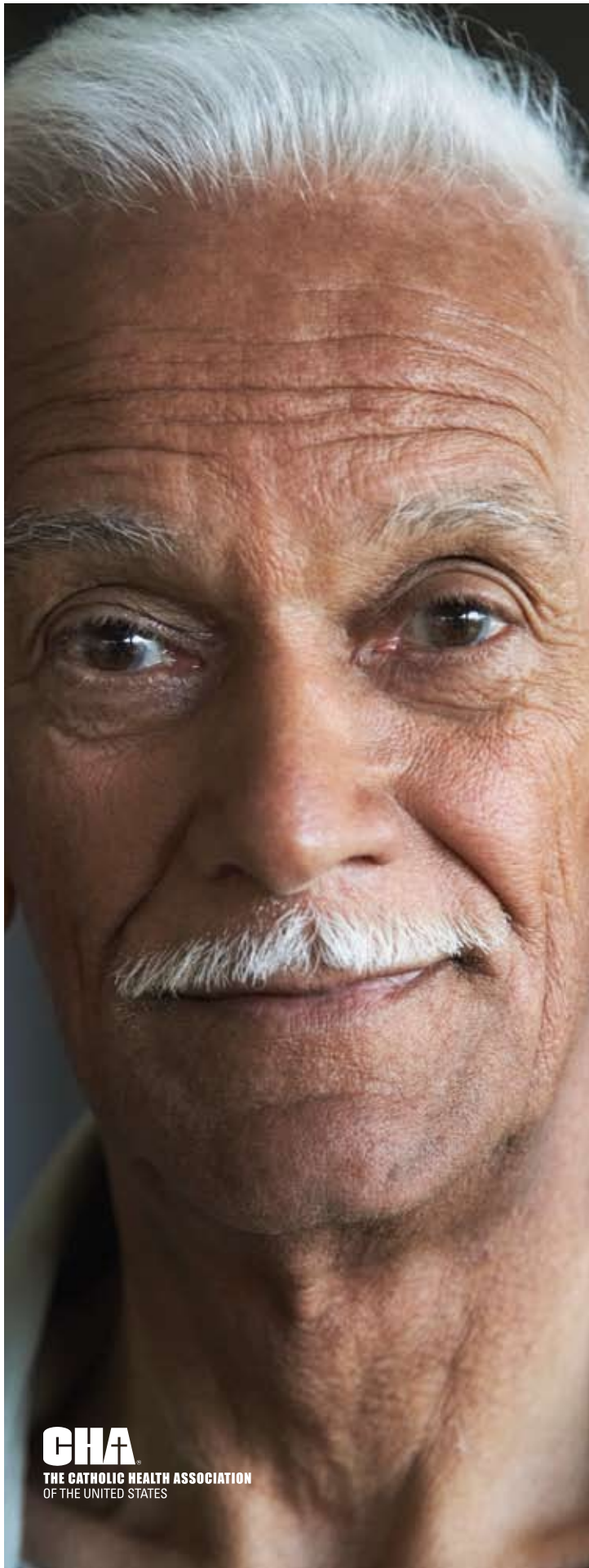


Advance Directives:

A Guide To Help You Express Your Health Care Wishes





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Many of us have journeyed with a family member, friend, or acquaintance during their dying and eventual death. We know first hand the anxiety, the anguish, and the sense of loss, as well as the moments of grace that so often mark this journey. We may also be only too familiar with the difficult and heart-wrenching decisions that often need to be made on behalf of a dying loved one. At times, the struggle over these decisions can distract us from even more important issues associated with a loved one's dying, for example, healing fractured relationships, attending to the person's discomfort, pain, and suffering, as well as to his or her spiritual needs, and saying good-bye.

Modern medical technology can often work wonders to bring about cures, slow a disease process, or alleviate symptoms of diseases or disabilities. But at times, this same technology can pose the most agonizing decisions to patients and their families about their use in sustaining the dying person's life. Medical technology sometimes merely prolongs the dying process or burdens the person without offering many, if any, benefits.

These difficult decisions about the use of medical technology are made even more difficult if the individual has not expressed and can no longer express his or her wishes about the use of particular medical interventions. In these situations, loved ones have to make these tough, sometimes heart-wrenching, decisions without input or guidance from the dying person. Family members might disagree about what should be done and who should decide, creating even more stress and conflict for them and for caregivers. If physicians disagree with the family because they are unsure about the patient's wishes or fear a lawsuit, the situation becomes even more complicated and unpleasant.

To help prevent these difficulties, Congress passed the *Patient Self-Determination Act* in 1991. The law affirms the right of patients and long-term care residents to make decisions about their own health care, to accept or refuse medical treatment, and to make an advance health care directive.

The law requires health care facilities to discuss advance health care directives with patients and residents when they are admitted to the hospital or long term care facility, or soon thereafter. Health care personnel must tell the person about their right to make their own medical decisions, find out if they have an advance health care directive, and ask whether they want to prepare a directive if they don't yet have one.

The best time to create an advance health care directive is before entering a hospital

or nursing home or becoming seriously ill, so that one can consider one's options carefully. This gives the individual time to ask questions and get information. Also, if the person wishes, he or she can name a trusted individual (a "surrogate") to make decisions for him or her in the event he or she is no longer able to do so.

Having an advance health care directive provides some peace of mind to individuals and their families by making it more likely that the patient's or resident's wishes will be carried out if he or she becomes unable to express them personally.

This guide is meant to help you in thinking about and preparing an advance health care directive. While it is written from the perspective of the Catholic tradition, most of what is said here is applicable to persons from any religious tradition.

Here are some questions and answers to provide you with information about advance health care directives and to help you begin thinking about preparing one for yourself.





Why should I be concerned about having an advance health care directive?

An advance health care directive allows you to exercise your right and responsibility to participate in decisions about your health care by making your wishes about medical care known in advance.

Having an advance health care directive **reassures your family**, loved ones and health care providers that they are honoring your wishes and values when you cannot express your desires or are unable to make decisions for yourself.

What is an advance health care directive?

An advance health care directive is a written declaration, made in advance of life-threatening illness or injury or age-related decline, about how your medical care should be handled if you are unable to make your own decisions.

In general, the document should be in writing, signed and appropriately witnessed.

What is the Catholic Church’s position on advance health care directives?

The church has not spoken directly on advance directives, but it has affirmed a patient’s right to make his or her own health care decisions. The 1980 Vatican *Declaration on Euthanasia* recognizes the patient’s right to make decisions about withholding or withdrawing treatment (excluding physician-assisted suicide and euthanasia) in collaboration with family members and physicians. So does the *Catechism of the Catholic Church* which states: “The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected” (#2278).

In addition, *The Ethical and Religious Directives for Catholic Health Care Services* (ERDs), a document issued by the United States Conference of Catholic Bishops that guides the practice of Catholic health care organizations, recognizes the right to execute an advance directive and appoint a surrogate decision maker (Directives 24 and 25). The ERDs also state that a person’s advance directive should be followed so long as it does not request anything contrary to church teaching (such as physician-assisted suicide).

Are there different types of advance health care directives?

There are two basic types of advance health care directive: Durable Power of Attorney for Health Care, and Living Will.



The **Durable Power of Attorney for Health Care** is a written document in which you name a trusted person to make health care decisions on your behalf if you become unable to do so for any reason. The person you select is usually called your “agent,” “health care surrogate,” or “proxy decision maker.”

This person can accept or refuse any type of medical treatment or procedure just as you would if you could make these decisions yourself. It is vital that the person you select know you, your health care wishes, and your values very well, so that he/she can make decisions at your time of need in accordance with your wishes and beliefs.

A **living will** is a written document that allows you to state in advance your preferences for treatment or non-treatment in the event you are nearing the end of life and are unable to make these decisions for yourself. The key focus is on treatments, or the withdrawal of treatments, especially life sustaining treatments, that you may or may not want to have in life-threatening situations that might arise in the future.

One shortcoming of a living will is that you are requesting or refusing a particular medical intervention(s) when you prepare the document without knowing what your actual medical condition might be in the future.

Which is better—a durable power of attorney for health care or a living will?

It’s best to have both documents—a durable power of attorney for health care and a living will—to cover both actual and possible future events. Forms for the durable power of attorney for health care often include a section for a living will so it’s easy to access information for both documents.





What should I do if I want a durable power of attorney for health care?

Here are some steps to help you prepare a durable power of attorney for health care. Keep in mind, however, that, although the focus in preparing a durable power of attorney for health care tends to be on completing the form, **the most important element is actually the conversations you have** both in preparing the form and in communicating what you have decided not only about treatment preferences, but also about your personal life goals, values, beliefs, and how you want to live while dying.

1. You can obtain a blank durable power of attorney form from an attorney, your state bar association, the Catholic Conference of your state, your local library or online from your state bar association and a variety of other organizations. Hospitals, nursing homes, home health agencies, and hospices also tend to have them. Review the form carefully. Contact your physician, clergy person, attorney or trusted friend if you have any questions. It is not required to engage the services of an attorney in order to prepare a durable power of attorney or a living will.

2. Determine who will be your surrogate, the person who will speak on your behalf if you are unable to. Whether a relative or friend, be sure the person you select knows you very well, including your values, your religious or spiritual beliefs, and activities and experiences that are important to you. Ask that person if he or she is willing to be your surrogate decision maker and whether he or she would be willing to carry out your treatment wishes.

3. Think about what medical treatments or interventions you might want or not want if you become permanently unconscious, terminally ill, have a medical condition or injury that requires you to be on life-support treatment for the rest of your life, or are advanced in age. It is highly recommended to discuss this with a loved one, friends, or other trusted individuals. If you are currently ill, it would be wise to speak with your physician. In addition to medical considerations, you will want to reflect on what is important to you in life, your personality, spiritual or religious beliefs, and the moral teachings of your religious denomination.

4. Discuss your choices with your surrogate and others who might be involved with your future medical care. Preparing an advance health care directive is a good opportunity to communicate your values, beliefs, and what's most important to you with people you care about and who will likely be involved in your health care. It is important for your surrogate, your family, and your doctor to know and understand your wishes.

5. Give copies of your advance directive to your surrogate and your physician(s). Keep a copy for yourself in an easily accessible place. You may also want to give copies to family members, your attorney and clergy.

What is my health care surrogate permitted to do?

You can authorize your health care surrogate to make decisions for you about accepting or refusing any medical treatments just as you would if you were able to make decisions. This includes decisions about an autopsy, organ donation, and disposal of your body if the document provides your health care surrogate with the authority to do so.

In turn, your surrogate is responsible for making health care decisions based on your expressed wishes, values, or beliefs, or what he or she determines is in your "best interest." For this reason, it is critical that you communicate your wishes and beliefs to your surrogate and provide him/her with a copy of your durable power of attorney for health care. If you wish, you may limit your surrogate's powers by specifying what he/she cannot do on your behalf (for example, withdraw a feeding tube).

When can my health care surrogate make decisions for me?

Your surrogate is permitted to make health care decisions for you only when your physician determines you are no longer able to make your own decisions or are unable to communicate your wishes.

What if I change my mind about my durable power of attorney?

You may change your durable power of attorney at any time, including selecting a different surrogate or changing your treatment wishes. You may also revoke your directive by destroying the document, or preparing a new written document. If you make any changes to your directive, be sure to inform your physician, attorney if applicable, and your surrogate, and preferably provide them with copies of the new, clearly dated version. The most recent version of your durable power of attorney for health care will trump any earlier versions.

Must health care providers follow my advance health care directive?

In general, health care providers should follow your advance health care directive as long as it has been properly prepared according to local and state laws. However, the provider does not have to follow an advance health care directive that is contrary to the religious beliefs or sincerely held moral convictions of the health care organization. For example, a Catholic health care provider will not perform euthanasia or physician-assisted suicide because they are contrary to Catholic teaching. A provider also does not need to follow a directive that asks for inappropriate or non-beneficial treatment that would offer little or no benefit to you.

Can state laws put any limits on carrying out what I express in my advance health care directive or on the decisions that my surrogate can make?

There are differences among state laws regarding advance health care directives. Most states do have some restrictions on the choices you or your surrogate can make. It is highly advisable that you check the law in your state. You can do this by contacting a lawyer, the local legal aid office, state bar association, or your state Catholic conference. It is also likely that you will find this information on the internet.





How should I decide what medical treatments I want or don't want?

There is **no ready made answer** that applies to all situations. However, there are some important things to keep in mind as you think about preparing an advance directive for health care.

1. What are your values and philosophy of life? Take time to reflect on your beliefs about life, suffering, and death. From a Catholic perspective, human life is a sacred gift from God. All persons, regardless of their medical or physical condition, possess inherent dignity and are worthy of our protection, care, and respect. Caring for human dignity and human life, however, does not mean that we must do everything possible to prolong physical life when death is inevitable. Catholics believe that death is a new beginning, a transition from this earthly life into eternal life. It is possible that a health care situation may arise in which an intervention or procedure is judged no longer to offer a hope of benefit to you or imposes burdens on you that outweigh any benefits.

2. What might be your future diagnosis and prognosis? Most people do not know what medical situations they will face in the future when they prepare their advance directive. Therefore, it is helpful to consider what types of treatments you would want or refuse if you are diagnosed with a terminal illness (an illness or disease that will eventually lead to death), or are close to death. Your decisions about treatment may vary depending on your diagnosis, whether you have a reasonable chance of recovery or have a terminal illness.

3. Is the treatment proportionate (ordinary) or disproportionate (extraordinary)? Catholic moral teaching says that all persons are obligated to use ordinary and proportionate means of preserving life. This means when a medical intervention

or procedure offers a reasonable hope of benefit to the patient in which the benefit outweighs the risks and/or burdens of the treatment (that is, the benefits are proportionate to the burdens), the patient should choose in favor of the medical intervention or procedure. Equally, patients may refuse a treatment or an extraordinary means of preserving life if it does not offer a reasonable hope of benefit or has risks or burdens that exceed any possible benefit (that is, the burdens are disproportionate to the benefits). For example, continued chemotherapy for an end-stage cancer patient may not offer any further benefit and may well impose considerable discomfort.

When you are assessing burdens and benefits, it is important to consider your total well-being as a person, and not just the benefits to a particular organ. In other words, some medical interventions may keep an organ system going, but are really not benefiting you as a whole person.

It is also important to consider whether the intervention itself is temporary and will help restore you to health or whether it is permanent and will do little or nothing to restore you to health or prevent death. For example, being on a machine that helps you breathe (a ventilator) for 2-3 days to recover from pneumonia is one thing. In this case, the technology is clearly beneficial, even though it may impose a temporary burden. Being on a breathing machine in the final stages of lung cancer may be something else. In this case, it could be that the breathing machine is prolonging the person's dying and/or is very burdensome for the patient.

In deciding which medical interventions to accept or decline, you will also want to consider the impact on you and your family emotionally, physically and financially.

4. What health care is available? What critical care interventions (medications, procedures, and mechanical means) will be realistically available to you at your local hospital or nursing home? Other factors to consider include your financial situation and health insurance.

Can I say in my advance health care directive that I don't want to be kept alive by a feeding tube?

You may request in your advance health care directive that you do not want to be kept alive with a feeding tube (often referred to as artificial nutrition and hydration) if you are terminally ill and the tube feeding is futile (that is, the body cannot absorb the nutrition), if the burdens of the tube feeding outweigh the benefits (that is, there are complications from the tube feeding such as lung infections and diarrhea), and/or if the tube feeding is merely prolonging your dying. In the rare event that you slip into a permanent vegetative state, and if you are in a Catholic hospital or nursing home, it is possible that the facility might not be able to honor your wishes and will need to arrange for your transfer to another facility.

If you are Catholic, it is advisable to discuss tube feeding with a clergy person or adviser who is familiar with recent church teaching regarding when it is permissible and not permissible to remove a feeding tube from someone in a permanent vegetative state.

Laws in some states do not permit removal of a feeding tube unless the patient or resident has explicitly stated his/her wishes. If you feel strongly about the use of a feeding tube when it is prolonging your dying or when the burdens of its use outweigh the benefits to you, you should state your wishes about this in your advance health care directive.

Decisions to discontinue tube feeding should never be made on the basis of a belief that the person's life has no value or to hasten the patient's death.

What about CPR (cardiopulmonary resuscitation)? If my heart stops, should I have to agree to have it re-started?

This is something you should discuss with your health care providers. For some individuals, it is beneficial; for others, it is not. It depends on your medical condition. CPR was first developed for people who suffer a sudden and unexpected cardiac or respiratory arrest, people who, for the most part, are healthy. It was not intended for people who have a life-threatening condition due to illness, injury, or advanced age. For many of these people, CPR is often not successful or leaves them worse off.



Many nursing homes require residents to express their wishes about CPR in a separate document, often referred to as a DNR (Do-Not-Resuscitate-Order).

What guidance does the Catholic Church offer for making these decisions?

The Catholic Church teaches that all life comes from God and that all human beings are created in the image and likeness of God. This gives human life its special meaning and an inherent dignity to human beings, regardless of their medical condition.

The church also teaches that life is a sacred trust over which we have been given stewardship. We are not owners of our lives, but caretakers. Hence, we have a duty to preserve our lives and do not have unlimited power over it.

For these reasons, the Catholic Church holds that it is immoral to intend one’s own or someone else’s death or to do something to bring death about. To deliberately bring death about is considered physician-assisted suicide if done by the patient or resident, and euthanasia if carried out by the physician.

Both physician assisted suicide and euthanasia are different, however, from withholding or withdrawing life-sustaining measures and other medical interventions because they no longer offer a reasonable hope of benefit to the person or have become excessively burdensome to him or her, preferably as judged by the individual. In these situations, there is recognition that medicine has reached its limits and it is time to allow the person to die from his or her disease, injury, or the effects of advanced age. Such decisions should be “considered as an acceptance of the human condition, or a wish to avoid the application of a medical procedure disproportionate to the results that can be expected, or a desire not to impose excessive expense on the family or the community” (*Declaration on Euthanasia*, Part IV, 1980).

Catholic teaching also recognizes that death is an inevitable part of life and is a transition to eternal life. The ultimate goal of human beings is everlasting communion with God. Hence, death should be accepted as part of the human condition and need not be delayed by all possible means.





Where can I go for more information about advance health care directives and end-of-life care for Catholics?

The following may be of assistance:

Christie, Dolores. *Last Rights: A Catholic Perspective on End-of-Life Decisions*. Lanham, MD.: Rowman & Littlefield Publishers, 2003.

Kelly, David. *Medical Care at the End of Life: A Catholic Perspective*. Washington, D.C.: Georgetown University Press, 2006.

Miller, Mark. *Making Health Care Decisions: A Catholic Guide to Advance Directives*. Liguori, MO; Liguori Publications, 2006.

Panicola, Michael. "Making Decisions About Medically Administered Nutrition and Hydration," *Making Health Care Decisions: A Catholic Guide*. Liguori, MO; Liguori Publications, 2006.

Sparks, Richard. "Making Decisions About End-of-Life Care," *Making Health Care Decisions: A Catholic Guide*. Liguori, MO; Liguori Publications, 2006.

For more help:

www.supportivecarecoalition.org

The Supportive Care Coalition consists of 18 Catholic health care organizations and seeks to promote palliative care throughout Catholic health care and beyond. Click on the “Resources” tab for information about advance directives and end-of-life decision making.

www.agingwithdignity.org

Aging with Dignity provides very useful information about planning for end-of-life care. In particular, they offer “Five Wishes,” a very popular advance directive form and process.

www.caringinfo.org

The website of Caring Connections contains much useful information about advance directives, including state specific forms.

www.practicalbioethics.org

“Caring Conversations” has been a hallmark of the Center for Practical Bioethics. A Caring Conversations Workbook is downloadable from the website. It includes a questionnaire to help one have “caring conversations,” an advance directive document, and frequently asked questions.

www.abanet.org

The website of the American Bar Association in its Public Resources section on Legal Topics contains a link for State Programs for Older Persons. The section contains useful information about advance directives.

Also check the websites of the Catholic conference of your state or of other states (e.g., search on the internet for “Wisconsin State Catholic Conference”). Many state Catholic conferences have their own advance directive form. Some even have a pastoral letter written by the bishops of the state.



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