# Conversations at the End of Life

ugust was an especially contentious month for those concerned about health care reform. Among the issues that caused special apprehension for a lot of people was whether any of the health reform bills under consideration contained provisions for euthanasia. Some critics of reform even spoke of "death panels." In fact, what one House bill would have allowed was reimbursement for physicians for counseling Medicare patients regarding end-of-life care, including how physicians could ensure that treatment would reflect patients' desires and provide access to palliative and hospice services if they were needed. As I write, it seems unlikely that such reimbursement will be in the final bill. Yet, as end-of-life care becomes more complicated, such discussions become increasingly important. One important point that needs to be discussed: Who should be part of such conversations. Because of the nature of end-of-life decisions, members of the clergy ought to have a role.

These sorts of conversations are difficult for families and often need facilitation of some sort. Many elderly people simply do not want to talk about their deaths. In the Aug. 31, 2009, issue of *Time*, for example, columnist Joe Klein wrote about his 89-year-old parents. He mentioned having lunch with his father and trying to discuss end-of-life issues with him: "It wasn't easy. My dad is very proud and independent. He didn't really want to talk about what came next. He was pretty sure, but not certain, that he's signed a living will. He was reluctant to sign an enduring power of attorney [i.e., durable power of attorney] to empower me, or my brother, to make decisions about his care and my mom's if he were incapacitated. I tried to convince him that it was important to make some plans, but I didn't have the strategic experience that a professional would have — and, in his eyes, I didn't have the standing. I may be a grandfather myself, but I'm still just a kid in my dad's mind."1

Klein's experience is replicated in many families: People don't want to talk about end of life, do not feel that they have the "standing" to bring

it up with their loved ones or simply do not know what to say. They look for a professional. Yet, in a recent Pew Research Center survey, when people were asked an open-ended question regarding with whom they discussed end-of-life treatments, no one gave "clergy" as an answer.<sup>2</sup>

# **DECISIONS, VALUES AND MEDICAL ETHICS**

If the only professional advice people receive is from a physician or lawyer, then end-of-life planning is simply clinical or legal. It becomes an articulation of the patient's "preferences." At first glance this might not seem to be a problem. The questions raised do seem clinical: "What kinds of treatments are acceptable or not acceptable to me? At some time should a do-not-resuscitate order be executed? Where and how do I want to spend my last days? Who will make end-of-life decisions if I am prevented from making them?" Yet if one looks below the surface, one realizes that the answers to these questions depend in part upon the values a patient holds. Furthermore, these questions can give rise to deeper existential questions: "What will I leave for others after I am gone? Do others really care about my dying? Has my life had meaning?" These are religious questions, and members of the clergy can be of help as patients and families try to deal with them. Even more specifically, the Catholic moral tradition (among other religious traditions) can help individuals by providing ethical guidance, a theological vision and a promise of care.

### **Ethical Guidance**

At least from the 16th century, the Catholic moral tradition has developed what has become

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### ETHICS



known as the ordinary/extraordinary distinction in medical ethics. The basis of this distinction is an analysis of the burdens and benefits of particular medical interventions. In the movement from preferences to values, this distinction can be of particular help to patients and their families as they face end-of-life decisions. The *Ethical and Religious Directives for Catholic Health Care Services* understand this distinction as a middle position between two unacceptable extremes:

The use of life-sustaining technology is judged in light of the Christian meaning of life, suffering and death. Only in this way are two extremes avoided: on the one hand, an insistence on useless or burdensome technology even when a patient may legitimately wish to forgo it, and, on the other hand, the withdrawal of technology with the intention of causing death.<sup>4</sup>

This position acknowledges that the Catholic tradition regarding end-of-life decisions will not have the exactness of a mathematical formula. This ambiguity can be disconcerting to those try-

ing to make a good decision. Patients and family members may not totally agree on whether to stop or continue aggressive treatment. It is here that a trusted member of the clergy can offer guidance.

## **Theological Vision**

The ambiguity inherent in the Catholic position further suggests that a person may need the assistance of a member of the clergy in articulating the spiritual or theological vision that guides such decisions. Again, the directives explain:

The truth that life is a precious gift from God has profound implications for the question of stewardship over human life. We are not the owners of our lives and, hence, do not have absolute power over life. We have a duty to preserve our life and to use it for the glory of God, but the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome.<sup>5</sup>

Thus the Catholic understanding of life is that it is a precious reality and must be respected; yet it is not ultimate. It is an important but transitory reality that prepares the person for a fuller life. Medieval writers spoke of the ars moriendi, the art of dying. One prepared for death by the life one lived. The Catholic bishops of Illinois, in a highly readable and straightforward pastoral letter on dying, "Facing the End of Life," offer a similar spirituality: "The key to dying well is living well. Living well means a life characterized by love of God and love of neighbor. Recognizing that the goal of our lives is eternal life with God, we prepare for that by prayer, reception of the sacraments, and care for those around us, especially the poor and the forgotten."6 The Catholic spiritual vision understands death as the person's final return in love to the God of love. Members of the clergy can help provide this richer context for those who must make difficult end-of-life decisions.

### **Promise of Care**

The contemporary legal context for interpreting end-of-life decisions has been patient autonomy; that is, in both legislative and judicial actions for over the past 20 years the focus has been to increase patient autonomy vis-à-vis other decision makers, including physicians and families.

This focus is reflected in the Patient Self-Determination Act, the Health Insurance Portability and Accountability Act, and the U.S. Supreme Court's Cruzan decision. Although this emphasis stems from a respect for an individual's decisions, it can also lead to medical neglect or abandonment. As Marshall Kapp has suggested, "Individualism and independence, if too rugged, may turn to health care nihilism." Rather than emphasizing autonomy, the Catholic tradition has emphasized care. As the directives state: "The task of medicine is to care even when it cannot cure."8 In Catholic thought, respect for the dignity of the person demands that one care for the patient. According to the Catholic tradition, when patients are appropriately resisting the onslaught of disease, they should have their caregivers' support. True caregivers, however, will also be honest with patients and will acknowledge the time when aggressive treatment directed toward cure is no longer caring. Again a member of the clergy can help a patient understand that he or she is not abandoned in such circumstances.

# **CLERGY FORMATION**

For members of the clergy to help patients and their families in end-of-life decisions, they themselves need to become more knowledgeable about end-of-life issues and be able to discuss them with their parishioners. This actually involves two distinct sets of skills. First, clergy members need to educate themselves on the nuances of end-of-life decisions. A thorough knowledge of Part Five of the directives is a good place to begin, but this is only a beginning. Through reading and possibly workshops and course work, members of the clergy can gain the competence needed to assist others.

Members of the clergy also need to know *how* to discuss these issues in an appropriate way with those who are facing terminal disease. The fear and inadequacy experienced by others in conversations about end of life are also experienced by the clergy. There are at present several ecumenical courses for clergy, such as Compassion Sabbath or the Florida Clergy End-of-Life Education Enhancement Project, designed to help members of the clergy develop the skills they need. Many local hospices also offer such training.

### Conclusion

The section on the care for the dying in the directives begins with a bold statement: "The Catholic

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health care ministry faces the reality of death with the confidence of faith." By providing ethical guidance, a theological vision and a promise of care, members of the clergy can make this bold statement more and more of a reality for those confronting end-of-life decisions.



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### NOTES

- 1. Joe Klein, "In the Arena," *Time* 174, no. 8 (August 31, 2009): 16.
- 2. The Pew Center for Research for the People and the Press, Strong Public Support for Right to Die: More Americans Discussing — and Planning — End-of-Life Treatment (2005): 15, 38 (q. 32), http://peoplepress.org/reports/pdf/266.pdf. To be fair, only 10 percent answered the survey by giving someone other than a family member, even though multiple answers were allowed. Those who said they had spoken to no one totaled 19 percent of the survey.
- 3. See, for example, Daniel A. Cronin, "The Moral Law in Regard to the Ordinary and Extraordinary Means of Conserving Life" in Russell E. Smith, ed., *Conserving Human Life* (Braintree, Mass.: The Pope John XXIII Center, 1989).
- United States Conference of Catholic Bishops, Ethical and Religious Directives for Catholic Health Care Services, 4th edition (Washington, DC: United States Conference of Catholic Bishops, 2004), Part Five: Introduction.
- 5. Ethical and Religious Directives.
- 6. Bishops of Illinois, Facing the End of Life (Chicago: Illinois Catholic Health Association, 2001), 2.
- Marshall B. Kapp, "Medical Empowerment of the Elderly," Hastings Center Report 19, no. 4 (July-August, 1989: 6.
- 8. Ethical and Religious Directives.
- 9. Ethical and Religious Directives



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