

*A Message on...*

## End-of-Life Decisions

*With this message, the Church Council of the Evangelical Lutheran Church in America, upon the recommendation of the Division for Church in Society, addresses some timely aspects of end-of-life situations and encourages further deliberation on the topic throughout this church. This message does not deal with the full scope of these complex matters. It draws upon a relevant social statement, "Death and Dying," of a predecessor church body as basis for the guidance it offers.<sup>1</sup>*

### THE OCCASION

An elderly woman contemplates in terror the possibility that she might be kept alive for months by means of life-support systems. A son visits a nursing home weekly to see his 95 year-old mother, who is stricken with Parkinson's disease and who wants to die. Family and friends share the slow, anguishing death of a young man with AIDS. Parents agonize with their pastor over what to do about their daughter who survives in a persistent vegetative state after a car accident.

Increasingly, people know from their own experience similar painful dilemmas. While the achievements of modern medicine have been used to prolong and enhance life for many, they have also helped create an often dreaded context for dying. Costly technology may keep persons alive, but frequently these persons are cut off from meaningful relationships with others and exist with little or no hope for recovery. Many fearfully imagine a situation at the end of their lives where they or their trusted ones will have no say in decisions about their treatment.

In this context, new emphasis is being placed on the rights of patients. Recent federal legislation, for example, requires all health care facilities receiving Medicare or Medicaid monies to inform patients of their right to make medical treatment decisions. This includes the right to specify "advance directives,"<sup>2</sup> which state what patients wish to be done in case they are no longer able to communicate adequately.

We consider the legislation consistent with the principle that "respect for that person [who is capable of participating] mandates that he or she be recognized as the prime decision-maker" in treatment.<sup>3</sup> The patient is a person in relationship, not an isolated individual. Her or his decisions should take others into account and be made in supportive consultation with family members, close friends, pastor, and health care professionals. Christians face end-of-life decisions in all their ambiguity, knowing we are responsible ultimately to God, whose grace comforts, forgives, and frees us in our dilemmas.

Which decisions about dying are morally acceptable to concerned Christians, and which ones go beyond morally acceptable limits? Which medical practices and public policies allow for more humane treatment for those who are dying, and which ones open the door to abuse and the violation of human dignity? Proposals in various states to legalize physician-assisted death<sup>4</sup> point to renewed interest in these old questions. ELCA members, congregations, and institutions need to address these questions through prayer and careful reflection.

## A CHRISTIAN PERSPECTIVE

Our faith as Christians informs and guides us in approaching personal and public decisions about death and dying today. Among the convictions that orient us are:

- ◆ *life is a gift from God, to be received with thanksgiving;*
- ◆ *the integrity of the life processes which God has created should be respected; both birth and death are part of these life processes;*
- ◆ *both living and dying should occur within a caring community;*
- ◆ *a Christian perspective mandates respect for each person; such respect includes giving due recognition to each person's carefully considered preferences regarding treatment decisions;*
- ◆ *truthfulness and faithfulness in our relations with others are essential to the texture of human life; and,*
- ◆ *hope and meaning in life are possible even in times of suffering and adversity; a truth powerfully proclaimed in the resurrection faith of the church.<sup>5</sup>*

"Whether we live or whether we die, we are the Lord's" (Romans 14:8). For those who live with this confidence, neither life nor death are absolute. We treasure God's gift of life; we also prepare ourselves for a time when we may let go of our lives, entrusting our future to the crucified and risen Christ who is "Lord of both the dead and the living" (Romans 14:9).

While these convictions do not give clear-cut answers to all end-of-life decisions, they do offer a basic approach to them.

## ALLOWING DEATH AND TAKING LIFE

### Withholding or Withdrawing Artificially-administered Nutrition and Hydration

Patients who once would have died because of their inability to take food and water by mouth can today be kept alive through artificially-administered nutrition and hydration. These measures are often temporary and allow many to recover health. At other times, however, they alone maintain life, and they may do so indefinitely. In those cases, is it ever morally permissible to withhold or withdraw such measures?

Food and water are part of basic human care. Artificially-administered nutrition and hydration move beyond basic care to become medical treatment. Health care professionals are not required to use all available medical treatment in all circumstances. Medical treatment may be limited in some instances, and death allowed to occur. Patients have a right to refuse unduly burdensome treatments which are disproportionate to the expected benefits.

When medical judgment determines that artificially-administered nutrition and hydration will not contribute to an improvement in the patient's underlying condition or prevent death from that condition, patients or their legal spokespersons may consider them unduly burdensome treatment. In these circumstances it may be morally responsible to withhold or withdraw them and allow death to occur. This decision does not mean that family and friends are abandoning their loved one.

When artificially-administered nutrition and hydration are withheld or withdrawn, family, friends, health care professionals, and pastor should continue to care for the person. They are to provide relief from suffering, physical comfort, and assurance of God's enduring love.

### **Refusal of Beneficial Treatment**

Patients and health care professionals share a common concern that medical treatment be beneficial. In most situations, they have a common understanding of that benefit. When agreement exists, patients generally are willing to receive treatment. There are situations, however, when patients and health care professionals disagree on what will benefit the patient, or on whether the expected benefit is worth the risks and burdens involved. What is morally responsible in these situations?

Because competent patients are the prime decision-makers, they may refuse treatment recommended by health care professionals when they do not believe the benefits outweigh the risks and burdens. This is also the case for patients who are incompetent, but who have identified their wishes through advance directives, living wills, and/or conversation with family or designated surrogates.

Health care professionals are obligated to inform patients of medical treatment options and what in their best judgment are the potential benefits and burdens of such options. They are also obligated to obtain the consent of patients to provide treatment. Where this consent is not given, they should accept the desired limits of treatment, even when they do not agree with the decision.

A patient's refusal of beneficial treatment does not free health care professionals from the obligation to give basic human care and comfort throughout the dying process which may follow. Family, friends, and pastor need to accompany the person and share the promise of God's faithfulness in life and death.

## Physician-Assisted Death

An emphasis on patients' rights, a health care system often unable to respond adequately to catastrophic illness, and the emergence of disease processes (such as AIDS and Alzheimer's disease) that threaten dramatic loss of human capacities are a few of the realities that have converged to create an environment where some patients ask that their life be ended. Is it ever morally permissible for a physician deliberately to act or authorize an action to terminate the life of a patient?

The integrity of the physician-patient relationship is rooted in trust that physicians will act to preserve the life and health of the patient. Physicians and other health care professionals also have responsibility to relieve suffering. This responsibility includes the aggressive management of pain, even when it may result in an earlier death.

However, the deliberate action of a physician to take the life of a patient, even when this is the patient's wish, is a different matter. As a church we affirm that deliberately destroying life created in the image of God is contrary to our Christian conscience.<sup>6</sup> While this affirmation is clear, we also recognize that responsible health care professionals struggle to choose the lesser evil in ambiguous borderline situations—for example, when pain becomes so unmanageable that life is indistinguishable from torture.

We oppose the legalization of physician-assisted death, which would allow the private killing of one person by another. Public control and regulation of such actions would be extremely difficult, if not impossible. The potential for abuse, especially of people who are most vulnerable, would be substantially increased.

Caring treatment that allows death to occur within the bounds of what is morally acceptable may help reduce the appeal of physician-assisted death. Hospice care offers promise of more humane treatment at the end of life. A more equitable health care system that more effectively responds to catastrophic illness and provides the needed follow-up care should also be a priority for those concerned about end-of-life decisions.

## MINISTRY IN PREPARATION FOR THE END OF LIFE

Advance directives are welcome means to foster responsible decisions at the end of life. Yet people are often overwhelmed and frightened when thinking about medical treatment and legal possibilities, and therefore do not take steps to prepare for the end of their lives. People recognize their rights as patients but at the same time feel unprepared to take on the responsibility.

Communities of faith should, can, and often do provide holistic ministry to prepare people for end-of-life decisions. Pastors can help people to deal with their fears and hopes. Congregations can offer opportunities for conversation and deliberation about the end of life. They can invite hospital chaplains, hospice care-givers, social workers, attorneys, or others knowledgeable about advance directives to help them consider the topic's many dimensions.

Church related hospitals, nursing homes, and other social ministry organizations are also encouraged to provide for continuing conversation and deliberation about their ministry at the end of life. The staff of these organizations need to understand the ethical principles that are to guide the care they provide. Ethics committees can play an important role in dealing with unresolved conflicts about treatment decisions.

We rejoice in the faithful and compassionate congregations, pastors, health care professionals, and church institutions who minister with persons who are dying and their families and friends. We give thanks for family and friends who minister to their loved ones. In the midst of often agonizing end-of-life decisions, we are reminded of the God-given mystery of both life and death. May the Holy Spirit grant to us all loving wisdom and confident hope in the Gospel's promise of eternal life.

#### ENDNOTES

1. The social statement, "Death and Dying," was adopted in 1982 by the Lutheran Church in America. In 1977 The American Lutheran Church developed an analysis paper, "Death and Dying," which was not an actual social statement, but also provides background for this message. Both are available from the ELCA Distribution Service.
2. "Advance directives" commonly include designation of a durable power of attorney, living wills, and an advance directive form. The exact meaning, however, may vary from state to state.
3. LCA, "Death and Dying," p. 3.
4. Physician-assisted death or "aid in dying" refers to situations in which a physician (or other health professional at the physician's request), in response to a patient's request, either administers a medication or performs a treatment, or enables the patient to do so, with the intent of bringing about that patient's death.
5. The above convictions are quoted from LCA, "Death and Dying," pp. 2-3.
6. LCA, "Death and Dying," p. 6.

*This message was approved by the board of the Division for Church in Society. It was adopted by the ELCA Church Council on November 9, 1992.*

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