Celebrating National Hospice and Home Care Workers

I am proud of the fact that most people understand what hospice is about today. This is a far cry from 1972 when I produced the first U.S. Senate hearings on hospice and helped write the first legislation to cover hospice under Medicare. There was at that time a fair amount of confusion. The New York Times, for example, went so far as to blast the U.S. Senate Committee on Aging in an editorial on the grounds that we were pushing euthanasia.

By 1982 when this legislation was finally enacted, there was still was a fair amount of misunderstanding. Congress was asked to enact a form of medical care which was palliative, not therapeutic. Many physicians did not understand. They viewed this as giving up on patients. Many said this behavior made them uncomfortable and put them in violation of their Hippocratic oath. They argued that the certification that someone was in the last six months of his or her life was anything but an exact science. They said they were being placed in an impossible position which would make them targets for wrongful death suits, because they did not do everything in their power to extend life. They said this was true even if the patient and his or her family consented to withholding tests and heroic medical procedures.

With every passing year, hospice has found increased acceptance. Members of the public have come to understand that it means helping patients live until the very end of their lives. It means helping them to manage their pain, to finish their unfinished business, and to help the families of the deceased cope with the loss of a loved one.

In 25 short years, hospice has come to be associated with life and not with death. Death, which gives life its definition, has come to be viewed as a normal part of life rather than as a failure of the medical establishment. Those near the end of life and their families have learned that they have options. They can take control over their final days on earth and choose how and where to spend them. They have the option to remain at home where most of us would prefer to be—well or sick—or to remain in a hospital or institutional setting.

The percentage of Americans who know about the existence of hospice has now topped 80 percent. The percentage of those who have experienced hospice either directly or through friends and relatives is almost as high. The percentage who have a positive view of hospice based on their experience tops 90 percent. Similarly, the overwhelming majority of Americans would like to see hospice services expanded in both public programs and those covered by private health insurance.

Seemingly everywhere I go, people come up to me when they learn about my role in helping make hospice available, and thank me for the positive experience they have had with hospices nurses who have helped them through the death of a loved one. While this is very gratifying, the credit of course, goes to the hospice workers on the front lines. These workers are indeed angels temporarily assigned to earth. How they do what they do, which is giving unlimited support to one dying person after another and to their families, is something of a mystery. I once asked Mother Teresa how she and other hospice workers avoided burning out. Her response was enlightening.

"Mind is everything," she said. "What matters is why you do what you do. If you care for the sick and dying out of duty and obligation, it will deplete you. If you do it out of love, it won't; it will energize you. The real test is to put as much love as you can into everything you do."

November is National Home Care and Hospice Month. This gives us the opportunity to say thank you to the thousands of hospice workers who care for those at the end of life. It also gives us the opportunity to thank their counterparts who work in home care helping Americans with infirmities and disabilities, to function at home with a maximum of human dignity. Home care and hospice nurses are the very personification of caring, which Mother Teresa said was the one word summary of the Golden Rule. "Caring is love in action," she said.