

Questions and Answers



Advance Directive
and End-of-Life
Decisions


Caring Connections
a program of the National Hospice
and Palliative Care Organization

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Introduction

This booklet addresses issues that matter to us all, because we all potentially are future patients. Advance directives—living wills and medical powers of attorney (which designate healthcare agents)—are valuable tools to help us communicate our wishes about our future medical care. The questions addressed in this guide are not simple; they reflect the complexity of the choices that most of us will face in the modern medical system. But to avoid thinking about these questions—to avoid thinking about our own dying—does not mean that these medical decisions will not arise. It only means that others will have to make them for us. Thoughtfully prepared advance directives can ease the burden on those who must make healthcare decisions for us.

Without advance directives, those making decisions for us might not be ones we would choose or might not make the choices we would make. Furthermore, decisions made might not be made by people who know us, but possibly hospital risk managers, lawyers or even the courts. Advance directives are now recognized throughout the country; the challenge for each of us is to make good use of these important documents.

Information in this booklet will help you ensure that your decisions about your own medical care at the end of life will be honored.

The National Hospice and Palliative Care Organization (NHPCO) envisions and works toward a world where individuals and families facing serious illness, death, and grief experience the best that humankind can offer. NHPCO offers consumers and caregivers resources, information, education and a compassionate presence through the NHPCO HelpLine, www.caringinfo.org and publications. To find a local hospice, request an advance directive, learn more about end-of-life care services or issues, or support our efforts please call NHPCO's **HelpLine** at 800/658-8898.

*This booklet is intended to provide general information only
and should not be construed as legal advice.
Individual situations often depend upon specific circumstances.*



Advance Directive

What They Are and What They Do

What are advance directives?

“Advance directive” is a general term that describes two types of legal documents:

- Living wills
- Medical power of attorney

These documents allow you to instruct others about your future medical care wishes and appoint a person to make healthcare decisions if you are not able to speak for yourself. Each state regulates the use of advance directives differently.

What is a living will?

A living will is a type of advance directive in which you put in writing your wishes about medical treatment for the end of your life in the event you cannot communicate these wishes directly. Different states name this document differently: for example, it may be called a “directive to physicians,” “health care declaration,” or “medical directive.” Regardless of what it is called, its purpose is to guide your family and doctors in deciding about the use of medical treatments when you are dying.

Your legal right to accept or refuse treatment is protected by the Constitution and case law. However, your state law may define when the living will goes into effect, and may limit the treatments to which the living will applies. You should read your state’s suggested document carefully to ensure that it reflects your wishes. You can add further instructions or write your own living will to cover situations that the state suggested document might not address. Even if your state does not have a living will law, it is wise to put your wishes about the use of life-sustaining medical treatments in writing.

What is a medical power of attorney?

A medical power of attorney is a document that lets you appoint someone you trust to make decisions about your medical care if you cannot make them yourself.

This type of advance directive can also be called a “healthcare proxy,” “appointment of a healthcare agent,” or “durable power of attorney for healthcare.” The person you appoint may be called your healthcare agent, surrogate, attorney-in-fact, or

healthcare proxy. The person you appoint through a medical power of attorney usually is authorized to deal with all medical situations, not only end-of-life decisions when you cannot speak for yourself. Thus, he or she can speak for you if you become temporarily incapacitated—after an accident, for example—as well as if you become incapacitated because of irreversible disease or injury.

Generally, the law requires your agent to make the same medical decisions that you would have made, if possible. To help your agent do this, it is essential that you discuss your values about the quality of life that is important to you and the kinds of decisions you would make in various situations. For example, how aggressively would you want medical treatments supplied if you had Alzheimer’s disease or if you were in a coma and unlikely to recover? Share your thoughts concerning someone you have known who was very ill and how you would want to be treated if you were in a similar situation. These discussions will help your agent to form a picture of your views regarding the use of medical treatments.

If this discussion does not take place, your agent will have to examine any general statements you might have made, your religious and moral beliefs, and what he or she knows about your values in general. When your wishes about a particular medical decision are not known your agent must act in your best interest, using his or her own judgment depending on your state’s law.

Some states let you appoint an agent within the living will. This is different from a medical power of attorney, because an agent appointed in a living will can only make decisions about using medical treatments, and only if you are in one of the medical conditions specified in your state’s law (such as “terminally ill,” “permanently unconscious,” or “imminently dying”).

You will find out more about appointing a healthcare agent beginning on page 14.

Why do I need advance directives?

Advance directives give you a voice in decisions about your medical treatment, even if you are unconscious or too ill to communicate.

As long as you are able to make and express your own decisions, you can accept or refuse any medical treatment. But if you become seriously ill, you might lose the ability to participate in decisions about your own treatment.

Research has shown that 80 percent of us now die in a medical facility such as a hospital or nursing home, as medical technology can now prolong life as never

before. The quality of that life, however, may be greatly reduced. As a result, many patients, families and caregivers face difficult questions about how much technology to use when the patient cannot get better. That means most of us will face a decision about whether to use life-sustaining treatments at the end of our lives. If we cannot speak for ourselves at that point, other people will have to make the decisions for us.

Providing your loved ones and caregivers with the information they need to make medical decisions for you is a great gift. It can spare them emotional anguish and conflict. Making end-of-life decisions for someone else is difficult and painful for loved ones and caregivers. You can make those decisions much easier for your family by talking about your wishes while you are able to do so. If your loved ones do not know your preferences, decisions are even harder to make and serious conflicts can arise between your family and medical caregivers or within your family itself. Without clear evidence about a patient's wishes, some care providers will continue treatment, not only because they are trained to do so, but also to protect themselves from any liability. Even if your loved ones believe that you would not want a treatment, they might not be able to stop it without some direction from you depending on the state.

Remember, it's up to you to take the initiative and express your wishes. Your family or doctor is not likely to raise the issue for you.

Why bother with advance directives if I want my family to make the necessary decisions for me?

Depending on your state's laws, your family might not be allowed to make decisions about life-sustaining treatment for you without written evidence of your wishes. Although doctors usually turn to the next of kin to make most decisions when patients cannot speak for themselves, a decision to withhold or stop life-sustaining treatment often is handled differently because of its final nature. Some state laws do permit family members to make all medical decisions for their incapacitated loved ones. However, other states require clear evidence of the patient's own wishes or a legally designated decision maker. Written evidence, such as a living will or medical power of attorney, generally is honored more readily in these situations than previously made oral statements.

Even in states that do permit family decision-making, you should still prepare advance directives for three reasons:

- You can name the person with whom you are most comfortable

(this person does not need to be a family member) to make sure your wishes are honored.

- Your advance directives will make your decisions known.
- It can help to resolve any conflict among family members.

Even families sometimes are reluctant to make decisions without knowledge of a person's wishes.

Over the years we have heard many families express thankfulness that their loved ones prepared advance directives and talked about the decisions written in them. Such preparation spares families the anguish of trying to guess what to do when they already are dealing with the pain of the illness and loss of a loved one.

Should I prepare a living will and also use a medical power of attorney to appoint an agent?

Yes. You can best protect your treatment wishes by appointing a healthcare agent and preparing a living will. Each offers something the other does not.

Benefits of appointing a healthcare agent. Medical decision-making is rarely simple. Treatment decisions must be made in response to changing medical conditions, and medical situations frequently unfold unpredictably. Decision-making often involves weighing the benefits and burdens of treatments and even evaluating the odds for success or failure.

The person whom you appoint as your agent can respond flexibly to changes or unanticipated situations in a way that no document can. In addition, you are legally authorizing that person to make decisions based not only on what you expressed in writing or verbally, but also on the knowledge of you as a person. Your agent can consider other concerns you might have, such as the effect of your illness on your family and the quality of life that matters to you.

Living wills address end-of-life decisions only. An agent appointed through a medical power of attorney usually can make healthcare decisions for you in a wider range of situations than those involving end-of-life care.

Benefits of having a living will. If your agent must decide whether medical treatment should be withheld or withdrawn to permit you to die, your living will can reassure your agent that he or she is following your wishes. Further, if the person you

appointed as agent is unavailable or unwilling to speak for you, if you have been unable to identify an appropriate agent, or if other people challenge a decision not to use life sustaining medical treatments, your living will can guide your caregivers. A thoughtfully prepared living will is a valuable supplement to appointing an agent.

What if I do not have anyone to appoint as my agent?

If you have no one to appoint as your agent, it is especially important that you complete a clear living will and that you talk about it with anyone who might be involved with your health care. This might include family members, even if you do not want one of them to be your agent. It also could include social workers, spiritual caregivers, visiting nurses, or health aides who are helping you in some context. You should discuss it with any physicians that you see regularly and give them a copy to put in your medical record. If you are admitted to a hospital or long-term care facility, you should have a copy of your living will made a part of your medical record.

When will my advance directives go into effect?

Your advance directives become legally valid as soon as you sign them in front of the required witnesses. However, they normally do not go into effect unless you are unable to make your own decisions and each state establishes its own guidelines for when advance directives become operative. The rules may differ for living wills and medical powers of attorney, as described below.

Living will. In most states, before your living will can guide medical decision making, two physicians must certify that you are unable to make medical decisions and that you are in the medical condition specified in the state's living will law (such as "terminal illness" or "permanent unconsciousness"). Other requirements also may apply, depending upon the state.

Medical power of attorney. Most medical powers of attorney go into effect when your physician concludes that you are unable to make your own medical decisions. If you regain the ability to make decisions, your agent cannot continue to act for you. Many states have additional requirements that apply only to decisions about life-sustaining medical treatments. For example, before your agent can refuse a life-sustaining treatment on your behalf, a second physician may have to confirm your doctor's assessment that you are incapable of making treatment decisions.

Your state specific advance directive provided by The National Hospice and Palliative Care Organization explains when the documents go into effect under your state's laws.

Will my advance directives be honored if I am in an accident or experience a medical crisis at home and emergency technicians are called?

In these emergency situations, unless you are able to speak for yourself, your consent to treatment is presumed. Once emergency personnel have been called, they are obligated to do what is necessary to stabilize a patient for transfer to a hospital, both from accident sites and from a home or other facility. After a physician fully evaluates the person's condition and determines the underlying conditions, advance directives can be implemented if warranted.

Emergency medical technicians cannot honor living wills or medical powers of attorney. However, in many localities, the specific crisis of cardiac arrest/respiratory arrest is addressed by a document called a "Non-hospital Do-Not-Resuscitate Order." Individuals with underlying conditions that would make resuscitation unwarranted under any circumstances can carry a special "do-not-resuscitate" (DNR) order signed by a doctor and in some states can wear a special bracelet or other indicator that such a signed order exists. These non-hospital DNR orders instruct emergency personnel not to perform cardiopulmonary resuscitation (CPR) (see page 19). These orders apply to situations in which the person's heart has stopped beating or breathing has stopped. For all other conditions, emergency medical technicians are still required to treat and transport the patient to the nearest hospital for evaluation by a physician. If you wish to find out whether non-hospital DNR orders are available in your locality, contact your local emergency medical service or department of health.

For more information about CPR, DNR orders and non-hospital DNR orders, see the National Hospice and Palliative Care Organization's Marketplace Catalog at www.caringinfo.org for end-of-life products or additional copies of Questions and Answers booklet, *Cardiopulmonary Resuscitation, Do-Not-Resuscitate Orders and End-of-Life Decisions*.

Will my advance directives be honored in another state?

The answer to this question varies from state to state. Some states do honor advance directives from another state; others will honor out-of-state documents to the extent they conform to the state's own law; and some states do not address the issue. In fact, a state would probably have to honor an advance directive that clearly expressed your treatment

wishes, because your constitutional rights and rights established by case law to accept or refuse treatment may be even broader than your rights under a specific state law—please check with your local Area Agency on Aging to verify your state’s law.

However, if you spend a significant amount of time in more than one state, we recommend that you complete the advance directives for all the states involved. It will be easier to have your advance directives honored if they are the ones with which the medical facility is familiar.

How can I change what is in my advance directives?

An advance directive remains in effect until you revoke it. If you complete a new advance directive, it invalidates the previous one. For this reason you should review your advance directives periodically to ensure that they still reflect your wishes. If you want to change anything in an advance directive once you have completed it, you should complete a new document.

Do I need a lawyer to prepare advance directives?

No. You can get state-specific documents and instructions about how to complete them correctly from The National Hospice and Palliative Care Organization on the Web site at www.caringinfo.org. Your local hospital, public health department, state bar association or state office on aging also may provide them. Generic forms that are not state-specific are available and may be used to supplement your wishes. However, review any supplemental forms to ensure that language in one form does not conflict with language in another form.

Read all of the instructions carefully to ensure that your document is witnessed properly and that you have included all of the necessary information. It might be wise to ask someone else to look over the documents for you to be sure that you have filled them out correctly.



Appointing a Healthcare Agent

Who can serve as my agent?

Your agent can be almost any adult whom you trust to make healthcare decisions for you. He or she can be a close family member or a good friend who is willing to assume the responsibility to make healthcare decisions on your behalf.

The important thing when appointing an agent is to make sure he or she understands your wishes about the use of medical treatment and is willing to respect them and to be assertive if necessary. Not everyone is comfortable making these types of decisions, and your agent might have to be persistent to ensure that your wishes are honored. Therefore, it is essential that you talk with the person before making the appointment, even if you plan to name your spouse, your adult child or another family member.

Who cannot serve as my agent?

Under most state laws, your attending physician cannot treat you and act as your agent at the same time. In some states your agent cannot be any healthcare worker caring for you in a medical facility unless the person also is a family member.

Can I appoint more than one agent?

You should not (and in many states you may not) appoint more than one person to act as your agent at the same time, because conflicts and confusion can arise. The result could be that no decision is reached or that court intervention becomes necessary.

Parents sometimes wish to appoint all of their adult children to act together as the agent, to avoid “playing favorites.” Instead, you could ask your children to decide among themselves who could be the agent.

Practical considerations such as location often make the answer obvious. Sometimes one adult child is more willing to take on the role than another.

You can appoint one or more alternate agents. If the first person you named is unwilling or unable to serve—for example, if he or she is ill then the next one is called upon to act as your alternate agent, and so on down the list of people you name as alternates.

Remember, in some states, appointing more than one person at a time can make the appointment invalid.

What should I tell my agent?

Your agent needs to know about the quality of life that is important to you and when and how aggressively you would want medical treatments provided.

For example, if you had a massive stroke, would you want to receive aggressive treatments (such as mechanical ventilation, antibiotics, or tube feeding) for a time, but have them stopped if there were no improvement in your condition? What kind of treatment would you want if you were in a state of prolonged unconsciousness and were not expected to recover? Would you want life support or would you rather receive palliative (comfort) care only? What are your views about artificial nutrition and hydration (tube feeding)? Do you want to receive these types of treatment no matter what your medical condition? On a trial basis? Never? If your heart stopped, under what circumstances would you want doctors to use CPR to try to resuscitate you?

Talking to your agent means discussing values and quality-of-life issues as well as treatments and medical situations. Because situations could occur that you may not anticipate, your agent may need to base a decision on what he or she knows about your values and your views of what makes life worth living. These are not simple questions, and your views may change. For this reason, you need to talk to your agent in depth and over time.



Preparing the Forms

Must my advance directives be witnessed?

Yes, every state has some type of witnessing requirement. Most require two adult witnesses; some also require a notary. Some states give you the option of having two witnesses or a notary alone as a witness. The purpose of witnessing is to confirm that you really are the person who signed the document, you were not forced to sign it, and you appeared to understand what you were doing. The witnesses do not need to know the content of the document.

Read the instructions and the documents carefully to ensure that the witnessing is done properly.

Who can be a witness?

All states require that your witnesses be adults. Beyond that, the requirements vary from state to state.

Generally, a person you appoint as your agent or alternate agent cannot be a witness. In some states your witnesses cannot be any relatives by blood or marriage, or anyone who would benefit from your estate. Some states prohibit your doctor and employees

of a healthcare institution in which you are a patient from acting as witnesses. Again, read the instructions carefully to see who can and cannot be a witness.

What should I do with my completed advance directives?

Make several photocopies of the completed documents. Keep the original documents in a safe but easily accessible place, and tell others where you put them; you can note on the photocopies the location where the originals are kept. **DO NOT KEEP YOUR ADVANCE DIRECTIVES IN A SAFE DEPOSIT BOX.** Other people may need access to them.

Give photocopies to your agent and alternate agent. Be sure your doctors have copies of your advance directives and give copies to everyone who might be involved with your healthcare, such as your family, clergy, or friends. Your local hospital might also be willing to file your advance directives in case you are admitted in the future.

How can I be sure my advance directives will be honored?

Simply completing advance directives will not ensure that your wishes will be honored. These documents are tools to help the decision making process. Their effectiveness depends largely on the way you prepare your loved ones and other caregivers for their use.

To best protect your treatment wishes, you should do two things:

1. Take the time to think your feelings through and state them fully, so that your advance directives truly reflect your treatment wishes.
2. Talk openly about your wishes with your family, your friends and your doctor.

Don't assume that others will know what you would want. Research shows that families' and physicians' who guess about a patient's preferences often are mistaken. Talking with the people who might have to act on your behalf ensures that they understand your wishes, gives them a chance to ask questions, and lets you determine whether they will follow your wishes even if your choices differ from theirs.

For more information about healthcare agents, see The National Hospice and Palliative Care Organization's Marketplace catalog at www.caringinfo.org for our Questions and Answers booklet, *Healthcare Agents: Appointing One and Being One*.



What are life-sustaining treatments?

Life-sustaining treatments are medical procedures that replace or support a failing essential bodily function (one that is necessary to keep you alive). For example, a ventilator (respirator) supports the breathing process; dialysis cleans the blood in case of kidney failure. They are also sometimes called life-support or life-prolonging treatments.

Why would I not want life-sustaining treatments?

If a good chance exists that a life-sustaining treatment will improve your condition (e.g., temporary use of a ventilator to support breathing until you are able to breathe on your own), you might accept the treatment. However, if your condition is complicated by many problems (e.g., serious brain damage, kidney failure) and continues to deteriorate with no likelihood of recovery, you might not want life-sustaining treatment.

Furthermore, if treatments sustain life but do not provide the quality of life or dignity you wish to maintain (e.g., your condition is irreversible and you are completely dependent on others for all aspects of care), you might not want life sustained under these conditions. On the other hand, because of personal or religious views you might want treatments continued as long as possible.

Medical decision-making often requires weighing the benefits of continued treatment against its burdens. By letting others know when, in your view, continued treatment would no longer be a benefit to you, you provide guidance to those who may at some time be called upon to make difficult decisions for you. When a person can no longer participate in these decisions, advance directives may offer the only guide to weighing the burdens and benefits of continued treatment.

Note: In making decisions about treatment, patients or their agents need to know the diagnosis (the exact nature of a person's medical condition) and prognosis (what is likely to happen because of that medical condition). The patient or the designated agent has a right to this information, and needs the information to make decisions properly. If physicians cannot provide an answer right away, find out when they will know more.

How can I learn more about the benefits and burdens of different medical treatments?

First, you should talk with your doctor. If you have a chronic or serious medical condition, your doctor should be able to tell you about treatments that might be especially relevant to your condition. In addition, The National Hospice and Palliative Care Organization Marketplace Catalog has publications that discuss some common types of life-sustaining treatment in detail.

What is CPR (cardiopulmonary resuscitation)?

CPR is not a single treatment, but a group of treatments used when heartbeat and/or breathing stop. CPR tries to get the person to breathe and the heart to beat again. It may consist only of mouth-to-mouth artificial respiration or forcing air into the lungs with a special device, or it can include repeated pressure on the chest, electric shock or drugs to stimulate the heart, and/or fluids and medication given by vein.

Why would I not want CPR?

When a person is seriously ill and near death, it is not unusual for the heart to give out.

This kind of death can be more comfortable than slowly dying from a disease with death delayed by intrusive medical treatments. Research shows that very ill patients who have a cardiac arrest and are resuscitated in the hospital have only a very small chance of recovering enough to leave the hospital. But in current medical practice, if the doctor has not written a DNR order for the patient, medical personnel usually try to resuscitate, no matter how hopeless the situation, and will keep trying until the heart simply will not restart.

In addition, if a person is resuscitated after not breathing even for just a few minutes, he or she may have severe brain damage because no oxygen has reached the brain. In that case, the resuscitation “succeeds” in the sense that the heart has restarted, but the patient is in a much worse condition than before the heart stopped. When making the decision about your wishes regarding CPR, it is important to think about what condition you would be brought back to if your heart were to stop beating and CPR was initiated.

Do I need to talk with my agent about specific treatments in my living will?

Because it is impossible to predict exactly what will happen at the end of our lives,

living wills and conversation cannot cover every situation. However, you should discuss the quality of life that matters to you, which offers your loved ones and physicians a guide to when you might want to refuse or accept medical treatment. In addition, you should discuss your feelings about the use of life-sustaining treatments that are most commonly used in end-of-life situations and over which controversy might arise, such as ventilators (breathing machines), CPR, artificial nutrition and hydration, or antibiotics as well as continued medical testing.

If you have been diagnosed with a terminal illness, your physician can provide you with more specific information about future possibilities and treatments, enabling you to plan thoughtfully, prepare your documents clearly, and talk with your agent and other loved ones in an informed way.

If I refuse life support, will I still receive treatment for any pain I might have?

Many people mistakenly think that by refusing aggressive medical treatments they could be refusing all medical care. This is not the case. A dying person needs medical care, but care whose goal is comfort, not cure. This often is called “palliative care.” It is not just pain medication, although pain management is an important part of palliative care. It also can include medications for depression and anxiety, or even surgery, radiation, antibiotics, or other treatments that normally are used to cure, but in this case are used to make the person more comfortable. Palliative care is care for the whole person and so may also include spiritual and social supports and well as support for those caring for the patient.

Can I refuse artificial nutrition and hydration (tube feeding)?

Yes. Artificial nutrition and hydration (often called “tube feeding”) are life-sustaining treatments, and your refusal is protected under the law. Much as a ventilator supports breathing or a dialysis machine replaces kidney function, tube feeding provides nutrition and fluid to the body.

As with other treatments, artificial nutrition and hydration can be used temporarily until the person can eat and drink again. Some people depend permanently on artificial nutrition and hydration, and still find life to be rewarding and meaningful.

On the other hand, difficulties about the use of artificial nutrition and hydration arise when patients are terminally ill or have suffered irreversible brain damage.

Artificial nutrition and hydration can delay such patients' dying for a long time, but cannot improve the underlying medical condition. In addition, the long-term use of artificial nutrition and hydration can cause new problems, such as infections. Artificial nutrition and hydration also may be uncomfortable, especially if the person must be restrained (tied down) so that the tubes are not dislodged. Some state laws require clear evidence of an individual's wish to refuse artificial nutrition and hydration before the treatment can be withheld or withdrawn. It is very important to make your wishes clear on this point even if your state law does not require it. Due to moral or religious conviction, some people believe that nutrition and hydration, even if supplied artificially, should never be stopped.

Is it painful to stop artificial nutrition and hydration?

No. Contrary to some claims, stopping artificial nutrition and hydration in dying, brain-damaged, or permanently unconscious patients does not result in painful death. A growing body of evidence shows that avoiding or withdrawing artificial nutrition and hydration allows a peaceful and pain-free death. Avoiding forced feeding in someone who is too sick to eat or drink is vastly different from keeping food and water away from a healthy person who is hungry and thirsty. Symptoms, such as dry mouth, can be managed with palliative care (comfort care).

For more information about the use of artificial nutrition and hydration see The National Hospice and Palliative Care Organization's Marketplace catalog at www.caringinfo.org for our Questions and Answers booklet, Artificial Nutrition and Hydration and End-of-Life Decision Making.



Other Questions

Once a medical treatment is started, can it be stopped?

Yes. There is no legal or ethical difference between withholding and withdrawing a medical treatment. Therefore, people who may want to try a potentially helpful treatment can do so without fear that, once started, it could not be removed. Professional organizations such as the American Medical Association, as well as the courts, have affirmed that it is ethical to discontinue medical treatments that do not benefit the patient. If the patient no longer wants a treatment, for any reason, providers are legally obligated to withdraw it.

In practice, however, caregivers might resist withdrawing a treatment once it has begun. A caregiver might believe he or she would be helping to cause death, even though the patient's condition is irreversible. Also, caregivers might be confused or misinformed about what the law requires and what constitutes ethical practice. They might mistakenly believe they cannot stop treatment, even with clear evidence that the patient would not want it. If a physician refuses to end treatment, the patient or family should find out the reason for the refusal.

Do healthcare providers run any legal risk by honoring advance directives?

No. Most advance directive statutes state explicitly that providers run no legal risk for honoring valid advance directives. No healthcare provider has ever been successfully prosecuted for honoring a patient's request to stop treatment. In fact, providers might run more legal risk when imposing treatment against a person's or healthcare agent's wishes.

What if my healthcare provider will not honor my advance directives?

In many states, healthcare providers can refuse to honor advance directives for moral or religious reasons. Some of those states require such individuals be removed from the case and transfer care of the patient to someone who will honor the patient's request. But in practice a healthcare provider's refusal to honor an advance directive can cause difficulties. For example, it may be hard to find a physician or facility willing to accept the patient. For this reason, it is important to ask in advance if a healthcare provider has personal views or if an institution has any policy that would prevent them from honoring a person's legal right to refuse treatment.

A refusal by a healthcare provider to stop treatment may stem from a misunderstanding of the law or medical ethics. Supplying the provider with the correct information might solve this type of difficulty. In other cases, a provider might believe that the patient's choice conflicts with his or her professional responsibilities. Many medical facilities have ethics committees that can help to resolve disputes over patients' wishes. In extreme cases, legal action might be required.

These examples show why it is so important to lay the proper groundwork for your advance directives. If you know that your personal doctor is unwilling to carry out your wishes, it would be wise to change to a physician who will respect them. In

addition, because conflict is possible, it is important to appoint an agent who is willing to work actively to have your wishes honored, and equally important to discuss your wishes with loved ones and physicians.

Who would make decisions about my medical care if I did not complete advance directives?

There is no simple answer to this question. In general, physicians consult with families when the patient cannot make decisions. But if the decision involves ending a treatment and will result in the person's death, the family may or may not be permitted to make the decision, depending on state law.

In some states treatment cannot be withheld or withdrawn without clear and convincing evidence that the person would refuse it. In other states, if the physician and the family agree, the treatment could be stopped without recourse to any outside authority (such as the courts). If any conflict about treatment exists among family members or between the family and the physician, treatment is likely to continue until the patient dies or the issue is resolved through legal action.

A number of states have passed surrogate decision-making statutes. These laws create a decision-making process by identifying the individuals who may make decisions for patients who have no advance directives. However, the person whom the law appoints to make decisions might not be the person you would want as your decision maker or might make decisions you would not want. Thus, it is important to name the person you do want by completing advance directives, including the appointment of an agent.

Is there federal law about advance directives?

Yes, the Patient Self-Determination Act (PSDA) is a federal law regarding advance directives. It requires medical facilities that receive Medicaid and Medicare funds to have procedures for handling patients' advance directives, and to tell patients upon admission about their rights under state law to use advance directives. The PSDA does not set standards for what advance directives must say; it does not require facilities to provide advance directive forms; and it does not require people to have advance directives. Rather, the PSDA's purpose is to make people aware of their rights.

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) evaluates and accredits nearly 19,000 healthcare organizations and programs in the

United States. An independent, not-for-profit organization, JCAHO has developed standards for the documentation of patient wishes regarding advance directives, which apply to the vast majority of healthcare institutions.

Will a pregnant woman's advance directives be honored?

Under some state laws, advance directive instructions to refuse treatment may not be honored while a woman is pregnant. If you wish your advance directives to apply during pregnancy, you will improve your chances of having this wish honored, although not ensure it, by stating the wish clearly.

Can I state my wishes about organ donation, cremation or burial in my advance directives?

Several states permit you to indicate your wishes regarding organ donation. In those states that do not specifically address the issue of organ donation you may state your wishes in your advance directive. However, you should consider expressing your wishes through a form designed for that purpose. You also should be sure to make your family aware of your wishes. Since your advance directive and the authority of your agent technically ceases upon your death, you should tell your wishes about cremation or burial to your family or the executor of your estate.

If I refuse life support, will my life insurance be invalid?

No. Terminating or withholding a medical treatment is not suicide and will not invalidate a life insurance policy. The cause of death is the medical condition, which the treatments can do nothing to reverse.

What is the difference between a "will," a "living trust" and a "living will"?

Wills (last will and testament) and living trusts are both financial instruments; they allow you to plan the distribution of your financial assets and property. In contrast, a living will deals with medical issues while you are alive. It allows you to express your preferences about your medical care at the end-of-life.

Wills and living trusts are complex legal instruments, and you might need legal advice to complete them. Although living wills and medical powers of attorney also are legal documents, you do not need a lawyer to complete them.

What is the difference between a financial “power of attorney”, a financial “durable power of attorney” and a “medical power of attorney”?

A power of attorney and a durable power of attorney are both legal documents that let you appoint someone to make financial decisions for you. A regular power of attorney is effective only while you can still handle your own finances, whereas a durable power of attorney remains valid even after you have lost the ability to make financial decisions (due to Alzheimer’s disease, for example).

A medical power of attorney (which in some states is called a “durable power of attorney for healthcare”) only permits the appointed person to make medical decisions for you if you cannot make those decisions yourself. It does not authorize the person to handle your financial affairs, and normally does not empower him or her to make decisions while you can still make them.

In most states, you can appoint the same person to make financial and healthcare decisions for you, but you must use separate documents to do so. To learn about your state’s law regarding financial powers of attorney or durable powers of attorney, contact a lawyer. For information about medical powers of attorney in each state, contact a lawyer or The National Hospice and Palliative Care Organization.

If you have questions that this booklet does not answer or if you would like to talk further about these issues, call The National Hospice and Palliative Care Organization at 800/658-8898, e-mail us at consumers@nhpco.org or visit our Web site at www.caringinfo.org where you will find a variety of resources and information and can order publications.



Common Terms Used In Talking About End-of-Life Care

Advance Directive

A general term that describes two kinds of legal documents, living wills and medical powers of attorney. These documents allow you to give instructions about future medical care and appoint a person to make healthcare decisions if you are unable to make them yourself. Each state regulates the use of advance directives differently.

Benefits And Burdens

A commonly used guideline for deciding whether or not to begin or stop medical treatments. A benefit can refer to the successful outcome of a medical procedure or treatment. Outcomes can be medical (e.g., the heart beats again) or functional (e.g., the person is able to walk to the bathroom after being incapacitated by a stroke), or one that supports the patient's values (e.g., the patient is able to die at home as wished).

However, a benefit from one point of view can be experienced as a burden from another and might be viewed differently by doctors, patients and families. For example, if a patient's heart stops, is resuscitated and starts beating again, this is a successful outcome from a medical point of view, and a doctor may consider it a benefit. To the patient who is dying from a serious illness or disease, resuscitation may cause further injury and may contribute to the overall experience of suffering. This success, from the doctor's point of view, might actually be experienced as an additional burden by the patient. Discussions of the benefits and burdens of medical treatments should occur within the framework of the patient's overall goals for care.

Case Law

Law that is based on a judge's decision in a court case, rather than by legislation.

Capacity: In the healthcare context, the ability to understand and appreciate the nature and consequences of health care decisions and to make an informed decision. The term competent is also used to indicate ability to make informed decisions.

Do-Not-Resuscitate Order (DNR)

A DNR order is a physician's written order instructing healthcare providers not to attempt cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest. A person with a valid DNR order will not be given CPR under these circumstances.

Although the DNR order is written at the request of a person or his or her family, it must be signed by a physician to be valid.

Euthanasia

Based on a term meaning “good death.” The term traditionally has been used to refer to the hastening of a suffering person’s death. “Mercy killing” is another term often used. Voluntary Active Euthanasia involves a physician engaging in an act to cause a patient’s death, such as by giving a lethal injection, with the patient’s full informed consent. Involuntary or Non-voluntary Active Euthanasia refers to an act to end a patient’s life, without that patient’s full informed consent.

Hospice Care

A program to deliver palliative care to individuals who are in the final stages of terminal illness. In addition to providing palliative care and personal support to the patient, hospice includes support for the patient’s family while the patient is dying as well as bereavement support to the family.

Life-Sustaining Treatment

Treatments (medical procedures) that replace or support an essential bodily function (may also be called life support treatments). Life-sustaining treatments include cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and hydration, dialysis, and certain other treatments.

Living Will

A type of advance directive in which an individual documents his or her wishes about future medical treatment should he or she be at the end of life and unable to communicate. It may also be called a “directive to physicians,” “healthcare declaration,” or “medical directive.” The purpose of a living will is to guide family members and doctors in deciding how aggressively to use medical treatments to delay death.

Medical Power of Attorney

A document that allows an individual to appoint someone else to make decisions about his or her medical care if he or she is unable to communicate. It may also be called a healthcare proxy, medical power of attorney or appointment of a healthcare agent. The person appointed may be called a healthcare agent, surrogate, attorney-in-fact, or proxy.

Palliative Care

A comprehensive approach to treating serious illness that focuses on the physical,

psychological, spiritual, and social needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, controlling pain and symptoms, and enabling the patient to achieve maximum functional capacity. Respect for the patient's culture, beliefs, and values are an essential component. Palliative care is sometimes called comfort care.

Physician-Hastened Death

Sometimes referred to as Physician-Assisted Suicide

A physician supplies the means, usually a prescription for a lethal dose of medication, which a terminally ill individual can use to end his or her own life.

Surrogate Decision-Making Laws

Refers to laws that allow an individual or group of individuals to make decisions about medical treatments for a patient who has lost decision making capacity and did not prepare an advance directive. Some state advance directive laws also refer to the designated healthcare agent as the surrogate.

Withholding or Withdrawing Treatment

Not beginning life-sustaining measures or stopping them after they have been used for a certain period of time.



Publications

Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying, by Maggie Callanan, Patricia Kelley and Stephanie Waxman. Drawn from more than twenty years experience tending the terminally ill.

NHPCO Catalog Number 713545

Dying Well: Peace and Possibilities at the End of Life, Ira Byock, MD. Stories of love and reconciliation in the face of tragedy, pain, and conflict.

NHPCO Catalog Number 715112

Dying at Home: A Family Guide for Caregiving, Andrea Sankar, Baltimore, MD. Johns Hopkins University Press, 1991.

National Hospice and Palliative Care Organization's Marketplace Catalog has a variety of useful publications designed to assist individuals with decision making about end-of-life medical treatments. For more information visit us at www.caringinfo.org.

Additional Web Resources

Association of Cancer Online Resources

www.acor.org

Excellent resources for patients and their loved ones related to cancer and pain management.

Caregiver Survival Resources

www.caregiver.com

This Web site has all types of resources and a wealth of information both general and specific. There are links to other health related Web sites, information on books, and disease-specific resources.

Caring Connections

www.caringinfo.org

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer engagement initiative to improve

care at the end of life, supported by a grant from The Robert Wood Johnson Foundation. The Caring Connections Web site provides free resources, information and motivation for actively learning about end-of-life resources and promotes awareness of and engagement in efforts to increase access to quality end-of-life care. Caring Connections helps people connect with the resources they need, when they need them and brings together community, state and national partners working to improve end-of-life care.

Family Caregiving 101

Familycaregiving101.org

The National Family Caregivers Association (NFCA) and the National Alliance for Caregiving have launched a new public education campaign in partnership with Eisai, Inc., to advise the growing population of family caregivers of the critical need to acknowledge their caregiver role, its impact on their lives, and their need for help.

Growth House: Guide to Death, Dying, Grief, Bereavement and End-of-Life Resources

www.growthhouse.org

This is an excellent starting point for information on the whole spectrum of issues related to the end of life for people of all backgrounds. This award-winning site calls itself “a gateway to resources for life-threatening illnesses and end-of-life issues.”

National Association for Home Care

www.nahc.org

This association provides an online guide to how to choose a home care agency. Its Web site also lists resources by state.

The Mayday Pain Project

www.painandhealth.org

This Web site provides a guide and index of Internet information to those in pain. This site is targeted at caregivers, family and friends of those suffering from pain.

Caring  *Connections*
a program of the
National Hospice and Palliative Care Organization

**National Hospice and Palliative Care
Organization**



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1700 Diagonal Road, Suite 625

Alexandria, VA 22314

Call our **HelpLine:800/658-8898**

Visit our Web site: www.caringinfo.org

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