that people want to be free of pain and able to die at home, surrounded by their loved ones, with their dignity intact and their families protected from financial impoverishment by their care needs. This list of preferences tracks almost perfectly with what hospice care at its best is able to offer.

## ❖ *Are these care preferences realized when the time comes?*

In the most recent data from the Brown University Center for Gerontology and Health Care Research, only 23 percent of Americans die at home. Fully half of all American deaths (which totaled 2,448,017 from all causes in 2005) occur in the hospital, with 23 percent in nursing homes.

## ❖ *Why is there a disconnect between what people say they want and the care they actually receive at the end of life?*

A 1997 survey by the national advocacy coalition American Health Decisions found that Americans approach the thought of their own dying with a mixture of dread and procrastination—fearing a medically intrusive, mechanical pathway to death yet avoiding the kinds of conversations with family and health providers that could make their preferences known and honored. In fact, research has shown that Americans are more likely to discuss the emotionally charged topics of drug use and sex with their teenaged children than to talk about end-of-life care preferences with aging parents.

Living wills and other advance directives, which capture hopes and wishes for future medical crises in a legally recognized document, have been completed by only 40

percent of Americans. And experts say these documents are less likely to be effective if they aren't accompanied by frank discussions with physicians and with loved ones—especially those who would be making medical care decisions if the individual were to become incapacitated. Some physicians can be reluctant to give honest prognoses to their seriously ill patients.

## ❖ *If physicians are sometimes reluctant to give a terminal prognosis, and if patients are unwilling to think about or talk about end-of-life care options and preferences, do many patients choose hospice care?*

Yes, last year 1.4 million people with life-threatening illnesses received care from America's hospices, according to the National Hospice and Palliative Care Organization. In 2007, 39 percent of all deaths in the United States were under the care of a hospice, up from 35 percent the year before. Thus, while fears and resistance to a hospice referral may be common, many people are able to overcome these hurdles at a time when hospice can help them realize an end-of-life experience that more closely resembles what Americans say they would want. ❖

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