

Facing the End of Life:

A Pastoral letter from the Bishops of Illinois

April 15, 2001

When Americans talk about death and dying, they often talk about controversy. Debates rage over assisted suicide and euthanasia, the role of medical technology, and the cost of health care.

We, the bishops of Illinois, write to you to proclaim that as Catholics we need to consider death in the context of our faith. Jesus Christ suffered, died, and rose from the dead. This central truth of our faith provides meaning to our lives. Because of who Jesus is, we are called to eternal life.

It is an unfortunate characteristic of American culture that issues of great importance are often separated from the context in which they can be understood. When we think about death and dying, it is hard to find meaning and hope if we forget our faith. We want to share our hope and conviction that the Catholic community can provide evidence of what it means, as we face the end of our lives, to be a civilization of love amidst a culture of death. In the words of the Apostle Paul, we will show you a "more excellent way" to consider the end of life. (1 Cor 12:31)

What We Believe

What was from the beginning,
what we have heard,
what we have seen with our eyes,
what we looked upon
and touched with our hands concerns the Word of life --
for the life was made visible;
we have seen it and testify to it
and proclaim to you the eternal life
that was with the Father and was made visible to us --
what we have seen and heard
we proclaim now to you,
so that you too may have fellowship with us;
for our fellowship is with the Father
and with his Son, Jesus Christ.
We are writing this so that our joy may be complete.
(1 Jn 1:1-4)

We begin with the message of eternal life and fellowship with God promised us by Jesus Christ. This is the context where we must start for any authentic understanding of the end of life. Only the fabric of faith provides us with the texture and richness to understand the meaning of the individual thread of our own life and death. We are not simply looking at medical technology, or the use of procedures, or how we can best care for people as they die: we are considering the purpose of human life. Because of our faith, we understand human life to be more than our time on this earth. The reason we are created, the point of our lives, is to spend all ages enjoying God's presence. Our time on earth has tremendous importance for it determines how we respond to God's call. But the value of human life is truly found in our supernatural destiny and recognition that death is not the end. As John Paul II wrote in his encyclical "Evangelium Vitae":

"Man is called to a fullness of life which far exceeds the dimensions of his earthly existence, because it consists in sharing the very life of God. The loftiness of this supernatural vocation reveals the greatness and the inestimable value of human life even in its temporal phase.

". . . At the same time, it is precisely this supernatural calling which highlights the relative character of each individual's earthly life. After all, life on earth is not an "ultimate" but a "penultimate" reality; even so, it remains a sacred reality entrusted to us, to be preserved with a sense of responsibility and brought to perfection in love and in the gift of ourselves to God and to our brothers and sisters." (Ev Vitae, 2)

Our life on earth is a sacred reality but one that is relative to the reality of our eternal life with God. We recognize that we all will die. But this death is not the end of our existence. Death remains as a frightening limit and a boundary beyond which we cannot see, except with faith.

Preparation for death is an essential part of life for a Christian. Those who avoid the topic of death and dying are making a serious mistake. Many individuals are misguided in their pursuit of money, pleasure, and personal advancement rather than attending to relationship with God, an acceptance of Jesus as Lord and Savior, and the honest prayer that the end of life will find them ready to meet God and enter Paradise. 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.

As we face a serious illness or come to the end of our lives, the sacraments become an urgent responsibility. Although it is important to consider the types of medical therapy we would or would not want as we face a serious illness, Christians must also think about the means by which we can be spiritually strengthened and comforted. Through the Sacrament of Penance, the Sacrament of the Sick, and the reception of Holy Communion, Christ is present to us as we face the difficult realities of sickness.

Our faith in Christ's resurrection and our hope for eternal life does not, however, remove the worry and concern that many have about how they will die. We must also acknowledge that fear of pain, unnecessary suffering, and the specter of dependency and helplessness are reasons why some are so frightened of the end of life. Some individuals seek control over every aspect of dying, and even ask for assistance in suicide or euthanasia. To those who are so frightened of the end of life they seek to control or hasten it, we respond by a consideration of three crucial issues: the role of medical care at the end of life, the proper understanding of suffering and the value of suffering, and the difficulty we as Americans have with loss of independence and control.

The Role of Medical Care at the End of Life

Our society demands clear answers and sharp distinctions. Catholics intent on faithfully following the dictates of their faith know that the Church's teaching authority does not extend to a definitive pronouncement on every clinical decision. We often are obliged to do our best in difficult situations guided by a conscience that is informed by the faith of the Church and the competent advice of a caring physician.

There are two extremes that must always be avoided. The first is an attitude that one can end life, either by an action, like a lethal injection, aimed at killing a patient or by deliberately withholding therapy with the goal of bringing about a person's death. The second extreme mistakes our respect for the value of life with vitalism, the erroneous belief that our life on earth has absolute value and all means must be taken for its preservation. The role of medicine is to respect the inestimable value of life while realizing the death of the body is not always a defeat.

We have emphasized our faith in Christ and the resurrection, but we need to fulfill that faith with works that speak clearly of the value of life, the dignity of the human person, the necessity of adequate pain and symptom control, and the power of our shared love for our brothers and sisters. Catholic health care should set the standard for excellence in end of life care for our nation. Hospitals and care facilities need to provide excellent palliative care services as part of the treatment plan for all serious illnesses, not just cancer. Hospice care should be a priority for development. Ideally, hospitals and parishes can work together to provide skilled and compassionate care for the dying and their families. Quality indicators of care must be developed and care pathways implemented that measure pain control, work to improve the relief of pain and other symptoms, and provide resources for doctors and nurses as they care for hospitalized patients. The dignity of those who suffer from chronic illness or who are in nursing homes must be respected.

Doctors need to learn more about pain and symptom control. Treatment of serious illness must always consider the need to relieve the physical distress of the person suffering as well as recognize the reality that all people will die. Physicians should not impose aggressive life sustaining therapies on persons for whom such treatments will simply prolong the dying process. Likewise, doctors do wrong who insist on maintaining invasive life support when the patient or his or her family make clear that the burdens of

treatment far exceed the benefits. A good Catholic doctor speaks openly about death and dying with her or his patients, is frank about the limits of medical care, works hard to preserve life and never deliberately takes life, but recognizes that there are times when treatments should be withheld or withdrawn.

Nurses, too, bear a special responsibility to ensure the comfort of their patients as well as help the dying and their families. Nursing care plans should be devised that emphasize symptom control, support for the family, and the importance of compassion. Experienced nurses can guide families and explain some of the symptoms in the last hours of life, easing fears and providing comfort for the patient. Likewise, wise nurses can help doctors grow in skill and recognize the necessity of expert pain control and relief of other distressing symptoms. Nurses, in their role as patient advocates, can work to ensure the patient is cared for as a person and that the individual is heard and understood, not simply approached as a disease to be treated.

Those who are not health care professionals also have a responsibility in improving end of life care. First, we need to work with legislators and others to improve access to health care in our country so all individuals with life-threatening illnesses can receive excellent care. Second, as individuals, we need to consider the type of care we would like to receive in the event of a life threatening illness. In Illinois, the Durable Power of Attorney for Health Care allows an individual to appoint a spokesperson to assist the physician in making decisions about care in the event the patient is unable to participate in the decision making process. Third, when we face end of life decisions for ourselves or our family members, we should choose on the basis of a conscience informed by our faith in Jesus Christ and Church teaching.

Several points can guide us in formulating an advance directive (such as establishing a Durable Power of Attorney for Health Care) or when we are faced with the necessity of deciding about life-sustaining therapy in the midst of a medical crisis.

There is no obligation to resort to every type of therapy in an effort to preserve life regardless of the likelihood of outcome. At the end of chronic illnesses like cancer or dementing illnesses, the benefit of life prolonging therapy is greatly limited. For those who are suffering from metastatic cancer, end-stage congestive heart failure, or advanced Alzheimer's disease or other dementia, it is difficult to see any justification for resuscitation in the event of cardiac arrest or the prolonged use of intubation and mechanical ventilation. The fact that aggressive therapy need not be continued is not to be misconstrued as an allowance that one can refuse ordinary care.

Decisions around the refusal or removal of artificial feeding and hydration can be difficult and troubling for families as well as physicians and staff. We want to provide what is the most compassionate and productive care for the good of those we love. When a person can swallow and digest food, it is never appropriate to stop feeding by hand and giving sips of water. On the other hand, to provide artificial feeding and hydration in some cases at the end stages of terminal diseases, like cancer, might directly increase the suffering of the patient and perhaps even, inadvertently, hasten death. In every case and

on every occasion we may not do anything that is aimed at causing or hastening the death of a patient. The National Conference of Catholic Bishops has provided principles that assist family members and physicians in making the necessary moral and ethical decisions on the provision of artificial feeding and hydration. Realizing that each case differs from every other case, families, physicians, and staff should feel free to consult with competent Church ethicists and advisors in reaching a decision. This consultation can also provide comfort for the caregivers in knowing that they have made a morally sound decision that best serves their patient and loved one.

We must not let some of the ambiguities of end of life decision making lead us, on one hand, to a neurotic fear that we will incur Christ's judgment for not acting with sufficient care, and on the other hand, to choose reckless or misguided care for our loved ones. In consulting with legitimate Church teaching, our consciences can be formed so that decisions made even in emotionally laden situations are moral, compassionate, and appropriate.

The Place of Suffering

We have emphasized that some may favor assisted suicide and euthanasia because of a fear of untreated pain. Pain should be treated aggressively. Catholic physicians and health care institutions have a solemn obligation to improve care for the dying with excellent symptom control. At the same time, suffering at the end of life is more than pain from the spread of cancer, or shortness of breath from emphysema, or weakness and fatigue from heart failure. Suffering is part of the existential burden of knowing that our time on earth is ending, facing the loss of relationships and the good things of life, and dealing with the loss of independence and freedom that terminal illness often brings. Even as people of faith, we fear death, for it is the end of the life that we have experienced. This too, is part of the suffering that we find as we face our dying.

We believe that suffering has value to the extent that it allows the individual to be open to Jesus Christ and experience the grace of a life transformed by the power of Christ even when, physically, that life is ending. Such suffering is salvific, for the person experiences the love of Christ in a way that recalls Christ's own love as demonstrated in his willing acceptance of death on the cross. There are those who would twist our Catholic appreciation of suffering into a peculiar glorification of pain. This is nonsense and a perverted caricature. Being in pain is useless. Uniting one's suffering with Christ is redemptive. This is part of our faith and a great truth that should not be lost.

Who Controls Our Death and Dying?

When we talk about the end of life, we face our limits: not only limits on our human lifespan, but limits on our knowledge, limits on our ability to understand our world and ourselves, our partial apprehension of the truth, and our fragmentary sense of what it means to be human. Acknowledging limitations and recognizing that we are unable to control all the aspects of our lives is not well accepted in our society. We are urged to be

in charge, to control our destiny, and to reject anything that limits our independence and mastery.

Our Catholic faith transcends any culture. In the face of a culture that asserts individual autonomy and the ability of individuals to control all aspects of life, we worship one who, as St. Paul writes: "though he was in the form of God, did not regard equality with God as something to be grasped. Rather, he emptied himself, taking the form of a slave, coming in human likeness; and found human in appearance, he humbled himself, becoming obedient to death, even death on a cross." (Phil 2:6-8).

As disciples of Jesus, the one who accepted the limitations of being human, we believe that there is a more excellent way to face the end of life than individualism, isolation, assisted suicide, and euthanasia.

Building a civilization of love amidst our current American culture of death will require many things. Most of all, building a civilization of love means we look to Jesus as our model of what it means to be human. St. Ignatius of Loyola, in a contemplation that encourages individuals to experience the depths of God's love, makes the telling observation that love is shown more in deeds than in words. How are we, as Catholics, showing our love for those who face the end of life?

A love shown in deeds, rather than just pious slogans, requires a major effort on the part of Catholic health care facilities, Catholic health care providers, Catholic social services, and our parishes, as well as a renewed recognition among all people that Christ's death brings with it the power to transform our own dying. There is an urgent need for marked improvements and rigorous standards in care for the dying. Individual Catholics, through prayer, service, and the development of prudent advance directives, can witness to the power of our faith in the resurrection. Parishes must consider how best to serve those who face the end of life, whether by special parish initiatives or by partnering with local Catholic hospitals. As citizens dedicated to the common good, we must continue to challenge our political system to provide universal access to basic health care.

We ask you to work with us to build a civilization of love that cares for the dying with the dignity and respect they deserve.

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