

A Guide to End-of-Life Care Decisions

A Brief Ethical Primer
on Medical Decisions
Regarding Life-Sustaining
Treatments
in the Catholic Tradition

A Supplement to "Health Care Directives: A Catholic Perspective"
FROM THE CATHOLIC BISHOPS OF MINNESOTA



Thank you to Fr. Tom Knoblach from whose work this guide was developed; the members of the MCC Life, Family, and Health Care Committee, and the National Catholic Bioethics Center for their edits and suggestions.

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LIFE IS A GIFT FROM GOD

The Catholic tradition acknowledges that life is a gift from God, our Creator. Indeed, human life is the foundation for the enjoyment of all other goods in this life. Further, God made the human person in His image and calls us to eternal life. Thus, the inviolable dignity of each individual human life, made in the image of God, is the basis of all other Catholic moral teachings.

Christ Reveals the Meaning of Our Lives

Because of the Incarnation, Christ shares fully in our life and therefore transforms every moment of human life, from conception to death. The saving work of Jesus does not eliminate suffering and death from the human condition. To the eyes of faith, however, He transforms their very meaning. We can join our own sufferings to those of Christ and share in His saving sacrifice in a profound way. When we complete the course of our earthly pilgrimage in God's sight, we can embrace death according to God's will as a passage to new life.

Medicine and Stewardship of the Gift of Life

Contributions of medicine and technology are an important part of our stewardship of the gift of life and our care for God's creation. Yet health care is not an end in itself. We assess the value of life-sustaining treatments in light of their impact on the individual human person, in his or her specific circumstances. It is true that we are responsible to reasonably preserve life and health in this world. At the same time, we also acknowledge the limitations of medicine and the fact that God calls us to eternal life and wholeness with Him.

The Middle Ground Between Euthanasia and an Overreliance on Technology

God's gift of human life is the foundation for all His other gifts. The most basic right of each person includes the right to preserve his or her life. When professional medical care is needed, we should consent to the reasonable use of appropriate medical care and treatment out of respect for our God-given dignity and the sanctity of life, and also so that we can meet our duties to God, our loved ones, and all who depend on us. When patients consent to medical interventions, they expect a cure, improvement, comfort, or life-sustaining help, but this does not mean that all such beneficial treatments are morally obligatory.

Why Dying Can Be More Difficult Today

In some ways, dying is more difficult today than in the past for several reasons:

1) Although the advances in medical technology allow improved quality of life and longevity for many, they also create new ethical challenges. We are now able to sustain life by means of technology not available to previous generations. ***But simply because we can prolong life does not necessarily mean that we must or that we ought to do so.*** These advances can make it difficult to determine when death occurs. They blur the lines of ordinary care and extraordinary technological interventions and raise questions about the allocation of limited medical resources.

2) Although death was once a familiar part of the life cycle, many people now tend to expect that the remarkable progress in medicine implies that they can avoid experiencing suffering and even death. Further, our culture inevitably marginalizes persons who are chronically ill, elderly, disabled, or dying because we exalt youth, vitality, productivity, and individual choice. Additionally, people tend to move more often, the population is aging, and patients often see a wide variety of health care providers rather than their “family doctor.” Thus, death can become a threat to

avoid whenever possible or “control” when it is no longer possible to avoid. Suffering, disability, and loss seem to be meaningless experiences for many and, increasingly, some propose assisted suicide and euthanasia as a reasonable solution to escape such meaningfulness.

3) Despite many advances in high-technology medicine, inadequate management of pain and other discomfort that may accompany dying remains a concern. In fact, this fear of uncontrolled suffering is part of the drive to legalize assisted suicide and euthanasia.



Euthanasia: A False Mercy



Euthanasia literally means “good death.” Among the ancient Greeks, the term was descriptive, referring to the happy circumstance of dying after a long and full life, surrounded by family and friends, and free from pain and suffering – an ideal scenario for life’s end. In recent years, however, some use this term to refer to the active ending of life to alleviate physical and/or psychological suffering. The Church defines the term: “by euthanasia is understood an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated” (Congregation for the Doctrine of the Faith, Declaration on Euthanasia *Jura et Bona* [May 5, 1980], n. 2).

Sometimes, people call euthanasia “mercy killing.” It seems preferable—an act of “mercy”—to avoid

suffering when possible, even by causing death, rather than to endure pain, despair, and a sense of being a burden to others. Assisted suicide is simply one form of euthanasia in which the patient directly ends his or her own life rather than indirectly by the action of another person.

The Catholic tradition, however, rejects euthanasia, whether inflicted by self or by others, as a false mercy. We agree fully that suffering is an evil to avoid when possible and we support pain and symptom management to alleviate physical discomfort and psychological distress. In fact, the Catholic tradition supports the palliation of pain by medications, even when this may hasten the person's death, as long as this effect is merely foreseen but not directly intended. The effects of original sin mar our world and limit our ability to prevent suffering. But directly acting to end a person's life is not the moral means to alleviate suffering.



Sickness and Death Affect the Whole Person

Although “death” is an event (a particular moment in which the soul leaves the body and earthly life ends), “dying” is often a process that extends over a period of time. This process of dying (especially in a prolonged illness) usually involves suffering at all levels of the person:

- *Physical*
- *Emotional/Psychological*
- *Relational/Social*
- *Spiritual*

Physical – Properly used, medicines for pain management are extremely effective. The Church teaches that the use of such pain relievers is completely acceptable, even if their use may cause unconsciousness or even hasten death, as long as the intention in using the medications is

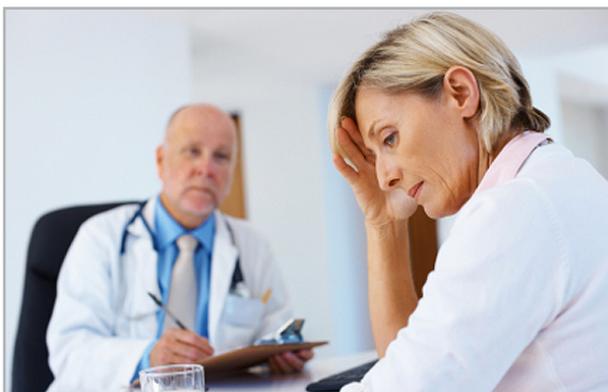


solely to alleviate pain and not directly cause death. Palliative care provides a wide range of medicines and techniques to control suffering, pain, and other symptoms accompanying serious illness. No one need suffer unbearably.

In addition, all care that would normally be given to patients is to be given to those who are terminally ill, dying, advanced in age, suffering from forms of dementia, or in the “persistent vegetative state.” We distinguish between **therapeutic** interventions, which intend to cure or heal an existing disease, and **palliative** means or interventions, which aim at providing comfort and alleviating suffering. Even when a cure is not possible, we are still obliged to offer comfort and normal care.

Emotional/Psychological – It is natural and normal for a person in severe illness, advanced age, or other situations approaching death, to experience a range of emotions including

disbelief, fear, regret, anxiety, sadness, anger, depression, and—on the other hand—eventual acceptance and peace. Sincere and empathetic listening,



the presence of family and friends, and gentle and understanding interactions by health care professionals will all help to alleviate the person’s emotional distress; these measures remind the person (and all those present) of his or her value as a unique person of infinite worth and dignity.



Relational/Social – The dying person may encounter isolation, loneliness, and inevitable changes in relationships with the need to bring closure and say good-bye to loved ones. The presence of family and friends is very important in times of illness, and especially as death nears. The dying person often experiences great comfort when loved ones surround him or her, even if he or she cannot consciously respond to them. Being present is also important for the family members and friends themselves, so that they may say their good-byes and come to acceptance and closure. Sometimes, there may be a need for reconciliation and forgiveness so that the person can die with peace of mind and spirit.

Spiritual – The mystery of death naturally opens us to the transcendent dimensions of human life. Yet this mystery can also cause a crisis of faith as it tests one's trust in God and hope for eternal life. The dying person should have the opportunity to visit representatives of his or her own faith community. Catholic patients should be strengthened in this final stage of life with pastoral care and the sacraments of Reconciliation, Anointing of the Sick, and the Eucharist (if they are able to receive Communion).



Medical Science and Accepting Death

There is a time in each life when we exhaust all reasonable possibilities of forestalling death. The Catholic tradition does not require prolonging earthly life in every possible way or at all costs. Such a position would be contrary to human dignity, moral intuition, and the will of God. ***When further efforts at sustaining earthly life are ineffective or unduly burdensome without providing reasonable hope of benefit, such efforts or interventions may be forgone or withdrawn if already in use.***

Accepting the limits of medical science and human efforts to forestall death is not a failure of faith or charity; in fact, it is an expression of faith and a commitment to accompanying the person through the final stages of his or her earthly pilgrimage.



When the time of death nears, our commitment to healing and care does not end, but it takes a different form: we turn our attention from efforts at restoring health and function toward maintaining comfort

and preparing for death. This time is unique to each person in his or her specific case, and a variety of factors and voices must come into play to discern it. Determining when this time has come can be difficult. The complexity of some cases, from medical and moral standpoints, can blur the line between a morally justified "allowing to die" and a morally repugnant "causing death" in the minds of those involved. The simplest criterion for drawing this line correctly is to honestly answer this question: ***"What will cause this death?"*** Is it the underlying pathology or injury which resists all reasonable efforts to cure or manage? If yes, then we are allowing the person to die by forgoing futile or excessively burdensome interventions. Or, on the other hand, would the action or omission taken cause death intentionally, without which action or omission life would continue for the present? If yes, then it is euthanasia.





Ordinary and Extraordinary Means

The tradition of the Church and the consensus of the medical community have long distinguished between ordinary means and extraordinary means to sustain life. Sometimes people use other terms for this distinction. One may see a discussion of “proportionate” and “disproportionate” means, emphasizing the difference between the expected benefit and the burdens incurred. **Proportionate means** are those that offer a reasonable hope of benefit and do not entail an excessive burden to the patient—that is, they do not impose serious risk, excessive pain, prohibitive cost, or some other extreme burden.

Sometimes people use the terms “ethically obligatory” and “ethically optional” to emphasize that evaluating the possible medical options is not merely a medical assessment but has an ethical component.

Whatever the terms used to make the distinction, the Catholic tradition holds that one is morally obliged to use ordinary means to preserve life. It is permitted, but not obligatory, to use extraordinary means.

Although this teaching is quite straightforward at the theoretical level, it can become quite difficult in actual cases to determine what is ordinary and to be done, and what is extraordinary and therefore not required. As noted above, advances in medical technology, changes in health care delivery, and other factors have made it increasingly complicated to draw a clear line between the ordinary and the extraordinary.

Assessing Ordinary and Extraordinary: PREHAB

Useful criteria for determining whether proposed interventions are ordinary or extraordinary include consideration of the following factors: Patient Preferences; Risk; Expense; Hope; Availability; and Benefits/Burdens. **The acronym PREHAB may help to remember these factors.**

Patient Preferences: Patient autonomy is an important value in health care ethics, rooted in the same commitments to responsibility and moral freedom as the need for informed consent for treatment. The competent patient has the primary say in what will or will not be done.

Health care providers, for their part, are normally obliged to follow the patient's wishes, if they are not contrary to law or the ethical obligations of the institution rendering care. Likewise, each patient is obliged to make medical decisions following these same criteria, including the responsibility to take reasonable measures to preserve life and health.

When the person becomes incapable of choosing due to unconsciousness or lack of capacity, family members or other proxy decision-makers enter the process. It is a great help in such instances to have an advance directive for health care decisions in place, which indicates the person's wishes so that other decision-makers will clearly know them. More information on advance directives is found on pages 23-27.

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Risk: When an intervention is still experimental, or when there is a danger in using the intervention for this particular person, there is risk involved. Any medical procedure entails some risk. We must, therefore, weigh the risks against the potential benefits in each circumstance.

Expense: This factor can relate to absolute or relative financial terms. Given contemporary concerns about rising medical costs and limited resources, it is important to assess expense carefully. Although expense can be a factor in determining whether an intervention is extraordinary or not, it is not the sole factor; the person's innate right to life takes precedence over costs. But expense may be a factor for consideration in the decision when risk or burden are high and hope of benefit is low.

Hope: This refers to the reasonable expectation that an intervention will have its intended benefits. This does not always mean hope of complete recovery or a return to full health and function. In some cases, such recovery is no longer possible, but we can still enhance the person's quality of life. We should calibrate our expectations based on a particular treatment's likelihood of bringing about its goal, as well as its overall effect on the well-being of the patient.

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Availability: This refers to access to a certain intervention for this person, here and now. For instance, if a person could only have access to a surgery through a hospital which is distant, but the required transport would present a grave risk, then such a surgery may be “unavailable” and thus extraordinary for that person, even if it is routinely done in the other hospital. Or, in situations of epidemic, when there is an overwhelming demand for the required equipment or personnel, those interventions may be “unavailable” in practical terms. In addition, as a general moral principle, the factor of availability reminds us that there are many places in our world where people do not have access even to the routine and minimal resources that we take for granted.

Benefits/Burdens: This is the core factor in determining whether a proposed intervention is ordinary or extraordinary. It refers to a “weighing” of the proposed intervention in terms of the expected benefits to the patient in relation to the burdens the patient would endure.

These benefits and burdens refer primarily to the effects of the intervention on the patient. We should consider secondarily and subordinately the benefits and burdens on the person’s family, caregivers, health care professionals, and society

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as a whole. Always at the center of the consideration is the patient, whose good we should not place in competition with other factors.

We should consider benefits and burdens holistically: that is, they include not only physical factors, but also emotional/psychological, relational/social, and spiritual effects. When the burdens genuinely outweigh the expected benefits foreseen, the intervention is extraordinary and may be legitimately forgone. Whenever the person is capable (sometimes termed "legally capable"), he or she has the right and responsibility to make this informed judgment. Sometimes, however, the person is not capable of making this decision due to unconsciousness, dementia, or some other factor. In such cases, proxy-decision makers and health care professionals dialogue together so that a reasonable decision can be made for the patient based on any known previously-expressed wishes of the patient and/or the patient's best interests.

It is well to emphasize again that we must discern ordinary and extraordinary means on a case-by-case basis. It is unique to each individual in the concrete circumstances of the moment. We should reassess the means regularly as time passes and the patient's status changes.

Withholding vs. Withdrawing Life-Sustaining Interventions

From an ethical standpoint, if we observe the above criteria, there is no moral difference between withholding an intervention and withdrawing one already in use. In either case, we discern whether the means in question are extraordinary and therefore ethically optional.

But it can be far more difficult emotionally to withdraw a means currently in use. Since death may result when the means is discontinued, it can seem like the decision to withdraw is the direct cause of death. Yet, if the discernment is correct, it is the underlying pathology that causes death; the withdrawal of means simply allows that pathology to take its natural course, no longer using technological means to forestall death.

Withholding a means can seem less dramatic, but it, in fact, takes greater moral certitude because we must determine whether the proposed means would be extraordinary. When withdrawing a means in use, there must be some evidence that the means is ineffective or excessively burdensome; withholding a means relies on speculation that it would be ineffective or burdensome. Nonetheless, we can ethically discern this according to the above criteria with due diligence in assessing the medical facts and likely outcomes.

MORAL CERTITUDE

It is crucially important to realize ethical decisions about weighty matters such as these are very complex and often uncertain. As the great Greek philosopher Aristotle noted over four centuries before Christ: "It is wisdom to expect no more certitude than the subject matter allows." Saint Thomas Aquinas noted the same reality: that we can have certitude at the level of principles, but the more we deal with specific cases, the greater the uncertainty we encounter. For this reason, the Catholic tradition does not require "absolute certitude"—the kind of logical necessity we find in mathematics, for instance—about such complex decisions in the face of the mystery of death. This is because we may not be able to come up with a completely satisfying, logically compelling argument about the course of action we choose to take; people of equally good will may differ in opinion; and we may have to deal with ambiguity and probabilities rather than clear guarantees.

The Church does require, however, that we have "moral certitude." We achieve this kind of certitude in dialogue with others. First, we listen to all the facts of the situation, including:

- The medical diagnosis and prognosis;
- The possible alternatives for treatment;
- The risks and benefits of each;
- The economic, psychological, and social costs foreseen with each; and
- The expressed wishes and preferences of the person.

MORAL CERTITUDE

We assess these facts without prejudice or bias and weigh them carefully in light of the accumulated wisdom found in the teachings of our faith. We take time to listen carefully to the voice of our conscience and seek God's will in sincere prayer. We consult with others who have special expertise in the various aspects of the question, and who can help us with honest discernment. Then, we reach a decision that we believe sincerely to be right in this specific case. These decisions are an exercise of the virtue of prudence; thus, they are sometimes known as "prudential judgments."



ADVANCE DIRECTIVES

Although people may express their preferences about care and treatment verbally, the law generally defines an advance directive as a written document an individual prepares to instruct health care professionals and family members about his or her health care preferences in case he or she is unable to communicate them at a decisive time. Advance directives are an extension of the legitimate right to direct one's own health care and to exercise one's responsibility and stewardship for the gifts of life and health. The Church supports advance directives as long as they direct care in accord with Catholic principles.

Since 1990, each health care facility that receives federal funds is obliged to ask a patient upon admission if the person has an advance directive, and, if not, if he or she would like to prepare one. No one may be denied services or given a different level of care if an advance directive is absent, nor is a person required to have one.

Advance directives took two general forms over the years, commonly called the "living will" and the "durable power of attorney for health care" (DPAHC). The living will was an earlier form of advance directive that attempted to be specific about interventions, spelling out particular conditions and technologies that a person would or would not desire in those conditions. Living wills have often proved ineffective in practice because they were

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made out well in advance of actual need, and it was impossible to predict one's precise medical situation, and how future circumstances and technological developments might affect one's preferences.

The DPAHC was developed to address these concerns. In the DPAHC, the person appoints a proxy decision-maker or "health care agent" (and usually an alternate if the first person is not available when need arises) to make health care decisions in his or her stead. This power of attorney for health care operates only if the patient is not able to make their own decisions; the agent can never override a capable person's wishes. Further, the agent advocates for the person's ongoing care needs, rather than only in situations of imminent death. The agent must make a sincere effort to give truly informed consent and to speak on behalf of the patient's best interests as the patient would view them. We presume that the patient clearly expressed his or her values and preferences to the agent before the agent must decide.

This durable power of attorney gives authority only for health care decisions (it does not grant the agent any power over the person's other legal or financial matters). The DPAHC formalizes what usually happens in the absence of any advance directive: those closest to the patient make decisions. More recently, other forms of advance directives combine features of these two approaches. They

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allow both the appointment of a health care agent to speak on one's behalf, and the indication of treatment preferences. Because there is such a variety of forms, those making an advance directive must read them carefully and seek expert advice, if necessary, to ensure that the form used accurately expresses the person's wishes and ethical commitments. **We encourage Catholics to use the Minnesota Catholic Health Care Directive, which is online at www.MNCatholic.org.** This form meets Minnesota legal guidelines for advance directives, provides a health care declaration consistent with Catholic teaching, and allows one to select a health care agent.

Among the issues the person should discuss with the health care agent is his or her preference regarding:

- cardio-pulmonary resuscitation (CPR);
- having a "do not resuscitate" order (DNR);
- the use of antibiotics to treat infections;
- surgery;
- hospitalization;
- medically-assisted nutrition and hydration;
- pain management strategies;
- continuing dialysis or other interventions or medications the person may be using;
- hospice and palliative care wishes; and
- desires for spiritual care.

Anyone can make an advance directive, and it does not require the services of an attorney. A person

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can revoke an advance directive at any time. One should file copies of the advance directive with one's primary physician, with one's health care agent, and perhaps with other family members; the goal is to make them readily available for consultation should the need arise.

Advance directives always require interpretation and application to the concrete specifics of each situation. Therefore, the most important factor in honoring a person's wishes is for those close to that person to discuss with him or her the person's preferences and values, so that the health care agent can speak with confidence and have access to current medical information about the person's condition, prognosis, and treatment options. This is why the appointment of an agent is always preferable to a mere list of treatments.

For more information about advance directives, please review the companion booklet to this guide, entitled "Health Care Directives: A Catholic Perspective," which includes the Minnesota Catholic Health Care Directive. It can be ordered or downloaded at:
www.MNCatholic.org/healthcaredirective

More recently, a document called POLST has been proposed to ensure that patient wishes are honored at the end of life. POLST stands for "Provider Orders

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for Life Sustaining Treatment.” Although the goal of honoring patient wishes and improving end of life care is laudable, there are some ethical concerns with informed consent and sufficient attention to detail and the current situation of a patient with a POLST form that need clarification. ***The bishops of Minnesota discourage the use of POLST for Catholic facilities and patients and encourage instead the careful dialogue with providers and the appointment of a health care agent as outlined above.*** Should a care facility mandate a POLST, the National Catholic Bioethics Center provides guidance for completing POLST forms consistent with Catholic teaching. The resource is available from both NCBC and at www.MNCatholic.org/healthcaredirective.



What If I Still Have Questions?

Of course, a guide like this is not meant to answer every question and give direction in specific situations. Patients and families should feel free to ask questions to health care providers, social workers, chaplains, and other appropriate staff in hospitals or long-term care facilities. Most facilities have an ethics committee or a similar resource that can help to address concerns and foster communication, so the health care agent can make the best decisions for the good of the person. Pastors, or other trusted persons familiar with Catholic moral teaching, can address questions that arise about Catholic doctrine.

If one encounters a difficult ethical question regarding one's own health care or the health care of another person for which you are responsible, the National Catholic Bioethics Center provides free consultation services. Consultations offer counsel related to the Church's teaching on bioethical issues and guidance in moral decision-making. **One can submit a consultation request by emailing Consults@NCBCenter.org. In emergency situations, an NCBC ethicist is available 24 hours a day, seven days a week by calling 215-877-2660. NCBC ethicists do not provide legal or medical advice.**

Conclusion

In dialogue with physicians, nurses, other health care professionals, ethics committees, family members, and other concerned persons, we can consider proposals for life-sustaining treatment in light of these criteria to determine whether they are, in the specific circumstances of this patient, ordinary and thus required, or extraordinary and thus allowed but not necessary. The goal of this discernment is always to do what we judge is best for the person who faces the mystery of death, and whom God calls to eternal life with Himself.

Further Reading

Evangelium Vitae (The Gospel of Life): On the Value and Inviolability of Human Life, Saint John Paul II, 1995; www.vatican.va/holy_father/john_paul_ii/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae_en.html.

Ethical and Religious Directives for Catholic Health Care Services, 5th Edition, United States Conference of Catholic Bishops, November 17, 2009; available at <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>.

"To Live Each Day With Dignity," a Statement on Physician-assisted Suicide, United States Conference of Catholic Bishops, June 16, 2011; www.usccb.org/issues-and-action/human-life-and-dignity/assisted-suicide/to-live-each-day/.

"Vatican Declaration on Euthanasia," Congregation for the Doctrine of the Faith, May 5, 1980; www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html.

This brochure is published by the bishops of Minnesota to provide guidance and support to Catholics as they consider important issues related to end-of-life decision-making for themselves and loved ones.

The information in this brochure should not be considered legal advice.

Published December 2018

Revised December 2022



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