

# CHANGING THE WAY WE CARE FOR THE DYING

**T**he gradual technological sophistication of U.S. healthcare has changed the way we understand and relate to many basic human realities. This is especially true of dying, which technology has affected most negatively. Perhaps healthcare reform will reverse this. Systemic reform provides an opportunity to make care of the dying more humane, less technology based.

Dying was once accepted and embraced as a natural part of life. Today it is regarded often only as a medical event to be managed by healthcare professionals. More than 80 percent of all reported deaths in the United States occur in healthcare institutions where people die in unfamiliar, and sometimes intimidating, surroundings. As a result, a dying person frequently is denied the opportunity to experience dying as a deeply personal event. In addition, family and friends often have little chance to accompany the person through the final phase of life.

We are all too familiar with the scene of the dying person tethered to tubes and electronic gadgetry in an intensive care unit. Held captive in a tangle of technology, the person is kept at a distance from the supportive presence and touch of family and friends by well-meaning but technologically oriented healthcare professionals.

We also are aware of persons who are abandoned in their dying because "nothing more can be done." Deemed "beyond technology," such

*Healthcare  
Reform  
Provides an  
Opportunity  
To Make  
Care of the  
Dying More  
Humane*

BY SR. JEAN deBLOIS,  
CSI, RN, PhD

persons are left alone to wait for death.

Human dying should not be regarded as a medical event to be managed by technocrats. Dying persons should neither be ignored when technologies prove futile nor handed over too

**Summary** Systemic healthcare reform provides an opportunity to make care of the dying more humane, less technology based. Dying persons should neither be ignored when technologies prove futile nor be handed over too hastily to professional and institutional care. Perhaps dying should be reclaimed and, where possible, taken back into the home, family, and community.

Caring appropriately for dying persons is made difficult today by a number of factors. Americans' death-denying attitudes drive much of what healthcare professionals do in both acute and long-term care settings. Frequently, the emphasis is on curative and rescue interventions to the neglect of all else. Finally, the U.S. family has become increasingly unable or unwilling to care for a dying family member at home.

The potential for significant reform of the healthcare system may change the way care is rendered to dying persons. Catholic healthcare providers should be leaders in reshaping the way dying persons are cared for. First, ethics committees should formulate, promulgate, and implement policies delineating the appropriate use of life-sustaining interventions. Second, long-term care givers need to overcome the troubling tendency to transfer dying persons to acute care facilities when death is imminent. Third, hospice services should be available and their use encouraged. Finally, representatives from Catholic healthcare should work with parishes to encourage the faith community to share in the responsibility of providing home care for dying persons.



*Sr. deBlois is senior associate, clinical ethics, Catholic Health Association, St. Louis.*



hastily to professional and institutional care. Perhaps, like birthing, dying should be reclaimed and, where possible, taken back into the home, family, and community.

Christian faith lends strong support to the proposal to consider anew the way we care for dying persons. For through the lens of faith we recognize in the experience of dying and death moments of both personal and communal grace and transformation. This faith dimension is at the heart of Catholic-sponsored healthcare. Thus as we consider the changes that healthcare reform will bring, Catholic healthcare providers should seize the opportunity to model more appropriate ways to care for dying persons. In doing so, Catholic healthcare can provide needed witness to the values and beliefs at the heart of our faith tradition and the healing ministry of Jesus and the Church.

#### DYING MADE DIFFICULT

Caring appropriately for dying persons is made difficult today by a number of factors. First, as Ernest Becker has noted, Americans are a death-denying culture.<sup>1</sup> Much of our individual and communal energy is expended in attempts to shield ourselves from the many signs of the inevitability of human diminishment and death. Fascination with the "culture of youth" and overuse of commercial products that mask the effects of aging are common expressions of this denial.

Second, death-denying attitudes drive much of what healthcare professionals do, in both acute and long-term care settings. Frequently, the emphasis in healthcare is on curative and rescue interventions to the neglect of all else. At times, of course, interventions aimed at overcoming death are appropriate. However, in an increasing number of cases, life-preserving measures are used regardless of whether they are justified. Many physicians and nurses violate their own personal beliefs and consciences and ignore the requests of dying patients to forgo the use of life-sustaining interventions even when death is imminent.<sup>2</sup>

Contributing to this practice is the proclivity of many healthcare professionals to equate a patient's dying and death with personal, professional, or technological failure. In the *New England Journal of Medicine*, one physician observed that preparing persons for death taxes the creativity and composure of the most skilled healthcare professionals.<sup>3</sup> A letter written in response suggests that it is not the technical

Perhaps, like  
birthing, dying  
should be  
reclaimed and,  
where possible,  
taken back into  
the home,  
family, and  
community.

aspects of medicine that are challenged by caring for a dying person. "Rather, it is the existential aspects, because they impinge on the physician as a person, not just as a professional in a social role. It is the person under the white coat who confronts with his dying fellow human being the ultimate letting go, finitude, and hunger for meaning of impending death."<sup>4</sup> In part, the discomfort of confronting these existential realities has led to recent proposals to allow physicians to give lethal injections to dying persons who fall into the category of "medical failure."<sup>5</sup>

Finally, the American family has become increasingly unable, and in some cases unwilling, to care for a dying family member at home. Smaller family size, increased geographic dispersion of family members, the need for both spouses to work outside the home, and growing divorce rates all influence a family's ability to provide a supportive community of concern for its members. This is particularly true when a family member is in need of specialized care.

Even when assistance is available, families often are reluctant to assume the responsibility of caring for a dying person at home. Many persons believe that it would deprive that person of necessary medical care. In addition, some people believe that the living should be protected from the dying. For many, the thought of witnessing the dying process is troubling. The desire to preserve intact the memory of the loved one leads some to ignore the fact that a person dying is still a person living.

#### REFORMING CARE FOR THE DYING

The potential for significant reform of the healthcare system may change the way we care for dying persons. Less money probably will be available to care for the dying in the acute care sector. This could be a positive outcome, especially because it might decrease the ill-advised use of life-prolonging interventions. At the same time, funding for alternative means of caring for the dying, such as hospice, may be more available in the future. As a result, dying persons may be cared for in environments more focused on care than cure and rescue.

Changing the way dying persons are cared for will require sensitivity, creativity, and compassion. Catholic healthcare providers should be leaders in this movement. First, in Catholic acute care settings, ethics committees should formulate, promulgate, and implement policies delineating the appropriate use of life-sustaining inter-

*Continued on page 52*



## GENETIC REVOLUTION

Continued from page 51

**G**oldsmith expects an evolutionary, rather than revolutionary, change in the healthcare system.

---

delivery with an "architecture grounded in pushing resources out into neighborhoods." Goldsmith applauds the proposal's anticipation of a rearrangement of healthcare spending priorities so that keeping hospitals full is no longer at the top.

But he expects an evolutionary, rather than revolutionary, change in the system. "It's going to take a generation to change the goal structure and values of healthcare executives and practitioners. You can't expect people who have grown up in an acute care matrix to say, 'What I learned to do is no longer relevant.'"

### AN EXCITING FUTURE

In spite of frustration at the pace of change, Goldsmith is "tremendously excited" about the future of healthcare. "We are headed toward a point where we will have the tools to improve the health status of a population of people—to convert what were viewed as unavoidable acts of nature into something we can manage as a society." This ability will ultimately be more satisfying for healthcare managers and for sponsors, he believes. "To be able to engage communities in improving their own health status, and in avoiding catastrophes, resonates more with the values that brought them into healthcare."

—Judy Cassidy

## CHANGING THE WAY WE CARE FOR THE DYING

Continued from page 49

ventions. Policy development must include vigorous educational efforts to help physicians, nurses, and others realize that dying is a natural part of living and efforts to overcome death should be guided by reason.

Dying persons should not be assaulted relentlessly with technologies to the extent that they are forced to die one organ system at a time. Rather, healthcare professionals should understand that the proper use of life-prolonging measures often requires forgoing efforts to sustain life while the person remains able to experience dying as a personal reality. Institutions must provide settings conducive to such an experience. Transforming a sterile and oppressive technological environment into a place where families feel welcome and patients experience comfort and solace may require both creativity and a commitment of additional resources.

Second, Catholic-sponsored long-term care givers need to overcome the troubling tendency to transfer dying persons to acute care facilities when death is imminent. Ethics committees and pastoral care and ethics education personnel must address the attitudes, fears, and lack of understanding that lead such care givers to distance themselves from patients' deaths. These facility personnel should also educate care givers so they understand the ethical distinction between killing and allowing a person to die by withholding or withdrawing life-sustaining interventions. Moreover, ethics committees and pastoral care and ethics education personnel need to help care givers and families understand that when it is appropriate to allow death to come, they have a unique opportunity to accompany dying persons on the journey toward new life.

Third, hospice services should be available and their use encouraged. Physicians familiar with hospice should educate those who are not in hospice goals and practices. Physicians and other care givers need to support dying

persons and their families in their interest in using hospice, rather than chastising them for "losing hope." Where possible, acute and long-term care administrators should develop hospice services under Catholic sponsorship to ensure that the insights of the faith tradition with regard to dying, death, and resurrection are an integral part of the way care is rendered.

Finally, representatives from Catholic healthcare should work with parishes to encourage the faith community to share in the responsibility of providing home care for dying persons. This may be as simple as regularly visiting with family care givers to offer support. It may mean providing respite time for family members or providing some meals or housekeeping services. It will always require the prayerful support of the parish community as it witnesses in faith to the promise of resurrection and new life.

Dying persons are among the most vulnerable members of the human family. The moral health and integrity of the broader community can be measured in part by the way we respond to their needs. As we anticipate more appropriate healthcare services in the future, let us not neglect to reform the way we care for the dying. □

### NOTES

1. Ernest Becker, *The Denial of Death*, Free Press, New York City, 1985.
2. Jane E. Brody, "Doctors Admit Ignoring Dying Patients' Wishes," *New York Times*, January 14, 1993.
3. Sidney Wanzer et al., "The Physician's Responsibility toward Hopelessly Ill Patients: A Second Look," *New England Journal of Medicine*, March 30, 1989, p. 847.
4. Duncan MacLean, "The Physician's Responsibility toward Hopelessly Ill Patients," *New England Journal of Medicine*, October 5, 1990, p. 975.
5. Howard Brody, "Assisted Death: A Compassionate Response to a Medical Failure," *New England Journal of Medicine*, November 5, 1992, pp. 1,384-1,388.