

## 10 Legal Myths About Advance Medical Directives

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<http://www.abanet.org/elderly/myths.html>

### **Myth 1:**

#### ***Everyone should have a Living Will.***

Living Will, without more, is not the document most people need. As a threshold goal, most people should have a Health Care Power of Attorney (or Health Care Proxy) that names a trusted person as agent or proxy. A still better alternative is to execute both documents or a single, combined "Advance Directive" that names a proxy and provides guidance about one's wishes. Unfortunately, because of statutory restrictions or inconsistencies within state law, many practicing attorneys advise clients to execute separate rather than combined documents. State advance directive laws are slowly moving toward acceptance of flexible, combined advance directives, but the states differ significantly in this regard.

The reason for the primary importance of the proxy appointment is simple. Most standardized living will forms are quite limited in what they can accomplish and what conditions they cover. For example, most provide instructions that apply only if the individual is in a terminal condition or permanently unconscious, yet the majority of health care decisions that need to be made for patients lacking capacity concern questions about day-to-day care, placement options, and treatment options short of "pulling the plug."

Moreover, most boilerplate instructions express fairly general sentiments about not wanting treatments that serve only prolong the dying process. Relatively few people disagree with this sentiment. However, applying it to a particular set of facts is more difficult than at first meets the eye. Virtually no interventions only prolong the dying process. Any intervention can produce multiple consequences, some predictable, some not so predictable. If an aggressive and possibly painful course of treatment will give the patient a 1 in 3 chance of recovering to the point of being able to converse again with loved ones for a least a few more months, is that hope enough to treat aggressively? What if the odds were 1 in 25?

Living will instructions always need interpretation, even when the terminal nature of an illness is clear. An agent or proxy under a health care power of attorney can do precisely that. The proxy, who should know the patient's values intimately, can respond to the actual facts and variables known when an actual health care decision needs to be made. Short of possessing a crystal ball, no one can anticipate the specific and often complicated circumstances fate will place them in. The proxy acts not only as legal decisionmaker, but also as spokesperson, analyzer, interpreter, and advocate.

One caveat: if there is no one close to the individual whom he or she trusts to act as health proxy, then the health care power of attorney should not be used. In this circumstance, the Living Will is safer, despite its limitations.

**Myth 2:**

***Written Advance Directives Are Not Legal in Every State.***

False. Every state recognizes both the proxy and living will type advance directives, although the laws of each state vary considerably in terminology, the scope of decisionmaking addressed, restrictions, and the formalities required for making an advance directive.

A more frequently raised question is whether an advance directive written in one state will be recognized in other states. In other words, is the directive portable across state lines. Many states expressly recognize out-of-state advance directives if the directive meets either the legal requirements of the state where executed or the state where the treatment decision arises. Several states are silent on this question. If there is doubt, the rules of the state where treatment takes place, not the state where the advance directive was signed, will normally control. However, even if an advance directive fails to meet technicalities of state law, health providers still should value the directive as important, if not controlling, evidence of the patient's wishes.

The threshold problem with most state provisions addressing portability is that they presumably require providers to be fully knowledgeable of the other state's law. Most use language derived from the Uniform Probate Code and similar to the following provision included in the now defunct Uniform Rights of the Terminally Ill Act:

A declaration executed in another state in compliance with the law of that state or of this State is validly executed for purposes of this [Act].

Colorado and Utah offer a more user-friendly approach to recognizing out-of state directives:

Unless otherwise provided therein, any medical power of attorney or similar instrument executed in another state shall be presumed to comply with the provisions of this [Act] and may, in good faith, be relied upon by a health care provider or health care facility in this state.

Thus, in these, states providers may assume that the out-of-state directive is valid unless they have actual knowledge to the contrary.

**Myth 3:**

***Just telling my doctor what I want is no longer legally effective.***

False. While it is better to have a written Advance Directive, oral statements remain important both on their own and as supplements to written directives.

Oral instructions may take many forms. A person physically unable to execute an advance directive may provide oral instructions that are reduced to writing by the doctor or another person, acting for the patient. Several states treat such statements as formal Advance Directives if witnessed properly. Less formal instructions in the nature of conversations with family, friends, or physicians will not have the same legal status of a written Advance Directive.

Nevertheless, informal oral statements have two important attributes. First, good health care decisionmaking requires good communication among all interested parties, and oral communication is our most natural and, indeed, primary mode of communication. Ideally, a formal advance directive serves to aid this kind of communication, not to replace it. Second, oral statements constitute important evidence of one's wishes and help expand upon, clarify, and reinforce individual preferences. The contents of the written Advance Directive should reflect a continuing conversation among the individual, physician, family, and close friends.

**Myth 4:**

*An Advance Directive means "Don't treat."*

False. While it is true that most people use Advance Directives to avoid being kept alive against their wishes when death is near, it is a mistake to assume that the existence of an advance directive means, "Don't treat." Advance directives are also used to say that the individual wants all possible treatments within the range of generally accepted medical standards. What is said depends upon one's particular wishes and values. Moreover, even when an advance directive eschews all life-sustaining treatments, one should always assume (and insist upon) continuing pain control, comfort care and respect for one's dignity.

**Myth 5:**

*When I name a proxy in my Advance Directive, I give up some control and flexibility.*

False. An individual gives up no authority or choice by doing an Advance Directive. As long as the person remains able to make decisions, his or her consent must be obtained for medical treatment. Health care providers cannot legally ignore the patient in favor of one's agent or written instruction. Indeed, in most states, health care advance directives are "springing." That is, they have no legal effect unless and until the patient lacks the capacity to make a health care decision. In a minority of states, immediately effective directives are permissible, but the maker always retains a right to override the proxy or revoke the directive.

There are situations in which a competent patient abdicates decisionmaking by saying, for example, "Do whatever my daughter thinks is best." However, this form of delegation of decisionmaking is effective only from moment to moment and needs to be rechecked at every significant decision point. Neither the proxy nor a written instruction can override one's currently expressed choice.

**Myth 6:*****I must use a prescribed Advance Directive form for my state.***

Usually false. In most states, you do not have to use a specific form. About 37 state statutes include forms for appointing proxies or for creating comprehensive advance directives. In the majority of these, the forms are optional. In about 18 states, the forms must be "substantially followed" or certain information disclosure language must be included in the form. Even with these requirements, changes and additions to standard language are permissible. Indeed, any form can and should be personalized to reflect the individual's particular values, priorities, and wishes. If you do not agree with language contained in an approved form, change the language. If changing the language creates any doubt about the validity of the form, then further legal consultation is in order. Above all, it is a mistake to pick up an "official" form and just sign it unchanged, without first being sure that it truly reflects one's specific wishes.

**Myth 7:*****I need a lawyer to do an Advance Directive.***

No, a lawyer is not needed. Yes, a lawyer is a helpful resource, but not the only resource, nor necessarily the best resource for all persons. Advance directives are not difficult to complete, but they require a few steps to do well. Try these steps for yourself, even if you already have an advance directive.

First, obtain an "official" or generally accepted form for your state, plus at least one or two additional advance directive forms from other sources. See the attached resource list for forms. This helps you see the variations in topics different advance directives cover and the alternative instructions they provide. The form-publishing business may be burgeoning, but most are inadequate in one respect or another. Even with the best drafting, there is no perfect form for everyone. People are different.

Second, discuss the contents of the forms with your physician, close family, and the person you may name as proxy. Most people find these discussions difficult to initiate, but they are extremely important. Gather information about your current medical condition and its implications for future medical problems; clarify your own values and wishes; and ask your physician, close family, and proxy if they are willing to support you in the way you want.

Third, complete the form you choose, being sure to add or modify language to reflect your wishes more accurately. Be sure to follow the witnessing instructions for your state exactly. Most, but not all states, require two completely disinterested witnesses. If you have a potential family conflict, special legal concern, or unusual request, additional legal drafting help may be needed. These circumstances call for consultation with a lawyer experienced in personal planning.

### **Myth 8:**

***Doctors and other health care providers are not legally obligated to follow my Advance Directive.***

Legally false, but as in many endeavors, reality muddies the waters. As a matter of law, it is clear that medical providers cannot treat an individual against his or her wishes. Consequently, if a physician acts contrary to a patient's clear instruction directive or contrary to the decision of the patient's authorized proxy, the physician risks the same liability he or she would face if the physician were to ignore a refusal of treatment by a fully competent patient. Treatment would constitute a battery. However, a few factors complicate the situation.

First, the doctor or health facility sometimes do not know about the existence of an advance directive. While federal law requires hospitals, nursing homes, and home health agencies to ask about and to document your Advance Directive, the document often does not make it into the appropriate record. It is up to the patient and those close to the patient you to ensure that everyone who might need a copy of the directive in fact has a copy.

Second, as noted earlier, people often do not express their wishes very clearly or precisely in advance directives. Simply using general language that rejects "heroic measures" or "treatment that only prolongs the dying process" does not give much guidance. Therefore, interpretation problems may arise. Giving a proxy broad authority to interpret one's wishes will help avoid this problem, except that sometimes proxies themselves are not quite sure what the patient would want done. This fact underscores the importance of discussing one's wishes and values with the intended proxy.

Third, in most states, if a physician or facility objects to an Advance Directive based on reasons of conscience, state law permits the physician or facility to refuse to honor it. However, facilities must notify the patient of their policies regarding advance directives at the time of admission. If a refusal occurs, the physician and facility should provide assistance in transferring the patient to a provider that will comply with the directive.

Fourth, persons who are dying, but living in the community, may face problems in having an advance directive followed if a crisis occurs and emergency medical services (EMS) are called (for example, by calling "911"). EMS personnel are generally required to resuscitate and stabilize patients until they are brought safely to a hospital. States are beginning to address this situation by creating procedures that allow EMS personnel to refrain from resuscitating terminally ill patients who are certified as having a "do not resuscitate order" and who have an approved identifier (such as a special bracelet).

### **Myth 9:**

***If I do not have an Advance Directive, I can rely on my family to make my health care decisions when I am unable to make decisions for myself.***

This is only partly true. If an individual does not have an advance directive naming a health decisions agent or proxy, several states expressly designate default "surrogates," typically family members in order of kinship, to make some or all health care decisions.

Only a few of these statutes authorize a "close friend" to make decisions, and then normally only when family members are unavailable.

Even without such statutes, most doctors and health facilities routinely rely on family involvement in decisionmaking, as long as there are close family members available and there is no disagreement. However, problems can arise because family members may not know what the patient would want in a given situation, or they may disagree about the best course of action. Disagreement can easily undermine family consent. A hospital physician or specialist who does not know you well may become the default decisionmaker.

In these situations, patients risk having decisions made contrary to their wishes or by persons whom they would not choose. Moreover, family members and persons close to patients experience needless agony in being forced to make life and death decisions without the patient's clear guidance. It is far better to make one's wishes known and to appoint a proxy ahead of time through an Advance Directive.

**Myth 10:**

*Advance Directives are a legal tool for old people.*

False. Don't think of this as an "old" people's issue. It may be natural to link death and dying issues with old age, but that is a mistake when it comes to advance directives. Consider that perhaps the most well known landmark court cases those of Nancy Cruzan and Karen Ann Quinlan involved individuals in their 20's. The stakes are actually higher for younger persons in that, if tragedy strikes, they might be kept alive for decades in a condition they would not want. An Advance Directive is an important legal planning tool for all adults.

<http://www.abanet.org/elderly/sources.html>

# **ABA Commission on Legal Problems of the Elderly**

## **Health Care Advance Directives Form**

### **Sources**

Partnership for Caring

#### **Planning for Incapacity: A Self-Help Guide.**

This is the title of a series of state specific guides published by Legal Counsel for the Elderly, American Association of Retired Persons, Projects Section. 601 E Street, NW, Washington, DC 20049. (Tel. 202-434-2120) Cost is \$5.00 per guide (\$3.00 if 10 or more copies ordered).

#### **Health Care Powers of Attorney: An Introduction and Model Form.**

Published by the American Bar Association, Commission on Legal Problems of the Elderly. This public education booklet provides background information about health care decision-making along with a sample health care power of attorney form and instructions that can be detached and used by readers. Copies are available from the ABA Commission on Legal Problems of the Elderly, 740 15th Street N.W., Washington, D.C. 20005-1022, at a cost of \$1.50 to \$.75, depending on the quantity ordered. For further information send an e-mail message to [alvarezm@staff.abanet.org](mailto:alvarezm@staff.abanet.org), call 202-662-8690 or Fax 202-662-8698.

#### **Values History Form,**

by Joan Gibson, Center for Health Law and Ethics, Institute of Public Law, University of New Mexico School of Law, 1117 Stanford, N.E., Albuquerque, NM 87131 (Tel. 505-277-5006). The form is also published in J. Gibson, "National Values History Project," *Generations*, 14 (Supplement 1990), pp. 51-64. Instead of focusing on particular medical scenarios and treatments, this form offers questions to help individuals clarify their fundamental values, priorities, and perceptions of the world that form the foundation for one's decisions. It can be very helpful as a preparatory step in doing an advance directive, but it is geared to a more educated and sophisticated audience.

#### **LOCAL SOURCES:**

Local Title III-funded (Older Americans Act) legal services programs, local hospitals, state or local offices on aging, bar associations, or state medical associations may all have informational literature on advance medical directives,



including forms.

American Bar Association

740 Fifteenth Street, NW

Washington, DC 20005-1022

Telephone: 202-662-8690

Facsimile: 202-662-8698

Email: [alvarezm@staff.abanet.org](mailto:alvarezm@staff.abanet.org)

<http://www.partnershipforcaring.org/Advance/index.html>

#### **ADVANCE DIRECTIVES**

“Advance Directive” is a general term that applies to two types of legal documents. The two basic types of advance directives, which may be called by different names, are:

## Living Wills

### Medical Powers of Attorney

These documents let you give instructions about the medical care you want to receive in the event that you become unable to speak for yourself due to serious illness or incapacity. (See Talking About Your Choices.) A living will provides specific instructions. A medical power of attorney names a person that you trust to make decisions on your behalf. (See Appointing A Health Care Agent and Being a Health Care Agent.) Each state treats these documents somewhat differently. (For more information see Frequently Asked Questions.)

You can obtain state specific documents at this web site by clicking on Download State Specific Documents.

You can obtain a printed set of documents for \$5.00 (plus tax where applicable: \$.41 for New York State residents and \$.29 for Washington, DC residents). Call 1-800-989-9455, (option 2) to order by credit card, or  
Send a check or money order to:

Partnership for Caring Publications  
325 East Oliver Street  
Baltimore, MD 21202

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[http://www.partnershipforcaring.org/Advance/talking\\_set.html](http://www.partnershipforcaring.org/Advance/talking_set.html)

## TALKING ABOUT YOUR CHOICES

We gratefully acknowledge the  
funding assistance provided by  
*The Robert Wood Johnson Foundation*

[click here for the pdf version of this booklet](#)

### **IT'S ALL ABOUT TALKING**

This booklet introduces you and your loved ones to the issues surrounding end-of-life decision making. It's all about talking- talking to your loved ones about your health care preferences; talking to your doctor about your options so that you can make informed decisions. Talking before a crisis can help you and your loved ones prepare for any difficult decisions related to health care at the end of life.

Exploring your thoughts and talking about your choices is an ongoing process. Start by planning for your end-of-life care.

Contact us at Partnership for Caring: America's Voices for the Dying if you have any questions. And refer to the resource list for other agencies and organizations that might be helpful to you.

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## **1. Advance care planning**

You can prepare for a potential medical crisis by taking steps today that ensure your participation in future health

care decisions :

GATHER the information you need to make the right choices for you. TALK about end-of-life decisions with your family, friends, doctor, the clergy and any others close to you to help determine what quality of life and which decisions are important to you. PREPARE and sign advance directives that accurately reflect your decisions and comply with your state's law. INFORM your loved ones and doctor about your preferences and give them copies of your advance directives.

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## 2. Talking about the issues

The following questions may help you discuss these issues with family, loved ones and an agent:

How do you want to be treated at the end of your life? Are there treatments you particularly want to receive or refuse? What are you afraid might happen if you can't make decisions for yourself? Do you have any particular fears or concerns about the medical treatments that you might receive? Under what circumstances? What makes those things frightening? What do phrases like no heroic measures or dying with dignity actually mean to you? (People often use these expressions with different meanings.)

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## 3. Talking with family and friends

Decisions about end-of-life medical treatments are deeply personal and should be based on your values and beliefs. Because it is impossible to foresee every type of circumstance or illness, it is essential to think in general about the quality of life that is important to you. You should consider your:

Overall attitude toward life, including the activities you enjoy and situations you fear; Attitude about independence and control, and how you feel about losing them; Religious beliefs and moral convictions, and how they affect your attitude toward serious illness; Attitude toward health, illness, dying and death; and Feelings toward doctors and other caregivers.

Other factors may be important, such as considering the impact of decisions on family and friends and determining whether loved ones will support your decisions concerning end-of-life treatments. Bring your family and friends into the process. Talk with them. They might need to advocate on your behalf if the medical condition prevents your active participation in decision-making. Discussions with loved ones are a vital foundation for making end-of-life decisions. Conversations that focus on decisions and why you are making them will relieve loved ones and health care providers from the need to guess what you would want.

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## 4. Talking with your doctor

Do not wait until a crisis occurs before discussing concerns about end-of-life treatments with your doctor. Chances are that he or she is waiting for you to start the conversation. When you discuss your concerns and choices:

Let your doctor know that you are completing directives. Ask your doctor to explain treatments and procedures that may seem confusing before you complete your directives. Make sure your doctor knows the quality of life that is important to you. Make sure your doctor is willing to follow your directives. The law does not force physicians to follow directives if they disagree with your wishes for moral or ethical reasons. Give your doctor a copy of your completed directives. Make sure your doctor knows the name and telephone number of your appointed health care agent. Assure your doctor that your family and your appointed health care agent know your wishes. One final point: reassess your decisions over time. They might change as circumstances in your life change.

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## 5. Preparing the right advance directive

Talking with loved ones, friends and others close to you helps determine your preferences concerning end-of-life treatments. Make certain that those preferences will be respected even if you lose the ability to participate in your health care decisions: sign an advance directive. "Advance directive" is a general term that describes two types of legal documents that "speak" for you in the event of incapacity:

A living will allows you to document your wishes concerning medical treatments at the end of life. A **medical power of attorney** (or health care proxy) allows you to appoint a person you trust as your health care agent, who is

authorized to make medical decisions on your behalf.

Advance directives are legally valid throughout the United States. The laws governing advance directives vary from state to state, so sign advance directives that comply with your state's law. Also, advance directives can have different titles in different states. Contact us for information about appropriate documents for your state.

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## 6. Talking with your health care agent

Your agent should be a person whom you trust, who knows your wishes about medical treatment and who is willing to take responsibility to ensure your wishes are followed.

Appointing an agent or accepting such an appointment can raise questions you might never have considered. you may reach a deepened understanding of yourself and your relationship with the person you appoint or who appoints you. Taking time to talk about the issues can be a rewarding experience in itself.

### SELECTING AN AGENT:

Select someone whom you trust and who understands your decisions. Because you are asking your agent to accept significant responsibility, be certain to ask your agent if he or she is willing to act on your behalf. Not everyone is able to be an effective agent. Talk to your agent about your wishes regarding end-of-life medical treatment. Even family members may not know how much treatment a loved one would be willing to accept near the end of life. Talking clarifies what you want and diminishes an agent's potential guilt and anguish over whether he or she is doing the right thing. Prepare and sign the appropriate forms for your state. Keep the original and give copies to your agent and alternate agents, family and doctors and have it placed in your medical record.

### BENEFITS OF HAVING AN AGENT:

The agent knows you and understands your wishes about medical treatments. He or she can make decisions in situations you might not have anticipated. An agent has flexibility. He or she can talk with your physicians about your changing medical condition and authorize treatment or have it withdrawn as circumstances change. If you have prepared a living will, your agent can interpret it in situations that were not foreseen. Be sure to make clear in your living will that your agent should make decisions on how to interpret it or when to apply it. Your agent can advocate for you. If health care providers resist following your wishes, your agent can negotiate with them and take any other necessary steps to see that your wishes are honored. In most states, your agent can make decisions any time you lose the ability to make a medical decision, not just decisions about the end of life.

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## 7. Acting as a health care agent

Providers and patients (or their agents) don't talk enough. As an agent, you will be responsible for working with providers to ensure that your loved one's wishes, including preferences about end-of-life treatments, are honored. If you become the decision maker for a loved one, take the following steps:

**Establish open communication with the doctor.** Identify the attending physician. Make an appointment to speak about your loved one's care. Be assertive in expressing your wishes. Clearly state the reasons behind your requests without being hostile. **Ask questions.** To be effective and to make informed decisions, learn as much as possible about your loved one's condition and prognosis. If you don't ask, the physician might not tell you everything you need to know to make an informed decision. Ask about the goals of the treatment plan- often, a physician's definition of recovery can be different from what is acceptable to you or your loved one. Some providers may have a hard time withholding or withdrawing treatments. **Seek the assistance of a social worker or patient representative.** Such professionals can help improve communication between you and the physician if necessary. **Don' be afraid to speak to the facility's administration.** If the physician is unresponsive, go directly to his or her superiors, including the chief of medicine, risk manager, hospital lawyer or administrator.

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## 8. Understanding life-support measures

Life support replaces or supports a failing bodily function. When patients have curable or treatable conditions, life support is used temporarily until the illness or disease can be stabilized and the body can resume normal functioning. At times, the body never regains the ability to function without life support.

When making decisions about specific forms of life support, gather the facts you need to make informed decisions. In particular, understand the benefit as well as the burden the treatment will offer you or your loved one. A treatment may be beneficial if it relieves suffering, restores functioning or enhances the quality of life. The same treatment can be considered burdensome if it causes pain, prolongs the dying process without offering benefit or adds to the perception of a diminished quality of life. A person's decision to forgo life support is deeply personal. When gathering information about specific treatments, understand why the treatment is being offered and how it will benefit your care.

#### **COMMONLY USED LIFE-SUPPORT MEASURES:**

- **Artificial nutrition and hydration:** artificial nutrition and hydration (or tube feeding) supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine or a vein. Artificial nutrition and hydration can save lives when used until the body heals. Long-term artificial nutrition and hydration may be given to people with serious intestinal disorders that impair their ability to digest food, thereby helping them to enjoy a quality of life that is important to them. But long-term use of the tube feeding frequently is given to people with irreversible and end-stage conditions. Often, the treatment will not reverse the course of the disease itself or improve the quality of life. Some health care facilities and physicians may not agree with stopping or withdrawing tube feeding. Therefore, explore this issue with your loved ones and physician and clearly state your wishes about artificial nutrition and hydration in your advance directive .
- **Cardiopulmonary resuscitation:** Cardiopulmonary resuscitation (**CPR**) is a group of treatments used when someone's heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart's function and cause blood to circulate. Electric shock and drugs also are used frequently to stimulate the heart. When used quickly in response to a sudden event like a heart attack or drowning, CPR can be life saving. But the success rate is extremely low for people who are at the end of a terminal disease process. Critically ill patients who receive CPR have a small chance of recovering and leaving the hospital. If you do not wish to receive CPR under certain circumstances, and you are in the hospital, your doctor must write a separate do-not-resuscitate (DNR) order on the chart. If you are at home, some states allow for a non-hospital DNR order. This order is written by a physician and directs emergency workers not to start CPR.
- **Mechanical ventilation:** Mechanical ventilation is used to support or replace the function of the lungs. A machine called a ventilator (or respirator) forces air into the lungs. The ventilator is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea). Mechanical ventilation often is used to assist a person through a short-term problem or for prolonged periods in which irreversible respiratory failure exists due to injuries to the upper spinal cord or a progressive neurological disease. Some people on long-term mechanical ventilation are able to enjoy themselves and live a quality of life that is important to them. For the dying patient, however, mechanical ventilation often merely prolongs the dying process until some other body system fails. It may supply oxygen, but it cannot improve the underlying condition. When discussing end-of-life wishes, make clear to loved ones and your physician whether you would want mechanical ventilation if you would never regain the ability to breathe on your own or return to a quality of life acceptable to you.

#### **ADDITIONAL ISSUES:**

The distinction often is made between not starting treatment and stopping treatment. However, no legal or ethical difference exists between withholding and withdrawing a medical treatment in accordance with a patient's wishes. If such a distinction existed in the clinical setting, a patient might forgo treatment that could be beneficial out of fear that once started it could not be stopped. It is legally and ethically appropriate to discontinue medical treatments that no longer are beneficial. It is the underlying disease, not the act of withdrawing treatment that causes death.

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## **9. Learning about pain management**

A common fear of both terminally ill persons and their loved ones is that the dying person will experience great suffering and pain. Many of us are more afraid of dying in pain than of death itself. Pain should be treated as seriously as the disease. Pain can significantly impair the quality of life of individuals, even causing them to give up

on living. A plan to manage pain should be as concrete as a plan to manage the disease.

In most cases, severe pain and physical discomfort can be managed through effective use of pain management and palliative care (symptom control). This can be accomplished through medical means, such as medications (narcotics and non-narcotics), surgery and nerve blocks, and non-medical means, such as relaxation therapies, biofeedback, massage and good nursing care. Reasons that many terminally ill patients experience a great deal of pain and suffering include:

Failure to tell others about their pain; Failure of providers and family to accept patients' reporting about the severity of their pain; Failure of providers to consider pain as seriously as other aspects of a patient's illness; Lack of knowledge among health care providers about the effective and appropriate use of medications and other tools to control pain; Fear that providing or taking adequate narcotics will lead to addiction; Lack of access to sufficient quantities of medications for patients on very high doses of narcotics; and Fear of causing death by providing aggressive pain management.

People with terminal illness may require extremely large doses of narcotics to control their pain. Despite the fact that clinical experience has shown that those who take narcotics for pain management rarely become psychologically addicted, myths about addiction from the use of narcotics are a serious barrier to effective pain management. Fears of causing death are similarly misplaced. It is important to recognize that the disease is causing death, not the medications and procedures used to control pain. Pain management is provided simply to keep the dying person comfortable.

#### **WAYS TO ENSURE GOOD PAIN MANAGEMENT:**

- Ask your doctor how he or she will manage any pain that might result from your illness. Different types of illness might require different approaches. The doctor should have a plan in mind or see that you have access to appropriate pain specialists.
- Consider what trade-offs you are willing to make for pain management. Some people would rather endure more pain if it meant they would be more alert.
- Don't be afraid to let your caregivers know when you are in pain. You should expect to have your pain taken seriously.
- Describe your pain as specifically as possible. Let the doctor know how it is affecting your ability to do specific things; when it is better or worse; where it falls on a scale of 1 to 10.
- When a pain management plan is implemented, follow the plan! The goal of good pain management is to keep you from experiencing pain. Once you are in pain it requires much more medication to bring the pain under control.

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## **10. Glossary**

**Advance directive** :A general term that describes two kinds of legal documents, living wills and medical powers of attorney. These documents allow a person to give instructions about future medical care should he or she be unable to participate in medical decisions due to serious illness or incapacity. Each state regulates the use of advance directives differently.

**Assisted suicide**: Providing someone the means to commit suicide, such as a supply of drugs or a weapon, knowing the person will use these to end his or her life.

**Brain death**: The irreversible loss of all brain function. Most states legally define death to include brain death.

**Capacity**: In relation to end-of-life decision-making, a patient has medical decision-making capacity if he or she has the ability to understand the medical problem and the risks and benefits of the available treatment options. The patient's ability to understand other unrelated concepts is not relevant. The term is frequently used interchangeably with competency but is not the same. Competency is a legal status imposed by the court.

**Do-not-resuscitate order**: A DNR order is a physician's written order instructing health care 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. A non-hospital DNR order is written for individuals who are at home and do not want to receive CPR.

**Hospice care**: A program model for delivering 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 support to the family during their bereavement.

**Living will:** A type of advance directive in which an individual documents his or her wishes about 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", "health care 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. This type of advance directive may also be called a health care proxy, durable power of attorney for health care or appointment of a health care agent. The person appointed may be called a health care agent, surrogate, attorney-in-fact or proxy.

**Palliative care:** A comprehensive approach to treating serious illness that focuses on the physical, psychological, spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, by controlling pain and symptoms, and by 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" or "hospice-type care."

**Surrogate decision-making:** Surrogate decision-making laws allow an individual or group of individuals (usually family members) to make decisions about medical treatments for a patient who has lost decision-making capacity and did not prepare an advance directive. A majority of states have passed statutes that permit surrogate decision making for patients without advance directives.

**Withholding or withdrawing treatment:** Forgoing life-sustaining measures or discontinuing them after they have been used for a certain period of time.

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## 11.Resources

### **AIDS Hotline**

1-800-342-AIDS (2437)

Operated by the Centers for Disease Control and Prevention. Provides general information about AIDS and HIV, as well as referrals to HIV testing facilities, medical services, counseling, and support groups. There is someone available to answer calls 24 hours a day and they maintain a national database of AIDS resources.

### **ALS Association**

2101 Ventura Boulevard  
Suite 321 Woodland, CA 91364  
1-800-782-4747

Provides information and educational materials about ALS (Lo Gehrig's Disease). They will provide referrals to physicians, support groups, and drug trials.

### **Alzheimer's Disease and Related Disorders Association**

919 N. Michigan Avenue  
Suite 100 Chicago, IL 60611  
1-800-272-3900

Provides general information on the disease and referrals to over 200 local association chapters for specific services.

### **American Academy of Hospice and Palliative Medicine**

11250 Roger Bacon Drive,  
Suite 8 Reston, VA 20190-5202 703-787-7718  
Fax: 703-435-5490  
aahpm@aahpm.org  
<http://www.aahpm.org>

Can provide referrals in many parts of the country to physicians who specialize in palliative care. Can also direct professionals to training programs for palliative care.

### **American Association of Retired Persons**

601 E Street NW  
Washington, DC 20049  
1-800-424-3410  
or 202-434-2277

Provides a wide range of services including counseling, advocacy, benefits, and entitlement information; activities and assistance to people who are homebound.

**American Pain Society**

5700 Old Orchard Road  
First Floor Skokie, IL 60077  
847-375-4715

Association of pain physicians. Provides referrals to pain facilities, physicians, and support groups.

**Cancer Care, Inc.**

1180 Avenue of the Americas  
New York, NY 10036  
1-800-813-HOPE (4673)  
In New York, 212-302-2400  
cancercare@aol.com  
<http://www.cancercare.org>

Provides support groups, educational programs, and workshops for cancer patients and their families. They operate a national referral service, and counselors on staff provide assistance to callers. Cancer Care also publishes *Helping Hand*, a useful resource guide for cancer patients and others.

**Cancer Information Service**

1-800-4-CANCER (422-6237)

Has 19 offices across the country. Answers any question related to cancer and Cancer treatment. Provides referrals to hospice, home care, and support groups.

**Genetic Alliance**

(formerly The Alliance of Genetic Support Groups)

4301 Connecticut Avenue,  
NW Suite 404 Washington, DC 20008  
1-800-338-GENE (4363)  
or 202-966-5557  
Fax: 202-966-8553  
info@geneticalliance.org  
<http://www.geneticalliance.org>

A nonprofit coalition of support groups, consumers, and professionals dedicated to promoting the common interests of children and adults with, or at risk for, genetic disorders. Specializes in linking people interested in genetic conditions with organizations that can provide support and information.

**Partnership for Caring:**

America's Voices for the Dying  
National Office  
1620 Eye Street, NW Suite 202  
Washington, DC 20006  
Phone: 202-296-8071  
Fax: 202-296 8352  
Hotline 800-989-9455

[pfc@partnershipforcaring.org](mailto:pfc@partnershipforcaring.org)  
[www.partnershipforcaring.org](http://www.partnershipforcaring.org)

Advocates for the rights of dying patients, provides legal and educational information about end-of-life decisions, and operates a counseling service for people with questions and concerns related to the implementation of advance directives and other end-of-life issues.

**Hospicelink**

1-800-331-1620

Provides general information on hospice care and referrals to hospices across the country.

**National Hospice and Palliative Care Organization**

1901 N. Moore Street, Suite 901

Arlington, VA 22209

1-800-658-8898 (hospice referral)

703-243-5900 (other questions)

<http://www.nho.org>

Offers information, patient advocacy, professional education, and referrals to hospice programs throughout the country.

**National Self-Help Clearinghouse**

25 W. 43rd Street,

Room 620 New York, NY 10036

212-642-2944

[www.selfhelpweb.org](http://www.selfhelpweb.org)

Part of a country wide affiliation of clearinghouses. Provides referrals to self-help organizations; mutual-support groups; and other national, state, local and community resources.

**Visiting Nurse Association of America**

11 Beacon Street,

Suite 910 Boston, MA 02108

1-888-866-8773

or 617-523-4042

Fax: 617-227-4843

Provides referrals to visiting nurse agencies nationwide and supports visiting nurse agencies in their commitment to provide the most effective, innovative, and personalized community-based care.

**Call Partnership for Caring: America's Voices for the Dying.** We have trained counselors who can help you navigate the health care system and sort through the information you are receiving from health care providers about end-of-life treatment decisions. If you hear something that is confusing or that just doesn't seem right, call Partnership for Caring at (800) 989-9455. We can help you understand the issues important to your situation.

[http://www.partnershipforcaring.org/Advance/agent\\_set.html](http://www.partnershipforcaring.org/Advance/agent_set.html)

## APPOINTING A HEALTH CARE AGENT

A health care agent is someone you designate to make medical decisions for you if, at some future time, you are unable to make decisions yourself. Your agent can be a close relative or a personal friend, but should be someone who knows you well and whom you trust.

Your agent will be your voice and your advocate. Because making medical decisions is rarely simple, it is difficult to foresee all of the possibilities in advance. Having an agent permits the same kind of flexible decision making that would occur if you were able to talk with your doctors, ask questions, weigh the benefits and burdens of the treatments involved, and make decisions based on specific circumstances.

Ideally, your agent should be someone who is not afraid to ask questions of the healthcare professionals in order to get information needed to make decisions. Your agent may need to be assertive to ensure that your wishes are respected. Not everyone is comfortable accepting this sort of responsibility; therefore, it is very important to have an honest discussion with the person you plan to appoint before you make the appointment.

When you select your agent, be sure to:

- Ask him or her if they are willing to accept this responsibility. Not everyone is able to be an effective agent.
- Talk to your agent about your wishes regarding end-of-life medical treatment. Even family members may not know how much treatment you would want at the end of life. Talking clarifies your wishes and diminishes an agent's potential guilt and anguish over whether they are doing the right thing.

· Prepare and sign the appropriate forms for your state. Be sure your agent, alternate agent and anyone who might be involved with your medical care has a copy.

For more information see Talking About Your Choices. For a more in-depth discussion of appointing a health care agent you can order Partnership for Caring's booklet Healthcare Agents: Appointing One and Being One.

[http://www.partnershipforcaring.org/Store/booklets\\_set.html](http://www.partnershipforcaring.org/Store/booklets_set.html)

## **QUESTION AND ANSWER BOOKLETS:**

1. Health Care Agents: Appointing One and Being One
2. You & Your Choices, Advance Medical Directives
3. Advance Directives and End-of-Life Decisions
4. Medical Treatments and Your Advance Directives
5. Artificial Nutrition and Hydration and End-of-Life Decisions
6. Cardiopulmonary Resuscitation, Do-Not-Resuscitate Orders, and End-of-Life Decisions.
7. Dying at Home
8. The Physician-Assisted Suicide Debate: Understanding the Issues

**Patients, family members, even health care professionals have many questions about end-of-life care ---- options, procedures, legal issues, and more. Often, they do not even know what questions to ask. These award-winning publications address both frequently asked questions and provide easy to understand answers. They help everyone talk about choices, reach informed decisions, and are excellent resources for consumers, educators, and professionals.**

### **Health Care Agents: Appointing One and Being One**

A health care agent is someone you designate to make medical decisions for you in the event that you are unable to make decisions for yourself. Selecting a health care agent for yourself or agreeing to be an agent for someone else requires preparation and communication. Often people don't know what issues to discuss. This booklet answers commonly asked questions and provides information to assist in effective decision making. \$5.95 [Click Here To Order](#)

### **You & Your Choices, Advance Medical Directives**

This illustrated booklet explains the basics of advance directives in simple terms. It describes six steps to completing and distributing living wills and medical powers of attorney and explains how individuals can make their choices known. \$3.50 [Click Here To Order](#)

### **Advance Directives and End-of-Life Decisions**

Advance directives refer to two legal forms: A living will and a medical power of attorney. (Sometimes called a durable power of attorney for health care, or health care proxy, or appointment of a health care agent) Why do I need advance directives? How do I use them? How can I reduce the chances of future conflict over medical care? These and 36 other frequently asked questions are all answered in this booklet. \$5.95 [Click Here To Order](#)

### **Artificial Nutrition and Hydration and End-of-Life Decision Making**

Deciding whether to use artificial nutrition and hydration (often called "tube feeding") can cause conflict and anguish for family members. Food and water are so powerfully linked with comfort and caring that we find it difficult not to provide them, even when they cannot help the patient. This booklet answers questions about tube feeding, patient comfort, and what to consider when making this decision. \$5.95 [Click Here To Order](#)

### **Medical Treatments and Your Advance Directives**

This helpful booklet explains the most common life support treatments and talks about pain management. This information can be useful to help complete advance directives or to weigh the benefits and burdens of specific

choices when decisions need to be made. This booklet includes a questionnaire that helps people explore their preferences. \$5.95 [Click Here To Order](#)

### **Cardiopulmonary Resuscitation, Do-Not-Resuscitate Orders, and End-of-Life Decisions**

The decision to resuscitate someone who has a cardiac or respiratory arrest is one of the most common end-of-life decisions people must make. This easy-to-understand booklet answers medical and legal questions about resuscitation, both hospital and non-hospital do not resuscitate orders, and ways to discuss the issues. \$5.95 [Click Here To Order](#)

### **Dying at Home**

More and more individuals are choosing to die at home in a familiar environment where they can remain connected to their family and friends at the end of their life. Yet often patients and their families do not understand what may be involved in carrying out this wish. This comprehensive booklet answers questions about medical treatment and other care as well as legal and practical considerations before and after death. \$5.95 [Click Here To Order](#)

**The Physician-Assisted Suicide Debate: Understanding the Issues** Across the country, debate about legalizing physician-assisted suicide continues to rage. Partnership for Caring takes no position on either side of the debate, rather, this booklet provides clear easy-to-understand discussion on the issues surrounding the debate. This unbiased, informative booklet summarizes the major issues that were before the Supreme Court in 1997, explains the basis for the courts decisions, and describes the implications of the decision. \$5.95 [Click Here To Order](#)

[http://www.partnershipforcaring.org/Resources/glossary\\_set.html](http://www.partnershipforcaring.org/Resources/glossary_set.html)

## **GLOSSARY OF TERMS**

The following terms may be used in discussions about end-of-life decision making.

**Advance Directives:** 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 health care 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 withhold or withdraw 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 it supports the patient's values (for example, the patient is able to die at home as he 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 is resuscitated and the heart 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 only 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.

**Best interest:** In the context of refusal of medical treatment or end-of-life court opinions, a standard for making health care decisions based on what others believe to be "best" for a patient by weighing the benefits and the burdens of continuing, withholding or withdrawing treatment. (Contrast with "substituted judgment.")

**Brain Death:** The irreversible loss of all brain function. Most states legally define death to include brain death.

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

**Case law:** Law made by court cases rather than legislation.

**Clear and convincing evidence:** A high measure or degree of proof that may be required legally to prove a patient's wishes. A few states require clear and convincing evidence that an incompetent patient would want to

refuse life-support before treatment may be stopped unless the patient has completed an advance directive authorized by the state's law.

**Constitutional law:** Law based on either federal or state constitutions. Generally, it concerns the fundamental principles that regulate the relation between the government and its citizens. The United States Supreme Court has ultimate authority to interpret the U.S. Constitution and decide the constitutionality of a law.

**Do-Not-Resuscitate (DNR) Order:** A DNR order is a physician's written order instructing health care 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.

**Double Effect:** According to the ethical principle known as the "rule of double effect," effects that would be morally wrong if caused intentionally are permissible if foreseen but unintended. An example is the administration of pain medication with the intention of relieving pain and with the possible unintended secondary effect of hastening death.

**Euthanasia:** The term traditionally has been used to refer to the hastening of a suffering person's death or "mercy killing". *Voluntary active euthanasia* involves an intervention requested by a competent individual that is administered to that person to cause death, for example, if a physician gives a lethal injection with the patient's full informed consent. *Involuntary or nonvoluntary active euthanasia* involves a physician engaging in an act to end a patient's life without that patient's full informed consent. See also *Physician-hastened Death (sometimes referred to as Physician-assisted Suicide)*.

**Guardian ad litem:** Someone appointed by the court to represent the interests of a minor or incompetent person in a legal proceeding.

**Incompetent:** See "Capacity."

**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, and bereavement support.

**Legislation:** Laws enacted by state or federal representatives. 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 cardio-pulmonary 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 if he or she is at the end of life and unable to communicate. It may also be called a "directive to physicians," "health care 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 health care proxy, durable power of attorney for health care, or appointment of a health care agent or surrogate. The person appointed may be called a health care agent, surrogate, attorney-in-fact, or proxy.

**Palliative Care:** A comprehensive approach to treating serious illness that focuses on the physical, psychological, spiritual, and existential 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 is an essential component. Palliative care is sometimes called "comfort care" or "hospice-type care." (Contrast with "best interests.")

**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 their own life.

**Substituted judgment:** The doctrine of substituted judgment permits an individual to make medical decisions for a patient when the patient is unable to communicate. The decision maker must make the decision the patient would have made under those circumstances. The decision maker is not permitted to choose what he or she thinks is best for the patient, rather what the patient would have chosen.

**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.

**Withholding or Withdrawing Treatment:** Forgoing life-sustaining measures or discontinuing them after they have been used for a certain period of time.