

ADVANCE DIRECTIVES

# Expressing Your Health Care Wishes

*The Catholic Health Association has developed this guide in collaboration with physicians, nurses, theologians and ethicists within Catholic health care. It is based on frequently asked questions to help you think about end-of-life decisions and prepare an advance health care directive. Although the guide reflects the perspective of the Catholic tradition, the information is helpful to people from any religious tradition.*

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# Expressing Your Health Care Wishes

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Many of us have experienced serious illness or journeyed with a family member, loved one, or friend during serious illness and eventual death. We know first-hand the anxiety, anguish, and sense of loss that mark this journey — as well as some treasured moments of grace.

Modern medical technology has given us wonderful opportunities to bring about cures, slow the process of disease, and alleviate symptoms. This same technology, however, can sometimes create difficult decisions for patients and their families when it merely prolongs the dying process, becomes burdensome to the patient and no longer provides a benefit.

These decisions become even more difficult for others if you have not expressed your wishes about the use of particular treatments and are no longer able to express your wishes on your own. In these situations, loved ones have to make decisions on your behalf without your input or guidance. Without this guidance, loved ones may disagree about what should be done, creating additional stress and conflict at an already difficult time.

Struggling with tough decisions about continued use of medical technology can also distract us from equally important issues such as attending

to our loved one's pain, healing hurt or broken relationships, caring for the dying person's spiritual needs and eventually saying goodbye.

To help prevent such difficulties, in 1991 the U.S. Congress passed the *Patient Self-Determination Act*. The law affirms your right to make decisions about your health care, to accept or refuse medical treatment, and to complete an advance health care directive.

It also requires health care personnel to inform you about your right to make your own medical decisions, to inquire whether you have an advance health care directive, and, if not, to ask whether you want to create one. Creating an advance directive gives you an opportunity to discuss these issues with your loved ones. Too often conversations about end-of-life treatment are postponed until the patient is too sick to participate.

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*You also must be prepared,  
for at an hour you do not expect,  
the son of man will come.*

**LUKE 12:40**  
**NEW AMERICAN BIBLE**

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Completing this document as early as possible gives you time to ask questions, get reliable information, and consider your options. And if you are completing a durable power of attorney or similar document, this also allows you the time to decide whom you want to name as an agent or "surrogate" to make decisions for you in the event that you are unable to do so. Advance directives should be reviewed as you get older and can be changed at any time, as long as you are still able to make your own decisions.





An advance health care directive can provide some peace of mind to you and your family by making it more likely that your wishes will be carried out if and when you are unable to express them yourself. ♦

All adults should  
have an advance  
health care directive.

# What is an advance health care directive?

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An advance health care directive is a document that is written in advance of an illness, injury, or age-related decline in which you cannot make your treatment preferences known.

Only the person for whom the advance directive is intended is able to make an advance directive. The document provides direction regarding life-sustaining treatment if and when you are no longer able to speak for yourself, and, in the case of the durable power of attorney, allows you to indicate a specific person to make decisions when you are unable to do so yourself. Since an advance health care directive is a legal document, it needs to be signed and appropriately witnessed and/or notarized, depending upon your state's law.

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

An advance directive is a way to help your family and professional caregivers honor your choices concerning life-sustaining treatments when you are no longer able to speak for yourself. It provides you with the opportunity to give directions regarding the types of life-sustaining medical treatments you desire while you are still capable of doing so.

An advance health care directive can also help reassure your family, loved ones and health care providers that they are honoring your wishes and values. This supposes, of course, that you



have talked to your agent about your values and wishes. Preparing an advance directive gives you the opportunity to talk with your family, and especially your surrogate, about these important decisions and about how you want those decisions to be informed by your faith and your values. It offers families a chance to have an important conversation that family members may be reluctant to engage in. Simply signing an advance directive without this conversation about your values and wishes may actually cause more confusion to loved ones and care givers. ♦

# What are the different kinds of advance health care directives?

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There are two basic types of advance health care directives: **1. the living will** and **2. the durable power of attorney for health care**. Depending upon the state, both of these documents might be called by different names. Today they are often combined into a single document.

## **Living Will**

State legislation for the living will began in the mid-1970s. A living will is a legal, written document in which you state in advance your wishes regarding desired medical treatments in the event that you are unable to express them to your doctor or health care team. Despite the name, the living will is not really a will at all but rather a statement regarding the treatments, especially life-sustaining treatments, you want or do not want in life-threatening situations that might arise at a future time. A living will gives guidance to your family, friends, and physician regarding your values, religious and spiritual beliefs, and your health care wishes. A living will does not take effect as long as you are able to speak for yourself.



There are two related shortcomings of a living will:

1. When you prepare the document you are describing treatments that you are requesting or refusing without knowing what your actual medical condition will be in the future. Therefore, these statements are often rather general.
2. Due to the general nature of a living will, doctors often find this document, if used by itself, to be too vague regarding your wishes for medical treatment. Because of this, many states have combined the living will and the durable power of attorney for health care into a single document.

## Durable Power of Attorney for Health Care

For these and other reasons, state legislatures developed a second type of advance directive, **the durable power of attorney for health care**, in the 1990s. The durable power of attorney differs from the living will because it allows you to name a person who is able to make health care decisions on your behalf if you become unable to do so.

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 in your name just as you would if you could make these decisions yourself. The agent is not supposed to state what treatments he or she personally prefers, but rather *what he or she believes you would choose*. For this reason, it is important that the person you select *knows your values and your health care wishes* so that he or she can make appropriate decisions in accordance with your wishes and beliefs. If you do not have an advance directive, many states prioritize by law a list of people able to make these decisions for you. ♦

# What is the position of the Catholic Church regarding advance health care directives?

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The Catholic Church affirms a patient's right to make his or her own health care decisions. The Catechism of the Catholic Church explains that: "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.) One of the purposes of an advance directive, especially the durable power of attorney for health care, is to establish who is legally entitled to speak for the patient.

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*He will wipe every tear from their eyes, and there shall be no more death or mourning, wailing or pain, for the old order has passed away..*

**REVELATION 21:4**

NEW AMERICAN BIBLE

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As specific laws regarding advance directives differ from state to state, the Catholic bishops of the United States have not given a general endorsement of advance directives. The United States Conference of Catholic Bishops (usccb), however, has offered guidelines for advance directive legislation consistent with Catholic moral principles.<sup>†</sup> In addition, *The Ethical and Religious Directives for Catholic Health Care Services* (ERDs), a document issued by the usccb that guides the practice of Catholic hospitals and other Catholic health care organizations, recognizes a person's right to execute an advance health care directive and to appoint a surrogate decision maker (Directives 24-25.) The ERDs explain that a person's advance health care directive should be followed as long as the person does not request anything contrary to Catholic Church teaching (for example, physician-assisted suicide.) Furthermore, in their 1999 pastoral message, "The Blessings of Age," the U.S. Catholic bishops encouraged people to have an advance directive, noting that **"advance directives can help your loved ones know your wishes."** ♦

<sup>†</sup> See "Guidelines for Legislation on Life-Sustaining Treatment."

# How do I prepare a living will or durable power of attorney for health care? Do I need a lawyer?

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It is relatively simple to set up an advance directive.

## **1. Obtain the form.**

You can obtain a form for the living will or durable power of attorney from your state's Office of the Secretary of State, your state bar association, an attorney, the Catholic Conference of your state, or your local library. Forms are also available online. Hospitals, nursing homes, home health agencies, and hospices often have these forms readily available.

## **2. Read the form carefully.**

Contact your physician, clergy person, attorney or trusted friend if you have any questions. You do not need to engage the services of an attorney to prepare a durable power of attorney or a living will. However, each state has its own legal requirements to guarantee that the advance directive has been properly witnessed. Be sure to follow your state's requirements.

## **3. Carefully consider your wishes.**

Think about what medical treatments or interventions you want or do not want if you become seriously ill, have a medical condition or injury that requires you to be on life-support treatment for the rest of your life, are advanced





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*Indeed, for your faithful, Lord,  
life is changed not ended, and,  
when this earthly dwelling turns  
to dust, an eternal dwelling is  
made ready for them in heaven.*

**PREFACE I FOR THE DEAD**

**ROMAN MISSAL**

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in age, or frail. It is very important to discuss these choices with loved ones, friends, and/or other trusted individuals and to speak to your doctor about your wishes. **In addition to thinking about medical considerations, you should carefully reflect about what is important to you in life, your spiritual or religious beliefs, and the moral teachings of your religious tradition.** It may be wise to speak to a priest or clergy person as well.



#### **4. Determine who will be your surrogate.**

If you are preparing a durable power of attorney for health care, determine who will be your agent or surrogate — the person who will speak on your behalf if you can no longer speak for yourself. Whether this is your spouse, a relative or friend, be sure that the person you select knows your values, including your religious or spiritual beliefs, and what medical treatments you desire or do not desire, so that he or she can speak about your health care decisions with medical personnel.

*Be sure to ask the person you want to name as your surrogate whether he or she is willing to act as your surrogate and carry out your treatment wishes.*

No one is required to act as an agent simply because they have been named in the durable power of attorney. It is amazing how many people do not know that they are someone's agent until they receive a phone call from the hospital asking about an important decision! Also, if you choose as your surrogate someone who is not your spouse or family



member, let your family know in advance. Otherwise, this can cause serious difficulties when doctors need the surrogate to make important decisions.

### **5. Communicate your values and choices.**

Discuss your values, beliefs, and choices with your surrogate and others who might be involved with your future medical care. Preparing an advance health care directive provides a good opportunity to talk with your family and explain your values and beliefs regarding these important decisions. The more detailed these discussions are, the better your surrogate, your family, and your doctor can know and understand your wishes — and the more likely they will be followed.

### **6. Make copies available.**

After you have prepared your advance directive, give copies to your surrogate and your physician(s). Keep the original for yourself in an easily accessible place and inform others, especially family members, where it is kept. You should also give copies to family members, close friends, your attorney, and

*Come to me, all you who labor and  
are burdened, and I will give you rest.  
Take my yoke upon you and learn  
from me, for I am meek and humble  
of heart; and you will find rest  
for yourselves. For my yoke is easy,  
and my burden light.*

**MATTHEW 11:28–30**

ROMAN MISSAL

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possibly clergy to ensure that medical personnel will be able to get a copy of your advance directive should the need arise. Some states have registries where you may record your advance directive.

Although the focus in preparing an advance health care directive often tends to be on completing the form, the more important element is the conversations you have both in preparing the form and in expressing your values and wishes to others. These occasions provide an opportunity to speak not only about treatment preferences, but also about your personal life goals, values, beliefs, and how you want to live while dying. ♦





# What does a durable power of attorney for health care permit my agent or surrogate to do?

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Generally, your health care surrogate is able to make decisions for you about accepting or refusing any medical treatment, just as you would if you were able to make the decisions yourself. 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.

## **Are there any limits to what a surrogate can consent to?**

Your surrogate is responsible for making health care decisions based on your expressed wishes, values, and beliefs, or, if these are unknown, what he or she believes is in your “best interest.” For this reason, it is critical that you communicate your wishes and beliefs to your surrogate and provide him or her with a copy of your durable power of attorney for health care. If you wish, you may explicitly limit your surrogate’s powers by specifying what he or



she can and cannot do on your behalf. However, because you do not know the precise circumstances in which your surrogate will need to make decisions, it is not wise to place too many restrictions on your surrogate. It is better to choose someone you trust, explain to him or her your values and preferences, and have confidence that your surrogate is willing and able to make the appropriate decision. ♦

# When does an advance health care directive go into effect?

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An advance health care directive goes into effect when you have a life-limiting illness or are permanently unconscious and are no longer able to communicate your wishes.

## **Can my health care surrogate overrule my health care decisions?**

If you have a durable power of attorney for health care, your surrogate is permitted to make health care decisions for you only when your physician determines that you are no longer able to make your own decisions or are unable to communicate your wishes to others, unless otherwise specified in the advance directive.

## **What if I change my mind about my advance health care directive?**

Although legislation varies in different states, in general you may revoke your advance health care directive at any time by an oral or written notification to your agent or health care provider, or by simply writing VOID on your document.

You automatically revoke an earlier directive by completing a new written document, as long as you are still able to make your own decisions.

*The most recent version of your durable power of attorney for health care will supersede any earlier versions.* If you make any changes to your advance directive, be sure to inform your physician, your surrogate, your family members, and your attorney (if applicable) and provide them with copies of the new, clearly dated version.

### **Must health care providers always follow the instructions given in my advance health care directive?**

In general, health care providers should follow your advance health care directive as long as it has been properly completed according to the laws of your particular state.

However, a doctor or hospital does not have to follow an advance health care directive that is contrary to the religious and moral convictions of the health care organization. For example, a Catholic health care provider will not perform physician-assisted suicide because it is contrary to Catholic moral teaching, even in states where physician-assisted suicide is legal. A provider also does not have to follow a directive that asks for inappropriate or non-beneficial treatment that would offer little or no benefit to you.

### **Can state laws restrict what I express in my advance health care directive or on the decisions that my surrogate is able to make?**

There are differences among state laws regarding advance health care directives, but most states do have some restrictions on the choices you or your surrogate can make. It is therefore wise to check the law in your particular state. You can do this by contacting the Secretary of State's office of your state, a lawyer, your local legal aid office, the state bar association, your state Catholic conference, or your doctor or health care team. You can also find this information on the Internet. ♦

# When preparing an advance directive, how do I decide which medical treatments are appropriate?

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There is no ready-made answer to this question that applies to all situations. However, there are some elements to keep in mind as you prepare an advance health care directive:

## **1. What are your values and your philosophy of life?**

Take time to reflect on your beliefs about life, suffering, and death. From a Catholic perspective — shared by many other faith traditions — human life is a sacred gift from God. All persons, regardless of their medical or physical condition, possess inherent dignity and are worthy of respect, protection, and care.

Respect 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 participation in the redemptive power of Christ's passion, and therefore, transformed by Christ's resurrection, it is a new beginning, a transition from this earthly life into eternal life. Situations often arise in which an intervention or procedure no longer offers real hope of benefit or imposes burdens upon a patient that outweigh the benefits.





## **2. Given your health history, what might be your future diagnosis and prognosis?**

Most often people who prepare an advance directive do not know the exact life-threatening medical situation they will face in the future. Nevertheless, it is helpful to consider what types of treatments you would want or would refuse if you are diagnosed with a life-limiting illness (an illness or disease that will eventually lead to death) or are close to death. Your decisions about treatment will vary depending on your diagnosis and whether you have a reasonable chance of recovery. It is wise, however, not to place too many limits on the options available to your surrogate. Possible treatment options that one rejects when healthy may actually be beneficial given a particular life-threatening illness.

Most people in the United States now die from chronic diseases that become life-limiting. These diseases have relatively predictable trajectories from onset of illness to death. If you are diagnosed with such an illness, it is important to speak to your physician regarding realistic health care options. This conversation also allows your physician to take into consideration your values and beliefs in relation to the treatment options available.

**3. Does the end-of-life treatment offer benefit without being excessively burdensome?**

Catholic moral teaching states that all persons are obligated to use ordinary or proportionate means of preserving life. However, the term “ordinary means” is not the same as ordinary medical care. Rather it is understood in terms of whether the particular medical treatment offers a reasonable hope of benefit to the patient that outweighs the associated risks and/or burdens of the treatment. If this is the case (that is, the benefits are proportionate to the burdens), the patient should choose in favor of the treatment. However, patients may refuse a treatment 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). This is what the Catholic moral tradition calls “extraordinary” or “disproportionate” means. For example, continued chemotherapy for an incurable cancer patient may not offer any further benefit to the person and may actually impose considerable discomfort. So for this particular cancer patient, this treatment becomes “extraordinary means” even though most would consider it an “ordinary” treatment option.

The ERDs state that “the well-being of the whole person must be taken into account in deciding about any therapeutic intervention or use of technology” (Directive 33.) When assessing burdens and benefits, the Catholic tradition considers one’s total well-being as a person and not just the benefits of the treatment to a particular organ. For example, a medical

intervention may replace your kidney function (e.g. dialysis) but, given your overall medical condition, may not really be a benefit to you.

As you consider benefits and burdens, it is also important to consider whether an intervention is temporary and will help restore you to health or whether it is permanent and will do little to restore you to good health or whether it may even prolong the dying process. For example, being on a machine that helps you breathe (a ventilator) for two or three days to recover from pneumonia is clearly beneficial, even though it may impose a temporary burden. Being on the same breathing machine in the final stages of lung cancer may be disproportionately burdensome and therefore “extraordinary means.”

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*The Lord is good  
to those who trust in him,  
to the one that seeks him.*

**LAMENTATIONS 3:25**  
NEW AMERICAN BIBLE

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In deciding which medical interventions to accept or decline, you may also want to consider the impact on you and your family emotionally, physically and financially. The *Catechism of the Catholic Church* explains that we must take reasonable care of our health, “taking into account the needs of others and the common good” (§2288.)

#### **4. What health care is realistically available?**

When trying to determine which medical interventions you desire, you should also consider the availability of the desired interventions (medications, procedures, and mechanical interventions) at your local health care facility. You may also need to consider your options in light of your particular financial situation and health insurance coverage.



## **What guidance does the Catholic Church offer for making these decisions?<sup>†</sup>**

This guide has already referred to several principles from the Catholic moral tradition that are rooted in the Church's teaching that life is a precious gift from God. We are not owners of our lives, but caretakers. Hence, we have a duty, all things being equal, to preserve our lives and do not have unlimited power over life. For this reason, the Catholic Church holds that it is immoral to intend one's own death or that of someone else, for example by means of physician-assisted suicide.

We have already seen, however, that physician-assisted suicide and euthanasia are different from withholding or withdrawing life-sustaining treatment and other medical interventions when they no longer offer a reasonable hope of benefit or have become excessively burdensome.

<sup>†</sup> A more complete description of the Catholic moral tradition regarding end-of-life decisions can be found in CHA's End-of-Life Guide, "Teachings of the Catholic Church: Caring for People at the End-of-Life."



In these situations, there is recognition that medicine has reached its limits to cure and it is time to allow natural death, while continuing to care for the patient in other ways, such as pain and symptom relief. 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” (Congregation for the Doctrine of the Faith, *Declaration on Euthanasia*).

Catholic teaching 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. Death should be accepted as part of the human condition and need not be delayed by all possible means. ♦

# Am I able to give instructions in my advance health care directive about specific medical treatments?<sup>†</sup>

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You may give specific instructions in an advance directive that limit what your surrogate may do. Before giving instructions about specific medical treatments, however, it is a good idea to consult with your doctor. Rather than place a lot of restrictions on your agent, it is better to choose someone you trust, who knows your beliefs, values and preferences, and have confidence that your agent is willing and able to make the appropriate decision.

The issue of tube feeding (artificial nutrition and hydration) requires special discussion. Laws in some states do not permit removal of a feeding tube unless the person has explicitly given his or her surrogate permission to do so. If you feel strongly about the use of a feeding tube when it is merely

<sup>†</sup>Such as feeding tubes or CPR (cardiopulmonary resuscitation)



prolonging your death 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 not be made on the basis of a belief that the person's life has no value or to hasten the patient's death but based on the burdens and benefits the treatment offers. Catholics may want to discuss this treatment with a priest or spiritual adviser who is familiar with recent church teaching.

### **What about physician orders for life-sustaining treatment?**

POLST (Physician Order for Life-Sustaining Treatment) is a document, written and signed by a doctor or other medical professional, which translates a patient's treatment plan into a medical order that can be used in all health care settings. The document is available in many, though not all, states. Some states may use a different name for the document. MOLST, COLST, MOST and POST are the most common, but your state may use a different title. Specific state laws govern how the document can be used, but the goal of POLST is to provide an active treatment plan for a patient who has serious advanced illness or frailty.

### **Is this form a type of advance directive?**

POLST is not an advance directive. Advance directives are legal documents in which a patient communicates preferences for future treatments. POLST is a medical order in which a doctor or other medical professional prescribes a current plan of care in a standardized way. POLST is intended for those patients with serious advanced, progressive illness and/or frailty and not for all adults. POLST can be based on an advance directive, but it functions as a stand-alone document.

## **What does the Catholic Church say about POLST?**

POLST and the shared decision making used to complete the document are consistent with Catholic moral teaching. Like advance directives, POLST is a tool that may be used well or poorly, for good or for ill. There is nothing inherent in POLST that is inconsistent with Catholic morality. It is the way in which the document is used and the actual choices made that are beneficial or problematic from the point of view of the Catholic moral tradition. The range of answers in most POLST forms — and the character of the advance care planning given in Catholic health care facilities — usually allows patients to make choices consistent with Catholic moral teaching.

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*What then shall we say to this?  
If God is for us, who can be against us?  
He who did not spare his own Son  
but handed him over for us all,  
how will he also not give us  
everything else along with him?*

**ROMANS 8:31–32**  
NEW AMERICAN BIBLE

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Although some bishops and Catholic conferences have supported their state’s version of POLST and some have voiced opposition to POLST as developed in their particular states, most bishops in the U.S. have neither endorsed POLST nor opposed it. ♦

# For more information:

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*This is one of a series of publications from the Catholic Health Association to help patients, families and caregivers with decisions about end-of-life care. We invite you view the accompanying guides for additional assistance. These and other resources are available to order or download at **[www.chausa.org](http://www.chausa.org)**.*





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