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End-of-Life Ethics: Preparing Now for the Hour of Death

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A brief but accurate look at the challenging questions surrounding end-of-life medical and moral issues. Pays attention to the social dimensions of what seem to be very private decisions and offers nuanced responses.

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Have you ever said to your family, "Don't put me on all those life-support machines and tubes"? Perhaps you had just visited a friend in the hospital or were simply reacting to stories such as those about Terri Schiavo, the Floridian who lived on life support for years before that life support was removed in 2005 in the midst of a national debate. Perhaps you had a sense that the life-support machines were not so much promoting life but, rather, simply delaying death. As a result, you perhaps know that you don't want to be in that situation.

Or perhaps you reacted very differently to experiences like Terry Schiavo's death. You are convinced that feeding tubes must be used. Perhaps you found yourself confused by the debate, disagreement, and polarization. You are wondering what faithful Catholics ought to do about these ethical issues and what role, if any, the government ought to play.

End-of-life issues touch the depths of our being, stir the emotions, and raise profound questions. They call for careful moral reasoning. In this chapter, we will look to the Hebrew and Christian Scriptures and to insights from our long Catholic tradition for guidance and wisdom in making moral decisions. We will suggest appropriate responses for us as faithful disciples of Jesus and as concerned citizens. We'll also consider what we can do now for the hour of *our* death by filling out an advance directive (a living will or health-care power of attorney).

Words of Wisdom

The Scriptures provide a foundation and a sure direction in helping us to respond to end-of-life questions by offering three major points: (1) life is a basic, but not absolute, good, (2) we are to be stewards of life, but we don't have complete control, and (3) we understand death in the context of belief in new life.

In the creation story in Genesis, we hear of the goodness of all creation (Genesis 1:31) and, in a special way, the sacredness of all human life, for we are created in God's image (1:27). Human life, then, possesses a dignity, rooted in who we are, rather than in what we do. Life is holy, deserving of respect and reverence. We know from experience that life is the foundation for all other goods: friendship, love, prayer, and all the other ways we enjoy and serve God and neighbor.

Life, however, is not an absolute good. There is a greater good: our relationship with God. We would not, for example, destroy our relationship with God through sin in order to save our physical life. The powerful witness of martyrs—and especially Jesus—testifies to this truth.

Stewardship, our second major point, must be distinguished from dominion. Stewardship implies that we have the responsibility to care for something that is not totally our own possession. Dominion, on the other hand, claims an ultimate control. Life, as we have already seen, is a gift of God, to be respected and reverenced. Jesus' whole life modeled the idea of stewardship, creatively nourishing the gift of life (see John 6:22–71).

The third point the Scriptures offer us is the conviction that death marks the transformation to new and eternal life. This belief does not deny the reality of death,

along with its suffering and separation. Yet life is changed, not ended. Our belief in everlasting life is rooted, of course, in the transforming experience of the resurrection of Jesus (see Luke 24:1–53; John 20:1—21:25). We, too, trust in God's loving faithfulness.

Euthanasia and Assisted Suicide

How, then do these three insights—life is a basic good, we are stewards of life, death is not the final word—enlighten end-of-life issues? How do they help us to sort through the dilemmas of euthanasia, assisted suicide, treatment, and use of life-support systems? The conviction that we are stewards of life grounds the opposition to euthanasia. We use our creativity to cure illness, but we also acknowledge that ultimately death cannot be avoided. As stewards, we respond with care and compassion to those who are suffering. Indeed, we have much to learn about better methods of pain control. Mercy killing *seems* to offer a solution to profound human fears: the fear of dying, of losing control, of being a burden, of being strapped with terrible pain. Mercy killing, however, moves beyond stewardship into dominion. Euthanasia, even for compassionate reasons, implies that we have absolute control over life and so contradicts who we are as faithful stewards of God's gift of life.

Similarly, with assisted suicide, recognizing both the good gift of life and our responsibilities as stewards prohibits choosing suicide or helping someone else to end his or her life. Assisted suicide, though rooted in frustration, pain, or despair, speaks of dominion, of attempting to seize ultimate control over life. It, too, contradicts the fundamental reality of our lives and so undermines our humanity.

Both of these decisions may seem to be very private decisions, yet they have profound implications for society. Many Church groups and others see that legalizing euthanasia and assisted suicide would further undermine reverence for life in our society, would reduce trust in the medical profession, and would put old and infirm people in very vulnerable positions. The public policy dimensions of the euthanasia issue are very serious and demand an intelligent, nuanced response that respects the dignity of all persons.

Treatment and Life Support

Questions about the use of medical treatments and life-support systems are distinct from—and yet often associated with—euthanasia. The scriptural insights can be very helpful with these issues even if they cannot give details. As good stewards, we believe that death is not the final word, that life is not an absolute good. Therefore, we do not have to keep someone alive "at all costs."

The Catholic tradition helps with the details, providing this guidance: ordinary means must be used; extraordinary means are optional. Ordinary means are medicines or treatments that offer reasonable hope of benefit and can be used without excessive expense, pain, or other inconvenience. Extraordinary means do not offer reasonable hope of benefit or include excessive expense, pain, or other inconvenience. What is important to remember is that "ordinary" and "extraordinary" refer not to the technology but to the treatment *in relation* to the condition of the patient, that is, to the proportion of benefit and burden the treatment provides the patient (see the Vatican's Declaration on Euthanasia, IV, 1980).

Many people remember when Cardinal Joseph Bernardin of Chicago decided to stop the treatment for his cancer. The treatment had become extraordinary. He did not kill himself by this choice but did stop efforts that prolonged his dying. He allowed death to occur. (This distinction between allowing to die and killing, as in euthanasia or assisted suicide, is of great significance in the Catholic tradition. The rejection of this distinction by several U.S. courts raises serious concerns.)

Within the Catholic Church, debate still surrounds the question of providing medical nourishment through a feeding tube. Let's look at two positions:

1. "Life must almost always be sustained." This position holds that the withdrawal of medically assisted nutrition and hydration cannot be ethically justified except in very rare situations. The fundamental idea for this position is the following: remaining alive is never rightly regarded as a burden because human bodily life is inherently good, not merely instrumental to other goods. Therefore, it is rarely morally right not to provide adequate food and fluids.

This position acknowledges that means of preserving life may be withheld or withdrawn if the means employed is judged either useless or excessively burdensome. The "useless or excessive burden" criteria can be applied to the person who is imminently dying but not to those who are permanently unconscious or to those who require medically assisted nutrition and hydration as a result of something like Lou Gehrig's or Alzheimer's disease. Providing these patients with medical nourishment by means of tubes is not useless because it does bring these patients a great benefit: namely, the preservation of their lives.

2) "Life is a fundamental but not absolute good." This approach rejects euthanasia, judging deliberate killing a violation of human dignity. On the other hand, while it values life as a great and fundamental good, life is not seen as an absolute (as we saw in the section on scriptural foundations) to be sustained in every situation. Accordingly, in some situations, medically assisted nutrition and hydration may be removed.

This position states that the focus on imminent death may be misplaced. Instead we should ask if a disease or condition that will lead to death (a fatal pathology) is present. For example, a patient in a persistent vegetative state cannot eat enough to live and thus will die of that pathology in a short time unless life-prolonging devices are used. Withholding medically assisted hydration and nutrition from a patient in such a state does not cause a new fatal disease or condition. It simply allows an already existing fatal pathology to take its natural course.

Here, then, is a fundamental idea of this position: if a fatal condition is present, the ethical question we must ask is whether there is a moral obligation to seek to remove or bypass the fatal pathology. But how do we decide either to treat a fatal pathology or to let it take its natural course? Life is a great and fundamental good, a necessary condition for pursuing life's purposes: happiness, fulfillment, love of God and neighbor.

But does the obligation to prolong life ever cease? Yes, says this view, if prolonging life does not help the person strive for the purposes of life. Pursuing life's purposes implies some ability to function at the level of reasoning, relating, and communicating. If efforts to restore this cognitive-affective function can be judged

useless or would result in profound frustration (that is, a severe burden) in pursuing the purposes of life, then the ethical obligation to prolong life is no longer present.

Disagreements in the Church

How are these significantly different positions judged by the Roman Catholic Church? There is no definitive Catholic position regarding these two approaches. Vatican commissions and Catholic bishops' conferences have come down on both sides of the issue. Likewise, there are Catholic moral theologians on both sides.

In an attempt to respond to this controversy in 1992, the Committee for Pro-life Activities of the National Conference of Catholic Bishops (now the USCCB) issued *Nutrition and Hydration: Moral and Pastoral Reflections.* This statement called for a presumption in favor of using medically assisted nutrition and hydration, but added that it may be removed in certain circumstances, e.g., when burdens outweigh benefits. This guidance was then included in the bishops' *Ethical and Religious Directives for Catholic Health Care Services.*

In 2004, Pope John Paul II, speaking at a Vatican conference, seemed to disagree with the U.S. bishops' statements by opposing the removal of medically assisted nutrition and hydration ("seemed" because there is debate about whether the pope allowed removal in some circumstances). In 2007 the Congregation for the Doctrine of the Faith (CDF) responded to specific questions concerning the use of artificial nutrition and hydration for patients in a persistent vegetative state (PVS). In light of its interpretation of John Paul's statement, the CDF wrote: "The administration of food and water even by artificial means is, in principle, an ordinary and proportionate means of

preserving life." Then in 2009, the U.S. bishops revised their *Ethical and Religious Directives for Catholic Health Care Services* to reflect this judgment.

Although these statements seem to affirm the "Life must almost always be sustained view," responsible Catholic moralists, including those involved in Catholic health care, have argued that the balancing of burdens and benefits is still present. They judge that the CDF's position contains inconsistencies (because Church teaching does permit the removal of respirators) and seems to come close to idolizing biological life by making it an absolute value. These moral theologians note that the CDF statement applies only to PVS patients. They also point out that all these statements deserve proper respect but that they are not infallible pronouncements. So disagreements continue. (For an article rich in context, nuance, and insight, read Daniel Sulmasy's "Preserving Life?" in *Commonweal*, December 7, 2007, Volume CXXXIV, Number 21.)

Advance Directives

Suffering, moral questions, and legal implications make death-and-dying situations so very difficult. What can we do to make our wishes known now for the time when we are no longer capable of making health-care decisions for ourselves? We can reflect and pray, discuss with our families and physicians, and indicate in writing our desires for health care by creating an advance directive.

There are two different types. The first type of document is the *living will*, a statement prepared in advance so that people, while competent, can direct their families and physicians concerning the type of treatment they want (or do not want) if

they become terminally ill and incompetent. The living will is recognized as a legal document.

On the other hand, the living will, by its nature being a document prepared in advance, may be seen as making a decision before the concrete situation has been faced. Because no one can foresee all the details of a future illness and medical procedures, the living will is limited but at least offers some reflection and foresight to the types of treatment desired.

The second type of document is the *health-care power of attorney.* In this document, an individual gives another person the legal authority to make health-care decisions when he or she is no longer able to do so. The decisions made by the appointed person (technically called an "attorney-in-fact" or sometimes "proxy" or "surrogate"; this person need not be an attorney-at-law) are based on the current medical condition of the patient and on the patient's previously expressed desires concerning treatment.

As a result, this form of dealing with dying-and-death situations seems to be preferable. It provides both for respect for the individual's desires concerning treatment and for current informed consent made by the attorney-in-fact who knows—after careful consultation with doctors, nurses, and chaplains—the specific medical options facing the patient. It does not rely merely on a previously written statement to cover all possible situations.

In appointing someone to act on your behalf, clearly you will choose someone you trust (e.g., a spouse, son, daughter, best friend) to be the attorney-in-fact, someone

with whom you have carefully discussed your wishes concerning treatment. Because laws vary from state to state, it is wise to consult a lawyer about both types of documents. Your physician may also be able to help you. Communication with your family and doctor is also an essential part of the process.

The Final Mystery of Life

Advance directives are for everyone of legal age, not just senior citizens. If this seems to you like too much effort, it is not! The whole process of planning now for the hour of death is a concrete way to express your care and love for your family and friends. It will allow them to know your desires clearly, especially since they will be the ones faced with the difficult and painful decisions. It lessens the possibility of friction or guilt feelings about relationships that frequently cause difficulties in such situations.

Planning now is also a responsible consideration of the appropriate use of the earth's resources. Certainly your decisions about types of treatment will have implications for costs, care, and use of scarce medical resources. Finally, planning now can be a prayerful experience, confronting the final mystery of life and trusting in our gracious God, the source and goal of all life.

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